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Integrating shared decision-making, expressing preferences and active participation of older adults in primary care nursing: a systematic review of qualitative studies and qualitative meta-synthesis

Pablo Martínez-Angulo [ID],[1,2] Manuel Rich-Ruiz [ID],[1,3,4] Pedro E Ventura-Puertos,[1,2] Salvador López-Quero[2,5]

ABSTRACT

Objectives To systematically synthesise the results of primary qualitative studies on how community-dwelling older adults experience shared decision-making processes, express preferences and actively participate in care.

Design Systematic review of qualitative studies and qualitative meta-synthesis.

Methods We focused on studies about community-dwelling participants aged ≥65 undergoing a health-disease process circumscribed to a primary healthcare setting, and the central theme should focus on either shared decision-making, expressing preferences or patient participation. We searched the following databases: MEDLINE, CINAHL, Web of Science, Scopus and PsycINFO (time publication frame 2012–2022). We excluded studies in those cases where the qualitative results were not analysed or unrelated to the phenomenon addressed, phenomena were not clear enough to be included or the setting did not occur in the community.

Results A total of 12 studies were included in this meta-synthesis. We appraised the quality of the selected studies through Critical Appraisal Skills Programme (CASP) Checklist. The metasummary comprised the frequency and intensity of qualitative patterns across the included studies. The meta-synthesis revealed four influential elements in their interaction: recognising personal qualities, facing professional characteristics, experiences of discrimination and a double-edged context.

Conclusions The phenomena studied were influenced by how older people approached their role in their binomial relationship with healthcare professionals. Those with a reinforced self-concept were better aware of health-disease-related situations regarding shared decision-making and the importance of being communicatively assertive. Professional characteristics were also crucial in how older people modulated their acting ability through their personality, communication skills and the approach healthcare professionals used towards older adults. Situations of discrimination generated through an imbalance of power inhibited the expression of

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This is the first meta-synthesis of qualitative research exploring in a joint perspective the phenomena of shared decision-making, the expression of preferences and active participation in older people living in the community.

⇒ The synthesis identifies core overarching elements that facilitate understanding the factors that originate, influence and condition the phenomena of study.

⇒ The synthesis highlights the importance of balancing power relations between older people and healthcare professionals so that real situations of shared decision-making, expression of preferences and active participation emerge.

⇒ Some studies constituting the synthesis have a limited methodological description, and an attempt was made to balance this by clearly and concisely organising their data.

preferences and hindered the active participation of older people. The context surrounding the participants influenced all these situations, key in tipping the balance between a therapeutic and a harmful side.

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INTRODUCTION

In the *World report on ageing and health*, the WHO stated that older people are expected to have a high use of health services due to the impact of multimorbidity on their abilities.[1] Following this statement, those health systems that care for older adults by taking their needs into account do so more effectively than those that only consider specific diseases separately as a reference in their care. Respecting older adults' autonomy and control, privacy, communication and identity

BMJ

is a way of meeting their dignity needs.[2] [3] Therefore, ensuring processes that manage effective and dignified primary care for older people seems crucial. However, unlike other population groups, these processes are often blurred in pursuit of an ageist conception through which older adults are considered people who, by definition, are incapable or cannot manage their care.[4–6] This ageism undermines care based on respect and inhibits the active involvement of older adults.[7] Within those effective and dignified processes that could represent a solution against ageism are shared decision-making, expressing preferences about care and engaging in active participation.[8–10]

Shared decision-making: a kind of controversial performance

Regarding the first of them, we understand shared decision-making as a process based on choice, option and decision talk, whose steps are: (1) introduce the choice, (2) describe options and (3) help the patient explore their preferences and make decisions.[11] [12]

These shared decisions can occur in a wide range of possibilities, from those dealing with clinical issues to others choosing to stay at home.[13] However, this concept remains controversial today because older patients often need more confidence to decide. This is hindered by insufficient or poor-quality information, adding to the issue that there are times when healthcare professionals do not include older people in the decision-making process.[14] Therefore, robust communication between healthcare professionals and the older patient and cohesive teamwork that creates an environment of security and trust are needed for this process to occur authentically and therapeutically.[15]

Expressing preferences=boosting autonomy

Incorporating patient preferences when designing or organising treatments is beneficial, according to Swift *et al*.[16] Similarly, fleeing from a merely positivist plane, listening to and introducing the preferences of patients into the modus operandi of healthcare professionals not only personalises medical treatment and nursing care but also validates and reinforces the self-concept of the older person, in addition to giving them a role of active agency, facilitating emotional relief and supporting their autonomy.[17] [18] This process is connected to the previous one of shared decision-making because when older patients decide freely, they have previously done so based on a preference.

Active participation: a meeting point

Knowledge of the preferences of older patients and their tailoring in the decision-making process is crucial to stimulate active participation.[19] [20] This active participation is considered one of the critical features for health intervention in older people to be effective, potentially alleviating even negative sensations derived from managing situations of illness.[21] The patient's participation in a health environment refers to actively collaborating in the care process with the health professional. This contribution can be performed by asking questions, expressing concerns or expressing preferences.[22] The patient's active participation is also considered part of patient-centred care and a requirement to conduct shared decision-making.[23]

Integrating shared decision-making, expressing preferences and active participation of older adults in primary care nursing

As the evidence has shown, these three processes are closely related and can even be interpreted as dependent on each other: to reach shared decision-making, it becomes necessary to express preferences and, in turn, deciding is already participating in some process. Integrating these phenomena can capture a deeper understanding of, on the one hand, how they inter-relate and what shapes them in the case of older adults.

On the other hand, this discovery would reveal which communicative elements become essential in the health-disease process of older adults, thus helping to adapt specific decision-making approaches in primary care situations.[24]

The term health-disease process refers to the sociocultural construction through which the individual experiences the moment of illness as a temporary transit that influences roles, expectations, representations and health behaviours uniquely and dynamically.[25] Thus, realising this study would also help develop specific approaches to handle this construct by identifying the determinants and elements that condition these experiences.[26]

In this way, addressing shared decision-making, expressing preferences and active participation in community-dwelling older adults, from the integrating approach of a qualitative meta-synthesis, may result in a new contribution to how a relationship based on respect and dignity of older adults emerge, contributing to avoiding ageist attitudes still present on the part of healthcare professionals.[27] [28]

Finally, considering the roadmap set by the WHO's report for the Decade of Healthy Ageing 2021–2030,[29] the purpose of the present qualitative synthesis was to systematically synthesise the results of primary qualitative studies on how community-dwelling older adults experience shared decision-making processes, express preferences and actively participate in care. In addition, we aim to synthesise what elements shape their appearance, inter-relation and how they condition the healthcare professional–older patient relationships.

METHODS
Design

Sandelowski and Barroso define qualitative research synthesis as a process and a product of scientific inquiry whose purpose is to systematically review and formally integrate the findings from completed qualitative studies.[30] Within qualitative research synthesis, there are a variety of methodological approaches.

First, we performed a meta-summary of effect sizes approach. We did this to obtain an empirical foundation for a subsequent qualitative meta-synthesis since we handled a collection of qualitative studies to determine the frequency and intensity of qualitative patterns intrastudy and across studies.[30] [31]

Second, and once we fulfilled the meta-summary of effect sizes, we conducted a qualitative meta-synthesis approach, since we analysed qualitative data across the selected studies, thus appraising, summarising and combining qualitative evidence to address the research question and, therefore, offering a novel interpretation of how shared decision-making, expressing preferences and active participation relate in the health-disease process of community-dwelling older adults.[30] [31] To address the part corresponding to the meta-synthesis, we approached Noblit and Hare's meta-ethnography[32] since it implies an interpretation similar to the qualitative methods of the studies we intended to synthesise. To do this, we adopted their main feature of reciprocal translation.[32] This synthesising technique aims to retain the particularity of the primary results even when they are synthesised and treat the original interpretations and explanations as data being translated across several studies to produce a synthesis.

We then share the notion about the qualitative meta-synthesis as something more than the sum of its parts, going beyond the primary interpretations from the selected studies, thus developing new contributions. This applies to our goal to synthesise and deliver a new interpretation of how the moment of shared decision-making appears in older patients in a community setting, how this is interrelated with expressing their preferences, and how it could be translated to patient participation. In addition, we maintained an explicit focus on contrasting and determining the elements that shaped the course of the study phenomenon.[33]

Besides, we performed a systematic review of qualitative literature, which required an exhaustive approach to searching and appraising selected qualitative studies.[34] This is consistent with how Sandelowski and Barroso also understand the search process of qualitative studies.[35]

The structure of this study is based on the six steps that Sandelowski and Barroso indicate to perform the meta-synthesis:[35] (1) conceiving the synthesis, (2) searching and retrieving literature, (3) appraising findings, (4) classifying findings, (5) synthesising findings into metasummaries and (6) synthesising findings into a meta-synthesis.

This meta-synthesis was prepared following the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement[36] (online supplemental table 1) and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research Statement.[37] In the same way, this meta-synthesis was registered in the International Register of Systematic Reviews (PROSPERO) with ID CRD42022363515.

Conceiving the synthesis

A reflection period was initiated before posing the research questions, which, throughout the meta-synthesis, would account for its circular and flexible nature.[38] This period was marked by the following moments: (1) defining the key concepts around which the qualitative synthesis should revolve, (2) deciding the perspective that will be adopted to address the phenomenon under study and (3) making sure of the challenge of establishing adequate methodological and theoretical bases for a meta-synthesis.

The research questions were:
1. How do shared decision-making moments appear in community-dwelling older patients?
2. How is this inter-related with expressing their preferences?
3. How could it be translated to patient participation?

Searching and retrieving literature

The qualitative studies to be included had to meet the following inclusion criteria to elucidate the focus of the meta-synthesis:
1. Participants aged ≥65, or median age ≥65 if mixed population (excluded if >25% of participants aged <60).
2. Participants were patients who were undergoing a health-disease process (acute or chronic).
3. Participants were clients of/interacted with primary healthcare services.
4. Original research studies conducted using qualitative methodology.
5. The central theme of the research was (Given that these three elements are closely related, as formerly stated, the research team considered addressing them separately to meet the first of the objectives of this meta-synthesis, which is to synthesise them providing a new joint interpretation.):
   i. Shared decision-making,
      OR
   ii. Patient preferences,
      OR
   iii. Patient participation.

The exclusion criteria were as follows:
1. Qualitative results of primary studies were not analysed or not related to the phenomenon addressed.
2. Phenomena were not clear enough to be included.
3. The setting did not take place in the community.
4. Seriously ill /end-of-life older participants.

