Title: Narrative review of literature on Unpaid Carers and the use of mobile text message technology

Author: Gwynedd Williams[1], MPH; Helen Lyndon[2, 3], RN, PhD, MSc, BSc (Hons), Anna Mankee-Williams[1] & Madi Stephens, MSc, BSc, RN[1]

Affiliations:

[1]Falmouth University, Research and Innovation, Penryn Campus, Falmouth, Cornwall, UK

[2] Cornwall Foundation NHS Trust, Cornwall, UK

[3] South West Clinical School, University of Plymouth, UK

Email: gwynedd.williams@falmouth.ac.uk

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[1]Falmouth University, Research and Innovation, Penryn Campus, Falmouth, Cornwall, UK

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[3] South West Clinical School, University of Plymouth, UK

Email: gwynedd.williams@falmouth.ac.uk

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Context: Carers are more likely than non-carers to report having a long-term condition or disability (Carers UK, 2020). As a result, carers are more likely to experience social isolation, loneliness, and poverty (Tinson *et al*., 2016). Despite these risks, mechanisms to routinely and regularly access and support carers are lacking.

Objective: To review published studies of adult carers to assess if mobile phone text message technology, can assist with accessing unpaid carers to understand their collective needs.

Method: A scoping review of published literature relating to adult unpaid carers and mobile technology, specifically text messaging.

Findings: The review found some evidence supporting the effectiveness of mobile phone text messaging interventions to specific carer populations. The review has identified a paucity of evidence surrounding the acceptability of mobile text message technology amongst unpaid carers.

Limitations: This review was limited to studies in English, time restraints, and the size of the research team to carry out a full systematic review. The review was undertaken as part of the Connected Health Care project which had already agreed on the parameters for a feasibility study on unpaid carers and the use of mobile phone text messaging.

Implications: Mechanisms to conveniently reach and understand the needs of unpaid carers are required. With the lack of evidence of widespread practical application of mobile phone text message technology particularly for carers, it seems timely to consider the role of technology, specifically, mobile phone messaging.

Keywords: carers, mobile technology, text messaging

Introduction

One in eight (8.8 million) adults in the UK are carers and are a valuable workforce who are estimated to save the UK economy £132 billion per year (Carers UK 2019). According to NHS Digital (2016), 36% of carers were delivering over 100 hours of care a week before the emergence of Covid-19. This burden has risen to 70% alongside the emergence of Covid-19 which has disrupted care services (Carers UK, 2020). This is likely to have significant implications on the health of carers who are often unable to meet their own needs (Mental Health Foundation, 2020). Carers UK (2020) found that 72% of carers reported mental ill-health and 61% reported physical health issues compared to 51% of non-carers. The disparity in reported health status between carers and non-carers highlights how caring can lead to poorer health outcomes (EuroCarers, 2018).

The Global Observatory for eHealth defines mobile health as 'medical and public health practices supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices' (World Health Organisation, page 6, 2011). A key component for the transformation of health and social care is digital transformation (NHS Long Term Plan, 2019). However, digital inequality is widening (Office National Statistics, 2019) and those without access to digital services and technology may be adversely affected (Carers UK, 2021). With high levels of mobile phone ownership coupled with mobile phone messaging in public health research and practice (Hall *et al.*, 2015), mobile technology in the form of mobile phone text messaging may provide an opportunity to reach carers. Reaching carers via convenient and acceptable methods are vital to help address the difficulty of accessing services by busy carers.

Access is particularly relevant where transport infrastructure is lacking, and to those who are older, in ill-health, are poorer and depend more on public transport (Citizens Advice, 2017). These issues are likely to influence access to support services for unpaid carers.

