

# The impact of long-term care needs on the socioeconomic deprivation of older people and their families: results from a scoping review

#### 

Instituto de Investigación en Políticas de Bienestar Social (POLIBIENESTAR)—Research Institute on Social Welfare Policy, Universidat de València

#### Rossella Martarelli

IRCCS-INRCA National Institute of Health & Science on Ageing, Centre for Socio-Economic Research on Ageing.

#### Francesco Belletti

International Center for Family Studies (CISF)

#### Giovanni Lamura

IRCCS-INRCA National Institute of Health & Science on Ageing, Centre for Socio-Economic Research on Ageing.

#### Research Article

**Keywords:** Aging, older people, long-term care, poverty risk, household, review

Posted Date: December 20th, 2022

**DOI:** https://doi.org/10.21203/rs.3.rs-2272155/v1

License: © (1) This work is licensed under a Creative Commons Attribution 4.0 International License.

Read Full License

#### **Abstract**

# **Background**

Long-term care (LTC), poverty, and socioeconomic deprivation are globally significant social issues. Ongoing population aging trends and the recent social and health emergencies caused by the COVID-19 pandemic crisis have highlighted the need for macro-level LTC and welfare system sustainability strategies. At the micro level, the relationship between LTC needs and the risk of socioeconomic deprivation and poverty should be taken into account to promote more targeted and innovative policies worldwide. This scoping review explores the relationship between LTC needs, the health status of older people, and the risk of socioeconomic deprivation for their families in order to understand how the literature interprets these concepts and the relationship between them and to identify any potential gaps in this regard.

### **Methods**

The methodology considers different relevant sources: a) the guidelines for ScR proposed by Lockwood et al. [1]; b) the Munn et al. [2] recommendations; c) the PRISMA guideline for Scoping Reviews [3]; and d) the Joanna Briggs Institute (JBI) checklist [4]; Sixty-three papers are included in the frequency analysis of 9 identified categories to respond of aims.

### **Results**

The findings reveal the existence of a debate that seeks to understand the different characteristics of the relationship between the investigated issues. Specific targets (such as older people, caregivers, and households) are used to identify LTC needs, while material deprivation or poverty is used to determine the conditions of deprivation. Relevant gaps in the literature are identified in terms of the concepts and approaches of the studies analyzed. The results indicate that the reciprocal relationship between LTC needs, supply, and the risk of socioeconomic deprivation is understudied.

# **Conclusions**

The simplification strategy used in many studies to reduce the relationship's complexity precludes an indepth analysis and debate on some relevant aspects, including the crucial two-way relationship between LTC needs/supply and the risk of socioeconomic deprivation. Future studies should focus on the causal relationship between the two phenomena and identify any internal factors that may be involved.

### 1 Background

In recent decades, the literature has revised the concept of poverty, which was traditionally defined in terms of income level [5] offering a vision of poverty as a more complex, articulated, and multidimensional phenomenon [6, 7] that is characterized by an intrinsic interconnectedness between different dimensions [8]. This is well reflected in the international plans developed to counteract multidimensional poverty, such as those identified by an initiatives like "Transforming our world, the 2030 Agenda for sustainable development" and the "Third ten-year action plan for the eradication of poverty (2018–2027)"[9], which promote the dissemination of studies for a more in-depth understanding of the dimensions of deprivation in order to better target those population segments characterized by specific social needs, for instance those related to long-term care (LTC) conditions.

At the same time, the impact of population aging on health and welfare systems around the world is widely recognized [10–12], resulting in an increase in the demand for formal and informal care [13] and making LTC a priority for national and international policies [14–18]. In this regard, European LTC schemes are complex combinations of health and social policies, services, and interventions [19, 10], whose sustainability is threatened by demographic and fiscal circumstances [20] and, to an even greater extent, by the recent COVID-19 pandemic. In this context, reducing inequalities in health and LTC provision remains a central pillar for many countries' sustainable development [21, 22].

Previous studies underlined the higher risk of social exclusion and social inequities for informal carers, who are often women who frequently feel compelled to limit their work and social lives to care for their relatives [23]. Over and above the indirect cost of LTC provision, out-of-pocket expenditure for private care is rising, even in advanced social protection systems [24]. For these reasons, Mitra and colleagues have recommended that future research should focus on the private side of LTC expenditure borne by families [25]. Within this framework, a number of studies have investigated and found that older people living in materially deprived conditions have a diminished ability to cover their own care needs [26, 27], a situation that has a significant impact on both their psychosocial well-being [28, 29] and cognitive health [30]. Despite these efforts, the literature largely overlooks the effects of health conditions on the socioeconomic status and related risk of socioeconomic deprivation (SED) of either dependent older people or the family members who care for them. Similarly, at policy level, initiatives and schemes supporting family carers do not seem to fully underpin these situations and are, therefore, unable to adequately counteract the risk of poverty and social exclusion arising from informal care activities for dependent people [31]. In light of the current state of affairs, there is an urgent need for a greater focus on the relationship between LTC needs and the risk of socioeconomic deprivation and poverty, to better understand the dynamics underlying this phenomenon and how innovative policies can be formulated globally to tackle it.

This scoping review study (ScR) seeks to contribute to the debate on this specific issue, thereby supporting future research on how health-related LTC expenses affect the financial situation of care recipients and the family members who care for them. Specifically, this study focuses on the identification of the primary research gaps, examining how the scientific literature addresses the multidimensional perspective of the socioeconomic deprivation concept.

This study was conducted within the framework of the Family International Monitor (FIM) and the SEreDIPE project (Horizon 2020 MSCA-IF-2019 Grant Agreement No. 888102). Using a multidimensional perspective of the concepts "family" and "deprivation" [32], both projects are concerned with familial material and social deprivation, with a particular focus on care needs.