We selected five databases (PubMed, CINAHL, Web of Science, Scopus and PsycINFO). PubMed for being one of the largest databases in the field of health sciences; CINAHL, for being one of the essential nursing databases; Web of Science, for its grand scope and number of indexed articles; Scopus and PsycINFO, for their great value in the psychosocial and psychological sphere, which encompasses a series of necessary nuances in shared decision-making, patient preferences and patient participation. We decided to use pertinent database filters further to ensure a thorough practice in the literature

search, thus helping to avoid the threat of failing to achieve sufficient strengthened informative insights in this study.[30] The filters used in the databases are the following: (1) the last 10 years because more than 80% of the studies found were performed from the year 2012, (2) nursing, to circumscribe the study phenomena to the discipline of nursing, (3) exclude MEDLINE records, in those databases other than PubMed, and that had it available to eliminate duplicates and (4) English/Spanish because they are the languages that the research team mastered. Both the filters applied and the search terms were adapted to the configuration of each database. We performed a comprehensive search strategy; its results are in the online supplemental table 2.

PM-A searched MEDLINE and CINAHL on 9 September, Web of Science and PsycINFO on 13 September and Scopus on 15 and 16 September 2022. Finally, all databases were searched on 22 September. This process was supported and followed by MR-R, as we explain next. At the beginning of the article screening phase, consensus meetings were held to agree on each step that would be carried out. We decided to use EndNote for screening. PM-A performed all screening stages, applied the eligibility criteria mentioned above and selected studies through a detailed review of the title, abstract and full

text for their inclusion. About 10% of the selected articles were chosen randomly and sent to MR-R for evaluation and to obtain feedback and check decisions made. Both authors read and reviewed all potentially relevant articles after that. All the research team agreed with the decisions and steps. Finally, 12 studies were selected for their inclusion (figure 1).

Appraising reports

After selecting the final reports, we performed an individual and a group appraisal. It consisted of, on the one hand, reading individually as many times as necessary to identify specific content and, on the other, comparing the studies collectively through a group meeting to address differences and similarities to establish a relationship between them and create summaries, adding to develop a consensus between the content found by the authors.[30]

We applied to the Critical Appraisal Skills Programme (CASP), a checklist focusing on qualitative studies' findings, validity and usefulness. The main strength of the CASP checklist resides in promoting a systematic approach by which the advantages and disadvantages of a study may be identified.[39] PM-A and MRR followed the checklist grid to evaluate the 12 chosen articles. After that, they shared the results. We understood this step as

Identification of studies via databases and registers

Identification

Records identified from:
  PubMed (n = 9)
  CINAHL (n = 39)
  Web of Science (n = 83)
  Scopus (n = 977)
  PsycInfo (n = 687)

Records removed *before screening*:
  Duplicate records removed (n = 1,010)

Screening

Records screened
(n = 785)

Records excluded
(n = 748)

Reports sought for retrieval
(n = 37)

Reports not retrieved
(n = 0)

Reports assessed for eligibility
(n = 37)

Reports excluded:
  Not older population (n= 3)
  Results not clearly separated from older participants group (n = 3)
  Not community-dwelling participants
  (n = 6)
  Participants not having any primary care service interaction (n = 4)
  Not appropriate topic (n = 6)
  Seriously ill/ End of life stage participants (n = 3)

Included
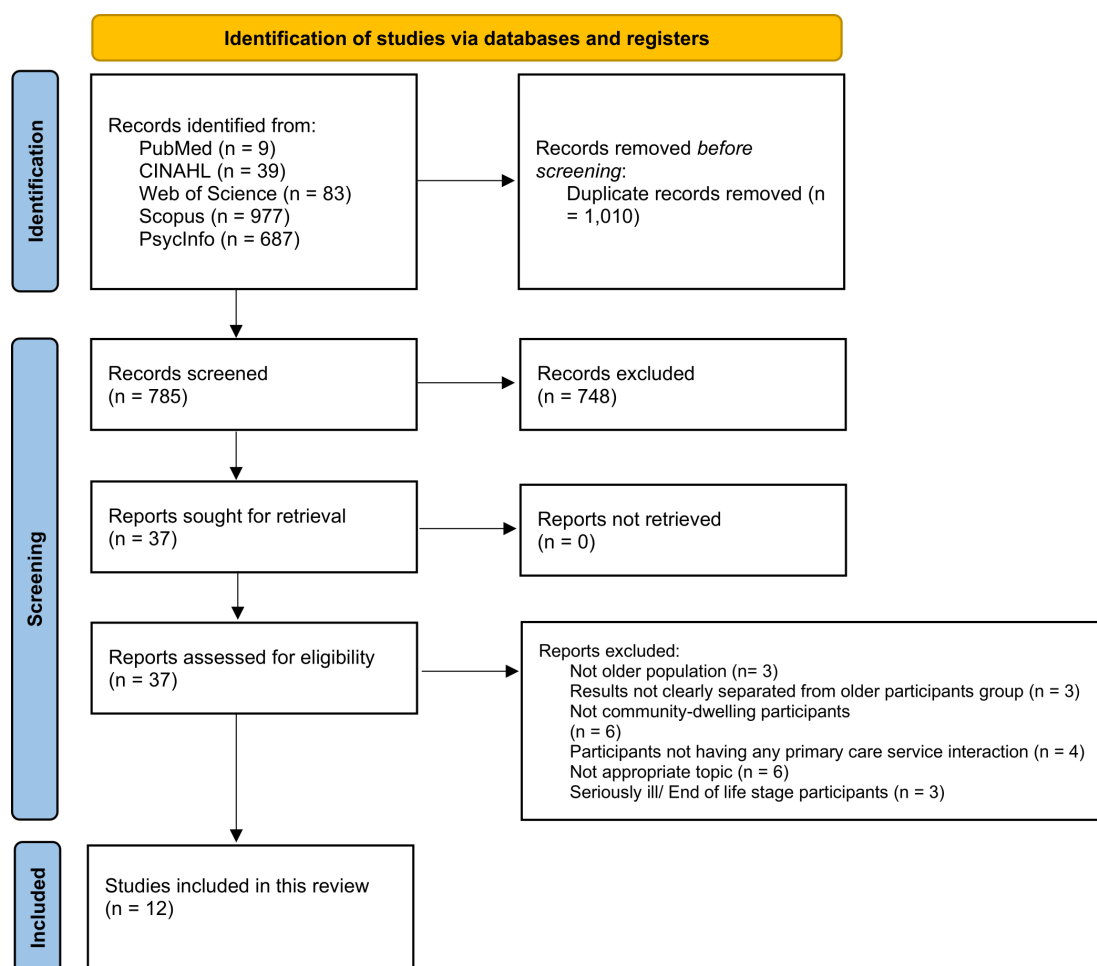
Studies included in this review
(n = 12)

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 statement flow diagram.

more than simply scoring or fixing anything because it helps to better understand the selected studies before embarking on the findings.[35]

Classifying findings

We considered the older participants of each selected study as the first-order generators of knowledge. Later, the authors of each study would be the second-order generators of knowledge by giving the first interpretations. Finally, we occupied the third position by providing a new interpretation of the knowledge generated by the first two. For this reason, this meta-synthesis could be understood as three different levels where we are the third interpreters of the first two.[30 35] We decided then to prioritise the life experiences of the first-order generators of knowledge. However, we did not completely rule out the interpretations of the second-order generators of knowledge because they served us as referential adequacy for the new interpretation of our study.[40]

We emphasised the content of the data sources when classifying the findings, but first, the research team met to reach a consensus to decide what would be considered data to include. Our final decision was to contemplate data as the quotes of the older patients (first-order generators of knowledge), considering the primary researchers' interpretations and abstractions (second-order generators of knowledge). All the data classified came from the results section of the selected studies. Considering this, we understood that our choice corresponded with data-based findings.[30] Data-based findings are compositions built through the analysis of extracts from interviews, observations or documents by the second-order generators of knowledge in primary qualitative studies.

Finally, we created an extraction rubric for the occasion to approach the findings of the selected primary studies uniformly and thus systematically extract the data for subsequent analysis. PM-A examined all those sets of potential findings to be included in our meta-synthesis to be extracted and MR-R supervised decisions made by the first. Only the findings that answered 'Yes' in all the items were integrated for the next phase.

The items that made up the rubric were the following:
1. The finding is closely related to shared decision-making/expressing preferences/active participation (Yes/No).
2. The finding comes directly from the first-order generators of knowledge (Yes/No).
3. The finding was analysed by the second-order generators of knowledge (Yes/No).
4. The finding held a profound qualitative meaning which could contribute to the meta-synthesis (Yes/No).

Analysis: synthesising findings into metasummary and meta-synthesis

The analysis phase results were managed and processed using the QSR NVivo V.12 computer software tool.[41]

The qualitative metasummary of effect sizes is a quantitatively oriented aggregation of qualitative findings, whose objective is to discover the frequency and intensity with which the findings are distributed within each study and across all of them.[42] In this way, performing a metasummary allowed us to identify selected studies' patterns and strengthen informative insights.

We did not consider the qualitative metasummary as an end, but as a bridge we crossed to build the meta-synthesis. Relying on the information obtained through the metasummary, we had as a reference the selected studies' patterns to create a new interpretation based on the new qualitative patterns synthesised in our work, thus answering the research questions we posed.

For the metasummary, we also calculated the magnitude of the effect sizes. Effect sizes address the frequency of occurrence of an experience sufficient to constitute a pattern, facilitating a further understanding of the studied phenomenon and an overview of how patterns of meaning are distributed across studies.[42 43] We calculated interstudy frequency effect size by taking the number of individual studies that contain a specific finding and dividing it by the number of total studies in the sample. In this way, we found the representation of subthemes across studies. We calculated intrastudy intensity effect size by taking the number of studies containing at least one category belonging to each subtheme, divided by the number of total sub-themes. Following this, we found the concentration of findings of each selected study.

The meta-synthesis is an interpretive integration of qualitative findings in primary research studies through interpretive data syntheses.[30] To achieve this, PM-A individually performed analysis through the phenomenological–hermeneutical considerations proposed by Ricoeur[44] and was supported by PEV-P and SL-Q.

In the preliminary analysis phase, the authors superficially read the included studies, obtaining a general meaning and writing a list of ideas to guide the analysis until reaching a raw explanation of the phenomenon studied.

At the first level of analysis (explanation), we selected nodes or whole units of meaning. The nodes or whole units of meaning were interpretative fragments of the first-order generators of knowledge that contained a basic meaning, an explanation and a justification of that meaning. We established a round-trip process between the nodes and the starting categories to ensure that the interpretative thread remained linked to the participants' life experiences. We considered as starting categories the interpretations and abstractions that the second-order generators of knowledge made of the first ones. After reviewing the nodes created and the studies selected, we ensured that every unit of meaning was noticed.

