Decision-making on the location of care of the elderly: protocol for a systematic review of qualitative studies

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ABSTRACT

Introduction The elderly must take part in the management of their own health. One of the aspects they should be able to decide on is the place where they want to live. The aim of this review is to synthesise qualitative evidence in order to understand how decisions are made on the location of care of the elderly.

Methods and analysis Systematic review of qualitative studies. Six databases have been consulted: Web of Science, PubMed, Scopus, CINAHL Complete, PsycINFO and Scielo Citation Index (from the beginning to 29 November 2017). The inclusion criteria will be: studies that deal with the decision-making process on the location of care of the elderly (already experienced by the participants), original studies, qualitative or mixed-method studies and studies written in English or Spanish. The obtained results will be exported to the Zotero bibliography manager. The references will be reviewed by title and abstract and, later, the complete texts will be reviewed for their inclusion. A tool created for this study will be used to extract the data. The quality will be assessed with Critical Appraisal Skills Programme Español. The data synthesis will be carried out using the constant comparative method. All this process will be performed independently by two reviewers. Enhancing transparency in reporting the synthesis of qualitative research has been used to draw up this protocol.

Ethics and dissemination This protocol did not require ethical approval, since it is a protocol for a systematic review. The plans to disseminate our results include publishing a research paper in a high-impact journal in our study area. Also, if possible, our results will be presented in scientific conferences. Besides, the obtained results will complement and discuss the doctoral thesis of one of the authors of the review.

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INTRODUCTION

Ageing has turned into an essential political question, due to the fact that both the proportion and the number of elderly people are increasing significantly worldwide.1 The ageing of populations all around the world will considerably increase the quantity of elderly people who are care-dependent.1

However, it is striking that the current healthcare systems and services do not properly suit the elderly’s individual preferences and diverse health needs1,5 which is the case across the world.1

In order to respond to the specific needs of this population, it will be necessary to adapt the healthcare services, placing the elderly in the centre of healthcare,1,3 thus being necessary to include them as active participants in the planning of healthcare1,3 and in managing their own health.1

To this lack of adaptation of healthcare systems and services, it is necessary to add the scarce existing literature about decision-making and ageing.4 This literature usually focuses on the different aspects that somehow hinder the participation of the elderly in their own healthcare.

These aspects are usually problems linked to the ageing process: cognitive5,6 and physical impairment.6,7 The elderly’s unwillingness to participate is also mentioned,5,6,8 with this responsibility thus falling on the family5,8 or on the doctor.6,7

Finally, another aspect presented as problematic for the elderly is the discrimination on the grounds of age in healthcare services.1

One of the aspects where the elderly should have control and the right to decide is the place where they want to live.1,5 Moreover, the ability of making their own decisions regarding the place to live has been considered by the elderly in a recent study as being
very important for them, although, at the same time, this decision is also considered as involving high emotional stress.

All of this justifies and leads to our main objective: to synthesise the existing evidence with qualitative methodology in order to achieve a deep understanding of how decisions are made on the location of care of the elderly. In order to reach this objective, this review has based its research question and subsequent search strategy on a structure of key elements that is specific for qualitative reviews: Population, Phenomena of Interest and Context (PRISMA-P) statement. This protocol has been registered in PROSPERO.

Therefore, our research question would be: how is the location of care of the elderly decided on? In turn, this question will be specified into the following aspects: (1) Who takes part in the decision about the location of care of the elderly? (2) How do the participants experience the decision-making process on the location of care? (3) What are the participants’ motives/reasons to decide on the location of care?

After searching in the Cochrane Library, Joanna Briggs Institute Systematic Review Databases and the International prospective register of systematic reviews (PROSPERO), no systematic reviews or systematic review protocols were found tackling this matter; therefore, it was decided to carry out a systematic review on the decision-making process on the location of care of the elderly. This protocol has been registered in PROSPERO.

METHODS
Design
Systematic review of qualitative studies.

It was decided to only study qualitative studies, due to the nature of the main objective of this research: to achieve a deep understanding of how the decisions on the location of care of the elderly are taken, since qualitative research is the type of research which may more efficiently and appropriately provide the necessary information to be able to answer our research question.

