


BMJ Open Financial interventions for family caregivers of individuals with chronic illness: a scoping review protocol

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ABSTRACT

Introduction There are 53 million caregivers in the USA providing informal care for individuals with chronic illnesses. These caregivers contribute significantly to the healthcare system, yet they may experience adverse consequences due to caregiving, including financial burden. The purpose of this scoping review is to fill a research gap on understanding the nature and effect of financial interventions for family caregivers.

Methods and analysis This study will use the Arksey and O'Malley scoping review framework to systematically search for articles in MEDLINE, PubMed, CINAHL Complete, Cochrane Library, PsycINFO, Dissertations & Theses Global, and Web of Science during April 2022. Articles published from 1997 to the present will be included for the review. Data from articles will be extracted and summarised for financial intervention nature, scope, measurement, effect and health system context.

Ethics and dissemination This study does not include human subjects; therefore, no ethical review will be undertaken. Findings will be disseminated in scholarly journals and at caregiving and ageing conferences, such as the Gerontological Society of America.

INTRODUCTION

There are approximately 53 million caregivers in the USA providing care for family members or friends with chronic illnesses.¹ Chronic illnesses are herein defined as conditions that last 1 year or more, require ongoing healthcare attention and/or limit daily activities.² Family caregivers assist with daily living activities and provide complex medical and nursing tasks at home.³ In addition, family caregivers navigate a multitude of healthcare-related tasks including assisting with health insurance claims, facilitating medical care and social services, and providing transportation to medical appointments.³ The estimated economic value of the unpaid contributions of family caregivers to chronic illness care is approximately US\$470 billion.³ Family caregivers experience multiple consequences due to their caregiving role, including financial distress.¹

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This review will use robust scoping review methodology using the Arksey and O'Malley framework.
- ⇒ This study will rely on a double screening and extraction approach to help limit bias.
- ⇒ This study will examine financial interventions across multiple databases to provide a broad understanding of financial interventions in family caregivers.
- ⇒ This review will limit sources to manuscript/articles written in English, so there may be examples of effective financial interventions that will not be included in this review.
- ⇒ This review will rely on researchers' determination of what constitutes a financial intervention through subjective assessment, so there is a possibility that some interventions will be excluded.

Financial distress or burden in family caregivers is related to multiple issues including direct and indirect costs of healthcare for the care recipient, changes to or loss of employment, and healthcare costs associated with the caregiver's own health. According to Schulz, out-of-pocket costs have been a substantial contributor to financial burden of family caregivers.⁴ Most family caregivers suffer steep out-of-pocket expenses related to caregiving, spending over US\$7000 on average for direct medical costs and indirect costs including food and meals, household goods, travel costs, home modifications and legal fees.³⁻⁵

Over half of employed caregivers of all ages have found it challenging to balance their work and caregiving duties; they report coming in late, leaving early or taking time off to fulfil their caregiving role.^{5 6} Over 75% of individuals who retired early due to family caregiving would have prolonged their engagement in the workforce if they had access to alternative work arrangements such as flexible hours/shifts, telecommuting,



compressed schedules, paid leave or phased retirement.^{5,6} Family caregivers who either disrupt their careers or leave the work force completely to fulfil their caregiving role can experience substantial economic risk and both short-term and long-term financial strains.³ Caregivers have lower income in later life, reduced engagement in the work force and lower net worth compared with non-caregivers.⁴ Mudrazija calculated that the total opportunity cost of forgone earnings among caregivers was about US\$67 billion annually.⁷

There are known physical and mental health consequences due to family caregiving including increased anxiety and depression, higher chronic illness rates and increased mortality risk.^{8–12} Experiencing health consequences due to caregiving and then managing short-term and long-term health issues is costly, with just over US\$6000 in annual costs for individuals with chronic illnesses.¹³

Clinically, this layered experience of financial distress and burden in family caregiving has not been fully addressed. While it is an understood issue of family caregiving, approaches to addressing financial distress have not been well defined.¹⁴ Financial distress is also a health equity issue, with women being more likely to suffer from poverty and/or rely on public assistance services due to their caregiving responsibilities.⁴ Caregivers who identify as Black or Latinx report greater financial strain.⁵

