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A Protocol for a Systematic Review of Qualitative Studies Exploring the Perception of Unmet Needs by Informal Caregivers of Older People in Portugal

Rita Lopes da Silva Ana Rita Jesus Maria David Silvério Rodrigues
Bruno Heleno

CHRC, NOVA Medical School – Faculdade de Ciências Médicas, Universidade Nova de Lisboa, Lisbon, Portugal

Keywords
Caregivers · Elderly · Unmet needs · Portugal

Abstract

Background: The number of informal caregivers continues to rise worldwide. In Portugal, 10% of the population are informal caregivers and recent studies suggest that current government policies may not adequately support this population. This review aimed to find and synthesize relevant research on perceptions of unmet needs of informal caregivers of older people in Portugal. ***Methods/Design:*** A qualitative synthesis approach will be used. Electronic searches will be conducted on PubMed, EMBASE, PsycINFO, Web of Science, Academic Search Complete, and CINAHL. Gray literature will be searched through Portuguese databases and contact with researchers and patient organizations. Qualitative studies that evaluated Portuguese caregivers' perceptions of unmet needs will be eligible. We will restrict to papers written in Spanish, English, or Portuguese and no date limitations will be applied. Data will be synthesized, and quality assessment will be done using CASP tool for qualitative research. PROSPERO registration number ID: CRD42022334859. ***Discussion:*** Findings from this future systematic review may lead to a better understanding of informal caregiving of older people in Portugal and may lead to the development of new policies and recommendations.

Protocolo para uma revisão de estudos qualitativos relacionados com a perceção das necessidades não satisfeitas dos cuidadores informais de idosos em Portugal

Palavras Chave
Cuidadores informais · Idosos · Necessidades não satisfeitas · Portugal

Resumo

Contexto: O número de cuidadores informais continua a aumentar em todo o mundo. Em Portugal, um em cada dez portugueses são cuidadores informais e estudos recentes sugerem que as políticas governamentais atuais podem não apoiar adequadamente esta população. Esta revisão tem como objetivos identificar e sintetizar a evidência recente mais relevante sobre a perceção das

karger@karger.com
www.karger.com/pjp

Correspondence to:
Rita Lopes da Silva, rita.lopes@nms.unl.pt

necessidades não satisfeitas dos cuidadores informais de pessoas idosas em Portugal. ***Métodos:*** Será utilizada uma abordagem de síntese qualitativa. Serão realizadas pesquisas eletrónicas nas bases de dados PubMed, EMBASE, PsycINFO, Web of Science, ACADEMIC SEARCH COMPLETE e CINAHL. A literatura cinzenta será identificada através da pesquisa de bases de dados portuguesas, contacto com investigadores e organizações de pacientes. Serão elegíveis todos os estudos qualitativos que avaliem as perceções dos cuidadores informais portugueses sobre as necessidades não atendidas. Serão selecionados artigos escritos em espanhol, inglês ou português, e não serão aplicadas limitações de data. Os dados serão sintetizados e a avaliação da qualidade será realizada utilizando a ferramenta CASP. Número de registo PROSPERO ID: CRD42022334859. ***Discussão:*** Os resultados desta futura revisão permitirão obter uma melhor compreensão dos cuidadores informais de pessoas idosas em Portugal e podem resultar no desenvolvimento de novas políticas e recomendações para esta população.

Introduction

The global population's life expectancy has increased significantly, thanks to advances in social, health, economic, and scientific fields. However, with aging comes health issues, social isolation, and a need for care [1]. As a result, informal caregiving has become a significant public health concern worldwide. In Portugal, older individuals currently are 23% of the population, with this number expected to rise in the future [2]. By 2060, the percentage of dependents in Portugal is projected to increase from 8.5% to 13.4% of the population [3], making the study of informal caregiving for older individuals especially important.