It is important to point out that in order to draw up this protocol, the work by Butler et al., a guide to draw up protocols of systematic qualitative reviews, and the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement have been used as informative support. At the same time, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA) statement (see online supplementary additional file 1) has also been used and completed to prepare this systematic review protocol.

Information sources
The consulted databases have been Web of Science (core collection of Web of Science), MEDLINE (through PubMed), Scopus, CINAHL Complete (through EBSCOhost), PsycINFO (through ProQUEST) and SciELO Citation Index (through Web of Science) (from the beginning to 29 November 2017).

In addition, the references in the papers which will be finally included will also be reviewed.

We expect to finish the review by autumn of 2018.

Search strategy
The search strategy has focused on five key concepts which are made up of different terms. The terms used to refer to each concept were linked using the connective ‘OR’, and then the four main concepts were linked using the connective ‘AND’; lastly, the connective ‘NOT’ was used to link these four concepts to the fifth one. The subject headings were used when necessary, and the terms were adjusted to the different databases used. The different search strategies used in each database are shown in Table 1.

Eligibility criteria
In order to contextualise the framework where this systematic review of qualitative studies will be carried out, it is essential to describe how some concepts of interest are going to be dealt with and understood throughout this review:

The elderly
In this research, the concept of elderly person will include all the people who are 65 or older, both having cognitive/physical impairment or problems or not. This decision was taken because in the literature review done by Smith and Crome about the relocation, it is said that not all studies dealing with it exclude people with more physical and cognitive impairment. In fact, the results of Dickinson’s study pointed out that, except for the elderly suffering from more severe impairment, the elderly with different degrees of memory impairment were able to preserve knowledge about their relocation.

Decision-making process
People tackle the decision-making process from a historical, social, interpersonal and cultural context. That is why, for this review, it has been decided to focus on three aspects that the authors consider crucial for this process: who takes part in the decision, how they go through this decision-making process and the motives and/or reasons to make the decision.

Due to this, no type of specific informer has been specified, in order to be able to respond in a wider manner to the aim of our review, focusing on discovering who the people who take part in the decision are. In this way, it will be possible to analyse not only what type of people/group takes part, but also to study if there is more than one participant, as well as the interrelations which are created throughout this decision-making process.

In addition, this systematic review focuses on the complete decision-making process, not only on the final decision. This is why, throughout the study, the different options chosen for the location of care will not be...
Table 1 Databases and search terms used to identify literature for review

