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Stakeholder perceptions of dementia in Colombia: a qualitative study

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Abstract

Background The global rise in dementia prevalence poses a significant public health challenge, particularly in low- and middle-income countries where resources for diagnosis, treatment, and support are constrained. Addressing this issue, the World Health Organization's 2017–2025 global action plan on dementia envisions a future where dementia is preventable, and individuals with dementia and their caregivers receive dignified support.

Methods Using a qualitative research design, this study explores stakeholder perspectives on dementia in Colombia, framed by the World Health Organization's global action plan. Semi-structured interviews were conducted with 12 key stakeholders from the academia, government, and the community. Data were analyzed using framework analysis.

Results The interviews revealed a lack of recognition and prioritization of dementia as a public health concern in Colombia. Stakeholders expressed consensus on several challenges, including inadequate community awareness, persistent stigma, insufficient services across care levels, a lack of education for healthcare professionals, and a deficit in research characterizing the dementia population. Paradoxically, participants noted a positive trend, indicating growing awareness among both scientific and non-scientific populations.

Conclusions Dementia must urgently be recognized as a public health priority in Colombia. The identified barriers underscore the struggles faced by individuals with dementia and their families, emphasizing the critical need for increased community and governmental awareness.

Keywords Dementia, Stakeholders, Public health, Dementia plan, Qualitative research

The article provides a qualitative analysis of stakeholders' perspectives on the dementia situation in Colombia, a middle-income country with limited resources for diagnosis, treatment, and support. It is framed within the context of the World Health Organization's (WHO) global action plan on the public health response to dementia, which emphasizes the need to improve the lives of people with dementia, their caregivers, and their families while mitigating the impact of dementia on communities and countries. Our study sheds light on the challenges and opportunities associated with optimizing the approach to dementia care in Colombia.

Introduction

Dementia is a chronic neurological disease that affects 50 million globally, and it is expected that this number rise to 82 million in 2030 and 152 million in 2050. It is estimated that a new case of dementia is diagnosed every 3 s. Moreover, 60% of persons with dementia live in low- and middle-income countries with limited resources for dementia diagnosis, treatment, and support [1].

Colombia is a middle-income country, with a dementia prevalence of 1.3% to 23.6%, according to different

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studies [2–4]. Furthermore, Colombia has the biggest population affected by a single genetic mutation on the presenilin 1 (PSEN1) gene, which is a cause of early-onset Alzheimer's disease [5]. In Colombia, dementia is a high-cost condition. The average minimum per year/person cost varies depending on the disease stage, being 750 USD for the mild stage, 2000 USD (moderate), and 4250 USD, with an average cost of 16,500 USD per person during eight years without including formal care costs and 49,500 USD including it [6].

The World Health Organization (WHO) and Alzheimer's Disease International (ADI) have taken initiatives to establish dementia as a global public health priority [7]. In 2017, the WHO published the global action plan on the public health response to dementia 2017–2025 that envisions a world in which dementia is prevented, and persons with dementia and their caregivers live well and receive the care and support they need to fulfill their potential with dignity, respect, autonomy, and equality. This plan aims to improve the lives of persons with dementia, their careers, and their families while decreasing the impact of dementia on them, their communities, and their countries. The global action plan comprises seven action areas: 1) dementia as a public health priority, 2) dementia awareness and friendliness, 3) dementia risk reduction, 4) dementia diagnosis, treatment, care, and support, 5) support for dementia caregivers, 6) information systems for dementia, and 7) dementia research and innovation [8]. As of 2023, the global response to dementia remains uneven, with only 39 out of the total member states, roughly a fifth of the world, having formulated a dedicated national dementia plan. Another 22 countries and territories are actively working on developing dementia plans or integrating them into broader national strategies for non-communicable diseases. This statistic highlights a significant gap in addressing the challenges posed by dementia on a global scale [9].

It has been reported that when designing and planning actions for care and support of this disease, perspectives from the actors directly involved with the disease are not always considered [10]. To ensure that the dementia plan is relevant to population needs, particularly persons living with dementia, their families, caregivers, and health providers, it is essential to include their opinions and participation. This also contributes to guarantee the plan´s appropriation and implementation [11, 12]. Moreover, stakeholders are crucial in establishing priorities to ensure that a dementia plan responds to the complex and multi-sectorial needs of the disease. As a consequence, engaging stakeholders can significantly improve the quality of life for individuals with dementia, addressing disparities in dementia care [13–15]; as this approach targets power imbalances, champions social justice, minimizes research waste, speeds up the translation of research into practice, and underscores the collaborative creation of knowledge with both researchers and lay stakeholders [16].

In Colombia, the older population is growing, by 2050, the proportion of people age 60 and over is estimated to increase to 25 percent (up from 13.9 percent in 2021) [17]; therefore, dementia prevalence is expected to rise [18] [18]. Nevertheless, evidence to guide the design of a national dementia plan is scarce. In particular, there are gaps in the comprehension and consideration different stakeholders have about this condition, the required public policies to respond to dementia prevention, diagnosis and treatment, care and family support, and the social and health care resources needed for optimum care. The country does not have policies oriented to Alzheimer's disease or related dementias, and there is no acknowledgment of the particular needs of this population [19]. Finally, there is no report of a national dementia plan [20].

In this study, we examined stakeholders' perspectives on the dementia situation in Colombia qualitatively, having as a framework the seven action areas of the WHO global action plan on the public health response to dementia.

Methods

From March to August 2021, we conducted a qualitative descriptive study [21, 22]. With this type of study, we sought to understand the perspectives of different types of stakeholders in the Colombian context regarding dementia epidemiology, public policy, research and care. This research was approved by Universidad de los Andes IRB (act1114/2019).

