# Gender Inequalities of Health and Quality of Life in Informal Caregivers in Spain: Protocol for the Longitudinal and Multicenter CUIDAR-SE Study

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# Table of Contents

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## Abstract

**Background:** The aging population and increased disability prevalence in Spain have heightened the demand for long-term care. Informal caregiving, primarily performed by women, plays a crucial role in this scenario. This protocol outlines the CUIDAR-SE study, focusing on the gender-specific impact of informal caregiving on health and quality of life among caregivers in Andalusia and the Basque Country from 2013 to 2024.

**Objective:** Analyze the gender differences in health and quality of life indicators of informal caregivers residing in two Spanish autonomous communities (Granada, Andalusia and Gipuzkoa, Basque Country) and its evolution over time, in relation with the characteristics of caregivers, the caregiving situation, and support received.

**Methods:** The CUIDAR-SE study employs a longitudinal, multicenter design across three phases, tracking health and quality of life indicators among informal caregivers. Utilizing a questionnaire adapted to the Spanish context that employs validated scales and multilevel analysis, the research captures changes in caregivers' experiences amid societal crises, notably the 2008 economic crisis and the COVID-19 pandemic. A multistage randomized cluster sampling technique is used to minimize study design effects.

**Results:** Funding for the CUIDAR-SE study was in three phases starting in January 2013, 2017, and 2021, spanning a 10-year period. Data collection commenced in 2013 and continued annually, except for 2016 and 2020 due to financial and pandemic-related challenges. As of March 2024, 1,294 participants have been enrolled, with data collection ongoing for 2023. Initial data analysis focused on gender disparities in caregiver health, quality of life, burden, perceived needs, and received support, with results from phase I published. Currently, analysis is ongoing for phases II and III, as well as longitudinal analysis across all phases.

**Conclusions:** This protocol aims to provide comprehensive insights into caregiving dynamics and caregivers' experiences over time, as well as understand the role of caregiving on gender inequality in health, considering regional variations. Despite limitations in participant recruitment, focusing on registered caregivers, the study offers a detailed exploration of health impacts of caregiving in Spain. The incorporation of gender perspective and the examination of diverse contextual factors enrich the study's depth, contributing significantly to the discourse on caregiving health complexities in Spain.

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## Title Page

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## Keywords

Caregivers; Gender Equity; Sex Differences; Health Status; Quality of Life; Longitudinal Studies; Multicenter Studies

## Introduction

## Caregiving in the international and Spanish context

In recent decades, Spain has witnessed significant demographic changes, marked by an aging population and a notable prevalence of disability among the elderly [1]. With the highest percentage of older adults in the Organisation for Economic Co-operation and Development (OECD), at 5% over the age of 80, Spain's aging population is expected to double by 2050, leading to a six-fold increase in public spending on long-term care (LTC) [2]. In addition, Spain is home to 4,380,000 people with disabilities as of 2020 where over two million receive personal or supervised care [3].

In the context of this study, informal care is defined as care activities carried out by people in the dependent person's immediate environment (relatives, friends, or neighbors), in a non-professional manner and who do not receive remuneration for the work they do (although they may sometimes benefit from financial benefits). Informal care is a pillar of LTC systems among OECD countries [4]. It is estimated that across 23 OECD countries, around 14% of people over 50 provide informal care on a daily or weekly basis [4]. In the European Union (EU), it is estimated that between 12-18% of the adult population aged 18-75 provide informal care on a daily or weekly basis [4]. Informal carers in Spain formed 12.4% of working age people aged 18-64 [5]. Spain's LTC landscape encompasses family-centric caregiving, often supplemented by domestic service employment, particularly among immigrant women [6]. Regional variations in this trend stem from differing government priorities, provision levels, labor market dynamics, and caregiving cultures.

