

The efficacy of telephone use to assist and improve the wellbeing of family caregivers of persons with chronic diseases: a systematic review protocol

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Review question/objective

The review objective is to synthesize the best available evidence on the efficacy of interventions using the telephone to improve the wellbeing of family caregivers of people with chronic diseases.

The review question is: What are the effects of interventions using the telephone versus other technologies, strategies, or usual care to improve the wellbeing of family caregivers of people with chronic diseases, in the physical, psychological, or spiritual domains?

Background

According to the World Health Organization (WHO), chronic diseases are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for the rehabilitation, or may be expected to require a long period of supervision, observation or care¹. Chronic diseases include hypertension, diabetes, cardiovascular diseases, cancer, stroke, and Alzheimer's disease, among others. Due to the characteristics and consequences of these diseases, those affected constantly need someone to support them and provide basic care, this person is often known as a caregiver.

The family caregiver refers to an adult, with kinship or affinity, who assumes the responsibilities of caring for a loved one living with a chronic and disabling disease, and participates in decision making. The family caregiver performs or supervises the activities of daily life to compensate for the malfunctions or limitations of the person in need of care².

The experience of being a caregiver for a person with a chronic disease is variable according to each situation. Often, it causes self-negligence, increased duties and responsibilities, health issues, anxiety, depression, and changes in lifestyle of the caregiver³. This means that caring becomes a stress factor that impacts negatively on the caregivers and may overloads them. In this sense, providing informal care has been conceptualized as a stressful life event⁴.

In recent years, Information and Communication Technologies such as the telephone, television, and internet have the potential to improve the quality of care and access to health services to different populations, including family caregivers of people with chronic diseases⁵

Since its invention, the telephone has been used as a fundamental tool in medical communication⁶, especially in industrialized countries⁷. Its use has been important to offer health care, including education, psychosocial therapy⁸, and emotional support⁹ for people with chronic illness and their family caregivers. According to Skipwith¹⁰, telephone use eliminates some of the major limitations of out-of-home interventions, such as traveling, making arrangements for an alternative caregiver, searching for an alternate caregiver, and worrying due to absence from the person being cared for. It also provides a means of reaching isolated or rural caregivers who have few or no available services. Telephone care can be a cost-effective, time efficient, and culturally acceptable intervention, and has a potential value with caregivers comparable to the outcomes derived from pioneer mental health services, such as crisis intervention, suicide hot lines, and information and referral services

Studies conducted in the United States¹¹⁻¹² and United Kingdom¹³⁻¹⁴, researching the possibility of using the phone in health has shown that people would like to have access to health care professionals by phone. The assessment of satisfaction with this medium was high in groups where this strategy was used¹⁵.

Chang and Nitta¹⁶ developed a controlled clinical trial to determine the perceived helpfulness of telephone calls to 83 caregivers of family members with dementia. Major reasons for perceived helpfulness were that participants were assisted in sharing thoughts and feelings, expressing feelings of being overwhelmed, discussing physical and psychosocial problems, forgetting the situation, seeking reassurance, and asking for information. The results from this study suggest that family caregivers can be helped through a variety of social support mechanisms, including the use of the phone even though several participants perceived the telephone calls to be lacking in helpfulness¹⁶.

Additionally, there are studies that demonstrate the efficacy of interventions executed by telephone, addressed to family caregivers, in decreasing the prevalence of anxiety, depression and reduced caregiver burden. However, most of these studies¹⁷⁻¹⁹ were conducted with family caregivers of people with Alzheimer's.

One notable study was when Tremont and colleagues¹⁷ conducted a randomized controlled clinical trial. They examined the preliminary efficacy of the Family Intervention: Telephone Tracking Dementia (FITT-D), a multi-component intervention that is delivered in 23 telephone contacts over 12 months. Thirty-three caregivers of patients with dementia were assigned to receive either FITT-D (n = 16) or standard care (n = 17). Each contact followed a standardized treatment manual, involving assessment and individualized application of interventions to address mood, family functioning, social support, and health. As a result of the study, caregivers receiving FITT-D exhibited significantly lower burden scores

and less severe reactions to memory and behavior problems than caregivers in the standard care condition.

In another case, Gallagher-Thompson and Heather¹⁸ conducted a study in China to explore the impact of a direct intervention in the home compared with telephone support for depression symptoms and perceived stress of Alzheimer patients' caregivers. The caregivers were randomly assigned to a telephone support condition (TSC) or to an in-home behavioral management program (IHBMP) that consisted of six modules aimed at learning skills to help caregivers cope with the stress derived from their work. Each module included one or more 90-minute session, focusing on information about caregiver stress, inappropriate thoughts, communication strategies, decisions at the end of life, and enjoyable activities. The comparison group consisted of telephone support for the caregivers through six calls in intervals of two weeks over 12 weeks. It was found that the first program, with a duration of four months, resulted in less stress on the caregiver and decreased levels of depression associated with caring, whereas the comparison group showed no variation. Caregivers with higher self-efficacy benefited from both treatments.

