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“I have alzheimer’s, but i’m still me”: Social representations and the struggle for dignity in dementia

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Abstract

Dementia is not only a neurodegenerative condition but also a profoundly social phenomenon shaped by cultural narratives, institutional practices, and power relations. The stigma surrounding dementia often reduces individuals to passive, dependent, and socially disconnected roles, negatively impacting their identity, autonomy, and well-being. This qualitative study explores the social representations of dementia in Andalusia, Spain, through the voices of people living with dementia, their families, and professionals in health, social care, and community organizations. Thirty-three participants took part in intentionally heterogeneous focus groups, and data were analyzed using critical discourse analysis with a focus on metaphors and collective imaginaries. Findings reveal a dominant representation of dementia centered on the loss of social value, reinforced by experiences of infantilization, exclusion, and institutional neglect. The diagnosis is often perceived as a point of rupture that triggers a process of “social death.” At the same time, counter-narratives emerged, highlighting identity, dignity, and the right to participation. Participants proposed concrete measures to transform the dominant narrative, including the use of respectful language, early diagnosis accompanied by emotional support, integrated non-pharmacological interventions, and public awareness campaigns. The study concludes that changing the social image of dementia requires a structural shift toward rights-based, person-centered approaches that challenge stigma and foster active citizenship. Such transformation must involve coordinated efforts across sectors and include the lived experiences of people with dementia at every stage of care planning and implementation.

Introduction

In recent decades, population aging has led to a steady increase in neurodegenerative diseases that cause dementia, particularly Alzheimer’s disease. Bacsu et al. estimate that more than 55 million people worldwide currently live with dementia, and this number is projected to rise to 153 million by 2050 [1].

The social perception of dementia remains largely negative and stigmatizing. The condition is often associated with the loss of identity, dependency, irreversibility, and a “living death,” generating fear, a sense of social exclusion, and a limiting view of those affected. This stigmatization affects not only individuals with dementia but also their families and support networks, creating barriers to help-seeking and access to appropriate health and social care [2].

Recent studies have documented how these biases hinder early diagnosis and comprehensive care. A 2023 systematic review analyzing qualitative studies on dementia-related stigma concluded that stigma delays help-seeking, restricts access to services, causes psychological distress, and reduces quality of life [3]. Furthermore, recent studies examining platforms like X (formerly Twitter) have identified stigmatizing narratives portraying dementia as a social burden—and in some cases—promoting discourses that justify euthanasia after diagnosis [4].

At the same time, there is growing recognition of the need to listen to the voices of people living with dementia, their families, and the professionals who support them, in order to challenge the dominant narrative. This rights-based, participatory approach seeks to empower people with dementia, dismantle stereotypes, and promote inclusive practices and policies. Reyes et al. in a descriptive review of participatory research methods in Alzheimer's and related dementias, identified 163 studies using community-based participatory or co-research approaches, emphasizing that genuine involvement enhances the design, social relevance, and transformative potential of research. However, only 23% of these studies actively involved people with dementia as core contributors to the research process [5]. This transformative approach goes beyond gathering opinions—it fosters the collaboration of people with dementia in the co-construction of knowledge and the development of actions grounded in lived experience, with the goal of advancing practices that uphold dignity, autonomy, and social inclusion.

In this context, the present study explores the social representations of dementia through the voices of those affected—individuals with dementia, family members, and professionals—with the aim of identifying potential strategies to transform the social image of the condition and strengthen person-centered policies and care practices.

Materials & methods

This is a qualitative study conducted in Andalusia, a region in southern Spain where approximately 120,000 people live with dementia [6]. The primary technique used was the focus group, selected for its ability to encourage participant interaction and facilitate collective reflection on the meanings attributed to dementia. The groups were purposefully and heterogeneously composed, with representation from key actors and sectors involved in the response to dementia in Andalusia: individuals living with dementia, family members, representatives of associations, social service and healthcare professionals, and members of scientific societies.

Each focus group session lasted between 60 and 90 minutes and was moderated by a trained qualitative researcher. The sessions with individuals living with dementia and their family members were held in person, while the rest were conducted online via Zoom. All sessions were video recorded, fully transcribed, and subsequently anonymized to ensure participant confidentiality. The interview guide included thematic axes related to the social perception of dementia, experiences of stigma, barriers to accessing services and resources, and opportunities to transform the dominant social image of the condition.

