Better Living with Rare Dementia: digital support

Given that people with rare forms of dementia are widely dispersed, digital interventions as a means of providing them with support could be a way forward. In the fourth article of our rare dementia series, **Joshua Stott** and **Aida Suarez-Gonzalez** report on their digital support platform Better Living with Rare Dementia

C aring for someone with a rare dementia can be particularly challenging. Among the factors contributing to this challenge can be relatively late diagnosis, an unusual symptom profile (Nicolaou *et al* 2010, Uflacker *et al* 2016) and the fact that many forms of rare dementia occur in younger people, which can have implications for employment, financial stability and childcare responsibilities (Allen *et al* 2009, Svanberg *et al* 2011, Van Vliet *et al* 2010).

Since people with a rare dementia are spread very widely and local expertise may be lacking, specifically tailored digital provision could be particularly helpful for this group. But to our knowledge no such provision is available, so our aim is to fill the gap through a project which we will describe here.

Our plan is to build a digital support platform for carers of people living with three different relatively rare dementias: posterior cortical atrophy (PCA), primary progressive aphasia (PPA), and behavioural variant frontotemporal dementia (bvFTD). As overarching frameworks we used the Medical Research Council framework for the development of complex interventions (O'Cathain *et al*

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2019) and a study relating to the development of a digital cognitive behavioural intervention for carers of people with dementia (Blak *et al* 2011).

We will illustrate the key considerations by outlining the first two phases in developing this digital platform: a) the information and data gathering and b) the co-production phase. We will then briefly elucidate how we plan to bring this together for the creation of a digital product.

Phase 1: Data-gathering
Phase one consisted of a data-gathering exercise, which was an iterative process of refinement and deepening understanding from different sources (see figure 1 below).

Academic literature
We used Google Scholar and PubMed to search for existing reviews and articles on digital interventions for dementia caregivers. Although we found recent literature reviews and meta-analyses relating to online support for dementia caregivers in general (eg, Christie *et al* 2018, Hopwood *et al* 2018), we found very few articles related to rare dementia online support. Consequently, we decided to take the findings on general online support into a wider discussion on whether any of them could be applied in a rare dementia context.

Key findings on general online support for dementia caregivers pointed to the importance of the following areas: ➤
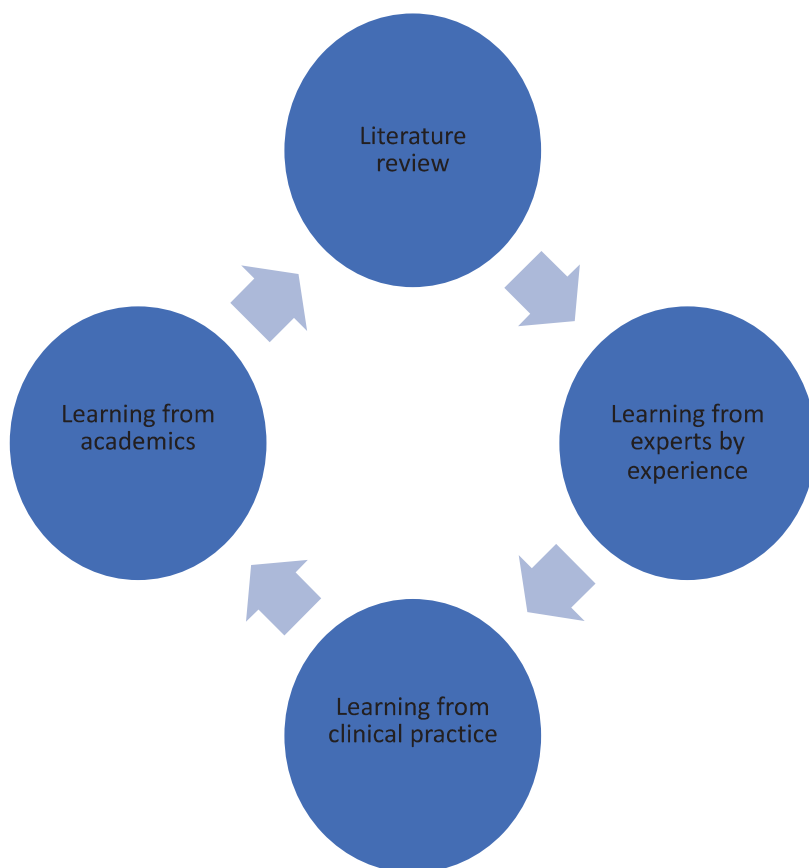