## Gender differences in informal caregiving and its impact on health and quality of life

The nature of informal caregiving includes its lack of visibility and social recognition. This informal caregiving is tied to personal relationships, domestic in nature, and predominantly carried out by women, which leads to being undervalued socially and economically [7]. Most of the informal care across 25 OECD countries are performed by women, where women represent 61% of daily carers [4]. The share of women carers being higher in South European OECD countries, with women being 76% of daily informal carers in Spain [4]. Gender roles are key, with women in Spain mainly taking on caregiving responsibilities, in addition, handling domestic tasks and sharing close kinship ties with those they care for [8-10].

Gender disparities extend to the type and amount of care provided. Women caregivers are more likely to provide personal care, companionship, and monitoring, often in intensive ways, while juggling family and work obligations, in comparison to men [11]. Despite its societal importance, caregiving can negatively impact caregivers' physical and mental health due to chronic stress from the physical and emotional burden [11-14]. Factors like the cared-for person's disability type and behavioral issues, especially dementia, alongside the care type and intensity, contribute to caregiver stress and health issues [11-19]. These effects on health can manifest as poor physical health, mental health challenges, unhealthy habits, and even premature death [11-19]. Variables like gender, age, socioeconomic status, and social support play a role in moderating these effects [11]. However, population-based studies show that almost one-third of caregivers do not experience negative impacts, particularly in the early caregiving stages [20].

Caregiving also affects other quality of life dimensions. It often reduces employment opportunities, leads to fewer work hours, and increases temporary work, affecting women more than men, potentially increasing poverty risk [9, 21]. Survey data in Spain highlight a higher prevalence of health, professional, economic, and personal problems due to the higher burden of caring [22]. The unequal burden on women's daily lives leads to higher stress, overload, and risk factors for their health [23-26]. Various studies confirm this pattern, indicating more psychiatric morbidity, depression, and poorer health perception among women caregivers [22-26]. However, while existing research underscores these trends, there's a need for further exploration through quantitative and qualitative methods [27].

## Need for follow-up and longitudinal studies

While existing evidence highlights caregiving's impact on health and quality of life, many studies suffer from limitations like small sample sizes and cross-sectional designs, often lacking control over confounding factors, such as education or socioeconomic status. To comprehensively address these issues, longitudinal studies are imperative. These studies not only counter cross-sectional biases, such as the "healthy caregiver" bias, but also track caregivers' health and quality of life changes over the caregiving journey [28]. Additionally, a deeper understanding of varied caregiving experiences and their effects on caregivers' health is crucial [19]. Longitudinal research on these aspects remains limited in the Spanish context, and the factors influencing the impact of caregiving over time still require in-depth exploration.

## The importance of crisis contextualization

In recent decades, women's engagement in the workforce and formal care services for dependents have surged, yet the ongoing crisis is bucking this trend by shifting caregiving responsibilities back to households [29]. The reduction in formal care services may intensify informal caregiving, potentially overburdening caregivers. With escalating unemployment, particularly affecting women, the adverse impacts of caregiving on employment and finances will worsen, especially in a landscape of diminished public support services. This scenario is expected to detrimentally affect caregivers' health and well-being, especially among women [30]. Vulnerable groups like the elderly, minors, dependents, and women will bear amplified health-related repercussions during crises [31]. Effective support networks, both formal and informal, can mitigate these effects, highlighting the importance of evaluating how informal networks, mainly family-based, impact women's health and quality of life as primary caregivers [32]. The study at hand was initiated in 2013, amidst the repercussions felt in the following years after the 2008 economic crisis which was then further compounded by the COVID-19 pandemic [33]. These two crises set the contextual background for the study, and therefore it is important to acknowledge these significant events' relevance in the realm of caregiving, and subsequently, in the study.

## The CUIDAR-SE study

CUIDAR-SE is the acronym derived from the terms care and follow-up (*cuidar* and *seguimiento* in Spanish) and is the abbreviated name of the project titled "Longitudinal study of women and men caregiver's health and quality of life in Andalusia and the Basque Country". This study was designed to analyze the effects of caregiving on different aspects of life, including health, in a sample of women and men providing informal care in Spain.

