**Title**

**Qualitative analysis of the Cognition and Flow (CoGFlowS) Study: An individualised approach to cognitive training for dementia is needed**

**Running title**

**Qualitative analysis of the CoGFlowS study**

**Authors**

Lucy Beishona, Victoria Hauntona,b, Hari Subramaniamc, Elizabeta B. Mukaetova-Ladinskac,d, Ronney B. Paneraia,b, Thompson Robinsona,b, Rachel Evleye

**Affiliations**

a University of Leicester, Department of Cardiovascular Sciences, Leicester, UK

b NIHR Leicester Biomedical Research Centre, British Heart Foundation Cardiovascular Research Centre, Glenfield Hospital, Leicester, UK

c The Evington Centre, Leicestershire Partnership NHS Trust, Leicester, UK

d University of Leicester, Department of Neuroscience, Psychology and Behaviour, Leicester, UK

eInflammatory, Injury & Recovery Science, School of Medicine, University of Nottingham, UK

**Corresponding author**

Dr Lucy Beishon

Room 419, Level 4 Clinical Sciences Building

Leicester Royal Infirmary

Leicester, LE2 7LX

Tel: 0116 252 3134, Email: Lb330@le.ac.uk

# Abstract

**Background**

Cognitive training (CT) may have benefits for both healthy older adults (HC) and those with early cognitive disorders [mild cognitive impairment (MCI) and dementia]. However, few studies have qualitatively evaluated home-based, computerised CT programmes.

**Objective**

We present the qualitative arm of a feasibility randomised controlled trial evaluating a CT programme for HC and people living with MCI or dementia.

**Methods**

Participants underwent semi-structured interviews after 12 weeks of CT. Where possible, participants were interviewed with their carers. The interview schedule and analysis were underpinned by the health belief model. Interviews were audio-recorded, transcribed, open-coded and categorised into themes. The analytical framework was developed, and themes were condensed under five major categories: benefits, barriers, threat, self-efficacy, and cues to action.

**Results**

37 participants underwent interviews. CT was feasible and acceptable to participants. Benefits included: enjoyment, improved awareness, benchmarking cognitive function, reassurance of abilities and giving back control. Barriers were more prevalent amongst those with dementia: problems with technology, frustration, conflict between patients and carers, apathy and lack of insight, anxiety or low mood, and lack of portability. HC and MCI perceived the severity of dementia risk as high, partially mitigated by CT. Participants living with dementia valued a more individualised approach to training, accounting for baseline characteristics.

**Conclusions**

CT was a feasible intervention for HC , and people living with dementia and MCI. Benefits were present, but the identified barriers need to be addressed for CT to be implemented successfully.

# Key words

Cognitive Dysfunction

Alzheimer’s disease

Mild cognitive impairment

Healthy aging

# Introduction

Cognitive training (CT) is a structured, guided programme of repeated practice on standardised tasks designed to target specific cognitive domains [1]. Recent systematic reviews and meta-analyses suggest CT may improve cognitive function in healthy older adults and those with early dementia and mild cognitive impairment (MCI) [2-4]. As a non-pharmacological intervention, CT may be attractive to patients owing to the limited potential for side-effects [5]. However, successful implementation requires sufficient engagement, commitment, and motivation from individuals [6]. Therefore, it is important to demonstrate that opportunity costs to the individual are offset [7]. Thus far, the majority of studies have quantitatively investigated the effectiveness of CT [2-4], or the mechanisms by which it may induce neuroplasticity [8]. It is important to understand the views, perceptions and beliefs of individuals which may moderate their interaction and engagement with CT, and thus modulate efficacy [6]. The majority of CT programmes have been developed in healthy populations, but the barriers to successful engagement may differ considerably for those living with cognitive disorders [9]. Qualitative studies of psycho-social interventions for dementia have found benefits for people living with dementia [10]. The majority of these studies evaluated facilitated or group-based therapies such as: cognitive stimulation therapy, cognitive rehabilitation and reminiscence therapy [10]. Computerised home-based CT is increasingly researched given its flexibility, portability, and lower associated costs, time and travel demands [11]. This may come at a cost of reduced effectiveness, as it requires motivation and commitment to maintain adherence [2, 12]. Few studies have qualitatively analysed the barriers to implementing home-based computerised CT programmes in those with cognitive impairment, and the challenges may be distinct from those associated with group-based programmes, and those conducted in healthy populations [9, 13]. Previous studies have evaluated home-based computerised CT in healthy older adults and MCI [11], and cognitive impairment associated with HIV and schizophrenia [13]. Thus, qualitative evaluation of home-based CT is needed to help inform the timely design and implementation of effective CT programmes for healthy older adults and people living with dementia.

The aim of this study was to therefore qualitatively evaluate a home-based, computerised CT programme for healthy older adults and people living with MCI or dementia, and to qualitatively investigate the results obtained in the quantitative phase (explanatory sequential mixed methods study). A healthy comparator group was specifically included to facilitate comparisons with those with cognitive disorders in terms of the barriers, and to understand how cognitive interventions that have been developed for healthy populations may require adapting and tailoring for those with cognitive disorders. This study sought to identify the experiences and perceptions of participants undergoing home-based CT, and the barriers to successful programme engagement in the context of the health belief model (HBM) [14].

# Methods

## Study design and sample selection

This was the qualitative phase of an explanatory sequential mixed methods research study [15]. The quantitative phase was a feasibility randomised-controlled trial of CT in healthy older adults, and people living with MCI and Alzheimer’s disease (AD), which has recently been published [16]. The final data integration phase of the mixed methods study is ongoing and will be reported when completed. Figure 1 summarises the structure of the mixed methods research study and the relationship between the phases. Healthy older adults were included as a control or comparator group in both the quantitative [16] and qualitative strands of the study. Participants in the training arm of the trial were offered the option of a focus group or semi-structured qualitative interview at the end of the 12-week training period. Where possible, carers for people living with dementia or MCI were recruited and interviewed as dyads. Thus, this was a convenience sample and size was limited by overall recruitment to the trial, but data saturation was reached for the majority of themes. Participants who did not complete the training or dropped-out were also eligible to be interviewed in the qualitative study. Participants were recruited between March 2019 and April 2020. Figure 2 summarises the recruitment process. The study had ethical approval from the Bradford-Leeds research ethics committee (ref: 18/YH/0396), and study procedures were conducted in accordance with Declaration of Helsinki. All participants provided written, informed consent or personal consultee declaration where participants lacked capacity. This study was conducted and reported in line with guidance on qualitative research [17].

Study specific inclusion criteria were as follows: healthy controls were free of any medical co-morbidity or medication that could adversely affect cognition (e.g. stroke, brain tumour, sedative drugs), MCI (NIA/AA or Petersen criteria) or AD (NIA/AA 2011 criteria) with mild to moderate deficits (Montreal Cognitive Assessment score of >9), willing to participate, capacity to consent to the study or personal consultee, patients on and off anti-dementia medications were included (acetylcholinesterase inhibitors, glutamate receptor antagonists), good understanding of written and spoken English, age ≥50 years, access to the internet and a computer/laptop. Exclusion criteria were defined by the larger quantitative trial and confined to major medical co-morbidities (severe heart failure (ejection fraction <20%), carotid artery stenosis, severe respiratory disease, major stroke) which are known to affect cerebral blood flow (a key outcome in the main trial). In addition, participants already enrolled into other interventional studies were excluded.