At the second level (naive comprehension), the nodes were organised according to these new categories. Once contained in them, they were regrouped by the affinity of meanings, creating codes capable of reaching greater abstraction.
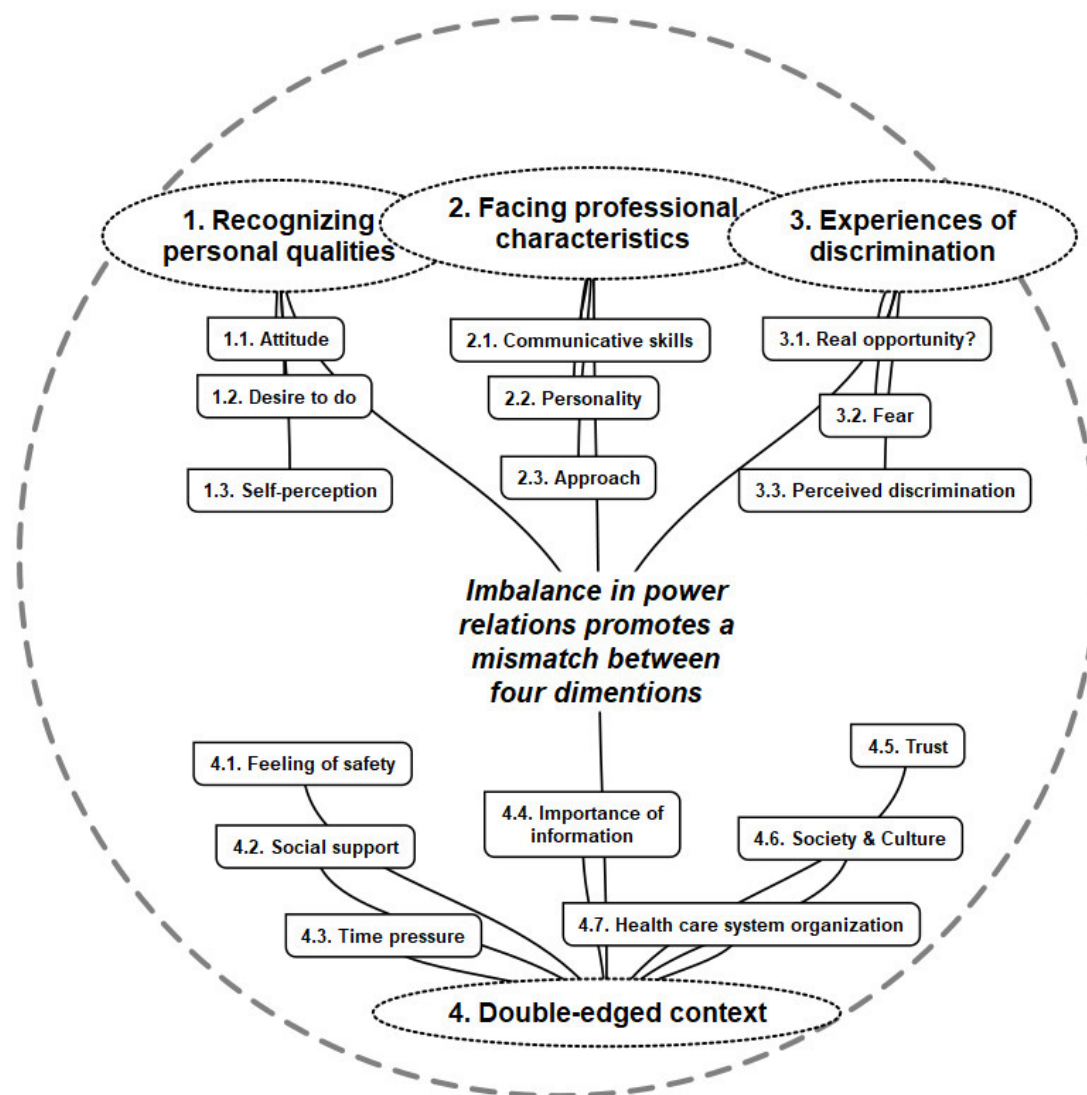
Figure 2 Meta-synthesis. Relationship between the four dimensions.

At the third level (in-depth understanding), we reached a greater understanding of the phenomenon through the hermeneutic arc. The hermeneutic arch is considered the achievement of a back-and-forth process that combines the preliminary understanding of the analysed phenomenon and the final interpretations of the data corpus, reaching the highest level of abstraction of meanings with the creation of study patterns, subthemes and categories.

Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting or dissemination plans of this research.

RESULTS

The results are presented in online supplemental table 3 for the effect size metasummary and narratively developed, as well as visually in figure 2 for the meta-synthesis. On the other hand, online supplemental table 4 shows intrastudies' characteristics (publication year, authors,

country, aims, age of the participants, sample size, characteristics of the participants, data collection tool, data analysis employed, relevant results of importance extracted from the article), and online supplemental table 5 shows characteristics across selected studies (design, older patients' health condition, sampling strategy, informants other than older patients, setting of data collection, field notes taken in addition to interviews, audio/visual recording, data coders, use of software, argued use of trustworthiness criteria, argued use of consolidated reporting framework).

According to CASP, the selected studies' scores were the following: 70% for one article, 75% for three articles, 80% for three articles, 85% for three articles, 90% for one article and 95% for one article (online supplemental table 6). Although all studies scored 70% or higher, no investigation would have been excluded based solely on possible poor quality.[30] The reviewers involved in the process agreed on all article criteria and scores.

Metasummary

The present study's effect size metasummary comprised the interstudy frequency effect size and intrastudy intensity effect size (online supplemental table 3).

Regarding the interstudy frequency effect size, within each subtheme, the most prominent categories were the self-perception of the older person, the approach of the health professional, the discrimination perceived in certain situations by the older person, and the importance of feeling safe. Likewise, regarding the intrastudy intensity effect size, the subthemes had an effect size of 92%, meaning that 11 out of the 12 studies contributed categories representing each. The authors want to state that no subtheme was considered over or underrepresented because all of them arose with strength beyond their frequency in the testimonies of the older people involved.[30]

Meta-synthesis

The end of the synthesising approach to reciprocal translation gave rise to an abstract integration of findings in the community-dwelling older adults' reports in the form of an 'imbalance of power relations'. This imbalance of power relations in shared decision-making, expression of preferences and active participation among older people in the community revealed two influential pillars in their interaction: the older person-healthcare professionals' binomial and a doubled-edged context. In turn, a third pillar fluctuates based on how power relations develop between the first two, the latter being situations of discrimination suffered by older people. The experiences that delivered this synthesis were assembled into four subthemes: recognising personal qualities, facing professional characteristics, experiences of discrimination, and double-edged context (figure 2).

Recognising personal qualities

Recognising personal qualities pertains to the capacity of older people to assume those interiorised values, attitudes, beliefs and qualities. This assumption acts: (1) as an initiator of an active intention to embark on their health-disease process, leading them to have an empowered agency to decide or, at least, take part in some way in the decisions that are made around their state of health or (2) hindering that intention, attending to a kind of self-sabotage regarding enjoying opportunities that allow them to decide, express their preferences or participate.

Considering the first of the two conceptions presented in the previous paragraph, the qualities facilitated personal characteristics in achieving truly centred care for the older patient.[45] These characteristics play a vital role in older people as an anchoring point for displaying concepts they identify as a bridge between the active-attitude *self* and the active-agency *self*. That bridge is built based on inner strength, positive attitudes and a sense of humour: 'I have been an active woman my entire life, so I decided that I should learn to walk again! I followed

a training programme every day; eventually, I made it' (Nilsen *et al*, p575).[45]

As older people crossed that bridge, they realised that effective and shared decision-making is a true reflection of having autonomy in the process, which, added to the performance of that autonomy, creates participation that leads to a feeling of responsibility. Therefore, being responsible for their health increases self-identity, self-esteem and confidence in older people, which is closely reflected in the execution of shared decision-making.[46] All of this generates a sense of control and power in older adults. This sense occurs because they also protect empowerment by safeguarding the autonomy-decision-making binomial. In this situation, they expressed their preferences autonomously and powerfully: 'I think it's a control issue with me…I manage my medical care and everything else in my life and I keep [my children] in the loop after it's done' (Crotty *et al*, p1495).[47]

The consequences of feeling responsible also affect active participation, which, in turn, is fed back with the self-perception of that active role in their care, which increases the satisfaction that once again increases their desire to participate in a kind of therapeutic circle.[8 48] This desire to participate was also considered a willingness to be fully informed and that this information should be based on evidence. In this way, older people declared that being fully informed is being prepared to face any process.[45 49]

Older people reported that being active in their daily lives and carrying out activities is also a way of making decisions, maintaining their coping skills and attending to their spiritual sphere.[45 46] Therefore, they highlighted having that self-perception of their needs and communicative assertiveness to express their preferences in managing their care: 'You have to be assertive. I don't feel that I have to be overly assertive, because my doctor responds to my feelings. But it's important to be assertive' (Mitchell *et al*, p6).[50]

Furthermore, personal qualities can act simultaneously as hindrances. Excessive politeness or stubborn behaviour leading to unrealistic goals interferes with the decision-making process, expression of preferences and therefore active participation, in turn, also interacts with professionals and their characteristics: 'It is not always easy to give one's opinion; often a lot should happen before I do so. For instance, I feel it is rude to express my opinion about the nurse whose behavior I do not approve, that would not be appropriate. I guess I should not tell this to you, either, but…' (Nilsen *et al*, p575).[45]

Facing professional characteristics

Facing professional characteristics pertains to all those requirements constituting healthcare, where numerous elements come together from the point of view of older persons. Professional characteristics were vital to decision-making, expression of preferences, and active participation. Healthcare professionals modulated these

characteristics by having the opportunity to create situations to develop older people as active agents in care.

This relationship must be built from a mutual understanding that makes decision-making a shared act, establishing a personal inter-relationship that allows an individualised approach to care for older adults.[49 51] Within this approach, giving a choice was raised as essential to promote patient involvement in decision-making: 'Certainly my GP [General Practitioner] always makes me decide, you know, "What would you like to do?" Well, I don't know, and I have sat there and said to him, "I don't know, what would you suggest?" [...] Sometimes I don't want to know what's happening for an operation or something you know. He never pushed the line. It was up to you, you had to…He couldn't make my mind up, but he could advise me, which he did' (Butterworth and Campbell, p711).[48]

Regarding expressing preferences, older people appreciated the flexibility and availability of those healthcare professionals who made efforts to listen to their priorities regarding the day and time of home visits or the mere fact of being there when they were needed: 'Sometimes, I cannot reach the toilet in time. I always have my mobile phone in my pocket, and I call the home care nurses immediately. Then they show up in a short time to help undress me and give me shower. This means a lot to me' (Nilsen *et al*, p574)[45]

The personality of the healthcare professionals played an essential role in bringing the older person closer to a *real* moment of shared decision-making, who highlighted honesty, kindness, understanding and respect as critical qualities.[45 49] In short, older people positively valued those professionals who treated them not as someone who depended on their clinical judgement but as 'equals': 'I feel more as an equal than I ever used to, and that helps me to have a sensible, constructive conversation with him. I think being asked to contribute treats you as a person with your own views and the ability to make that decision for yourself […] but also to realise that I use them to help me with my health care' (Butterworth and Campbell, p713).[48]

However, to achieve the status of 'equal', older people considered it necessary to deal with professionals whose communication skills would encourage them to feel heard and to be actively involved in their care. Hence, communicative and active listening skills promote a communicative relationship centred on the older patient.[48 51 52] This added to a less paternalistic attitude on the part of the healthcare professionals, enhanced communication by the preferences of older people: 'Today we expect an awful lot more out of the health service than when I had my children 40 years ago. But I think one's attitude changes; you have a better overall view. The more you're involved, the more you see what a vast and overwhelming organisation it is. You just hope they're getting it right. […] The sort of hierarchy of the medical profession was very different, wasn't it, and they very much made the decisions for you' (Butterworth and Campbell, p712)[48]

Experiences of discrimination

Experiences of discrimination pertain to the encounter between certain personal qualities of older adults and characteristics of the healthcare professionals that caused, on certain occasions, situations of discrimination. Thus, an imbalance in their relationship originated 'illusions' of moments of agency, perceptions of ageist attitudes and even fear or dread.