The considerable contribution that carers make to society is acknowledged in the Department of Health action plan (2018). This plan promotes the use of creative and cost-effective technology to support carers. In addition, the National Institute of Clinical Excellence (NICE) has developed quality standards to improve the quality of care that adult carers (16+) receive (National Institute of Clinical Excellence, 2019). This scoping review looks to evaluate the evidence relating to mobile technology, specifically mobile phone text messaging, as an acceptable method of reaching carers, which may improve access in rural areas. This review was undertaken as part of the wider Connected Health Care project (CHC), which is a collaboration of healthcare and technology partners in Cornwall and Scottish Highlands, UK. For this review, a carer is defined as a person over 18 years who supports someone else in their daily life (National Health Service, 2021).

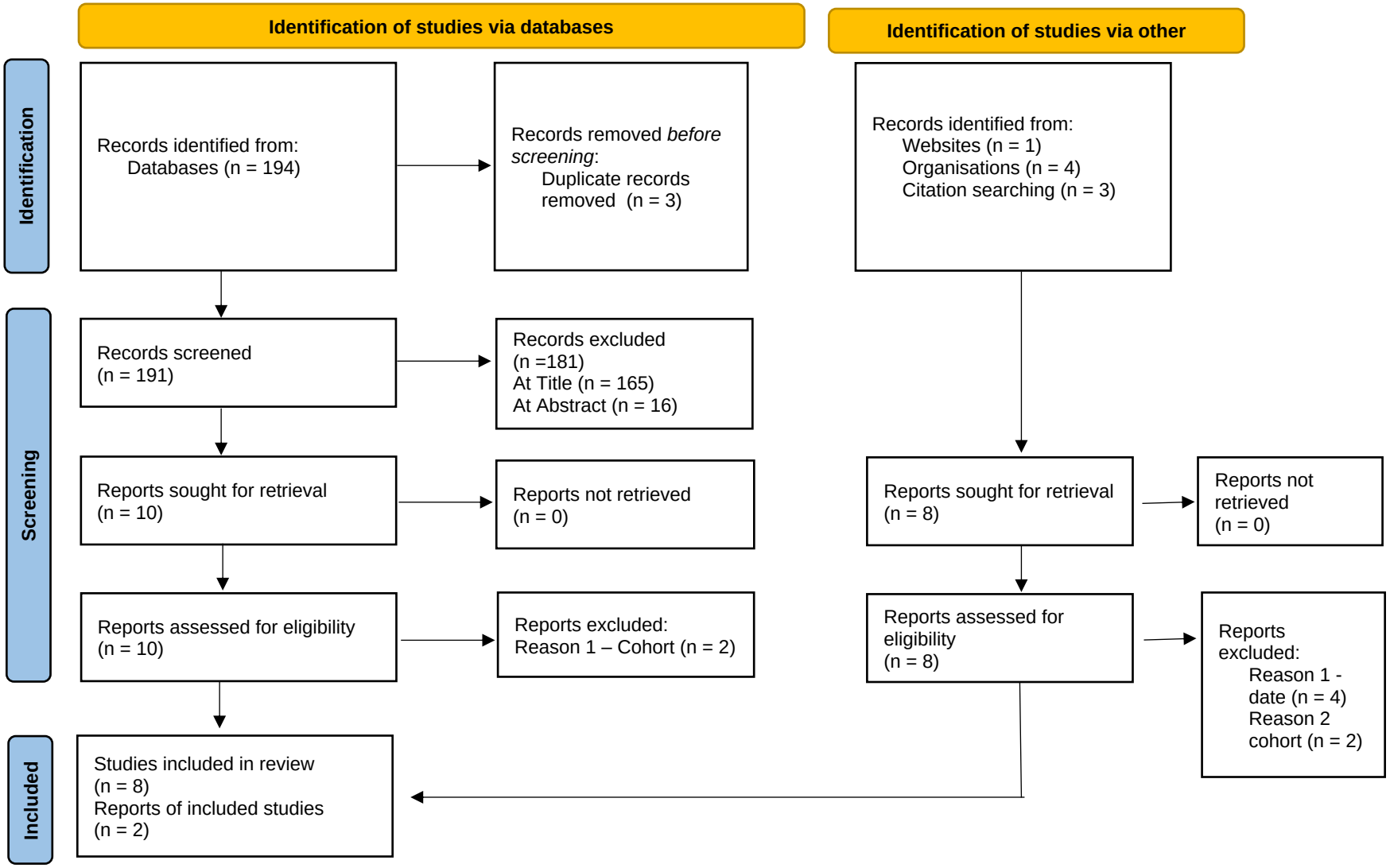
Methods

The Cochrane Database was searched, initially for secondary review data, using the advanced search function to limit the search for "Carer*" AND "mobile technology" OR "text message" in the title only within the last five years. Papers were included if they were written in English, published after 2015, concerned carers over the age of 18 and using mobile technology, particularly mobile phones. Papers were accepted if they included the cared for and carers collectively. Whilst the primary focus of this review was the acceptability of usage of mobile phone text message technology in the carer population, articles were included if they explored the effectiveness of mobile phone interventions as the primary outcome. Due to the low level of data specific to carers use of mobile phone text message technology and the small proportion of carers in the general population, papers relating to mobile phone effectiveness in the general population were included. Due to the low level of secondary review data, primary level data was searched for during April and May 2021. The following keywords “unpaid carer*” AND “text message*” OR “mobile technology” in the title only were used within the last five years. ProQuest via Open Athens was used to search PsychInfo, MEDLINE, Health Research Premium Collection. The Carer Research & Knowledge Exchange Network (CAREN) was searched, separately, and excluded the keyword “Carer*”. The search strategy is reported in a PRISMA Flow Diagram (Figure 1) (Page *et al*., 2020).

Published reports on dedicated specialist sites including the National Institute of Clinical Excellence, Carers UK, and NHS Digital were searched to identify non-peer-reviewed research relating to carers. Reference lists of papers were hand searched for relevant titles.