## Intervention

The protocol for the study has been published previously [15]. In brief, participants were randomised using sealed envelope©, with a block-size of four and stratified by patient group. Participants were asked to train for 30 minutes, five times per week for 12 weeks. The CT programme was an online based, multi-domain software program provided by Lumosity©. Exercises were selected to cover five core cognitive domains (attention, verbal fluency, language, visuospatial, and memory) assessed in the quantitative arm of the trial [15]. Full details of the programme can be found in the pre-published protocol and quantitative trial results [15, 16]. The programme was adaptive, such that the difficulty increased incrementally according to participant performance. It was anticipated that at the initial levels, the majority of participants (including those with cognitive disorders) would be able to engage with the CT programme. However, feasibility of the intervention across the three groups was a key research question. The programme was only available on a desktop computer or laptop, not on a tablet or smartphone due to lack of compatibility with these devices. Participants used their own computers and laptops. Although loans were available, none were required for the purpose of the study. Participants were provided with a demonstration of the CT programme at the end of the baseline assessment. A set-up guide and troubleshooting information for commonly occurring issues was provided for the participant to access the CT programme at home. Where participants were unable to set-up the training at home, a researcher (LB) undertook a home visit to set-up the training. Thereafter, a weekly telephone call or email was provided at the participant’s preference for support and to troubleshoot any issues that arose with the training programme. A number of technological issues arose which were resolved through Lumosity© as the study progressed.

***Philosophical positions***

The CogFlowS study assumes a position of multiple worldviews; a postposivitism approach was adopted for the quantitative outcome measures [16], whereas a constructivism approach was used for the qualitative aspects of feasibility, and the barriers and facilitators to CT. The final position assumed by this study was pragmatism, which was applied to the mixed methods analysis of this study (unpublished data) [18-20]**.** Multiple worldviews allow the researcher to assume multiple stances taking both biased and unbiased approaches; delivered in this study through a mixture of quantitative and qualitative techniques [20]. In the pragmatic approach, the research questions are prioritised [18-20], therefore a practical approach was taken to guide methodological choices to answer the research questions in this study. The pragmatic or multiple paradigm positions lend themselves better to studies of feasibility which often combine both qualitative and quantitative methods. This facilitates a practical approach to understanding the success or nature of a trial, puts feasibility as the primary focus, and allows the researcher to utilise multiple methods and resources to meet this aim.

## Conceptual framework

The use of a conceptual framework remains contentious amongst qualitative researchers, though when used appropriately, it can strengthen the quality and rigour of the research [21]. Here, the health belief model (HBM) was used as the core theoretical framework to underpin the research questions, the design of the interviews and focus groups, and to form the foundation of the analysis and reporting of the results of this study. The application of CT in practice requires both motivation and time commitment, and therefore a significant change in behaviour to adopt the intervention into daily life. Thus, a framework reflecting the complexity of behaviour change was used to construct the qualitative aspect of the study. The HBM was first described by Becker et al in 1974 in order to model preventative health behaviours in the United States, and to successfully design and implement interventions to target behavioural change [14]. The HBM is composed of six core constructs (Table 1, Figure 3) [14]. An updated version of this model was developed by Rosenstock in 1994, who added the perceived threat (sum of severity and susceptibility), taken as an indicator of motivation to avoid particular outcomes, and expectations (sum of benefits, barriers, and self-efficacy), taken as an indication to the extent or motivation towards a given action [14, 22, 23]. The HBM has been used across a range of disciplines to study and understand preventative health behaviours, including: infectious diseases, vaccination and chronic disease [22, 24, 25]. The HBM is not the only available model for behavioural change. In a scoping review by Davis et al [26], 82 different theories were identified for modelling behavioural change. Amongst the most frequently studied were: Social Cognitive Theory, Theory of Planned Behaviour/Reasoned Action, and the Transtheoretical Model of Change [26]. The HBM does have a number of limitations, namely, a lack of predictive power, poor construct definition and inconsistent application [24, 27]. However, a recent review by the National Institute of Health and Clinical Excellence (NICE), suggested that when applied systematically, the HBM can provide a comprehensive model for understanding behaviour change [27]. Currently, guidance is lacking on the most appropriate model to use, with limited evidence for any model in informing behavioural interventions, and this choice remains largely at the discretion and preference of the researcher [26].

## Researcher position, reflexivity, and rigour

The main research priority was the quantitative evaluation of the randomised trial, and we acknowledge that the post-positivism approach will have fed into the design and evaluation of the qualitative strand of this study. To mitigate against this, and to ensure qualitative rigour throughout the study conduct, a primarily qualitative researcher (RE) objectively reviewed the design, analysis, and interpretation of the study. Furthermore, to mitigate against the risk of bias presented by one researcher (LB) conducting all of the quantitative and qualitative analysis in this study, the analysis and interpretations were independently reviewed by RE.

## Interviews

Focus-groups were not conducted due to lack of participant interest and insufficient numbers completing the training at similar times. The interval schedule was underpinned by the six core constructs of the HBM: perceived barriers, perceived benefits, self-efficacy, cues to action, perceived susceptibility and perceived severity (Figure 3) [14]. Interviews were conducted by LB in participant’s homes, or at their follow-up visit to the Cerebral Haemodynamics in Ageing and Stroke Medicine research space at the Leicester Royal Infirmary. Where possible, participants with a diagnosis of dementia or MCI were interviewed jointly with their carer as a dyad. Thus, each dyad resulted in one interview transcript. A topic guide was developed by two researchers (LB & RE) to prompt topics that needed to be discussed, and was framed around the HBM. Development of the topic guide was an iterative process, and concepts which emerged from the initial interviews were subsequently incorporated into later interviews. The topic guide was modified as appropriate to the context of the conversation during the interview. The topic guide can be seen in Supplementary Material 1. Due to Covid-19, three interviews were conducted remotely by video-link. Interviews were recorded using a digital audio recorder, and notes were made on non-verbal and paralinguistic clues. Interviews were approximately 20-30 minutes duration.

## Data analysis

The findings from the semi-structured interviews were evaluated using framework analysis [28]. The digital recordings of the interviews and focus groups were transcribed verbatim, the transcripts were read in detail, i.e. line-by-line, and open codes were formed categorising and conceptualising the responses and identifying the major themes. The coding of the first few transcripts was checked by a second researcher (RE) to ensure consistency in coding.

Following this initial coding the analytical framework was developed; this was an iterative process and developed through coding of additional transcripts. Once the final transcript was coded, the analytical framework was used to generate the framework matrix. The framework matrix was developed in NVivo 11 (QSR International), and allowed for the recognition of patterns and outliers within the data. Transcripts were reviewed by participants for accuracy (respondent validation) [29]. All participants had only few, or minor, corrections to the transcripts.

# Results

Thirty-seven participants (10 healthy older adults, 4 MCI, 5 AD, 9 carer-patient dyads [2 MCI, 7 AD]) completed semi-structured interviews. Three of these participants dropped-out early from the main trial, but these participants were still invited to and completed the interviews as patient-carer dyads. The mean age of participants who completed the training was 68 years, and 39% were female. The baseline characteristics and main trial outcomes for the training group are summarised in Table 2. Of the 28 transcripts, 25 responses were received from participants, with all having no or minor changes. There was consistency between carer and participant coding. Results are presented according to the six main constructs of the HBM.

## Perceived barriers

Overall, there were a number of barriers identified from the semi-structured interviews. Barriers common to both healthy and patient groups included: difficulty with the instructions, poor visual acuity, dexterity and arthritis (particularly for exercises requiring speed), environmental distractors, technical issues, fatigue, learning curve. In particular, problems with technology could cause significant frustration, and hamper motivation and engagement. Participants felt they needed greater support, and there was a sense of futility when problems were encountered:

*“the frog leap one I found that really kind of frustrating because even though I felt that I was doing what I was supposed to, it wasn’t picking up and I had to keep repeating it over and over again, and then I felt that was soul destroying for me because I kind of felt that I was following but effectively it was saying that I wasn’t” – p7 (MCI)*

Frustration was commonly reported by all participants and was related to: problems with technology, difficulty with certain exercises, less enjoyable exercises, inability to improve or progress, and insufficient instructions.