We propose a scoping review to examine financial interventions across chronic illness types and healthcare contexts. This will fill a research gap because there are no existing scoping reviews addressing financial interventions in family caregivers. Financial interventions are defined as interventions that address one or multiple dimensions of financial burden/well-being including systems navigation and access, financial literacy or assistance, asset building, events or attractions, paid leave, employment and educational support, and transportation and housing.¹⁵ There is global variability with healthcare delivery and funding and governmental support for family caregiving, so healthcare context will be noted to provide a deeper understanding of the interventions.¹⁶ We are using a scoping review methodology because we are answering a broad question and seeking to determine the depth, range and nature of financial interventions in family caregiving.^{17,18}

AIMS AND REVIEW QUESTION

Our objective is to summarise the existing research on financial interventions in family caregivers of individuals with chronic illnesses between 1997 and the present. Our research questions are: What is the scope of financial interventions for family caregivers of individuals with chronic illnesses? What are the outcome variables that are examined to measure effectiveness of financial interventions in family caregivers of individuals with chronic illnesses? What are the heterogeneous effects of financial interventions in family caregivers of individuals

with chronic illnesses? What is the health system context (country, health system organisation, source of funding for healthcare delivery) for financial interventions in family caregivers of individuals with chronic illnesses?

METHODS

This scoping review protocol has been registered with the Open Sciences Framework database (doi:10.17605/OSF.IO/ECKX2).¹⁹ The focus of this scoping review is on existing research of financial interventions for family caregivers of individuals with chronic illnesses between 1997 and the present. These dates were chosen to align with publication of the first *Caregiving in the U.S.* report from the National Alliance for Caregiving in the United States that addressed employment challenges of family caregivers and the Institute of Medicine's report *Approaching Death: Improving Care at the End of Life*.^{20,21} Between 1997 and the present, The Family Caregiver Alliance was established as a national organisation in the USA (2001),²² the Institute of Medicine published their report, *Crossing the Quality Chasm*, that focused on improving care quality through patient-centred care (2001),²³ and clinical practice guidelines for palliative care were published (2004).²⁰ Family caregiver engagement is vital in the approach to patient-centred palliative care.²⁴

The first step of the Arksey and O'Malley framework for scoping reviews, identifying the research question, was used for initial development of the research question and protocol.¹⁷ The four remaining steps will be used to identify articles, and extract and summarise data: 2) identifying relevant studies; 3) study selection; 4) charting the data; 5) collating, summarising and reporting results.¹⁷ We will follow PRISMA reporting guidelines for scoping reviews to promote transparency and reproducibility.²⁵ Our review will follow a systematic and transparent process to identify research studies examining financial interventions in family caregivers of individuals with chronic illnesses.

Patient or public involvement

Due to the nature of scoping reviews, there will be no patient or public involvement in the research process. Despite this, several of the researchers are or have been family caregivers with personal and academic understanding of the impact of caregiving on financial well-being.

Eligibility criteria

Scoping reviews are intended to be broad in character to understand the nature and scope of research surrounding the main concept of interest.¹⁷ Therefore, we will use research articles, dissertations and theses that are searchable on research databases or journal sites. We are focused on family caregivers of individuals with chronic illness; therefore, we will include articles with care recipients that meet the definition for having a chronic illness (identified in introduction). Family

caregivers are defined as family members, friends and neighbours of individuals with chronic illnesses—they may be reimbursed for their services, but their role is primarily defined by their relationship to the care recipient. Articles containing experimental and quasi-experimental research methods with a full description of a financial intervention will be included. Financial interventions will be those that specifically target an aspect of financial well-being including, but not limited to, the following: systems navigation and access; financial literacy and skills; financial assistance; asset building; events or attractions; paid leave; employment and educational support; transportation; housing.¹⁵ Mixed methods or multi-method articles will be included if there are experimental and quasi-experimental research methods that include a financial intervention. Articles, dissertations or theses will be excluded if they are not available in English, family caregiver data are indistinguishable from care recipient data, they are solely qualitative in nature, or they do not include primary study data such as study protocols, reviews, commentaries or metasyntheses.