Sampling

For participant selection, stratified purposeful sampling was used [23]. For this sampling strategy, four strata were created: 1) members from the community and associations of persons living with dementia and their families, 2) clinicians (psychiatrists, neurologists, geriatricians), 3) dementia researchers, and 4) members of government institutions. This strategy was aimed at engaging participants possessing in-depth and rich knowledge about dementia in Colombia. The goal was to gain insights into their perceptions of the disease, explore alternative approaches to addressing this condition, and examine ways in which stakeholders could actively participate in the development of a national dementia plan.

Initially, the principal investigator (AG) identified potential participants of each stratum. Subsequently, the list was expanded, incorporating suggestions from various stakeholders who considered input from their own working or professional circles and individuals recognized for their contributions to dementia-related work in the country. Based on these inputs, the authors made a final list of participants considering their experience and representation within each stratum. The final list included twenty persons that were invited to participate via e-mail. With the ones who accepted the invitation, an interview was scheduled according to their availability.

Data collection

Using a guide, we conducted semi-structured interviews using video calls via Google Meets®. This approach for data collection allowed us to follow social distancing rules imposed by the Colombian government in response to the COVID-19 pandemic while tried to keep the features of conventional face-to-face interviews using a synchronous online approach [24].

Table 1 shows examples of the questions included in the guide for the three topics that guided this study. Interviews lasted approximately one hour and were recorded and transcribed verbatim. The principal investigator (AG) reviewed transcriptions to verify the accuracy of information provided by each participant.

Data analysis

Data were analyzed using framework analysis, an analytic approach appropriate to analyze qualitative data for public policy formulation [25, 26]. Framework analysis adopts a systematic way to select and classify information using key themes, and five steps are followed: familiarization, framework, indexing, charting, and interpretation [27, 28]. Each of the seven WHO action areas served as a major theme, with three key subthemes under each: Current Situation, Challenges, and Opportunities. NVIVO 12 (Doncaster, Australia: QSR International Pty Ltd) was used for the organization needed for the data analysis.

Results

Twelve of the twenty persons invited to participate were interviewed. Eight persons did not participate because seven did not respond to our e-mail invitation, and one was unavailable. Of the participants, two were community members from associations of relatives of persons living with dementia; two were clinicians, two were dementia researchers, and one was a member of a government institution. The other five participants had mixed roles: three clinicians- researchers and two clinicians – government workers. Eight participants were from Bogotá, and four among them resided in different Colombian cities, namely Cali, Medellín, Barranquilla, and Manizales. On average, participants had experience working on dementia for 13.7 years (Table 2).

Results are described according to the seven action areas of the WHO global dementia plan. Area six, information systems for dementia, was not mentioned by participants and thus was not included in the results. Because overlap, some aspects regarding dementia risk reduction were included in the public health response and awareness section.

Dementia as a public health priority

In general, participants described that in Colombia, dementia is not given importance, and it is not considered a public health priority.

> *'In our country, dementia is an invisible disease.' (P02)*

> *'Colombian government is not aware of the magnitude of the problem.' (P01)*

All participants agreed that dementia was not receiving the attention it deserved from the government for various reasons. Firstly, they noted that the government has not allocated sufficient economic and human resources toward understanding and addressing dementia. While some efforts have been made, there is a lack of unified guidelines for approaching dementia between the health minister and regional health departments. Additionally, the participants were not aware of any initiatives from the healthcare sector aimed at prioritizing dementia. They pointed out that most of the dementia initiatives in the country were grassroots efforts, indicating a lack of official support. The group also highlighted the importance of understanding specific population characteristics, genetic factors, and population risk profiles, which the government has not thoroughly studied. Moreover, the government has yet to assess the impact of social determinants of health, such as poverty, social isolation, and health and education barriers.

> *´The ministry has worked on publishing national guidelines; however, their reach is limited as they do not impact the general population or the training of healthcare professionals. ´ (P04)*
> *'Decisions are taken top-down, without taking population background to formulate or implement public policies; these policies are usually taken from other contexts, countries with different characteristics without considering our country's diversity. As a result, policies do not work.'(P10)*

Participants pointed out that the outlined above showed backwardness compared to high-income countries and others from Latin America.

> *'Dementia is a public health issue in high-income*

Table 1 Examples of questions included in the interview

Topic	Question
Perceptions about dementia in Colombia	- How much importance is given to dementia in Colombia? - Is dementia considered a public health priority in Colombia? Why? - How do you think the general public perceives/understands dementia in Colombia?
Experience working in the dementia field in Colombia / Knowledge about the situation of dementia in Colombia	- What kind of interventions have been carried out to address this problem in Colombia? - Which actors have been involved in the interventions that have been carried out? Why and how? - Do you know of any kind of public policy that might have some influence on dementia prevention? Are there any policies that target dementia directly or indirectly?
Challenges, barriers and opportunities to address dementia in Colombia	- Based on your experience. What are the main constraints for formulating and implementing public policies or interventions to address dementia in the country? - What are the alternatives and opportunities to overcome the identified barriers? - Who should be involved in these initiatives?