Figure 1: Phase one of intervention development

➤• blended human and online rather than a purely online approach to promote intervention efficacy and adherence

• initial identification of outcomes most likely to be impacted (e.g depression, anxiety, knowledge, social isolation)

• identification of key barriers to accessing technological interventions, such as unsuitability of content, complexity of accessing it, worries about using technology or about data security, and the time commitment

• few, if any, digitial support interventions have been implemented for dementia caregivers, so implementation should be considered at the outset of any new project

• identification of NICE-recommended components for caregiver interventions in dementia (eg, psychoeducation, responding to behaviour that challenges).

In drawing up our digital plans, we also took account of the Web Content Accessibility Guidelines and corresponding guidelines from AbilityNet.

Academic experts
We consulted with academic experts who had developed online tools for people with dementia and their caregivers, such as mediated communication training for people with PPA (Rogalski *et al* 2016), an online tool for carers of people with young onset dementia (Metcalfe *et al* 2019), and a CBT tool for dementia carers (Blak *et al* 2011).

These consultations confirmed our earlier findings and also emphasised simplicity of content, careful presentation, and consideration of whether interventions could have harmful as well as beneficial effects.

Clinical practice
We learnt from clinical practice in two ways, the first being to discuss interventions with colleagues working in Rare Dementia Support, a national charity. This emphasised the need to think about commonalities as well as differences in the caregiver experience across diagnostic groupings, and to be led by the problems carers themselves say they face and to find solutions that we know from the literature work.

These discussions inspired a modular approach to our digital intervention, in which modules would be based on the problems that carers report and some modules would be shared across diagnostic groups while others would be specific to particular diagnoses.

We also learned from clinical practice in mental health. We broadened our enquiry

Consideration	Sources
The need to have a human/online blended tool	Reinforced by all sources
Identification of key outcomes	Academic literature initially (built upon in other conversations)
Identification of key barriers and facilitators to access	Academic literature initially (built upon in other conversations)
Critical import of implementation being considered from the beginning	Academic literature, academic experts and clinical practice
Use of a modular approach with some modules shared and others specific to diagnostic category	Academic experts refined and expanded by experts by experience
Taking a user-led approach in identifying key problems and basing modules around those rather than being led by theory in the first instance.	Academic experts refined and expanded by experts by experience
Need to balance simplicity of presentation with enough depth of content	All sources
Importance of thinking about accessibility and different accessibility needs for different groups	Academic experts/Experts by experience
Need to think about potential harms of interventions as well as benefits	Academic experts

Table 1: Key considerations arising from phase 1

to widely used mental health digital support tools (eg, www.silvercloud.com) in order find out about facilitators and barriers to implementing them. We interviewed clinicians who use these interventions in NHS psychological therapy services, which re-emphasised many of the earlier findings such as the need for a human component alongside the digital, and particularly the importance of accountability and risk management procedures.

Experts by experience
Phase two of our project allows for extensive work with people with lived experience, but our initial discussions in phase one helped us to identify key modules for the tool as well as outcomes that should be measured. These were elaborated in phase two.

Phase one outcomes
Key considerations arising from phase one are summarised in table 1 above. Based on these a draft programme was drawn up for the co-production phase.

Phase 2: Co-production
Public and patient involvement (PPI) benefits research by increasing its relevance, facilitating implementation and improving the cost-benefit of its delivery

(Staley 2019). For the development of this intervention, we followed a collaborative approach of this kind during the co-production phase.