A critical discourse analysis approach was applied to the data, rather than a purely descriptive content analysis. This method allowed us to identify not only the explicit content but also the underlying structures, ideological tensions, interpretative frameworks, and power relations embedded in the narratives surrounding dementia (Hamui & Vives 2022).

Metaphors used by participants were central to the development of an interpretative model aimed at capturing the social representations that shape the collective imaginary around dementia. These representations influence not only care practices and policy development but also the subjective experience of those living with the condition. In qualitative research, metaphors are powerful tools for understanding and analyzing data, as they connect complex concepts to more familiar ones, offering new perspectives. They are especially useful in exploring subjectivity, creativity, and social context, helping to interpret both practices and social phenomena [7].

The analytical process was iterative and collaborative. It involved open coding of transcripts, the development of emergent categories, and their subsequent theoretical articulation. This work was carried out by an interdisciplinary team, engaged in ongoing dialogue with both the empirical data and the theoretical frameworks of social representations and a rights-based approach.

Results

A total of 33 participants from diverse backgrounds took part in the focus groups. The discourse was organized into three main categories: (1) people living with dementia; (2) family members; and (3) professionals.

Discourse of people with dementia

- **Dementia as social loss:** People diagnosed with dementia describe the greatest impact not as clinical or cognitive, but social: a loss of value, invisibility, and a breakdown in their relationships with others. Phrases like "You're no longer useful," "They push you aside," and "Society has turned its back on us" are frequently repeated. The diagnosis is perceived as the loss of status as a "valid" person, shaping a collective imaginary that associates dementia with uselessness, total dependency, and passivity.

"Once you have Alzheimer's, you're no longer considered capable of speaking to anyone."

- **From silent stigma to self-exclusion**: Stigma emerges both in explicit forms and as internalized self-exclusion. Some individuals consciously step back to avoid discomfort or rejection. While some choose to conceal their diagnosis, others resist by openly acknowledging it.

"I have Alzheimer's, but I'm not stupid."

The family as an ambivalent space. The family is both a fundamental support network and a setting where stigma is reproduced. Testimonies describe children dismissing or interrupting the person's speech, attributing any difficulty to the disease, which generates frustration.

"They say, 'We already know that, Mom'… but that doesn't mean what I say isn't valid."

This shows that stigma can also emerge from well-meaning but paternalistic or overprotective environments.

- **Lack of institutional recognition:** Participants report systemic neglect: late diagnoses, minimal follow-up, lack of neurologists, and barriers to non-pharmacological treatments. There is a perceived violation of their right to dignified care.

"They treat us like third-class citizens."

Frustration is also expressed regarding the lack of implementation of public policies, despite official plans being approved.

- **The struggle for identity and dignity:** Despite the stigma, many people with dementia see themselves as active agents, with decision-making capacity, humor, and a desire to contribute to society. Participation in associations, community projects, theater, and daily activities helps preserve identity.

"I have Alzheimer's, but I'm still me." "I go to the theater, tend my garden, and give talks. How am I not useful?"

This self-perception contrasts with the dominant image of the passive patient.

Discourse of family members

- **Diagnosis as a dangerous social label:** A dementia diagnosis quickly leads to social labeling, transforming how others view the person and disrupting family dynamics. Affected individuals are often no longer treated as valid interlocutors.

"It's a dangerous label... they lose all their roles... they become forgotten."

The diagnosis marks a turning point, often before there is significant disability. In couples, it alters relationships and decision-making processes.

"You lose your partner in conversation—you have to make decisions alone."

- **Families caught between protection and disorientation:** Families often feel unaccompanied after diagnosis. Health systems fail to provide emotional support or clear information, leaving families confused. Associations become vital spaces for guidance and mutual support.

"And now what do we do?" That's how they leave the neurologist's office—crying, like little children."

They emphasize the progressive nature of loss and the emotional burden of caregiving.

"Every day something new happens. It's like a regression, like they're going back to childhood... and that's hard to accept."