These 'illusions' were well exemplified when healthcare professionals made older people see that they could decide when they did not. Older people declared that they felt this delusion when professionals made decisions for them rather than together with them when handling a considerable amount of overly technical information. This gave the older patients the feeling that they could only make a decision when it was explicitly communicated to them.[8 53] Communication barriers, sustained by a lack of encouragement to listen to the concerns of older patients or to satisfy their communication needs,[50 54] could be overcome if healthcare professionals had given older people a real opportunity to participate by making decisions about their possible illnesses and treatment: 'No, nobody asked what I felt about being discharged. I did not protest the decision at the time. But, thinking back now, I would like to protest it because I did not feel safe enough at the time' (Nilsen *et al*, p574).[45] This is a dead end where professionals did not show enough transparency. Older people considered them as power figures whom they were not able to question: 'I don't want to do that [discuss reducing medication] because then I disregard my GP's advice, my GP expects me to follow her advice' (van Bussel *et al*, p4).[55]

This power imbalance caused older people to fear when they came up with situations in which they 'challenged' that authority.[53 55] The fear of expressing their preferences due to a possible unwanted consequence and becoming responsible for their own decisions inhibited a balanced and therapeutic relationship: 'I am not going to be stubborn because if something would happen, it would be my own fault' (van Bussel *et al*, p4).[55]

The circumstances raised the older person's perception of being treated differently due to several factors, such as age (ageism), ethnic identity, socioeconomic condition, health condition or language.[49 50 53 55] For this reason, healthcare professionals showed no confidence in older patients when it came to involving them in the discussion of decisions related to their health[49]; older adults were considered as people who, due to ageing, were marked by disease and symptoms, something that prevented professionals from contextualising the older people's health condition in their life stage: 'Sometimes I feel that they think you are still a young guy because you have to reach certain [blood pressure] levels, which might not be relevant anymore for older people' (van Bussel *et al*, p4).[55]

On the one hand, the professionals were not transparent when dealing with individual cases because they were not crystal clear about the consequences of the choices that could be made, generating a moment of uncertainty.[53 55]

On the other hand, this created in older adults a feeling of dependency on the professional, coming to feel objectified, invisible and undervalued; coming to not feel like an active agent of their own care, accepting paternalistic attitudes from the health system.[53–55] Such context, which created communication barriers, decreased the participation of older adults: 'It's so hard to get them to pay any attention to you. They don't listen to what you're saying. 'You're an old lady and, tada, tada, tada'—you know?" (Bynum *et al*, p225).[8]

Double-edged context

Double-edged context pertains to a scenario that played a crucial role when calibrating personal qualities and professional characteristics, even going so far as to shape the appearance of discriminatory situations. This scenario gained importance to provide older people with positive tools to reinforce concepts that drove them to decide, express themselves and participate effectively or to deprive them of any potential opportunity to develop on that level. Depending on the older person's circumstances, everything would indicate therapeutic performance in the healthcare professional–older patient relationship or a frustrated one.

In these terms, a poor health system organisation had great importance, according to older adults. The overload of work resulted in healthcare professionals always being in a hurry. In addition, there was a lack of longitudinal care; therefore, older people did not feel a continuous personalised approach because, once and again, they were attended to by different professionals each time they used the health system.[45 49 50] This excessive workload brought significant problems with time available to be optimally attended. The fact that healthcare professionals did not dedicate the time that the older people considered necessary prevented them from having a good conversation, feeling that they lacked the opportunity to 'open up', thus interfering in expressing their preferences.[45 49 54] This situation led older people to feel not like a person but like a number: 'Some practicing doctors have a tendency to get into a routine of you being a number' (Mitchell *et al*, p5).[50] Something like this prevented the development of relationships of trust with the professionals that would shed some light on this frustrating reality.[51 54]

The conducts, behaviours and ideologies have their raison d'être in society and culture, which immediately affected how the relationships between the healthcare professional and the older patient were established. This is something that older people also made explicit through differences in approach depending on the nature of the patients, the way healthcare professionals addressed them and how professionals managed that relationship.[48 50 54] In line with the way to manage these relationships, management and the importance of information gained prominence, being able to act as a facilitator or hinderer of the context of the relationship with professionals in older people.[8 49 54 55] The more quality information adapted to the older adult was provided considering the first possibility, the greater the engagement had in their care. Nevertheless, the problems came when the information was inconsistent between professionals, confusing older adults by providing conflicting information: 'Then I asked for info [about the pneumococcal vaccine] and the practice nurse said it has been around for years but the hospital doctor said it was new' (Sheridan *et al*, p37).[54] The older people declared in any case that when they came across professionals who did not provide them with enough quality information, it led to an inability to act, which added to a feeling of not being listened to. It gave rise to the older person's disempowerment: 'I like to have lots of options in front of me so that I know I can make an informed decision. But I don't feel like that way when I go to the doctor, I feel dis-empowered' (Brown *et al*, p3).[49]

Something that favoured empowerment in the decision-making process and facilitated assertive communication in the older person was surrounding themselves with a circle of trust or important ones who supported them at decisive moments.[47 50] In other words, having social support from family or friends represented a valuable tool for the relationships with healthcare professionals and the use of the health system: 'My husband is taking care of me and he helps me a lot. Without him, I would need a lot more help from the healthcare services' (Nilsen *et al*, p575).[45]

Finally, all these elements could be found in the sense of security that combined receiving help when needed, being duly informed of their rights as clients of the health system, or dealing with professionals and flexible routines in a continuous and non-sporadic manner. The older patients also highlighted the figure of the home care nurse as a link between various levels of healthcare.[45]

DISCUSSION

This systematic review of qualitative studies and qualitative meta-synthesis comprises 12 primary qualitative studies. It provides a comprehensive understanding of how the moment of shared decision-making appears in older patients in a community setting, how this is interrelated with expressing their preferences and how it could be translated to patient participation. Our results are consistent with the theory of van Dijk[56] of discourse and power because our meta-synthesis reveals that these three study phenomena are affected to a great extent by an (im)balance in the power relations established between the older person and the healthcare professionals. The personal qualities, professional characteristics and the context in which they occur shape the appearance of *real* situations of decision-making, expressing preferences and active participation; their inter-relation and how they condition to care for the older patient. The reproduction of the participants' discourse of primary studies suggests that older adults' feelings of frustration and of not being heard in situations sensitive to ageism and abuse of power from the health system and the importance of a context influencing all the above could be highlighted on occasions. The shared decision-making experience, the

expression of care preferences and active participation within it are highly complex interweaving that follows communicative, relational, and personal patterns.

Discussion of findings

In general terms, older people revealed numerous elements influencing the appearance of *real* situations of shared decision-making, expressing preferences and active participation. Our results suggest that *real* shared decision-making situations are not reduced to specific moments or issues. Still, *real* situations of shared decision-making comprise the perceived feeling by older people as empowered, having control over one particular situation and asserting their autonomy. All this is potentially enhanced by professional characteristics that care providers have and might benefit that feeling perceived by older patients. This is consistent with a recent study by Egan *et al*[57] that places primary care nurses as crucial elements in enhancing the performance of older people in decision-making processes. However, as we also reflected in the results of our study, implementing shared decision-making in older people is challenging.[58]

Sometimes, older people did not commit to shared decision-making due to their way of being or conceiving the relationship with their reference healthcare professional. Those healthcare professionals who did not understand older people, added to a changing context, weighed down potential therapeutic relationships. According to our findings, this represented an interference with the care that could have been perfectly avoidable. This result is supported by other reviews that highlight the interrelation of elements such as the patient, the patient–healthcare professional relationship, the organisation of the health system or the importance of teamwork in a therapeutic performance that allows engaging and promoting the involvement of the patients.[59–61] The interest and 'desire to do' become critical elements in the personal qualities of older people that mean a beginning to establish that therapeutic relationship, as reported by Gillespie *et al*.[62]

However, as explained throughout the study, personal qualities are not the only factors to consider. Regarding healthcare professionals, the meta-synthesis performed by Clancy *et al*[2] determined the importance of establishing positive relationships with older people. This is consistent with our study because older patients appreciated dealing with healthcare professionals who allowed them to express their feelings and preferences. In addition, professional characteristics such as having confidence and the ability to control emotions are critical concepts for a promising approach in the healthcare professional–patient relationship.[63]

From van Dijk's theoretical perspective on discourse and power, our study results are consistent with his conception of communication as inequality reproducing element.[56 64] It adds to understanding how the phenomena studied are inter-related, degenerating into situations of discrimination when the discourse serves as a vehicle for the dominating elements. This result is consistent with other reviews that displace older people to a passive role on numerous occasions, endangering the balance of power between them and healthcare professionals and highlighting the discourse as a power-holding tool.[65 66] This tool can feed the feeling of living in a *mirage* of opportunities. For older patients, this *mirage* translates into a lack of opportunities to participate in care, despite feeling motivated, in a kind of imbalance of power between the healthcare professionals and the older patients where communication has an essential role, as Ozavci *et al*[67] showed in their systematic review. Ageism situations appear when the characteristics of the disease are confused with a physiological stage, such as the ageing process. These results are consistent with the Stereotype Embodiment Theory, which explains an internalisation of ageism in society, thus unconsciously acquiring stereotypes due to ageist messages that society itself sends through the institutions, in this case, the healthcare system.[68] From the perspective of ageism and compared with other reviews about young adults, elements such as communication and information delivery in decision-making are equally important.[69 70] However, although similar needs are shared in both populations, older people deal with ageist attitudes on the part of society, as our results have shown, in addition to a scarcity of studies focusing on how to empower older people in transitional decision-making processes.[71] For this reason, when healthcare professionals adopt ageist behaviours, they limit the possibility of older people developing and expressing themselves as active agents of change, creating a marginalisation based on these unbalanced power relations.[72] In contrast, based on our study, we meet the qualitative synthesis of Strandås and Bondas[73] when a more therapeutic nurse–patient relationship has been managed to demonstrate that it promotes communicative openness and a boost to positive sensations; in other words, to share moments of accessibility in care.