Three participants dropped-out of the training programme with a diagnosis of dementia, but there were no drop-outs amongst the healthy or MCI groups. Barriers were high amongst the three drop-outs, in particular, high levels of anxiety and stress, apathy, and problems with technology were present amongst these participants. These barriers are now discussed in more detail.

Compared to participants with a diagnosis of dementia, the majority of healthy participants found the programme user-friendly and straight-forward. However, healthy participants felt the instructions could be improved, particularly information on scoring of the exercises:

*“I wouldn’t say difficult…..but they don’t describe it fully…….they certainly don’t go into how the thing is scored, whether it’s against the clock or not.” – p4 (healthy)*

For healthy participants, time and work commitments were a key barrier to training, and more-so than in the participants with dementia. Participants were often fatigued after work, and this hampered engagement:

*“I think I managed to do three a week, each week, but it wasn’t always that easy……….because I’m working often the only time I can do the training is kind of in the evening and that’s meant I’m sometimes a bit tired by the time I get to it” –p10 (healthy)*

The lack of portability in the programme prevented healthy participants from being able to “train on the go”. Certainly, flexibility to fit the programme in around their schedule was an important priority for older adults, and fixed or facilitated sessions were less acceptable to participants.

Participants recognised that trying to complete the programme whilst tired or over-practising exercises could affect their performance and be counter-productive, particularly where that did not translate into improved performance:

*“yeah I think it made myself more aware of the fact that actually I’m tired, I’m not focussing I’ve got something else on my mind and I guess it raised my level of awareness of that side of things” – p10 (healthy)*

Participants noted there was a learning curve, but that over time their understanding and thus performance and enjoyment improved with practice:

*“I got less frustrated with it as I went on. So why was I frustrated? It was new, I think probably most people would get frustrated with a new computer system when they first use it and I don’t really know what it is it wants you to do and so in that sense it was frustrating, certainly, the anxiety of doing the training got less and less with time” – p4 (healthy)*

Participants with dementia reported finding the instructions “confusing”, and the exercises were not always intuitive. In particular, reminders of the instructions throughout the exercises would have been beneficial:

*“mainly when you couldn’t remember what you were doing because it tells you at the beginning what to do and then you get onto the game and then you get confused, you forget what its told you so it doesn’t jog your memory what to do, you just have to keep going and hope you get it right” – p11 (AD)*

Pre-morbid education levels and computer literacy were lower amongst participants with AD and MCI than healthy participants, and limited engagement with, and understanding of, the programme for some participants.

In keeping with healthy participants, the majority of participants with dementia also preferred a flexible, home-based programme. However, this was associated with fewer social benefits, and increased friction between participants and their carers which some felt may be reduced with group or facilitated sessions:

*“I just wonder whether if this was conducted in a room……where people got together apart from their families because I think though [patient] is really good with the kids, he tends to get annoyed with me if I’m trying to get him to do something” – carer for p12 (AD)*

Although portability was a priority for healthy participants, this was less important for participants with AD or MCI, who were more familiar with a desktop computer than tablets or smart phones. In addition, working on a computer reduced barriers for those with lower visual acuity and arthritis:

*“because my eyesight is no longer a hundred percent I’m quite happy on a computer. I’m more at home at doing it on the computer, the small keys on my mobile, you know” – p9 (MCI)*

Compared to healthy participants, exposure to and proficiency with technology was more variable amongst participants with dementia or MCI, and was a barrier to successful engagement, particularly with time-based exercises:

*“you found some of them too fast for you to coordinate the mouse or the keyboard. The speed was just a bit fast sometimes” – carer of p26 (AD)*

Compared to healthy participants, the “learning curve” was more challenging for participants with dementia, and many struggled with adapting to new situations and acquiring new skills. For a minority of participants with dementia (n=3), difficulty with completing the exercises were insurmountable and led to negative feelings, reduced self-esteem, and ultimately drop-out from the programme:

*“Carer: You just couldn’t pass them. Couldn’t pass the exercises could you? So it made you feel a failure that you couldn’t cope with the exercises.*

*Patient: I don’t know about that. Or maybe I just didn’t want to. If you like I’ve given up.” -Carer and p2 (AD).*

Participants with a diagnosis of AD had more variable effects to mood than healthy participants or those with MCI; ranging from positive effects, to mild annoyance or irritation, to significant anxiety and stress resulting in drop-out from the study:

*“I think like with the word one, a bit depressed because I thought I should be able to do these and that gets me down because I think it’s hard, I think there’s something wrong with me” – p11 (AD)*

For participants with AD, apathy, lack of insight, and severity of the dementia could be significant barriers to engaging with the training programme. Two participants were unable to complete the study, in part due to lack of motivation, and dementia severity:

*“Motivation is something that’s really gone, you know, motivating [patient] to do a lot of things isn’t as easy as it used to be” – carer for p12 (AD)*

## Perceived benefits

Although barriers were present, there was a high completion rate of the programme (25 out of 28 participants completed), and a number of benefits were identified by participants: enjoyment and interest, benefit to self or others, learning new skills, visible progress, entertainment, taking back control, relief and reassurance, benchmarking, maintaining an active mind, and improved awareness.

In particular, enjoyment was a common feature to those who completed the programme and participants identified a sense of benefit either to others by improving knowledge through research or to themselves by participating and completing the programme:

*“I definitely felt that it improved my abilities to think because I had something to think about very hard in those programmes” – p17 (AD)*

Enjoyment was linked to performance, with participants finding exercises more enjoyable where they performed better or progressed further. Regardless of diagnosis, all participants saw benefit to keeping the mind active, (the “use it or lose it” principle), and akin to “exercising a muscle”. Both healthy and participants with dementia felt the programme increased their awareness of areas they struggled with, allowing them to focus on, and improve this domain:

*“I think it made me more aware of areas that I struggle…….I wasn’t concentrating, so that showed me that when I think I’m concentrating I’m not always” – p13 (AD)*

Healthy participants and those with MCI were less likely to identify benefits to function than those with dementia, and may have been as a result of a relatively high level of baseline function:

*“well I’ve not really got any challenges with my day to day activities really because I’ve got mild cognitive impairment so it’s not the worst part of it” - p5 (MCI)*

Few healthy participants or those with a diagnosis of MCI noticed direct effects of the programme on their mood, but a number commented on positive feelings they experienced during the programme, which tended to be linked with their performance, a sense of achievement, or progression:

*“yeah it made me feel quite happy, it made me feel if I’d got a better score I felt that I’d progressed so it made me feel good because I’d achieved something even if it was only ten points more or something. I just felt good because I’d achieved something a bit better” - p16 (healthy)*

Participants with dementia were more likely to identify benefits to their memory than healthy participants, which may have been due to greater scope for improvement, but also due to greater “buy in” as a result of higher perceived potential for benefit. In keeping with healthy participants, few people with dementia identified transfer effects or functional improvements. One participant with MCI was able to develop strategies taken from the programme and apply them to their daily life:

*“I think it has helped me to re-look at things and break it down and do it by its size rather than trying to do what you used to do and do everything in one go” – p7 (MCI)*

Unique to participantswith dementia, MCI and their carers was a sense of relief and reassurance in their ability manage the programme and complete the exercises. Participants used the programme to benchmark their current level of cognitive function, and reassure themselves of their ability:

*“I was pleased with my abilities, it proved that I was, there was quite a lot there that I could cope with” – p12 (MCI)*

Amongst participants with dementia and MCI, stability of symptoms, and prevention of deterioration, was as beneficial as improvement:

*“the path we’re on we understand eventually is downward and the fact that there was no downward progression was good” – carer for p19 (AD)*

