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Challenges in Organizing End-of-Life Care for Dementia Patients in Latin America: A Qualitative Study

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Abstract

Individuals living with dementia undergo a slow but steady deterioration in both mental and physical abilities. This progressive loss makes it particularly difficult for patients, family caregivers, and health professionals to arrange appropriate end-of-life care in a suitable setting. The present study seeks to explore the difficulties involved in planning and delivering end-of-life care for people with dementia across Latin America. A qualitative research design was adopted for the study. Data were gathered through two focus groups, one individual interview, and one dyadic interview. In total, 15 stakeholders participated, representing 12 Latin American countries: Argentina, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Mexico, Paraguay, Peru, and Uruguay. The collected data were examined using thematic analysis to uncover recurring patterns.

Despite noticeable variations between and within countries, end-of-life care was frequently shaped by prevailing socioeconomic conditions. These conditions created significant obstacles to healthcare access; left the potential of informal caregivers largely untapped; were influenced by deeply rooted societal norms and cultural beliefs about caregiving; were affected by the specific course of dementia itself; and suffered from insufficient policy support, lack of adequately trained personnel, and limited service availability. Across Latin America, providing end-of-life care to people with dementia presents substantial difficulties for the individuals themselves, their caregivers, and the broader healthcare system. Clear pathways for improvement are urgently required so that all people with dementia and their families can experience the end-of-life period with sufficient and fair support.

Keywords: Dementia, End-of-life, Latin America, Qualitative research

Introduction

Dementia is a long-term, incurable illness marked by a continuous worsening of cognitive abilities along with behavioral alterations that lead to growing dependence on others [1]. It ranks among the main sources of severe health-related distress and places a heavy load on societies and healthcare systems—a burden projected to rise by 264% from 2016 to 2060 [2]. Given its rising occurrence and the strain it imposes on both caregivers and health services, dementia has become a key public health concern [1, 3].

The rate of dementia in Latin America exceeds that observed in most other parts of the world [3]. Current estimates indicate that 4.5 million individuals in Latin America and the Caribbean were living with dementia in 2019, a figure expected to reach approximately 13.7 million by 2050—almost double the anticipated growth for the United States and Canada combined [3]. Furthermore, the death rate among people with dementia is believed to be roughly 1.6–5.7 times greater than in those without the condition [4].

In addition, numerous elements can affect how end-of-life care is provided to people with dementia. The uncertain disease progression, problems with communication, difficulties in evaluating and controlling symptoms, and the extensive dependency that comes with advanced stages all hinder the delivery of proper care at the end of life.

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Overall, individuals who die from dementia tend to receive lower-quality end-of-life care than those dying from cancer [5], often experiencing insufficient pain relief, avoidable medical procedures, and restricted access to specialist palliative services [6–8]. These issues are even more pronounced in Latin America because of vulnerable healthcare systems, economic uncertainty, shortages of formal care settings and professional training, traditional gender roles that assign caregiving mainly to women, marked differences in socioeconomic status [9], weak healthcare infrastructure, ongoing stigma, limited public knowledge [10], and wide gaps in availability of palliative care and advance care planning [11].

Although a formal framework for public health action on dementia is already in place [12], major gaps persist globally in the extent to which dementia is treated as a pressing public health priority. Some parts of the world, for example, Africa [13], still lack national dementia plans, whereas other regions, such as Europe, have made considerable progress in establishing national dementia strategies [14]. In Latin America, only a handful of countries (Chile, Costa Rica, Cuba, the Dominican Republic, and Mexico) currently have national dementia plans [15]. Of those plans, only the ones developed by Chile [16], the Dominican Republic [17], and Mexico [18] actually address palliative care.

Even though it is clearly important, end-of-life care for people living with dementia remains largely under-studied, especially in low- and middle-income countries that face scarce healthcare resources and carry a heavier overall burden [9–11]. A recent analysis of the place of death across Latin America showed striking differences in the locations where people with dementia die: hospital deaths made up 69% of cases in Brazil, whereas in Guatemala, only 4.7% of such deaths occurred in hospitals [19]. While these patterns of place of death differ substantially, they reveal little about the real difficulties encountered when arranging end-of-life care.

Previous studies have not adequately examined the barriers to delivering end-of-life care for individuals with dementia or the specific conditions in which their deaths take place. For this reason, gaining a clearer, deeper insight into how end-of-life care for dementia is structured across Latin America was considered essential. Accordingly, the current study set out to investigate the challenges of organizing end-of-life care for people with dementia in Latin America. The two central research questions were: (1) How is end-of-life care for people with dementia organized across 12 Latin American countries? and (2) What factors influence the provision of end-of-life care for people with dementia?

