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## Designing a telephone intervention program for family caregivers\*

Desenho de um programa de intervenção com uso de telefone para cuidadores familiares

Diseño de un programa de intervención con uso de teléfono para cuidadores familiares

Leidy Johanna Rueda Diaz<sup>1</sup>, Diná de Almeida Lopes Monteiro da Cruz<sup>2</sup>

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<sup>1</sup> Universidad Industrial de Santander, Escuela de Enfermería, Bucaramanga, Colombia.

<sup>2</sup> Universidade de São Paulo, Escola de Enfermagem, São Paulo, SP, Brazil.

### ABSTRACT

**Objective:** Describing the development process of a nursing intervention program to promote the adaptation of family caregivers for people with chronic diseases in Colombia and Brazil. **Method:** A developmental study in which an intervention program was created as proposed by the *UK Medical Research Council* for developing and evaluating complex interventions. **Results:** The program was organized into five weekly sessions of 40 minutes duration applied over the telephone, which integrated the activities of Caregiver Support and Improvement in Coping. **Conclusion:** Following the recommendations of the *UK Medical Research Council* allowed designing an intervention program of high methodological rigor based on existing scientific evidence, and based on a theoretical model from the nursing discipline which will increase the understanding of their mechanisms of action in improving the well-being of family caregivers.

### DESCRIPTORS

Nursing Care; Caregivers; Family; Chronic Disease.

### Corresponding author:

Leidy Johanna Rueda Diaz  
Universidad Industrial de Santander,  
Escuela de Enfermería  
Carrera 32 No. 29-31 Piso 5 – Bucaramanga  
680002 – Colombia  
[ljruedad@uis.edu.co](mailto:ljruedad@uis.edu.co)

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## INTRODUCTION

Given that taking care of a person with chronic illness can significantly affect physical and emotional health, social life and financial resources, a variety of clinical trials have been developed to test support interventions<sup>(1)</sup> to reduce anxiety<sup>(2)</sup>, stress<sup>(2-3)</sup>, depression, and overload<sup>(1)</sup>, as well as to improve well-being<sup>(1,4)</sup> and the quality of life<sup>(4-5)</sup> of family caregivers. These interventions include counseling<sup>(2)</sup>, support groups<sup>(2,4)</sup>, psychotherapy<sup>(6-7)</sup>, multi-component interventions<sup>(1)</sup>, psychoeducational interventions<sup>(1,4,6,8)</sup>, individual skills training, and behavior management training, among others<sup>(9)</sup>. It is noteworthy that most of the studies have been developed with family caregivers of people with Alzheimer's disease in the United States and European countries.

Interventions directed at family-caregivers can take place in different contexts (at home, in the service), involve a variable part of the family (the whole family, some elements, or, at the limit, just one) and encompass diverse contents, which can also be transmitted in different ways (didactic predominance of information transmission or skills versus emotional work or sharing; "low-complexity", informal interventions versus structured interventions, in groups or with families)<sup>(10)</sup>.

However, in addition to the efficiency/effectiveness of these interventions still being questionable, there is a shortage of publications in the literature describing the process of developing interventions for family caregivers. Thus, this article aims to describe the process of developing a nursing intervention program that promotes the adaptation of family caregivers of people with chronic diseases in Colombia and Brazil.

An intervention development study reports the reasons, decision-making processes, methods and findings that occur between the initial idea of an intervention until it is ready for a pilot study or feasibility study prior to an evaluation in a large clinical trial<sup>(11)</sup>.

## METHOD

The intervention program was created following the proposal of the *UK Medical Research Council* for developing and evaluating complex interventions<sup>(12)</sup>. The program was developed in three stages, as described below.

In the first stage, the existing and relevant evidence on interventions for family caregivers was established. For this, we searched for original articles and systematic reviews in the Medline, PsychInfo, and Cochrane Library databases. Keywords included family caregivers, interventions, programs, chronic diseases, and Alzheimer's, among others. From the literature, interventions for family caregivers that had been evaluated as well as barriers and challenges in their implementation were identified. A systematic review was also carried out<sup>(13)</sup> to identify the best available evidence of the effectiveness of interventions for family caregivers using the telephone.