In summary, articles included in this review must contain:

- ▶ Family caregivers as study participants
- ▶ Care recipients with chronic illness
- ▶ Experimental or quasi-experimental methods
- ▶ Financial interventions

Articles will be excluded based on the following criteria:

- ▶ Article not available in English
- ▶ Caregiver data cannot be distinguished from care recipient data
- ▶ Qualitative data alone
- ▶ Do not contain primary study data

Information sources and search strategy

The primary sources of evidence will include research articles, dissertations and theses identified in the following databases: MEDLINE (EBSCO), PubMed (NCBI), CINAHL Complete, Cochrane Library, PsycINFO, Dissertations & Theses Global, and Web of Science. We will filter for articles published between 1997 and the present. We will start with a search framework designed using MeSH terms and adapted as needed for each database: ((Caregiver AND (family OR

child OR spousal OR partner OR unpaid OR informal OR friend OR neighbor)) OR (Carer AND (family OR child OR spousal OR partner OR unpaid OR informal OR friend OR neighbor))) AND (Chronic illness OR Chronic Disease OR Multiple Chronic Conditions) AND (Financial OR Economic OR Financial Support OR Financial Stress) AND ((Intervention AND Methods) OR (Intervention OR Psychosocial Intervention OR Internet-Based Intervention) (please see online supplemental appendix 1 for search strategies by database). A hand search of the following palliative care, health systems and policy, ageing and chronic illness journals websites will also occur using keywords from the search strategy above: *Supportive Care in Cancer*; *The Gerontologist*; *Families, Systems and Health*; *BMC Supportive and Palliative Care*; *Journal of Hospice and Palliative Medicine*; *Journal of Hospice and Palliative Nursing*; *Chronic Illness*; *Health Affairs*. Manual searches of reference lists from included articles will not occur due to the potential for bias with this approach.²⁶

Selection of sources of evidence

Sources of evidence will be reviewed and selected following PRISMA guidelines and tracked in Covidence.²⁵ Titles and abstracts will be reviewed independently by two team members for each article based on review inclusion and exclusion criteria. Full-text articles will then be reviewed by two team members per article based on review inclusion and exclusion criteria. Any disagreements between team members during evidence selection will be arbitrated and agreed on by the team leader. Once the sample of articles has been selected, team members will review, extract and synthesise data according to the study research questions.

Data extraction

We will be examining study type, caregiver participant demographics, sample size, and both the nature, scope, measurement and effect of the financial well-being interventions and the outcomes used to assess effectiveness of the interventions. We will also identify the health system context (country, mode of healthcare funding/delivery) in which the financial intervention was tested (see [table 1](#) for extraction template).

Table 1 Template for data extraction

Authors, title and study design	Participant characteristics (caregiver age, gender, race, ethnicity, socioeconomic status, education, relationship to care recipient, care recipient diagnosis and total number of participants)	Nature of financial intervention (what was done) and scope of financial intervention (whom did it target)	Measurement of intervention efficacy	Outcome/ effect of financial intervention	Country where financial intervention delivered and studied	Healthcare system characteristics, including funding sources
—	—	—	—	—	—	—

In alignment with scoping review methodology, quality appraisal of the evidence will not occur.¹⁷ Our goal is to rapidly identify and synthesise the existing evidence regarding financial interventions in family caregivers of individuals with chronic illnesses. Research gaps and opportunities for future research will be identified during this process.

Data synthesis

Using tables and narrative synthesis, we will create a quantitative and qualitative summary of findings including the scope of financial interventions, the outcome measures used, the efficacy of financial interventions and the healthcare system context for the financial interventions. Opportunities for future research and gaps in the literature will be identified with this synthesis.

ETHICS AND DISSEMINATION

This scoping review does not include human subjects; therefore, no ethical review will be undertaken. Findings from this scoping review will be disseminated through publication in a peer-reviewed journal. Findings will also be presented at an ageing conference, such as the Gerontological Society of America.

DISCUSSION

This scoping review will fill a research gap in understanding the existing literature for financial interventions in family caregivers of individuals with chronic illnesses. By identifying the scope of interventions, outcome measures, efficacy and healthcare system context for financial interventions in this population, we can identify strategies for moving forward to better address financial well-being in family caregivers.

Potential limitations of this review include limiting sources to English language because there may be interventions reported that are excluded from this review due to publication language. Another limitation is the determination of what constitutes a financial intervention through reviewers' subjective assessment. Financial interventions have been defined a priori, as noted previously in the manuscript, and there will be group arbitration for any disagreements about manuscript inclusion or exclusion. Any amendments made to this protocol will be reported in the final manuscript.

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Contributors MCTH conceived of the presented idea. MCTH developed the scoping review plan. CTPP, CP, SW, KD, TG, LAJ, VP and SF verified the scoping review plan and methods. MCTH and CTPP drafted the manuscript. All authors edited the final manuscript.

