Exploring User Expectations of Brain-Training and Coaching Technologies for Cognitive Health

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Abstract. User-centred evaluation of brain-training and coaching applications is discussed, with a focus on dementia. A brief outline of outcomes measures used for cognitive training is presented. The design of a set of four patient and public involvement workshops is described which are intended to examine user aspects of relevance to brain-training, including motivation, attitudes to learning, trust in technology and cultural relationships to the playing of games and their content. The groups involved researchers, facilitators, three people living with dementia and three care-givers, two of these being dyads. Data was audio recorded and field notes were taken. Initial results are given from the ongoing qualitative study.

Keywords: User-centred design, evaluation, pervasive healthcare.

1 Introduction

Brain-training commonly refers to digital games or computers or mobile devices which are specifically designed to train a variety of cognitive skills including memory, focus, processing speed and perception. A major criticism of the creators of brain-training apps is that they over claim the strength of evidence and the extent to which they lead to generalisable cognitive benefits that may help with activities of daily living [1]. On the other hand there is evidence that these apps may help older people improve cognitive skill and slow down cognitive decline due to ageing [2].

Dementia is a syndrome that results from changes in brain pathology where an individual's engagement with mentally stimulating activities as well as social engagement and a healthy lifestyle, could influence its onset or progression [3]. Whilst there are difficulties in showing the benefits of specific cognitive training or interventions, there is growing interest in and consensus about which psychosocial factors contribute to cognitive reserve, defined as the capacity of the brain to compensate for brain pathology [4]. The potential to intervene with a mixture of cognitive training exercises and lifestyle coaching begs the question of how best to support people with digital technologies. For those who are encouraged to improve cognitive health, and in particular persons living with dementia for which medical treatment is currently very limited, in considering technological solutions it is important to understand user expectations, both positive and negative. Expectations are influenced by a number of internal and external factors which need to be understood in more detail.

The work described in this paper is part of a larger project which is seeking to develop and evaluate cognitive training programmes supported by digital technology that are aimed at promoting good cognitive health and encouraging behaviours that promise to reduce the risk of dementia [5]. In addition it aims to provide a cognitive measurement and monitoring function to assist in the detection of cognitive impairment, with a potential to screen for or diagnose dementia at a pre-symptomatic stage [6]. The goal of better understanding expectations is to guide the choice of a viable set of evaluation measures for such technologies.

It is known that persons with lived experience of dementia wish to be included in the development of assistive technologies [7]. As part of the evaluation of new healthcare technologies, Patient and Public Involvement (PPI) can be employed effectively to inform the design and conduct of clinical trials [8] and it increases the quality of health and social care research in general [9]. PPI ensures a focus on the topics which concern health service users the most; Brett et al. showed that the involvement of users at an early stage in research can help to prioritise research questions, assist in the development of experimental protocols including patient reported outcome measures, and inform the analysis and dissemination of results [10]. It thus ensures that research is grounded in the lived experience of affected groups, increasing its relevance and helping to enable the long-term sustainability of research. PPI will be used most immediately in our current research to inform the design of an upcoming longitudinal brain imaging study, which will investigate the potential for brain-training programs to reduce the mental workload required to undertake specific cognitive activities [11]. It will also influence the design of the brain-training and coaching app being designed in the wider Horizon 2020 research programme and inform its future evaluation.

2 Background

The scientific literature is replete with examples of observed benefits of cognitive training. Numerous studies have investigated the effects of cognitive training on a variety of outcomes within diverse populations, with many studies showing moderate benefits within areas such as verbal memory, nonverbal learning, attention, verbal cognition, psycho-social functioning and general cognition and large gains in working memory [12]. Meta-analysis has demonstrated that computer-based cognitive interventions can have moderately beneficial effects in cognition, anxiety and depression in persons living with dementia [13]. However, due to differences in how individual studies measure occupational and educational attainment, differences in populations being measured and differences between the types of cognitive training provided, definitive and comprehensive models of the efficacy of these interventions remain elusive [14, 15].

2.1 Outcome Measures

Amongst the important outcome measures for assessing cognitive training with people who have cognitive impairment are those that aim to reveal subjective and objective change in the performing of activities of everyday life. Whilst there are a variety of methods to assess people's capabilities to perform everyday tasks [16-18], activities of daily living (ADL) are generally taken to mean people's regular self-care activities and extent these can be done independently. ADL provides a measurement functional status, particularly in regard to older people, people who have suffered an injury, or people living with dementia. An individual's ability to perform ADL is sometimes assessed by self-reported questionnaire [16, 19, 20] but can also be assessed using task-based assessments such as the Timed Instrumental Activities of Daily Living (TIADL) [21, 22]. Here, instrumental activities include tasks such as food preparation, driving, medication use and financial management.