The title and abstract were first screened for relevance before being included in a full-text review. CASP critical appraisal tools were used to critically appraise articles retained for full text.

Figure 1 – PRISMA Flow chart of search strategy (Page *et al*., 2020)



Results

Ten studies were identified, six reviews (no meta-analysis) and four primary studies. Included studies are summarised in Table 1. No data was found on the acceptability of mobile phone text message interventions specific to carers, but some data was found on the effectiveness of mobile phone interventions within both the carer and general population (Dwyer *et al.*, 2021 and Hall *et al.,* 2015). This review highlights gaps in evidence base around acceptability, and usability of mobile phone text message technology and the impact on caregiver quality of life and improvement in knowledge and skills in the carer population.

Table 1: Summary of included studies

Author, year, country	**Aim of Study**	**Study Design**	**Target Population**	**Key results**
Bergstrom *et al.*, 2017, Sweden	Exploration of ICT support in adult carers of older adults and to identify the impact on carer outcomes	Interrogative review	Adult carers	Presented key characteristics of included studies at Meso, Macro, and Micro level. Future technology-based interventions should actively involve carers to produce acceptable and high levels of usability about information technology only.
Brimblecombe *et al*., 2018, UK	Overview of the international evidence on effective support for unpaid carers	Scoping Review	Carers (age not defined)	Found tentative evidence for positive impact on carer stress. No evidence on burden or quality of life improvement.
Carers UK, 2021, UK	To understand the experience of carers & former carers in the UK	Snapshot Survey	Adult carers and former carers	42% of Carers stated online GP appointments made their caring role easier. 29% would continue to access services digitally. Barriers identified included privacy issues and lack of access to up-to-date devices.
Dale *et al.*, 2018, UK	Exploration of coproduction of a web-based initiative promoting resilience and coping.	Mixed-method study	Informal carers (age not defined)	describes a theoretical framework for coproduction but was unable to conclude on the effectiveness.
Dwyer *et al*., 2021, Australia	Exploration of text-based e-mental health counselling using language patterns as a predictor.	Scoping Review	Those with a mental health condition (any age)	An identified gap in the evidence base of text-based counselling particularly in under-served groups.
Fuller-Tyszkiewicz *et al*., 2020, Australia	Evaluation of self-guided mobile app-based psychological intervention	Randomised Controlled Trial	carers of people with a physical or mental disability	mHealth psychological interventions were effective for caregivers experiencing stress.