The importance of a context that can be positive or negative for the appearance of *real* situations of shared decision-making, expression of preferences and active participation in older people has become apparent. The fact that nurses and doctors have little time to care for patients, in addition to an excessive workload, blames a deficient organisation of the health system in a certain way, thus negatively impacting in quality of care and professional performance, being consistent with other reviews.[74 75] Furthermore, positive social support in older people facilitates dealing with hostile situations and reinforces their communicative assertiveness, communicating their preferences more frequently.[76 77] The feeling of security in this study appeared along with other closely related concepts, such as the importance of receiving adequate and personalised information and the confidence that healthcare professionals knew how to transfer them. Regarding this feeling of safety, older people also stated that the possibility of continuing their recreational or spiritual activities in the community comforted them

and prevented feelings of loneliness or isolation, thus consistent with the scoping review conducted by Fakoya *et al.*[78]

Strengths and limitations

The main strength of the present study is that it represents the first qualitative meta-synthesis that gives greater depth to understanding the phenomena of shared decision-making, the expression of preferences and active participation in community-dwelling older adults, jointly and not separately. The new interpretation offered by this study has highlighted the importance of power relations in triggering situations of ageism regarding the studied phenomena. Thus, our meta-synthesis underlines elements that healthcare professionals could consider incorporating into their daily practice and thus promote a therapeutic relationship of *real* situations of shared decision-making, expression of preferences and active participation in nursing care. Including studies whose participants had mental conditions could also have enriched our meta-synthesis. However, this was discarded because we considered older patients with mental impairment to be another type of group with very particular characteristics that could influence the phenomena studied, compared with older people without any cognitive impairment. In addition, the number of articles selected (n=12) for the present study can be interpreted as low compared with the studies considered for screening before title review (n=785). To justify this, a critical review of the articles found that a large majority of the articles did not reach the necessary depth in the study of any of the inclusion phenomena, either because they did not provide detailed information regarding the phenomenon development in the older patient, or for being listed as one more intervention to be studied without enjoying the prominence the study required to be incorporated. Due to language issues, interesting investigations may have been lost by handling only English and Spanish. This meta-synthesis includes studies from Europe, America and Australia, providing a broad perspective that, in turn, is a window to the peculiarities between the different cultures, how the study phenomena arise, and how power relations are established in the process. By including studies from Asia and Africa that could have passed the eligibility filter, we would have understood these similarities and variations from a global perspective. Focusing this study on the nursing field could be considered a limitation. However, we thought it necessary since there is little evidence of the inclusion and importance of the nursing figure in these processes, particularly in decision-making, which hardly exists in conceptual models of interprofessional shared decision-making.[69] For this reason, this study broadens the depth of the phenomena studied in a discipline that is only sometimes integrated into them. Our decision not to exclude studies because of limited descriptions of methods may be questioned. However, we strive to distribute the data and findings relatively evenly by subthemes (online supplemental table 3) to strengthen the informative insights of the results beyond the methodological quality of the primary studies.[30 35] Furthermore, one of the issues in qualitative profile studies is that the relationships between the participants and the researchers may have influenced the findings they obtained. However, this has enriched their nuance and adjusted to the particularity of shared decision-making situations, expressing preferences and active participation of older people and giving extra complexity to the depth of each study. Moreover, the researchers' knowledge and relationship with the participants may have been crucial for recruiting key participants and their subsequent data collection. In addition, the reflections made by the researchers could have increased the informative insights of the studies. Lastly, even though the methodology used in this study prevents the participation of older people, it becomes necessary to continue qualitative research that addresses this complex phenomenon that we have integrated.

CONCLUSION

This meta-synthesis is based on previous studies revealing the implicit complexity in shared decision-making situations, expressing preferences and active participation of community-dwelling older adults. These phenomena are influenced by how older people approach their role in their binomial relationship with healthcare professionals. Those with a reinforced self-concept know that their personality has traits that make them face health-disease-related situations effectively and be communicatively assertive. In contrast, others with specific profiles make them lose sight of their potentially essential role in 'taking care of themselves'. Healthcare professional characteristics are vital in how older people modulate their acting ability. Their personality, their communication skills and the type of approach healthcare professionals use towards older adults are what this study has reflected. The study phenomena are distorted due to how older people and healthcare professionals relate. When there is an imbalance of power between the two, reproduced through the discourse in those cases in which the relationship is not therapeutic, it causes situations of ageism. Then, the older person can perceive discrimination, differentiating the shared decision-making situations from those that are not (mirages), inhibiting the expression of their preferences, and preventing them from participating in their care. The context is a component that rose strongly, tipping the balance from one therapeutic side to another of *domination*, and vice versa, regulating how the study phenomena appear, interrelate and condition care in community-dwelling older adults. Regarding implications for future research and clinical practice, the great asset of this study is to offer a joint vision of the phenomena studied, allowing, on the one hand, favouring more integrative research and, on the other, making visible the care of the three elements to create new nursing-based interventions that act by synthesising them.

Author affiliations
¹Department of Nursing, Pharmacology and Physiotherapy, Faculty of Medicine and Nursing, University of Córdoba (UCO), Córdoba, Andalucía, Spain
²Interdisciplinary Research Group in Discourse Analysis (HUM380), University of Córdoba (UCO), Córdoba, Andalucía, Spain
³Nursing and Healthcare Research Unit (Investén-isciii), Instituto de Salud Carlos III, Madrid, Spain
⁴Ciber Fragility and Healthy Aging (CIBERFES), Madrid, Spain
⁵Department of Language Sciences, Faculty of Philosophy and Letters, University of Córdoba (UCO), Córdoba, Andalucía, Spain

ORCID iDs
Pablo Martínez-Angulo http://orcid.org/0000-0003-1515-2210
Manuel Rich-Ruiz http://orcid.org/0000-0003-3317-267X

REFERENCES

1 World Health Organization. World report on ageing and health. 2015. Available: https://apps.who.int/iris/handle/10665/186463
2 Clancy A, Simonsen N, Lind J, et al. The meaning of dignity for older adults: A meta-synthesis. *Nurs Ethics* 2021;28:878–94.
3 Šaňáková Š, Čáp J. Dignity from the nurses' and older patients' perspective: A qualitative literature review. *Nurs Ethics* 2019;26:1292–309.
4 Butler RN. Ageism: A Foreword. *J Soc Issues* 1980;36:8–11.
5 Marques S, Mariano J, Mendonça J, et al. Determinants of Ageism against older adults: A systematic review. *Int J Environ Res Public Health* 2020;17:2560.
6 Rababa M, Hammouri AM, Hweidi IM, et al. Association of nurses' level of knowledge and attitudes to Ageism toward older adults: cross-sectional study. *Nurs Health Sci* 2020;22:593–601.
7 Wyman MF, Shiovitz-Ezra S, Bengel J. Ageism in the health care system: providers, patients, and systems. *Contemp Perspect Ageism* 2018:193–212.
8 Bynum JPW, Barre L, Reed C, et al. Participation of very old adults in health care decisions. *Med Decis Making* 2014;34:216–30.
9 Chiu C, Feuz MA, McMahan RD, et al. "Doctor, make my decisions": decision control preferences, advance care planning, and satisfaction with communication among diverse older adults. *J Pain Symptom Manage* 2016;51:33–40.
10 Hoffmann T, Jansen J, Glasziou P. The importance and challenges of shared decision making in older people with Multimorbidity. *PLOS Med* 2018;15:e1002530.
11 Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine* 1997;44:681–92.
12 Elwyn G, Frosch D, Thomson R, et al. Shared decision making: A model for clinical practice. *J Gen Intern Med* 2012;27:1361–7.
13 Roy N, Dubé R, Després C, et al. Choosing between staying at home or moving: A systematic review of factors influencing housing decisions among frail older adults. *PLOS ONE* 2018;13:e0189266.
14 Coulter A, Collins A. *Making shared decision-making a reality: no decision about me, without me*. London: King's Fund, 2011.
15 Hestevik CH, Molin M, Debesay J, et al. Older persons' experiences of adapting to daily life at home after hospital discharge: a qualitative Metasummary. *BMC Health Serv Res* 2019;19:224.
16 Swift JK, Callahan JL, Vollmer BM. Preferences. *J Clin Psychol* 2011;67:155–65.
17 Houska A, Loučka M. Patients' autonomy at the end of life: A critical review. *J Pain Symptom Manage* 2019;57:835–45.
18 Wendler D, Rid A. Systematic review: the effect on Surrogates of making treatment decisions for others. *Ann Intern Med* 2011;154:336–46.
19 Jansen J, McKinn S, Bonner C, et al. General practitioners' decision making about primary prevention of cardiovascular disease in older adults: A qualitative study. *PLOS ONE* 2017;12:e0170228.
20 Wrede-Sach J, Voigt I, Diederichs-Egidi H, et al. Decision-making of older patients in context of the doctor-patient relationship: A typology ranging from "self-determined" to "doctor-trusting" patients. *International Journal of Family Medicine* 2013;2013:1–10.
21 Medicine NA of S Engineering, and, Education D of B and SS and, Division H and M. *Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System*. National Academies Press, 2020.
22 Street RL, Millay B. Analyzing patient participation in medical encounters. *Health Commun* 2001;13:61–73.
23 Charles C, Gafni A, Whelan T. Decision-making in the physician–patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine* 1999;49:651–61.
24 Muthalagappan S, Johansson L, Kong WM, et al. Dialysis or conservative care for frail older patients: ethics of shared decision-making. *Nephrol Dial Transplant* 2013;28:2717–22.
25 Laurell AC. La Salud-Enfermedad Como Proceso social. *Rev Latinoam Salud* 1982;2:7–25.
26 Arredondo A. Análisis Y Reflexión Sobre Modelos Teóricos del Proceso Salud-Enfermedad. *Cad Saúde Pública* 1992;8:254–61.
27 Butler RN. Combating Ageism. *Int Psychogeriatr* 2009;21:211.
28 Palmore E. The Ageism survey: first findings. *Gerontologist* 2001;41:572–5.
29 Michel J-P, Leonardi M, Martin M, et al. WHO's report for the decade of healthy ageing 2021–30 sets the stage for globally comparable data on healthy ageing. *The Lancet Healthy Longevity* 2021;2:e121–2.
30 Sandelowski M, Barroso J. *Handbook for synthesizing qualitative research*. springer publishing company, 2006.
31 Sutton A, Clowes M, Preston L, et al. Meeting the review family: exploring review types and associated information retrieval requirements. *Health Info Libr J* 2019;36:202–22.
32 Noblit GW, Hare RD, Hare RD. Meta-Ethnography. In: *Meta-Ethnography: Synthesizing Qualitative Studies*. 2455 Teller Road, Thousand Oaks California 91320 United States of America: SAGE, 1988.
33 Sandelowski M, Docherty S, Emden C. Qualitative Metasynthesis: issues and techniques. *Res Nurs Health* 1997;20:365–71.
34 Leary H, Walker A. Meta-analysis and meta-synthesis Methodologies: rigorously Piecing together research. *TechTrends* 2018;62:525–34.
35 Ludvigsen MS, Hall EOC, Meyer G, et al. Using Sandelowski and Barroso's meta-synthesis method in advancing qualitative evidence. *Qual Health Res* 2016;26:320–9.
36 Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLOS Med* 2009;6:e1000097.
37 Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 2012;12:181.