In a notable previous study of a cognitive intervention; the Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) trial [23], measures of cognitively demanding real-world activities were largely assessed using self-reports, including the 'minimum dataset', but task-based assessments were also used, including processing speed using complex tasks, a road-sign test and the above TIADL test. Other studies have linked cognitive remediation and cognitive training to improvements in the activities of daily living. Carter, Oliveira, Duponte and Lynch [24] highlight two studies in which cognitive skills training helped to support people perform the activities of daily living. In the first study, they performed a post-hoc analysis of ADL improvement scores collected on acute stroke patients who were either assigned to a cognitive skills remediation programme or given an alternative course of treatment. It was discovered that those with higher scores showed significantly better personal hygiene, bathing and toilet activity improvements. Using a separate dataset the authors also showed significant correlations between cognitive skills and ADL.

Self-reported questionnaires are a less objective measure of cognitive improvement than observation. However, self-reported measures of ADL do tend to correlate highly with important real world outcomes, including the likelihood of institutionalisation [25]. Whilst there are a wide variety of outcome measures which are typically reported in cognitive training studies, many of these focus specifically on clinical or cognitive outcomes and there is a great deal of heterogeneity of selected outcome measures between studies [26].

By adopting a user-centred approach via PPI, we aim to explore whether and how people living with dementia and their carers conceptualise cognitive changes through a medical lens or otherwise. In order to improve the face validity on future research and to investigate which possible benefits of cognitive training would be meaningful and important to people living with dementia and their caregivers the topic of 'What counts as meaningful improvement?' was chosen for our first focus group in consultation with stakeholder groups (see later). It is intended that these insights will enable us to better understand the key areas of concern in the lived experience of people affected by dementia and so to ensure that any training or rehabilitation regime is able to focus upon relevant and meaningful improvement metrics.

2.2 Motivation & Learning, Trust and Barriers to Inclusion

As for any healthcare or assistive technology, potential for non-use or abandonment [27] is an issue for individuals living with dementia and their carers. Motivation and engagement are key factors likely to impact upon the success of cognitive training regimes [28] and it is suggested that gamified aspects offer the promise of personalised strategies to improve engagement [29]. To investigate factors which influence motivation and engagement, the paradigm of Dweck's Mindset [30] is useful as a theoretical framework. Dweck suggests that those who believe that their intelligence is fixed are likely to see any difficulties as failures whilst those who believe their intelligence is malleable will view difficulties as a challenge and an opportunity for growth. For this reason, exploring factors associated with motivation and life-long learning is another important topic of discussion with potential users of technologies designed for improving cognitive health. Given that game mechanics can influence engagement and adhesion [31] and subsequently, motivation and commitment to 'serious gaming' regimes [28, 29], we specifically wanted to explore whether the literature reflected the understandings of our participants.

Digital brain-training and cognitive rehabilitation programs also offer the opportunity for monitoring cognition, wellbeing and overall health. Developing digital methods for monitoring healthcare needs, may help to facilitate more timely intervention and optimize the allocation of health and community care resources [32]. However, patient views around cognitive screening tools are complex and multi-faceted and it is unclear which specific factors promote or reduce the acceptance of screening tools [33].

In addition to factors surrounding trust and motivation, we also wanted to explore barriers to digital inclusion which may leave some of the most marginalised in society without access to promising new developments in health technologies [34]. Whilst exclusion is decreasing over time, it is suggested that numerous barriers still remain and these may be a particular issue for at-risk groups [35].

3 Method

3.1 Focus Groups

In order to investigate attitudes and perceptions of cognitive training and screening technologies, we conducted a series of focus group meetings with people with dementia and caregivers. After reviewing the literature and in conjunction with our consortium partners, the following topics were chosen, as introduced in the last section:

1. What counts as meaningful improvement?
2. Motivation and learning
3. Trust in digital diagnosis
4. Barriers to digital inclusion

Prior to commencement, we also discussed the acceptability and relevance of these discussion topics with members of our organisation's standing PPI groups which have expertise in mental health and dementia respectively. Focus group sessions were designed to be three and a half hours in total and involved lunch and regular breaks. Each was split into two sessions; one before and one after lunch to cover a sub-topic within each main topic. Data collection was conducted through audio recordings and handwritten field notes by the researchers present.

3.2 Participants

Participants for the focus group were recruited via Join Dementia Research (www.joindementiaresearch.nihr.ac.uk/); an online platform which supports research involving participants affected by dementia. Our focus groups (those conducted to date) comprised of the same six participants, three living with dementia and three carers of people with a diagnosis of dementia. PPI members are experts-by-experience, due to their firsthand knowledge of dementia diagnoses and cognitive difficulties as well as their own perceptions of technology designed with dementia in mind.