> *countries and some Latin American countries; they have included dementia in the public agenda, asking for resources and designing plans for its attention. For example, in France, before WHO established dementia as a public health priority, in 2007, they launched a program for dementia care; other countries like Australia, Belgium, and Canada have strategies designed from their own specific characteristics.' (P10)*

Secondly, no policies approached dementia directly, and there was no national registry of persons living with dementia. However, the participants that have been involved with the government and working on public policy development, such as the national aging policy, mentioned that the government has been working on some interventions for older persons that benefits indirectly persons living with dementia. Some examples provided by the participants were the ratification of the Inter-American Convention on Protecting the Human Rights of Older Persons, updating the national aging policy, updating the national route for care and maintenance of mental health that includes brief screening tools for cognitive impairment and research projects as SABE study, and the national mental health survey. Locally, there are community tools for older persons' participation. Even though a researcher and a clinician mentioned:

> *'There are no policies focused directly on dementia. Policies such as mental health and aging address*

Table 2 Participant Characteristics

Participant ID	Gender	Role	Location	Experience in dementia work (years)
P1	Female	Researcher	Bogota	15
P2	Female	Clinician/Government	Bogota	12
P3	Female	Community member	Bogota	22
P4	Male	Clinician/Government	Bogota	10
P5	Male	Government	Bogota	24
P6	Male	Clinician/Researcher	Bogota	8
P7	Male	Clinician	Bogota	8
P8	Female	Clinician/Researcher	Medellin	14
P9	Male	Clinician/Researcher	Manizales	20
P10	Female	Researcher	Bogota	16
P11	Female	Community member	Barranquilla	10
P12	Female	Clinician	Cali	6

> *topics like human rights, dignified and healthy old age, and disabilities without approaching dementia in depth; the same happens with disabilities and vulnerable populations policies. Some resolutions, like 055/2018 and 5592/2015, focus scarcely on dementia-related topics.'(P10)*
> *'Policies for noncommunicable diseases such as obesity, diabetes, and hypertension, known dementia risk factors, ignore this association and dementia preventable nature.' (P06)*

Third, participants commented that there was no health promotion and disease prevention approach for dementia in Colombia. There were no community awareness campaigns with a national scope for the community to learn about dementia modifiable risk factors, early signs and symptoms, and how to seek help.

> *'Awareness and prevention campaigns are not conducted regularly; only occasional campaigns are held.'(P03)*

Fourth, the available resources and dementia references on official governmental documents were tangential, superficial, and from the approach of other conditions such as chronic diseases or orphan diseases.

> *'We have regulations with partial recognition, with guidelines for the aging stage which are unclear and do not deepen the needs of persons living with dementia.' (P06)*

However, this view of the importance and priority given to dementia varies depending on the stakeholder involved; researchers and government participants perceived a growing interest in this condition on the part of the government. On the other hand, clinical actors and members of family associations of patients thought that dementia did not have governmental visibility because it is a disease of older adults who are frequently not "taken into account" or perceived as important by the health system. The clinical participants and members of patient associations also mentioned the importance that older adults have gained due to the COVID-19 pandemic, not because of dementia, but because of their needs and vulnerability to some medical conditions.

> *´Due to the pandemic, aging has gained different significance as the issue has become more visible´(P05)*

The participants mentioned that the most involved and interested stakeholders in generating changes and advances regarding dementia in the country had been the researchers and the community, which have led different activities that seek to draw attention to dementia, such as symposiums for professionals and the community, informative campaigns through social networks, the inclusion of dementia in the training of health care workers. However, these efforts are usually carried out at the local level by small and centralized groups; as a result, the expected impact and scope were not enough.

> *'Then one sees that sometimes it is challenging to reach the entire population in the way that one would like, but I believe that it is important to remember that even though we are on the right track, all the efforts are still quite insufficient.' (P09)*

The researchers and clinicians who participated acknowledged that the government had made some efforts to study the current state of dementia in the country, mainly through initiatives such as the SABE Survey (2015), the Mental Health Survey (2015), and the publication of the national dementia guideline for clinical practice in 2017. However, the participants also noted that the evidence provided by these studies was insufficient to guide effective public policies for dementia care. The data quality was deemed inadequate, and its application in settings beyond the clinical was limited. As a result, there was a need for more comprehensive and higher-quality data to inform public policy decisions on dementia. One participant specializing in dementia echoed this sentiment, underscoring the urgency of improving the quality of data and evidence available to support better dementia care policies:

> *'The needs of persons living with dementia and their caregivers that go beyond the medical, family, political, social and economic aspects have not been identified.'(P08)*

The participants proposed several alternatives to improve government care for dementia in the country. For example, the participants proposed the creation of dependencies/offices in the Ministry of Health and Social Protection and in the health secretariats to generate public health initiatives and establish lines of action for the care of older people, ensuring the creation and implementation of the national dementia plan which should be focused on establishing actions plans and resource allocation, strengthening memory clinics, community awareness campaigns, early diagnosis strategies, and dementia treatment, pharmacological and non-pharmacological.

> *'We have to stablish departments/offices within the Ministry of Health and Social Protection or the Health Secretariat dedicated to dementia: implement public health actions and set guidelines for the care of older adults in the country.' (P02)*

Finally, to improve the public health response to dementia, the importance of changing the problem identification strategy and studying the phenomenon directly with the affected population was mentioned, as well as designing public policies from end users and dementia professionals' perspectives, who are the ones who give real-world ideas to transform them into concrete actions to support patients and their families.

> *"Shift the model of problem identification and study to directly engage the affected population, and implement policies from the perspective of those impacted, including end-users and professionals, who provide ideas to transform them into concrete actions." (P10)*

Dementia awareness and friendliness

> *'Colombia is a heterogeneous country; the representation, experience, and imaginary of dementia are different in all contexts.' (P10)*

For the participants, the knowledge and importance that the general community gives to dementia were insufficient since, in most cases, the symptoms are attributed to "normal" aging, associated with a person's expected to decline over the years. According to participants, understanding dementia because of aging leads persons to live with this condition and their relatives to adapt and generate tolerance towards the symptoms, therefore delaying diagnosis.