In Europe, informal carers supply approximately 80% of all care [4]. In Portugal, it is estimated that around 10% of the population are informal carers, with 70% being women caring for their parents [5–7]. According to the European Association Working for Carers (Eurocarers), informal caregivers are individuals who provide unpaid help to someone with a chronic illness, disability, or other long-term health or care need outside of a professional or formal framework [4]. However, the definition of an informal carer varies by country as legal policies are implemented to support this group of individuals. In Portugal, the law distinguishes between main and non-main informal carers. The former is defined as a family member, such as a spouse or other relative, who supplies care permanently, lives in the same house, and does not receive any wage for the care provided. Non-main informal carers supply care regularly, but not permanently, and may receive wages for their work [8].

The role of caregivers varies depending on the cause of disability of the older person they are caring for, but there is often a chronic disease care trajectory. As time goes on, caregivers take on more tasks, ranging from aiding with daily activities to navigating healthcare and social service systems [9]. While caregiving can be rewarding, unmet needs can lead to negative outcomes such as psychological distress and depression [10], strain on social relationships [11], and decreased work performance [12]. Earlier research has found several risk factors for adverse effects of caregiving, including the intensity of caregiving, being female, having a close relationship with the care recipient, living with the care recipient, and the presence of challenging behavioral symptoms in the care recipient [13]. Additionally, high-need and high-cost patients are more likely to report unmet needs for informal care and adverse outcomes [14]. A recent survey showed differences among European countries concerning legal recognition of carers, carer needs, support measures available to carers, including training, respite care, and social measures [4]. This is in line with the results of a systematic review, which included data from 17 countries, suggesting that carers preferred home care and needed access to respite, information, counseling, education, and professional advice, as well as social, financial, and emotional support [15]. Neither of these studies provided data for Portugal.

Synthesizing the research on this topic in Portugal would be valuable for two reasons. First, Portuguese policymakers need country-specific data to develop policies and interventions that address the most pressing problems and to better understand the context in which policies and intervention will be implemented. Some studies about this topic exist, but they are published in Portuguese [16, 17] and may not have met the eligibility criteria for international systematic reviews. Second, Portugal recently approved a law defining new rights and support measures for informal carers [8], but gray literature suggests that most are unaware of these rights and find that the support measures do not entirely fulfill their needs [18–21]. To help policymakers, it is important to map the existing literature and find which areas require more studies. Therefore, we propose to update the evidence about the perceived unmet needs of informal

caregivers of older people in the Portuguese context through a qualitative systematic review. The aim of this paper was to describe the protocol for a systematic review of qualitative studies about informal caregivers' perception of unmet needs when caring for older people in Portugal.

Methods/Design

We will conduct a systematic review of qualitative studies that specifically report on the unmet needs of informal caregivers of older persons in Portugal. This protocol follows the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocol (PRISMA-P) guidelines and Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines [22, 23]. To ensure the completeness and accuracy of our review, we have applied PRISMA-P and ENTREQ checklists to this protocol, which are available in online supplementary additional File 1 (for all online suppl. material, see https://doi.org/10.1159/000541629). This protocol has been registered with the International Prospective Register of Systematic Reviews (PROSPERO) under registration number ID: CRD42022334859.

ENTREQ, which stands for "Enhancing transparency in reporting the synthesis of qualitative research," is a framework that supplies guidance on how to conduct and report systematic reviews of qualitative research. It is important in qualitative research synthesis because it helps ensure that the review process is rigorous, transparent, and replicable. The framework consists of 21 items that should be reported in any systematic review of qualitative research. The review systematic schedule is available in the online supplementary additional file 2.

Eligibility Criteria

Types of Studies

This review will include studies that use qualitative methods for data collection such as interviews (individual or focus groups), observation and qualitative methods for data analysis. Mixed-methods studies will be considered if qualitative method was corresponding with the criteria previously described.

Types of Participants

This review will focus on studies that involve informal caregivers of older individuals living in Portugal. Our definition of an informal caregiver of an older person in Portugal aligns with the criteria outlined in the literature, referring to a family member who is over 18 years old and provides care to an individual over 65 years old living in the same household, without receiving any remuneration for their caregiving services [8]. We will exclude studies that involve hospitalized or institutionalized individuals receiving care and formal or professional caregivers.