38 Atkins S, Lewin S, Smith H, *et al*. Conducting a meta-Ethnography of qualitative literature: lessons learnt. *BMC Med Res Methodol* 2008;8:21.
39 Kuper A, Lingard L, Levinson W. Critically appraising qualitative research. *BMJ* 2008;337:337/aug07_3/a1035.
40 Lincoln YS, Guba EG, Pilotta JJ. Naturalistic inquiry. *International Journal of Intercultural Relations* 1985;9:438–9.
41 Dhakal K. Nvivo. *J Med Libr Assoc* 2022;110:270–2.
42 Sandelowski M. Real qualitative researchers do not count: the use of numbers in qualitative research. *Res Nurs Health* 2001;24:230–40.
43 Onwuegbuzie AJ. Effect sizes in qualitative research: A Prolegomenon. *Qual Quant* 2003;37:393–409.
44 Ricoeur P. *Interpretation Theory: Discourse and the Surplus of Meaning*. TCU Press, 1976.
45 Nilsen ER, Hollister B, Söderhamn U, *et al*. What matters to older adults? exploring person-centred care during and after transitions between hospital and home. *J Clin Nurs* 2022;31:569–81.
46 Hedman M, Pöder U, Mamhidir A-G, *et al*. Life memories and the ability to act: the meaning of autonomy and participation for older people when living with chronic illness. *Scand J Caring Sci* 2015;29:824–33.
47 Crotty BH, Walker J, Dierks M, *et al*. Information sharing preferences of older patients and their families. *JAMA Intern Med* 2015;175:1492–7.
48 Butterworth JE, Campbell JL. Older patients and their Gps: shared decision making in enhancing trust. *Br J Gen Pract* 2014;64:e709–18.
49 Brown EL, Poltawski L, Pitchforth E, *et al*. Shared decision making between older people with Multimorbidity and Gps: a qualitative study. *Br J Gen Pract* 2022;72:e609–18.
50 Mitchell J, Williams E-DG, Perry R, *et al*. You have to be part of the process": A qualitative analysis of older African American men's primary care communication and participation. *Am J Mens Health* 2019;13:155798831986156.
51 Beverly EA, Wray LA, LaCoe CL, *et al*. Listening to older adults' values and preferences for type 2 diabetes care: A qualitative study. *Diabetes Spectr* 2014;27:44–9.
52 Moe A, Ingstad K, Brataas HV. Patient influence in home-based Reablement for older persons: qualitative research. *BMC Health Serv Res* 2017;17:736.
53 Doekhie KD, Buljac-Samardzic M, Strating MMH, *et al*. Who is on the primary care team? professionals' perceptions of the conceptualization of teams and the underlying factors: a mixed-methods study. *BMC Fam Pract* 2017;18:111.
54 Sheridan NF, Kenealy TW, Kidd JD, *et al*. Patients' engagement in primary care: Powerlessness and compounding jeopardy. A qualitative study. *Health Expect* 2015;18:32–43.
55 van Bussel E, Reurich L, Pols J, *et al*. Hypertension management: experiences, wishes and concerns among older people—a qualitative study. *BMJ Open* 2019;9:e030742.
56 Dijk T van. *Discourse and Power*. Bloomsbury Publishing, 2017.
57 Egan C, Naughton C, Caples M, *et al*. Shared decision-making with adults Transitioning to long-term care: A Scoping review. *Int J Older People Nurs* 2023;18:e12518.
58 Shepherd J, Gurney S, Patel HP. Shared decision making and Personalised care support planning: pillars of integrated care for older people. *Clinics in Integrated Care* 2022;12:100097.
59 Bunn F, Goodman C, Russell B, *et al*. Supporting shared decision making for older people with multiple health and social care needs: a realist synthesis. *BMC Geriatr* 2018;18:165.

60 Langberg EM, Dyhr L, Davidsen AS. Development of the concept of patient-Centredness – A systematic review. *Patient Educ Couns* 2019;102:1228–36.
61 Lundby C, Graabaek T, Ryg J, *et al*. Health care professionals' attitudes towards Deprescribing in older patients with limited life expectancy: A systematic review. *Br J Clin Pharmacol* 2019;85:868–92.
62 Gillespie RJ, Harrison L, Mullan J. Deprescribing medications for older adults in the primary care context: A mixed studies review. *Health Sci Rep* 2018;1:e45.
63 Claesson M, Jonasson L-L, Lindberg E, *et al*. What implies registered nurses' leadership close to older adults in municipal home health care? A systematic review. *BMC Nurs* 2020;19:30.
64 Molina-Mula J, Gallo-Estrada J. Impact of nurse-patient relationship on quality of care and patient autonomy in decision-making. *Int J Environ Res Public Health* 2020;17:835.
65 Guarinoni MG, Dignani L, Motta PC. Shared decision making: a Scoping review. *Prof Inferm* 2016;69:141–9.
66 Mannheim I, Wouters EJM, Köttl H, *et al*. Ageism in the discourse and practice of designing Digital technology for older persons: A Scoping review. *Gerontologist* 2022.
67 Ozavci G, Bucknall T, Woodward-Kron R, *et al*. A systematic review of older patients' experiences and perceptions of communication about managing medication across transitions of care. *Research in Social and Administrative Pharmacy* 2021;17:273–91.
68 Levy B. Stereotype embodiment: A Psychosocial approach to aging. *Curr Dir Psychol Sci* 2009;18:332–6.
69 Ofori-Ansah S, Evans M, Jones J, *et al*. Decision-making experiences of young adults with long-term conditions. *J Ren Care* 2022;48:24–40.
70 Wilson K, Flores SA, Olaniran BO, *et al*. 123. Healthcare autonomy among adolescents and young adults in the United States: A Scoping review. *Journal of Adolescent Health* 2023;72:S70–1.
71 Kraun L, De Vliegher K, Ellen M, *et al*. Interventions for the empowerment of older people and informal Caregivers in transitional care decision-making: short report of a systematic review. *BMC Geriatr* 2023;23:113.
72 Ayalon L, Tesch-Römer C. Contemporary perspectives on Ageism. In: *Contemporary Perspectives on Ageism*. Cham: Springer International Publishing, 2018.
73 Strandås M, Bondas T. The nurse–patient relationship as a story of health Enhancement in community care: A meta-Ethnography. *J Adv Nurs* 2018;74:11–22.
74 Pérez-Francisco DH, Duarte-Clíments G, Rosario-Melián JM, *et al*. Influence of workload on primary care nurses' health and burnout, patients. *Safety, and Quality of Care: Integrative Review Healthcare* 2020;8:12.
75 Torrens C, Campbell P, Hoskins G, *et al*. Barriers and Facilitators to the implementation of the advanced nurse practitioner role in primary care settings: A Scoping review. *Int J Nurs Stud* 2020;104:103443.
76 De Maria M, Tagliabue S, Ausili D, *et al*. Perceived social support and health-related quality of life in older adults who have multiple chronic conditions and their Caregivers: a Dyadic analysis. *Soc Sci Med* 2020;262:113193.
77 Felton BJ. Coping and social support in older people's experiences of chronic illness. In: *Stress And Coping In Later-Life Families*. Taylor & Francis, 1990.
78 Fakoya OA, McCorry NK, Donnelly M. Loneliness and social isolation interventions for older adults: a Scoping review of reviews. *BMC Public Health* 2020;20:129.

Supplemental material

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Supplementary Table 1. Checklist of items to include when reporting a systematic review or meta-analysis.

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	1, 2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	2, 3, 5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6, 7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	6, 7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	7

Page 1

Section/topic	#	Checklist item	Reported on page #
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7, 8, 9
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7, 8
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	7, 8, 9
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	8, 9
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	7
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	8, 9
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	10
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome-level assessment (see Item 12).	7
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group and (b) effect estimates and	Not applicable

Page 2

Section/topic	#	Checklist item	Reported on page #
		confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	10-16
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	7
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	10
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., health care providers, users, and policy makers).	17-19
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review level (e.g., incomplete retrieval of identified research, reporting bias).	19, 20
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	21
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	21

Page 3

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Database	Query no.	Search strategy	Results
PUBMED	#1	(((("decision making, shared"[Majr]) OR ("shared decision making"[Title/Abstract])) OR ("shared decision-making"[Title/Abstract])) OR ("mutual decision making"[Title/Abstract])) OR ("mutual decision-making"[Title/Abstract])	
	#2	(((("patient preference"[Majr]) OR ("patient preferences"[Title/Abstract])) OR ("preferences, patient"[Title/Abstract])) OR ("preference, patients"[Title/Abstract])) OR ("preferences, patients"[Title/Abstract])	
	#3	((((("patient participation"[Majr]) OR ("engagement, patient"[Title/Abstract])) OR ("patient engagement"[Title/Abstract])) OR ("involvement, patient"[Title/Abstract])) OR ("patient involvement"[Title/Abstract]))	
	#4	(((((((("aged"[Majr:NoExp]) OR ("aged, 80 and over"[Majr:NoExp])) OR (elder*[Title/Abstract])) OR ("elderly people"[Title/Abstract])) OR ("older"[Title/Abstract])) OR ("older people"[Title/Abstract])) OR ("old people"[Title/Abstract])) OR (old adult*[Title/Abstract])) OR (older adult*[Title/Abstract])	
	#5	((((("qualitative research"[MeSH Terms]) OR ("focus groups"[MeSH Terms])) OR ("qualitative methods"[Title/Abstract])) OR ("qualitative study"[Title/Abstract])) OR ("interview"[Title/Abstract])) OR ("experience"[Title/Abstract])	
	#6	((#1 OR #2 OR #3) AND #4 AND #5) AND (nursing [sh])	
		Filters applied: Last 10 years; Nursing[subheading]; English; Spanish.	**9**
CINAHL	#1	MM ("decision making, shared") OR TI ("shared decision making" OR "shared decision-making" OR "mutual decision making" OR "mutual decision-making") OR AB ("shared decision making" OR "shared decision-making" OR "mutual decision making" OR "mutual decision-making")	
	#2	MM ("patient preference") OR TI ("patient preferences" OR "preferences, patient" OR "preference, patients" OR "preferences, patients") OR AB ("patient preferences" OR "preferences, patient" OR "preference, patients" OR "preferences, patients")	
	#3	MM ("patient participation") OR TI ("engagement, patient" OR "patient engagement" OR "involvement, patient" OR "patient involvement") OR AB ("engagement, patient" OR "patient engagement" OR "involvement, patient" OR "patient involvement")	
	#4	MM ("aged" OR "aged, 80 and over") OR TI ("elder" OR "elders" OR "elderly" OR "elderly people" OR "older" OR "older people" OR "old people" OR "old adult" OR "old adults" OR "older adult" OR "older adults") OR AB ("elder" OR "elders" OR "elderly" OR "elderly people" OR "older" OR "older people" OR "old people" OR "old adult" OR "old adults" OR "older adult" OR "older adults")	
	#5	MH ("qualitative research" OR "focus groups" OR "qualitative methods" OR "qualitative study" OR "interview" OR "experience") OR TI ("qualitative research" OR "focus groups" OR "qualitative methods" OR "qualitative study" OR	