For participants with dementia, benefits to the programme were related to the stage of cognitive impairment, where benefits were seen to be greater for those at an earlier stage of cognitive decline:

*“I think the idea’s good, it’s just at what stage you’d get somebody to do it….maybe the earlier you did this the better it would be to keep them stimulated for longer” –carer of p12 (AD)*

Despite the negative effects on mood described in the barriers section, participants with dementia, also described positive feelings, particularly where they saw improvement, progress, or achievement:

*“to see that I was actually achieving something, getting better at certain things than I started off I suppose that’s really the ideal thing is to see an achievement isn’t it?” – p15 (AD)*

Finally, for participants with dementia or MCI, completing the programme gave participants a sense of control, allowing them to take a positive action against a degenerative disease with few treatment options:

*“because you feel you’re improving something and of course you know as you get older things are going to deteriorate and you feel as though you’re doing something to stop that” – p10 (MCI)*

## Perceived threat (risk susceptibility and severity)

Perceptions of risk susceptibility varied between participants, but was felt to be multifactorial (age, diet and lifestyle, physical and mental activity, sleep, and family history). Participants felt the risk was inevitably high due to the prevalence of dementia, and cognitive decline was considered to be part of “normal ageing”. Risk was perceived to be lower in participants with a more positive outlook. Healthy participants and those with MCI felt there was as an opportunity to apply preventative strategies to strengthen their cognition and protect against dementia:

*“the main thing is to stay positive and to help yourself now and do everything that you can to even delay that………but it’s just making the most of what you have now and strengthening it as much as you can” – p7 (MCI)*

Current state of memory was seen to be predictive of future dementia risk, with a better memory being more protective:

*“only that my father has severe memory loss and I just think that my memory is not as brilliant as it should be generally so that makes you think I wonder what it will be like in the future” – p7 (healthy)*

For all participants, the severity of the risk was acknowledged to be high, and was dependent on a number of factors, (social support, severity of the dementia, level of insight, early planning and preparation).

## Self-efficacy

Developing “strategies” by which to successfully complete or circumvent the exercises was seen as a challenge and motivating factor. The majority of participants were motivated by monitoring their progress and performance through the programme, and certainly, perceived improvements facilitated programme adherence:

*“mostly because I wanted to sort of see what effects it did actually have on me, so I thought the more I do it the better my score on some of the games…….that means that I improved myself, my memory, so I achieved that much so that really sort of pushed me to keep doing it, doing better so that I could improve myself basically” – p16 (healthy)*

However, for some, monitoring scores and progress was counter-productive, particularly when they were not improving:

*“some days you did better and other days he’d do worse than the very first time he did it, then you got a bit down hearted” – carer of p11 (AD)*

One participant described the feedback as a “generic pat on the back”, and would be more valuable if it was more personalised. In general, participants would have preferred a more tailored programme, taking into account education, occupation, and current dementia severity, with personalised feedback on performance:

*“they’ve got to be explaining what you’re supposed to be doing and a purpose other than the obvious thing of identifying sea urchins, sea animals, that’s obvious what that’s about but what is that actually helping? To get some feedback on my brain, I am coping, how I’m doing?” – p25 (AD)*

Participants also enjoyed the challenge, and although more difficult exercises entered an element of frustration, participants recognised that these exercises were pushing or stretching them more than simpler exercises that were easier to complete:

*“well keeping your brain active and making new links and making you push yourself to do things that you might not otherwise do so you know some of the activities I probably wouldn’t choose to do but making me do those…” – p19 (healthy)*

Adherence to the programme was generally good but for some participants this deteriorated over time:

*“when I first came here and I went home I was doing it religiously, but then it slipped my mind and then I found it difficult to get it back in the routine” – p13 (AD)*

Adherence was fostered through a sense of commitment and investment to completing the training:

*“well since I’d started it- invested the time that I had I wouldn’t want to stop it part way through……but also I’m interested to see what it could tell you about my own condition” – p3 (MCI)*

Participants preferred exercises to be “prescribed”, providing a better challenge, and reducing the risk of training a limited number of cognitive domains, and prevent participants selecting exercises which more enjoyable, but not necessarily “training” the brain:

*“if you chose the games you’d probably only choose the easy games and I quite liked the challenge with what I found the more difficult ones because I got quite determined I wanted to be able to do it!” –p16 (healthy)*

Furthermore, healthy participants and those with MCI acknowledged their ability was likely to fluctuate and were more accepting of that, which provided additional resilience:

*“I knew that even though I was working as hard as I could there were days when it was not one of my good days but I just accepted that and I didn’t feel like it affected my mood” – p7 (MCI)*

The competitive nature of the programme was also a motivating factor, not wanting to be “beaten by the computer”. Participants felt encouraged by the positive feedback and reinforcement the programme provided which instilled a sense of achievement and satisfaction:

*“at the end of each day’s thing it said keep it up didn’t it? It gave him a sentence, a bit of encouragement, come back for the next session” – carer of p26 (AD)*

## Cues to action

The majority of participants were able to meet the target of five sessions per week, and different strategies were employed to achieve this (e.g. incorporation into daily routine, prompts or reminders). For participants with AD and MCI, carer support was often integral to completing the programme. For some this was a positive experience, becoming a shared journey between participants and their carers, with carers enjoying the participant’s engagement with the programme:

*“well he wouldn’t have managed if I hadn’t helped him to get onto it every time but that got better………but I quite enjoyed watching him do them but you know, you did get frustrated if you couldn’t remember what to do” –carer for p21 (AD)*

For carers there was the added challenge of taking a “step-back” and allowing the participant to undertake the programme without providing too much support:

*“sometimes it is quite challenging not to interfere too much, to leave him to it……I try to take a step back” – carer of p21 (AD)*

For participants with dementia, it was important to balance variety of exercises with sufficient repetition such that participants could track their progress and facilitate familiarity with the exercises:

*“The repetition of the puzzles as we became more familiar made it smoother and less restrained but at the start it was a bit frustrating” – carer of p19 (AD)*

Participants had mixed views on the role of CT in dementia risk reduction, many aligned the benefits with keeping mentally active, and whilst it was seen “not to do any harm”, participants felt it may delay but not prevent the trajectory towards dementia:

*“if you’re inclined to get dementia it will help keep it off a little bit but I think if you’re going to get dementia you’re going to get it anyway, nothing can stop it” – p11 (healthy)*

Participants discussed the role of brain stimulation in dementia risk reduction and getting that message through is a potential cue or trigger to adopting behaviour change. However, there was a level of scepticism, particularly amongst healthy participants around the effectiveness of CT, and a number of participants cited the importance of having sufficient evidence which would primarily affect their decision whether or not to undergo a preventative programme:

*“I don’t whether there’s scientific evidence to prove that, I work on evidence, so if I think there’s evidence to support that…….I would certainly do it but I know there is evidence that people who have an active mind, who participate, and socialise and so on, are less likely to suffer from dementia so I know those factors I’m not sure of brain training in inverted commas directly will affect that but again I would be interested see whether the data proves that I’d certainly do it” – p6 (healthy)*

Certainly, evidence was more often cited as a trigger to taking up behavioural intervention than more generic sources, such as the media. One participant entered the study with preconceptions about the lack of effectiveness of CT, which they felt were reinforced by the programme, and would opt to do other activities for mental stimulation. Preconceptions were influenced by the commercial nature of the programme, and concerns around the validity of prior research. For some participants with dementia there were alternative activities that provided more benefit and stimulation, for example one participant and carer discussing informal reminiscence:

*“I just have to repeat everything several times but then suddenly you will remember something. We try and talk about things from the past, lovely holidays, travelling the world, and people that we’ve met, and you know I try and get you to remember things” – carer of p2 (AD)*

Figure 4 conceptualises the major themes and their relationship to the HBM, and Table 3 summarises the interview data under the six constructs of the HBM.