#### 2 Methods

To ensure the highest possible standards of reporting, this ScR is based on a methodology that considers the recommendations formulated by the following relevant sources: a) the guidelines for ScR proposed by Lockwood et al. [1]; b) the Munn et al. [2] recommendations; c) the PRISMA guideline for Scoping Reviews [3]; and d) the Joanna Briggs Institute (JBI) checklist [4]. The chosen guidelines are coherent and non-overlapping, as possible risks in this regard (e.g., Lockwood including suggestions from PRISMA guidelines and the JBI checklist) have been adequately considered. The full details of this study protocol are described in Martarelli et al. [33]. By combining these methods, it is ensured that the review's path remains linear and focused, in accordance with Lockwood and Munn's recommendations, while the PRISMA and JBI approaches concurrently limit the loss of potentially useful papers on the topic. Moreover, specific guidelines support different aspects, such as the suitability of chosen methods (JBI checklist) and the analysis of data (PRISMA). Lastly, the incorporation of these suggestions enabled the authors to consider the pre-planning phase as the starting point for the design of the ScR study protocol. This allowed the authors to focus on a complex and multidimensional issue, such as the relationship between LTC needs and care strategies and the risk of SED. Figure 1 depicts the ScR's flowchart.

# 2.1 Pre-planning

Lockwood and colleagues [1] point out that pre-planning is the phase that determines a review project's success. The brainstorming and brief preliminary research conducted during this phase enabled the authors to clarify the conceptual framework, determine specific research questions, and identify the set of keywords necessary to implement the search.

# 2.2 Conceptual framework

The relationship between LTC care needs and SED risk is composed of three main elements: a) care needs, often expressed through the identification of a specific target of study; b) socioeconomic deprivation, understood as a multidimensional factor; and c) the characteristics of the relationship between these two factors. Figure 2 illustrates that there are two possible directions in which this relationship can develop. The first relates to the situation of people, including those in later life, who live in SED conditions and can therefore count on the reduced availability of social, health, and economic resources [26, 27], which in turn contributes to diminished self- care capacity, as well as a deterioration of their health, autonomy, and overall living conditions [27, 29]. The other direction concerns dependent older people with a reduced self-care ability, who seek to cover their LTC needs via healthcare-seeking behaviors based on cost-coping mechanisms, such as the direct buying of care provision [34, 35] or via

informal care (e.g., a reduction in employment income) [37, 38]. In both cases, these mechanisms impact on the socioeconomic status and, consequently, the associated SED risk for both older people and their family caregivers (co-residing or otherwise). To analyze these mechanisms, this study uses the concept of multidimensional deprivation based on Eriksons' Theory [39], as it allows us to emphasize that SED encompasses more than just material deprivation and economic impoverishment, and to underline that economic and social inclusion aspects are core dimensions to take into account when examining the effects of care strategies for dependent older people and family caregivers.

# 2.3 Research questions, methods, and keyword identification

This review examines the scientific literature to evaluate the relationship between LTC needs and the risk of socioeconomic deprivation for older people and their caregiving relatives. At the end of the preplanning phase, three specific research questions were formulated to address this general objective: 1) to scan and evaluate the literature on the topic of older adults who require LTC and their socioeconomic status; 2) to identify any conceptual gaps and the most debated unresolved issues in the literature; and 3) to determine the extent to which the so-called "multidimensional perspective" is being applied to the SED concept. To this end, the authors chose a quantitative approach based on frequency and content analysis (see Table 1 for an overview of the analytical categories considered in relation to the three research questions).

Table 1
Study aims/research questions by selected analytical categories

Categories	Aims / Research questions		
	No. 1	No. 2	No. 3
1. Target of population	Х	Х	
2. The study's aims <sup>1</sup>	Χ	Χ	Х
3. Perspective on the health-SED relationship <sup>2</sup>	Х	Χ	х
4. Distribution of deprivation dimensions 3			Х
5. Multidimensional deprivation level <sup>4</sup>			Х
6. Countries involved in the selected studies	X	Х	
7. Income level of the countries	X	X	
8. Type of data (primary or secondary)	X	X	
9. Typologies of design (longitudinal or cross-sectional studies)	X	Х	

<sup>1:</sup> The purposes as contextualized and expressly argued by the authors (focus on title words, abstracts or, if present, dedicated paragraphs);

As shown in Fig. 2, the authors identified a set of keywords to cover the chosen conceptual framework's concepts and relationships. As detailed in the protocol paper [33], the authors searched various databases using the keywords defined in the pre-planning phase that were strictly related to the above objective. Thirteen keywords were included in the first set of searches: "long-term care," "older people," "elderly," "aged," "caregiver(s)," "family caregiving," "impoverishment," "deprivation," "socioeconomic deprivation," "economic," "economic impact," "poverty," and "multidimensional poverty." After the initial exploratory searches, additional keywords were added progressively in order to refine the search: "household," "expenditure," "healthcare expenditure," "spending," "payments," "economic impoverishment," "costs," "burden," "socioeconomic status," "socioeconomic/socioeconomic," "household," and "social differences," "informal care," "care," "carers," "(inter)generational," "activities of daily living," "ADL limitations," "functional limitations," "disability," "life expectancy," "health," "health problems," "income,"

<sup>&</sup>lt;sup>2</sup>: How the authors argued about the cause-effect relationship between the investigated factors, i.e. whether they used the one-way or the two-way concept of the health-SED relationship (the former involves having a default setting whereby either health directly affects SED or SED directly affects health; the latter implies addressing the issue of bi-directionality);

<sup>&</sup>lt;sup>3</sup>: All the dimensions through which people – according to the authors of the selected articles – experience deprivation (considering that this ScR aims to find out whether or not monetary and non-monetary dimensions were simultaneously included);

<sup>&</sup>lt;sup>4</sup>: Articles were scored on the basis on the number of dimensions considered

"low-income," and "low-income countries." Forty-one keywords were used in total, since they were deemed to be congruent with the conceptual framework (Fig. 2).

# 2.3.1 Selection process

The entire search process was conducted between March 2021 and April 2022. Four of the most important research databases were accessed: Pubmed, Scopus, Web of Science, and Wiley Online Library. A few items were also extracted from non-digital archives or other electronic databases, i.e., "Journal Storage" (JSTOR) and "Cambridge Core" (the books and journals platform from Cambridge University Press). As indicated above, all of the selected search terms were English words.