Phenomena of Interest

The phenomena of interest are unmet needs, which are defined as aid that is partially or not received, as reported by informal caregivers who experience difficulties [24]. Examples of unmet needs include financial support, caregiver support, primary care/medical specialties, and labor regulation [25].

Context

This review will focus on informal caregivers of older people living in community-based settings in Portugal, including their private homes and licensed residential facilities such as day-care centers.

Information Sources

Our search strategy will aim to find all available studies, both published and unpublished, including pre-print studies such as theses, dissertations, conference proceedings, and abstract books. We will conduct a comprehensive search of international databases: PubMed, EMBASE, PsycINFO, Web of Science, Academic Search Complete, Scopus, and CINAHL. In addition, we will search Portuguese databases, such as SciELO and IndexRMP, using relevant Portuguese terms. We will also search for gray literature in the Open Access Scientific Repositories of Portugal, the Digital Bank of Theses and Dissertations (https://comum.rcaap.pt). We will contact the Portuguese Informal Carer Association and selected researchers to identify technical reports or white papers that may have not been published in traditional publishing channels.

Search Strategy

We will include studies published in Portuguese, English, and Spanish without any restrictions on the year of publication. The full search strategy is available in the online supplementary additional file 3.

Patients and Public

Patients and the public will not be directly involved. As this study will use secondary data, we will not use person-identifiable data. Datasets used and/or analyzed during the current review will be available from the corresponding author of the included individual studies upon reasonable request. We will establish a small group of carers in different contexts and use an adapted TRANSFER approach to identify how the findings might be applied to different settings by inviting topic experts

and patient and public involvement representatives who represent a range of contexts to comment on the objectives and the perspective is taken for the plan of analysis (Munthe-Kaas 2020).

Study Records

Selection Process

Duplicated articles will be removed, and two researchers (R.L.S., A.M.) will independently screen titles and abstracts. Full-text articles will be assessed independently by the same two researchers to determine their eligibility for inclusion. Any discrepancies will be resolved through discussion or by consulting a third researcher. In cases where necessary data are missing, we will contact the authors via email to request the information. The selection process will be documented in a PRISMA flow diagram [22], which will outline the reasons for exclusion at each stage of the screening process [25].

Data Management

Article screening and selection will be managed using the online platform Rayyan (https://www.Rayyan.ai/).

Data Collection Process

Two researchers, R.L.S. and D.R., will independently extract data from the findings, results, discussion, conclusions, and interpretations of the selected studies. In case of disagreements, the researchers will discuss and reach a consensus. The data will be extracted directly from the study papers and recorded verbatim into NVivo-11 software by QSR International.

Data Items

One researcher (R.L.S.) will collect additional information for each included study, including the year(s) of data collection, year of publication, authors, title, study population, study setting, study location, and data collection method (e.g., interviews, focus groups, document analysis).

Outcomes and Synthesis Strategy

To find key categories and themes from the qualitative data, we will employ a thematic synthesis approach [26]. We intend to do the analysis by extracting direct quotations from participants, narratives, and generate descriptive themes from each study. We will conduct an open, inductive analysis, starting with open coding. As the objectives of the study are primarily contextual, concerned with understanding people's experiences, attitudes, and the nature of the system, the inductive approach keeps a close focus on people's experiences and ideas.

Risk of Bias in Individual Studies

The quality of each study will be assessed using the Critical Appraisal Skills Programme (CASP) tool [27]. Two researchers (R.L.S., D.R.) will independently assess the quality of each study. Any disagreements will be resolved through discussion. The CASP tool is the most used tool for quality appraisal in health-related qualitative evidence syntheses, with endorsement from the Cochrane Qualitative and Implementation Methods Group. Each checklist is composed of 10 questions which should be answered with "yes," "no," or "can't tell." There is no scoring system, but instead a subjective evaluation of each study.