Discussion

## Summary of results

In summary, the study and CT programme were feasible and acceptable to healthy older adults and participants with dementia or MCI, as evidenced by the high completion rate and number of perceived benefits. Key priorities for all participants were: flexibility in the timing of the programme, and greater personalisation of the training and the feedback on an individual basis. Key barriers to participation were: lack of device portability, poor instructions, difficulties with technology, apathy, dementia severity, and conflict between patients and carers. There was limited qualitative evidence for the presence of any transfer effects. However, participants did see benefit in keeping mentally active as part of a healthy lifestyle contributing to the prevention of dementia, and maintenance of cognitive function. Perceptions regarding risk susceptibility to dementia varied between participants but risk severity was perceived to be high. Participants felt there was a lack of sufficient evidence on whether CT could mitigate this risk, but some would consider the use of a CT programme if the benefits were scientifically proven.

## Results in context of the HBM

Despite the high number of barriers to action, particularly amongst participants with a diagnosis of dementia, completion rate of the trial was high (89% completed the programme). Although benefits were present, few perceived transfer effects were identified, and benefits were more general (e.g. increased awareness, sense of control), consistent with previous studies [30]. Participants with dementia or MCI were more likely to identify benefits to their memory or abilities compared to healthy older adults, which may be due to greater “buy-in”, given they had potentially more to gain from completing the programme. The high completion rate is therefore discordant with the balance of barriers and benefits identified in this analysis. Despite significant barriers to training, many participants were able to maintain motivation and adherence. A central theory to the HBM is that where the severity of the threat is perceived to be high, the individual is more likely to engage in health related behaviours perceived to reduce that risk [23]. Thus, the willingness to take part in and complete a trial of CT for healthy older adults and MCI may reflect the high perceived severity of a dementia diagnosis recognised by all participants. Similarly, participants with dementia may be willing to adopt a cognitive intervention despite its side effects due to the high chance of deterioration, and limited treatment options available. Although perceived susceptibility was felt to be low and multifactorial, the overall perceived threat (combination of perceived severity and susceptibility), was seen to be high which may moderate individual’s decision making [23]. Perceived threat is dependent on the level of knowledge on dementia risk [14]. This was a sample of well-educated healthy older adults, and in part this may have moderated the interaction with the CT programme. Interestingly, participants were not overly influenced by media reports, and were largely evidence driven in their choices to adopt cognitive intervention to prevent dementia or sustain cognitive function. Family history was commonly identified as a significant risk factor by healthy participants, and acted as a prompt to engage in cognitively healthy lifestyles, and both physical exercise and cognitive stimulation were seen to facilitate this. Maintaining independence is a key priority for healthy older adults [31] and preventative programmes are appealing to maintain cognitive function [11, 30]. However, healthy older adults in Finland expressed similar doubts on the effectiveness of prevention strategies, with an element of futility, and strongly-held perceptions on hereditary dementia risk [32]. Thus, where risk is felt to be non-modifiable, this may hamper engagement with preventative programmes.

Self-efficacy describes the belief and confidence an individual has in their ability to execute a given task [33]. Thus, where self-efficacy is perceived to be low in relation to an intervention, this will reduce engagement [33]. In addition to self-efficacy, perceived locus of control, as internal (i.e. within the individual’s control) rather than external (beyond their control), is also important for successful behaviour change [33]. Thus, people need both the skills to effect change, and the belief and confidence to do so [33]. For the majority of participants, CT was able to improve and foster a sense of self-efficacy by providing regular positive feedback, and improving participant’s self-esteem and motivation through a sense of achievement. In particular, CT was empowering for participants with MCI and dementia, improving their sense of control by allowing them to take a positive action to improve their cognitive function. However, this was not universal and self-efficacy was greater amongst healthy older adults compared to those with cognitive impairment. Indeed, three participants with dementia dropped-out of the programme, in part due to lack of confidence and self-efficacy to complete the programme. These participants also had a number of internal barriers (e.g. severity of dementia, apathy), which were not easily modifiable to enhance engagement with the programme. The concept of futility in dementia prevention has been previously identified as a barrier to successful engagement, [9, 34], and was evident amongst participants in this study. One solution may be to combine CT with cognitive behaviour therapy to address the impact of negative emotions or thoughts on programme engagement [9].

Barriers to engaging effectively with the programme were more prevalent amongst participants with dementia compared to healthy older adults and people living with MCI. Apathy is one of the most common neuro-psychiatric symptoms in dementia, and is associated with poorer outcomes [35, 36], and was a significant barrier here, resulting in reduced motivation and engagement. Apathy is commonly associated with lack of insight, which was a significant barrier to CT for patients with cognitive impairment associated with HIV and schizophrenia [13]. Lack of insight may reduce the perceived susceptibility and vulnerability to further deterioration in cognitive function, and thus may inhibit a person’s willingness to engage with cognitive intervention. Self-awareness and insight can be enhanced by CT, and have been demonstrated previously for those with acquired brain injury [10] and healthy older adults [30]. However, increasing awareness and insight can also result in anxiety, emotional stress and poor self-esteem, consistent with previous studies [10, 34, 37]. Compared to healthy older adults and those with MCI, participants with dementia were less resilient to difficulties, and self-efficacy was more likely to be compromised at a lower threshold as a result. Thus, CT presents specific challenges that are unique for patients with dementia, which will require specific adaptations and additional support.

## Intervention components, feasibility and recommendations

The majority of participants in this study preferred a flexible, home based programme, due to time and work commitments. Group based CT may be more effective than home based [3], but is limited by: time and motivation, life commitments (e.g. family, work), [13, 38, 39], poor health and mobility, and transport [30, 40]. Here, CT resulted in conflict between patients and their carers, and carers had a tendency to over-support participants. Group-based CT was felt to potentially avoid this friction, and may also provide greater social interaction. This may be particularly beneficial to those who are lonely, isolated or cognitively impaired [30, 38, 39], and has been identified as a key aspect of “successful ageing” [41]. A particular advantage of group-based sessions may be to offer normalisation of experiences related to memory loss and ageing [34, 37]. However, group-based cognitive interventions can have side-effects (i.e. anxiety), which can negatively impact on engagement with the programme [10, 30]. Anxiety was a barrier for participants with dementia, and resulted in drop-out in this study and others [13]. Therefore, CT needs to be flexible and meet the needs of the individual.

Access to technology can be a barrier to implementing home-based programmes [30, 42], although this was not identified here or in other studies [11, 40]. Problems with technology can be a significant source of frustration for participants [11, 13, 30, 40], and participants need access to an environment conducive to training [13, 30, 39]. Furthermore, learning a new skill, combined with technology can be problematic for older adults, and more-so those with cognitive impairment [39]. A graded increase from paper and pen to computer exercises may reduce the number of new skills required at the outset. Increasingly, wide array of platforms are available to engage with CT, but platform preference varied between participants, and multiple options should be available. However, programmes are not easily adapted and translated between platforms, reducing accessibility.

Participants valued more individualised feedback [11], and programmes should be tailored to individual’s occupation, education and dementia severity to ensure they are achievable. Many CT programmes have been developed and tested in healthy populations, and may not be applicable to patients with dementia. Thus, CT programmes need to be developed and evaluated specifically for different populations. Exercises should be relatable to everyday life, and were found to be abstract and confusing by participants in this study and others, resulting in reduced engagement [11, 30, 39]. Table 4 summarises the key recommendations for the adaptation of CT programmes for people living with dementia.