- **Fear, denial, and self-diagnosis:** Dementia is still linked to death and deterioration, which fosters denial and delays in diagnosis.

"I want to know what I have—as long as it's not Alzheimer's."

Stigma remains latent; many families hide the diagnosis to avoid judgment.

"People still hide it. If it's cancer, you say it. If it's mental illness, people feel ashamed."

- **Invisibility of early-onset or atypical dementia:** Dementia is often associated only with Alzheimer's in older adults, marginalizing other forms that affect younger populations.

"We have people diagnosed at 35, with young children, and no one explains anything to them."

- **Double stigma in socially excluded populations:** People facing poverty, homelessness, or migration status experience a double stigma: for their condition and their social position.

"They see us as victims of misfortune. They see them as responsible for their fate."

This has real consequences on access to services and types of care.

- **The right to visibility:** Families advocate for speaking openly about dementia as a way to humanize it and protect those affected.

"My wife says it naturally. If she forgets something, she lets people know." "I tell the neighbors: if you see her alone, you'll know something's wrong."

Especially in rural areas, community awareness can be lifesaving.

- **Transforming language and promoting dignity:** Families stress the need to stop using terms like "patient" or "sufferer" and instead refer to people with dementia as adults deserving of respect.

"You have to talk to them like adults. They don't need special treatment—just humane treatment."

Changing language is key to changing practice and public perception.

- **Associations as support and transformation hubs:** Associations are vital for day-to-day support, offering direct care and emotional support for caregivers.

"Associations are built for both the person with dementia and the caregiver. They are key to our daily lives."

They also foster visibility, community education, and participation of those living with the diagnosis.

Discourse of professionals

The discourse of professionals is presented disaggregated by sector. First, healthcare professionals—both from primary and hospital care and scientific societies—who provide care to people with dementia. Second, professionals from social services, both community-based and those specialized in elderly care. Third, professionals from community pharmacies and psychology or neuropsychology experts involved in prevention and early detection of cognitive decline.

Healthcare professionals

- **The emotional impact of diagnosis:** Interviewed healthcare professionals consistently describe the dementia diagnosis as a highly emotional event for both the person affected and their family. It is portrayed as a "blow," marking the beginning of anticipatory grief, uncertainty, emotional overload, and fear regarding the degenerative course of the illness.

"When it finally has a name and a diagnosis, it usually hits hard in every way." "The family feels like something is crashing down on them."

- **A social imaginary centered on loss and the end:** Professionals perceive that society links dementia with the end of life—associating it with people who lack memory and value. This representation drives those diagnosed into social isolation, denial of the diagnosis, and the rupture of social ties.

"Society puts that person in a different box—no longer valid." "Dementia equals bed and diapers."

- **Stigma and infantilization:** Social stigma leads professionals to speak to family members rather than the person diagnosed. This includes paternalistic attitudes, infantilization, and the tendency to exclude the person from decisions, even in early stages.

"We don't even look them in the eye—we go straight to the family." "A paternalistic attitude kicks in automatically."

- **Fragmentation of care resources:** Professionals recognize the availability of valuable resources (associations, cognitive stimulation, the Dependency Law), but access is hindered by delays, territorial disparities, and lack of systemic organization.

"The resources exist; the problem is how to access them." "The Dependency Law is outrageous in terms of wait times."

- **Complexity and potential of early diagnosis:** While primary and hospital care professionals view early diagnosis as complex and often late, representatives from scientific societies are more optimistic, pointing to progress in early detection and the promise of new therapies and clinical trials.

"Alzheimer's used to be hidden, now we talk more and diagnose earlier." "Most people come in when they're no longer aware of the diagnosis."

- **Lack of systemic response:** Primary and hospital care professionals stress that the system offers inadequate information and support. Scientific societies emphasize the need to train care teams for better support, acknowledging the shortcomings but also highlighting room for improvement. Given the long trajectory from mild cognitive impairment to advanced dementia, patients can and should be supported to express their will and make decisions about their care.

"We lack time, training, and coordination to anticipate needs." "We need to focus more on advanced care planning and respecting patient will."

- **Image of the person with dementia:** People with dementia can and should remain involved in decisions, especially about their own care. However, families and professionals often limit the person's autonomy immediately after diagnosis.