| Database       | Search terms                                                                 | No of articles |
|----------------|-----------------------------------------------------------------------------|---------------|
| PubMed         | (Aging [MeSH] OR Aged [MeSH] OR “Ageing” OR “Older people” OR “Older adults” OR “Elderly” OR “Elders”)) AND (“Decision Making”[Mesh:NoExp] OR Consensus [MeSH Terms] OR Uncertainty [MeSH Terms] OR “Choice Behavior”[Mesh:NoExp] OR Dissent and Disputes [MeSH Terms] OR “Negotiating”[Mesh:NoExp] OR Patient Participation [MeSH Terms] OR “Decision Making” OR “Patient participation” OR “Patient Involvement” OR “Patient Engagement”) AND (“Placement” OR “Location of care” OR “Relocation” OR “Relocating” OR “Transition”) AND (Independent living [MeSH] OR Housing for the elderly [MeSH] OR “Residential Facilities”[Mesh:NoExp] OR Assisted Living Facilities [MeSH Terms] OR Homes for the Aged [MeSH Terms] OR Nursing Homes [MeSH Terms] OR “Institutionalization”[Mesh:NoExp] OR “Independent living” OR “Aging in Place” OR “Institutionalization”) NOT (Intellectual Disability [MeSH] OR Substance-Related Disorders [MeSH] OR “Mental Retardation” OR “Mental Deficiency” OR “Drug Dependence” OR “Drug Addiction” OR “Substance Abuse” OR “Drug Abuse” OR Palliative Care [MeSH] OR Terminal care [MeSH] OR Life support care [MeSH] OR Advance care planning [MeSH] OR “Palliative care” OR “Terminal care” OR “End of life care” OR “Hospice care” OR “Life support care” OR “Advance care planning” OR “Advance directives” OR “Place of death”) | 120 |
| CINAHL Complete| (MH “Aged”) OR (MH “Aged, 80 and Over”) OR (MH “Frail Elderly”) OR (MH “Aging+”) OR “Older people” OR “Older adults” OR “Elderly” OR “Ageing” OR “Elders”) AND (MH “Decision Making”) OR (MH “Consensus”) OR (MH “Decision Making, Clinical”) OR (MH “Decision Making, Ethical”) OR (MH “Decision Making, Family”) OR (MH “Decision Making, Patient”) OR (MH “Dissent and Disputes+”) OR (MH “Consumer Participation”) OR “Patient participation” OR “Patient involvement” OR “Patient engagement” OR “Decision Making”) AND (MH “Community Living”) OR (MH “Assisted Living”) OR (MH “Institutionalization”) OR (MH “Housing for the Elderly”) OR (MH “Residential Facilities”) OR “Independent living” OR “Aging in Place” OR “Institutionalization”) NOT (MH “Intellectual Disability+”) OR (MH “Substance Use Disorders+”) OR “Mental Retardation” OR “Mental Deficiency” OR “Drug Dependence” OR “Drug Addiction” OR “Substance Abuse” OR “Drug Abuse” OR “Terminal Care” OR “Palliative Care” OR “Advanced Care Planning” OR “Advance Directives+”) OR (MH “Advanced Care Planning”) OR “Place of death”) | 79 |
| PsycINFO       | (SU.EXACT(“Aging”) OR “Ageing” OR “Elderly” OR “Elders” OR “Older people” OR “Older adults”) AND (SU.EXACT(“Decision Making”) OR SU.EXACT.EXPLODE(“Choice Behavior”) OR SU.EXACT(“Client Participation”) OR “Patient participation” OR “Patient involvement” OR “Patient engagement” OR “Decision making”) AND (SU.EXACT(“Relocation”) OR “Relocating” OR “Location of care” OR “Placement” OR “Transition” OR “Relocation”) AND (SU.EXACT(“Assisted Living”) OR SU.EXACT(“Retirement Communities”) OR SU.EXACT(“Aging in Place”) OR SU.EXACT(“Institutionalization”) OR SU.EXACT(“Residential Care Institutions”) OR SU.EXACT(“Nursing Homes”) OR “Independent living” OR “Aging in place” OR “Institutionalization”) | 54 |
| Scopus         | (TITLE-ABS-KEY(“Aging” OR “Older people” OR “Older adults” OR “Elderly” OR “Elders”)) OR (INDEXTERMS(“Aged” OR “Aging”)) AND (TITLE-ABS-KEY(“Decision making” OR “Patient participation” OR “Patient Involvement” OR “Patient Engagement”) OR (INDEXTERMS(“Decision making” OR “Consensus” OR “Uncertainty” OR “Dissent and Disputes” OR “Choice Behavior” OR “Negotiating” OR “Patient participation”) AND (TITLE-ABS-KEY(“Relocation” OR “Placement” OR “Location of care” OR “Relocating” OR “Transition”) AND (TITLE-ABS-KEY(“Aging in Place” OR “Institutionalization” OR “Independent living”) OR INDEXTERMS(“Aged” OR “Aging”) OR “Older adults” OR “Elderly” OR “Ageing” OR “Elders”)) | 195 |

Continued
specified, and the election of articles will not be filtered on the basis of that, but it will focus on the experiences of the participants throughout the process, thus being essential to understand the motives and/or reasons behind the decisions. In this way, it will be easier to understand in a more complete manner how this decision on the location of care or moving to a different place. In this review, both relocation and transition will be taken into account.