> *'There is community permissiveness towards the elderly about forgetfulness, behavioral changes, and psychiatric symptoms.'(P06)*

On the other hand, the participants mentioned that there were many myths related to dementia. Among these myths, they talked about the relationship between dementia and madness, the idea that neuropsychiatric conditions are divine punishment, and that the disease also causes aggressiveness in persons, making them dangerous to the community, resulting in isolation, exclusion, and early institutionalization due to shame of the relatives. This phenomenon was described for persons who already had a diagnosis of dementia.

> *´There are many myths surrounding this issue. People with dementia are often viewed as potentially aggressive or a danger to the community, leading to social exclusion, and caregivers may end up confining or institutionalizing them out of shame or embarrassment.' (P04)*

Despite what was cited regarding the lack of information and knowledge of the disease, and little understanding of the symptoms in the general community, the participants pointed out that in recent years there has been a contrast between persons living in urban areas and rural areas. Urban residents have greater economic resources and access to information, leading them to show a growing interest in learning about the subject and greater concern when memory symptoms begin compared to persons from rural areas, whom they considered had less knowledge or awareness of the disease. From the perspective of the participants, this increase in knowledge about the disease among people in urban areas may explain the rise they observed in consultations in recent years, as mentioned by one clinician-researcher:

> *'People who are more educated have access to information and are increasingly aware that aging is not a synonym of memory deterioration or behavioral changes, and it is more frequent that they consult now in mild and moderate stages of neurocognitive impairment, in fact, the diagnosis of patients with mild neurocognitive impairment has grown exponentially if we compared ten or fifteen years ago.' (P08)*

The participants also mentioned that there have been different interventions focused on increasing knowledge and raising awareness in society, such as community outreach workshops, workshops on caring for persons with dementia, and the first community meeting on dementia carried out in Bogota (the capital city of Colombia) and developed by a public health sector neurology department.

> *"Various interventions have been introduced to raise community awareness about dementia. Some Health Promoting Entities (EPS) now educate primary care doctors on early dementia diagnosis, aiming to improve early detection. Additionally, the Colombian Association of Psychiatry hosts training sessions on dementia at its congresses, furthering professional knowledge. Universities have begun including dementia in their student curricula, ensuring future healthcare providers are better prepared to address this growing concern. Memory clinics have also emerged, providing collaborative, consensus-driven care with both diagnostic and therapeutic goals. Finally, neuropsychologists are leveraging social media to educate the broader community, helping to dispel myths and foster understanding around dementia´. (P07)*

As future steps, a participant with clinical and governmental experience drew attention to the importance of promoting investment in the older people (silver economy), where companies design their products focused on the needs of the older people and persons living with dementia, in addition to creating a social/business responsibility towards caregivers:

> *'I can envisage the creation of a solidarity economy can help address the needs of caregivers who cannot work due to their caregiving responsibilities.' (P04)*

Another aspect highlighted by the participants was the importance of working with the media to provide practical and truthful information to unify criteria and knowledge at the community level using the concepts of healthy and unhealthy aging in the general population through recreational and simple symbolic models focused on the rural, low-income and low-education population.

> *'People should talk about this over coffee in the afternoon; people should even hum a song that raises awareness of healthy aging and, incidentally, unhealthy aging.'(P06)*

Dementia risk reduction

Continuing with what was mentioned above, the participants said that failures in community education and awareness of the disease had, as a consequence, unawareness in the population of the causes of dementia, its preventive nature, the warning signs, and the importance of an early diagnosis, as well as the relationship of dementia with chronic non-communicable diseases, also, that the symptoms generated by dementia went beyond memory loss and could affect other aspects such as behavior, language or ability to make decisions.

> *'Much-needed awareness campaigns that have an impact on prevention are sorely lacking '. (P12)*
> *´There is a lack of connection between dementia and chronic conditions that are well-known, modifiable risk factors, such as smoking, alcohol consumption, traumatic brain injury, and air pollution´. (P06)*

Dementia diagnosis, treatment, care, and support

The study participants reported a shortage of qualified personnel to care for persons with dementia, and health professionals, particularly general practitioners, lack knowledge about the disease. They emphasized the need for updated, unified, and clarified concepts related to dementia among health professionals. One clinical participant stated:

> *'Primary care physicians, general practitioners, and doctors from other specialties are only focused on the physical, for example, hypertension or diabetes. The healthcare system lacks adequate time and screening methods during medical appointments. At the same time, the doctor does not have an approach to ask about issues of cognitive decline, therefore generating a delay in diagnosis and early intervention´. (P07)*

Regarding the diagnostic process of dementia, the participants mentioned the barriers to communication with health professionals since the terms they used to communicate the diagnosis were confusing. Words such as senile dementia, Alzheimer's disease, and major neurocognitive disorder were unclear to family members and patients. This is evidenced in what was mentioned by a participant member of the community and from an association of relatives of persons living with dementia:

> *'A lady told me: at this moment, I do not know if my mother has a major neurocognitive disorder if she has dementia, if she has Alzheimer's, or if she has senile dementia.'(P03)*

In addition to what was mentioned about the terminology used, from the analysis of the interviews, some participants concluded that the time available to communicate and explain the diagnosis was short, which led the families to begin the process of understanding and assimilating the disease alone. As a result, there was an erroneous approach to the condition due to misinformation, as mentioned by a member of the community and an association of relatives with dementia:

> *'Doctors do not have the time to guide a family on what to do in certain situations, how to get together as a family, how to structure a support network, understand difficult behaviors and address them as a family, how to establish a management consensus, what decisions to take, how to plan everything, it is difficult for the doctor to dedicate the time to do that, they have lots of work. Family members end up searching the internet and making treatment modifications without any recommendation from health professionals.'(P03)*

