

## Feedback:

Thank you for the opportunity to review this paper. I want to commend the authors on the focus of their study. This is a very interesting area for a review and could add new insights into the barriers to sufficient care of older adults. In general, a stronger scientific approach and more focused content is needed. From the outset it is unclear why a scoping review was chosen over a systematic review. Language issues were highlighted in-text and I added suggestions could support you in clarifying the contents of the paper and strengthening its academic value.

## PLOS ONE

### The impact of long-term care needs on the socio-economic deprivation of older people and their families: A scoping review protocol

--Manuscript Draft--

<b>Manuscript Number:</b>	PONE-D-22-09758
<b>Article Type:</b>	Study Protocol
<b>Full Title:</b>	The impact of long-term care needs on the socio-economic deprivation of older people and their families: A scoping review protocol
<b>Short Title:</b>	Long-term care needs and the socio-economic deprivation of older people and their families
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<b>Keywords:</b>	older people; family caregivers; Long-term care; informal care; socio-economic deprivation; catastrophic health expenditure; out-of-pocket spending.
<b>Abstract:</b>	<p>Major global problems such as population ageing, long-term care and the socio-economic burden of chronically ill older people and their families are urgent issues. Research in this field contributes to the growing international literature on health-related quality-of-life instruments, but little is known about the links between the related variables. Thus, the scoping review this protocol refers to <del>is being carried out to</del> <b>plans to</b> examine the socio-economic consequences of older people's poor health on their economic conditions and their families. In particular, the main aims <del>to be pursued</del> are: a) to map the main concepts that characterise the body of the reference literature; b) to identify conceptual gaps or unexplored research areas to be addressed; c) to <del>delve into the ways of arguing</del> <b>illuminate</b> about the difficulties that affect a large number of families with older members to care for, with particular attention to the concept of socio-economic deprivation, which includes material living conditions as well as social aspects (e.g. in the form of loneliness experienced as a consequence of health disorders). This protocol paper fulfils the purpose of clarifying the planned methodological phases, including the sub-phases, and listing the techniques used. A three-step approach <del>is being applied; it consists of</del> <b>a preplanning phase</b>, protocol phase, and conduction and reporting phase <b>is followed</b>. The preliminary stages of the protocol design are part of a dedicated project within the Open Science Framework platform <b>and</b>. <del>They are also</del> included in a Research Square preprint. <b>This proposed project will contribute to</b> Multidisciplinary research on the <b>intertwining of connections between ill health and poverty and could</b> <del>can</del> support critical reflections on the <del>reference literature</del> <b>current evidence</b> and <b>guide future</b> <del>possible innovative</del> policies to <b>alleviate this double burden</b>.</p>
<b>Order of Authors:</b>	Rossella Martarelli Georgia Casanova Giovanni Lamura
<b>Additional Information:</b>	

Question	Response
<p><b>Financial Disclosure</b></p> <p>Enter a financial disclosure statement that describes the sources of funding for the work included in this submission. Review the <a href="#">submission guidelines</a> for detailed requirements. View published research articles from <a href="#">PLOS ONE</a> for specific examples.</p>	<p>The study is being supported by the Family International Monitor (FIM) and the International Centre for Family Studies (CISF). Also, GC was supported by the the Marie Curie European Fellowship Grant (Grant Agreement No. 888102).</p> <p>Details:</p> <p>The scoping review this protocol refers to is part of the Horizon 2020-funded SEreDIPE project, i.e. the European Commission is to be considered as a funding body (call for proposal: H2020-MSCA-IF-2019; project code: 888102; project period: 16 March 2021 - 15 March 2023). SEreDIPE is an acronym for “Socio-Economic (SE) deprivation related to the effect of the presence of Dependent older people: strategies for</p>
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N/A - the protocol does not report results

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# **The impact of long-term care needs on the socio-economic deprivation of older people and their families: A scoping review protocol**

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## **Abstract** [Please see in-text recommendations above]

1 Major global problems such as population ageing, long-term care and the socio-economic burden of  
2 chronically ill older people and their families are urgent issues. Research in this field contributes to  
3 the growing international literature on health-related quality-of-life instruments, but little is known  
4 about the links between the related variables. Thus, the scoping review this protocol refers to is  
5 being carried out to examine the socio-economic consequences of older people's poor health on  
6 their economic conditions and their families. In particular, the main aims to be pursued are: a) to  
7 map the main concepts that characterise the body of the reference literature; b) to identify  
8 conceptual gaps or unexplored research areas to be addressed; c) to delve into the ways of arguing  
9 about the difficulties that affect a large number of families with older members to care for, with  
10 particular attention to the concept of socio-economic deprivation, which includes material living  
11 conditions as well as social aspects (e.g. in the form of loneliness experienced as a consequence of  
12 health disorders). This protocol paper fulfils the purpose of clarifying the planned methodological  
13 phases, including the sub-phases, and listing the techniques used. A three-step approach is being  
14 applied; it consists of preplanning, protocol phase, and conduction and reporting phase. The  
15 preliminary stages of the protocol design are part of a dedicated project within the Open Science  
16 Framework platform. They are also included in a Research Square preprint. Multidisciplinary  
17 research on the intertwining of health and poverty can support critical reflections on the reference  
18 literature and possible innovative policies.