As a result of the 24 different keyword combinations emerging from the search process (see [33] for details), 21,200 items, excluding duplicates, met the criteria for selection. They were screened for the scoping review, i.e., included or excluded according to the study protocol's criteria. The following articles were chosen for inclusion on the basis of these selection criteria: a) those focused on the relationship between poor health and the aging process, long-term care needs, and the socioeconomic deprivation of chronically ill older people and their families; b) those proposing solutions to the economic problems triggered by health needs; c) those proposing social innovation policies; d) those based on a specific method (quantitative or qualitative) or mixed methods (i.e., either of these categories); e) both surveys and systematic or scoping reviews; f) those referring to "primary" or "secondary" studies; g) those conducted in high-income or low- and middle-income countries (i.e., either one of the latter two); articles based on a comparative perspective were also included; h) those that were published within the past five years; exceptions to this rule are articles chosen due to the relevance of the sources, published within the past ten years as a maximum; i) those written in English; and j) those published in peer-reviewed journals.

Two researchers (GC and RM) independently screened the extracted items on the basis of titles and abstracts. In the end, 21,131 articles were excluded for failing to meet the criteria. Therefore, a total of 69 articles were provisionally selected. A second check of excluded and included papers was undertaken, resulting in the inclusion of a total of 63 papers in the ScR.

No other references were found by manual searching or by analyzing the references of included articles. Annex 1 contains the complete list of selected papers, including their bibliographic data.

### 2.3.2 Data extraction

In order to organize the information for analysis purposes, the authors arranged the collected papers by date, from oldest to newest, then numbered and labeled them sequentially from 1 to 63. On the basis of a modified JBI data extraction form, a set of 9 categories of analysis were determined in accordance with the goals of the ScR and typologies of analysis (Table 1). Two researchers (GC and RM) independently extracted the items based on the identified categories. To collect common information, a thematic and content analysis [40] based on ex-post categorization of variables [41] was performed to (1) detect the presence of variables in each selected study, and (2) identify the selected variable's different modalities.

# 2.3.3 Data analysis and reporting

The quantitative analysis was based on the frequency calculation of internally determined modalities for each selected category and summarized in reporting tables (Table 2 to Table 6). Given their complexity, additional details are provided for three of the variables in order to better clarify their internal definition. First, 11 different modalities were identified based on the nine dimensions used by Erikson's theory to measure the multidimensionality of the deprivation concept utilized by the selected studies. The authors decided to separate "material state" from "network ties" and "social integration" for a better correspondence with the dimensions utilized in the articles and to provide a more accurate evaluation of the deprivation concept's multidimensional degree. The final list of dimensions is detailed in Table 4.1. Secondly, the degree of multidimensional deprivation was calculated by adding the number of dimensions used by each article. The definition of three multidimensional levels (low, medium, and high) facilitates the observation of the distribution of levels in deprivation's multidimensional concept. Lastly, the World Bank classification of the country's income level (low, medium-low, medium-high, and high) was applied and reported in Table 5.2.

#### 3 Results

The ScR found 63 papers in the ten years covered (see the full list in annex 1). This study's first finding is that there is a certain level of interest in scientific literature as regards the association between older people's health conditions and their socioeconomic conditions.

# 3.1 LTC needs defined by targets: older people, caregivers, and households

As for the relationship between people's LTC needs and deprivation dimensions, 80% of the analyzed articles target a specific population (Table 2). Specifically, older people are the most researched target (23 of 63 articles), followed by household (15 articles; 23.8%), and caregivers (13 articles; 20.6%). The indepth analysis of the data reported in Table 2 confirms the prevalent research strategy of targeting older people by mixing the groups of the oldest-old (80 or above) and the younger senior population (65–75 years) in order to estimate the potential level of care needs.

Table 2
Target of population investigated

Targets	n.	%
Older people	23	36.5
Households and/or heads of households	15	23.8
Caregivers	13	20.6
No specific target	7	11.1
Not applicable	5	7.9
Total	63	100

A case in point is provided by Flores-Flores et al. (2018), who focus on the impact of poverty on health insurance opportunities and the use of preventive services. Their study includes three different age groups: 65-70, 71-75, and 76-80. The study also shows a higher incidence of limitations in activities of daily living among the oldest-old, whose rate of disability is about 5 times that of people aged 36 to 64 years. The study by Wilkinson.et al. [42] also offers a clear example, as it targets Medicare beneficiaries aged 65 + to emphasize their need for all those services that Medicare, the well-known federal health insurance program in the USA, does not cover (i.e., long-term services and support for personal care and assistive devices). This article investigates the extent to which the financial burden borne by older American people is commensurate with the level and intensity of their care needs. Moreover, some studies apply a different concept of "older age," due to the need to investigate not only the age group to which an individual belongs, but also whether or not the average age at first infirmities tends to change significantly over time. In fact, they not only look into how old "older people" are, but also the age at which older adults are "really old". To this end, they cover a wide spectrum of individuals, including those aged 60 and older. Murayama et al. [43], for example, conducted a study on long-term changes in functional capacity among older people in Japan (2020). Based on data drawn from the National Survey of the Japanese Elderly (NSJE), this study focuses solely on those aged 60 years and over at baseline. The Myanmar Aging Survey (MAS) also uses a sample of persons aged 60 and older, as described by Teerawichitchainan et al. [44]: their article defines "older people with long-term care needs" as those reporting one or more physical difficulties, not only the inability to perform activities of daily living—both instrumental and non-instrumental activities, i.e., IADL and ADL, respectively – but also difficulties with physical functions such as "lifting 5 kg in weight," "walking up and down stairs," "walking 200 to 300 meters," "crouching/squatting," and "using fingers to hold things."