Author, year, country	Aim of Study	Study Design	Target Population	Key results
Ganzalex-Fraile *et al.*, 2021, UK	To assess remotely delivered interventions that reduce the burden and improve mood and quality of life	Systematic Review	Caregivers of people with dementia (international)	Remotely delivered interventions may slightly reduce caregiver burden and improve caregiver depressive symptoms when compared with the provision of information alone.
Hall *et al*., 2015, USA	Exploration of mobile text-messaging interventions that improve health and support behaviour change that can influence practice	Systematic Review	Adult population	The majority of published TMIs were effective at addressing diabetes self-management, weight loss, physical activity, smoking cessation, and medication adherence for ART. Limited evidence exists to determine the most efficacious intervention characteristics, and more research is needed to determine best practices, assess longer-term effects in more diverse populations, and determine the cost-benefit and cost-effectiveness of TMIs.
Marston and Samuels, 2019, UK	Review of international age-friendly frameworks	Scoping Review	carers of people with disability	identified the lack of focus on the power of technology, particularly for older carers.
Stiels *et al*., 2019, UK	Exploration of carers' engagement with electronic assistive technology and telecare	Qualitative / observational	Carers who respond to a user of telehealth/telecare	Telecare can support carers in their caring role.

A systematic review relating to carers and remotely delivered information, highlighted that unpaid carers' research into interventions to improve the situation of family carers would be of value (Ganzalex-Fraile *et al*., 2021). This review focused on specific carers of those with dementia, the primary focus being improving care for the cared for. The findings concluded that results for outcomes such as carer quality of life and improvement in carers knowledge and skills were imprecise, in part because few studies measured them. Ganzalex-Fraile and colleagues concluded that interventions to improve the situation of family carers would be valuable and, importantly, reported no harmful effects of the intervention. A further systematic review related to technology-based support for carers of home-dwelling older people (Bergstrom *et al*., 2017). They concluded that future technology-based interventions should actively involve carers to produce acceptable and high levels of usability in any technology developed.

Hall *et al.,* (2015) reported that mobile phone text-message Interventions (TMIs) were effective at addressing diabetes self-management, weight loss, physical activity, smoking cessation, and medication adherence in the general population. Furthermore, these researchers recommended that TMIs should focus on specific health outcomes in a wider range of settings and populations and that specific components of TMIs such as mobile phone text messaging may be more effective than multi-component TMIs. Brimblecombe *et al.,* (2018), explored broad types of psychological support, training, and education delivered by assistive technology (AT) in the carers' population. The researchers concluded that effectiveness was influenced by the care need and type of support offered.

A randomised control trial evaluated the effectiveness of an intervention targeted specifically at carers providing care to individuals with dementia, Parkinson's disease, and psychosis (Fuller-Tyszkiewicz *et al*., 2020). Again, this study did not provide insight into the acceptability of mobile phone text message technology to carers. One study explored the co-production of digital programmes for carers to promote resilience and coping through supporting the effective use of web-based information and other resources (Dale *et al*., 2018). Whilst Dale and colleagues (2018) highlighted the biopsychosocial context of caring should inform the production of interventions, and acknowledged that barriers such as lack of time, access, and digital skills existed within the cohort. Data was found about carer involvement in telecare and concluded that telecare can support carers in their role, with the focus on supporting the cared for but supported the need for co-production (Steils *et al.*, 2019).

Whilst some research has focused on age-friendly initiatives, there is little consideration and discussion around the needs of mid-older adults who are carers of children/young people and dependent adults with disabilities (Marston and Samuels, 2019). Where multiple forms of mobile technology were used as an intervention this was generally targeted at specific conditions or cohorts with carers included along with their cared-for, rather than included as a separate cohort with separate needs. Dale and colleagues (2018) identify the need for proactive, personalised prompts which may have value in supporting carers. Dwyer *et al.,* (2021) focused on mobile phone text-based e-mental health counselling services to identify individuals at risk of psychological distress or self-harm. This study found that mobile phone text-based communications analysed using computational linguistic techniques, can be used to predict treatment progression and identify those at risk of mental health conditions and suicide.

