

## RAPID RESEARCH IN COVID-19 PROGRAMME

### Co-design of a carer support app: connecting carers to help prevent infection and improve resilience

#### AIMS

We aimed to co-design a new app (called *Caring Together*) for carers. We then aimed to launch the app and gather feedback on whether and how it helped carers of people with life-limiting conditions: (1) look after people during COVID; and (2) reduce the risk of infection by providing support via an app rather than face-to-face methods.

#### KEY FINDINGS

- A carer support app called 'Caring Together' was co-designed using a rapid development approach, with three carers, an experienced app design company and academics with expertise in carers, online communities, and digital learning.
- Carers of people with life-limiting conditions who had used the app and engaged in the Caring Together online community said they felt it had considerable potential for providing support to carers; it provided a useful means for carers to connect with each other.
- The app did not replicate other social media platforms; it offered unique opportunities for learning and support.
- Carers appreciated having a carer-only online space to share experiences and facilitate opportunities for learning.
- Carers sought out information on the app, wishing for both user-generated content drawing from personal experiences, and content provided from credible external organisations.
- App users recommend its use to other carers of people with life-limiting conditions.
- The app meets multiple Scottish government policy goals of addressing carer needs, building community supports, and tackling loneliness in vulnerable groups.

#### WHAT DID THE STUDY INVOLVE?

A co-design process was used to develop the interface and user functions, create content, branding, and consider how best to facilitate the online community.

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The app allowed for a mix of *information provision* and *peer support and engagement*, both of which are essential elements for building online communities and facilitating learning. The app included four core topics where carers could share experiences: (1) Caring During COVID, (2) Caring for the Carer, (3) Money Advice, and (4) Useful Contacts. There was also an area for 'resources' where carers (and the research team) could provide links to information they thought would be helpful to others. Users were able to 'like' and comment on posts, as well as report - via a simple drop-down list of options - how they were feeling at the time of posting.

The study commenced May 2020. The app and Caring Together online community was launched on July 21<sup>st</sup> 2020. Qualitative interviews with carers who had used the Caring Together app were conducted in August and September 2020.

Ethical approvals were granted by the University of Stirling's General University Ethics Panel (ref: 19/20 912).

## WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

### Participants

Fourteen carers consented to the study and to use the app. Ten carers used the app; they had a mixture of caring experiences, including Parkinson's disease, Alzheimer's, cancer, and complex multiple morbidities. They self-rated from 1-5 their level of being at ease with technology, with 1 being lowest and 5 highest. Carers reported a range of 3 to 5, and a mean score of 4.

### Use of the Caring Together app

During the five week test period, 11 unique posts were made by users, resulting in a total of 114 interactions. Nearly a quarter (28/114) of interactions with the app occurred outside of 9-5 hours, indicating the app was useful when other carer and health services may have been less available. Use of the app peaked 11 days after it was launched and then levelled-off at around 8 log-ins per day.

All carers stated that they felt the Caring Together app and online community created within the app had considerable potential to provide information and support to them in future.

*I think it's really, really good, it's just exactly what we're after. (Interviewee 1)*

All carers reflected that its utility would increase when there are more posts, and more time to engage with it and with others using the app: in other words, to build a sense of community. Carers felt that the mix of users was of benefit, resulting in more opportunities to learn from others about caring related issues without being focused on disease-specific issues. Participants commented that they tended to rely on other illness-specific sources for this kind of information.

### COVID-19

The app was developed, launched and tested during Level 3 Lockdown. Consequently carers, along with the rest of the population, had greater freedom of movement and in-person connection than they had in the previous few months. Interviewees speculated on the potential utility of the Caring

Together community in greater levels of lockdown:

*If that app had been available especially at the worst times for me yes I would've looked at it, yeah definitely. I'd of looked at it for help and doing stuff and where to go and what to do and what to look out for and obviously chatting to other people would possibly have helped as well, you know, going through their own experience and the fact that it's not just you, you know, it affects other people.  
(Interviewee 3)*

This was reinforced by the later interviews (mid-September), in which participants began reflecting upon the rise in the app's usefulness as time passes and restrictions increase. One carer reflected that the app and the Caring Together community had been helpful in normalising her approach to shielding:

*It's been interesting reading other people's comments [on the app] and seeing how we've been coping and what they've been doing. Because I think, especially since Parkinson's isn't in the high risk category, I think loads of people on the app have still been shielding with them, which is what we've been doing. So I think it makes us more comfortable that what we've been doing is right for us.  
(Interviewee 2)*

## Support

Carers appreciated the flexibility of being able to log in at a time that suited them and found it to be a useful addition to fixed-time video-conference support sessions run by some disease-specific organisations.

