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**EMOTIONAL EXPERIENCE OF THE FAMILY CAREGIVER
OF THE DEPENDENT ELDERLY AT HOME:
A SCOPING REVIEW PROTOCOL**

**EXPERIÊNCIA EMOCIONAL DO FAMILIAR CUIDADOR
DO IDOSO DEPENDENTE NO DOMICÍLIO:
PROTOCOLO DE REVISÃO SCOPING**

**EXPERIENCIA EMOCIONAL DEL CUIDADOR FAMILIAR
DEL ANCIANO DEPENDIENTE EN EL DOMICÍLIO:
PROTOCOLO DE REVISIÓN SCOPING**

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ABSTRACT

Population ageing is the expression of the demographic changes in recent decades, leading to important repercussions in families, the community and society. It's important to know the emotional experience of the family caregiver of the dependent elderly at home, in order to provide for their well-being and emotional needs associated with the condition of care.

Objective: To identify and map the knowledge production on the emotional experience of the family caregiver of the elderly dependent at home.

Review Question: What is the emotional experience of the family caregiver of the dependent elderly at home?

Review Method: The review will follow the methodology recommended by The Joanna Briggs Institute⁽¹⁾ and it is planned to search for published and unpublished studies in various databases and to analyze the relevance of the articles. Data extraction and synthesis will be carried out by two independent researchers.

Keywords: Dependent Elderly; Emotions; Emotional Experience; Family Caregiver; Home.

RESUMO

O envelhecimento populacional é a expressão das alterações demográficas nas últimas décadas, conduzindo a importantes repercussões nas famílias, na comunidade e na sociedade. Importa conhecer a experiência emocional do familiar cuidador do idoso dependente no domicílio, de modo a providenciar o seu bem-estar e necessidades emocionais associados à condição de cuidar.

Objetivo: Identificar e mapear a produção de conhecimento sobre experiência emocional do familiar cuidador do idoso dependente no domicílio.

Questão de Revisão: Qual é a experiência emocional do familiar cuidador do idoso dependente no domicílio?

Método de Revisão: A revisão seguirá a metodologia preconizada pelo The Joanna Briggs Institute⁽¹⁾ e planeia-se a realização de pesquisa de estudos publicados e não publicados em diversas bases de dados e a análise da relevância dos artigos. A extração e síntese dos dados será realizada por dois investigadores independentes.

Palavras-chave: Domicílio; Emoções; Experiência Emocional; Familiar Cuidador; Idoso Dependente.

RESUMEN

El envejecimiento de la población es la expresión de los cambios demográficos de las últimas décadas, lo que conlleva importantes repercusiones en las familias, la comunidad y la sociedad. Es importante conocer la experiencia emocional del cuidador familiar del anciano dependiente en el hogar, para poder proporcionar su bienestar y necesidades emocionales asociadas a la condición de cuidador.

Objetivo: Identificar y mapear la producción de conocimiento sobre la experiencia emocional del cuidador familiar del anciano dependiente en casa.

Pregunta de revisión: ¿Cuál es la experiencia emocional del cuidador familiar del anciano dependiente en casa?

Método de revisión: La revisión seguirá la metodología recomendada por The Joanna Briggs Institute⁽¹⁾ y está previsto buscar estudios publicados y no publicados en diversas bases de datos y analizar la relevancia de los artículos. La extracción y la síntesis de los datos serán realizadas por dos investigadores independientes.

Descriptores: Ancianos Dependientes; Cuidador Familiar; Domicilio; Emociones; Experiencia Emocional.

INTRODUCTION

The population decrease, the deceleration of demographic growth, and a continuous process of demographic aging substantiate the general lines of characterization of the recent demographic situation in Portugal. Eurostat projections⁽²⁾ predict that in 2,050, people aged 55 or older represent almost half (47.1%) of the total population in Portugal. In recent decades, there has been a continuous increase dependency ratio⁽³⁾ in the elderly people, a trend that should continue; and it is expected that in 2050, in Portugal, the elders' dependency ratio will reach a peak of 65.8 %⁽²⁾. In Portugal there will be around 110,355 dependent people at home, of which 48,454 will be totally dependent people⁽⁴⁾.

In Europe, 80% of care is provided by informal caregivers⁽⁵⁾ and Portugal has the highest rate in Europe (12.4%) of care provided to the elderly person by family members in a home context⁽⁶⁾.

The literature states that most elders' care providers are their family members⁽⁷⁻¹⁶⁾, mostly women, unpaid and take care of the dependent elderly person in self-care in view of the affective, parental, physical proximity, express will of the dependent and feeling of obligation^(7,9,10,14,16,17).