"We should keep asking them what they want, even after diagnosis." "The challenge is helping others understand they're still active individuals."

- **Emerging transformative proposals:** Healthcare professionals advocate for changing the public narrative—replacing the image of final-stage decline with stories of participation, dignity, and active living. They call for integrated, interdisciplinary, person-centered care models and emphasize the crucial role of associations as providers of psychosocial and educational support. Additionally, they stress the need for professional training to eliminate paternalistic and stigmatizing practices.

Community and specialized social services professionals

- **From accompaniment to disappearance:** Social services professionals observed that, following a diagnosis, the individual's social and emotional networks tend to withdraw. Family, friends, and community connections gradually fade, often due to fear, discomfort, or difficulty coping with decline.

"Their environment starts to disappear. That leads to the person being increasingly cornered and objectified." "Many don't come anymore because they can't bear to see what someone once active and intelligent has become."

This abandonment is not necessarily intentional, but structural—rooted in a broader societal denial of aging, vulnerability, and death.

- **Between compassion and rejection:** There is a superficial empathy toward people with dementia, particularly in public or family discourse, but it rarely translates into real engagement in caregiving or support in everyday life. A clear duality emerges: people feel pity for the person but avoid their presence.

"We feel sorry for them, but we don't want to see them sitting in a café with us." "The diagnosis stirs emotion, but when it comes to involvement, many walk away."

Here, stigma is fueled by ageism, fear of decline, and a utilitarian view of life.

- **Processes of resignation and "social death":** One of the most powerful categories that emerged is the process of resignation, where both the individual and their environment passively accept isolation and loss of meaning.

"Some people decide: the sooner it's over, the better." "Admission to a nursing home has a certain meaning—it's not a neutral act." "When they lose hearing or speech, no one communicates with them anymore."

This highlights how the loss of communication—both literal and symbolic—deepens stigma and exclusion. The person stops being seen as a social subject and becomes a "managed body."

- **Structural axes of social stigma:** Interviewed social service professionals link stigma to deeper structural issues. First, aging itself—a culturally rejected condition. Second, the vulnerability of professional caregiving, which is often feminized and precarious. Third, poverty and dependence, which increase invisibility.

"This sector is stigmatized because it's mostly female and poorly paid." "Wage gaps affect staff turnover and the quality of relationships."

Stigmatization affects not only people with dementia, but also those who care for them. The stigma associated with dementia is closely tied to issues of distributive justice and social rights.

- **Circles of care and community-based strategies:** Despite the critical diagnosis made by interviewed professionals, several proposals for change emerged. These include training in alternative communication methods for people with dementia, real implementation of personalized care circles, public campaigns featuring real faces and positive testimonials, and sustained, equitable investment in community social services and in-home support to avoid institutionalization.

Community pharmacy and cognitive stimulation professionals

- **Mechanisms for concealing cognitive decline:** Interviewed professionals noted that, in early stages, individuals with cognitive impairment often display remarkable abilities to hide their symptoms. This "intelligence to mask" is seen as a self-protective strategy in a social environment that responds to diagnosis with pity, rejection, or infantilization.

"The cleverness people show when trying to hide early cognitive decline." "When you say Alzheimer's, it's like you're suddenly useless."

People avoid a formal diagnosis because to make the disease visible is to risk losing their rights and social credibility.

- **Breakdown of biographical continuity:** Professionals reported that the diagnosis often closes more doors than it opens: people may lose their jobs or the opportunity to volunteer; their family role is diminished; they may lose financial control or even their driver's license. Families tend to make decisions on their behalf without consultation, resulting in a deep rupture in their life narrative.

"They tell them to stop working when they're still capable." "When do we have the right to take away someone's ability to decide about their own life?"

This reflects an ethical tension between safety and autonomy—one that families often resolve through fear and overprotection, sidelining the person from decision-making processes.

- **Diagnosis as a bureaucratic maze:** Professionals denounced a fragmented and slow system: from primary care to a specialized diagnosis, the process can take 12 to 24 months. Added to this are the bureaucratic hurdles to accessing benefits under Law 39/2006 on Personal Autonomy and Dependency Care, lack of resources in rural areas, and the absence of automatic disability recognition for neurodegenerative diseases like Alzheimer's.