The second largest category of studies, comprising nearly a quarter of the 63 papers analyzed, concerns those who see the household or the head of the household as their main research target. In this case, the focus of the research is on the relationship between the health conditions of older family members and eventual material deprivation aspects for a specific member (e.g., an older member, head of the household) or the entire family. An example of this approach is provided by Guerchet et al. [45], whose

investigation focused on how the presence of care-dependent older members affects the economic functioning of their households, classified according to disease evolution and level of persistence (for instance, by distinguishing between "chronic-care households" and "incident-care households"). This 2018 study is distinguished by its use of reliable financial strain indicators (e.g., loans, shares, and extra work) and its examination of a wide range of household income components (both stable and transitory components). The article by Salari et al. [46] on the most relevant household characteristics associated with "catastrophic health payments" is another example in this regard. Based on data from the Kenya Household Health Expenditure and Utilization Survey 2018 (KHHEUS), this study draws conclusions regarding the impoverishing effect of the presence of older members, particularly in terms of the health-seeking behavior of those afflicted with chronic diseases. In addition, Zhao et al. [47] investigated the relationship between chronic disorders and catastrophic health expenditure in China after controlling for two factors: household size and older members requiring care (i.e., those aged at least 60 years old).

The 13 publications with caregivers as the study's primary research target specifically focus on informal care contexts and the implications on caregivers' quality of life and social and material deprivation aspects. Belonging to this group, the study by Zhou et al. [48] is one of the few articles focusing on the relationship between the health status of caregivers and that of "care recipients," e.g., spouses or older parents requiring care. This is an important point since informal caregivers often complain about their mental state (anxiety, depression, exhaustion, etc.). This study also explains how the income level of adult children influences caregiving decisions, since the likelihood of receiving assistance from one or more adult children appears to increase as their average income decreases. Butrica et al. [49] also focus on caregivers, although their article almost exclusively investigates the direct costs of parental or spousal caregiving. Carers are repeatedly described here as having few job opportunities and a lower percentage growth in assets. Finally, the article by Messer [50] can be cited as evidence that material deprivation among sick older people is occasionally partially self-imposed since they are ashamed to admit to their economic and health requirements. This is also one of the few qualitative studies that we were able to find, allowing us to observe how easily health costs may lead to a tense family environment.

Finally, in the seven papers that do not disclose a specific target in their objectives, older people emerge as the primary care recipient category, confirming that some literature tends to consider this category as a proxy for identifying care needs.

# 3.2 The material dimension of deprivation attracts most attention

Table 3.1 depicts the distribution of each deprivation dimension utilized by the reviewed articles. The data emphasize a traditional view of deprivation, as material wealth is the most frequently analyzed dimension (84.1% of publications), followed by health status (81%) and educational/social status (47%). Occupational status, social network ties, and marital status are mentioned in 35 cases, while the housing context is discussed in 30 of them. The level of social integration (16), work-life balance (4), perception of safety (3), and political participation (2) are the least cited dimensions.

Table 3
The concept of deprivation: dimensions and multidimensional level

3.1 Dimensions of deprivation	n.	%
Material wealth (e.g. income; savings; assets)	53	84.1
Health status (self-reported health, health insurance coverage, and health services accessibility)	51	81
Education/ social status	47	74.6
Occupational status	35	55.6
Social network ties	35	55.6
Marital status	35	55.6
Housing	30	47.6
Social integration level (e.g. presence or absence of barriers that prevent people from participating in society)	16	25.4
Work-life-leisure balance (e.g. caregiving burden in terms of lack of spare time)	4	6.3
Perceived safety	3	4.8
Political participation	2	3.2
Total	63	
3.2 Multidimensional deprivation level (score 1-10)	n.	%
High (range: 7–9)	17	27.0
Medium (range: 5–6)	27	42.9
Low (range: 2-4)	10	15.9
Not applicable	9	14.2
Total	63	100

Despite the trend to focus on material impoverishment, the definition of deprivation in 54 articles (85%) includes at least two different dimensions. In ten of these papers (15.9%), the concept of deprivation comprises a low number of dimensions. Table 3.2 highlights that 44 studies (around 70%) applied a medium (42.9%) or high (27%) level of multidimensionality to the deprivation concept. From an overall analysis of the results presented in Table 3, it is possible to conclude that the material dimensions (e.g., material wealth, educational level, occupational level, and marital status) are preferred over others for describing deprivation. In the majority of cases, multidimensional definitions of deprivation include at least one or more of them. These findings underline that social dimensions are viewed only as secondary or integrative components of the primary, largely material characteristics of the SED state of older people and their families.

# 3.3 Little room for a two-way perspective of the relationship between healthcare needs and SED

The emphasis placed on poverty and material deprivation by the majority of studies impacts on the design of the studies themselves. More often than not, the relationship between health and the deprivation of older people and families is examined by focusing on material impoverishment. Around 24% of publications included in the ScR (15 out of 63) discuss socioeconomic deprivation, while 60% (38 out of 63) examine the material impoverishment of people from the perspective of health conditions (Table 4). In particular, 24 articles (38.1%) discuss the financial impact by focusing on the financial burden as a result of chronic diseases and the subsequent health care consumption. In contrast, the relationship between people's health and material deprivation is dealt with by 14 cases (22.2%). In ten papers (15.9%), the study objectives are not focused on the direct association between health and deprivation issues; instead, they only offer general reflections on the health and deprivation situations of older people and families, as is typical of review studies.

# 4. Focus And Direction Of The Investigated Relationship Between Health, Care Needs And Sed

4.1. Focus of the study	n.	%
Relationship between health and socio-economic deprivation (SED) factors	15	23.8
Relationship between health and material deprivation factors	14	22.2
Financial burden due to chronic conditions and health care consumption	24	38.1
General purposes	10	15.9
Total	63	100
4.2. Direction of health-SED relationship	n.	%
health affects socio-economic conditions (health as an explanatory variable)	24	38
socio-economic conditions affect health (health as a dependent variable)	24	38
two-way concept of the health-SED relationship (they mutually influence each other)	10	16
other (i.e. indirect relationship)	5	8
Total	63	100

Forty-eight papers (76%) preferred to present a linear, one-way perspective of the relationship between older people's health status and SE conditions. Ten articles (16%) adopted a two-way perspective to describe the relationship, therefore providing a more comprehensive view of this complex theme, and five publications (8%) approached the topic by discussing the indirect connection between the health status

of older people and SE circumstances. Table 4.2 highlights that there is no favored route for observing the relationship: the number of studies (24) analyzing the health problems of older people as a factor impacting upon the SE situation corresponds to the number of investigations focusing in the opposite direction of the relationship.