## **Introduction**

19 The global population is getting older ~~and older~~. In 2020, people aged at least 65 represented 9.3%  
20 of the worldwide population, and they are expected to increase to 16.0% by 2050 [1]. The oldest  
21 segment of the population, in particular, is on the rise: the so-called oldest-old (those over 80 years  
22 old) account for 6.3% of the total population in Europe, and their incidence is expected to double by

23 2050 [2] [3]. The number of older people in need of long-term care (LTC) is set to grow radically  
24 worldwide, together with the need for formal and informal care [4].

25 Caring for the state of health of older people involves interventions at the biomedical and  
26 psychosocial levels and measures of economic interest [5], and all of them weigh on the balance of  
27 families. In particular, long-term care has been included among the highest priorities of national and  
28 international policies [6]. Many international research projects (e.g. EUROFAMCARE, ANCIEN,  
29 INTERLINKS, MOPACT, and Cequa) focussed their attention on LTC and its different aspects and  
30 actors. Considering their role as primary caregivers, families are essential stakeholders in the LTC  
31 context [7] [8] [9]. In 2017, Mita et al. [10] [11] pointed out that the cost of LTC was high  
32 compared with incomes typical of many countries. Even in countries with advanced social  
33 protection systems, family-givers' care-related out-of-pocket expenditure is not negligible; more  
34 and more families buy private care services. In addition to direct costs, they are involved in  
35 difficulties derived from a variety of indirect costs: the more time they spend caring for older  
36 people, the less they work, and this quickly results in a reduction in earning capacity [12] [13] [14].

37 There is no shortage of studies on the interplay between the socioeconomic deprivation of older  
38 people and their health conditions. Material deprivation reduces the possibility of coping with  
39 health needs and problems [15] [16] and influences both the psychosocial well-being [17] and the  
40 cognitive conditions of these people [18]. Moreover, as indicated in many studies, the combined  
41 effect of economic impoverishment and socio-relational deprivation creates remarkable differences  
42 in life expectancy, since wealthy seniors generally live longer [19] [20].

43 Nevertheless, it should be stressed that studies carried out in this field, while remarkable for the  
44 great attention paid to the effects of economic hardship on health conditions, often overlook the  
45 impact of health conditions on the socio-economic status (SES) of impaired or chronically ill  
46 people. Therefore, further studies on how health problems and related expenses affect the economic  
47 situation of families are necessary, especially to investigate the relationship between the type of  
48 approach to care provision for older adults unable to accomplish activities of daily living (ADL) —

49 both formal and informal care — and the socioeconomic deprivation of the older adults themselves  
50 and that of their families.

51 Promoting research in this field could facilitate a more open debate about the reference literature as  
52 well as an innovative approach to both social and economic policies. Guided by our intention to  
53 support research in this field and contribute to its dissemination, we decided to conduct a scoping  
54 review (ScR) that mainly aims to: 1) systematically scan and evaluate the literature developed on  
55 the issue of older adults who need to be provided with LTC and their SES; 2) intercept any  
56 conceptual gaps as well as the most debated unsolved issues that characterize the reference  
57 literature; 3) explore the extent to which the so-called “multidimensional perspective” is being  
58 applied to the socio-economic deprivation concept (SED); 4) identify the main outcomes achieved;  
59 5) highlight the most useful insights on the policies to be applied as well as any suggestion for  
60 future research. This type of review and the method of application allow us to meet these objectives  
61 and to provide an up-to-date summary on the state of the art of scientific research on this issue.  
62 Moreover, this study will enable us to capture the meaning of the key concepts and definitions used  
63 in this field by researchers worldwide; therefore, it will also allow us to test their level of use in  
64 following a multidimensional perspective. This protocol paper aims to describe the methodological  
65 steps followed in our literature review process and help stimulate the production of new studies —  
66 both systematic and non-systematic reviews — on multidisciplinary research on such complex  
67 phenomena.

68 This study is part of a cross-national research effort promoted by the Family International Monitor  
69 (FIM). The research plan of FIM [21] aims to investigate how a condition of deprivation —  
70 understood as material and social deprivation — can affect families worldwide. The study is also  
71 part of the EU-funded SereDIPE project (Horizon 2020 MSCA-IF-2019 Grant Agreement No.  
72 888102), focused on the economic impoverishment of families with impaired older people and  
73 managed by the University of Valencia. Both projects deal with the concepts of “family” and  
74 “deprivation” from a multidimensional perspective [22].

## Materials and Methods

75 This study refers to a composite but coherent set of methodological indications describing the  
76 rationale for undertaking a scoping review and the necessary procedures. We refer to: a) the  
77 Lockwood et al. guidelines [23] on how to set up a scoping review (ScR); b) the Munn et al.  
78 recommendations for structuring this type of study [24]; c) the Preferred Reporting Items for  
79 Systematic reviews and Meta-Analyses extension for Scoping Reviews [25]; d) the Joanna Briggs  
80 Institute (JBI) checklist [26].