## Strengths, limitations, and future directions

The strengths of this study were a relatively large sample reaching data saturation for the majority of themes, and the use of the HBM to underpin the design and analysis of the study [43]. Selection bias may have selected participants who are more computer-literate and who have access to technology. Although the HBM has a number of limitations, when applied systematically, it can provide a comprehensive model for understanding behaviour change [18]. Three interviews were conducted remotely by video-link which may have reduced the recording quality and identification of para-linguistic cues. Future studies should investigate the comparable acceptability of different types of cognitive interventions.

# Conclusions

In conclusion, a home-based computerised CT programme was feasible and acceptable to healthy older adults, and the majority of participants with dementia and MCI, and their carers. However, a number of key barriers were identified which need to be considered in order for home-based CT programmes to be adapted for people living with dementia, and facilitate successful implementation.

**Acknowledgements**

We would like to acknowledge the input of the members of the patient and public involvement group and trial steering committee in the development and oversight of this study. We would like to acknowledge Lumosity© for providing the cognitive training software used in this study.

**Funding sources**

LB is a Dunhill clinical research training fellow (RTF1806\27). TGR is a National Institute for Health (NIHR) Senior Investigator. The views expressed in this article are those of the author(s) and not necessarily of NIHR or the Department of Health and Social Care. Lumosity© provided the cognitive training programme but did not provide any financial support and were not involved in the design or implementation of the study.

**Conflicts of interest**

None to declare

# References

[1] Gates NJ, Vernooij RW, Di Nisio M, Karim S, March E, Martinez G, Rutjes AW (2019) Computerised cognitive training for preventing dementia in people with mild cognitive impairment. *Cochrane Database Syst Rev* **3**, Cd012279.

[2] Hill NT, Mowszowski L, Naismith SL, Chadwick VL, Valenzuela M, Lampit A (2017) Computerized Cognitive Training in Older Adults With Mild Cognitive Impairment or Dementia: A Systematic Review and Meta-Analysis. *Am J Psychiatry* **174**, 329-340.

[3] Lampit A, Hallock H, Valenzuela M (2014) Computerized cognitive training in cognitively healthy older adults: a systematic review and meta-analysis of effect modifiers. *PLoS Med* **11**, e1001756.

[4] Zhang H, Huntley J, Bhome R, Holmes B, Cahill J, Gould RL, Wang H, Yu X, Howard R (2019) Effect of computerised cognitive training on cognitive outcomes in mild cognitive impairment: a systematic review and meta-analysis. *BMJ Open* **9**, e027062.

[5] Zucchella C, Sinforiani E, Tamburin S, Federico A, Mantovani E, Bernini S, Casale R, Bartolo M (2018) The Multidisciplinary Approach to Alzheimer's Disease and Dementia. A Narrative Review of Non-Pharmacological Treatment. *Front Neurol* **9**.

[6] Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M (2008) Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ* **337**, a1655.

[7] Lampit A, Valenzuela M, Gates NJ (2015) Computerized Cognitive Training Is Beneficial for Older Adults. *J Am Geriatr Soc* **63**, 2610-2612.

[8] Beishon L, Intharakham K, Swienton D, Panerai RB, Robinson TG, Haunton VJ (2020) Neuroimaging Outcomes in Studies of Cognitive Training in Mild Cognitive Impairment and Early Alzheimer's Disease: A Systematic Review. *Curr Alzheimer Res* **17**, 472-486.

[9] Choi J, Twamley EW (2013) Cognitive rehabilitation therapies for Alzheimer's disease: a review of methods to improve treatment engagement and self-efficacy. *Neuropsychol Rev* **23**, 48-62.

[10] Dugmore O, Orrell M, Spector A (2015) Qualitative studies of psychosocial interventions for dementia: a systematic review. *Aging Ment Health* **19**, 955-967.

[11] Haesner M, O'Sullivan JL, Govercin M, Steinhagen-Thiessen E (2015) Requirements of older adults for a daily use of an internet-based cognitive training platform. *Inform Health Soc Care* **40**, 139-153.

[12] Gates NJ, Sachdev P (2014) Is cognitive training an effective treatment for preclinical and early Alzheimer's disease? *J Alzheimers Dis* **42 Suppl 4**, S551-559.

[13] Ferreira-Correia A, Barberis T, Msimanga L (2018) Barriers to the implementation of a computer-based rehabilitation programme in two public psychiatric settings. *S Afr J Psychiatr* **24**, 1163.

[14] Jones CL, Jensen JD, Scherr CL, Brown NR, Christy K, Weaver J (2015) The Health Belief Model as an Explanatory Framework in Communication Research: Exploring Parallel, Serial, and Moderated Mediation. *Health Commun* **30**, 566-576.

[15] Beishon L, Evley R, Panerai RB, Subramaniam H, Mukaetova-Ladinska E, Robinson T, Haunton V (2019) Effects of brain training on brain blood flow (The Cognition and Flow Study-CogFlowS): protocol for a feasibility randomised controlled trial of cognitive training in dementia. *BMJ Open* **9**, e027817.

[16] Beishon LC, Panerai RB, Budgeon C, Subramaniam H, Mukaetova-Ladinska E, Robinson TG, Haunton VJ (2021) The Cognition and Flow Study: A Feasibility Randomized Controlled Trial of the Effects of Cognitive Training on Cerebral Blood Flow. *J Alzheimers Dis*. doi: 10.3233/JAD-201444.

[17] O’Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA (2014) Standards for Reporting Qualitative Research: A Synthesis of Recommendations. *Acad Med* **89**, 1245-1251.

[18] Johnson RB, Onwuegbuzie A (2004) Mixed methods research: a research paradigm whose time has come. *Educational researcher* **33**, 14-26.

[19] Johnson RB, Onwuegbuzie AJ, Turner LA (2007) Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research* **1**, 112-133.

[20] Creswell JW, Plano Clark VL (2011) *Designing and conducting mixed methods research*, SAGE Publications.

[21] Collins CS, Stockton CM (2018) The Central Role of Theory in Qualitative Research. *International Journal of Qualitative Methods* **17**, 1609406918797475.

[22] Janz N, Becker M (1984) The health belief model: a decade later. *Health Educ Q* **11**, 1-47.

[23] Rosenstock I (1974) Historical origins of the health belief model. *Health Educ Monogr* **2**, 328-335.

[24] Munro S, Lewin S, Swart T, Volmink J (2007) A review of health behaviour theories: how useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health* **7**, 104.

[25] Harrison JA, Mullen PD, Green LW (1992) A meta-analysis of studies of the Health Belief Model with adults. *Health Educ Res* **7**, 107-116.

[26] Davis R, Campbell R, Hildon Z, Hobbs L, Michie S (2015) Theories of behaviour and behaviour change across the social and behavioural sciences: a scoping review. *Health Psychol Rev* **9**, 323-344.

[27] Taylor D, Bury M, Campling N, Carter S, Garfield S, Newbold J, Rennie T (2006) A Review of the use of the Health Belief Model (HBM), theTheory of Reasoned Action (TRA), the Theory of PlannedBehaviour (TPB) and the Trans-Theoretical Model (TTM) to study and predict health related behaviour change. *NICE*, 4-77.

[28] Gale NK, Heath G, Cameron E, Rashid S, Redwood S (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* **13**, 117.

[29] Hansen EC (2006) *Successful Qualitative Health Research: A Practical Introduction*, Maidenhead: Open University Press.

[30] Shtompel N, Ruggiano N, Thomlison B, Fant K (2019) Dyadic, Self-Administered Cognitive Intervention for Healthy Older Adults: Participants’ Perspectives. *Activities, Adaptation & Aging*, 1-20.

[31] Tkatch R, Musich S, MacLeod S, Kraemer S, Hawkins K, Wicker ER, Armstrong DG (2017) A qualitative study to examine older adults' perceptions of health: Keys to aging successfully. *Geriatr Nurs* **38**, 485-490.