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		"interview" OR "experience") OR AB ("qualitative research" OR "focus groups" OR "qualitative methods" OR "qualitative study" OR "interview" OR "experience")	
	#6	(#1 OR #2 OR #3) AND #4 AND #5	
		Filters applied: Last 10 years; Articles; Nursing; Exclude MEDLINE records; English; Spanish.	**39**
WEB OF SCIENCE	#1	TS=("decision making, shared" OR "shared decision making" OR "shared decision-making" OR "mutual decision making" OR "mutual decision-making")	
	#2	TS=("patient preference" OR "patient preferences" OR "preferences, patient" OR "preference, patients" OR "preferences, patients")	
	#3	TS=("patient participation" OR "engagement, patient" OR "patient engagement" OR "involvement, patient" OR "patient involvement")	
	#4	TS=("aged" OR "aged, 80 and over" OR "elder" OR "elders" OR "elderly" OR "elderly people" OR "older" OR "older people" OR "old people" OR "old adult" OR "old adults" OR "older adult" OR "older adults")	
	#5	TS=("qualitative research" OR "focus groups" OR "qualitative methods" OR "qualitative study" OR "interview" OR "experience")	
	#6	(#1 OR #2 OR #3) AND #4 AND #5	
		Filters applied: Last 10 years; Articles; Nursing; English; Spanish.	**83**
SCOPUS	#1	INDEXTERMS ("decision making, shared") OR TITLE-ABS-KEY ("shared decision making" OR "shared decision-making" OR "mutual decision making" OR "mutual decision-making")	
	#2	INDEXTERMS ("patient preference") OR TITLE-ABS-KEY ("patient preferences" OR "preferences, patient" OR "preference, patients" OR "preferences, patients")	
	#3	INDEXTERMS ("patient participation") OR TITLE-ABS-KEY ("engagement, patient" OR "patient engagement" OR "involvement, patient" OR "patient involvement")	
	#4	INDEXTERMS ("aged" OR "aged, 80 and over") OR TITLE-ABS-KEY ("elder" OR "elders" OR "elderly" OR "elderly people" OR "older" OR "older people" OR "old people" OR "old adult" OR "old adults" OR "older adult" OR "older adults")	
	#5	TITLE-ABS-KEY ("qualitative research" OR "focus groups" OR "qualitative methods" OR "qualitative study" OR "interview" OR "experience")	
	#6	(#1 OR #2 OR #3) AND #4 AND #5	
		Filters applied: Last 10 years; Articles; Nursing; English; Spanish.	**977**
	#1	mjsub("decision making, shared") OR ti("shared decision making" OR "shared decision-making" OR "mutual decision making" OR "mutual decision-making") OR ab("shared decision making" OR "shared decision-making" OR "mutual	

		decision making" OR "mutual decision-making") OR if("shared decision making" OR "shared decision-making" OR "mutual decision making" OR "mutual decision-making")	
PSYCINFO	#2	mjsub("patient preference") OR ti("patient preferences" OR "preferences, patient" OR "preference, patients" OR "preferences, patients") OR ab("patient preferences" OR "preferences, patient" OR "preference, patients" OR "preferences, patients") OR if("patient preferences" OR "preferences, patient" OR "preference, patients" OR "preferences, patients")	
	#3	mjsub("patient participation") OR ti("engagement, patient" OR "patient engagement" OR "involvement, patient" OR "patient involvement") OR ab("engagement, patient" OR "patient engagement" OR "involvement, patient" OR "patient involvement") OR if("engagement, patient" OR "patient engagement" OR "involvement, patient" OR "patient involvement")	
	#4	mjsub("aged" OR "aged, 80 and over") OR ti("elder" OR "elders" OR "elderly" OR "elderly people" OR "older" OR "older people" OR "old people" OR "old adult" OR "old adults" OR "older adult" OR "older adults") OR ab("elder" OR "elders" OR "elderly" OR "elderly people" OR "older" OR "older people" OR "old people" OR "old adult" OR "old adults" OR "older adult" OR "older adults") OR if("elder" OR "elders" OR "elderly" OR "elderly people" OR "older" OR "older people" OR "old people" OR "old adult" OR "old adults" OR "older adult" OR "older adults")	
	#5	ti("qualitative research" OR "focus groups" OR "qualitative methods" OR "qualitative study" OR "interview" OR "experience") OR ab("qualitative research" OR "focus groups" OR "qualitative methods" OR "qualitative study" OR "interview" OR "experience") OR if("qualitative research" OR "focus groups" OR "qualitative methods" OR "qualitative study" OR "interview" OR "experience")	
	#6	(#1 OR #2 OR #3) AND #4 AND #5	
		Filters applied: Last 10 years; English; Spanish.	**687**

Supplementary Table 2: Complete search strategy and filters applied for the meta-synthesis.

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Supplementary Table 3. Effect size metasummary.

| Comprehensive theme | "The imbalance in power relations" promotes a mismatch between the assumption of personal qualities, professional characteristics, and a double-edged context, which can create experiences of discrimination in the elderly | | | | | | | | | | | | | | | | Intrastudy intensity effect size |
| Sub-theme | Recognizing personal qualities | | | Facing professional characteristics | | | Experiences of discrimination | | | Double-edged context | | | | | | | Individual studies´ contribution to sub-themes |
Categories	Attitude	Desire to do	Self-perception	Communicative skills	Personality	Approach	Real opportunity?	Fear	Perceived discrimination	Feeling of safety	Social support	Time pressure	Importance of information	Trust	Society & Culture	Healthcare system organization	
Brown EL et al., 2022	X	X	X		X	X			X				X	X		X	100% (4 out of 4)
Nilsen ER et al., 2021	X	X	X	X	X	X	X			X	X	X	X			X	100% (4 out of 4)
van Bussel E et al., 2019	X		X	X		X	X	X	X	X			X	X			100% (4 out of 4)
Mitchell J et al., 2019			X	X		X			X	X	X	X			X		100% (4 out of 4)
Doekhie KD et al., 2018	X		X			X	X	X	X				X				100% (4 out of 4)
Moe A et al., 2017	X	X		X		X	X			X				X			100% (4 out of 4)
Crotty BH et al., 2015	X	X	X				X			X	X		X	X			75% (3 out of 4)
Hedman M et al., 2015	X	X	X			X	X		X	X	X			X		X	100% (4 out of 4)
Butterworth JE et al., 2014	X	X	X	X	X	X			X	X		X	X	X	X	X	100% (4 out of 4)
Beverly EA et al., 2014		X	X	X	X	X			X	X				X			100% (4 out of 4)
Bynum JPW et al., 2014	X	X	X	X		X	X		X				X				100% (4 out of 4)
Sheridan NF et al., 2012		X	X	X	X	X			X	X	X	X	X	X	X		100% (4 out of 4)
Interstudy frequency effect size Representation of sub-themes in individual studies	75% (9 out of 12)	67% (8 out of 12)	92% (11 out of 12)	67% (8 out of 12)	42% (5 out of 12)	92% (11 out of 12)	58% (7 out of 12)	17% (2 out of 12)	75% (9 out of 12)	75% (9 out of 12)	42% (5 out of 12)	34% (4 out of 12)	67% (8 out of 12)	67% (8 out of 12)	25% (3 out of 12)	34% (4 out of 12)	

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Article no.	Year	Author/ Country	Aims	Age of the participants in years (Mean age)	Sample size (Female/ Male)	Characteristics of the participants[1]	Data collection	Data analysis[2]	Relevant results of importance extracted from the article
P1	2022	Brown EL et al./England	To explore factors influencing Shared Decision Making from the perspectives of older patients with multimorbidity and GPs, to inform improvements in personalized care	65-84 (Unknown)	8 (7/1)	With 2 long-term health problems (n = 3) With 3 long-term health problems (n = 4) With ≥4 long-term health problems (n = 1)	Focus group interview	Braun and Clarke´s (2006) thematic analysis	The barriers to patient enablement for effective shared decision-making were illustrated by the following themes: medicolegal vulnerability, perceptions of time pressure, and a lack of continuity of care; the facilitators´ themes that emerged: increasing consultation duration and improving continuity
P2	2021	Nilsen ER et al./Norway	To explore person-centered care provided to a group of older adults (65+) by understanding their experiences of care received, their participation in care and what matters to them during and after the transition process between hospital and home	72-87 (77,9)	8 (6/2)	Living in own house with a partner (n = 3) Living alone in own house (n = 2) Living alone in own apartment connected to a health center (n = 2) Living in a rented apartment connected to a health center with a partner (n = 1)	Semi-structured individual interview	Gadamer´s (1990) hermeneutic approach	To facilitate shared decision-making, the older care recipients and their relatives must be adequately informed, empowered, and prepared. When discussing treatment and care options with older adults, it is important to talk to them in understandable and relatable language and encourage them to share their experiences. Additionally, it is important to clarify the person's existing knowledge of their own health issues
P3	2019	van Bussel E et al./Netherlands	To explore older peoples' experiences, preferences, concerns and perceived involvement regarding hypertension management	74-93 (81,1)	15 (10/5)	With ≥2 chronic conditions in addition to hypertension (n = 8) With <2 chronic conditions, in addition to hypertension (n = 7) High education (n = 7) Middle education (n = 4) Primary education (n = 2)	Semi-structured individual interview	Braun and Clarke´s (2006) thematic analysis	Older people describe having little involvement in hypertension management, although they have several concerns. Reasons for not discussing the subject included low priority of hypertension concerns, reliance on GPs, or trust in GPs to make the right decision on their behalf. Interviewees would like to discuss tailoring treatment to their needs, deprescription of medication, and ways to reduce side effects. They expected GPs to be more transparent on treatment effects