"Someone died before receiving official recognition of their disability." "They ask us to wait a year and a half, but the disease progresses in months."

This institutional invisibility reinforces the perception that dementia is not a priority on the political or healthcare agenda.

- **Dementia as inevitable decline:** According to these professionals, society still sees dementia as an irreversible, end-of-life condition associated only with extreme deterioration.

"It's viewed as something hopeless—inevitable decay." "It's like you're already at the very end."

This imaginary discourages families from seeking cognitive stimulation services or using support resources until the disease is already severely disabling.

- **Between pessimism and hope:** Professionals acknowledged a shift in how dementia and cognitive decline are approached. While it used to be assumed that "nothing could be done" after a diagnosis, there is now growing awareness that cognitive stimulation, emotional support, and early detection can slow disease progression and improve quality of life.

"There's a lot we can do—even in very early stages." "We professionals also need to confront our own stigmas."

However, this new outlook often clashes with lingering stigmas within families and institutional practices.

- **Education, awareness, and participation:** Professionals proposed several concrete measures to change the social image of dementia: ongoing awareness campaigns—not limited to designated dates; early contact with people living with dementia in schools; accessible directories of services provided to individuals and caregivers at diagnosis; formal recognition of non-pharmacological therapies and cognitive stimulation as part of public benefits; and early psychological and follow-up support for families.

Discussion

The analysis of the discourse gathered from the various participant groups enabled the construction of an interpretive model that illustrates how the social image of dementia is shaped in the current Andalusian context. This model reveals a central structuring dimension—the loss of social value—around which other dimensions are organized that reinforce, sustain, or challenge the prevailing collective imaginary.

The loss of social value emerges as the central axis across all discourses. Dementia is not perceived solely as a medical condition, but as a social marker that strips individuals of their symbolic and functional value. Upon diagnosis, many people are seen as "useless," "burdens," or "invalid," even before any evident functional disability appears. This representation triggers processes of exclusion, isolation, and loss of personal agency, and constitutes the core of the social stigma surrounding the disease.

Stigma, as a cultural imaginary, reflects a dominant narrative that associates dementia with irreversible decline, absolute dependence, and the end of active life. This imagery, reinforced by media and institutional discourse, generates fear, rejection, and silence. People with dementia are infantilized, rendered invisible, or outright excluded from public spaces and decision-making processes that directly affect them.

This finding aligns with previous studies indicating that individuals with dementia suffer deep social stigma that systematically undermines their personhood through dehumanization and social exclusion. Research involving individuals living with Alzheimer's disease highlights how societal perceptions reduce them to a state of "social death" [8]. This stigma arises from multiple sources, including medical reductionism, fear of cognitive decline, and entrenched cultural narratives [9].

The extent of social stigma is such that people with dementia have been metaphorically described as "zombies"—a representation that marginalizes them and separates them from society, their communities, and even their families [10].

In this context, particular attention must be paid to the effects of progressive social withdrawal and the loss of emotional and social support networks. Friends, neighbors, and even family members tend to withdraw due to fear, discomfort, or lack of understanding. The person with dementia gradually loses their social bonds, exacerbating their vulnerability and deepening their disconnection from the outside world.

Social isolation has a significant and detrimental impact on people with dementia, as it exacerbates cognitive decline and psychological symptoms and may accelerate disease progression. A recent systematic review by Suárez-González et al. reported that 60% of included studies noted cognitive changes, and 77% described significant cognitive deterioration [11]. Azevedo et al. specifically noted that 53% experienced memory function decline, while 31.2% felt more sadness and 37.4% reported increased anxiety [12].

Lazzari et al. quantified the risk, revealing that prolonged loneliness and social isolation increase the risk of dementia by between 49% and 60%. The evidence is particularly strong in studies of isolation during the COVID-19 pandemic, suggesting that restrictions on social interactions can have immediate and potentially long-term neurological consequences [13].