In the second stage, the theoretical concept of the family caregiver as an adaptable individual and the intervention program as a contextual stimulus from the perspective of Roy's Adaptation model were developed.

In the third stage, the first version of the intervention program was designed from consulting the specialized

literature identified in the first phase, especially the systematic reviews on interventions for family caregivers<sup>(1,4-5,9)</sup>, and taking into account some of the suggestions pointed out by the authors in the primary studies<sup>(14-15)</sup>.

In order to determine the content relevance of the intervention sessions and the feasibility of its application using the telephone, a pilot study was carried out from July 3 to September 19 in the city of São Paulo, and from August 1 to September 13, 2014 in the city of Bucaramanga, after approval of the research by the Research Ethics Committee (CEP) of the Nursing School of the Universidade de São Paulo, by the Universidad Industrial de Santander and by the University Hospital of the Universidade de São Paulo. Caregivers were recruited by convenience from the outpatient clinics at the University Hospital of Santander (Bucaramanga, Colombia) and at the unit of Radiotherapy and Chemotherapy of the same institution, in addition to the Home Care Program of the University Hospital of the Universidade de São Paulo (HU-USP-Brazil). Family caregivers who met the following inclusion criteria were included: being a family caregiver of a person with chronic illness, being 18 years or older, knowing how to read and write, providing care to the care recipient for more than 1 month, having telephone service, and scoring at least 14 points on the Caregiver Role Strain scale. This scale was developed for a controlled clinical trial in the thesis from which this article was extracted. After acceptance/signing of the free and informed consent form (ICF), a nurse collector verified whether the family caregivers met all inclusion criteria. Next, sociodemographic data and data corresponding to an evaluation of the Caregiver Role Strain scale were collected through an interview.

Caregivers were included in each of the pilot studies by signing the Free and Informed Consent Form. Caregivers received five intervention sessions conducted over the telephone.

In order to carry out the pilot study, a group of seven nurses (three Colombians and four Brazilians) who fulfilled the following criteria were selected: having the title of nurse and having a minimum clinical practice of 1 year in areas related to care of people with chronic diseases or family caregivers. Each of the intervening nurses participated in an 8-hour training session to carry out the intervention tested in this study. These nurses were instructed to fill out the Intervention Session Record during each telephone interview with the caregiver and the Intervention Session Review Record immediately after each telephone contact. The Intervention Session Record had to include the date, session number, start time, end time, session duration and observations made by the caregiver about each of the sessions. The Intervention Session Review Record had to include: The highlights of the intervention session; Difficulties during the session; Questions regarding the content or procedures of the session; Suggestions for improving the content or procedures of the intervention session. The data collected in the records filled out by the nurses were transcribed in full and organized according to the aspects evaluated in each of the records. The most frequent and practical observations according to the criterion of the principal investigator were taken into account for adjusting the manuals and journals. The same adjustments applied in the Spanish version were applied in the Portuguese version and vice versa in order to ensure that both versions were identical.

## RESULTS

### IDENTIFYING THE EXISTING EVIDENCE

*Interventions for family caregivers.* Although the evidence on the efficacy/effectiveness of interventions for family caregivers is contradictory, most of them suggest that multicomponent interventions<sup>(1)</sup> of a psychoeducational nature<sup>(1,4,6,8)</sup> seem to have a positive influence on the psychosocial well-being of family caregivers, improving their subjective well-being, decreasing depression, overload<sup>(1)</sup> and anxiety<sup>(6)</sup>. They can also improve family functioning<sup>(4)</sup>, increase the perception of health, social support, competence, preparation for the role of caregiver<sup>(6)</sup>, in addition to improving the skills and knowledge of caregivers<sup>(8)</sup>. Teaching coping strategies to caregivers individually or in groups also seemed effective in improving the psychological health of the caregiver, both immediately and a few months later. Group interventions are less effective than individual interventions<sup>(7)</sup>. Other authors have pointed out that support and education can be the most valuable and effective tools to improve the quality of life of the caregiver, family involvement, optimistic attitude, developing and strengthening their coping skills, and reducing their uncertainty<sup>(5)</sup>. Several authors have also pointed out that the most successful interventions are multidimensional, meaning interventions that focus on multiple stressors and other risk factors that affect the health and well-being of caregivers<sup>(14-15)</sup>. It seems that multidimensional interventions are more effective than one-dimensional programs, considering that by addressing several themes the chances of one of them relating to a certain problem of the caregiver is more likely.