Materials and Methods

This study is embedded within the broader “Place of Death in Latin America” project [20], which maintains a database containing death certificate records and statistical summaries from 12 Spanish- and Portuguese-speaking countries in Latin America (Argentina, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Mexico, Paraguay, Peru, and Uruguay). To develop a richer understanding of the elements that shape where people die in the region, a qualitative component was added. This component explored the organization of end-of-life care from the perspectives and lived experiences of professionals and caregivers supporting individuals with dementia across 12 countries.

Two focus groups were organized. For those unable to join the focus groups, one individual interview was conducted with a healthcare practitioner, and one dyadic interview was conducted with a bereaved family caregiver of a person with dementia and the physician who had cared for the patient. Reporting of the findings follows the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [21].

Participant recruitment

The aim was to secure at least one representative from each country. Candidates were located via professional contacts, organizational websites, and social media channels of national dementia groups in every participating country, except Paraguay, which has no national dementia association.

Purposive sampling was employed to recruit participants from a wide range of roles and medical specialties involved in dementia care (including psychiatry, geriatrics, primary care, palliative care, patient- and family-support organizations, community volunteers, informal caregivers, and academics with specialized expertise). Altogether, 37 professionals working in different fields and 18 national or regional dementia-related associations were approached by email. Each received a clear description of the study, supporting research articles [20, 22], and an official invitation to take part. Of the 55 emails sent, 12 people agreed to participate, one professional introduced a colleague from his own country, and another recommended inviting a bereaved caregiver he had previously supported.

Data collection

Links to Zoom sessions with two alternative time slots were sent to everyone who expressed interest in participating in a virtual focus group. The timing was nevertheless adjusted flexibly to match the participants’ own schedules. Two authors (T.P. and P.H.A.) led all the group discussions and interviews in Spanish during November and December 2023. T.P. holds qualifications as a medical doctor and sociologist, whereas P.H.A. is

a trained psychologist. Both are Latin American women working in palliative care research and bring substantial expertise in qualitative methods.

At the outset of each session, verbal consent was reconfirmed, and all attendees explicitly agreed to have the conversation recorded. A concise overview of the participants and the study's objectives was given, after which everyone was invited to pose questions. The conversation opened with broad questions designed to prompt reflection on the end of life and the common locations where individuals with dementia pass away.

Once the initial exchange had taken place, summary statistical figures on the place of death among people with dementia across the 12 countries [23] were introduced to spark further discussion. Two further prompting questions followed: What elements appear to shape end-of-life care and the location of death for people with dementia in your country? And in what ways could the delivery of end-of-life care for these patients be strengthened? After these prompts, the discussion became lively as participants shared detailed accounts of the end-of-life realities for people with dementia in their respective nations. The wide range of professional and personal experiences with dementia patients and their families was deliberately used to guide additional lines of questioning and to stimulate contrasting opinions, thereby enabling a richer, more layered examination of the subject. Every participant received the complete country-level data, except the bereaved caregiver and the physician involved in the dyadic interview, who received only basic study information.

No one other than the invited experts and the two facilitators was present during any of the sessions. All meetings were audio-recorded. The facilitators kept field notes and reviewed them immediately afterward. The recordings were converted into text using Whisper AI, an automated speech-to-text program [24]. P.H.A. listened to every recording while carefully checking and editing the resulting 152 pages of transcripts. Participants were not asked to review or correct the transcripts. For this article, all selected quotations were anonymized and rendered into English.

Data analysis

Reflexive thematic analysis served as the main method for spotting, examining, and describing patterns across the dataset [25]. The process followed a semantic orientation, which entailed summarizing the content, organizing the stories, and interpreting what the accounts revealed about the meanings, importance, and consequences of the themes — including the ways end-of-life care is structured and the influences that affect it.

The software MAXQDA [26] was used to store the material and support the analytic work. Detailed procedures for conducting reflexive thematic analysis were defined in advance. Any differences in interpretation were resolved through open conversation, with codes and themes repeatedly compared and then checked against the raw data. The full analysis was performed in Spanish, following the conventional stages [27]:

(1) P.H.A. and T.P. immersed themselves in the material by reading it multiple times and recording initial observations.

(2) Codes were developed inductively (starting with open coding, then moving to axial and selective coding), with the first round carried out by P.H.A.

(3) The two researchers jointly reviewed and compared emerging subthemes before grouping them into overarching main themes through discussion.