There was an equal gender split and the group included two dyads of spouses where in one dyad the participant with dementia was male and in the other was female. The group was also ethnically diverse, and represented a variety of different backgrounds and experiences. Up to three members of our institute's standing PPI groups were also present in each workshop to assist with facilitation, who also contributed their lived experience of memory or mental health problems, their relationships to technology and opinions about these.

3.3 Ethics

Whilst PPI activities do not always require ethical approval [36], in order to maximise data yield we wished to record each of our sessions with a voice recorder to provide additional data for subsequent review and analysis. Prior to seeking ethical approval, one of our standing PPI team members reviewed the ethics application and supporting documents (participant information sheet, consent form, protocol documents) and check these documents for readability and acceptability. Ethical approval was granted by the Faculty of Medicine and Health Sciences Research Ethics Committee (Approval number: 333-1906). Participants were fully informed as to the purpose and methods of the study and given an opportunity to ask questions. We understood consent according to the legal definition of the Mental Capacity Act Code of Practice (Mental Capacity Act 2005) and adhered with best-practice guidance for assessing capacity provided by the British Medical Association. Under the Mental Capacity Act 2005, capacity relates to the ability to make and understand the consequences of specific decisions. We would not make any legal judgments which related to diagnosis, power of attorney or capacity in general. All participants were provided with an information sheet prior to their involvement and asked to sign a consent form confirming they understood the purposes and method of the study. Transportation was provided for participants and they were each paid an involvement fee in line with INVOLVE guidelines [36].

3.4 Materials

All participants, including workshop facilitators were provided with name badges in order to facilitate an informal, first name basis tone to the discussions. During our first session, we used short power-point presentations to introduce concepts related to cognition, and clinical trial design which served as the basis of our discussion. In the second session participants were asked to bring in some personal items to guide the discussion and on opposite walls of the room were pinned up sheets of paper containing dichotomous statements about motivation. In the third session a set of ideation cards from the UnBias project [37] were used in order to facilitate discussions around fairness and algorithmic bias. In the fourth and final workshop a flip-chart was used to record part of the group discussion.

4 Results

The four workshops were conducted between October 2019 and January 2020. To date, an initial analysis has been conducted of the first two of them from field notes and a first pass of listening to the audio recordings. As the project is work-in-progress, full thematic analysis will be completed once all of the audio recordings have been transcribed using a professional transcription service.

4.1 Meaningful Improvement

In the first workshop, participants began by exploring the concept of cognition, and how technology might be used to help mitigate its decline. At first participants appeared skeptical about the use of technology in general, and in particular, how games might be used to improve cognition. Many participants considered themselves to have low technological literacy, yet towards the end of the session it transpired that many of the participants were familiar with and regular played a host of phone and tablet-based word-based and numerical puzzle games, such as Scrabble and Sudoku. Participants were enthusiastic about these types of applications, although conceptualised them as puzzles rather than computer games. Those who discussed playing puzzle games were also enthusiastic about competitive and social gaming and the dyads mentioned playing the same games or playing with others online. Other participants mentioned using a Kindle or an iPad to build their own up their own confidence in technology. Participants discussed concepts relating to cognitive offloading, such as calendar, navigation and scheduling applications. One participant added mentioned that he felt technology helped him to stay organised:

> *"My brain is better now with computers".*

These examples from the group discussion demonstrate a potential disconnect between people's own familiarity and use of technology with that of their self-perception.

The main topic for the day, meaningful improvement, was discussed at length, with participants drawing upon examples in their own lives. However, a consensus formed that improvement was hard to quantify, may fluctuate over time, and may be subjective and difficult to define. Participants with dementia also stated that often, it was their partners who noticed changes before they did themselves, meaning that assessing one's own cognition may be difficult. Despite this, participants also mentioned the importance of functional measures of well-being, such as the activities of daily living, physical health and self-care. Participants discussed that although they were aware that dementia was a progressive neurodegenerative disease, they held a firm belief that staying active and keeping the brain active was a central feature in slowing or mitigating their cognitive decline and maintaining independence. The link between mood, cognition and self-care was discussed at length, with many participants saying that they often felt unable to think properly or to focus when they had low mood.

Attendees of the focus group also mentioned a variety of hobbies and group activities such as 'Singing for the Brain' and 'Forget Me Notts', the latter referring to a local Nottinghamshire-based community group. However, one participant mentioned that many of the activities in these groups were Euro-centric or were particular to the local area and thus were difficult to relate to and could be exclusionary.