Its longitudinal analysis of quantitative data, with data collected three times every 12 months, in each of the three phases, allows the study to capture caregivers' experiences during both crises and their ongoing repercussions.

The CUIDAR-SE study also incorporates a gender approach in all its aspects, meaning not only in analysis with sex-disaggregated data, but in its design. The study was designed to conduct comparisons between women and men. This gender perspective has not been found as a focus in previous studies, and therefore illustrates the study's importance.
Furthermore, this study is multicentric in nature. There are notable differences between the two contexts at hand. Andalusia (south of Spain) has been characterized in the last decades by being a "familistic regime with subsidized public support", with supports primarily focused on economic

benefits. Whereas in the Basque Country (north of Spain), following an “optional familist” model, other social protection services have been further developed to support care and there is a high participation in the domestic market [6, 7]. In 2023, the public dependency system, in both regions, has granted more services to support care than economic benefits [34].

As the economic crisis impacts all regions, Andalusia appears to experience more pronounced effects than the Basque Country, potentially accentuating these disparities further. Consequently, this investigation is apt for addressing these dynamics in both contexts. The multidimensional approach facilitated by a multicenter design enriches the study's uniqueness and significance.

## Objective

To analyze the gender differences in health and quality of life indicators of informal caregivers residing in two Spanish autonomous communities (Granada, Andalusia and Gipuzkoa, Basque Country) and its evolution over time, in relation with the characteristics of caregivers, the caregiving situation, and the support received.

The CUIDAR-SE study is divided into three phases, currently in the CUIDAR-SE III phase. Each phase has its respective specific objectives demonstrated below.

## Specific Objectives

### *Phase I*

1. Describe the characteristics of the care situation and the indicators of health and quality of life at different times in the care process.
2. Analyze the changes (evolution) produced in the health and quality of life of informal caregivers over time.
3. Study the differences in the health and quality of life of women and men informal caregivers and their associated factors in relation to the characteristics of the informal caregivers.
4. Compare the health and quality of life of women and men caregivers, as well as its evolution, in two different national contexts: Granada and Gipuzkoa.

### *Phase II*

1. Study the evolution of health-related quality of life (HRQoL) and the burden of caregivers, based on the informal and formal support (financial benefits and services) received, analyzing the differences between women and men caregivers.
2. Estimate the economic value of informal care time and its evolution during the care process, as well as the differences in this value depending on the sex of the caregivers, the support received, and the characteristics of the care provided (tasks and intensity).
3. Compare the two provinces studied, the evolution of HRQoL and the burden of caregivers based on the formal and informal support received, and the economic value of care.

### *Phase III*

1. Analyze the evolution of perceived health, morbidity in chronic pathologies, and the mental health of women and men caregivers, based on the characteristics of the care provided and the support they receive.
2. Know the differences between women and men informal caregivers in the use of health services for their own health needs, their medication use, and the evolution at different moments of the care process.
3. Analyze the evolution of the problems derived from care, in women and men caregivers, related to aspects of health, work and professional, economic, leisure, free time and family life, depending on the characteristics of the care they provide and the support they receive.
4. Study the support needs experienced by women and men caregivers at different times in the care

process, depending on the characteristics of the care they provide and the formal and informal support they receive.

5. Compare between Granada and Gipuzkoa the health indicators studied, use of health services, medication use, and problems and support needs exposed in the previous objectives.

**Methods**

## Design

This study is a multicenter (Granada, Andalusia and Gipuzkoa, Basque Country) longitudinal repeated measures study where the caregiver population is followed up at three moments in time known as *waves*, each 12 months in duration, for each *phase* (I, II, III) of the CUIDAR-SE study that initiated in 2013 and is ongoing.

## Participants

Participants are composed of all persons aged 18 years or older living in family dwellings in the provinces of Granada and Gipuzkoa who provide unpaid care for a person in a situation of dependency and are co-inhabiting with the individual or not, among other criteria (Table 1).