81 S1 Fig shows the conceptual framework used to identify independent and dependent variables.  
82 Increasingly common diseases such as chronic conditions, whose incidence rate constitutes a matter  
83 of public concern in both developed and developing countries, represent the main consequence of  
84 the population ageing phenomenon, and particularly of the extension of the oldest-old population  
85 segment. Older people's extended care needs cause a sharp increase in demands for informal care,  
86 the socio-economic burden of which is often borne by a family member. Macro-level demographic  
87 factors and institutional responses radically affect family dynamics at the micro-level, including the  
88 organizational adaptations and family adjustments covered by this ScR. Risk factors for SED  
89 among older people afflicted with ADL limitations and their families derive from two independent  
90 variables: a) the availability and affordability of LTC services for chronically ill older people; b) the  
91 probability of having to rely on informal caregiving and experiencing SED precisely because of the  
92 amount of family caregiving hours, mainly associated with chronic diseases whose medical care  
93 costs are hard to deal with.

94 The above-mentioned guidelines enable us to realize: a) all of the steps to be taken, i.e. 1) pre-  
95 planning; 2) protocol; 3) conducting and reporting; b) how to distinguish a ScR from a traditional or  
96 systematic review, i.e. how to achieve all of the objectives and present the results; c) how to  
97 sequence all of the study's stages and sub-stages; d) the type of information to be provided, such as  
98 the types of sources or 'effect measures' extracted from the selected studies (e.g., prevalence ratios

99 for functional limitations; income inequality ratios; at-risk-of-poverty rate etc.). Finally, this  
100 protocol aligns with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for  
101 Protocols 2015 (S1 Checklist). S2 Fig shows a detailed representation of the steps and sub-steps of  
102 this ScR.

## Preplanning

103 This stage is based on the formulation of a series of broad questions: 1) What are the socio-  
104 economic conditions of families with impaired older people? 2) Is it true that most of these older  
105 people and their families are about to fall into ruin? 3) How can family caregivers cope with the  
106 economic burden of care for the old? In response to these initial questions, we agreed to: 1) identify  
107 and draw up the boundaries of the main concepts used, as well as any gaps traceable in the  
108 reference literature, in order to understand how the set of changing relationships between economic  
109 and health conditions is being explored and put into perspective; 2) investigate whether these  
110 families are so socio-economically deprived that they really experience both a concrete economic  
111 impoverishment and social marginalization, or whether they have some social support to mitigate  
112 such pressing difficulties; 3) identify the types of evidence and tools for measuring the health care-  
113 seeking behaviour of older people in need and their health requirements.

## Brainstorming

114 The brainstorming phase allowed us to: a) identify the most suitable type of study; b) adjust and  
115 improve all the points enumerated above. To begin with, each author assessed the structuring level  
116 of our initial questions and goals independently of the others, based on the several available scoping  
117 reviews and his/her own previous knowledge; this was followed by a brainstorming session which  
118 helped us to discuss our opinions, especially in relation to the possibility of addressing systematic  
119 reviews. We were in agreement on the main lines, i.e. that such a set of non-stringent questions and  
120 goals could be appropriate for an extensive investigation of the reference literature. Moreover, when  
121 compared to the seven goals listed by Lockwood et al. (S2 Fig), our initial purposes turned out to be

122 very appropriate for a scoping review. We were able to confirm that most of those seven goals  
123 could be pursued and that this type of study could be undertaken. The brainstorming phase, i.e. an  
124 in-depth debate about the extent to which our questions should be defined, also allowed us to refine  
125 these and generate a final list of questions, which are: 1) To what extent are such families hit by  
126 socioeconomic deprivation? 2) How much does the cost of care for the old contribute to their  
127 economic hardship? 3) How thoroughly does the reference literature deal with these issues? 4) What  
128 are the most commonly found definitions of the “socioeconomic deprivation” concept in the  
129 reference literature? Finally, our initial purposes were slightly revised and definitively fixed on the  
130 basis of these ‘new’ questions.

### **Definitive aims**

131 This study aims to: 1) identify the main key concepts used; 2) pinpoint any little explored  
132 conceptual areas or countries where research needs to be strengthened; 3) examine how  
133 socioeconomic deprivation and related phenomena are conceptualized and debate whether the main  
134 definitions are consistent with our concept of “multidimensional deprivation”; 4) identify and report  
135 on the main existing results and insights provided, particularly those that stakeholders and  
136 policymakers can benefit from, e.g. in terms of social innovation.

137 This broad scope of objectives allowed us to filter through as many studies and evidence as  
138 possible, regardless of the countries in which the studies were conducted.

### **Initial keywords**

139 A list of keywords was also drawn up in the planning stage, which included:

140 Long-term care, older (elderly) people, caregiver, family caregiving, impoverishment, deprivation,  
141 socioeconomic deprivation, economic, economic impact, poverty, and multidimensional poverty,  
142 since many researchers frequently use the term “poverty” as a synonym for “socioeconomic  
143 deprivation” in their articles. As detailed in the chapter referring to the “Protocol”, these keywords  
144 were used to begin investigating all the relevant studies.

## Protocol

145 The protocol phase consists of: 1) a detailed explanation of the study phases, which is precisely the  
146 purpose of drafting this document; 2) a detailed explanation of the selection process: which studies  
147 and related research articles are concretely sought? What criteria do we refer to during the selection  
148 process? Since this is a scoping review, choosing broad criteria is strictly necessary (S2 Fig);  
149 therefore, we are only required to define three criteria: a) participants; b) concepts; c) context; 3) a  
150 detailed list of any information related to the study's development.

