Alzheimer's Disease International

The global voice on dementia

World Alzheimer Report 2024

Global changes in attitudes to dementia

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Foreword

Paola Barbarino,
Chief Executive Officer, Alzheimer's Disease International

Have attitudes to dementia changed in the last five years? Like many others, I have been awaiting the release of this year's Attitudes to dementia survey with bated breath.

This massive endeavour first came about when Alzheimer's Disease International's (ADI) board included in my job description that one of my targets for success was to help decrease stigma globally. Back then I thought: "That is a huge goal and even if I managed to do something about it, how exactly I am going to measure that if there is no global benchmark for dementia stigma?" Then my next thought was: "Let's roll up our sleeves and create one!"

So I established the inaugural Attitudes to dementia survey in 2019, for which ADI entrusted the London School of Economics and Political Sciences (LSE) with the analysis, with the aim of repeating the survey at regular intervals to measure whether our collective work was having any impact on attitudes to dementia.

The 2024 survey marks the first follow-up survey, and this first comparison will require attentive reading to understand all the nuances. The changes, some radical, some subtle, over the past five years will be of great interest to all of those who, like our member organisations, work so hard to raise awareness of dementia and Alzheimer's in their countries.

Our hope is that these facts and figures will form a solid framework for national advocacy strategies and will help negotiate better outcomes for people living with dementia and their families all over the world.

The most important thing the report tells us is that we cannot be complacent. Stigma remains high and can take many forms, including self-stigma. It can creep up on you from many different directions when and where you least expect it. This comment from a person living with dementia who filled out the survey illustrates one facet of it and paints a world of miscomprehension, isolation, and disengagement:

> **"I am not going anywhere so people don't notice I am ashamed"**

In 2019, many countries did not see the critical importance of ADI's survey, as often happens with new initiatives. Whilst we received just under 70,000 answers at the time (for which we can never been grateful enough), many of these were from high-income countries, with only two or three countries dominating the scene. The final results were obviously weighted, but we would have loved to receive more input from lower- and middle-income countries.

Our wishes have been fulfilled this time; we received fewer replies – still a huge amount at just over 40,000 – but from a much broader spectrum of countries (166) and a lot more evenly distributed between regions and income groups. I personally cannot thank participants enough. It was not an easy survey to complete.

Some of you will read the report cover to cover and pore over its findings, others will speed-read it. For the latter, here are four things that struck me the most in this report:

- In 2019, one of the most incredible findings was that 62% of health and care practitioners (such as doctors and nurses) thought that dementia was a part of normal ageing. This year, that number has grown to 65%. This begs the question: What do we have to do, how long do we have to shout from the rooftops to make sure that medical professionals receive sufficient training to identify dementia as a condition caused by a set of diseases, Alzheimer's being the most prevalent?

  Why does this matter? To people living with dementia and their families all over the world, knowing that their relative has a correct diagnosis could:

  - open the door to support groups, information, and feeling part of a community;
  - enable them to receive better care in a timely fashion;
  - open access to new life-prolonging treatments;
  - last but not least, educate people about the modifications that can be made to enable the person diagnosed to live in their own home more comfortably for longer.
- Underscoring that, the second finding that surprised me was that over a quarter of respondents expressed the belief that moving a family member with dementia to a care home, even against their wishes, would be the best option. Most surprisingly, that belief increased substantially in low-/lower-middle income countries, where there is not a strong care home sector.
- It is not all bad. There are plenty of things that give us hope, like the fact that the number of people who believe dementia is caused by an unhealthy lifestyle has broadly increased to 61% in higher- and middle-income countries, indicating that the message on risk reduction and prevention (see the World Alzheimer Report 2023) is getting through to the general public (It has however decreased in lower-income countries, why that is will be the subject of further studies…).
- Finally, over 80% of the general public believes they can change the support provided to people living with dementia through their vote! This is great news; advocacy can work, and I am sure this will put a spring in our step for all of us trying to persuade governments to do more.

I could go on, but instead I will leave you with this quote, which has brought this publication to life for me like nothing else:

> **"They're just normal people, they have dementia but there's no, like, they're not different and people with dementia should be treated the same way, and they should be treated with care because obviously they can forget stuff, and they're just people so they're just the same as us, there's nothing different with them."**
>
> *British adolescent, from the essay by Esra Hassan and Nicolas Farina page 135.*

This really gives me hope that the message is coming across. As you will read in these pages, stigma is multifaceted and hard to pin down. However, I do believe that by engaging the younger generations, dementia stigma will hopefully disappear in the same way as cancer stigma, and that, in due course, we will no longer need for this global survey to be repeated.

Until then, we must continue to work together. Our joint voices will continue to make a difference for all those who live with dementia and their families.

London, September 2024

Executive summary

For over a decade, Alzheimer's Disease International (ADI) has been advocating for increased awareness of dementia across the world. Awareness is a nebulous concept, but an important one. Knowledge of dementia plays a key role in how the condition is understood by various stakeholder groups, and how people living with dementia and their carers are treated.

Every three seconds, someone, somewhere, develops dementia. In 2019, some 55 million people were estimated to have dementia across the world, a figure predicted to increase to 139 million by 2050 according to the WHO.[1] The annual cost of dementia was estimated to stand at US $1.3 trillion in 2019, a figure set to more than double by 2030 to $2.8 trillion. As the world population ages, dementia is becoming one of the leading causes of death in the world, making it all the more urgent for healthcare practitioners, policymakers, and the wider public to seize the significance of the condition and take action to mitigate its negative effects on individuals living with dementia, their families and carers, and societies as a whole.