Table 1. Inclusion and exclusion criteria for participants in the CUIDAR-SE study.

| **Inclusion Criteria** | **Exclusion Criteria** |
|---|---|
| | |
| Registered in the records of caregivers available in the health districts of Granada (Primary Care Health District) or in the Gipuzkoa Provincial Council (Social Services Registry) at the time of the beginning of the phase. | Presents characteristics that prevent answering the questionnaire in its language and/or a change of address is foreseen that prevents follow-up. |

Agreements with the institutions were made to ensure the availability of data on caregivers. From the registries listed (Table 1), subjects for each phase of the CUIDAR-SE study have been selected using multistage randomized cluster sampling using municipalities as primary units, census sectors as secondary units, and caregivers as final units. The initial sample size calculations were 1,180 people, however due to resource limitations, the sample size was reduced, remaining an equal sample size in terms of sex and province (Table 2).

For each subsequent phase, participants that expressed their willingness to collaborate in future phases were retained. The ongoing follow-up involves the same initial cohort of participants, with the exception of additional individuals recruited during the inception of CUIDAR-SE II to address attrition observed at the conclusion of CUIDAR-SE I.

Table 2. Sample sizes and sex distribution of the phases of the CUIDAR-SE study (2013 – 2024).

| | **Wave** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | |
| **Phase** | **Men** | **Women** | **Total** | **Men** | **Women** | **Total** | **Men** | **Women** | **Total** |
| **I** | *2013* | | | *2014* | | | *2015* | | |
| | 265 | 345 | 610 | 208 | 259 | 467 | 155 | 199 | 354 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **II** | *2017* | | | *2018* | | | *2019* | | |
| | 361 | 478 | 839 | 259 | 351 | 610 | 184 | 254 | 438 |
| **III** | *2021* | | | *2022* | | | *2023 Ongoing* | | |
| | 96 | 165 | 261 | 57 | 98 | 155 | 51 | 99 | 150 |

## Participant Recruitment and Follow-Up

The persons selected are initially contacted by means of a letter by those responsible for the registries, by which they will ask for permission from the persons contacted to participate in the study. Once permission is obtained, a member of the research team contacts the participant to describe the scope and objectives of the study, resolve their doubts, guarantee their participation, and request their consent. At the time of data collection, signed informed consent forms are collected. For those who do not consent, basic information is obtained to characterize their refusal to take part in the study.

Participant follow-up occurs at baseline, at 12 months and at 24 months, for each phase of the CUIDAR-SE study. No new subjects will be included after the start of each wave of the study. Subjects may leave the follow-up process due to the following cases: 1) end of the follow-up period, 2) death of the caregiver, 3) definitive cessation of the caregiving situation (death or recovery of the cared-for person or cessation of the caregiver's role due to other circumstances), 4) relocation of residence outside the provinces of the study, and 5) any other circumstance that makes it impossible to locate the caregiver. The information collected on participants who have left the follow-up will be incorporated into the analysis if they have participated in at least two moments of measurement.

## Survey Questionnaire Instrument

The questionnaire developed for the study "Health care in the domestic setting: care and caregivers in Andalusia" by García Calvente, 1999, proved useful to identify the health impact of caregiving tasks and its application in this project is considered very appropriate [10]. This questionnaire was updated and adapted to the objectives of the CUIDAR-SE study, considering, among other things such as context, the perception of the new aids instituted under the development of the Spanish Dependency Law. In addition, the scales EUROQOL, the DUKE-UNC of 11 categories, the ZARIT scale of burden, and the GOLDBERG of 12 categories were selected for inclusion in the study questionnaire due to their widespread usage in similar research endeavours and validation for use within our study context [35-38].