151 This document is the final version of our study protocol, and results from a series of preliminary  
152 stages which, in turn, allowed us to complete the drafting of the protocol design, contained within a  
153 dedicated OSF project (Open Science Framework). Available online: <https://osf.io/xq58z>.  
154 Registration DOI: 10.17605/OSF.IO/XQ58Z.  
155 Research Square preprint: <https://www.researchsquare.com/article/rs-816117/v1>.

## Writing the protocol

156 This protocol is being drafted in accordance with the aforementioned guidelines. It mainly aims to  
157 illustrate the study's methodological framework and the types of materials and data to be used or  
158 obtained, such as: variables to be analyzed, gaps to be identified, and summary charts to be created.  
159 To this end, every effort has been made to make the study's content clear, methodologically reliable  
160 and adequately planned. The protocol also clarifies the link between questions and objectives (see  
161 previous paragraphs). Finally, it aims to describe how the unfinished steps will be completed.

## Selection process and eligibility criteria

162 Thus far, all articles were imported from the following databases (sorted by number of items  
163 found): PubMed, Wiley Online Library, Web of Science, and Scopus. We also consulted the main  
164 research library of the University of Cambridge (Cambridge University Library), which provided  
165 some useful references. All data is stored in cloud-based archives (Mendeley/EndNote X9).

166 The participants, concepts, context (PCC), and eligibility criteria that underpin this study are  
167 described below.

168 Participants: older adults in need of LTC and their family caregivers (both the family members who  
169 live with the older people and the ones who provide indirect assistance are included). We refer, in  
170 particular, to the so-called oldest-old people who cannot perform routine activities of daily living or  
171 self-care, regardless of their type of health problems. Moreover, the number of participants is not  
172 limited by the type of family or the country in which they live; both single-parent families (e.g.  
173 older people living alone) and married couples, with or without adult children, are included.

174 Concepts: a) the socioeconomic deprivation of impaired older people provided with LTC; b) the  
175 socioeconomic deprivation of their families. In detail: 1) “Older adults in need of (or provided with)  
176 LTC” are the ones affected by a reduced ability to perform routine activities, such as washing or  
177 bathing, dressing, feeding, transferring, and mobility, owing to age-related functional decline or  
178 chronic health problems. The fact that they depend on the treatment they need makes LTC  
179 indispensable; 2) LTC refers to services that help people in need of care, especially the old, with  
180 their physical and emotional needs over an extended period of time. LTC is by far the greatest  
181 health-care need of older adults and includes informal care [27]; 3) “informal care” is generally  
182 referred to as “unpaid care”, mainly provided by a person connected to the older adult being taken  
183 care of, e.g. a spouse, child, or other relative. Nevertheless, the growing need for care among home-  
184 dwelling older adults is leading to the involvement of a higher number of people to support the old;  
185 4) the term “family caregiving” represents the situation in which older adults are cared for by one or  
186 more family members, defining families in the broad sense, i.e. as individuals with a specific  
187 personal (S1 Fig). Family caregivers, in fact, can manage and provide home-based LTC both  
188 directly and indirectly; 5) the term “socioeconomic conditions” synthesizes a host of detectable  
189 factors, i.e. family assets, income, in work-benefits (if any), and savings and social ties related to  
190 the socio-demographic characteristics of family members. All of these are elements to which we  
191 must attribute the worsening or containment of LTC’s economic burden. In the case of illness, the



192 combined effect of a shortage or absence of these factors may alternatively lead to: a) “catastrophic  
193 health expenditure”, which occurs when out-of-pocket health expenditure exceeds a certain ratio of  
194 household income to health spending; b) “economic impoverishment”, which occurs when average  
195 household consumption falls below the international or national poverty threshold as a result of care  
196 expenses.

197 Context: all types of long-term care services for older people, especially informal care, in all  
198 geographical areas (both western and non-western countries). Nevertheless, the search process is  
199 conditioned by the considerable number of relevant studies conducted in low- and middle-income  
200 countries (respectively: LICs and MICs).

201 Eligibility criteria: in addition to the basic criteria illustrated above (PCC), it must be specified that:  
202 a) all studies investigating factors and policies that link activities, situations, or conditions such as  
203 old age, poor health, long-term care, health-related behaviours, and socioeconomic deprivation of  
204 families with older members affected by ADL limitations are included; b) studies proposing  
205 solutions to the economic problems triggered by health needs are particularly taken into account; c)  
206 special consideration is given to the ones outlining socially innovative solutions; d) all types of  
207 quantitative studies are included; e) qualitative studies and mixed methodologies, although scarce,  
208 are also included; f) all types of countries are considered in order to see whether there are any  
209 methodological differences that are somehow linked to the specific type of context; g) primary and  
210 secondary studies are considered; among the latter, systematic and scoping reviews are also taken  
211 into account; h) all selected relevant articles are no older than five years; exceptions to this rule are  
212 those selected due to the pertinence of the sources, of up to a maximum of ten years; i) all selected  
213 articles are to be written in English; j) empirical publications in peer-reviewed journals are  
214 preferred.