The concepts of dementia awareness and stigma are intricately related under the umbrella of attitudes to dementia. The report poses the question "what is stigma?" through an essay that seeks to define dementia-related stigma and to better understand its component parts based on power, stereotypes, prejudice, and discrimination.

In 2019, Alzheimer's Disease International (ADI) commissioned a global survey on attitudes towards dementia conducted by the London School of Economics and Political Science (LSE), seeking to understand what were the prevailing beliefs, knowledge, and attitudes about the condition at that specific point in time. The 2019 survey garnered responses from some 68,000 participants, making it a landmark study on attitudes to dementia with unprecedented outreach – and the global baseline from which to measure future change.

Five years later, ADI and LSE have conducted a follow-up survey in order to see whether attitudes to dementia have changed since. Like in 2019, LSE developed the survey to target four key groups, (1) people living with dementia, (2) carers, (3) health and care professionals and (4) the general public, with analysis being provided in three categories: knowledge, attitudes, and behaviour. The 2024 survey garnered more than 40,000 responses, which, while less than in 2019, still represents a significant number of respondents from around the world sharing their views on dementia, allowing us to see how perceptions of the condition have changed – or not – in the past five years. The analysis contained within these pages is non-exhaustive given the extensiveness of the survey, and more insights will undoubtedly be gleaned over time at the global and national levels.

The time between 2019 and 2024 has seen major global upheavals: the COVID-19 pandemic that stretched healthcare systems beyond their capacity, large-scale and violent conflicts, and economic turmoil – all of which may have influenced social and political attitudes and discourse towards dementia. In times of hardship, marginalised and vulnerable populations are often the first to suffer the consequences, and this report explores some of the ways this has played out for people living with dementia.

In addition to the survey, ADI commissioned essays to include in the report and provide complementary reflections and viewpoints on the rich topic of attitudes to dementia. The essays have been divided into three sections: expert essays, case studies of stigma, and case studies addressing stigma. The expert essays look at how attitudes to dementia influence, or are influenced by, broad issues such as gender, COVID-19, popular culture, or access to diagnosis and treatment. Case studies of stigma looked at how dementia stigma might express itself in specific instances, such as in some cultures or age groups, in the context of armed conflict, or the life experiences of people with dementia in their own words. Case studies addressing stigma look at some avenues through which attitudes to dementia have been improved throughout the world – whether by changing the terminology used to refer to dementia, providing support to LGBTQI+ people living with dementia, or outreach to children and young people. This section also includes testimonies from ADI member associations in lower- and middle-income countries about the significance of the 2024 survey for them, in areas often neglected by dementia research.

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[1] "Ageing and Health," World Health Organization, https://www.who.int/news-room/fact-sheets/detail/ageing-and-health.

Key findings

The data, evidence, and case studies from this 2024 World Alzheimer Report highlight the complex and persistent nature of stigma and dementia worldwide. Our 2019 report provided an unprecedented baseline of global stigma data. Five years on, new data help us reflect on what has changed (or not), but certainly on what needs to change if we are to improve outcomes for people living with dementia worldwide. Here, we distil key findings into three categories: knowledge about dementia, attitudes and beliefs, and behaviours. This framework enables us to describe how knowledge about dementia can influence attitudes and beliefs – and ultimately behaviours toward people impacted by dementia.

Knowledge

- 80%* of the general public think dementia is a normal part of ageing, a dramatic increase compared to 66% in 2019.
- 65%* of health and care professionals (HCPs) believe dementia is a normal part of ageing, up from 62% in 2019.
- Over 96% of the general public believe in the value of a medical diagnosis.
- Over 93% of the general public believe there are things we can do to improve the lives of people with dementia.
- Over 58% of the general public believe dementia is caused by an unhealthy lifestyle. This number increased since 2019 across high-income countries (HICs) and upper-middle income countries (UMICs) but decreased dramatically in lower-/lower-middle income countries (LMICs).
- Over a quarter of people globally believe there is nothing we can do to prevent dementia, with an increase from 2019 to 37% in LMICs.
- Over 43% of the general public believe, at least in part, that dementia is caused by lack of family support, a dramatic increase since 2019, especially in HICs.

Our 2024 World Alzheimer Report has revealed the troubling reality that nearly 80% of the general public and, more worryingly, 65% of health and care professionals, still believe that dementia is a normal part of ageing. This is a concerning increase from our 2019 survey numbers, as we know that this lack of understanding can delay diagnosis and access to treatment and support.

There are also varying degrees of understanding around causal attributions of dementia; with a dramatic increase of people in high-income countries believing that lack of family support can cause dementia and over a quarter believing there is nothing we can do to prevent dementia.

The news regarding levels of knowledge is not all bad, however. The number of people who believe that dementia is caused by an unhealthy lifestyle has increased to over 61%, suggesting that messaging around the importance of dementia risk reduction is gaining traction. Finally, an overwhelming majority of the general public believe in the value of a medical diagnosis and that there are things we can do to improve the lives of people living with dementia.