Non-peer reviewed information provided insight into carers' needs and the barriers they experience to accessing services (Carers UK, 2020). A Carers UK survey into the use of digital technology found that 42% of carers thought remote health services such as online GP appointments made their caring

role easier (Carers UK, 2021). The same survey reported that 39% of Carers found that digital ways of keeping in touch with friends and family were beneficial but did not refer specifically to mobile phone text messaging. Carers UK concluded that whilst there is potential for continuing to use technologies of all kinds to support carers, there were perceived barriers, including concerns about lack of privacy, the need for up-to-date devices, and the value of face-to-face contact. Despite these difficulties, 29% of Carers wanted to continue accessing services digitally.

Discussion

This review has found limited data specific to mobile phone text messaging use within the general carer population. Some data were found that related to general technology with some relating to specific mobile phone text message interventions aimed at specific carer populations primarily aimed at improving the wellbeing of the cared-for. This review has highlighted a lack of knowledge relating to the usability and acceptability of mobile phone text message technology within the general adult caring population. Consistent outcomes measures on the impact of carers quality of life and increases in knowledge and skills are required (Ganzalex-Fraile *et al*., 2021).

With high ownership of mobile phones (Hall *et al.*, 2015), this technology may improve access to carers. Hall and colleagues (2015) identify the need to focus on specific populations and outcomes and Dale and colleagues (2018) that personalised TMI's may be effective in health promotion in the carer population. Further research is needed to understand the acceptability of such methods for the different sub-groups within the caring population, particularly those in rural and remote areas (Dwyer *et al*., 2021).

There are many sub-groups with specific needs within the general carer population including older carers, young carers, carers transitioning into adult life, and dual carers of both the young and old. Whilst there is some evidence of the effectiveness of psychosocial interventions targeted at those who care for people with dementia (Hall *et al*., 2015), there is little evidence on how best to reach carers to understand their needs and support their health and well-being rather than that of the cared for. There appears to be a lack of evidence on how best to reach carers and understand the different needs of specific sub-groups.

The early months and years can be a critical time for carers as they struggle in their new role unaware of the support that is available to them or unsure how to request it or if they are eligible (Carers UK, 2020). As the UK government works to identify carers so support can be given, accessibility remains an issue. The evidence from this review, together with the ambition of the UK Department of Health and Social Care suggests that mobile phone text message technology may present an opportunity to access carers to gain their feedback to help shape and influence the support services they require. In addition, this approach may provide an opportunity to support

them with health-promoting messages and other informational support to improve their health and wellbeing and allow them to continue in their caring roles. Further research is required to understand if mobile phone text message technology is an acceptable method of reaching informal carers and understanding their needs.

Limitations

Time restraints and the size of the research team restricted the depth of this review, with search terms being restricted to the title only for a pragmatic approach. In addition, the review was confined to the parameters of the broader research project that was predominantly interested in researching mobile phone text message technology. Searches were limited to the databases the research team had access to.

Conclusion / Implications for research and practice

This review has generated limited new insights into how mobile phone text message technology may be effective for the general caring population or specific sub-groups. There is an evidence gap with little evidence on whether mobile phone text message technology is effective in providing informational advice and health-promoting messages to support carers' health and wellbeing. Co-production has been found to be important and any future research should consider this, particularly considering the lack of findings on acceptability.

In practice, mobile phone text message technology may provide a relatively inexpensive and convenient means for care providers to reach and understand the needs of different sub-groups of carers. It may also offer a convenient, unobtrusive method that allows them to continue their caring role. This approach may be of particular use to services in remote and rural areas, particularly during the COVID-19 pandemic and subsequent crises in health and social care. This review concludes that further research into the acceptability, reach and effectiveness of mobile phone text messaging in the carer population should be undertaken.

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