[32] Rosenberg A, Coley N, Soulier A, Kulmala J, Soininen H, Andrieu S, Kivipelto M, Barbera M (2020) Experiences of dementia and attitude towards prevention: a qualitative study among older adults participating in a prevention trial. *BMC Geriatr* **20**, 99.

[33] Rosenstock IM, Strecher VJ, Becker MH (1988) Social learning theory and the Health Belief Model. *Health Educ Q* **15**, 175-183.

[34] Matthews ML, Wells Y, Pike KE, Kinsella GJ (2018) Long-term effects of a memory group intervention reported by older adults. *Neuropsychol Rehabil*, 1-15.

[35] Nobis L, Husain M (2018) Apathy in Alzheimer's disease. *Curr Opin Behav Sci* **22**, 7-13.

[36] Breitve MH, Brønnick K, Chwiszczuk LJ, Hynninen MJ, Aarsland D, Rongve A (2018) Apathy is associated with faster global cognitive decline and early nursing home admission in dementia with Lewy bodies. *Alzheimers Res Ther* **10**, 83.

[37] Vandermorris S, Davidson S, Au A, Sue J, Fallah S, Troyer AK (2017) ‘Accepting where I'm at’ – a qualitative study of the mechanisms, benefits, and impact of a behavioral memory intervention for community-dwelling older adults. *Aging & Mental Health* **21**, 895-901.

[38] Cuevas HE, Stuifbergen AK, Brown SA, Rock JL (2017) Thinking About Cognitive Function: Perceptions of Cognitive Changes in People With Type 2 Diabetes. *Diabetes Educ* **43**, 486-494.

[39] Merriman NA, Bruen C, Gorman A, Horgan F, Williams DJ, Pender N, Byrne E, Hickey A (2019) "I'm just not a Sudoku person": analysis of stroke survivor, carer, and healthcare professional perspectives for the design of a cognitive rehabilitation intervention. *Disabil Rehabil*, 1-11.

[40] Shatil E (2013) Does combined cognitive training and physical activity training enhance cognitive abilities more than either alone? A four-condition randomized controlled trial among healthy older adults. *Front Aging Neurosci* **5**, 8.

[41] Reichstadt J, Sengupta G, Depp CA, Palinkas LA, Jeste DV (2010) Older adults' perspectives on successful aging: qualitative interviews. *Am J Geriatr Psychiatry* **18**, 567-575.

[42] Hedman A, Lindqvist E, Nygård L (2016) How older adults with mild cognitive impairment relate to technology as part of present and future everyday life: a qualitative study. *BMC Geriatr* **16**, 73.

[43] Hennink MM, Kaiser BN, Marconi VC (2017) Code Saturation Versus Meaning Saturation: How Many Interviews Are Enough? *Qual Health Res* **27**, 591-608.

[44] Fayanju OM, Kraenzle S, Drake BF, Oka M, Goodman MS (2014) Perceived barriers to mammography among underserved women in a Breast Health Center Outreach Program. *Am J Surg* **208**, 425-434.



Figure 1. Schematic diagram of the CogFlowS study summarising the explanatory sequential mixed methods design, and stage of quantitative (QUAN) and qualitative (QUAL) data collection and integration.



Figure 2. Recruitment flow chart for the study. Participants who dropped out were eligible for interview in the qualitative study. Where possible carers were interviewed alongside participants with a diagnosis of mild cognitive impairment (MCI) or dementia (Alzheimer’s disease – AD). In this instance, one interview transcript was produced per dyad.



Figure 3. The Health Belief Model adapted from [44].



Figure 4. Sub-themes within four major themes of the Health Belief Model.

|  |  |
| --- | --- |
|  | **Health Belief Model Constructs** |
|  | *Risk susceptibility*  The subjective perception of the risk the individual is at from a state or condition. |
|  | *Risk severity*  Subjective evaluation of the seriousness of the consequences associated with the state or condition. |
|  | *Benefits to action*  The subjectively understood positive benefits of taking a health action to offset a perceived threat. This perception will be influenced not only by specific proximal factors, but an individual’s overall ‘health motivation’. |
|  | *Barriers to action*  The perceived negatively valued aspects of taking the action, or overcoming anticipated barriers to taking it. |
|  | *Self-efficacy*  Act or task specific self-confidence, i.e. belief in one’s ability to execute a given behaviour. |
|  | *Cues to action*  Reminders or prompts to take actions consistent with an intention, ranging from advertising, to personal communications from health professionals, family members and/or peers. |

Table 1. The six constructs of the health belief model [14].

|  |  |  |  |
| --- | --- | --- | --- |
| **Demographics/outcome** | **Healthy** | **MCI** | **Dementia** |
| n | 10 | 6 | 12 |
| Age (years) | 63.0 (7.1) | 69.8 (11.4) | 71.2 (8.2) |
| Sex (n,% female) | 6 (60) | 2 (33) | 9 (75) |
| Ethnicity (n,% Caucasian) | 10 (100) | 6 (100) | 12 (100) |
| Education (years) | 18.5 (3.6) | 14.8 (3.3) | 14.4 (3.5) |
| **Mean (SD) Pre-intervention** | | | |
| Cognition (ACE-III) | 97.2 (2.8) | 91.3 (6.5) | 77.2 (13.5) |
| Quality of life (DEMQOL) | 106.4 (5.9) | 90.8 (8.3) | 94.5 (12.0) |
| Mood (GDS-15) | 0.8 (0.6) | 3.3 (1.4) | 2.8 (2.9) |
| Everyday activities (Lawton IADL) | 8 (0) | 7.7 (0.5) | 5.4 (1.9) |
| **Mean (SD) Δ change Post-intervention** | | | |
| ACE-III | 0.2 (1.6) | 0.2 (3.9) | 2.1 (4.8) |
| DEMQOL | 1.5 (2.7) | 2.7 (6.4) | 2.4 (7.7) |
| GDS | -0.1 (0.7) | -1.0 (1.3) | 0.3 (1.8) |
| Lawton IADL | 0.0 (0.0) | -0.3 (0.5) | 0.3 (1.3) |

Table 2. The baseline characteristics and major trial outcomes of participants who completed the CT programme and semi-structured interviews for the qualitative study. Data are mean (standard deviation [SD]), or number (percentage). Data for post-intervention are delta change from baseline scores. MCI= mild cognitive impairment. ACE-III= Addenbrooke’s Cognitive Examination III, DEMQOL= Dementia Quality of Life, GDS-15= Geriatric Depression Scale (15 item), IADL= Instrumental Activities of Daily Living.