## Scoping review and evidence source details

215 The features characterising the scoping review and the sources referred to can be summarised as  
216 follows:

217 a) Scoping review title: Ageing, Long-Term Care, Poverty, and Socioeconomic Deprivation of  
218 Families: results from a scoping review;

219 b) Types of evidence sources: scientific journals; mainly research articles;

220 c) Details of evidence sources: we will list a number of items such as authors, publication dates,  
221 journal titles, volumes, and materials (if any) attached to the selected articles. All this information  
222 will be published at the end of the selection process;

223 d) The year of publication of the most recent sources among those selected: 2020;

224 e) Countries: we will also compile a list of countries where the selected studies were carried out. All  
225 this information will be published at the end of the selection process;

226 f) Types of evidence: most of the findings that we typically expect result from quantitative studies,  
227 often reinforced by the application of indicators (e.g. of disability or socioeconomic deprivation).  
228 For the most part, these studies turn out to be conducted on the basis of *secondary data*, resulting  
229 from both cross-sectional and longitudinal studies. Qualitative studies are uncommon.  
230 Measurements of the probability of experiencing genuine economic impoverishment and social  
231 exclusion (after adjusting for age and income), as well as the degree of association between socio-  
232 relational deprivation and health problems, are generally the most common outputs;

233 g) Concepts and context of selected studies: the ways in which it is possible to care for older people  
234 in need of LTC in all countries, especially in middle- or low-income countries (MICs; LICs). The  
235 types of caregiver activities and the types of health problems of assisted persons are not indicated  
236 (bar a few exceptions). These studies mainly delve into: 1) the different shortcomings of national  
237 social protection systems; 2) the economic consequences that affect families; 3) the role played by  
238 social skills in order to avoid falling into material and social deprivation;

239 h) Participants in the selected studies: 1) caregivers: spouse or adult children (especially the ones  
240 cohabiting with the persons who need to be cared for, but this is not always specified); 2) care  
241 recipients: old, old-old and oldest-old impaired people; 3) families: all types of families (including  
242 those with adult children living elsewhere, although this is not clearly specified).

243 i) Details and results to be extracted from evidence sources:

244 1) Measurement properties of Activities of Daily Living scales (ADLs) used by most national  
245 surveys [28] [29], e.g. need assistance, received assistance, duration, special equipment, and  
246 perceived level of difficulty; 2) Items and measurement properties of the Frailty Index used by  
247 some of the selected studies (56-items FI), e.g. disabilities, self-reported health conditions, hearing,  
248 eyesight, cognitive function, and depressive symptoms; 3) Measurement properties of the Index of  
249 Multiple Deprivation 2004, used to identify the most and the least deprived areas in the UK.

## **Conducting and reporting**

250 This phase includes all the actions carried out or to be carried out at the operational level, from the  
251 beginning to the end of the study. Therefore, it also refers to the outputs of our first exploratory  
252 investigation. This initial step allowed us to identify the keywords we needed to use to perform a  
253 second selection, both to make a selection of chosen articles and to select new ones. A total of over  
254 ten new keywords were identified. We selected four main thematic areas to refer to in order to  
255 search for the most useful keywords: 1) family; 2) older people to be cared for; 3) assistance; 4)  
256 socioeconomic deprivation. Most of these new keywords pertain to the fourth area, e.g. healthcare  
257 expenditure, spending, payments, economic impoverishment/costs, burden, socioeconomic status  
258 (SES), and social differences. With regard to the first and the third, we added “household” and  
259 “informal (home) care”, respectively.

260 In total, 24 different keyword combinations (Tables 1-2) were used to carry out the exploratory  
261 phases described here; while the first step is to be referred to combinations 1, 3, 5, 7, 9, and 11, the  
262 secondary research phase, as well as the recursive selection process, derives from combinations 2,

263 4, 6, 8, 10, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, and 24. Each of the combinations was  
 264 entered into one of the above-mentioned databases (PubMed, Scopus, Web of Science, Wiley  
 265 Online Library, and Cambridge University Library).

**Table 1. Keyword searching in PubMed**

1	(((caregiver[Title]) AND (poverty[Abstract])) OR (socioeconomic deprivation[Abstract])) AND (older people[Abstract]) <sup>1</sup>
3	(((("2019/01/01"[Date - Publication] : "2019/12/31"[Date - Publication])) AND (long term care[Title])) AND (socioeconomic deprivation[Abstract])) OR (poverty[Abstract]) <sup>2</sup>
6	(((poverty) AND (older people)) AND (informal care[Title/Abstract])) OR (home care[Title/Abstract]) <sup>3</sup>
8	((family caregiver[Title/Abstract]) AND (socioeconomic deprivation[Title/Abstract])) OR (poverty[Title/Abstract]) <sup>4</sup>
10	(((home care[Title/Abstract]) OR (informal care[Title/Abstract])) AND (older people[Title/Abstract])) OR (elderly[Title/Abstract]) AND disability[Title/Abstract]) <sup>5</sup>
11	(((("Age and ageing"[Journal]) AND (long term care[Title])) AND (socioeconomic deprivation[Title/Abstract])) OR (poverty[Title/Abstract]) <sup>6</sup>
16	(((("Australasian journal on ageing"[Journal]) AND (intergenerational)) OR (ageing)) AND (costs) <sup>7</sup>
17	(((poverty[Title/Abstract]) OR (multidimensional poverty[Title/Abstract])) AND (disability[Title/Abstract])) OR (functional limitations[Title/Abstract]) AND (low-income countries) <sup>8</sup>
19	((((disability[Title] AND (poverty[Title/Abstract])) OR (deprivation[Title/Abstract])) OR (economic costs[Title/Abstract])) AND (older people[Title/Abstract])) OR (elderly[Title/Abstract]) AND (low income) <sup>9</sup>
20	(((poverty[Title] OR (multidimensional poverty[Title])) OR (deprivation[Title])) AND (age[Title/Abstract])) OR (ageing[Title/Abstract]) <sup>10</sup>
21	(((socioeconomic[Title] OR (socio-economic[Title])) AND (health[Title/Abstract])) OR (health problems[Title/Abstract])) AND (care[Title/Abstract]) OR (ADL limitations[Title/Abstract]) <sup>11</sup>
22	(((life expectancy[Title/Abstract]) AND (social differences[Title])) OR (elderly[Title])) AND (socioeconomic status[Title/Abstract]) <sup>12</sup>
23	(((poverty[Title] OR (healthcare expenditure[Title])) AND (income[Title/Abstract])) OR (low-income countries[Title/Abstract])) AND (deprivation[Title/Abstract]) OR (payments[Title/Abstract]) <sup>13</sup>
24	(((family caregiver[Title] OR (older[Title])) AND (burden[Title/Abstract])) OR (socioeconomic status[Title/Abstract])) AND (activities of daily living[Title/Abstract]) OR (functional limitations[Title/Abstract]) <sup>14</sup>