Attitudes

- Between 29% (HICs) and 32% (LMICs) of the general public felt that people with dementia are dangerous more often than not – an increase from 2019.
- Over 64% of the general public believe people with dementia are impulsive and unpredictable, a slight increase from 2019, especially in UMICs.
- Over a quarter of respondents from the general public expressed a belief that moving a family member with dementia to a care home, even against their wishes, would be the best option. This number increased significantly in LMICs since 2019.
- Over 60% of the general public believed it is important to remove family responsibilities from people with dementia to avoid stressing them, an increase from 2019 data, especially in LMICs.
- Over 80% of general public respondents indicated a willingness to take a genetic test to determine their risk of developing dementia.
- More than 90% of carers and respondents from the general public said they would be encouraged to get a diagnosis if a disease-modifying treatment was available.

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* This is an average of global data. For breakdowns by World Bank income groups, please see Chapter 2.

- Over 85% of health and care professionals said they would be encouraged to *give* a diagnosis if there was a treatment that could prevent or slow the progression of dementia.
- More than 80% of the general public believe that they can change the support provided to people with dementia through their vote.

There were some real changes in overall attitudes toward people living with dementia since 2019. There was a general increase in the view that people living with dementia are dangerous and unpredictable in their behaviour, as well as an increased perception that it is important to remove family responsibilities from people with dementia to avoid stressing them. Significantly, more than 27% of respondents from the general public expressed a belief that moving a family member with dementia to a care home, even against their wishes, would be for the best.

In contrast, the majority of the general public showed a willingness to be proactive in determining their own health journeys in relation to dementia, with over 80% of respondents indicating a willingness to take a genetic test to determine their risk of developing dementia, and more than 90% of respondents saying they would be encouraged to get a diagnosis if a disease-modifying treatment was available. Equally, over 85% of health and care professionals said they would be encouraged to *give* a diagnosis if there was a treatment that could prevent or slow the progression of dementia.

Behaviours

- 88% of people living with dementia indicate experiencing discrimination, up from 83% in 2019.
- 36% of the general public in LMICs are willing to keep their dementia a secret, a significant increase from 19% in 2019.
- Carers and people living with dementia tended to report higher levels of loneliness than the general population.
- Over 50% of people with dementia and their carers experienced anticipated discrimination.

  For people with dementia:
  - 36% stopped applying for or continuing work
  - 29% avoid or discontinue close personal relationships
  - 24% (nearly a quarter) avoid seeking help, care, or treatment due to concerns about potential treatment by pharmacists or other customers.
  - 22% avoid visiting banks due to fear of judgement
  - 31% avoid social situations due to concerns regarding the reactions of others

  For carers:
  - 43% stopped inviting friends over due to concerns about how they might treat their loved one
  - 47% stopped accepting invites to visit friends or family
  - 40% avoided joining social groups or activities due to concerns about reactions to their loved one
  - 34% avoided going out in public with the person they care for due to fears of perception
  - 41% of carers avoid travel or taking vacations due to concerns that the person they care for could be treated negatively

Not surprisingly, these findings strike to the heart of the World Alzheimer Report. Behaviour outlines the 'real-world' impact of stigma – it stems from public and structural stigma and can often manifest as discrimination. It is important to note that this report outlines experiences of discrimination by others, but also levels of 'anticipated discrimination,' which can hinder and individual from participating fully in life due to fear of rejection. In this report, the experience of anticipated discrimination was most profound in family carers. It is clear that people living with dementia, and those who care for them, are experiencing high levels of discrimination and/or fear of discrimination, which is impacting severely on their quality of life. This is significant.

Recommendations

The survey data, essays, and case studies included in this report paint a complex picture of global attitudes to dementia. These attitudes are complicated, often interrelated, and, sometimes, entangled. But this interconnectedness can work in our favour. By tackling stigma across multiple fronts, at the public, structural, and individual levels, each can have an impact on the next – and like dominoes, gradually knock down barriers to inclusion, to work towards a future in which dignity, respect, and inclusion are no longer a dream for people living with dementia, but a reality.

ADI recommends stepping up efforts globally to tackle stigma across three fronts:

Public

- **Awareness-raising campaigns need to change and include behaviour change.** We need to make messages clearer. Dementia is *not* a normal part of ageing. Awareness-raising campaigns must be targeted and direct; with simple facts and easy-to-remember anecdotes about what dementia is and what it is not. We also need to focus on creating environments that encourage positive behaviours towards people with dementia. By changing the way society interacts with people living with dementia, we can foster greater understanding and inclusion, which over time can reduce stigma.
- **Messaging matters.** Increased levels of discrimination underscore the need for messaging that goes beyond awareness raising to ensure that the right information is getting across. People with dementia can still lead meaningful and active lives. We need to break down misconceptions that create fear and feed prejudice, with representation from people living with dementia and their carers to demonstrate the true and human face of dementia, in all of its diversity.
- **Public perceptions influence policy – so how we represent dementia matters.** Stigmatising portrayals of people with dementia – as frail, elderly, an empty shell – perpetuate a hopeless view that contributes to apathy amongst policymakers who must decide where best to invest scant resources. Policies and structural stigma will never improve unless we change this narrative and portray the full and rich diversity and experience of the dementia journey.
- **Anti-stigma tools and communication must be promoted.** The higher levels of fear demonstrated within the survey indicate that the public doesn't always know how to connect or respond to people who have dementia. Public awareness campaigns need to include examples of tools and proactive communication techniques – many of which already exist – on how to engage with a person living with dementia, how to recognise unmet needs, or how to use simple active listening to connect in a non-threatening manner.

