



Review

A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer's, vascular or mixed dementia in the community



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ABSTRACT

Background: The objective of this review was to assess the effectiveness of interventions delivered by telephone, internet or combined formats to support carers of community dwelling people living with Alzheimer's Disease, vascular dementia or mixed dementia.

Method: English language literature published up to 2016 was searched. The initial search included: MEDLINE, Cumulative Index to Nursing and Allied Health (CINAHL), and PsycINFO. A second search was conducted using Medical Subject Headings (MeSH) and keywords for eight databases. The review included randomised controlled trials, non-randomised controlled trials, quasi-experimental and pre-post studies from published and grey literature. Studies selected for retrieval were assessed by three independent reviewers for methodological validity prior to inclusion in the review using standardised critical appraisal instruments.

Results: Twenty-two studies were included in the review of which 13 were studies of telephone-delivered interventions, five were internet-delivered interventions and four were delivered in a combination of telephone and internet formats. In this review the successful outcomes from the combined telephone and internet delivery exceeded that of telephone alone and internet alone. Very few studies addressed programs for specific types of dementia.

Conclusion: When considering the ratio of number of studies to successful outcomes, combined telephone and internet delivery of multicomponent interventions demonstrated relatively more positive outcomes in reducing depression, burden and increasing self-efficacy than telephone alone or internet alone. Further studies are necessary to evaluate the effectiveness of interventions targeted at specific types of dementia and to understand which components of interventions are most effective.

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Contents

1. Introduction	219
2. Methods	219
2.1. Types of participants	220
2.2. Types of interventions	220
2.3. Types of studies	220
2.4. Exclusion criteria	220
2.5. Search strategy	220
3. Results	220
3.1. Social support and mental health needs	220

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3.1.1.	Telephone support	220
3.1.2.	Outcomes for telephone interventions	221
3.1.3.	Psychoeducation	222
3.1.4.	Psychotherapy	222
3.1.5.	Supportive interventions	222
3.1.6.	Multicomponent	222
3.2.	Internet interventions	223
3.3.	Telephone and internet combined delivery	224
3.3.1.	Supportive interventions	224
3.3.2.	Multicomponent interventions	224
3.4.	Clinical parameters and holistic interventions	224
3.5.	Interventions addressing specific types of dementia	224
4.	Discussion	224
4.1.	Main new findings	225
4.2.	Limitations	225
5.	Conclusion	226
	Conflict of interest	226
	Description of author roles	226
	References	235

1. Introduction

Dementia is a major public health challenge with individual, family, societal and national impacts (Sousa et al., 2009). In Australia, 298,000 people are estimated to have dementia (all causes) and population projections predict a rise in dementia from 400,000 in 2020–900,000 in 2050 (Australian Institute of Health and Welfare, 2012). Over 90% of community-dwelling people living with dementia receive care from one or more informal or family carers, usually a co-residing spouse or partner (57%) and/or an adult child (36%) (Australian Bureau of Statistics, 2012). There is evidence that compared with other carers, those caring for people with dementia report a significantly higher caregiving burden resulting from difficulties with housing, employment, financial circumstances, carer and care recipient personal relationships and the lack of access to formal and informal supports (Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourtzi, 2007). In addition, maintaining mental health is challenging for many carers, and levels of mood disorders such as anxiety and depression have been found to be high among family carers of people living with dementia (Li, Cooper, Bradley, Shulman & Livingston, 2012).

Family carers benefit from support in the form of education about dementia, psycho-education, and counselling (Elvish, Lever, Johnstone, Cawley & Keady, 2013; Gallagher-Thompson & Coon, 2007; Parker, Mills & Abbey, 2008). However, the demands of caring can make commitment to education or counselling programs challenging, especially when conducted face to face (Godwin, Mills, Anderson & Kunik, 2013).

Increasingly the benefits of telehealth or information communication technology (ICT) to support family carers in their own home are being studied (Elvish et al., 2013; Gallagher-Thompson & Coon, 2007; Godwin et al., 2013; Mason & Harrison, 2008; Powell, Chiu & Eysenbach, 2008; Schoenmakers, Buntinx & Delepeleire, 2010; Thompson et al., 2007). However, no reviews have considered the possible benefits of this type of support for specific types of dementia, especially vascular dementia, which is the second most common type of dementia after Alzheimer's Disease, and mixed dementia. These types of dementia share complex vascular risk factors that may respond positively to being monitored and managed through telehealth. The potential benefits to patients, carers and society from the management of vascular risk factors, while present in the stroke literature, (Hachinski, 1992; Korczyn, Vakhapova & Grinberg, 2012; Langa, Foster & Larson, 2004), is largely absent from the dementia literature. In addition, of the few studies evaluating the impact of telehealth or

ICT on family carers, the effectiveness of different categories of interventions have not been compared.

Telehealth support using telephone and internet delivery to enhance health outcomes may be simplified into two distinct but complementary streams (Bulik, 2008; Hopp, Hogan, Woodbridge & Lowery, 2007). The aim of the first stream is enhancing social support or mental health of clients. This stream includes aims such as enhancing quality of life, improving mental health, reducing social isolation, providing education or skills training, adding surveillance and support, and assessing and servicing clients and family needs. A second major use of ICT is in community based chronic disease management, such as assessment of clinical parameters e.g., blood values, blood pressure, respiratory function etc. by means of automated or client-activated systems that feed information back to clinicians and health services. Such systems were designed to store data for easy accessibility for review and identification of abnormal results. The underlying goal of both streams is to produce practical, convenient, timesaving and cost effective solutions to complex health care needs (Webb & Williams, 2006).

This review fills a gap in the literature by examining the impact of both streams of telehealth, telephone or internet-delivered support on carers and people living with dementia, and investigating whether there is any evidence for effectiveness of such programs directed specifically to the main types of dementia, namely Alzheimer's Disease, vascular dementia and mixed dementia. Therefore, the research questions addressed in the present review were:

1. To what extent is telephone, internet or combined delivery effective at addressing social support and mental health needs of family carers of people living with dementia in the community?
2. To what extent is telephone, internet or combined delivery of models effective in assisting family carers manage clinical risk factors of people living with dementia in the community?
3. To what extent have these interventions addressed specific needs associated with types of dementia including people living with vascular dementia, mixed dementia or Alzheimer's Disease?

2. Methods

The literature published up to December 2015 was searched for relevant papers (initial searches were conducted up to 2014 then

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