Several carers reflected on the importance of an app and space which was solely for carers. Many drew on a familiar trope of being ignored or second place to the person they were looking after. They drew comfort from having an app which was designed solely for them: the space as designed, allowed them to focus on their own needs:

*For carers, a lot of the time, your friends although as I say, they are lovely and a lot of them are very caring towards me, don't get me wrong, (...) they still would always ask how [husband] is first, so they don't always appreciate what it's like.  
(Interviewee 7)*

## Learning

The amount and type of learning varied between participants. They valued the input of other carers, which was characterized as confirmation and encouragement of current practices alongside learning something new or coming to appreciate a different perspective.

*I'd be looking for advice via other people's experience as carers, I would like to compare notes and get hints and tips, maybe practical advice. When my wife gets worse, I would like advice on how to cope with it by seeing how others have coped' (Interviewee 8)*

## Limitations

A robust (albeit accelerated design and development process) was adopted, in order to custom build the app for this project. Some of the desired features were not possible due to time and/or budget restrictions. Recruitment of carers to test the app was slow, and the sample size of 20 was not achieved.

## WHAT IMPACT COULD THE FINDINGS HAVE?

### Impact of the findings for carers

- The app holds the potential to grow in use and breadth of content, providing continued need for relevant and timely information and support.
- The app is likely to increase in salience as Scotland moves between levels of lockdown, limiting opportunities for uninterrupted continual face-to-face supports.
- The Caring Together app does not generate an instant community however, and it will take time to grow the number of users and both engage and connect those most isolated.
- This project has provided important groundwork toward the aim of enabling carers to feel better supported and more able to care during COVID, and beyond.

### Impact of the findings for practice

- Hospices, disease-specific charities and other organisations providing services to carers of people with life-limiting illnesses, can offer the app to carers.
- The app will enable service providers to direct carers toward this Caring Together community and network of other carers supporting people with palliative care needs.
- The Caring Together app could be used nationally and internationally, with Scotland placed as an international leader in technology-enabled carer supports.

### Impact of the findings for policy

Caring Together addresses key objectives in the carers' strategy policy, of providing support and information to carers. Caring Together:

- Recognises carers' needs as central to the provision of palliative care, as defined by the World Health Organisation, and operationalised in Scottish palliative and end of life care policy.
- Meets Scottish Government objectives and Third Sector priorities of promoting more connected communities, and supporting carers.

Maintaining and refining the app will be key in ensuring the ongoing impacts for carers, service providers and policy, to ensure sustained benefit for carers across Scotland.

## HOW WILL THE OUTCOMES BE DISSEMINATED?

We will use our established networks with The Scottish Partnership for Palliative Care, hospices, and the national CHAIN network for palliative care to promote the Caring Together app and the research findings. Dissemination will use Twitter. To increase reach to carers, relevant Third Sector

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partners (carer organisations) will be tagged in tweets and sent direct emails with the study's findings.

Media releases by the University of Stirling will be used, in agreement with CSO, to promote the study's findings to the public. An academic peer review article will be written summarising the key learning for researchers engaged in work around COVID, carers, digital support, and online community and learning.

Our next research will seek to refine the app, building on the feedback from this project. We will then combine the app with online education resources for carers. Consequently, the app becomes part of a bigger suite of materials, which support carers and facilitates a robust community to continue to provide essential care to people with life-limiting conditions. The follow-on study will be a randomised control trial of distance learning combining education resources and this app. The proposed study builds on the Chief Investigator's prior work in distance learning for carers, and online learning pedagogies and community building of the co-applicant. Having developed a prototype and collected useful data on the app, we can now proceed to develop this much needed resource which facilitates online learning within a community context, supported by an app which provides digital technologies and spaces suited for the needs and learning practices of carers.

**CONCLUSION**

The 'Caring Together' app has the potential to be useful to carers of people with life limiting conditions and to provide them with an easily accessible place to gain and give support. Embedding Caring Together into routine practice will be important in ensuring its continued utility and providing a space in which carers can create a sustainable supportive community.

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**ADDITIONAL INFORMATION**

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