Similarly, Winter and Gitlin¹⁹ conducted a controlled clinical trial to evaluate the feasibility and effectiveness of support groups led by professionals, using the telephone, for female family caregivers of community-dwelling dementia patients. Recruited through various community sources, 103 female caregivers were randomized to the telesupport treatment group or a control condition. Effects on caregiver burden, depression, and personal gains were evaluated at 6 months, the main end point. Older caregivers (65 years old or older) in the telesupport group reported lower depression than control group caregivers.

A preliminary search of Cochrane Database of Systematic Reviews, Joanna Briggs Institute Library of Systematic Reviews, Medline, CINAHL and PROSPERO found three systematic reviews²⁰⁻²² about this topic:

A review²⁰ of eight papers conducted in 2007 of the effects of interventions for adult family caregivers of people who have had a stroke assessed the effects of caregiver training interventions. Examples of such interventions include education and counseling, social problem solving partnerships, psycho-educational telephone support groups, a nurse-led education and support program, as well as a support program delivered in hospital or at home. The review found that all interventions tested in the RCTs provided some benefit, although trials were generally of low quality, preventing firm conclusions being drawn.

Legg and colleagues²¹ reviewed, in 2010, eight studies and categorized interventions into three groups: support and information, teaching procedural knowledge/vocational training, and psycho-educational type interventions. The review included one trial assessing a telephone intervention with family caregivers of stroke survivors. For caregivers' stress or strain, they found no significant results within categories of intervention, with the exception of one single-center study examining the effects of a 'vocational training' type intervention. This study found a mean difference between the intervention and comparator group at the end of scheduled follow-up of -8.67 (95% confidence interval -11.30 to -6.04, $P < 0.001$) in favor of the 'teaching procedural knowledge' intervention group. They did not pool the results of all the studies because of substantial methodological, statistical and clinical heterogeneity.

In 2010, a systematic review²² of interventions for non-professional caregivers of individuals with dementia was published. The purpose of this report was to systematically review the evidence on the effects of caregiver interventions on burden, mood (including depression and anxiety), and ability to manage problematic behavior, as well as the effects on care. The authors had limitations on generalizing findings from the review of technology-based interventions, which included the telephone, because the findings were largely descriptive and did not appraise the quality of the included studies. However, the studies reviewed provide a comprehensive overview of Information and Communication Technologies services available for individuals with dementia and their caregivers.

The three systematic reviews²⁰⁻²² reported that the heterogeneity of the interventions included in the studies made it impossible to establish which intervention was most effective. This indicates that no studies exist that independently assessed the effectiveness of telephone intervention in caregivers of persons with chronic diseases, like the review proposed here.

Given the impact chronic diseases have on the quality of life of people and their families, it is important to establish interventions that are more efficient and less expensive than standard or routine care to promote the wellbeing of family caregivers. Despite studies that demonstrate the usefulness of the phone to make health interventions, there is no summary of evidence of the effectiveness of its use. Therefore, filling this gap is important for health professionals, so they may base decisions on the use of telephone interventions to improve the wellbeing of family caregivers of people with chronic diseases.

Keywords:

Caregivers; chronic disease; telephone; psychological stress; physiological stress

Inclusion criteria

Types of participants

The review will consider studies that include family caregivers of people with chronic diseases regardless of the diseases, severity and duration of care. The caregiver may be a relative, friend or neighbor of the person with a chronic illness. Care must be performed at home.

Types of intervention(s)

The review will consider studies that evaluate psycho-educational, psychosocial and psychotherapeutic interventions, using the telephone to reinforce personal strengths, resources and coping skills of caregivers in order to improve their wellbeing in the physical, psychological and spiritual domains.

The psychoeducational²³ interventions aim to improve caregivers' knowledge about themselves, care recipients, and the environment. This type of intervention focuses on teaching caregivers to deal and cope with stressors by providing comprehensive information on their care recipients' disease, resources and services that caregivers can use, and other specific coping skills such as problem solving. The psychosocial interventions²⁴ are those used to enhance the caregiver's social and psychosocial functioning and improve social skills, interpersonal relationships, and communication. The objective of

all psychosocial intervention is to integrate caregiving into the community, and as such, increase their sense of autonomy. Examples include engagement and outcome-oriented assessment, the family's assessment of the patient's needs, and coping strategy enhancement. Psychotherapy²³ is another form of intervention that is often used in conjunction with psychoeducation, involving individual counseling to caregivers by trained professionals. This type of intervention is usually designed to teach coping skills and problem solving techniques through the cognitive behavioral approach.