The participants involved in the clinical care of patients with dementia mentioned that the healthcare companies and the institutions that provide health services offer services such as the memory clinic, which seek to provide comprehensive, consensual, and discussed diagnosis and therapeutic orientation to persons with dementia and their families, there are also services such as day hospitals and in some institutions training is provided to primary care health personnel for early diagnosis of dementia. However, these services are usually available only in large urban areas, thus generating inequitable access to dementia diagnosis, treatment, care, and support in the country. Moreover, they also mentioned that during the care process for persons with dementia, there were no standardized protocols, and there was disarticulation in care and treatment strategies. The current model does not allow an adequate approach with 20-min consultations and long waiting times to access the services.

> *´The current healthcare model does not allow for proper diagnostic and therapeutic approaches to dementia, with only 20-minute consultations, lack of interdisciplinary teams, and long waits for access to specialists. Accessing memory clinics is extremely challenging, and outside of Bogotá, these clinics are non-existent in other cities. ´(P07)*

The participating members of the community and relatives of persons living with dementia mentioned that the non-pharmacological therapies and treatments offered were not oriented towards the older adults and their needs, which decreases their adherence and effectiveness to medicine, in addition to delays in opportunities and changes in the services, some of them are provided intermittently. As mentioned by a member of the community:

> *'My mother once received some therapy in a room with little children, and she was an old woman painting a house; as she was still quite connected, she told me: I am not going back to this anymore, I am not going to be wasting time.' (P11)*

As mentioned by a dementia specialist for further steps, it is necessary to decentralize memory clinics to increase their number and improve access to them to provide comprehensive monitoring of the process and the natural evolution of the disease. As well as creating more day and long-stay centers to offer services to the older people with residential/non-hospital bed costs. Additionally, awareness must be generated in healthcare companies about how the diagnosis of dementia is made to improve care times, access, and training of professionals who care for patients from primary to tertiary care.

> *´Long-term care centers should be organized to offer services for older adults, providing residential (non-hospital) bed options at an affordable cost. ´(P05)*

Support for dementia caregivers

The interviewed members of community-family associations highlighted how they had played a vital role in the development of guidance programs for family members where issues related to the care of persons with dementia are addressed, including the importance of support networks, tips for understanding and addressing the behaviors of persons living with dementia, advice for decision-making, planning, and quality of life. The participants also mentioned interventions led by foundations to offer virtual classes for older adults and by international non-governmental organizations that develop initiatives at the local level. However, until now, there has not been enough social mobilization to make dementia visible and pressure decision-makers to generate public policies for patients and their caregivers. One participant, a member of family associations, mentioned the relevance of her role in the approach to dementia:

> *'We, from the foundation, do not replace the doctor, but we are an important complement; we have an orientation program where we tune in a bit to the reality of the situation, identify needs and provide information.' (P02)*

The participants, reported that due to the COVID-19 pandemic, associations and foundations had had a greater reach, and links have been established with the different family-patient's groups at the national level; however, the number of foundations available is not enough to meet the growing demand of persons living with dementia in the country. They proposed to continue using the virtual tools to carry out workshops with a greater reach to the different associations and groups of family members/patients in the country.

> *´To improve dementia care in the country, various interventions and structural changes are essential. There is a need to leverage lessons from the pandemic by continuing discussions with both local and international experts to expand knowledge and strengthen relationships between associations. ´(P11)*

Dementia research and innovation

The interviewed clinicians and researchers mentioned that some academic and research groups had conducted research and interventions related to dementia. In general, dementia research in the country has been oriented towards characterizing the population with this condition, developing genetic studies, and clinical trials for pharmacological and non-pharmacological interventions. Usually, research has been conducted in communities near the research groups in a few universities in the country. As an example, it was highlighted by the participants the recent publication of the book on the validation of neuropsychological tests for the Colombian population, which allows making a neuropsychological diagnosis adapted to the population.

Regarding education in dementia, academic and research groups have taken the initiative in training health professionals through symposiums, seminars, diploma courses, and congresses and including dementia as a subject of study within the curriculum of undergraduate and graduate students. Likewise, these groups have been involved in socialization and community awareness at the local level through community talks and symposiums for the community. All these initiatives have taken place in most cases with little funding and use of the institutions' or researchers' resources, which makes it difficult to generate solid lines of work at the research level.

> *'I believe that those of us who are interested in these issues have to work almost with our resources, with our own time, then they become efforts, precious but very disaggregated, we work a lot from the immediate need that we observe and with the resource at hand that we have, so it is challenging to be able to make a clear line, towards the generation of public policies and that also has to do with financing, how does one dedicate 100% to an issue without financing?'(P08)*

According to the participants, as future opportunities, universities and research groups could have a more significant role by continuing training programs in dementia for health professionals in urban and rural areas through virtual platforms. The participants involved in the academy, clinicians, and community representatives agreed that it was necessary to increase research at the local level and promote collaborations between the different groups that do dementia research in the country. The participants mentioned the importance of the academy empowering communities and accompanying the conversation with the government to implement public policies. Finally, the participants emphasized the importance of teamwork and the union of medical associations, foundations, research groups, clinicians, and independent professionals specialized in dementia to make visible the situation of dementia in the country, involving decision makers, leading campaigns, and presenting projects to be financed by the government.