Structural

- **We need to recognise and challenge structural stigma.** This report touches upon some of the society-level conditions and institutional practices that exacerbate structural stigma impacting people living with dementia, including racism, social determinants of health, disablism, and sexism. These systemic level practices need to be challenged head-on through equitable policies that promote inclusion and provide equal opportunity and access to support and care for those impacted by dementia.
- **Equitable and inclusive policies start with national dementia plans.** National dementia plans remain the most effective way for governments to develop, legislate, and fund dementia-inclusive policies that promote equitable access to treatment and care as well as dementia-inclusive environments. Dementia plans encourage a whole-systems approach to breaking down stigma through collaborative working across health and care systems, community organisations, and public/private entities.
- **Access to dementia diagnosis, care, and treatment is a right.** One key factor in the persistent stigma and fear surrounding dementia is the belief that nothing can be done to treat or slow down the progression of the condition. While there is still no cure, symptomatic treatments exist, and disease-modifying treatments are available in some countries. More than 90% of respondents said they would seek out a dementia diagnosis if they knew a disease-modifying treatment was available. This overwhelming response should be viewed as a call for governments and international organisations to ensure equitable access to pharmacological, non-pharmacological, and lifestyle treatments and therapies, regardless of age, background, income, or country of residence.

- **Vote: dementia is a political issue.** With 83% of the general public believing that their vote can influence dementia policy, it's clear that dementia is a factor they wish to see addressed in candidates' political platforms. The 2024 Attitudes to dementia survey proves that there is a real appetite from constituents for their political leaders to play an active role in creating environments where people living with dementia can be supported, cared for, and thrive for as long as possible.

Individual

- **Include the voice of lived experience.** Fundamental to any anti-stigma initiative is to include the input and representation of people living with dementia to ensure their views, experiences, ideas, and desires are front and centre in all the detail and practicalities of our programmes. The voices of people with dementia will break down barriers – and this can enhance self-esteem, quality of life, promote social inclusion, and improve overall wellbeing.
- **Support carers.** This survey revealed the true impact of experienced and anticipated discrimination on carers. They experience more loneliness and reported a poorer quality of life than the general population and health and care professionals. Whether due to societal prejudices or internalised stigma, the burden of dementia should not be carried alone. ADI calls on governments to provide solid support networks and person-centred services to create truly dementia-inclusive communities, in which those living with the condition– and those who care for them – no longer feel isolated and cast aside. Individuals who care about dementia, whether they are directly affected or not, should also be encouraged to take action to change the way dementia is discussed and treated.
- **Invest in training health and care providers.** With 65% of healthcare professionals still believing dementia is a normal part of ageing and 59% thinking members of their own profession tend to ignore the person living with dementia – there is a clear and urgent need to improve and expand dementia education, training, and professional development for clinicians and other health and long-term care professionals. They are on the frontline and deserve access to all necessary tools to ensure they can break stigma and encourage deeper understanding and expertise of dementia.
- **Take individual action.** While ADI is a strong advocate of governmental and institutional-level responses to address structural issues, every single one of us has the power to make a difference at our own level, as shown in the box below. Every person reading this report can act today to make the world a better place for people living with dementia, in ways big and small. In the words of Noriyo Washizu, one of the contributing authors of this report, "a journey of a thousand miles begins with a single step."

Five things you can do:

1. **Educate yourself.** Contact your local Alzheimer or dementia organisation (which can be found on ADI's website) or check out the resource section on ADI's website to learn more about dementia and how you can break the cycle of stigma.
2. **Reach out to someone who has dementia.** Do something meaningful for a family impacted by dementia that you know, or volunteer to help at a charity or an Alzheimer or dementia association. Small acts of service add up.
3. **Advocate.** Does your home country have a national dementia plan? Is there a clear pathway for accessing timely diagnosis or post-diagnostic care? Write to the policy makers in your country to insist that dementia become a priority.
4. **Reduce your own risk.** There is a lot you can do to reduce your own risk of developing dementia and enhance your brain health. It's never too late, or too early, to start! Take a look at the World Alzheimer Report 2023 for an accessible and easy-to-read introduction to the topic.
5. **Post about dementia.** Use social media to share the findings of this survey and to challenge others to learn more.

Chapter 1:

What is stigma?

A participant of the annual Kahuna Kupuna surf contest in San Francisco, California in August 2024. Loosely translated from Hawaiian, "Kahuna Kupuna" means "Big Chief Wise Elder," a fitting name for the only amateur surf contest in the world specifically designed for surfers aged 40 and over. (Alex Kornhuber)

What is 'stigma'?

Jessica Young,[1] JB Orange,[2] and Christopher Lind[3]

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> **"People with dementia look forward to the day when we no longer have to be defined by our disease or our disabilities, and we are all treated equally."**
>
> *Kate Swaffer, dementia activist*[1]

The World Alzheimer Report 2019 presented the largest global survey of attitudes to dementia at the time. Findings outlined in the original report showed that stigma impacts the everyday lives of people with dementia in complex and harmful ways. Five years on, we return to the topic to explore further how we can continue to address the harms associated with dementia-related stigma. In this chapter we revisit:

1. What the word 'stigma' means
2. The impact stigma can have on people with dementia and people close to them
3. What we can do about stigma to reduce its harmful effects

We summarise briefly five different types of stigma and share some recent advances in strategies to reduce dementia-related stigma.