Relocation process

Generally speaking, the authors of this systematic review understand that the final decision after this decision-making process on the location of care may be simplified into two options: staying in the usual location of care or moving to a different place. In this review, both decision-making processes will be taken into account. More precisely, as regards the decision of relocating, it is interesting to highlight a couple of aspects:

First, the literature describes different types of relocation, as the following examples mentioned by Smith and Crome14. home to institution, intra-institutional and inter-institutional or institution to home, and these may be voluntary or involuntary, patients may be healthy or ill and the relocation may be well-planned or ill-planned. Yawney and Slover17 propose four types: from one community setting to another, from the community to an institution, from one institution to another and from an institution to the community.

Throughout this review, an institutional setting will be understood as those centres or institutions where the
elderly are admitted to in order to receive care or supervision from healthcare professionals (e.g., a nursing home for the elderly). On the other hand, the community setting, seen as the opposite of the institutional setting, includes homes, different types of housing or locations of care that are within the community context which promote or support the elderly’s independent living (either if they have some help or supervision or not).

According to this, in this review we will deal with all relocations starting from the community setting, regardless of the chosen location of care, as long as they are permanent.

Second, different authors have described different phases in the relocation process, or, more precisely, in the institutionalisation process,\textsuperscript{18} \textsuperscript{19} the decision-making process thus being an event taking place before the institutionalisation itself. This is why this review will only analyse and extract information linked to the phases of the process considering the moment where the decision of relocating is taken. Therefore, the phase where the participants are at, or whether the study deals with the complete institutionalisation process or only some phases, is irrelevant when it comes to including the studies in this review, since, in all these cases, only the information about the decision-making process will be taken into account.

**Location of care**

Lastly, as the different locations of care have been poorly and inconsistently described in the literature,\textsuperscript{20} it is important to point out that, throughout this review, the ‘decision on the location of care’ will be understood as any one that involves deciding on a permanent or long-term location of care for the elderly, regardless of the environment/place where they are relocated, either a home, community or institutional setting.

Therefore, all the decisions focusing on temporary locations of care, such as stays in hospitals, rehabilitation facilities or other healthcare centres, with the aim of tackling an acute or temporary healthcare problem, will not be taken into account, since hospitalisations due to severe illnesses/problems are described as inevitable,\textsuperscript{21} hospital care thus seen as necessary when patients are seriously ill.\textsuperscript{21} \textsuperscript{22}

Therefore, the decisions on relocating to try to solve specific health problems (for instance, psychiatric inpatient care), decisions on where to take care of people with substance abuse problems or the decision of relocating people with intellectual disabilities will not be taken into account in this review, since the authors consider that the mentioned health problems are specific and extensive enough to constitute their own research questions.

On the other hand, this review will not include the studies linked to deciding the place where one wants to die either, since, as stated by Agar et al\textsuperscript{23} the place of care must not be understood as the same thing as a place of death. Due to this, the studies dealing with decisions linked to the end of life, the care for the terminally ill, choosing the place where one wants to die, palliative care, advance care planning or advance directives will not be taken into account.

The eligibility criteria that will be used in the development of this systematic review are detailed below.

The studies eligible to be included in this review would be: (1) those dealing with decisions on the location of care of the elderly, adults who are 65 or older (when studies refer to decisions about a wide age range, the studies will be included if the average age is 65 or older, or if these studies analyse subgroups of people whose average age is 65 or older); (2) these studies must deal with the decision-making process on the location of care already experienced by the participants; (3) original studies; (4) qualitative or mixed-method studies; (5) written in English or Spanish (languages spoken by team members).

The studies will be excluded if they are: (1) studies where relocation has started in an institutional environment; (2) studies about deciding about the end of life, terminal patient care, palliative care, advance care planning, advance directives and/or the place to die; (3) studies about decisions on the location of care connected to substance abuse or intellectual disabilities; (4) studies about decisions on temporary locations of care, acute care and/or specific health problems, such as psychiatric inpatient care; (5) doctoral theses or conference proceedings (conference abstracts); (6) studies whose complete text is not accessible.

Qualitative research studies will not be limited by methodology (phenomenology, grounded theory, action research, ethnography, etc), while in the mixed-method studies only the qualitative components of the research will be included and analysed. However, those mixed-method studies where it is not possible to tell if the results were obtained with quantitative or qualitative methods will be excluded.