> *´From an academic perspective, it is essential to contribute by developing dementia training programs for professionals not only in capital cities but also in rural areas through virtual platforms. This approach can help raise awareness about the disease and improve early diagnosis. Additionally, fostering collaborative work among researchers focusing on dementia within the country can enhance understanding and drive progress in addressing this growing health issue.´ (P01)*

Table 3 and Fig. 1 summarize the findings of this study for each of the action areas of WHO global dementia plan.

Discussion

This study was aimed at having a better understanding of the situation of dementia in Colombia, taking as a reference the global action plan proposed by WHO and identify routes to offer solutions focused on the needs of persons involved with the disease [29–31]. Thus, in this article, we describe the perception of various stakeholders on dementia in Colombia, a Latin American middle-income country where this condition is expected to grow due to the rising older population. Participants of this study represented a group with experience and knowledge about the situation of the disease in the country.

Engaging stakeholder perception is essential for the development of a national dementia plan that effectively meets the goal of preventing, mitigating, and addressing dementia fairly and equitably, especially in low- and middle-income countries, which are expected to face the largest number of cases of this disease in the coming decade's [32, 33]. Recognizing the need to develop or improve instruments, technologies, and public policies for the care of persons living with dementia and their families enable us to identify the weaknesses and strengths of the country and enhance the standards of daily care practice for the disease [34].

The high prevalence of the disease, and its high social and economic impact on families, caregivers, and communities, affecting both high-income and low-income countries, have made this disease a global public health priority that requires government action as stated by WHO and ADI [7, 35, 36]. In low- and middle-income countries where resources are limited compared to high-income countries, the response to dementia as a public health priority in terms of its identification, prevention, recognition, and management is still low [37]. In Latin America, health systems have failed to provide the complex and multidisciplinary actions required by persons with chronic diseases such as dementia [38], which also occurs in Colombia, as mentioned by the participants in this study.

Additionally, in Colombia, there are no policies directly focused on dementia, and the participants are unaware of the existence of a national dementia plan or strategy, which implies a delay compared to other countries in the region [39]. However, the absence of this type of policy is not a particular case in Colombia. Even in high-income countries, including dementia as a public health priority is a recent advance reflecting this pathology's multidimensionality and complexity and the need for its approach to go beyond the traditional health-disease approach [40].

Public policies are recognized as essential to address the impact of dementia on resources and health spending; the strengthening of policies guarantees the identification of prevalence, risk factors, diagnosis, treatment, and social support needed by persons living with dementia and their families [41, 42]. The participants mentioned how, due to this lack of public policies and government action, non-governmental organizations and research groups from academic institutions are the most involved actors with the comprehensive approach to dementia, carrying research and training of the health care workers, which is a phenomenon that is frequently evidenced in low- and middle-income countries [34]. Due to the lack of public policies in many countries, low-cost strategies have been established to compensate for the absence of formal services, creating support networks that seek to generate interventions that improve knowledge and dementia approach [43].

Participants highlighted the importance of designing public policies based on the country's needs and characteristics, considering its cultural, social, and biological diversity. For the appropriate design and adjustment of dementia policies, they must be adjusted to national realities and the capacities of each country to achieve adequate adoption of policies [44]. In addition, it has been seen that national dementia policies, even in countries with advanced economies and leaders in the global community, still have room for improvement to strengthen their plans, especially on issues such as early detection, risk reduction, and prevention, which must be aligned with the latest scientific developments [44].

On the other hand, the participants mentioned how there is still a vast ignorance of dementia in the community, it is considered a normal part of aging, and it is associated with magical thinking with negative connotations and stigma. This finding is consistent with what was evidenced in the 2019 World Alzheimer's Report, which found that approximately two-thirds of people considered dementia a normal part of aging and 1 in 4 interviewees considered that there is nothing to do to prevent dementia, in addition to the stigma associated with the diagnosis where 35% of caregivers have concealed the diagnosis of a person with dementia [45].

In low- and middle-income countries, memory problems and their impact on quality of life are considered minor problems. This normalization creates stigma and barriers to the care and diagnosis of persons living with dementia [46, 47]. The participants in this study mentioned that there is a tolerance on the part of the relatives of persons with dementia regarding cognitive and psychiatric symptoms in the elderly, which coincides with what has been described in the literature and that has been explained as a product of the lack of knowledge of the disease and low expectations regarding the functional performance of older adults [48].

Recently, a change in knowledge and attitudes towards dementia has been described in low- and middle-income countries: urban groups with more significant economic resources know more about the disease and consult at the first symptoms thanks to access to information [47, 49]. It has also been described that people with high educational levels have better knowledge of the disease and attribute its cause to biological factors than those with low education who attribute it to religious/moral factors [50]. This inequity in access to knowledge about the disease generates a more significant burden on vulnerable populations. Therefore, it is crucial to consider the importance of designing accessible strategies adapted to the language and educational level of the communities to improve the early identification of dementia symptoms and promote the search for an early diagnosis and thus reduce regional and educational disparities presented in the knowledge of dementia [51].

Regarding the diagnostic process of dementia, participants mentioned the different barriers between health professionals and the community. The 2019 ADI report showed how 40% of those interviewed consider that health personnel ignores persons with dementia, and 70% believe that doctors were competent for the diagnosis and treatment of dementia [45]. Barriers similar to those mentioned by the participants in this study have been described, such as time [52, 53], lack of clarity in the terms used to communicate diagnosis [54], which has a negative impact on pharmacological and non-pharmacological treatment as well as on the prognosis of the disease, since a comprehensive approach focused on improving the quality of life of persons living with dementia cannot be made [55]. The ADI 2021 survey identified the situation regarding the diagnostic process of dementia from the point of view of persons living with dementia and their caregivers; the lack of time, information, and explanation about the diagnosis and prognosis of the disease was mentioned, finding whereas only 45% of persons with dementia and their caregivers feel that they were given adequate information at the time of diagnosis, barriers to diagnosis were identified as lack of access to qualified clinical staff (47%), fear of diagnosis (46%), costs (34%), clinicians mentioned lack of training to perform the diagnosis (37%), and lack of access to specialized diagnostic tests, the increase in the number of consultations and people seeking diagnosis was also mentioned as a challenge for the future [56]. These barriers were similar to those mentioned by the participants of this study.