|  |  |  |
| --- | --- | --- |
| **Theme** | **Participant No.** | **Quote from interview** |
| **Risk Susceptibility** | | |
| Healthy | 20 | *“I don’t think so well I hope not [dementia risk]. I do try and do exercise and as much sleep as possible at night and eat fairly well, I’m not overweight if there’s anything else I could do to prevent it [dementia] I’d do it”* |
| MCI | 3 | *“I would imagine that there’s a distinct chance that [dementia] might happen, I mean it does happen quite a lot to most people and given that I know my memory is failing in fact”* |
| **Risk severity/dementia severity** | | |
| Healthy | 4 | *“Quite high I should think and it depends on, obviously depends on level, and depends on a whole variety of other things as well. So do I want to develop dementia? No thank you, if I’m offered the choice but I don’t think I’m being offered a choice”* |
| MCI | 9 | *“it’s difficult, I have a good friend who is now deeply into dementia and he’s still managing to live at home independent because there’s about half a dozen people watching over him all the time. I would hope that I would still be able to, even if I couldn’t get out about, still be able to live independently in my own home and I don’t know, I’ve not really noticed any serious impairment it’s just that I did get worried twelve months ago and sought the doctor’s advice and here I am and I’m far more reassured than I was twelve months ago”* |
| Dementia | 15 | *“at the moment I can do everything that I always have done, my memory is certainly different, a lot different to what it was although I can still do my job or job that I did my apprenticeship in so I’m ok there so at the moment I’m not too bad but obviously that’s a downward spiral I suppose so it will change I’m aware of that and I know it will change at some point”* |
| **Benefits to action** | | |
| Healthy | 6 | *“I don’t whether there’s scientific evidence to prove that, I work on evidence…..but I don’t know that there is evidence to support that so if it proves that is the case I would certainly do it [brain training] but I know there is evidence that people who have an active mind, who participate, and socialise and so on, are less likely to suffer from dementia so I know those factors. I’m not sure if brain training in inverted commas directly will affect that but again I would be interested see whether the data proves that I’d certainly do it”* |
| MCI | 7 | *“because I could see the benefit from it and I felt it was good for me and I felt that that sort of challenging, I enjoyed it and I felt it really did work and I’ve found that there was definitely a benefit to it”* |
| Dementia | 25 | *“the brain games exercised me and that was good, and I think that with some of the games I was doing pretty well and I improved a little bit as the time went on so that’s been good”* |
| **Barriers to action** | | |
| Healthy | 10 | *“well I think your intervening with Lumosity and to get the penguin pursuit fix because that that was an annoyance whenever it came up it would be oh for heaven’s sake do I even bother to do this because it’s going to upset everything I can’t won’t be able to get past it easily and so maybe I should just stop for tonight”* |
| MCI | 12 | *Carer: “but then of course the problem is that you want to interject and tell her what’s right and what’s wrong which is obviously not what the programme is about at all and therefore you would try to stop to do that”* |
| Dementia | 2 | *Carer: “You just couldn’t pass them. Couldn’t pass the exercises could you. So it made you feel a failure that you couldn’t cope with the exercises”*  *Patient: “I don’t know about that. Or maybe I just didn’t want to. If you like I’ve given up”*  *Carer: “I think yes you have become disillusioned with what’s happening to you”* |
| **Self-efficacy** | | |
| Healthy | 15 | *“so I thought the more I do it the better my score on some of the games and that means that I improved myself, my memory, so I achieved that much so that really sort of pushed me into keep doing it, doing better so that I could improve myself basically”* |
| MCI | 12 | *“I was pleased with my abilities, it proved that I was, there was quite a lot there that I could cope with, practice makes perfect of course and a lot of them are there for challenges and to test people and some would find them hard and some probably wouldn’t find particular ones hard but I do find things like that a challenge”* |
| Dementia | 13 | *“sometimes I used to feel quite satisfied when I got a personal best, you know, I know they weren’t great scores and probably a five year old would have done as well but they were good to me”* |
| **Cues to action** | | |
| Healthy | 1 | *“it [brain training] might lower it [risk of dementia] but I don’t know whether there’s enough evidence yet to say that for definite so that’s just based on really what I hear in the media”* |
| MCI | 10 | *Carer: “I think [patient’s] improved since he’s been aware of trying to use your brain and when you get that message that’s quite a big factor I think”* |
| Dementia | 21 | *Carer: “but I kept having to remind him [patient], you know let’s get the puzzles tonight or, and then once we got going then it was fine, he’d just forget”* |

Table 3. The six constructs of the Health Belief Model with interview data summarised under each theme by diagnosis.

|  |  |
| --- | --- |
| **Barrier** | **Recommendation** |
| **Participant characteristics** | |
| Low self-efficacy | * Motivational interviewing pre-intervention and identification of potential barriers |
| Anxiety and depression | * Intervention pre-screening * Combined cognitive-behavioural therapy with training |
| Apathy | * Intervention pre-screening * Motivational interviewing alongside the intervention |
| Conflict between patient and carers | * Option for home- or group-based, or a combination of the two * Greater facilitator in-person or telephone support |
| Dementia severity | * Intervention pre-screening * Lower difficulty levels to make the intervention applicable to a wider range of people living with dementia |
| **Intervention characteristics** | |
| Lack of individualised feedback | * Provide information on individual performance, areas of weaknesses, and ways in which performance could be improved |
| Lack of tailored intervention | * Pre-screening of education level, literacy, and occupation to tailor the difficulty level and applicability of exercises |
| Lack of computer literacy | * Pre-intervention screening and testing to identify suitability of intervention * Pre-intervention training * Increase number of devices available for the programme to offer choice to participants based on which technology they are most comfortable with * Paper and pen alternatives for those with low levels of computer literacy * The option to slow the increment in difficulty |
| Poor instructions | * Involve people living with dementia and their carers in the development of the instructions to ensure they are easy to follow and relate to the exercise clearly * Reminders of the instructions available throughout for reference |
| Abstract exercises | * Indicate the purpose of the exercise and how it might translate to everyday life * Increase the relevance of exercises to everyday task so they are more applicable to everyday life |

Table 4. Barriers identified to CT in this study for participants with dementia and the recommendations for adaptation of future CT programmes.

**Supplementary material 1. Interview topic guide**

**Welcome and introduction**

**Seek consent to continue and to audio-record the interview (if applicable).**

**Let them know that no personal identifiable data will be recorded and a participant number will be allocated to them**

**Research Questions**

1. What are the barriers to brain training in patients with dementia?
2. What are the facilitators (benefits) to brain training in patients with dementia?
3. Could brain training programs be adapted further to support the participation of patients with dementia?
4. Are there any additional benefits to brain training programs not measured by traditional methods as perceived by the patients and their carers?
5. To explore the lived experience of the patient and their carer and the impact brain training has on them and their life

Section 1. Evaluating the Brain Training Program/ Study Design

* How did participants/carers find the program? (opening question)
* What were the positive aspects to completing the program? (RQ2/4)
* What were the negative aspects to completing the program? (RQ1)
* Did any issues or difficulties arise during the program and how did you manage these? (RQ1/2)
* Do you have any suggestions to improve the program for future studies? (RQ 3)

Section 2. Feasibility (RQ3/4)

* Was it difficult to achieve the minimum number of sessions required to complete the program and if yes, why?
* Were the study assessments the right duration?
* Was the frequency of study visits acceptable?
* Would you make any changes to the study visits to make the experience better for people with dementia?

Section 3. Impact on patients and their carers

* How did the program affect your day to day life? (RQ5)
* Did the frequency or duration of the training interfere with your day to day life? (RQ4)
* How do you feel the brain training program affected your mood? (RQ4)
* How do you feel the brain training program affected your memory? (RQ4)
* How do you feel the brain training program affected your ability to carry out day to day activates? (RQ4)

Section 4. The health belief model

1. Risk susceptibility
   1. How likely do you think you are to develop dementia? (healthy volunteers, MCI)
   2. How do you think undertaking a brain training program affects your risk of developing dementia? (HV, MCI)
2. Risk severity
   1. If you were to develop dementia, how serious do you think the consequences would be for you? (HV, MCI)
   2. How severe do you think your memory difficulties are? (AzD, MCI)
   3. How do you feel the brain training program has affected the severity of your symptoms? (AzD, MCI)
3. Benefits to action
   1. What helped you to complete the brain training program? (RQ2)
4. Barriers to action
   1. What stopped you with you completing the brain training program? (RQ1)
5. Self-efficacy
   1. If you experienced difficulties, how did you overcome these to complete the program? (RQ1/2)
6. Cues to action
   1. Did anything support or prompt you to complete the program? (RQ1/2)
   2. Did any thoughts, feelings or symptoms affect you completing the program? (RQ1/2)

**Anything not covered?** Is there anything that we haven’t covered in the interview that you think we should know or think about?

**Closing and thanks -** check that the participant is still happy for you to use all the information provided and offer the possibility to erase sections of the recording.

Thank them for their time and contribution.