<sup>1</sup>Filters (2): Abstract; Journal; <sup>2</sup>Filters: (5): Abstract; Journal Article; English; MEDLINE; Aged: 65+ years; <sup>3</sup>Filters (6): Article; Last 5 years; English; MEDLINE; Aged 65+; 80 and over; <sup>4</sup>Filters (5): Article; Last 5 years; English; Aged: 65+; 80 and over; <sup>5</sup>Filters (7): Article; last 5 years; English; 80+; 45+; 45-64; 65+; <sup>6</sup>Filters (4): Journal Article; from 2019/1/1 to 2019/12/31; English; MEDLINE; <sup>7</sup>Filters(4): Journal Article; time span: from 2016/1/1 to 2019/12/31; English; MEDLINE; <sup>8</sup>Filters (3): Article; 1/1/2017-31/12/19; English; <sup>9</sup>Filters (3): Articles; last 10 years; English; <sup>10</sup>Filters (5): Article; English; 01/01/2019-present; 65+ and 80+ years; <sup>11</sup>Filters (3): Article; English; last 10 years; <sup>12</sup>Filters (3): 45-64 years; aged: 65+ years; time span: from 01/01/19 to 31/12/2019; <sup>13</sup>Filters (3): from 01/01/2019 to 31/12/20; article; English; <sup>14</sup>Filters (3): from 01/01/2019 to 31/12/20; article; English.

**Table 2. Keyword searching in the remaining databases**

2	"intergenerational" anywhere and "ageing" anywhere and "expenditure" anywhere published in the "Australasian Journal on Ageing" <sup>1</sup>
4	keywords to enter: ageing; generational; spending; family <sup>2</sup>
5	(ABS( <i>expenditure</i> ) AND KEY ( <i>older</i> AND <i>people</i> ) AND ABS ( <i>family</i> )) <sup>3</sup>
7	TOPIC: (impoverishment) AND TOPIC: (household) AND TOPIC: (caregiver) OR TOPIC: (deprivation) OR TOPIC: (poverty) AND TOPIC: (elderly) AND TOPIC: (aged) AND DOCUMENT TYPES: (Article) AND LANGUAGE (English) <sup>4</sup>
9	(TITLE-ABS-KEY ("older AND people" OR elderly) AND TITLE-ABS- KEY ("household AND impoverishment") OR ABS (deprivation) AND KEY (economic)) AND (LIMIT-TO (SUBJAREA,"MEDI") OR LIMIT TO (SUBJAREA,"SOCT")) <sup>5</sup>
12	""informal care" OR "home care"" anywhere and ""older people" OR "elderly"" anywhere and "carers" in Abstract <sup>6</sup>
13	""informal+care"+OR+"home+care"" anywhere and ""older people" OR "elderly"" anywhere and "carers" in Abstract <sup>7</sup>
14	"economic" anywhere and ""older people" OR "aged"" anywhere and "family" anywhere and "caregivers" in Abstract and "intergenerational" anywhere <sup>8</sup>
15	""poverty"+OR+"multidimensional poverty"" in Abstract and "health" OR "informal care" OR "long term care" in Abstract <sup>9</sup>
18	""informal care" OR "long term care"" in Abstract and "family" anywhere and ""aged" OR "elderly"" in Abstract and "carers" anywhere <sup>10</sup>

<sup>1</sup>Wiley Online Library; <sup>2</sup>Cambridge University Press. Filters (3): Journal "Ageing & Society"; 2016-2021; "only show content I have access to";

<sup>3</sup>Scopus. Filters: not applied; <sup>4</sup>Web of Science. Categories: (health care sciences services OR sociology OR health policy services OR social issues).

<sup>5</sup>Scopus; <sup>6</sup>Wiley Online Library. Filters (3): 2012-2021; *Health&Health care*; Journals; <sup>7</sup>Wiley Online Library. Filters (5): journals; all dates;

Health Economics; Australasian Journal on Ageing; Scandinavian Journal of Caring Sciences; <sup>8</sup>Wiley Online Library; <sup>9</sup>Wiley Online Library.

Filter: 2015-2010; <sup>10</sup>Wiley Online Library. Filter: 2015/2019.