In the Lancet Commission on Dementia 2020, it is mentioned that more than 40% of dementia cases can be prevented or delayed if modifiable risk factors are addressed and call on nations to set ambitious targets

Table 3 Summary of Dementia Landscape in Colombia according to action areas of WHO global dementia plan

Action Area	Summary	Sample Quote
Dementia as a public health priority	Participants expressed concerns about insufficient government attention, resources, and unified guidelines. They noted the lack of policies directly addressing dementia and highlight the need for a comprehensive approach	"In our country, dementia is an invisible disease."
Dementia awareness and friendliness	The participants emphasized insufficient awareness in Colombia about dementia, attributing symptoms to normal aging. Myths persist, leading to isolation and early institutionalization. Urban areas show greater awareness, with growing interest and consultations	"Colombia is a heterogeneous country; the representation, experience, and imaginary of dementia are different in all contexts."
Dementia risk reduction	Community education and awareness failures contribute to a lack of understanding about dementia causes, prevention, and early signs. Participants stressed the need for improved education and community campaigns regarding modifiable risk factors and the importance of early diagnosis	'Much-needed awareness campaigns that have an impact on prevention are sorely lacking '
Dementia diagnosis, treatment, care and support	Challenges in dementia care included a shortage of qualified personnel, lack of knowledge among health professionals, and confusion in diagnostic terminology. Limited access to services, absence of standardized protocols, and inadequate non-pharmacological therapies were also highlighted. Participants proposed decentralizing memory clinics	…´ The healthcare system lacks adequate time and screening methods during medical appointments. At the same time, the doctor does not have an approach to ask about issues of cognitive decline, therefore generating a delay in diagnosis and early intervention'
Support for dementia caregivers	Family associations played a vital role in guidance programs for caregivers. Despite increased reach due to the COVID-19 pandemic, there was insufficient social mobilization and not enough foundations to meet the growing demand. Virtual tools were proposed to continue workshops and support programs for caregivers	"We, from the foundation, do not replace the doctor, but we are an important complement."
Dementia research and Innovation	Dementia research in Colombia has focused on population characterization, genetic studies, and clinical trials, mostly conducted in communities near research groups. Limited funding challenges solid research lines. Participants advocated for increased training programs, collaboration between research groups, and involving decision-makers to implement public policies	"I believe that those of us who are interested in these issues have to work almost with our resources."