(4) In dedicated working meetings, both researchers evaluated the coherence and relationships between the themes.

(5) Final definitions and names for the themes were agreed upon during virtual working sessions.

(6) P.H.A. produced an initial narrative account, which was then repeatedly discussed and polished together with T.P.

Results and Discussion

Participants

15 individuals from all 12 participating Latin American countries participated in the study. Among them, twelve represented various professional fields, two acted as community representatives (volunteers), and one was a bereaved caregiver of a person who had lived with dementia. This mix ensured a broad spectrum of viewpoints. Due to differing availability, the sessions were organized into four separate online meetings lasting 54-137 min. The first focus group lasted 137 min, the second lasted 106 min, the single individual interview lasted 54 min, and the dyadic interview — involving a bereaved caregiver and the patient's treating physician — lasted 106 min. **Table 1** provides an overview of the participants' backgrounds and countries of origin.

Table 1. Participants' general characteristics.

Country	Professional background of participant	Gender	Type of participation
Argentina	Specialist in psychiatry	Female	Focus group 2
Brazil	Expert in physiotherapy, palliative care, and bioethics	Male	Focus group 1

Chile	Physician working in primary care	Female	Focus group 1
Colombia	Specialist in geriatrics	Female	Focus group 1
Colombia	Psychiatrist	Male	Dyadic interview
Colombia	Caregiver who experienced bereavement	Female	Dyadic interview
Costa Rica	General medical doctor and neuroscientist	Female	Focus group 1
Ecuador	Volunteer acting as a community representative	Female	Focus group 1
Ecuador	Sociologist with expertise in gerontology	Male	Focus group 2
El Salvador	Primary healthcare physician	Male	Focus group 1
Guatemala	Volunteer serving as a community representative	Male	Focus group 1
Mexico	Physician specialized in geriatrics and internal medicine	Female	Focus group 1
Paraguay	Neurology specialist	Male	Individual interview
Peru	Geriatrician and physician in palliative care	Male	Focus group 2
Uruguay	Physician in primary care	Male	Focus group 1

Themes and subthemes

The key topics that emerged from the focus groups and interviews were organized into five broad themes capturing the main factors that shape the arrangement and location of end-of-life care for individuals with dementia: (1) socioeconomic contexts create major obstacles to (equitable) access to healthcare services; (2) the potential of and support for informal caregivers remains largely untapped; (3) societal norms and cultural expectations strongly influence practices and expectations around care and informal caregiving; (4) the dementia trajectory itself generates distinct difficulties; and (5) insufficient guarantees around policies, skilled workforce, and services for end-of-life dementia care severely limit available options **(Table 2)**. It is nevertheless important to recognize that all themes and subthemes were closely linked and together determined the end-of-life realities faced by people with dementia and their caregivers.

Table 2. Themes and subthemes regarding the factors influencing end-of-life care organization for people with dementia in Latin America.

Main theme	Subtheme	Explanation
Socioeconomic conditions act as major obstacles to fair access to healthcare services	Social and economic determinants of health	Examines how socioeconomic status, healthcare accessibility, and insufficient support networks affect the structure and delivery of end-of-life care
	Systemic inequalities	Highlights difficulties in accessing healthcare for individuals with dementia, particularly due to uneven resource distribution, especially in rural settings
The abilities and contributions of informal caregivers are not fully utilized or supported	Responsibility in decision-making	Emphasizes the burden of making critical care decisions, including ethical concerns and accountability faced by patients and caregivers
	Burden of caregiving	Investigates the physical, emotional, and financial pressures placed on those caring for individuals with dementia
Cultural norms and societal expectations influence care practices and informal caregiving roles	Cultural differences	Focuses on how cultural background and language impact access to care as well as decisions related to treatment and end-of-life care
	Social expectations	Describes the effect of implicit societal norms regarding the role of informal caregivers for people with dementia
The progression of dementia itself creates distinct challenges	Course of dementia	Describes the complexity of dementia, including progressive cognitive decline and variability in symptoms and severity over time
	Suffering experienced by people with dementia	Addresses the emotional, physical, and psychological distress faced by individuals living with dementia
Limited policy support, workforce capacity, and service provision restrict choices in end-of-life dementia care	Policy and legal structures	Discusses issues related to the availability, understanding, and accessibility of legal frameworks for dementia care
	Awareness and education among the public and professionals	Stresses the need for improved education for healthcare workers and broader systemic challenges in training and public awareness
	Healthcare system support and available tools	Describes elements of palliative and end-of-life care, with a focus on integrating palliative approaches into primary healthcare

	Role of community and informal support networks	Highlights broader societal and structural gaps, emphasizing the importance of community-based initiatives and awareness to strengthen support systems

The bereaved caregiver endorsed many of the subtle caregiving details described by other participants during the focus groups. Moreover, specific national characteristics clearly affected the conditions under which end-of-life care for people with dementia is organized. As one contributor pointed out, the differences across countries are so extreme that "it can range from having such good and excellent services that people choose it, to having such horrible and deficient services that I will never be able to access anything other than dying at home" (Primary care physician from Uruguay).