The certainty of the evidence of each study will be assessed using Grade – Confidence in the Evidence from Reviews of Qualitative Research (Grade-CERQUAL) Tool. Two researchers (R.L.S., D.R.) will independently assess the certainty of each study. Any disagreements will be resolved through discussion. The Grade-CERQUAL tool is an approach for assessing how much confidence to place in the findings of a qualitative evidence synthesis. The overall assessment of confidence (high, moderate, low, very low) is made based on an assessment of four components: methodological limitations, coherence, adequacy, and relevance.

Reporting

The report of this qualitative systematic review study will follow ENTREQ research statements for reporting syntheses of qualitative studies [22].

Discussion

Qualitative research can have a place in Health Policy Making, especially if politicians and participants are included in the investigation process and results discussion [28]. Our work will comply with the Cochrane-Campbell Handbook for Qualitative Evidence Synthesis that describes in detail the process of preparing and maintaining systematic reviews of qualitative evidence. Our project also includes patient perspectives, evidence from associations and experts, and public representatives.

When completed, this systematic review will contribute to a better understanding of the state of informal caregiving for the elderly in Portugal. By identifying the perceived unmet needs of informal caregivers, better strategies and policies can be developed following recent literature [9]. Our review is expected to result in recommendations that may improve caregiving, caregivers' quality of life, and personal satisfaction in the Portuguese

context [1]. As pilot projects to support informal caregivers are becoming increasingly prevalent in Portugal, the findings of our study will be useful in defining these projects more clearly. Evidence from studies conducted in other countries has led to the development of more tailored strategies to address the unmet needs of informal caregivers [29–31]. Moreover, the synthesis of information from this review may give rise to new opportunities for research in this field, such as conducting qualitative studies in Portugal.

Strengths and Limitations

This systematic review aimed to synthesize qualitative research on informal caregiving of older people in Portugal, which to our knowledge, is the first of its kind. Our focus was on research designs that provide a deep understanding of cultural perceptions of health within communities, allowing us to inform policymakers and planners in developing tailored strategies to meet the needs of informal caregivers. One major strength of this project was our search for gray literature in Portuguese databases. While informal caregiving is a widely discussed topic in Portuguese academia and society, there appear to be few formal publications in the international peer-reviewed literature. However, we have found Master theses on the topic and including gray literature in our search will help us map the existing evidence and find possible gaps. By disseminating our findings through peer-reviewed journals, events, and presentations, we aim to make this body of research more visible and ensure our recommendations reach relevant stakeholders to contribute to the development of effective policies and strategies to support informal caregivers of older people in Portugal.

We recognize that the usefulness of our findings could have been enhanced by involving members of the public or policymakers in the refinement of our research question and the analysis of our data. To mitigate this limitation, we plan to engage with representatives of informal carers and present preliminary results of our synthesis at research conferences, thereby incorporating feedback and perspectives from those who are directly impacted by our findings. This will help ensure that our recommendations are relevant and applicable to the needs and experiences of informal caregivers of older people in Portugal.

Review Author Reflexivity

Our review team includes authors with different clinical practice backgrounds. At the outset of the review protocol, we all held the view that individuals have a right to make their own healthcare decisions, including about their health needs when caring for older people. Moreover, we believe that it is important for people to have easy access to balanced and transparent information about caring for older people, including about adverse effects and evidence gaps. We recognized that potential tensions exist between public health, community obligation, and individual choice. Throughout the review process, authors involved with selecting studies for inclusion, data extraction, analysis and interpretation of the findings will be asked to reflect and articulate how their perspectives and experiences might influence the shape and conclusion of the review. We will consider how our individual and collective views, beliefs, and experiences will influence the choices we will make in terms of the scope of the review and our review methods, our interpretation of the data, and our interpretation of our own findings.

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Statement of Ethics

An ethics statement is not applicable because this study is based exclusively on published literature.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

R.L.S.: conceptualization, funding acquisition, investigation, methodology, project administration, resources, visualization, and writing – original draft preparation. A.R.J.M. and D.R.: methodology, writing – original draft preparation, writing – review and editing, and investigation. B.H.: supervision, methodology, writing – original draft preparation, writing – review and editing, and investigation. All authors approved the final manuscript.

Data Availability Statement

The data that support the findings of this study will be available on request from the corresponding author.

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