A systematic review<sup>(13)</sup> conducted to evaluate the effectiveness of telephone interventions for family caregivers of people with chronic diseases evidenced that the tested interventions have the potential to improve and increase the well-being of family caregivers; however, there is still insufficient evidence to reach any definitive conclusion regarding their effectiveness.

*Barriers for the implementation of interventions.* Time constraints may limit the participation of caregivers in intervention studies<sup>(16-20)</sup>. This population experiences significant demands for their time and attention, for their care duties and other commitments, which generate feelings of overload<sup>(21)</sup>, a lack of time<sup>(22)</sup>, and a lack of energy or motivation to take on additional tasks<sup>(22)</sup>, as is the case with intervention programs.

### THEORY DEVELOPMENT

Taking into account the importance of using Nursing models as a guide for the development of studies from a nursing perspective, the Roy Adaptation model was chosen for providing a conceptual framework that allows to explain how the proposed research program works to improve caregiver role strain, the well-being and the quality of life of the caregiver from a holistic perspective of nursing. It has been theorized that the intervention program is a contextual stimulus that interacts with other contextual stimuli to reduce

the intensity of the focal stimulus effect (the responsibility of caring for another individual) in the family caregiver, and to stimulate and strengthen the regulatory and cognator subsystems, thereby promoting adaptive responses identifiable in the four adaptive modes. It was theorized that the activities of the selected Nursing Intervention Classification (NIC) would act as inputs into the regulatory and cognator subsystem through mind and body connections. The interventions strengthen the cognator system by promoting changes in perceptions related to the care experience by providing information, by stimulating the use of strategies for solving problems of daily living and by developing skills. Learning happens when the family caregiver integrates new knowledge into their daily lives, and assigns new positive values and meanings to their own lives. This integration promotes the stabilization of the regulatory system. The effect of the interventions on coping subsystems generates adaptive responses, interpreted as a reduction in caregiver role strain, increased positive perception of emotional well-being and improved perception of quality of life.

A critical element that was part of the intervention program as input into the adaptive system was the intensity of the intervention. It was proposed that the regulatory and cognator subsystem would be positively and significantly affected by 40 minutes of individualized telephone sessions once a week for 5 weeks. Given that this study theorized that the adaptation level of family caregivers with caregiver role strain is compromised due to having assumed the responsibility of caring for a relative with chronic disease, it was proposed to take the family caregiver to a level of compensatory adaptation through the intervention program.

### INTERVENTION MODELING

The following principles were established to guide development of the intervention program: the intervention program, as a contextual stimulus, will promote adaptation of family caregivers of people with chronic diseases; the intervention program will be focused on family caregivers diagnosed with caregiver role strain; the intervention program will adopt the standard language of the NANDA International Nursing Diagnoses Classification (NANDA-I), of the Nursing Interventions Classification (NIC) and the Nursing Outcomes Classification (NOC); the intervention program will be multidimensional, meaning that it will provide information and support to facilitate the care of the care recipient and coping with stress-producing situations.

The intervention program will be carried out over the telephone; the intervention sessions will be individualized; the intervention program will be psychoeducational, with content on self-care, the recipient disease and the impact of care on the health and well-being of the caregiver; and it will provide opportunity for expressing feelings and emotions associated with the performance of the caregiver role.

The intervention program will be flexible enough to respond to the needs of the family caregiver without compromising its fidelity and replication.

## THE INTERVENTION PROGRAM “TAKING CARE OF ME TO TAKE CARE OF OTHERS”

The intervention program named “*Taking Care of Me to Take Care of Others*” was divided into five sessions that integrated activities of the following interventions of the Nursing Intervention Classification (NIC): Caregiver support and Coping improvement. These interventions were chosen as they are considered to promote and facilitate the adaptation of family caregivers with the nursing diagnosis of “Caregiver role strain”.