The finalized questionnaire was piloted during CUIDAR-SE phase I in a sample of 20 participants belonging to both provinces to guarantee its comprehension and adequacy. A summary of the structure of the questionnaire can be found in Table 3. The questionnaire was also later complemented with questions found in the 2008 EDAD; a survey on disability, personal autonomy and situations of dependency conducted by the National Statistics Institute of Spain [40].

Table 3. Structure summary of the finalized questionnaire of the CUIDAR-SE study.

| **Block** | **Questionnaire Structure** | |
|---|---|---|
| | | |
| **I** | Household Structure and People in Care | Section A. Household Structure<br>Section B. General characteristics of the care recipient |

| | | |
|---|---|---|
| **II** | Characteristics and Intensity of Care | Section C. Type of Care (Care Tasks)<br>Section D. Specific tasks related to the use of Health Services for the Care Recipient<br>Section E. Frequency, Intensity, and Duration of Care<br>Section F. Other Domestic and Care Workloads of the Caregiver<br>Section G. Burden |
| **III** | Support, Needs and Demands | Section H. Social Support<br>Section I. Informal care support<br>Section J. Formal care support<br>Section K. Needs and demands |
| **IV** | General and Mental Health Status | Section L. General State of Health<br>Section M. Morbidity, Mental Health, and Medication Use<br>Section N. Use of Health Services<br>Section O. Preventive Practices<br>Section P. Healthy Habits<br>Section Q. Satisfaction with Life |
| **V** | Consequences of Care on Health and Quality of Life | Section R. Impairment of Health<br>Section S. Professional and Labor Aspects<br>Section T. Economic Aspects<br>Section U. Aspects of Leisure, Free time, and Family life<br>Section V. Perception of Positive Effects of Care |
| **VI** | Contingent Economic Evaluation of Care | |
| **VII** | Sociodemographic | |

## Data Collection

A survey technique is used by conducting a personal interview with the caregiver, using the questionnaire. The questionnaire is applied by means of a personal interview at the caregiver's home, or, when this is not feasible, in-person at a care center (health or social services center, depending on the province). The interview is conducted by specially trained interviewers from a company specializing in nationwide surveying.

The research team provided training workshops to interviewers at the Andalusian School of Public Health, oriented towards understanding the structure and layout of the questionnaire and to provide context for the questions asked in the questionnaire. There is continual interaction between the research team and the interviewers during fieldwork, establishing a quality control protocol.

## COVID-19 Implications

Collection was not completed in 2020 due to the COVID-19 pandemic, and therefore the first wave of phase CUIDAR-SE III was performed subsequently in 2021, 2022, and ongoing. In-person interviews were replaced with telephone interviews using computer-assisted telephone interviewing in 2021 and onwards. Certain variables were eliminated to reduce the length of the telephone questionnaire, and questions regarding COVID-19 were added to explore different dimensions of the COVID-19 pandemic and their impact on self-perceived caregiver health and other aspects of life.

This new questionnaire was piloted among 60 members of the current cohort to ensure the comprehensibility of each item and appropriate interview duration.

## Data analysis

The sampling units of the multistage randomized cluster sampling previously mentioned are stratified to reduce study design effects. Municipalities are stratified by size where allocation is proportional to the population of each corresponding municipality, and caregivers are stratified by sex. Data cleaning and aggregation of variables are conducted in accordance with the study objectives.

Every wave undergoes two kinds of analyses: 1) a cross-sectional analysis which includes descriptive and associative analysis between dependent and independent variables (Table 4 and 5), using bivariate and multivariate logistic regression, and a 2) longitudinal analysis using multilevel analysis. Analysis with a gender perspective is also conducted. All analyses are performed in SPSS.