**Data collection process**

The search results have been exported to the Zotero bibliography manager, in order to store, manage and organise the obtained bibliographical references. In addition, a register of the obtained results in the searches in each database has been kept.

The obtained citations have also been reviewed, deleting those which were repeated in the different databases.

Later, all these citations will be reviewed by title and abstract independently by two reviewers. These reviewers will meet to discuss the results and, in the case of disagreement, a third reviewer will mediate. All the doubtful citations will be included so that their complete text is read.

Finally, the complete text of all the included citations will be obtained, in order to assess if they must be included in the review. All the texts will be read in full and will be assessed by two reviewers independently, in order to decide if they must be included. These reviewers will meet to discuss the results and, in the case of disagreement, a third reviewer will mediate. If, after reading a complete paper or text, the information is not enough,
or clear enough, the paper will finally be excluded from the review on the basis of the lack of information.

The above-mentioned steps will be reported using a flow chart.

**Extraction of data**

In order to identify the information on the results of the studies, we will follow a previous study on methods to thematically synthesise qualitative research in systematic reviews, and we will consider all text marked as ‘results’ or ‘findings’ in the papers to be the results of the studies, also adding all the text included under the title ‘conclusions’. Both the participants’ quotes and the authors’ interpretations will be taken into account, since the extraction of this information (through both channels) helps to guarantee that the results obtained in the review are fully based on the real experiences of the participants in the studies, as proposed by Butler et al.\(^1\)

To perform this task, a tool for data extraction specifically created for this review, based on the needs of our study, will be used, as proposed by Butler et al.\(^1\).

This tool will be piloted with a small number of papers (from two to four) in order to check its usefulness, and it will be modified if required. The information to be extracted from each paper will be: title; year of publication; country; language; authors; objective of the study (main objective and, if applicable, secondary objectives); design; methodological basis; sample; strategy, size, inclusion and exclusion criteria, characteristics of the participants; techniques/methods for information collection; data analysis methods/techniques; ethical considerations; results: the participants’ quotes and the authors’ interpretations; final conclusion; strengths and limitations and comments by the reviewers.

All the obtained information will be classified into tables.

The extraction of information will be carried out by two reviewers independently. These reviewers will meet to discuss the results and, in the case of disagreement, a third reviewer will mediate.

**Quality appraisal**

The quality of the included studies will be assessed using Critical Appraisal Skills Programme Español (CASP-e): Plantilla para ayudarte a entender un estudio cualitativo.\(^2\) This tool includes 10 questions designed to help to assess qualitative research studies, answering ‘Yes’, ‘No’ or ‘Can’t tell’ to each question: the first two questions deal with the objectives of the research and the advisability of the qualitative methodology; these two questions are screening questions—only if the answer to both questions is ‘Yes’ it is worth proceeding with the remaining questions.\(^3\) The remaining questions deal with: the research method, the strategy for selecting participants, data gathering techniques, relationship between researcher and object of study, ethical issues, data analysis, exposure and applicability of the research results.\(^4\)

This tool, in its English version, has already been used in different review papers.\(^5\)\(^6\)\(^7\)\(^8\) While the tool will be tested with a sample of the studies to confirm that both reviewers are using it properly, as well as that the tool is clear and useful.

As regards the use of the studies’ quality as an exclusion criteria, some authors in the bibliography choose to exclude papers from their studies according to their quality,\(^9\)\(^10\) while others include all the papers.\(^2\)\(^11\) Since the objective of our review is to provide an overview of how the location of care of the elderly is decided on, we will not exclude papers on the basis of their quality.\(^11\)

However, the quality appraisal performed on each study included will be reflected, organising this information into a table. In addition, as the viability and importance of attempting some kind of sensitivity analysis will be a fundamental focus in future studies,\(^10\) this systematic review will study the relative contributions of the different studies to the results of this review according to their quality, a process already performed by other authors before.\(^2\)

The critical quality appraisal will be carried out by two reviewers independently. These reviewers will meet to discuss the results and, in the case of disagreement, a third reviewer will mediate.