4.2 Motivation and Learning

In the second session, participants explored motivation and learning. They were asked to bring into the session a specific item or story which represented something which had motivated them or something which they had accomplished. One participant brought a hand-drawn picture they were proud of. Another mentioned the pleasure of working on an allotment, another the achievement of cooking from memory and one participant mentioned that they had taken up tennis in later life. We used these examples as an ice-breaker to explore motivating factors which may be harnessed in cognitive training and coaching applications. Participants mentioned that involvement in their hobbies allowed them to challenge the myths about what older people were capable of. This included personal perceptions of their limitations. Hobbies and social activities were seen as a way to mitigate the decline of cognition, and some participants mentioned they had seen others who were less active, deteriorate very quickly. Participants also discussed the social nature of some of their hobbies which helped them to stay motivated over a longer period of time. One participant mentioned both the importance of saying active in retirement, in addition to how his own hobby enabled him to become part of a community:

“I took up gardening again when I retired … fill the time in, because I’d seen too many people, before I retired, who’d packed up work, and they’d just go downhill … they’d got nothing to do, and anytime I ran into ‘em [they said], ‘Oh don’t retire, there’s nothing to do, all you do is watch the telly’. Well, we watch the telly in the evening, but I can always find plenty to do since I’ve retired, with the garden, and I took up bowling, bowls…You’ve got to give yourself an interest. Gardening, I’ve found is ideal, if you’ve got an allotment, you’ve got a community”.

In the second part, participants explored their attitudes to learning and motivation by means of dichotomous statements which were broadly related to Dweck’s concepts of fixed and growth mindsets, as introduced earlier. The statements were placed on opposite walls and participants were asked where on the continuum they stood between diametrically opposed positions such as ’I am naturally good at things*’* versus ‘I am good at things because I have practiced them.*’*

There was a wide range of differing views on people’s own conceptions of the malleability of their cognitive skills, thus suggesting that a single approach to framing the benefits of cognitive training would be insufficient.

5 Discussion

Participants who attended the focus group may not necessarily have been aware of the concept of cognitive reserve or the research which lay behind it, nevertheless, participants had a good intuitive understanding of the concept, which they were able to discuss at length. Perhaps somewhat surprising in our discussion groups were participant attitudes towards acquiring new skills later on in life. One participant claimed he had “never really been a reader”, yet had become an avid reader after retirement, suggesting that people are often very eager to pick up new skills later on in life. Our discussions suggest that there are many factors which motivate people to stay cognitively, physically and socially active later in life, and that maintaining good cognitive health is an important priority for people living with dementia and their carers.

5.1 Limitations

Participants were invited to join the focus group using the research recruitment tool, Join Dementia Research. We specifically invited only participants who had stated that the severity of their dementia was mild to moderate. This of course excludes people living with dementia whose symptoms are more severe, and therefore the findings from this focus group are most likely not representative of people living with dementia at a later stage. However, we were fortunate to be joined by a participant who had experience in caring for his wife in the later stages of dementia, which allowed for a broader discussion. There is often a tension between carers’ wishes to ensure that their care recipients are safe and well, and the desire to respect individual autonomy [38]. The relative importance afforded to each of these considerations may change as the symptoms of dementia progress and a person's capacity to understand the consequences of their decisions deteriorates.

Participants who chose to list themselves on Join Dementia Research, are also much more likely to be actively involved in other dementia research (as some of our participants were), and therefore their experiences and expectations of research may be different from the general population. Nevertheless, for our purposes of helping to guide future clinical research, participants were able to bring their own experiences of how trials work in practice to the specific research questions, particularly around the discussion about meaningful improvement. Some participants in the group also had firsthand experience of other dementia research programs, which they were able to draw on for the purposes of discussion.

5.2 Further Work

We are continuing to analyse the data generated from our workshops, and intend to use Thematic Analysis [39] to systematically identify salient and important issues which arose during discussions. PPI volunteers involved in the workshops will also be invited to help during the analysis phase of our research. Involving those with lived experience in the data analysis can help to create meaning from the data and provide valuable perspectives in interpreting findings [40].

Using insights gained from the PPI workshops, we will be conducting iterative longitudinal trials on the effectiveness of the Brain+ Recover app on various cognitive abilities. In particular, we will investigate whether the brain-training app reduces the mental workload places on participants for similar tasks following a training regime. It has been shown that functional Near Infra-Red Spectroscopy (fNIRS) can be used to estimate mental workload, and therefore enables an objective, continuous and detailed insight into mental effort on cognitively demanding tasks [11, 41]. We also intend to use the insights garnered from PPI to provide guidance on future clinical validation as well as further development of the commercial Brain+ software.

6 Conclusions

Patient and public involvement in digital health research is essential in enabling high quality understanding of areas of importance which are guided by the lived experiences of the target user-group. As experts-by-experience, people living with dementia and carers are willing and able to offer detailed opinions, which are relevant to the development and evaluation of technologies for cognitive health. By taking into account their expectations and life experiences and from understanding potential barriers, research goals can be orientated towards people's actual needs, rather than the perceived needs of technology developers alone. Furthermore, methodological issues which relate to adherence of study protocols, and general willingness to participate in research, can be explored in full with the hopes of increasing the quality of future work.

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