There are significant changes in the caregivers' lives, as caring for a dependent elderly family member at home has consequences that are felt physically, emotionally and socially, and are manifested in a range of changes felt by caregivers⁽⁹⁾, considering that the expenditure of energy, the tension caused by the complexity of caring for a dependent elderly person at home and the fact that care has become a systematic practice lead the family member to focus only on caring and put himself secondary, which may even constitute a morbidity factor⁽¹⁷⁾.

Every care experience is susceptible to emotionality, which is why the theme of emotions in health, as a transdisciplinary area of study, has received the attention of various disciplines, such as nursing, psychology, sociology, philosophy or neurology.

In fact, the emotional experience of the family caregiver is intense and prolonged, and emotional disruptions jeopardize their well-being^(9,10,17-20).

According to Diogo⁽²⁰⁾, "when we consider emotions as an experience, we speak of a subjective-interior experience laden with an affective echo as a meaningful reality for oneself". Thus, the emotional experience encompasses the whole range of emotions and feelings that family caregivers of the dependent elderly person at home "experience in the most diverse care situations they experience, reading and conserving meanings of this experience"⁽²⁰⁾. "Experiences can include a phenomenon such as caring, but also experiences related to human health and disease conditions, such as loss-pain, anxiety, hope, despair, love, loneliness, spiritual self, heightened sense of consciousness, experiences related humanities and concepts of existence"⁽²¹⁾. Within the scope of this study, the emotional experience of the family caregiver of the dependent elderly person at home encompasses the range of emotions and feelings experienced in the care process.

Within the scope of this review, it is considered that emotions relate to what the person feels, which can be positive or negative, can be disturbing or rewarding, are triggered by an event (event or person) associated with an emotional experience, and with an essential emotionality in life to feel present and alive, through the awareness of these emotions⁽²⁰⁾.

The emotional mind and the rational mind intersect and complete each other, "proving that our reasoning is guided by emotional tones and the way they are experienced"⁽²²⁾. Damásio⁽²³⁾ argues that "it does not seem that reason has any advantage in functioning

without the help of emotion. On the contrary, emotion is likely to aid reason, especially when it comes to personal and social matters involving risk and conflict”.

Peixoto e Machado⁽²⁴⁾ argue that the emotional overload inherent in performing the role of caregiver sometimes leads to depression and isolation, due to intrapsychic factors that interfere with self-concept, namely, loss of self-esteem, of mastery (...), as well as a feeling of personal annulment, isolation, incompetence in performing the role of caregiver and failure to recognize gains in the face of the situation.

In the face of a critical event, if the caregiver is not equipped with adequate problem-solving mechanisms, it may “trigger psycho-emotional and social disorganization, often accompanied by negative feelings”⁽²⁴⁾. It is important to emphasize that in the process of caring the positive aspects play a fundamental role in mediating the stress and burden of the family caregiver⁽²⁴⁾.

Faced with the repercussions of caring for a dependent elderly relative at home, Schulz and Patterson⁽²⁵⁾ consider that the increase in the number of informal caregivers constitutes an important Public Health problem. Thus, family caregivers should “be the target of the attention of health services, not only because they are a vulnerable group that are at risk of multiple and serious physical and mental health conditions, but also because they represent a partnership in the care of people who care”⁽²⁶⁾, and the potential and vulnerabilities of family caregivers of the dependent elderly person at home should be valued.

A preliminary search on the Open Science Framework⁽²⁷⁾ and on Figshare⁽²⁸⁾ revealed that there is no scoping review (published or to be carried out) on the emotional experience of the family caregiver of the dependent elderly person at home. Thus, it is pertinent to prepare a scoping review, which follows the principles advocated by The Joanna Briggs Institute⁽¹⁾, the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) flowchart⁽²⁹⁾, recommended for scoping reviews, suggested by the EQUATOR Network (Enhancing the QUALity and Transparency Of health Research) (2022).

INCLUSION CRITERIA

Considering the theme of the review, the mnemonic PCC (Population, Concept, Context) was used, recommended by The Joanna Briggs Institute⁽⁴⁾, which is reflected in the title, objective and inclusion criteria. It was established:

P (Population): Family caregiver of dependent elderly person

C (Concept): Emotional experience

C (Context): Home.

Participants

In the scoping review, studies focusing on informal caregivers, family members, adults, aged 19 or over (31), of any gender, ethnicity or culture, who are unpaid and who provide care to dependents elderly person. The family members (aged 65 or over) will be considered in the home context.

Decree-Law No. 101/2006 defines dependency as the “situation in which the person is found, due to lack or loss of physical, mental or intellectual autonomy, resulting from or aggravated by chronic illness, organic dementia, post-traumatic sequelae, disability, severe and/or incurable disease in an advanced stage, absence or scarcity of family support or of another nature, he is unable, by himself, to carry out activities of daily living”⁽³²⁾.