First, we ensured that people with dementia and their care partners remained involved in the decision-making process from conception to delivery. And we followed the Guidance for Reporting Involvement of Patients and the Public (GRIPP), to plan, document and report our PPI practice (Staniszewska *et al* 2017).

Recruitment
To assist us in the process of developing the digital support platform we recruited a group of 16 people with lived experience in our three dementia subtypes, PCA, PPA and bvFTD, including both care partners and people with the conditions. We also recruited health professionals in these areas.

Contact was made through the service Rare Dementia Support (RDS) and the Canadian partners of the Rare Dementia Impact study (Brotherhood *et al* 2019). We distributed flyers with information about our study among RDS members and arranged email contact and video call meetings with those who expressed interest. All this was done remotely owing to the pandemic.

Problem to solve	Theme of the module	What experts by experience said
Lack of understanding of the disease and its symptoms	Information about the disease with a particular focus on non-memory symptoms	"We want something positive and helpful" "The tool also needs to provide supporters' guidance on how to help others (relatives, friends) to engage with the person with PPA"
Not knowing how to provide appropriate support	Training on how to provide positive support	"We as care partners should count with resources and skills" "I want to be included in things. Not excluded just because I cannot speak"
Not knowing where to get help	Information about services and resources	"RDS was helpful and local support groups" "Power of Attorney is important – He also received an OT assessment and appointment with RNIB" "Social services websites are useful"
Fear, grief, anxiety and negative psychological state	Adjust to life with the condition and development of habits for good mental health	"Whatever my mood is, it has a significant impact on him" "It is important to have hope that something can be done to make life better"
Perception of loneliness	Join support groups and subtype-specific communities	"I enjoy my PCA local support group. It's relaxed because everybody is in the same position" "I attended a gathering with people who did not have PPA, and I felt it was not for me"

Table 2: Outcomes of interactive sessions

Method of participation
We ran one-to-one interactive sessions by video conference and also phone, usually with the care partner and the person living with dementia but in some cases only with the care partner. All had to be able to use technology, but all participants engaged satisfactorily with the video call service chosen for the meeting. We had as many of these remote meetings as were needed.

Development of materials
Mock designs of our digital intervention manuals were shared with participants in advance of the video conference, along with instructions and a shortlist of questions for discussion during the meeting. Materials were designed on standard easy-to-read principles, while notes of the meeting were taken and distributed to participants afterwards in the same format.

Two Canadian PPA support group facilitators took part in the revision and development of the materials, bringing their wisdom and years of experience to the table. Among many rich contributions, they advised "avoiding toxic positivity", and stressed the role of interactive activities and detailed education about the disease, giving space for context and understanding how these dementias are different from Alzheimer's disease.

Intervention components
We agreed on the number of intervention modules, length and content, and the order in which they would be administered. It was jointly decided that the information would be presented in various modalities: videos, vignettes, written material in printable format, visual images and real stories of people with dementia narrated in the first person (see table 2, left).

Phase 3: Creating platform
Our first task in phase three was to find a developer for the digital platform and discuss costs and requirements. For example, should it contain video clips with tips to manage dementia symptoms, printable material for people to download, and a simple design to favour accessibility?

The platform - which we have named Better Living with Rare Dementia - is still in development, but we expect that it will look like a simpler version of the online learning service FutureLearn. Participants will be able to log in using a standard procedure based on username and password entry. Once logged in users will land on a home page and be invited to play an introductory overview of the programme.

Then, the first of five topic-specific modules of learning will start. Users can stop and restart the sessions as they please and make progress at whatever pace works best for them. All progress will be saved after each session. Once one module is completed, participants will be encouraged to move to the next until all of them are completed.

Conclusion
Better Living with Rare Dementia aims to become a digital intervention designed and co-produced to improve access to good quality support for care partners of people living with these conditions. The tool will be trialled as part of the Rare Dementia Impact project, and it is our ambition that it will eventually be translated into many languages and rolled out worldwide. ∎