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REFERENCES

- 1 National Alliance for Caregiving, AARP. *Caregiving in the U.S., 2020*. Washington DC: National Alliance for Caregiving, 2020.
- 2 Centers for Disease Control & Prevention. About chronic diseases. Available: <https://www.cdc.gov/chronicdisease/about/index.htm> [Accessed Feb 2022].
- 3 Reinhard S, Feinberg LF, Houser A. Valuing the invaluable 2019 update: charting a path forward, 2019. Available: <https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html> [Accessed 6 Nov 2021].
- 4 Schulz R. Economic impact of family caregiving. In: Schulz R, Eden J, eds. *Families caring for and aging America*. Washington D.C.: National Academies Press, 2016. <https://www.ncbi.nlm.nih.gov/books/NBK396402/>
- 5 Skufca L, Rainville C. *Caregiving out-of-pocket costs study*. Washington, DC: AARP Research, 2021.
- 6 Feinberg LF, Skufca L. *Managing a paid job and family caregiving is a growing reality*. Washington, DC: AARP, 2020.
- 7 Mudrazija S. Work-related opportunity costs of providing unpaid family care in 2013 and 2050. *Health Aff* 2019;38:1003–10 <https://doi.org/10.1377/hlthaff.2019.00008>
- 8 Bevans M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA* 2012;307:398–403.
- 9 DePasquale N, Polenick CA, Davis KD, et al. The psychosocial implications of managing work and family caregiving roles: gender differences among information technology professionals. *J Fam Issues* 2017;38:1495–519.
- 10 Greene J, Cohen D, Siskowski C, et al. The relationship between family caregiving and the mental health of emerging young adult caregivers. *J Behav Health Serv Res* 2017;44:551–63.
- 11 Perkins M, Howard VJ, Wadley VG, et al. Caregiving strain and all-cause mortality: evidence from the REGARDS study. *J Gerontol B Psychol Sci Soc Sci* 2013. ;68:504–12. 2013.
- 12 Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs* 2008;108:23–7.
- 13 O'Neill Hayes T, Gillian S. Chronic disease in the United States: a worsening health and economic crisis. American Action Forum, 2020. Available: <https://www.americanactionforum.org/research/chronic-disease-in-the-united-states-a-worsening-health-and-economic-crisis/> [Accessed Feb 2022].
- 14 Swartz K, Collins LG. Caregiver care. *Am Fam Phys* 2019;99:699–706.
- 15 Glenn NM, Allen Scott L, Hokanson T, et al. Community intervention strategies to reduce the impact of financial strain and promote financial well-being: a comprehensive rapid review. *Glob Health Promot* 2021;28:42–50. 2021.
- 16 World Health Organization. *World Health statistics 2018: monitoring health for the sustainable development goals*, 2022. Available: <https://www.who.int/docs/default-source/gho-documents/world-health-statistic-reports/6-june-18108-world-health-statistics-2018.pdf>

- 17 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.
- 18 Sucharew H, Macaluso M. Progress notes: methods for research evidence synthesis: the scoping review approach. *J Hosp Med* 2019;14:416–8.
- 19 Hebdon MCT, Cuong P, Pottapalli V. Financial interventions in family caregivers. open sciences framework, 2021, October 4. Available: <https://doi.org/10.17605/OSF.IO/ECKX2>
- 20 Loscalzo MJ. Palliative care: an historical perspective. *Hematology ASH Education Program* 2008;1.
- 21 National Alliance for Caregiving and AARP. *Caregiving in the U.S., 1997*. Bethesda, MD: National Alliance for Caregiving, 1997.
- 22 Institute of Medicine (US) Committee on Quality of Health Care in America. *Crossing the quality chasm: a new health system for the 21st century*. Washington DC: National Academies Press, 2001.
- 23 National Consensus Project for Quality Palliative Care. *Clinical practice guidelines for quality palliative care*. 4th ed. Richmond, VA: National Coalition for Hospice and Palliative Care, 2018. <https://www.nationalcoalitionhpc.org/ncp>
- 24 Alliance FC. 1997–2017: caregiving then and now, 2018. Available: <https://www.caregiver.org/news/1977-2017-caregiving-then-and-now/>
- 25 Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018;169:467–73.
- 26 Vassar M, Atakpo P, Kash MJ. Manual search approaches used by systematic reviewers in dermatology. *J Med Libr Assoc* 2016;104:302–4.