Table 4. Three categories of dependent variables: 1) health and health related quality of life, 2) other dimensions of quality of life, 3) economic value of informal care.

| **Category** | **Dependent Variables** | **Description** |
|---|---|---|
| | | |
| Variables related to health and health related quality of life | Health related quality of life | EUROQOL: EQ-5D-DL is a self-assessed questionnaire comprised of a 5-component scale including mobility, self-care, usual activities, pain/discomfort and anxiety/depression [35]. |
| | Perceived health | Likert: Bad, Fair, Good, Very Good, Excellent |
| | Deterioration of health because of care | Yes/No |
| | Suffers from a chronic disease | Yes/No, Number and Type of chronic diseases suffered |
| | Mental health | GHQ 12 scale [38] |
| | Lifestyles | Presenting unhealthy behaviors in at least one of the following factors: alcohol consumption, smoking, hours of sleep, physical activity, diet. |
| | Burden | Zarit Caregiver Burden Scale validated for use in the Spanish population, consists of 22 questions 5 possible answers scored from 1 to 5, which establishes 12 different degrees of overload depending on the score obtained: without overload, light overload, and intense overload [37]. |
| | Use of health care services | Yes/No, Number and Type of healthcare service used |
| | Medication Use | Yes/No, Number and Type of medications, |

| | | |
|---|---|---|
| | | Prescribed or not |
| Variables related to other dimensions of quality of life:<br>Problems derived from care, in work, economic, leisure, and family life | | Yes/No |
| Variables related to other dimensions of quality of life:<br>Time to care for self, derived from care | | Yes/No |
| Variable related to economic value of informal care | | Value according to the willingness to pay for care and value according to the willingness to be compensated for care. |

Table 5. Three categories of independent variables: 1) caregiver characteristics, 2) caregiving situation, and 3) support received.

| **Category** | **Independent Variables** | **Description** |
|---|---|---|
| | | |
| Caregiver characteristics | Sex | Male/Female |
| | Age | Continuous |
| | Province of Residence | Granada/Gipuzkoa |
| | Place of Residence | Rural/Urban |
| | Education Level | Without studies: Lower than primary, Primary: EGB/elementary, High school: FP/BIP/Higher high school, Superior: University or others. |
| | Employment Situation | With paid work or without paid work |
| | Social Class | Five categories according to the occupation and according to the National Classification of Occupations of 1994 [41]. |
| | Health Status prior to caregiving perceived | Good (Excellent, Very Good, Good) and Deficient (Regular, Bad) |
| | Relationship between care recipient and the caregiver | Spouse/Partner, Child, Father/Mother, Other |
| | Lives with the care recipient | Yes/No |
| Caregiving situation: | Sex | Male/Female |
| | Age | Continuous |

| | | |
|---|---|---|
| Characteristics of the care recipient | Degree of dependency | Moderate Dependency, Severe Dependency, Great Dependency |
| | Cognitive impairment or behavioural problems | Yes/No |
| Caregiving situation: Caregiving characteristics | Type of tasks | Personal care, physical mobility, domestic or accompanying tasks within the home and in use of health services, care related to sickness, tasks outside the home. |
| | Intensity | Daily hours of care |
| | Frequency | Weekly days of care |
| | Duration of care | Years of caring |
| | Number of dependent people cared for | Number |
| Support received | Informal support | Unpaid support from family or social environment: Yes/No |
| | Formal support | Formal support received in the last 12 months, financial benefit (FB) and/or home help (HH): without FB or HH, with FB without HH, without FB and with HH, with FB and HH. |
| | Perceived social support | DUKE-UNC Social Support Index with 11 items validated for use in the Spanish population: low support if score ≤ 32, high social support if score >32 [36]. |

Bivariate analysis is used to determine the prevalence of each dependent variable in relation to the independent ones. The respective associations are analyzed by logistic regression analysis with adjustment for age. Multivariate logistic regression analysis with calculation of odds ratios (ORs) is performed to determine the likelihood of poor health (or another situation of quality of life) according to caregiving characteristics.