Defining 'stigma'

The word 'stigma' describes when a person or a group of people is treated unfairly because the person or group is perceived to be 'different.' [2] The person or group is not treated in the same way as people who are perceived to be 'normal.' They could be perceived as different in a variety of ways, for example, by their ethnicity, religion, physical abilities, mental health, or sexual orientation. They could also be perceived as different because they have dementia.

Figure 1: A person with a label of dementia

The word 'stigma' originates from Greek, meaning a 'mark' or 'brand.' Dementia symptoms or a diagnosis is often perceived as a 'mark' or a 'label' that sets a person apart from what is widely considered 'normal' (Figure 1). In this report, we use the word 'stigma' to refer to the ways we treat people with dementia unfairly because of that mark or label. We also use the word 'stigma' to refer to the unfair treatment of people close to a person with dementia because of their relationship with them.

One common model for understanding stigma shows that it has three main components: 'negative stereotypes,' 'prejudice,' and 'discrimination'[3] (see Figure 2).

According to the model, 'stigma' occurs when a person:

- internalises negative **ideas and assumptions** about people with dementia (negative stereotypes),
- holds negative **feelings** toward people with dementia because of negative stereotypes (prejudice), and
- uses **actions** that treat a person with dementia unfairly (discrimination).

We describe each of the three components in more detail.

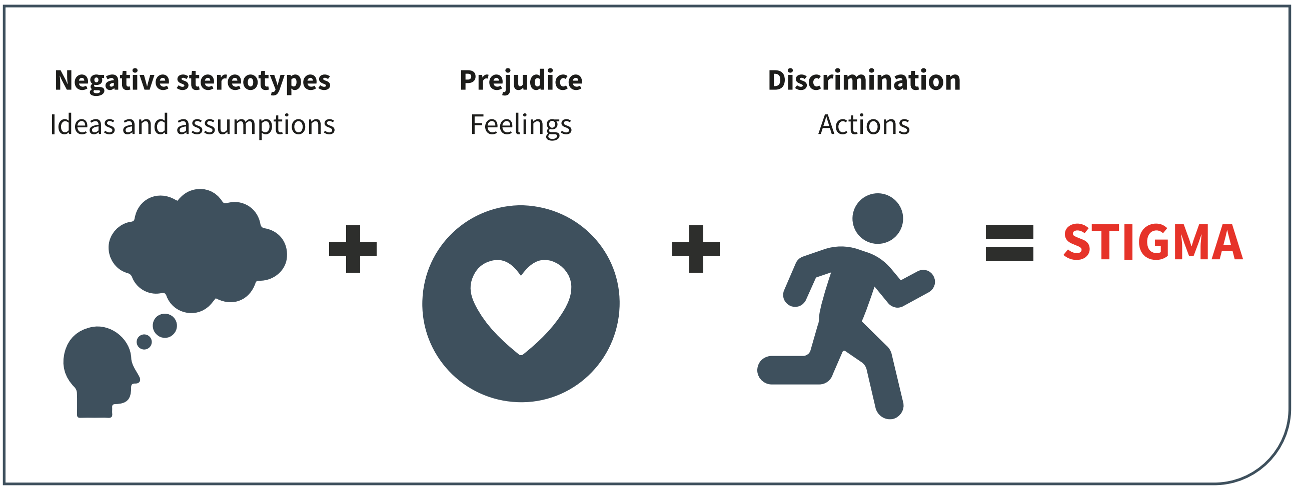

Figure 2: Three components of stigma, adapted from Rüsch, Angermeyer and Corrigan (2005)

Negative stereotypes: ideas and assumptions

Stereotypes are common **ideas or assumptions** about people with the same mark or label. For example, people marked or labelled as 'women' often are stereotyped as more emotional and physically weaker than people marked or labelled as 'men.' However, many do not fit those stereotypes, and there are many diverse experiences of gender beyond those two labels. Stereotypes group together people by the same marks or labels, and permit others to assume that they are all the same.[2]

Negative stereotypes portray people with a certain label as less important, capable, or valuable than people without that label. Negative stereotypes depict dementia as an entirely negative experience (Figure 3). Dementia is depicted as completely devastating, debilitating, frustrating, severe, hopelessly incurable, and leading to a complete loss of abilities.[4,5,6,7]

We can learn, internalise and share these stereotypes, even if we do not believe them.[8] For example:

1. **We share them through words.** We could share negative stereotypes by labelling people with dementia as 'sufferers,' 'demented,' or 'victims.'[9,10] We could also share them by talking about dementia as a 'living death' or 'a fate worse than death.'[5,7,11]
2. **We share them through pictures.** For example, pictures or images of people with dementia in the media often match the negative stereotypes.[9] For example, they might show a person who looks old, weak, sad, and distressed.

Dementia stereotypes

People with dementia are:

- a burden on families
- a danger to themselves
- old
- weak
- incompetent
- distressed
- untrustworthy

Figure 3: Negative stereotypes of people with dementia

Prejudice: negative feelings

Prejudice occurs when internalised dementia stereotypes lead to negative feelings toward people with dementia, such as fear, shame, anxiety, embarrassment, or even disgust.[5,9,12–14] The depth of these feelings can be impacted by a person's age, gender, ethnicity, culture, and their understanding of dementia.[15] These negative emotions then can lead to negative or unfair actions toward people with dementia.