Within the scope of this review, family is considered as the “social unit or the collective whole composed of people linked through consanguinity; affinity; emotional or legal relationships; the unit or whole being considered as a system which is greater than the sum of the parts”⁽³³⁾.

Concept

In this review, studies that address the emotional experience of the family caregiver of the dependent elderly person at home will be considered.

Context

Studies developed in the community, in a home context, will be considered. Studies conducted in any other context of care for the elderly (hospital environment, residential structures to support the elderly people and social structures to support the older person at home provided by formal caregivers) will not be included in the review.

Evidence source types

For this scoping review, primary studies of a quantitative, qualitative and mixed nature will be considered, as well as secondary studies, such as systematic literature reviews, integrative literature reviews, scoping reviews and narratives.

Quantitative studies may include experimental studies (including randomized studies, non-randomized studies, quasi-experimental studies) and observational studies (descriptive studies, cohort studies, cross-sectional studies, case studies), among others.

Qualitative studies can include phenomenology, ethnography, grounded theory and action research.

All published and unpublished studies (gray literature) in Portuguese, Spanish and English will be considered. Other languages will not be considered due to the impossibility of translation.

RESEARCH STRATEGY

The research strategy adopted for this scoping review will include published and unpublished studies (grey literature) and will consist of three steps⁽¹⁾. In the first stage, an initial search will be carried out in the CINAHL[®] Complete and MEDLINE[®] Complete databases (Via EBSCOhost), using keywords in natural language, followed by the analysis of the words contained in the title, abstract and indexed terms in the articles found, from in order to allow identification of other relevant terms for the scoping review.

Using all the keywords and search terms identified, in the second stage, a search will be carried out in each database included in the review (CINAHL[®] Complete (Via EBSCOhost), MEDLINE[®] Complete (Via EBSCOhost), B-ON, Psychology and Behavioral Sciences Collection (via EBSCOhost), RCAAP (Repositórios Científicos de Acesso Aberto de Portugal), **Academic Search Complete** (via EBSCOhost), **Scopus**, **Google Scholar**, Web of Science and **PubMed**) using the Boolean operators OR and AND (Table 1⁷). The selection of articles eligible for the scoping review will be carried out according to the PRISMA-ScR Flowchart⁽²⁹⁾. Thus, after eliminating the repeated articles, the title (in a first phase) and the abstract (in a second phase) are read, and articles that do not meet the aforementioned inclusion criteria, that do not refer to the theme or answer the research question. Thus, the articles considered relevant to the research will be read in full.

In the third stage, the bibliographical references of the selected documents will be analyzed, in order to identify additional studies relevant to the theme of the scoping review. The research is considered completed when the systematic repetition of articles is verified, thus assuming the saturation of the research through the electronic research platforms.

DATA EXTRACTION

Data extraction, considering the recommendations of The Joanna Briggs Institute⁽⁴⁾, will be carried out by two independent researchers, taking into account the objective, review questions and inclusion criteria. Any disagreements between researchers will be resolved through discussion with a third independent researcher, in order to reduce research bias and ensure maximum accuracy and objectivity.

A proposed table was developed to proceed with data extraction, which contains key information on all articles selected for review (Table 2⁷), namely:

- Author(s);
- Year of publication;
- Country of origin;
- Kind of study;
- Goals;
- Methodology/Methods;
- Population/sample;
- Emotional Experience of the Family Caregiver of the dependent elderly person at home;
- Pathology of the dependent elderly person;
- How long have you been in the caregiver role?

It should be noted that the extraction table is a dynamic instrument that may change while data extraction is in progress.

PRESENTATION AND INTERPRETATION OF RESULTS

In order to meet the objectives outlined for the scoping review, the results will be presented in the form of a table, providing a logical synthesis of the data. The discussion of the data will be carried out in a descriptive format, in the form of a narrative⁽³⁴⁾.

Authors' contributions

SV: Study coordination, study design, collection, storage and data analysis, review and discussion of results.

PD: Study design, data analysis, review and discussion of results.

EC: Study design, data analysis, review and discussion of results.

LE: Study design, data analysis, review and discussion of results.

All authors read and agreed with the published version of the manuscript.

Ethical Disclosures

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Table 1 – Research Strategy Summary.^κ

Database	Search Terms
CINAHL Complete (via EBSCOhost)	(family caregivers OR (caregivers AND family) OR informal caregivers) AND ((elderly OR aged OR aged, 80 and over) AND dependent) AND (Emotional experience OR Emotions OR Caregiver Attitudes) AND (Home OR Domicile OR Home Health Care)
MEDLINE Complete (via EBSCOhost)	(family caregivers OR (caregivers AND family) OR informal caregivers) AND ((elderly OR aged OR aged, 80 and over) AND dependent) AND (Emotional experience OR Emotions) AND (Home OR Domicile OR Home Nursing)