For this review, only interventions conducted by telephone will be considered, without any face-to-face encounters or use of a computer. The intervention by telephone should not be part of another intervention and is without restriction on the frequency or number of calls. Furthermore, the intervention must be performed by a health professional such as a nurse, doctor, or psychologist.

Comparator/control intervention(s)

Foreseen comparisons of intervention trials include:

- Comparison between psycho-educational and/or psychosocial and/or psychotherapeutic individual intervention using a telephone versus the same individual intervention using other forms of intervention. For example: web-based, the use of computer software, or face-to-face communication.
- Comparison between psycho-educational and/or psychosocial and/or psychotherapeutic individual interventions using telephone versus standard or routine care, or no additional care.

Types of outcomes

This review will consider studies that include the following outcome measures for family caregivers:

- Psychosocial wellbeing, including anxiety, depression, burden and strain of caregiving, mental health, social relationship measured, active coping strategies by, for example, Hospital Anxiety and Depression Scale²⁵, Beck Anxiety Inventory²⁶, Beck Depression Inventory²⁷, Zarit Burden Interview²⁸⁻²⁹, Caregiver Strain Index³⁰⁻³¹, Utrecht Coping List³², Perceived Stress Scale³³.
- Physical wellbeing, including somatic complaints measured by, for example, Medical Outcomes Study 36-item Short Form Healthy Survey(SF-36)³⁴, Health Conception Scale³⁵, General Health Questionnaire³⁶⁻³⁷.
- Spiritual wellbeing, measured by (a) faith in a transcendent force; (b) personal relationships with God, others, and self; and (c) empowering transformation of and liberating consolation from adversity by, for example Spiritual Health Scale³⁸, The Spiritual Scale³⁹, The Spirituality Index of Well-Being⁴⁰, Spiritual Well-Being Questionnaire⁴¹, Spiritual Well-Being Scale⁴²

Types of studies

This review will include randomized clinical trials. In the absence of randomized clinical trials, studies of quasi-experimental design will be considered for inclusion.

Search strategy

The search strategy used for the review will focus on finding articles published in Portuguese, English and Spanish since 1995. Since its creation, the telephone has been a means to tele-health care, but it was not until 1990 that it began to appear in the major advances in health care, along with the use of information and communication technologies⁵ and studies on using the telephone to this capacity⁷. For these reasons, the start of the search is limited to 1995.

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken, followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies.

The databases to be searched include:

CINAHL

Pubmed

Embase

ProQuest

PsychINFO

Cochrane Central Register of Controlled Trials (CENTRAL)

IBECS

LILACS

The search for unpublished studies will include:

ProQuest Dissertations and Theses

Cybertesis

Biblioteca Digital de Teses e Dissertações

ADT

Diva

RCAAP- Repositório Científico de Acesso Alberto de Portugal

Theses Canada

Ethos

DART-Europe E-Theses Portal

National ETD Portal

Assessment of methodological quality

Quantitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data collection

Quantitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI-MAStARI (Appendix II). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

Data synthesis

Quantitative papers will, where possible be pooled in statistical meta-analysis using JBI-MAStARI. All results will be subject to double data entry. Effect sizes expressed as odds ratio (for categorical data) and weighted mean differences (for continuous data) and their 95% confidence intervals will be calculated for analysis. Heterogeneity will be assessed statistically using the standard Chi-square and also explored using subgroup analyses based on the different study designs included in this review. Where statistical pooling is not possible the findings will be presented in narrative form including tables and figures to aid in data presentation where appropriate.

Conflicts of interest

The reviewers have no conflicts of interest in conducting this review.

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Appendix I: MASTARI appraisal instrument

JBI Critical Appraisal Checklist for Randomised Control / Pseudo-randomised Trial

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Was the assignment to treatment groups truly random?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were participants blinded to treatment allocation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was allocation to treatment groups concealed from the allocator?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were the outcomes of people who withdrew described and included in the analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were those assessing outcomes blind to the treatment allocation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were the control and treatment groups comparable at entry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were groups treated identically other than for the named interventions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Were outcomes measured in the same way for all groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Were outcomes measured in a reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

Appendix II: MASTARI data extraction instrument

JBI Data Extraction Form for Experimental / Observational Studies

Reviewer Date

Author Year

Journal Record Number

Study Method

RCT ☐ Quasi-RCT ☐ Longitudinal ☐

Retrospective ☐ Observational ☐ Other ☐

Participants

Setting

Population

Sample size

Group A Group B

Interventions

Intervention A

Intervention B

Authors Conclusions:

.....
.....
.....

Reviewers Conclusions:

.....
.....
.....

Study results

Dichotomous data

Outcome	Intervention () number / total number	Intervention () number / total number

Continuous data

Outcome	Intervention () number / total number	Intervention () number / total number