Socioeconomic contexts create important barriers for (equitable) access to healthcare services

Economic and social determinants of health (subtheme)

Several Latin American countries continue to experience sociopolitical instability that impacts the entire population, regardless of income level. For instance, while the caregiver from Colombia was supporting her mother with dementia, periods of intense social unrest and violent demonstrations caused "road closures and access difficulties. M.E [the caregiver] had trouble getting medications and services for her mother" (Psychiatrist from Colombia).

In addition, personal situations directly influence both the person with dementia and their caregivers by affecting key economic and social determinants of health, such as educational attainment, quality of and access to healthcare, and availability of suitable care facilities and services during the final stages of life. Discussing patterns of place of death, one specialist observed that "with a higher level of education, there are probably more resources, better social support, and many of these patients have [health] insurance [to allow hospitalizations]" (Geriatrician and palliative care physician from Peru).

Structural inequities (subtheme)

Such systemic inequalities also play a decisive role in end-of-life care. Participants repeatedly emphasized sharp resource disparities between rural and urban settings. This disparity is especially pronounced in countries like Paraguay, where economic gaps and living conditions remain major challenges, and in Uruguay, where financial status has less influence on access, but regional resource distribution still creates barriers. Experts remarked: "Other [people] don't die in the hospital because there isn't one in their area" (Neurologist from Paraguay) and "In an area with around 600,000 people, there are two institutions with a capacity for about 100 people. So, in reality, the access is very, very, very limited" (Primary care physician from Chile).

The potential of and support for informal caregivers is under-tapped

Decision-making responsibilities (subtheme)

In most Latin American countries, families provide most of the caregiving, and the home serves as the central location for care. Consequently, many families shoulder the full responsibility for daily support and joint decision-making, often without sufficient guidance or external support. This responsibility becomes especially demanding when formal support structures are weak or absent. Caregivers often need emotional and psychological assistance to manage the uncertainty and anxiety that accompany these difficult choices.

Professionals who receive proper training can better equip families to reach decisions that respect the patient's preferences and actual needs. For example, the caregiver who participated shared her hope for more hands-on professional involvement: "(. . .) It would be really great if the doctor came to the house, attended to the patient, and also helped you resolve many of the doubts that worry you. 'Am I doing this right?' 'Am I acting wrong?'" (Bereaved caregiver from Colombia)

Caregiving burdens (subtheme)

Insufficient training, minimal outside help, and the constantly evolving challenges and complexities of daily caregiving — added to the pressure of making difficult choices — frequently result in considerable strain for families. This strain commonly appears as ongoing stress and profound emotional fatigue. Over the course of this often lengthy process, families who can afford it and find suitable help may hire private paid caregivers. Even then, these hired assistants often lack proper training in dementia care, which can create new problems and increase pressure. As the bereaved caregiver from Colombia shared,

I had nurses who stole things from my home. That put the entire family at risk (…) instead of giving my mother her medicine, they were taking it themselves (…) these drugs are sold on the black market, so they earn extra cash that way. We ended up having to create a checking system to make sure she actually received the pills (…) We had to set up cameras because of the thefts (…) we had to put all those measures in place to confirm she was getting her medication, that she wasn't being mistreated, and that they weren't leaving her in tears (…) (Bereaved caregiver from Colombia)

Similar patterns emerge across countries when it comes to the support needs of both caregivers and people with dementia. Participants expressed concerns about the very limited choices they face because resources are often scarce or unavailable. They also emphasized the significant personal expenses associated with treatments, therapies, and essential equipment. These costs, together with the advancing illness, put serious financial pressure on families, especially those in more disadvantaged regions. As several participants noted: "It largely depends on the healthcare system and how few real options exist to fulfill people's wishes (…) but in the end it all comes down to their financial situation" (Geriatrician from Colombia) and "In Ecuador the public system is quite weak (…) if you can afford private care you can get it, but the quality is basic. Most people cannot access private services fully, and booking an appointment through social security is extremely hard" (Community representative [volunteer] from Ecuador).