266 While referring mainly to the aforementioned databases, other digital materials were also found, i.e.  
 267 a book available online (using the following keywords: "abstract"; "family caregiving"; "economic  
 268 impact") and an article extracted from the "JSTOR" library ("Proceedings. Annual Conference on  
 269 Taxation and Minutes of the Annual Meeting of the National Tax Association"; search filters (3):  
 270 2018-2021; "only Journals"; refined by: "Family caregiving"). Non digital materials, including  
 271 books on poverty-related issues, were also examined (two items, i.e. a book and an article  
 272 published in the journal "On Intimacies: cultures and practices in current societies" — Issue 3/2017:  
 273 working carers).

## **Initial selection outputs**

274 Thirty-five research articles were initially selected using PubMed and Scopus as a starting point,  
275 followed by Web of Science. This first selection also includes studies concerning the relationship  
276 between material and social deprivation and self-perceived well-being, or the connection between  
277 an early withdrawal from working life and family caregiving. The last articles offer us many  
278 insights into the economic situation of women in particular and the level of decrease in earning  
279 capacity of family caregivers in general. In any case, most of the selected articles deal with the issue  
280 of health inequalities among older people; others emphasize that it is easily possible to fall into  
281 material deprivation even in high-income countries (HICs) when faced with serious health  
282 problems. It also does not seem to us to be insignificant that some of the first articles we found  
283 indicated that there is urgent need to thoroughly revise the methods and techniques for measuring  
284 the impact of ageing on the economic situation of countries.

## **Second selection**

285 The additional keywords mentioned above turned out to be highly suitable as selection tools, since  
286 this second step allowed us to find many other relevant studies.  
287 Together with those selected in the previous step, 63 research articles could be counted so far. The  
288 articles we are now finding are more focused on family economic difficulties and on how families  
289 act to ward off any type of economic impoverishment. What is striking is the fact that many older  
290 people around the world give up care or reduce it significantly. The drawing of a flow chart is  
291 planned in order to represent the entire search process in our final article. This graph will show how  
292 many articles were definitively selected, as well as how many were rejected and why.

## Quality assessment: Data extraction

293 Once the search process is finalised, we will begin to take note of the studies' main features with  
294 the intention of identifying the extent to which the studies explain their aims, methods, and results.  
295 This process, which is referred to as "quality assessment", consists of two sub-stages: 1) data  
296 extraction: data will initially be extracted as text variables using a dedicated data extraction  
297 instrument (S1 Table). All the main features of each article will be summarized on the basis of a  
298 classification grid made up of the following items: a) name of the authors; b) title; c) year of  
299 publication; d) keywords; e) type of study (e.g. national or government census, questionnaire-based  
300 survey); f) type of methodological framework (e.g. quantitative methods); g) type of techniques  
301 used in the data analysis phase (e.g. statistical analyses, type of interviews, focus groups); h) quality  
302 of reporting, i.e. how thoroughly sampling methods and measurement tools are described; i) aims  
303 and type of results provided by the authors; j) type of country to refer to. Finally, all these articles  
304 will be labelled as "high relevance, medium relevance, or sufficiently relevant studies" (with  
305 respect to our purposes); 2) data coding: after being illustrated with a text string, each of the options  
306 of the aforementioned items will be summarized in a numeric code, or rather, paired off with a  
307 numerical label representative of a certain concept to refer to, e.g. "1" if the study is a  
308 questionnaire-based survey, "2" if the study is a secondary data-based survey, and so on (item 5).  
309 Item 6, which refers only to the methodological framework of the selected studies, will be  
310 represented like this: "1" if only quantitative methods are available, "2" if only qualitative methods  
311 are available, "3" if only mixed methods are available. This coding process transforms each item  
312 from a mere property to a variable. Such a process, which is usually referred to as "data coding", is  
313 the most systematic way of synthesizing and re-presenting information and empirical objects. Once  
314 all the extracted information is each assigned a code, it will be possible to carry out a statistical-  
315 descriptive analysis. Microsoft Excel 2007 will be used to enter all coded data into a searchable  
316 database.

## **Data analysis**

317 We agreed to conduct a predominantly qualitative analysis, with the intention of identifying and  
318 tracing the boundaries of overlapping or unexplored conceptual areas. We will use the latest version  
319 of Maxqda to analyze all qualitative data. We will also perform basic statistical analyses, such as  
320 univariate or bivariate analyses, in order to get the frequency distribution of some of the  
321 aforementioned variables and to obtain cross tabs, e.g. referring to the comparison between HIC  
322 care systems and LIC care systems. We will also try to conduct a meta-analysis, if possible, in order  
323 to combine all the main results concerning LICs (e.g. the tendency for health inequalities to rise)  
324 with the results of other countries, especially with regard to the problem of economic  
325 impoverishment as a result of the state of health.

## **Data synthesis and reporting**

326 To summarize the main findings, all data will be represented in table form and, when appropriate, in  
327 graphic form, in a manner that aligns with the purposes of this ScR. A narrative summary will  
328 describe how this study can be fully reproduced and how the data answers the research questions.  
329 Not too many images will be inserted, in accordance with Munn et al. The main significant  
330 differences between low-, high-, and middle-income countries, in terms of out-of-pocket medical  
331 expenses, life expectancy, and the working conditions of family caregivers, will be presented as a  
332 summary to help illustrate the different political contexts in which the problem of “unpaid care” can  
333 emerge (see “Table 3”).