# 3.4 Paucity of comparative studies and analyses of primary data

The ScR analysis enables the emergence of specific characteristics of geographical representativeness. More than 80% of the reviewed papers focus on a single country, while comparative studies are in the minority (17.5%). Table 5.2 emphasizes that the vast majority of research is undertaken in high- and middle-income countries; only one publication focuses on the issue in a low-income country. This is the article by Gabani et al. [51], which examines the percentage of Liberian households living below the so-called "poverty line" before and after taking out-of-pocket (OOP) health expenditures into account.

Table 5
Territorial representativeness

5.1. Number of countries involved in the selected studies	n.	%
One country (national or sub-national level)	51	81
Two or more countries (cross-national research)	11	17,5
Not applicable (no country list)	1	1,5
Total	63	100
5. 2. Income level of the countries involved in the selected studies	n.	%
Middle-income	27	42.8
High-income	32	50.8
HMICs	3	4,8
Low income	1	1.6
Total	63	100

In relation to the considerably more regular availability of data for high-income countries, it is relevant to note that 84% of the papers reviewed are based on secondary data studies, whereas less than 5% are based on primary research studies (Table 6.1). This may be due to the greater availability of cross-sectional studies (42.9%) in comparison to longitudinal studies (20.6%).

Table 6
Typologies of study: data and design

6.1 Data typology	n.	%
Secondary data analysis	53	84.1
Theoretical studies	7	11.1
Primary research studies	3	4.8
Total	63	100
6.2 Type of design	n.	%
		00.6
Longitudinal	13	20.6
Cross-sectional	13 27	42.9

#### 4 Discussion

The analysis of the scientific literature demonstrates that there is interest in the causal relationship between LTC needs and SED, despite the results highlighting several gaps. The first relates to the definition of LTC needs. The widespread use of older population targets as proxies for the volume of LTC needs precludes a comprehensive analysis of the entire concept in all its complexity, including its composition in terms of demand for both health and social care services [52, 53].

Second, the use of older people as a proxy for identifying LTC needs contributes to an overrepresentation of care recipients in studies focusing on older people, even when the investigated problems are not strongly linked to the health or social care received and instead focus on economic and social aspects.

However, the ScR did identify some studies whose specific primary research target was caregivers and families, often defined by the "head" of the household. These two groups, however, are not jointly considered in the literature, indicating that research often prefers to focus on (and deal with) a single specific target rather than choosing a multiple-target population, which would more accurately reflect the complexity of most real-life LTC caregiving situations [10, 54]

A third issue is that the concept of LTC needs is frequently defined in terms of health status or disability conditions, as opposed to ADL/IADL limitations, thus promoting a health-centered view of care needs. A similar simplification approach is also found with regard to the multidimensional deprivation concept, which is heavily influenced by material and other easily measurable dimensions, resulting in the use of a concept of deprivation referring to the most traditional poverty and social inclusion definitions in most cases [55–57]. In consequence, when defining the socioeconomic conditions of families, the aspects

connected to the social life often remain undervalued, albeit a growing number of studies identify them as pillars of informal carers and care recipient's wellbeing and quality of life [58–60].

Nonetheless, SED and its core characteristics appear to be gradually gaining prominence in policymakers' formulation of suggestions and recommendations for the establishment of LTC policies. Cash benefit schemes and support policies for working caregivers continue to be the main initiatives proposed to partially mitigate the effects of caregiving's out-of-pocket financial burdens, even if their effectiveness are debated in the literature [31]. The more extensive availability of single-country studies and secondary data sources confirms that scientific research in this field, in an effort to reduce the complexity of the triangle "LTC needs, health conditions of older people, and socioeconomic conditions," has not yet found methodological and economical sustainable solutions that permit the gathering of more cross-national and primary data.

In the coming decades, population aging will significantly accelerate in the countries of the global South [9], posing a new challenge. The lack of attention dedicated thus far to low-income countries has created a significant gap in the evidence pertaining to these countries, thereby prohibiting an in-depth, urgently required analysis of the future sustainability of their developing welfare, health, and social care systems [61]. Finally, the simplification strategy applied to many studies to lessen the complexity of the topic under investigation precludes an in-depth debate of some additional aspects. These include the understudied two-way relationship between LTC needs, supply, and the risk of socioeconomic deprivation; the marginal consideration of caregiving and SED's social components in the majority of research; the widespread use of material poverty as a synonym for SED, which increases the risk of losing the numerous social exclusion aspects; and, the lack of comparative or longitudinal studies.

Despite the wealth of information provided by this scoping review study, some limitations should be considered when interpreting its results. These limitations are primarily attributable to the study's exploratory objectives. In light of the dearth of literature recognizing ADL limitations in order to measure LTC needs, the set of keywords has been broadened to include health conditions and disability, two concepts that do not always refer to dependent people. A similar search strategy was applied to the SED concept in conjunction with poverty and other material deprivation-related keywords, thus diminishing the selective power to offset their overrepresentation in the analyzed literature. The decision to use frequency distributions provides a user-friendly format for describing the results, but precludes the detection of potential internal links among the selected variables. Lastly, the study lacks an in-depth qualitative analysis of content to identify and summarize the key findings and recommendations included in the discussion section. To our knowledge, and despite these limitations, this study is the first attempt to provide an overview of the literature examining the relationship between LTC needs and SED in both care recipients and caregiving families.

