Web-based technologies to support carers of people living with dementia: a protocol for a mixed methods stepped-wedge cluster randomized controlled trial

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Abstract

Background: Informal carers play a significant role in supporting people living with dementia however carers in rural areas are often isolated, with limited access to support services. Although dementia friendly communities provide valued support for carers, access to them is limited, as they are few and geographically dispersed.

Objective: This study's aim was to increase support and services for rural informal carers of people living with dementia by using information and communication technologies accessed through an integrated website and mobile application: the Verily Connect App. The objective of this protocol is to detail the research design used in a complex study that was situated in a challenging real-world setting integrating web-based and on-ground technology and communication. Therefore, it is anticipated that this protocol may enable the research of others exploring similar complex concepts to be strengthened.

Methods: A stepped wedge open cohort randomized cluster trial was used to implement Verily Connect across 12 rural Australian communities. The Verily Connect intervention delivered online curated information about dementia, a localised directory of dementia services and supports, group and individual chat forums, and peer support by videoconference. During the implementation phase of 32 weeks, Verily Connect was progressively implemented in four 8-weekly waves of three communities per wave. Usual care, used as a comparator, was available to carers throughout the study period. Participants and researchers were unblinded to the intervention. There were three cohorts of participants: carers, volunteers, and staff; participants were recruited from their communities. The primary outcome measure was perceived carer social support measured using the Medical Outcomes Study – Social Support Survey. Volunteers and staff provided feedback about their participation in Verily Connect as qualitative data. Qualitative data were collected from all cohorts of participants by interviews and/or focus groups. Process evaluation data were

collected through interviews and memos written by research staff. Data about costs of implementing Verily Connect were collected by research team members and evaluated by a health economist.

Results: Between August 2018 and September 2019, 113 participants were recruited. There were 37 carers, 39 volunteers and 37 staff. The study was complex due to the involvement of multiple and varied communities of carers, volunteers, health service staff, and research team members originating from five universities. Web-based technologies were used as intervention strategies to support carers and to facilitate the process of undertaking the study.

Conclusions: The Verily Connect trial enabled testing and further development of an online approach to increasing support for carers of people living with dementia across a diverse rural landscape in Australia. This protocol provides an example of how to conduct a pragmatic evaluation of a complex and co-designed intervention involving multiple stakeholders.

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KEYWORDS