Discrimination: actions

Discrimination occurs when a person with dementia is treated unfairly because of negative stereotypes and prejudice towards them.[3] People with dementia can be discriminated against by a range of different people, for example by members of the general public, family members, health and care professionals, the judicial system, or employers.

People with dementia also can be discriminated in a range of different ways.[9,12,13,16–22]

For example, people with dementia can be:

- avoided socially
- kept away from other people
- have their dementia diagnosis hidden from them
- not be offered rehabilitation or treatment
- excluded from making decisions about their own life
- made to live somewhere without their consent (i.e. involuntary institutionalisation)

Five types of stigma

There are quite a few different types of dementia-related stigma. Here, we describe five of them: 'public stigma,' 'self-stigma,' 'courtesy stigma,' 'affiliate stigma,' and 'structural stigma.'[9,12,23] There may be other similar types, but these are the most common ones.

Type 1: Public stigma

Public stigma is the most common type of dementia-related stigma.[9] It occurs when the general public and/or health professionals hold prejudice toward people with dementia and, as a result, discriminate against them (Figure 4). For example, a person may internalise the stereotype that people with dementia are a danger to themselves, this may lead to prejudice in the form of fear, and that could result in social discrimination, where they avoid a person with dementia entirely.

Type 2: Self-stigma

Self-stigma occurs when people with dementia hold negative feelings toward themselves, which then impacts their actions in a way that harms them (Figure 5). A dementia diagnosis or perception of dementia symptoms could make a person with dementia feel ashamed, anxious, embarrassed, vulnerable, invisible, and lead to low self-confidence.[5,12,16,24] These feelings can cause people with dementia to withdraw, and in a way 'self-discriminate.' It may cause them to avoid other people, hide their symptoms or diagnosis from others, not ask for help, and/or refuse rehabilitation and treatment.[12,14,16,17,20,25] These behaviours further socially isolate people with dementia, and act as a barrier to them being well supported and maintaining their quality of life.

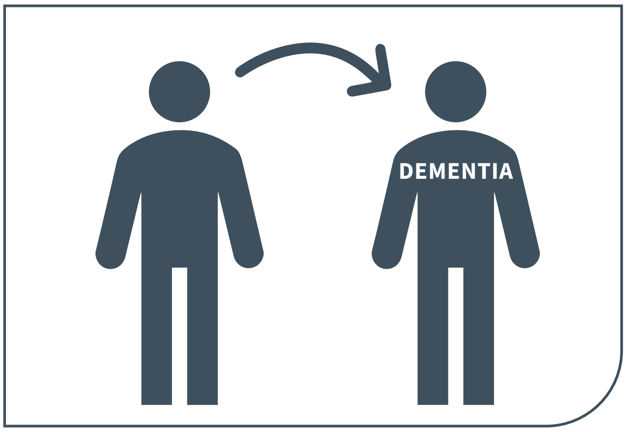

Figure 4 Public stigma

Figure 5: Self-stigma

Type 3: Courtesy stigma

Courtesy stigma occurs when family, friends, or health and care providers are discriminated against because of their relationship to the person with dementia (Figure 6).[26,27] For example, stereotypes of family and carers being 'neglectful' could invoke feelings of disgust toward them.[23,28] In turn, those feelings may lead to discrimination against family members, friends or formal caregivers or health professionals. In courtesy stigma, discrimination often manifests socially. For example, people close to the person with dementia could be avoided socially, excluded from or not invited to attend special events, shunned, or talked about behind their backs.[17,23,27–29]

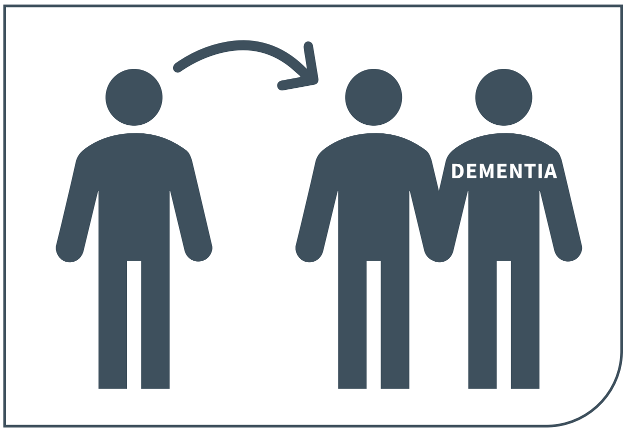

Figure 6: Courtesy stigma

Type 4: Affiliate stigma

Affiliate stigma is like self-stigma for people close to the person with dementia. It occurs when family, friends, or health and care providers internalise negative stereotypes of family and carers (see stereotypes described in 'courtesy stigma' section above) (Figure 7). This could make them feel "anger, fear, and shame,"[23] possibly leading them to:

- hide their relationship with the person with dementia from others
- hide the person with dementia's diagnosis from others
- isolate themselves socially
- not ask for help

Figure 7: Affiliate stigma

Type 5: Structural stigma

Structural stigma occurs when institutions discriminate against people with dementia through the use of laws, policies, and practices (Figure 8). This sort of discrimination could include:

- Limiting eligibility for health services and supports
- Residential institutions that confine people with dementia
- Hospitals and residential institutions that restrict access by family members, and/or
- Healthcare staff receiving limited education about best-practice dementia care[30,31]

Figure 8: Structural stigma

Acknowledging, addressing, and reducing

Understanding the three components (stereotypes, prejudice, and discrimination) and five different types of stigma (public stigma, self-stigma, courtesy stigma, affiliate stigma, and structural stigma) can help us find effective ways to reduce dementia-related stigma, and to improve the lives of people with dementia and people close to them.[8,12]

There are many different ways we could start to reduce dementia-related stigma.[15,32] Here we present just a few of them. For example:

1. We can challenge negative stereotypes by:
    - Media, advocacy organisations, and researchers using words and images that reflect balanced depictions of dementia. For example, using images that depict individuality, a person-centred focus, and family connections.[6] For example, using person-centred language such as 'person with dementia' rather than 'demented person.'
    - Using accurate public health information about dementia[33,34]
    - Providing specific dementia-related stigma education programmes[35–37]
    - Paying attention to and following the advice of advocates with dementia, such as members of Dementia Alliance International or ADI's Global Dementia Experts Panel
    - Sharing the capabilities and diverse experiences of people with dementia. Some recent examples are:
        - BUDI Orchestra- Musical performances by people with dementia[38]
        - 'Cracked'- Theatre and film about relationships with people with dementia[39]
    - #WorldAlzDay- Social media campaigns sharing diverse experiences of dementia[40]
2. We can challenge prejudices by:
    - Understanding how stereotypes shape our feelings about dementia
    - Recognising when our actions are led by fear, shame, guilt etc.
3. We can challenge discrimination by:
    - Understanding how prejudices shape our actions toward people with dementia
    - Supporting rehabilitation access
    - Supporting social connections for people with dementia and families
    - Challenging discriminatory policies and practices
    - Supporting people with dementia to inform research, policy development, advocacy, and care services[30,33,41,42]

People with dementia deserve to live meaningful lives that are not constrained by disease, or disability, nor by others' perceptions or actions. As dementia advocate Kate Swaffer notes, challenging stigma is one way to work toward equal treatment and non-discrimination of people with dementia.