### **Conclusions**

The relationship between LTC needs, the health status of older people, and the risk of socioeconomic deprivation for their families attracts the interest of specialised literature. many studies adopt a simplification strategy to easer explored the high complexity of concepts and the crucial two-way relationship between LTC needs/supply and the risk of socioeconomic deprivation. This strategy does not allow for achieving in-depth knowledge of this relationship. Future studies should thoroughly analyze the causal relationship between the two concepts and uncover the underlying factors that characterize it. Systematic reviews and longitudinal studies should also be encouraged to foster a comprehensive understanding of the bidirectional influence between the two phenomena.

#### **List Of Abbreviations**

LTC

Long-term care

ScR

Scoping Review

JBI

Joanna Briggs Institute

SED

socioeconomic deprivation

FIM

Family International Monitor

**ADL** 

**Activities Daily Living** 

**IADL** 

Istrumental Activities Daily Living

#### **Declarations**

Ethics approval

not applicable

Consent for publication

not applicable

Availability of data and materials

not applicable

#### Competing interests

The authors declare that they have no competing interests

#### **Funding**

The study is being supported by the Marie Curie European Fellowship Grant (Horizon 2020 MSCA-IF-2019 Grant Agreement No. 888102) and by Family International Monitor (FIM) project funded by International Center for Family Studies (CISF).

#### **Authors' contributions**

GC, GL and FB conception of the study, GC design of the work; RM and GC the acquisition and analysis; GC interpretation of data; GC have drafted the work or substantively revised it. GL and FB supervised the draft, providing comments. All Authors approved the submitted version.

#### **Acknowledgements**

not applicable

#### References

- 1. Lockwood C, Dos Santos KB, Pap R. Practical guidance for knowledge synthesis: Scoping review methods. Asian Nursing Research. 2019 Dec 1;13(5):287-94.
- 2. Munn Z, Peters MD, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC medical research methodology. 2018 Dec;18(1):1-7.
- 3. Page M. J. [et al.]. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Syst. Rev.* 2021, *10*, 1–11. DOI: 10.1186/s13643-021-01626-4.
- 4. JBI GLOBAL WIKI. JBI Manual for Evidence Synthesis | Appendix 2.3: JBI Qualitative data extraction tool.
  - (https://wiki.jbi.global/display/MANUAL/Appendix+2.3%3A+JBI+Qualitative+data+extraction+tool (accessed on 04 June 2021).
- 5. Hagenaars, A., & De Vos, K. The definition and measurement of poverty. *Journal of human resources*, 2018.pp 211-221
- 6. Alkire S, Foster J. Counting and multidimensional poverty measurement. Journal of public economics. 2011 Aug 1;95(7-8):476-87..
- 7. Whelan CT, Nolan B, Maitre B. Multidimensional poverty measurement in Europe: An application of the adjusted headcount approach. Journal of European social policy. 2014 May;24(2):183-97.
- 8. Atkinson AB. Measuring poverty around the world. InMeasuring Poverty around the World 2019 Jun 18. Princeton University Press.
- 9. United Nations, population ageing and sustainable development, POPFACTS, No. 2017/1. 2017 (https://www.un.org/en/development/desa/population/publications/pdf/popfacts/PopFacts\_2017-1.pdf).

- 10. Spasova S, Baeten R, Vanhercke B. Challenges in long-term care in Europe. Eurohealth. 2018;24(4):7-12.
- 11. Cylus J, Figueras J, Normand C. Will population ageing spell the end of the welfare state? A review of evidence and policy options (2019). Will population ageing spell the end of the welfare state? A review of evidence and policy options (2019). 2018.
- 12. Howdon D, Rice N. Health care expenditures, age, proximity to death and morbidity: Implications for an ageing population. Journal of health economics. 2018 Jan 1;57:60-74.
- 13. Abdi S, Spann A, Borilovic J, de Witte L, Hawley M. Understanding the care and support needs of older people: a scoping review and categorisation using the WHO international classification of functioning, disability and health framework (ICF). BMC geriatrics. 2019 Dec;19(1):1-5.
- 14. Barczyk D, Kredler M. Long-term care across europe and the us: The role of informal and formal care. Forthcoming in Fiscal Studies. Barczyk Daniel Kredler Matthias. 2018.
- 15. Birtha, M., Rodrigues, R., Zólyomi, E., Sandu, V., & Schulmann, KFrom disability rights towards a rights-based approach to long-term care in Europe. Vienna. European Centre for Social Welfare Policy and Research.2019.
- 16. European Commission, Section: Publication and documents. Study on exploring the incidence and costs of informal long-term care in the EU. Brussels, DG Employment, Social Affairs & Inclusion.2021. (https://ec.europa.eu/social/main.jsp? catId=738&langId=en&pubId=8106&furtherPubs=yes)
- 17. Gori C. Changing long-term care provision at the local level in times of austerity—a qualitative study. Ageing & Society. 2019 Sep;39(9):2059-84.
- 18. WHO Framework for countries to achieve an integrated continuum of long-term care. Geneva.2021. (https://www.who.int/publications/i/item/9789240038844).
- 19. European Commission. Long-term care report: trends, challenges and opportunities in an ageing society. 2021. Volume I. Brussels. EC Directorate-General for Employment, Social Affairs and Inclusion. Publications Office (https://data.europa.eu/doi/10.2767/677726).
- 20. Mosca I, Van Der Wees PJ, Mot ES, Wammes JJ, Jeurissen PP. Sustainability of long-term care: puzzling tasks ahead for policy-makers. International Journal of Health Policy and Management. 2017 Apr;6(4):195..
- 21. Roy J, Tscharket P, Waisman H, Abdul Halim S, Antwi-Agyei P, Dasgupta P, Hayward B, Kanninen M, Liverman D, Okereke C, Pinho PF. Sustainable development, poverty eradication and reducing inequalities.
- 22. European Commission. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on the European Care Strategy.2022. Brussels (https://ec.europa.eu/info/law/better-regulation/have-yoursay/initiatives/13298-European-care-strategy\_en).
- 23. Phillips D, Duffy C, Fahy M, Dowling-Hetherington L, Paul G, Moloney B, Fealy G, Kroll T, Lafferty A. Beyond the COVID-19 pandemic for working carers across the European Union: work, policy and