A combined model including men and women caregivers with adjustment for all other variables was built to analyze the association between sex and health/quality of life. Forward stepwise selection is used to add variables shown to be significant in the bivariate analysis and other relevant variables from the theoretical model. The same variables are used to build separate models for men and women caregivers to explore factors associated with the studied dependent variable. The magnitude of association in the three models is estimated using ORs with a confidence interval of 95%. Variance inflation factor analysis rules out multicollinearity between the variables.
To explore both how individual and group level factors influence trends observed over time, the combination of a longitudinal analysis using multilevel methods is utilized. The effect of the independent variables on each of the dependent variables is done by means of generalized linear mixed models of a binomial-response when the dependent variable is qualitative, or Gaussian when the dependent variable quantitative. This methodological approach allows for both the analysis of temporal variability in the measurements and heterogeneity among individuals, incorporating

random effects into the model coefficients.

A contingent economic evaluation is performed part of phase II, of which the methodology can be found in other papers from our research group [39].

## Ethical Considerations

The CUIDAR-SE study is conducted according to the guidelines outlined by the Declaration of Helsinki and the law for the protection of patients' rights (Law 15/2002). Clinical data is not collected as part of this study. Data collection procedures ensure confidentiality, with participant identifiers encrypted using numerical codes managed solely by the research team. These measures are implemented in strict accordance with the data protection laws and regulations in force (Organic Law 3/2018 of December 5, Protection of Personal Data and guarantee of digital rights). Ethical approval was granted by the Research Ethics Committee of Granada (Andalusia) and the Research Ethics Committee of Euskadi (Basque Country). Participants provide their written informed consent to participate in the study and are assured anonymity and confidentiality. All data exchanges adhere to the most up-to-date EU and national data protection regulations.

### Results

The CUIDAR-SE study received funding for each phase of the study starting for phase I on January of 2013, phase II in January of 2017, and phase III in January of 2021 to fund the ongoing 10-year project. Data collection started in 2013 and has continued every year, excluding 2016 due to financial constraints and 2020 due to the COVID-19 pandemic. Total enrollment for the CUIDAR-SE study as of March 2024 stands at 1,294 participants. Data collection for year 2023 is ongoing. There has been ongoing data analysis, initiated after the first wave of data collection in phase I, which investigates gender disparities in caregiver health, quality of life, burden, perceived needs and services and support received. Results from the first phase have been published [21,39,42-44]. Currently, work is underway on the data collection of phase III, the data analysis of phases II and III, and on the longitudinal analysis of all phases.

### Discussion

## Contributions of the CUIDAR-SE Study

The CUIDAR-SE study is a pivotal research initiative that will delve into the multifaceted world of caregiving in Spain. With a rigorous longitudinal approach that encompasses three waves of data collection at 12-month intervals, for three different phases, the CUIDAR-SE study provides the opportunity to capture the evolving experiences of caregivers. Starting in 2013, against the backdrop of the 2008 economic crisis and later with the global COVID-19 pandemic, this temporal perspective enables a comprehensive understanding of caregiving impacts that appear with time within the context in which it occurs. Another distinctive feature of the CUIDAR-SE study is its commitment to incorporating a gender perspective in its design and analysis. This emphasis extends beyond sex-disaggregation of data, to a holistic integration of gender considerations, setting it apart from previous research endeavors in this domain and in Spain. By facilitating gender-based comparisons, the study allows for differential experiences of women and men caregivers to be captured, adding depth to the understanding of caregiving dynamics. Moreover, the CUIDAR-SE study's multicentre nature with collaboration between research groups with extensive involvement in the field of caregiving, positions it as a pioneering effort. The variation in caregiving contexts between the Andalusia and Basque Country regions allows for a more complex understanding on how different social norms, economic structures, and varying social service support systems influence caregiving.

While other longitudinal studies exist in this field, our study enhances the value of longitudinal design by integrating a gender perspective and fostering multicentre collaboration. This approach provides unique insights into the interplay of major societal events, regional contexts, and gender dynamics, thereby enriching the understanding of caregiving experiences and caregivers' roles more broadly.