Societal norms and cultural expectations shape the practices and expectations around care and informal caregiving

Cultural variations (subtheme)

Cultural aspects are equally critical when examining end-of-life care for people with dementia in Latin America. Issues such as religious beliefs, language, family relationships, and societal attitudes toward older age all play important roles in how dementia is handled. For example, one participant pointed out that in Mexico, "sometimes decisions ignore the person's actual functional abilities; ageism takes over instead. Once someone is elderly, certain treatments are simply no longer considered" (Geriatrician and internist from Mexico).

Societal expectations (subtheme)

Choices about the care setting and the place of death made by people with dementia and their families are also shaped by broader societal views on institutional care, dementia, and dying itself. These preferences are often complicated by differing opinions between the patient and their relatives. In Peru, for instance, strong family closeness is central to both caregiving and decisions about where care and death should occur. Yet even when patients wish to die at home, family members may find it emotionally or practically too difficult to make that happen: "People generally want to die at home. Family members' willingness depends on how emotionally ready they feel to stay with the person until the end. Some are comfortable with it, others are not" (Geriatrician from Colombia). In addition, families often avoid discussing these matters openly because "our culture makes it hard to talk about death, even if the person with dementia still has considerable cognitive capacity" (Primary care physician from El Salvador).

Participants' contributions revealed the deep emotional challenges and cultural differences involved in caregiving and final decisions. These include a widespread preference for dying at home, rooted in cultural values. One expert explained that in many Latin American societies, caring for a relative at home is regarded as a basic moral duty and a clear sign of love and respect. At the same time, considering placement in a professional facility often elicits strong feelings of guilt, though their intensity varies across countries. For example, an expert observed, "Argentine culture tends to be very judgmental about this. Placing a family member in someone else's care feels extremely guilt-inducing and painful — at least that is how I see it as a psychiatrist" (Psychiatrist from Argentina).

A similar pattern was described in Guatemala:

When the person dies away from home, the family often carries feelings of guilt. They feel more comfortable keeping the person at home because they worry about what might happen when they are not there and cannot visit. Even in public facilities, visiting hours are very restricted — not daily, only at specific times. These practical constraints lead many families to conclude it is better to keep the patient at home. (Community representative [volunteer] from Guatemala)

In contrast, the situation in Uruguay is noticeably different:

There is not much guilt attached to placing patients in institutions. Once dementia reaches an advanced stage, long-term care facilities for the elderly become a common and accepted option. In my own practice and among most colleagues, we tend to reassure families that it is understandable when the patient grows highly dependent, and the family reaches exhaustion. In those situations, institutions are a practical resource that is used regularly. It is quite normal. (Primary care physician from Uruguay)

The dementia trajectory itself presents challenges

Dementia trajectory (subtheme)

The nature of the dementia journey creates numerous difficulties for the individuals living with the condition, their families, and the healthcare system, particularly toward the end of life. Participants noted gradual worsening, unpredictable fluctuations, timing issues, overall complexity, and an increasing inability to communicate, which creates considerable uncertainty and makes it difficult to manage care at home. Yet when discussing the actual place of death, the hospital was not always viewed as the ideal environment: "The support from nurses is sometimes not very suitable. I feel they are not well trained in dealing with the human side — not just for the patient, but also for the family member who is providing care" (Bereaved caregiver from Colombia).

Experts described how medical complications, additional health conditions, and the immediate causes of death can shape the kind of care needed and influence decisions about care settings. They noted that accompanying issues such as respiratory or urinary tract infections and episodes of delirium can make the underlying dementia even more difficult to manage.

In the later stages, infections, pneumonia, and problems from pressure sores occur frequently, along with the natural decline caused by dementia itself. These issues often require hospital admission. (Geriatrician and internist from Mexico).

In most cases of Alzheimer's disease, the decline is quite gradual, whereas vascular dementia can involve more sudden changes, and this pattern often leads to hospital stays. (Primary care physician from Uruguay)

Such medical setbacks or "downward turns" vary according to the stage of dementia and the specific type of dementia involved. Participants stressed that home care without extra specialized assistance can result in unnecessary suffering: "It is very upsetting for families to watch their relative die while struggling to breathe, in pain, screaming, or clearly distressed" (Psychiatrist from Colombia). It was evident to the participants that people with dementia frequently need additional medical intervention and, at times, hospital care: "Whenever something went wrong with my mother, the only option I had — since I didn't have a direct contact number — was to take her to the emergency room" (Bereaved caregiver from Colombia).