- gender considerations. International Journal of Care and Caring. 2022 Feb 1;6(1-2):289-98.
- 24. Lera, J.; Pascual-Sáez, M.; Cantarero-Prieto, D. Socioeconomic inequality in the use of long-term care among European older adults: An empirical approach using the share survey. *Int. J. Environ. Res. Public Health.* 2021, *18*, 1–14. DOI: 10.3390/ijerph18010020.
- 25. Mitra S, Palmer M, Kim H, Mont D, Groce N. Extra costs of living with a disability: A review and agenda for research. Disabil Health J. 2017 Oct;10(4):475-484. doi: 10.1016/j.dhjo.2017.04.007. Epub 2017 Apr 24. PMID: 28501322
- 26. Loibl, C. Living in poverty: Understanding the financial behaviour of vulnerable groups. In *Economic Psychology*, 1st ed., Ranyard R., Ed.; Wiley J. and Sons Ltd: Chichester, West Sussex, UK; The British Psychological Society (BPS): London (Greater London), UK, 2017; pp. 421–434. DOI: 10.1002/9781118926352.
- 27. Guimarães, R. M.; Andrade, F. C. D. Healthy life-expectancy and multimorbidity among older adults: Do inequality and poverty matter? *Arch. Gerontol. Geriatr.* 2020, *90*, 104157. DOI: 10.1016/j.archger.2020.104157.
- 28. Woo, J.; Yu, R.; Cheung, K.; Lai, E. T. C. How Much Money Is Enough? Poverty and Health in Older People. *J Nutr Heal. Aging* 2020, *24*, 1111–1115. DOI: 10.1007/s12603-020-1444-y.
- 29. Hajek, A.; König, H. H. Does the beginning and the end of income poverty affect psychosocial factors among middle-aged and older adults? Findings based on nationally representative longitudinal data. *Aging Ment. Heal.* 2021, *25*, 906–912, DOI: 10.1080/13607863.2020.1725740.
- 30. Chen, L.; Cao, Q. Poverty increases the risk of incident cognitive impairment among older adults: a longitudinal study in China. *Aging Ment. Heal.* 2020, *24*, 1822–1827. DOI: 10.1080/13607863.2019.1663491.
- 31. Salido MF, Moreno-Castro C, Belletti F, Yghemonos S, Ferrer JG, Casanova G. Innovating European Long-Term Care Policies through the Socio-Economic Support of Families: A Lesson from Practices. Sustainability. 2022 Mar 30;14(7):4097.
- 32. Family International Monitor. Family and Relational Poverty 2020 Report, 1<sup>st</sup> edition Belletti, F.; Casanova, G., Eds.; UCAM | Servicio de Publicaciones: Murcia, 2020. ISBN: 978-84-18579-79.
- 33. Martarelli, R., Casanova, G., & Lamura, G. The impact of long-term care needs on the socio-economic deprivation of older people and their families: A scoping review protocol. *PloS one*.2022. *17*(8), e0273814.
- 34. Ghibelli P, Barbieri D, Fernandez JL, Knapp M. The role of public and private actors in delivering and resourcing long-term care services. Social Protection Innovative Investment in Long-Term Care (SPRINT) working paper D. 2017;2.
- 35. Costa-Font, J., Courbage, C., & Zweifel, P. Policy dilemmas in financing long-term care in Europe. *Global Policy.* 2017. *8*, 38-45.
- 36. Albertini, M., & Pavolini, E. Unequal inequalities: The stratification of the use of formal care among older Europeans. *The Journals of Gerontology: Series B.* 2017. *72*(3), 510-521.

- 37. Quashie, N. T., Wagner, M., Verbakel, E., & Deindl, C. Socioeconomic differences in informal caregiving in Europe. *European Journal of Ageing*.2021. 1-12.
- 38. Tur-Sinai, A.; Casanova, G.; Lamura, G. Changes in the Provision of Family Care to Frail Older People in Familistic Welfare States: Lessons from Israel and Italy. J. Aging Health 2019, 32, 972–986.
- 39. Erikson EH. Childhood and society. WW Norton & Company; 1993 Sep 17.
- 40. Braun, V.; Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol., 3, 77–101, doi:10.1191/1478088706qp063oa.Cantril H., 1965. The Patterns of Human Concerns. New Brunswick: Rutgers University Press. 2015-06-25.
- 41. Guest, G., Namey, E. E., & Mitchell, M. L.. Collecting qualitative data: A field manual for applied research. 2012. Sage.
- 42. Wilkinson LR, Ferraro KF, Mustillo SA. Wealth in Middle and Later Life: Examining the Life Course Timing of Women's Health Limitations. Gerontologist. 2019; 59(5):902-911. DOI: 10.1093/geront/gny048.
- 43. Murayama H, Liang J, Shaw BA, Botoseneanu A, Kobayashi E, Fukaya T, et al. Socioeconomic Differences in Trajectories of Functional Capacity Among Older Japanese: A 25-Year Longitudinal Study. J. Am. Med. Dir. Assoc. 2020; 21(6):734-739. DOI: 10.1016/j.jamda.2020.02.012.
- 44. Teerawichitchainan B, Knodel J. Long-Term Care Needs in the Context of Poverty and Population Aging: the Case of Older Persons in Myanmar. J. Cross. Cult. Gerontol. 2018; 33(2):143-162. DOI: 10.1007/s10823-017-9336-2. ISBN/ISSN: 01693816.
- 45. Guerchet MM, Guerra M, Huang Y, Lloyd-Sherlock P, Sosa AL, Uwakwe R, et al. A cohort study of the effects of older adult care dependence upon household economic functioning, in Peru, Mexico and China. PloS ONE. 2018; 13(4):e0195567. DOI: 10.1371/journal.pone.0195567.
- 46. Salari P, Di Giorgio L, Ilinca S, Chuma J. The catastrophic and impoverishing effects of out-of-pocket healthcare payments in Kenya, 2018. BMJ Glob Health. 2019; 4(6):e001809. DOI: 10.1136/bmjgh-2019-001809.
- 47. Zhao Y, Oldenburg B, Mahal A, Lin Y, Tang S, Liu X. Trends and socio-economic disparities in catastrophic health expenditure and health impoverishment in China: 2010 to 2016. Trop Med Int Heal. 2020; 25(2):236-247. DOI:10.1111/tmi.13344.
- 48. Zhou J, Yang L. Who is taking care of the Chinese functionally impaired older people? The characteristics of family caregivers from China Health and Retirement Longitudinal Study. Australas J Ageing. 2021; 40(2):e143-e154. DOI: 10.1111/ajag.12859.
- 49. Butrica BA, Karamcheva NS. The Impact of Informal Caregiving on Older Adults' Labor Supply and Economic Resources. National Tax Journal Proceedings. Annual Conference on Taxation and Minutes of the Annual Meeting of the National Tax Association. 2018; 111:1-27. https://www.jstor.org/stable/26939416.
- 50. Messer M. Poor, old and in need of care: A qualitative study about the consequences for home care and participation. Ger. Med. Sci. 2019; 17:Doc08 (20190809). DOI: 10.3205/000274. ISSN: 1612-3174. urn:nbn:de:0183-0002740.