In the first session, the meaning of being a caregiver and caring were discussed, and the deep breathing technique for

the caregiver to be able to relax. In the second session, the effects of care on health, the well-being of the caregiver and the caregiver’s rights were discussed. In this session, the muscle relaxation technique was introduced. The third session addressed the feelings that the caregiver could experience as a result of caregiving, as well as aspects related to assertive communication. In the fourth session, the problem-solving technique was approached to help the caregiver better deal with the difficulties of their daily lives. The fifth and last session dealt with the importance of one’s own health, such as caring for oneself (self-care) and time management.

Chart 1 summarizes the interventions/activities of each session, as well as their contents.

**Chart 1** – Sessions of the “Taking Care of Me to Take Care of Others” intervention program – São Paulo, SP, Brazil, 2014.

INTERVENTION SESSION	INTERVENTION/ACTIVITIES	CONTENT
1. Being a family caregiver	<i>Caregiver support:</i> Determining the knowledge level of the caregiver, teaching the caregiver stress control techniques.	<ul style="list-style-type: none"> <li>- Information on chronic diseases.</li> <li>- Meaning of being a family caregiver.</li> <li>- Consequences of care.</li> <li>- Strain management: breathing control exercise.</li> <li>- Breathing Diary.</li> </ul>
2. A little more about being a caregiver	<i>Caregiver support:</i> Investigating the positive and negative aspects of care. <i>Improving coping:</i> Encouraging the caregiver to identify their own strengths and weaknesses, instructing the caregiver on the use of relaxation techniques.	<ul style="list-style-type: none"> <li>- Care effects on the health and well-being of family caregivers.</li> <li>- The rights of family caregivers.</li> <li>- Muscle relaxation technique.</li> <li>- Relaxation Dairy.</li> </ul>
3. Feelings and communication	<i>Improving coping:</i> Encouraging the expression of feelings, perceptions and fears. Providing training on social skills.	<ul style="list-style-type: none"> <li>- Identifying feelings.</li> <li>- Assertive communication.</li> </ul>
4. Solving problems	<i>Improving coping:</i> Assisting the caregiver in solving problems in a constructive manner.	<ul style="list-style-type: none"> <li>- Problems and their solutions.</li> <li>- Problem solving technique.</li> </ul>
5. Taking care of me to take care of others	<i>Caregiver support:</i> Teaching caregiver maintenance strategies of health care in order to maintain their own physical and mental health.	<ul style="list-style-type: none"> <li>- Importance of one’s own health care.</li> <li>- How to take care of yourself.</li> <li>- Time management and activities planning.</li> </ul>

## PILOT STUDY

The convenience sample consisted of 18 family caregivers (nine in Colombia and nine in Brazil), 89% of the caregivers in Colombia and 78% in Brazil were female, with a mean age of  $46 \pm 13.2$  years for Colombian participants and of  $52 \pm 10$  years for Brazilian participants. Regarding the degree of kinship, 56% of caregivers of both nationalities were children of care recipients.

The intervention sessions were standardized through a manual, which for this study was called the Intervenor’s Manual. It described the structure of each of the intervention sessions in detail, along with the instructions to be followed by the intervenor. Further, it included a description of each of the topics covered in the intervention sessions to ensure that the content was faithfully expressed so that caregivers participating in the research received the same content in the same order with the appropriate language. Nevertheless, it was suggested to the intervenors that they could replace terms from the caregiver’s handbook narrative when they considered that this substitution would make the session contents more easily understandable.

The caregivers received a diary called the Family Caregiver’s Diary to support the development of intervention sessions. This instrument was intended to assist caregivers in any doubts that

arose during or after the intervention session, as well as to reinforce and promote the practice discussed during the sessions. Both the Intervenor’s Manual as well as the activity diary were prepared in Spanish and in Brazilian Portuguese.

From the data collected from the records filled out by the intervening nurses during the pilot study, the session contents were reviewed and some information was removed from both the manual and the caregiver activity diary as they were deemed not pertinent or not relevant to family caregivers. We clarify that family caregivers at the beginning of the research were advised not to return the journals to the researchers, as they might be apprehensive about its completion. For this reason, data from family caregivers’ journals were not analyzed. The final versions of the Intervenor’s Manual and the caregiver’s diaries were used for developing a controlled clinical trial.