The suffering of people with dementia (subtheme)

Moreover, because dementia is a long-term, incurable, and steadily worsening condition, it brings both emotional and physical distress to those affected. This distress can stem from many sources, including declining mental abilities, loss of everyday skills and independence, additional health problems such as falls and fractures, and the side effects of treatments. However, the very nature of the disease — especially the increasing difficulty in communication — makes it hard for caregivers and patients to recognize and properly manage this suffering: "You often see patients on benzodiazepines, with risky combinations of multiple medications, and experiencing intense emotional distress, because we know that in dementia (…) there comes a stage of profound suffering" (Psychiatrist from Argentina).

Inadequate assurance of policies, skilled workforce, and services for end-of-life dementia care limits options

Legal and policy frameworks (subtheme)

The structure of the healthcare system and its governing rules play a vital part in how end-of-life care is arranged. Although differences exist between countries, several shared problems undermine effective care: weak healthcare policies, fragmented services, insufficient or missing support systems, and limited public knowledge of the relevant legal rules. These issues determine how easily families can move through the system.

In Peru, for instance, the practical and administrative difficulties of arranging a home death often push families toward hospital care:

Although some families do wish for and have the necessary support for the patient to die at home, the great majority end up in the hospital because they need to obtain the death certificate promptly, complete all the required documents, organize the wake, and handle other formalities. (Geriatrician and palliative care physician from Peru)

Public awareness and education (subtheme)

The widespread lack of reliable knowledge represents yet another major obstacle. This barrier "must be dismantled through targeted educational programs, sharing of clear information, and further research, enabling government bodies at all levels to develop effective policies" (Psychiatrist from Argentina). The experts highlighted the urgent need for greater awareness and education aimed at both healthcare professionals and the general population. For instance, many people in Colombia remain unaware of the current law regarding advance directives, which means "families often have no clue about their relative's wishes or preferred place of death" (Geriatrician from Colombia).

Participants repeatedly pointed out that healthcare workers frequently lack sufficient understanding of how dementia advances, how to control its symptoms, and how to apply basic palliative care approaches. This knowledge shortfall commonly leads to inadequate advice and poorer quality support because "many professionals simply do not comprehend the specific requirements of people with dementia, particularly once the disease reaches its advanced phase" (General physician and neuroscientist from Costa Rica). As a direct result, individuals with dementia often undergo aggressive medical procedures close to the end of life. These unnecessary interventions drive up health system costs and create heavy out-of-pocket expenses for families. Examples include extended hospital admissions, unsuitable drug prescriptions, or invasive treatments that provide minimal benefit to the patient's comfort or quality of life while consuming valuable resources. One bereaved caregiver described the experience this way:

During her hospital stay, they administered platelets, gave fluids because she was severely dehydrated, inserted a feeding tube since she refused to eat, and used it to deliver nutrition. Her potassium was low, so they corrected

that as well. Essentially, every vital sign was abnormal, and the medical team worked to stabilize whatever they could. (Bereaved Caregiver from Colombia)

By contrast, education and proper training are regarded as key sources of empowerment. Participants emphasized that clear, timely guidance from the healthcare team is essential to helping families navigate caregiving and make critical decisions at the right moment. In many countries, good professional advice makes a substantial difference for both caregivers and patients. For example,

The clinic took charge of training the paid caregivers. They showed us safe techniques for changing the bed without hurting the patient and for moving her from one position to another. That training was extremely helpful and made the whole process much smoother. (Bereaved caregiver from Colombia)

In reality, when families establish contact with palliative care specialists in good time, they often feel more confident about keeping their loved one at home. They receive the right instructions and appropriate home-based support throughout. The final decision rests with the family, but it depends heavily on when they connect with the palliative team. (Primary care physician from El Salvador)

Families can become overwhelmed and fearful because they lack basic information about what steps to take next. They may dread the moment of death, unsure how they should react or what to expect. Many feel unequipped to care for their relative. However, once they receive clear explanations and practical assistance, that fear tends to ease. They gain confidence and the necessary tools to face the situation with greater calm. (Geriatrician and internist from Mexico)

Support and instruments provided by the healthcare system (subtheme)

Specialized expert teams capable of offering guidance and information are available only occasionally. In practice, the formal assistance and practical resources provided by the healthcare system — including dedicated programs, interventions, medical supplies and equipment, and access to palliative services — are crucial for supporting this vulnerable group. Experts stressed the importance of reinforcing primary care so that everyday needs can be handled locally, while more complicated cases are promptly referred to specialist services. As one expert put it:

Relying solely on specialized palliative care teams to manage every case is not realistic or sustainable for any country, given the large number of patients involved. The most practical approach to enabling home deaths — when that is the patient's wish — is to integrate basic palliative care into primary care services for less complex situations. Patients with advanced dementia typically face issues such as pressure ulcers or infections. Still, their final-stage needs are generally manageable by a primary care doctor or nurse with basic training. (Primary care physician from Uruguay)

Community involvement and informal support systems (subtheme)

Because extra assistance is so essential and formal resources are often scarce, participants emphasized the critical role of community networks and informal support structures working together with the official healthcare system. They argued that addressing caregiving challenges requires solutions that extend well beyond the formal health care system and must include community-level support and government initiatives, such as appropriate housing options and caregiver training. Particular attention was given to the value of discussing death and caregiving openly within communities, especially by involving primary care physicians and encouraging honest conversations about care, illness, and the end of life. In Colombia, one expert noted that "many of us are actively running awareness campaigns, speaking to communities and doctors across the country about the law on advance directives" (Geriatrician from Colombia).

Summary of main findings

Where people with dementia die in Latin America differs markedly from one country to the next [19]. This qualitative study builds on those statistical patterns by exploring the practical difficulties of arranging end-of-life care for individuals with dementia across 12 Latin American countries. Five core themes were identified: (1) socioeconomic contexts create major obstacles to (equitable) access to healthcare services; (2) the potential of and support for informal caregivers remains largely untapped; (3) societal norms and cultural expectations shape practices and expectations around care and informal caregiving; (4) the dementia trajectory itself presents distinct challenges; and (5) inadequate guarantees regarding policies, skilled workforce, and services for end-of-life dementia care severely restrict available options.

Interpretation of main findings

Some of the difficulties highlighted in this study are widespread across the region, whereas others vary considerably by country. One shared issue involves the powerful influence of socioeconomic conditions, social determinants of health, and deep structural inequalities that block fair access to healthcare services. These factors were shown to intensify caregivers' workload and to play a decisive role in shaping both access to care and final decisions at the end of life. The difficulty of tackling these socioeconomic realities compounds another common challenge: the unpredictable course of dementia itself. Variations in symptom severity and progression heighten

the emotional, physical, and psychological strain experienced by people with dementia and their families, making end-of-life care especially demanding.

Other barriers uncovered here may carry different weight or consequences in each national context. The analysis shows that informal caregivers' abilities are often underused, leaving many with substantial unmet needs. They frequently take on complete responsibility for daily care and decision-making with little knowledge or outside help. There is therefore an urgent need to strengthen both formal and informal support systems for people with dementia and their families throughout Latin America. Community-based efforts and awareness-raising activities should engage government structures but must not depend on them exclusively. This broad, coordinated strategy aims to deliver well-rounded assistance to families through the healthcare system and wider social networks. It also calls for confronting societal attitudes toward dementia, death, and caregiving to make open discussion more common and reduce stigma [28]. Other studies have similarly stressed the value of normalizing conversations on these subjects and expanding public education [29].

Cultural elements further influence healthcare access, advance care planning, and end-of-life choices, underscoring the need for clear communication and early patient and family involvement in decision-making [30]. The participating experts illustrated how cultural attitudes, health literacy gaps, language barriers, and severe structural inequalities limit healthcare access for people with dementia, especially because of uneven resource distribution in rural areas. These observations are consistent with earlier findings from countries such as Peru, where low-income, rural, and Indigenous populations face disproportionate public health disadvantages and higher rates of underinsurance among older adults [29].

The present results are in line with previous research showing that limited healthcare coverage, scarce resources, cultural practices, and political instability all affect a country's capacity to handle the growing burden of neurological conditions [31]. Although some progress has been made in the region to improve care for people with dementia and their caregivers, major gaps in professional education remain regarding dementia, end-of-life care, and available support programs. For example, even though Costa Rica and Colombia have established laws and initiatives for elderly care, low awareness of these resources prevents their effective use. This problem is worsened by the scarcity of support services, leaving families to manage without sufficient guidance. Earlier work also recommends that information exchange should extend beyond national borders to include the sharing of data, successful practices, and policy ideas at regional and global levels [32].