P4	2019	Mitchell J et al./USA	To provide missing details on older African American men's first-hand experiences with primary care communication and participation, including their perceptions on how patient–provider communication, physician behaviors, and other health system factors influence the quality of their care	Unknown (65,9)	15 (0/15)	High education (n = 11) Primary education (n = 3) Retired (n = 10) Disabled (n = 1) With full or part-time employment (n = 4)	Semi-structured individual interviews conducted by phone	Thematic analysis	Two of the primary themes identified, perceptions of rushed care and racial or ethnic bias in care and communication, focused on important reasons for dissatisfaction with the primary care health experience. The theme regarding companions as a source of support highlighted how older African American men in the study viewed and valued the contributions of their significant others who accompanied them on medical visits. The final theme concerning participants' confidence, assertiveness, and self-advocacy, revealed the salience of men's self-perceptions and demonstrated how men in the study felt fully capable of speaking up for themselves during healthcare interactions
P5	2018	Doekhie KD et al./Netherlands	To openly explore the perspectives of patients, informal caregivers and primary care professionals on patient involvement in the decision-making process in primary care team interactions	62-98 (81,6)	19 (15/4)	With ≥2 chronic conditions (n = 18) With <2 chronic conditions (n = 1)	Semi-structured individual interview	Content analysis	Some patients feel limited in taking on an active role because of their interactions with professionals. They feel treated like passive bystanders in their own care process and that the professionals make decisions for them instead of with them. These patients want to be actively involved and feel obliged to express this explicitly. Other patients want to express their own opinions and wishes but hesitate to do so because of possible negative reactions. Patients sometimes feel that professionals do not always value their opinion, while in some situations, they feel they know best
P6	2017	Moe A et al./Norway	To gain knowledge about conversation processes and patient influence in formulating the patients' goals	67-90 (80)	8 (5/3)	Living in own private home (n = 8) Married (n = 5) Widow (n = 3)	Semi-structured individual interview	Vaismoradi´s (2016) content analysis	Challenges in the process were sometimes limited patient involvement, which led to ascribed goals formulated by the health worker. Patients' active participation in the conversations mainly varied with tactics or ways of professional leadership and communication skills used during conversations. When the personnel displayed active listening skills and allowed for patient participation in interactions, this led to patient-staff negotiations and clarification of rehabilitation goals. More often the staff limited

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								and controlled patient participation when patients responded to ascribed goals formulated by the health worker. The findings highlight that patients' share in communication should be taken more into account than what is found. Dialogue where the health staff asked both open and clarifying questions and showed skills in active listening motivated patient participation
P7	2015	Crotty BH et al./USA	To identify how patients older than 75 years wished to share their health information with their caregivers and to understand how elders and families approached the spectrum of information sharing and control	75-86+ (Unknown)	30 (26/4)	Asian (n = 1) White (n = 29) High education (n = 23) Middle education (n = 5) Primary education (n = 2)	Focus group interview	Immersion/ crystallization technique through an iterative process	The more independent elder participants had difficulty picturing themselves losing control of their decision-making capabilities and having to rely on their children. Throughout discussions, elders acknowledged the importance of keeping a sense of control of their health care and decision-making. Elders expressed a level of certainty in their decision-making abilities and did not want their family to hinder their sense of control. Control exerted regarding health information depended on the context of an elder's age and health status. Elders acknowledged that sharing all parts of their health information would be important during an emergency but would not be necessary or ideal daily. Elderly participants recognized that health information and decision-making are more likely to be shared as they age or as health issues arise
P8	2015	Hedman M et al./Sweden	To describe the meaning of autonomy and participation among older people living with chronic illness in accordance with their lived experience	65-84 (Unknown)	16 (7/9)	Urban setting (n = 10) Rural setting (n = 6) Living alone at home (n = 7) Living with another person at home (n = 9)	Semi-structured individual interview	Giorgi´s (2009) descriptive phenomenological psychological method	The meaning of autonomy and participation emerged when it was challenged and evoked emotional considerations of the lived experience of having a chronic illness. The meaning of autonomy and participation was living a life apart, yet still being someone able as an older person living with chronic illness. The meaning of autonomy and participation was still being trustworthy and being given responsibility The meaning of autonomy and participation was being seen and acknowledged

P9	2014	Butterworth JE et al./England	To investigate the association between older patients' trust in their GP and their perceptions of shared decision making	65-95+ (Unknown)	20 (11/9)	With ≥1 chronic conditions (n = 14) Married (n = 7) Divorced (n = 3) Widow (n = 6) Never married (n = 2)	Semi-structured individual interview	Thematic analysis	Some participants expressed definite trust in a GP's opinion, particularly those who had experienced continuity of care. An explanation of this opinion was usually valued, however, and perceived by participants to represent patient involvement, augmenting their trust. The provision of patient choice as a method of involvement was frequently valued and expressed greater trust in a GP who provided a definitive view in respect of their care. Participants discussed trust in the context of factors that affected their preferences for involvement. The oldest participants acknowledged increasing awareness of their own health and self-confidence in older age, wishing for information about ever more complex healthcare requirements. Characteristics that facilitated their involvement in decisions about their health care were a patient-centered, caring, attentive, and holistic approach; appearing open and honest; and treating the patient as an equal.
P10	2014	Beverly EA et al./USA	To explore older adults' values and preferences regarding type 2 diabetes care	60-83 (71,3)	25 (14/11)	Range of health conditions, including diabetes among the participants = 2-7 High education (n = 13) Married (n = 15) Retired (n = 21)	Focus group interview	Content analysis	Some participants said that their physician had never explicitly asked them about their values and preferences for diabetes care and, as a result, had not seriously considered their values and preferences for care. Overall, participants valued a strong working relationship with their diabetes physicians. Further, older adults valued physicians who encouraged them to be involved in their own care and listened to their concerns. Interestingly, several participants discussed end-of-life decision-making preferences in three of the five focus groups. For them, diabetes care preferences that would allow them to maintain the quality of life they valued extended beyond immediate treatment decisions. These individuals said that It was their choice whether to continue with their treatments and it was their choice whether to be resuscitated

P11	2014	Bynum JPW et al./USA	To understand the level of participation of very old adults, understand the process by which participants experience medical decision making, and identify barriers to greater participation in their health care decision making, in particular those that may be modifiable	80-93 (84)	29 (17/12)	Black (n = 6) Non-Hispanic white (n = 23) Widow (n = 17) Married (n = 10) Divorced (n = 1) Single (n = 1) Middle education (n = 14) High education (n = 15)	Semi-structured individual interview	Constant comparative method	The differences in decision processes across the types of care, from surgery to routine testing, highlight the importance of whether the participants felt there were any options for them to consider or even any decision to be made. There were many instances in which the participant did not perceive a choice or even that a decision was being made. Many participants described low overall participation. Some explicitly stated that they did not participate. Several barriers in communication between the patient and physician could interfere with patients engaging in the decision process. Communication barriers precluded the possibility of information sharing and dissuaded participants from asking questions
P12	2012	Sheridan NF et al./New Zealand	To explore what poor older adults, who mostly belong to ethnic minority groups with high needs, say they want from clinicians and uncovered patient powerlessness and low engagement in primary care consultations	55-75+ (Unknown)	42 (21/21)	From minority ethnic groups (n = 32) Living with family (n = 33) Living alone (n = 6) In residential care (n = 3)	In-depth interview	Street´s (2009) communication model	Few differentiated between seeing a nurse or doctor, and only one participant said a GP had made a home visit. Most participants described their relationship as 'very good', 'fine', or 'clinical', but their stories of interactions with either GPs or practice nurses revealed dissatisfaction. Being objectified and feelings of invisibility were expressed, as the practice nurses' lack of involvement. Repeatedly participants reported being upset at how they were spoken to and feeling unheard or disregarded. Cultural gestures were also seen to play an important part in revealing the subtext

[1]Only those characteristics with the most relevant information for this meta-synthesis were extracted from each study.

[2]The terminology used by the authors in the denomination of the analytical process to be followed has been respected.

Supplementary Table 4. Intra-studies characteristics.

Supplementary Table 5. Characteristics across selected studies.

Item	No. of studies addressing each item (n = 12)
Design	
Phenomenology	2
Hermeneutics	1
Grounded theory	1
Naturalistic inquiry	1
Not specified	7
Older patients´ health condition[2]	
Diabetes	5
Hearing problems	2
Vision problems	2
Physical limitation	2
Stroke	2
Parkinson´s disease	2
Cancer	3
Rheumatic disease	1
Arthritis	3
Gout	1
Hypertension	3
Cardiovascular disease	4
Heart disease	3
Kidney disease	2
COPD	3
Asthma	2
Osteoporosis	1
Depression	2
Epilepsy	1
Paraplegic	1
Neurological diseases	2
Musculoskeletal diseases	1
Multiple sclerosis	2
Not specified	4
Sampling strategy	
Purposive	9
Consecutive	1
Convenience	1
Not specified	1
Informants other than older patients	
Yes	3
No	9
Setting of data collection[1]	
Community site	2
Senior center	1
Home	7
University room	1
General practices	2
By phone	1
Field notes taken in addition to interviews	
Yes	9
Not specified	3
Audio/visual recording	
Audio recorded and transcribed verbatim	12
Data coders	
Two or more coders	9
One coder	2
Not specified	1
Use of software	
NVivo	4
Atlas.ti	3
Dedoose	1
MAXQDA Plus	1
Not specified	3
Argued use of trustworthiness criteria	
Yes	8
Not specified	4
Argued use of consolidated reporting framework	
COREQ	4
Not specified	8

[1,2] An article may have multiple responses for these items (not mutually exclusive).

Supplementary Table 6: Analysis of the studies included in the meta-synthesis using the instrument for qualitative studies Critical Appraisal Skills Programme (CASP).

Criterion \ Articles	Brown EL et al. (2022)	Nilsen ER et al. (2021)	van Bussel E et al. (2019)	Mitchell J et al. (2019)	Doekhie KD et al. (2018)	Moe A et al. (2017)	Crotty BH et al. (2015)	Hedman M et al. (2015)	Butterworth JE et al. (2014)	Beverly EA et al. (2014)	Bynum JPW et al. (2014)	Sheridan NF et al. (2012)
1. Was there a clear statement of the aims of the research?	+	+	+	+	+	+	+	+	+	+	+	+
2. Is a qualitative methodology appropriate?	+	+	+	+	+	+	+	+	+	+	+	+
3. Was the research design appropriate to address the aims of the research?	-	+	-	-	+	+	-	+	-	-	+/-	-
4. Was the recruitment strategy appropriate to the aims of the research?	+	+/-	+	+	+	+	+	+	+	+	+	+
5. Was the data collected in a way that addressed the research issue?	+/-	+/-	+	+	+	+	+	+/-	+/-	+	+	+
6. Has the relationship between researcher and participants been adequately considered?	-	+	-	-	+/-	-	-	-	+	-	+/-	-
7. Have ethical issues been taken into consideration?	+	+	+	-	+	+	+/-	+	+	+/-	-	+
8. Was the data analysis sufficiently rigorous?	+	+/-	+	+	+	+	+	+	+	+	+	+
9. Is there a clear statement of findings?	+	+	+	+	+	+	+	+	+	+	+	+
10. How valuable is the research?	+	+	+	+	+	+	+	+	+	+	+	+
Overall Score (%)	75	85	80	70	95	90	75	85	85	75	80	80

Legend:
+ = Yes = 10 points; +/- = Can´t tell = 5 points; - = No = 0 point