Public institutions, meanwhile, act as agents of exclusion. Rather than offering integrated and humanized support, the health and social care system often reproduces exclusion through service fragmentation, lack of intersectoral coordination, long waiting times, and limited recognition of the rights of people with dementia. This experience of neglect leads to a generalized perception of institutional abandonment and reinforces the belief that there are few real opportunities for meaningful intervention or improved quality of life.

Moreover, stigma remains a significant issue among healthcare and social service professionals, many of whom exhibit negative attitudes and pervasive biases that affect the care provided to people with dementia.

Numerous studies reveal that professionals in healthcare and social services hold stigmatizing attitudes toward dementia. Wenhong Zhao et al. found that healthcare professionals' knowledge about dementia ranged from low to moderate, often accompanied by negative attitudes [14]. Auerbach et al. identified underlying biases such as ageism and "therapeutic nihilism" that hinder adequate care delivery [15].

Herrmann et al. confirmed that stigmatizing attitudes are more pronounced among professionals with limited knowledge of the disease and less direct contact with people with dementia [16]. Nguyen et al. further emphasized that healthcare professionals themselves contribute to the perpetuation of negative stereotypes, prejudice, and discrimination [17].

The discourse analysis in this study also revealed the powerful role of language in generating exclusion. Terms such as "patient," "case," or "burden" perpetuate a passive and depersonalized image of people with dementia. Likewise, professional practices that exclude individuals from conversations—speaking only to accompanying relatives or caregivers—reproduce a logic of the "absent subject." Changing the language is thus both a political and transformative act.

Recent scientific literature demonstrates how language profoundly shapes how professionals understand, communicate with, and care for people with dementia, and how this communication style significantly affects treatment and perception by both individuals and their families.

Michael et al. showed that language shapes social perceptions of dementia, influencing care practices and help-seeking behaviors [18]. Rasmussen et al. revealed that communication challenges in dementia are complex and impact language production, topic maintenance, and conversational coherence [19].

Dooley et al. further emphasized that professionals face major challenges in communicating with people with dementia, particularly in balancing diagnostic clarity with emotional sensitivity. Research suggests that linguistic barriers may marginalize patients and complicate the provision of care [20].

The findings of this study also demonstrate that individual and social conditions such as age, gender, social class, and residential setting intensify stigma. People experiencing homelessness, women caregivers, individuals living in poverty, or those in rural areas face greater access barriers and fewer opportunities for inclusion. These intersecting factors reinforce structural stigma that goes beyond the disease itself.

Finally, despite the predominance of stigma, all participant groups expressed narratives of resistance and proposals for change. People with dementia asserted their identity, dignity, and right to participation. Associations are actively working to change both language and public perceptions. Professionals across sectors are beginning to question their own practices, promote person-centered care models, and advocate for greater institutional investment. Key proposals include:

- Public awareness campaigns that dismantle stigmatizing narratives.
- Active participation of people with dementia in decision-making processes that affect them, both in daily life and care planning.
- Professional training in respectful, rights-based communication.
- Visibility of atypical dementia cases and early-onset diagnoses.
- Full integration of non-pharmacological therapies and cognitive stimulation in public systems of long-term care.

Conclusion

The findings of this qualitative study offer insight into the social image of dementia as a collective construction shaped by stigma, fear, and representations that reduce affected individuals to a passive, dependent, and socially disconnected condition. Dementia is not only a neurological disease, but also a deeply social phenomenon, influenced by cultural narratives, institutional practices, and power dynamics that directly impact the lived experiences of those affected.

In contrast to this prevailing narrative of exclusion, alternative discourses and practices are emerging—centered on dignity, participation, and the recognition of rights. People living with dementia, along with their families, associations, and some professionals, are driving a paradigm shift that calls for more inclusive policies, more respectful language, and integrated care strategies that provide timely support, clear information, and emotional accompaniment from the moment of diagnosis.

Transforming the social image of dementia is an urgent and collective task. It requires more than isolated health or social interventions—it demands a structural change that encompasses public communication, professional training, service planning, and the active involvement of people with dementia in all decisions that affect them. Only through this comprehensive approach will it be possible to move toward a truly person-centered care model, grounded in social justice.

Declarations

Conflicts of interest: The authors declare no conflicts of interest or financial disclosures related to this research.

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