**Data synthesis**

The review we propose will be carried out with the aim of increasing the scientific production in the field of qualitative research and, more precisely, in the field of systematic reviews, since the inclusion of qualitative research in systematic reviews is still a big challenge.\(^30\) At the same time, the literature states the methods to synthesise and review evidence in order to tackle questions different from efficacy issues are much less developed.\(^31\)

Dixon-Woods et al.\(^23\) state in their review about possible methods for qualitative and quantitative synthesis of evidence that the choice of synthesis type (either interpretative or integrative) is probably linked to the research question of the review. In addition, this review also points out different methods to synthesise the qualitative and quantitative evidence that might be used (narrative summary, grounded theory, meta-ethnography, meta-synthesis, meta-study, realist synthesis and Miles and Huberman’s data analysis techniques, content analysis, case survey, qualitative comparative analysis and Bayesian meta-analysis).\(^32\)

According to Butler et al.,\(^11\) the chosen synthesis method will depend on the review’s type and goal. That same article also points out that, regardless of the chosen method, it is important to clearly report each of the steps, and how they are going to be taken, as this provides reproducibility, transparency and trust in the review’s results.\(^11\)

This is why, in order to synthesise the qualitative evidence included in this systematic review, a widely used and known method in the field of qualitative research will be used—the Constant Comparative Method.\(^33\) This method is being used today to synthesise qualitative evidence,\(^34\) and
many researchers use it outside of Grounded Theory, which is the approach chosen for this review. The synthesis of data will be performed by two authors independently, and these results will be reviewed and discussed by all the authors in order to make sure that they suit the original information.

The software to be used to analyse all the information is Weft QDA.

**Patient and public involvement**

Patients and/or public are not involved in this study.

**Ethics and dissemination**

Thanks to this systematic review of the literature, we will achieve a deep understanding of how the decision on the location of care of the elderly is taken.

In addition, dealing with qualitative methodology studies will allow us to widely appraise the experiences that the main actors go through in this decision-making process that is so important in the elderly’s lives which will help us to understand not only the reasons and emotions underlying this decision, but also to create new knowledge on the topic, useful both for researchers involved in this research field and all the people involved in this decision-making process today.

This work will also help to improve the field of study of systematic reviews of qualitative studies, since, in this research’s final report, information will be provided on each of the steps taken to develop this systematic review which will help future researchers who wish to continue working on the review of qualitative studies.

Also, as this is a review unrestricted in time, it will allow us to analyse how this decision has been posed in time, in order to see if it has changed in the way of proceeding and in the emotions provoked by this choice in different time periods.

Our study can also have some limitations. The results obtained from this review will be limited by the inherent nature of qualitative research, apart from the limitations of the individual studies included. On the other hand, this protocol also has some limitations linked to the search strategy. There is no precise terminology to refer to the main key terms of the review; in addition, the used search terms had to be modified in order to adapt the strategy to each of the consulted databases, so maybe not all terms that might be linked to the topic of interest are found. Also, since it uses language limits, this review will not deal with research carried out in languages different from English or Spanish.

However, we have intended to assure the quality of this review protocol by leaning on the work by Butler et al., the PRISMA-P statement and the ENTREQ statement, the latter being the one to be used as a guide to develop the complete final systematic review. In addition, another tool will be used to check and report about the quality of the included studies, thus providing transparency and reliability to the review process. Also, it bears pointing out that, if any change were to be made in the process or the performed procedures, these would be clearly and precisely reported, providing due explanations and reasons.

The plans to disseminate the results of this systematic review include publishing a research paper in a high-impact journal in our study area. Also, if possible, the results of this research will be presented in scientific conferences. In addition, the obtained results will be suitable for informing, guiding, complementing and discussing the doctoral thesis of one of the authors of the review which is under way.

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**Contributors**

G-S-G conceived the study and the study design. G-S-G developed and executed the search strategy. G-S-G, R-S-d-R and M-R-R helped draft the protocol, edited the draft protocol, read and approved the final manuscript.

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**Competing interests**

None declared.

**Patient consent**

Not required.

**Ethics approval**

This protocol did not require ethical approval, since it is a protocol for a systematic review.

**Provenance and peer review**

Not commissioned; externally peer reviewed.

**Open access**

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