## DISCUSSION

This study provides an example of developing an intervention program to promote the adaptation of family caregivers of people with chronic diseases to be tested in a clinical trial. To our knowledge, this is the

first study that describes the process of developing a nursing intervention program following the proposal of the *UK Medical Research Council* which integrates the standardized language of the NANDA, NIC, and NOC, and a Nursing theory.

The family caregiver's profile, the previously-developed interventions, as well as the possible barriers in its implementation were identified from the pertinent literature on the subject. Roy's model of adaptation allowed us to delineate an explanatory theory on the impact of an intervention program's effect on the adaptation of a family caregiver with caregiver role strain from a holistic nursing perspective.

During the modeling phase of the intervention, the pilot study allowed to refine the theoretical contents of the intervention with the aim of making the intervention program more acceptable to the target population. This was also useful for evaluating practical aspects of the intervention protocol, including recording and implementing telephone calls, and to establish key aspects of the intervention content.

As a limitation of this study we can point out the fact of having only considered the participation of family caregivers in the pilot study phase. Some authors have emphasized the relevance of developing content of

intervention programs for family caregivers in partnership with the main actors involved, since this strategy is more likely to motivate potential participants in the future<sup>(23-24)</sup>. However, aspects related to the time and costs of the study prevented the involvement of family caregivers in the first research phases.

Although the process followed for the development of the "Taking Care of Me to Take Care of Others" intervention program has allowed for generating and improving an intervention proposal for family caregivers of people with chronic diseases, this process was time-consuming and it took approximately 18 months to be completed.

## CONCLUSION

Following the recommendations of the *UK Medical Research Council* allowed us to design an intervention program of high methodological rigor based on existing scientific evidence and anchored on a theoretical model from the Nursing discipline which allows us to increase our understanding of the way the intervention program works to improve the well-being of the family caregiver.

We emphasize that the results of this study may support other health professionals in developing and improving interventions aimed at enhancing the well-being of family caregivers of people with chronic diseases.

## RESUMO

**Objetivo:** Descrever o processo de desenvolvimento de um programa de intervenção de enfermagem para promover a adaptação dos cuidadores familiares de pessoas com doenças crônicas da Colômbia e do Brasil. **Método:** Estudo de desenvolvimento no qual o programa de intervenção foi criado segundo a proposta do *UK Medical Research Council* para o desenvolvimento e a avaliação de intervenções complexas. **Resultados:** O programa foi organizado em cinco sessões semanais, de 40 minutos de duração, aplicadas por telefone, que integraram as atividades de Apoio ao cuidador e Melhora do enfrentamento. **Conclusão:** Seguir as recomendações da *UK Medical Research Council* permitiu o delineamento de um programa de intervenção, de alto rigor metodológico, fundamentado em evidências científicas existentes, sustentado em um modelo teórico próprio da disciplina de enfermagem o que permitirá aumentar a compreensão dos seus mecanismos da ação na melhora do bem-estar do cuidador familiar.

## DESCRIPTORES

Cuidados de Enfermagem; Cuidadores; Família; Doença Crônica.

## RESUMEN

**Objetivo:** Describir el proceso de desarrollo de un programa de intervención de enfermería para promover la adaptación de los cuidadores familiares de personas con enfermedades crónicas de Colombia y de Brasil. **Método:** Estudio de desarrollo en el que el programa de intervención fue creado según la propuesta del *UK Medical Research Council* para el desarrollo y la valoración de intervenciones complejas. **Resultados:** El programa fue organizado en cinco sesiones semanales, de 40 minutos de duración, aplicadas por teléfono, que integraron las actividades de Apoyo al cuidador y Mejora del enfrentamiento. **Conclusión:** Seguir las recomendaciones de la *UK Medical Research Council* permitió el diseño de un programa de intervención, de alto rigor metodológico, fundamentado en evidencias científicas existentes, sostenido sobre un modelo teórico propio de la disciplina de enfermería, lo que permitirá aumentar la comprensión de sus mecanismos de acción en la mejora del bienestar del cuidador familiar.

## DESCRIPTORES

Atención de Enfermería; Cuidadores; Familia; Enfermedad Crónica.

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