## Limitations

The CUIDAR-SE study, although primarily quantitative in nature, recognizes the value of incorporating qualitative methodologies to delve deeper into the impact of crises and social norms on caregiving. Past endeavours by the research team have involved the utilization of qualitative methods within this domain [45]. This experience underscores the team's commitment to continuing this methodological integration in future studies, with the aim of augmenting the findings of the CUIDAR-SE investigation and mitigating this methodological limitation. The prospect of incorporating mixed-method approaches in futures research endeavours holds substantial potential for enriching discourse within this field.

An important constraint inherent in longitudinal studies is that of lower-than-expected recruitment rates. Such limitations can impede the study's capacity for conducting comprehensive analyses and may introduce survival bias, particularly prevalent in studies of extended duration. To address this concern, the CUIDAR-SE study has employed corrective measures, including a comparative examination of baseline characteristics between participants lost to follow-up to those retained within the study cohort. In addition, recruitment efforts during the inception of the CUIDAR-SE II phase aimed to replenish the participant pool with individuals with comparable characteristics to those recruited at the study's outset. We emphasize for future longitudinal studies of a long duration to prioritize not only a substantial initial sample size but also to consider budget allocations initially to accommodate potential recruitment challenges.

Participant recruitment, conducted through registration in the Primary Care Health District and Social Services Registry of Granada and Gipuzkoa, respectively may introduce variances in baseline characteristics. Methodological efforts are undertaken during the analysis phase to ensure the comparability of participants from the different regions, thereby homogenizing the study population. This is achieved by considering factors such as degree of dependency of the person receiving care, the financial support received, and various sociodemographic characteristics of caregivers.

Another limitation of the CUIDAR-SE study is that all participants are solely registered caregivers. However, it is posited that individuals who opt not to register with the corresponding health district or social services registry likely allocate minimal time to caregiving or are of lower caregiving intensity. Thus, the caregiver profile in our study is that of a long-term caregiver providing high-intensity care. Extrapolation of future study results should be to caregivers with a similar profile, who we believe should be the priority target for support interventions.

## Conclusions

The CUIDAR-SE study offers a thorough exploration of caregiving, utilizing a longitudinal design across three waves of data collection. Its focus on gender dynamics and collaboration between regions provides valuable insights into caregiving experiences. While recruitment limitations exist, the study's emphasis on long-term caregivers highlights the need for crucial support interventions. Ultimately, CUIDAR-SE stands as a pioneering effort aimed at addressing the intricate facets of caregiving, not only within Spain, but also in other countries where caregivers' health and quality of life are similarly impacted.

## Declarations

Ethics approval and consent to participate: Not applicable
Consent for publication: Not applicable

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**Data Availability**

The datasets generated belongs to the CUIDAR-SE survey and are owned by the Escuela Andaluza de Salud Pública and governed by this institute’s regulations as they contain potentially sensitive personal information. Those interested in viewing the data can contact María del Mar García Calvente, main researcher of the CUIDAR-SE Study. Escuela Andaluza de Salud Pública. Cuesta del Observatorio, 4, 18011 Granada, Spain. E-mail: mariadelmar.garciacalvente@gmail.com.

**Author’s contributions**

MMGC and MRL conceived and designed the study and planned the strategy for analyzing and interpreting the results. MMGC coordinated the research team and obtained funding. MRL supervised the fieldwork and data quality control. DJM drafted the manuscript and made substantial contributions to its writing. All authors have reviewed successive versions of the manuscript and have approved the final version.

**Conflicts of Interest**

The authors declare that they have no competing interests.

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## Abbreviations

OECD: Organisation for Economic Co-operation and Development
LTC: Long-term care
HRQoL: Health-related quality of life
GHQ-12: Twelve-item general health questionnaire

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# Supplementary Files

# Existing Peer-Review Reports from Funding Agencies (for protocols/proposals only)s

URL: http://asset.jmir.pub/assets/ee34a8538cbd1091e67ed682ccedd7c9.pdf

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