**Table 3. Conducting and reporting: The third phase of the study and related outputs**

Sub-phase		Description	Output/s
3A	<i>INITIAL SELECTION</i>	Examination of a broad area of knowledge on the issue of family health care spending and socioeconomic deprivation (SED)	35 items selected
			Identification of key concepts and keywords (over ten new useful keywords)
3B	<i>SECOND SELECTION</i>	Refinement of the search process through the new keywords identified ( <b>choosing selected items</b> )	At present: 63 items collected
		Additional items to be found ( <b>advanced search</b> )	
3C	QUALITY ASSESSMENT	Data quality assessment (what kind of data/results?)	List and classification of the main features of selected articles ( <b>data extraction</b> ); <i>JBI</i> data extraction tool (text variables)
			Codification of all extracted information ( <b>data coding</b> ). Data storage: <i>Microsoft Excel</i>
			Identification of the type of analysis (what kind of variables can be analyzed?)
3D	DATA ANALYSIS	<b>Bibliographic Documentary Analysis</b> (combining automatic and manual procedures within the analysis process)	Identification of any conceptual gap and/or redundancy in research or basic knowledge
		Meta-analysis?	Identification of any significant differences due to the <u>country</u> in which the selected studies were carried out
			Identification of data relationship sets and numerical measures (in the case of meta-analysis)
3E	DATA SYNTHESIS and CONCLUSIONS	All factors linked to the relationship between family caregiving and <b>material and social deprivation</b> will be listed	Summary tables
		Representation of the level of <b>economic impoverishment</b> differentiated by country	Graphics

## Discussion

334 We wrote about a paucity of publications on the economic burden of care for older people requiring  
335 LTC and the impact of health expenditure on their families' economic situation. However, the term  
336 "paucity" does not imply that available studies on this issue are scant. Indeed, when compared to  
337 the multitude of studies on the poor state of health of deprived older people, they are not enough for  
338 a truly exhaustive investigation: there is a compact two-way relationship between health and  
339 socioeconomic deprivation, and both directions need to be studied in-depth. We would also like to  
340 draw the attention of stakeholders and policymakers to the general issue of increasingly

341 burdensome health costs and the difficulty of quantifying the number of people whose economic  
342 impoverishment and socio-relational deprivation are due solely or primarily to health spending.  
343 Many people, including older adults, refuse or partially refuse treatment, i.e. they are incorrectly  
344 estimated to be living above the so-called 'poverty line'. Thus, a rough estimate of the worldwide  
345 incidence of poverty is being discussed. This issue contributes to the urgency of our study, but at  
346 the same time it should be considered as a limitation, since we cannot confirm the number of people  
347 who turn out to be less deprived than they appear to be, nor how many people would be officially  
348 classified as 'poor', i.e. economically impoverished, had they received or agreed to receive  
349 appropriate assistance. This paper shows the path to follow to carry out a thorough ScR on the  
350 socio-economic deprivation of older ill people and their families precisely because it serves as a  
351 flexible, although structured, search map. A brief overview of what has been done so far is enough  
352 to see how this issue is scarcely present in the reference literature, despite its relevance to the public  
353 debate. This research protocol supports knowledge-sharing practices and underlines the necessity of  
354 following a complete and integrated methodological cycle, including the preliminary stages. The  
355 long design processing time, a limit that needs to be made explicit, is due to the intricate  
356 relationships between the core issues examined and those related to them. On the other hand, any  
357 effort to promote future research necessarily implies precise methodological schemes. Therefore,  
358 we decided to adopt a multi-stage design, aligned with all of our methodological criteria.

## Authors' contributions:

359 **Rossella Martarelli**

360 Data curation, Writing – Original Draft Preparation, Validation

361 **Georgia Casanova**

362 Conceptualization, Methodology, Data curation, Writing – Original Draft Preparation, Funding  
363 Acquisition, Validation

364 **Giovanni Lamura**

365 Validation, Writing – Review & Editing

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## Supporting information

**S1 Checklist. PRISMA-P 2015 checklist.**

**S1 Table. Data extraction tool.** A, Study details and characteristics; B, Details or results to be extracted.

**S1 Fig. Research concepts and goals.**

**S2 Fig. The study's methodological framework.**

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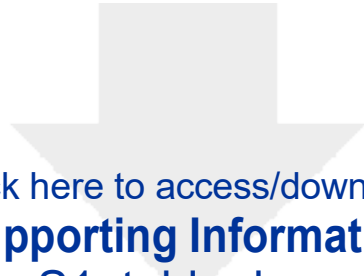
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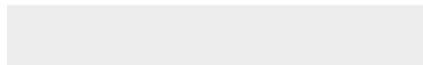
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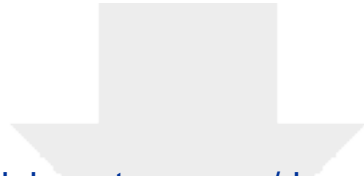
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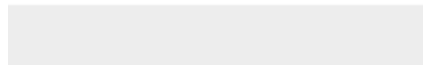


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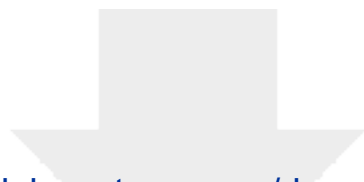


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