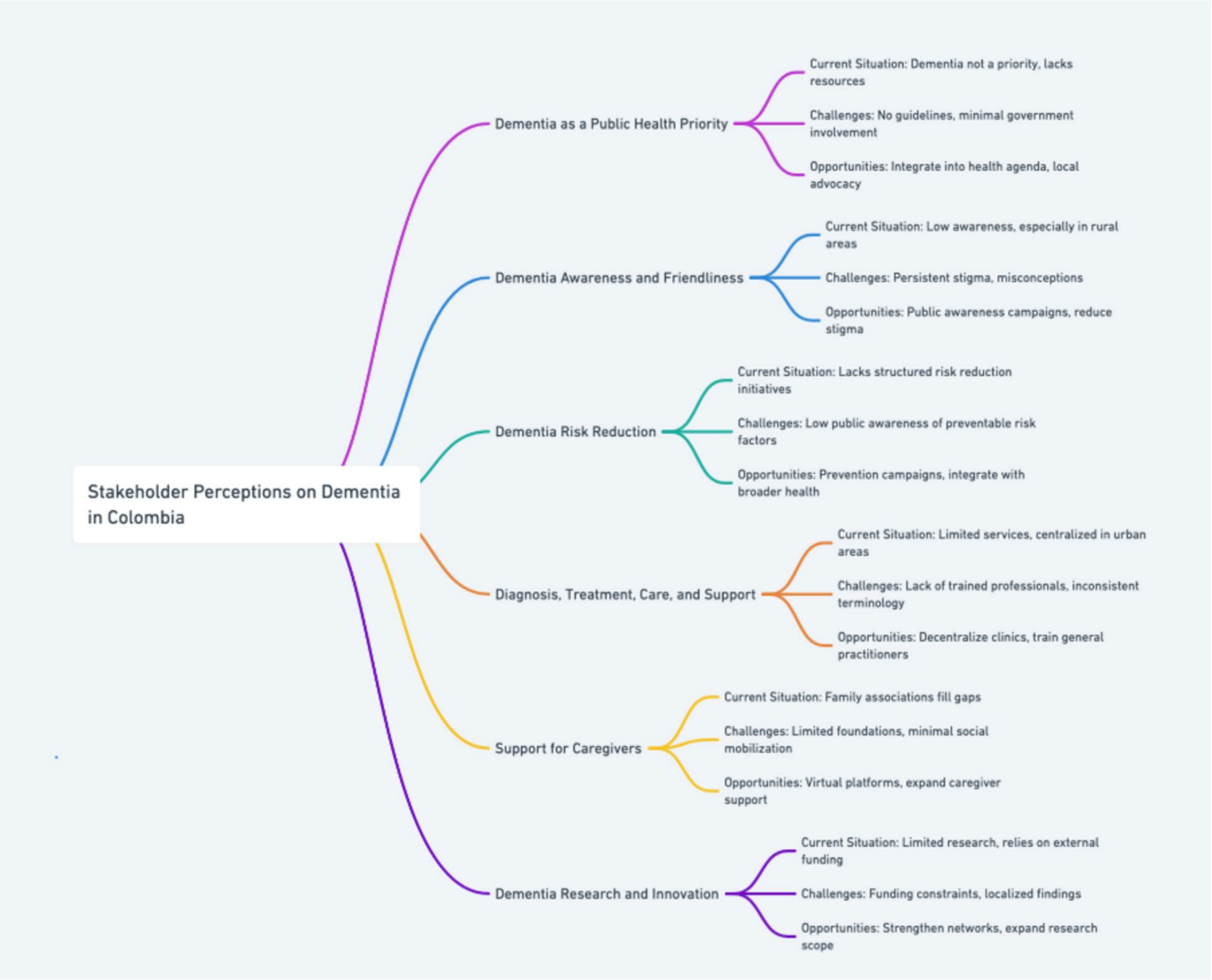

Fig. 1 Three main findings for each action area of WHO global dementia plan

for prevention [57]. Therefore, in the absence of a disease-modifying treatment accessible to all, dementia research needs to be focused on understanding risk factors, their influence on incidence and prevalence, and how to carry out interventions at a population level that improve community brain health [58, 59]. The International Network for Dementia Prevention Research recommends establishing the particular risk profile for each country to develop approaches at the level of national policies, strategies for groups and regions with specific risks or vulnerability, and personalized and individualized interventions according to risks and needs. Of each person and allocate resources to educate and train the general public [60], healthcare professionals, and decision-makers in dementia prevention [61]. As mentioned by the participants, in Colombia, there is no prevention strategy for dementia, and the available plans for noncommunicable diseases do not acknowledge their relationship with dementia.

In the perceptions of the participants in this study, we find how they described the COVID-19 pandemic as an opportunity to make visible the needs of older adults and use technological resources to improve communication and support for caregivers of persons living with dementia. The COVID-19 pandemic generated an important change in the dynamics of society. It highlighted the importance of optimizing the health of the elderly and producing remote and low-cost health responses for chronic conditions [61], such as telemedicine for maintaining persons living with dementia [62]. Despite the challenges imposed by the unexpected appearance of the pandemic, the use of technological resources made it possible to guarantee the continuity of comprehensive care for persons with dementia and their families and even broaden the scope and coverage of some interventions [63–65].

Finally, as opportunities and challenges for the future, the participants highlighted the importance of addressing dementia comprehensively and based on the country context, identifying the needs of persons with dementia and their caregivers, designing evidence-based interventions, and adapting strategies to particular characteristics of the country. In addition, a collaborative effort is required between the community, research groups, health providers, decision-makers, and the government to improve the quality of life of persons with dementia and their families and reduce the characteristic inequities that are present in low- and middle-income countries such as Colombia [66, 67].

This research implies that there is a strong willingness among stakeholders to participate in designing a national dementia plan, highlighting an opportunity for the government to prioritize regular meetings with key participants, including academic leaders, clinicians, caregivers, and community representatives. Engaging these stakeholders in a collaborative process would enhance the inclusivity and effectiveness of the national plan. A crucial recommendation is to involve academia and clinicians in crafting culturally sensitive, accessible messaging about dementia, tailored to address misconceptions and stigma within Colombian communities. By working closely with the public, these professionals can help position dementia as a medical condition, rather than a natural part of aging, thereby improving understanding and reducing stigma. Additionally, fostering collaborative networks among government agencies, academic institutions, non-governmental organizations, and healthcare providers can create valuable support systems and training programs. This approach would empower caregivers, build local capacity, and improve the quality of life for individuals with dementia and their families, addressing regional disparities in care across Colombia.

Limitations

While this study significantly contributes to our understanding of the dementia landscape in Colombia from diverse stakeholder perspectives, it is crucial to acknowledge the limitations, with the primary constraint being the relatively small sample size. Not all invited stakeholders participated in interviews, potentially excluding views particularly from government officials and decision-makers. However, the perspectives of those who participated in the interviews are oriented in the same direction, with which it could be considered that the inclusion of new participants would not lead to substantial changes in the results reported here. Additionally, a notable proportion of participants were located in major cities with more accessible resources for dementia care. Recognizing these limitations, it is important to consider that individuals in regions with limited access to resources might perceive challenges differently than depicted in this study. To address this, future research efforts should prioritize the inclusion of stakeholders from rural areas or smaller cities in Colombia for a more comprehensive understanding.

Conclusion

Dementia is a multidimensional disease that must be approached holistically. This study showed the perception of dementia by actors with experience in the subject from different points of view (academy and research, clinic, government, and community) in a low- and middle-income country, describing the multiple barriers in the entire dementia process. Disease from early detection of symptoms through diagnosis and treatment. This study highlights the challenges and opportunities to optimize the approach to this pathology at the population level. Without a national dementia plan, this information is vital as a substrate for designing a dementia policy adapted to the needs and perceptions of the actors directly involved with the disease.

Abbreviations

WHO	World Health Organization
ADI	Alzheimer's Disease International
PSEN1	Presenilin 1 gene

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Authors' contributions

AGB and DL conceived and designed the study. AGB conducted data collection and analysis. AGB and DL contributed to the interpretation of results. AG drafted the manuscript, and all authors critically revised it. All authors read and approved the final version of the manuscript.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This research was approved by Universidad de los Andes IRB (act1114/2019). All the participants signed written informed consent to participate.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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