This study further indicates that professional support for caregivers and people with dementia must be expanded across Latin America. More equitable resource allocation and stronger health education training programs are needed. Previous research has proposed practical ways to incorporate a palliative approach into dementia care in long-term settings; similar ideas could be adapted for other environments. These include embracing palliative principles, providing comprehensive training for the entire workforce (including support staff and care assistants), and introducing tools and policies that improve care and staff well-being [33]. Additional studies highlight how health inequalities, limited geriatric training in medical schools, low public awareness, and ongoing stigma around dementia continue to undermine care quality [29]. Thorough preparation of healthcare professionals in dementia care — with emphasis on better symptom control, avoidance of unnecessary procedures, and truly patient-centered approaches — together with targeted support and education for family members, is essential for easing caregiver strain, improving patient outcomes, and reducing overall healthcare costs.

In addition to confirming the themes raised by the professional participants, the bereaved caregiver brought unique first-hand perspectives on the everyday realities of home care (such as carefully tracking medication, the dangers posed by untrained paid helpers, and the need for monitoring systems to prevent theft). She also highlighted the importance of receiving validation and reassurance from clinicians, the frequent reliance on emergency departments when direct assistance was unavailable, and the perceived shortcomings in the compassionate, human side of hospital nursing care.

Strengths and limitations

This research used a combination of focus groups and interviews to gather in-depth insights into the themes under study. The qualitative analysis is based on the perspectives of dementia care experts, caregivers, and professionals from 12 Latin American countries. The participants' feedback provided rich, detailed insights into end-of-life care for people with dementia, deepening understanding of regional realities. Despite outreach to national and regional organizations to participate, only 1 or 2 experts from each country joined the study. Therefore, one limitation is the potential bias introduced by participants' specific characteristics (including their expertise, work environments, and personal experiences). This could affect the validity of their responses. Furthermore, the findings should be treated with care, as they may not fully reflect the viewpoints of all Latin American countries or key stakeholders, such as representatives from healthcare systems, other professionals involved in dementia care, or caregivers.

The addition of a bereaved caregiver's input provided valuable operational insights into day-to-day risk management, emotional support needs, and adjustments to service access. This enhanced the practical implications for improving care strategies. However, the lack of direct input from individuals with dementia themselves is a

notable gap, as their experiences—particularly regarding managing comorbidities, facing stigma, and receiving care from both the healthcare system and their families—were not captured.

Implications for policy and practice and suggestions for future research

The study's findings offer clinicians and policymakers concrete examples of the dementia-related challenges and needs in Latin America. When developing policies and interventions, policymakers should account for socioeconomic disparities and structural barriers that limit access to healthcare. Cultural differences and the specific needs of rural populations must also be factored in. Given the complexities of dementia, it is vital to adopt a multi-stakeholder approach, ensuring the involvement of a wide range of actors in the creation of national plans. These plans should address inequalities and reflect societal norms and expectations [9, 34]. Effective strategies should include improved financial and welfare support, strengthened collaboration within multi-disciplinary teams, and advocacy for early detection and care management [34].

For clinicians, it's important to recognize societal norms and the underused potential of informal caregivers within their practices. Incorporating culturally sensitive, open communication could foster advanced care planning, reducing burdensome treatments and providing clarity to medical professionals, individuals with dementia, and their families [35]. Future research should focus on subcultures and the specific dynamics at play in different regions to provide a more detailed understanding of the situation. Longitudinal studies would be particularly valuable in tracking disease progression and evolving needs over time, guiding more effective and culturally relevant policies and practices.

Lastly, given the lack of robust policy frameworks, skilled healthcare workers, and adequate services for end-of-life dementia care, healthcare policymakers and professionals should look to international models of dementia care. These frameworks emphasize the importance of awareness, early diagnosis, quality care, and fostering dementia-inclusive communities, which can help identify systemic issues and potential areas for improvement [11]. Additional research across other Latin American countries would be essential to explore their unique challenges and characteristics in end-of-life dementia care.

Conclusion

The study underscores that providing proper end-of-life care for individuals with dementia and their caregivers in Latin America is fraught with challenges. These challenges arise from a combination of cultural, geographical, economic, social, and dementia-related factors. While certain issues—such as cultural attitudes toward care and the inherent complexities of dementia—are difficult to address through policy or interventions, other factors highlighted in this study are more amenable to change. These should be the primary focus for improving end-of-life care policies in the region. Key areas for improvement include ensuring a well-trained, diverse workforce for dementia care, empowering family caregivers, and addressing structural inequities in care provision. By identifying these critical areas, this study offers guidance on how Latin American countries can enhance support for individuals with dementia and their families during the end-of-life process.

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