- 51. Gabani J, Guinness L. Households forgoing healthcare as a measure of financial risk protection: An application to Liberia. Int. J. Equity Health. 2019; 18(1):193. DOI: 10.1186/s12939-019-1095-y. PMID: 31823823.
- 52. Carrera F, Pavolini E, Ranci C, Sabbatini A. Long-term care systems in comparative perspective: Care needs, informal and formal coverage, and social impacts in European countries. InReforms in long-term care policies in Europe 2013 (pp. 23-52). Springer, New York, NY.
- 53. Noguchi T, Nakagawa T, Komatsu A, Ishihara M, Shindo Y, Otani T, Saito T. Social functions and adverse outcome onset in older adults with mild long-term care needs: A two-year longitudinal study. Archives of Gerontology and Geriatrics. 2022 May 1;100:104631.
- 54. Katreniakova Z, Levyova M, Giertl M, Nagyova I. Participatory approach in developing the long-term care strategy in Slovakia. European Journal of Public Health. 2019 Nov 1;29(Supplement\_4):ckz186-226.
- 55. Spicker, P. (2007). Definitions of poverty: twelve clusters of meaning. *Poverty: An international glossary*, 1(84277-84824), 229.
- 56. Rawal N. Social inclusion and exclusion: A review. Dhaulagiri Journal of Sociology and Anthropology. 2008;2:161-80
- 57. Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. . Shifting our conceptualization of social inclusion. *Stigma research and action*. 2012. *2*(2), 75-84..
- 58. Verbakel E, Metzelthin SF, Kempen GI. Caregiving to older adults: Determinants of informal caregivers' subjective well-being and formal and informal support as alleviating conditions. The Journals of Gerontology: Series B. 2018 Aug 14;73(6):1099-111.
- 59. Wagner M, Brandt M. Long-term care provision and the well-being of spousal caregivers: An analysis of 138 European regions. The Journals of Gerontology: Series B. 2018 Apr 16;73(4):e24-34
- 60. Gagliardi C, Piccinini F, Lamura G, Casanova G, Fabbietti P, Socci M. The Burden of Caring for Dependent Older People and the Resultant Risk of Depression in Family Primary Caregivers in Italy. Sustainability. 2022 Mar 13;14(6):3375.
- 61. Hussein S, Ismail M. Ageing and elderly care in the Arab region: policy challenges and opportunities. Ageing International. 2017 Sep;42(3):274-89.

### **Figures**

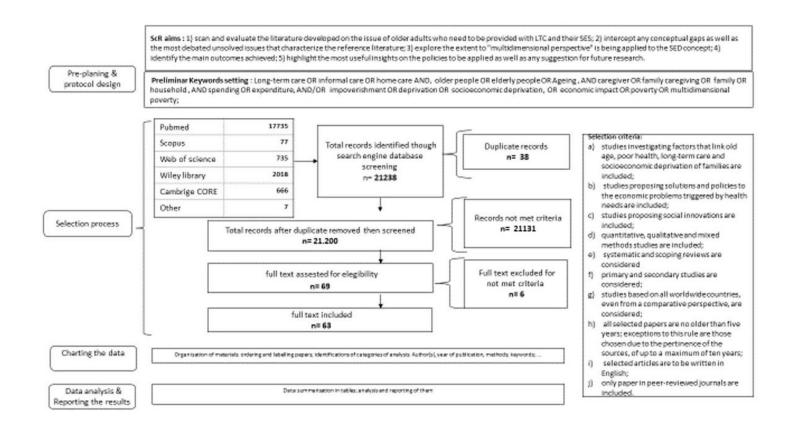
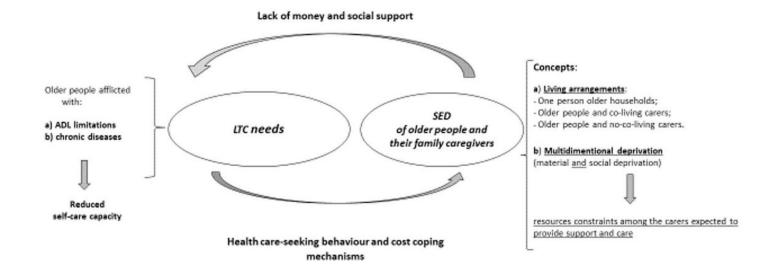


Figure 1
Flowchart of scoping review

Figure 2



Conceptual framework of the relationship between LTC needs and socioeconomic deprivation (SED) risk

# **Supplementary Files**

This is a list of supplementary files associated with this preprint. Click to download.

• annex1.doc