References

1. Alzheimer's Disease International, *World Alzheimer Report 2019: Attitudes to dementia*. 2019.
2. Goffman, E., *Stigma: Notes on the management of spoiled identity*. 1963, New York, NY: Simon and Schuster.
3. Rüsch, N., M.C. Angermeyer, and P.W. Corrigan, *Mental illness stigma: concepts, consequences, and initiatives to reduce stigma.* Eur Psychiatry, 2005. **20**(8): p. 529–39.
4. Crichton, P., H. Carel, and I.J. Kidd, *Epistemic injustice in psychiatry.* BJPsych Bulletin, 2017. **41**(2): p. 65–70.
5. Low, L.F. and F. Purwaningrum, *Negative stereotypes, fear and social distance: a systematic review of depictions of dementia in popular culture in the context of stigma.* BMC Geriatr, 2020. **20**(1): p. 477.
6. Cuadrado, F., et al., *How to improve attitudes towards dementia? Reframing as a tool to overcome the stigma around Alzheimer's disease.* Patient Education and Counseling, 2023. **115**.
7. Ballenger, J.F., *Framing Confusion: Dementia, Society, and History.* AMA Journal of Ethics, 2017. **19**(7): p. 713–719.
8. Young, J.A., et al., *Expanding current understandings of epistemic injustice and dementia: Learning from stigma theory.* J Aging Stud, 2019. **48**: p. 76–84.
9. Werner, P., et al., *From History to Intervention: A Sociocultural Analysis of Dementia Stigma*, in *Dementia and Society*, E. Schokkaert, M. Vandenbulcke, and R.-M. Dröes, Editors. 2022, Cambridge University Press: Cambridge. p. 25–44.
10. Swaffer, K., *Dementia: Stigma, Language, and Dementia-friendly.* Dementia, 2014. **13**(6): p. 709–716.
11. Werner, P., C.N. Shpigelman, and L. Raviv Turgeman, *Family caregivers' and professionals' stigmatic experiences with persons with early-onset dementia: a qualitative study.* Scand J Caring Sci, 2020. **34**(1): p. 52–61.
12. Nguyen, T. and X. Li, *Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature.* Dementia (London), 2020. **19**(2): p. 148–181.
13. Philip, G., et al., *Exploring stigmatizing perceptions of dementia among racialized groups living in the Anglosphere: A scoping review.* Aging and Health Research, 2024. **4**(1).
14. Lopez, R.P., et al., *Managing Shame: A Grounded Theory of How Stigma Manifests in Families Living With Dementia.* J Am Psychiatr Nurses Assoc, 2020. **26**(2): p. 181–188.
15. Herrmann, L.K., et al., *A Systematic Review of Alzheimer's Disease and Dementia Stigma Research: How Might We Move the Stigma Dial?* American Journal of Geriatric Psychiatry, 2018. **26**(3): p. 316–331.
16. Wong, K.L.Y., G. Johnson, and D. O'Connor, *Living with dementia: Exploring the intersections of culture, race, and dementia, stigma.* Dementia (London), 2024: p. 14713012241249796.
17. Oliveira, D., et al., *Experiences of stigma and discrimination among people living with dementia and family carers in Brazil: Qualitative study.* Ageing and Society, 2023. **43**(2): p. 447–468.
18. Low, L.F., et al., *Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners.* Dementia (London), 2019. **18**(7–8): p. 2856–2905.
19. O'Connor, D., J. Mann, and E. Wiersma, *Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship.* Journal of Aging Studies, 2018. **44**: p. 45–51.
20. Cations, M., et al., *Health Professional Perspectives on Rehabilitation for People With Dementia.* Gerontologist, 2020. **60**(3): p. 503–512.
21. Johnson, R., et al., *The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment.* Social Science & Medicine, 2015. **143**: p. 117–27.
22. Stites, S.D., J.D. Rubright, and J. Karlawish, *What features of stigma do the public most commonly attribute to Alzheimer's disease dementia? Results of a survey of the U.S. general public.* Alzheimers Dement, 2018. **14**(7): p. 925–932.
23. Abojabel, H. and P. Werner, *Exploring family stigma among caregivers of persons with Alzheimer's disease: The experiences of Israeli-Arab caregivers.* Dementia (London), 2019. **18**(1): p. 391–408.
24. Maxfield, M. and J. Greenberg, *Anticipated Stigma and Dementia-Related Anxiety in Middle-Aged and Older Adults.* GeroPsych (Bern), 2021. **34**(1): p. 13–22.
25. Ashworth, R., *Perceptions of stigma among people affected by early- and late-onset Alzheimer's disease.* Journal of Health Psychology, 2020. **25**(4): p. 490–510.
26. Werner, P., *Stigma and Alzheimer's disease: A systematic review of evidence, theory, and methods*, in *The stigma of disease and disability: Understanding causes and overcoming injustices* P.W. Corrigan, Editor. 2014, American Psychological Association: Washington, DC.
27. Werner, P. and H. AboJabel, *Who internalizes courtesy stigma and how? A study among Israeli Arab family caregivers of persons with dementia.* Aging Ment Health, 2020. **24**(7): p. 1153–1160.
28. Werner, P. and A. Hess, *Examining courtesy stigma among foreign health care workers caring for persons with Alzheimer's disease: A focus group study.* Home Health Care Services Quarterly, 2016. **35**(2): p. 69–85.
29. Greenwood, N., G. Mezey, and R. Smith, *Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness.* Maturitas, 2018. **112**: p. 39–45.
30. Bacsu, J.-D.R., et al., *Understanding stigma of dementia during COVID-19: a scoping review.* Frontiers in Psychiatry, 2024. **15**.
31. Jacobs, R., et al., *Stigma and its implications for dementia in South Africa: a multi-stakeholder exploratory study.* Ageing and Society, 2022: p. 1–31.
32. Bacsu, J.D., et al., *Stigma Reduction Interventions of Dementia: A Scoping Review.* Can J Aging, 2022. **41**(2): p. 203–213.
33. Stites, S.D., et al., *Identifiable Characteristics and Potentially Malleable Beliefs Predict Stigmatizing Attributions Toward Persons With Alzheimer's Disease Dementia: Results of a Survey of the U.S. General Public.* Health Commun, 2018. **33**(3): p. 264–273.
34. Lawlor, B., *The local and global imperative to raise public awareness and knowledge about dementia.* Arq Neuropsiquiatr, 2018. **76**(11): p. 729–730.
35. Herrmann, L.K., et al., *A new curriculum to address dementia-related stigma: Preliminary experience with Alzheimer's Association staff.* Dementia (London), 2019. **18**(7–8): p. 2609–2619.
36. Kim, S., et al., *Dementia Stigma Reduction (DESeRvE): Study protocol for a randomized controlled trial of an online intervention program to reduce dementia-related public stigma.* Contemporary Clinical Trials Communications, 2019. **14**: p. 100351.
37. Alipour Chermahini, M., et al., *The Impacts of an Educational Program by Using Group Discussion on Perceived Stigma Among the Family Caregivers of People with Alzheimer's Disease.* Jundishapur Journal of Chronic Disease Care, 2021. **10**(3).
38. Reynolds, L., et al., *'The stigma attached isn't true of real life': Challenging public perception of dementia through a participatory approach involving people with dementia (Innovative Practice).* Dementia, 2017. **16**(2): p. 219–225.
39. Kontos, P., et al., *Projecting a Critique of Stigma Associated With Dementia on Screen: The Impact of a Canadian Film on the Importance of Relational Caring in the Community.* Gerontologist, 2024. **64**(2).
40. Tenzek, K.E., et al., *Staying connected: Alzheimer's hashtags and opportunities for engagement and overcoming stigma.* Journal of Aging Studies, 2023. **66**.
41. Phillipson, L., et al., *Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project.* Dementia (London), 2019. **18**(7–8): p. 2679–2694.
42. Hossain, M.Z. and F. Mughal, *Dementia and revivalist Islam: New perspectives to understanding dementia and tackling stigma.* J Eval Clin Pract, 2021. **27**(2): p. 213–217.

Chapter 2:

Attitudes to dementia survey results

A father and son in the village of Monjolos, in northeastern Brazil in 2015 (Domenico Pugliese)

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1. Background

Addressing the stigma associated with dementia is a global challenge given its profound impact on individuals, families, and societies around the world. Dementia-related stigma exacerbates the challenges faced by those living with the condition and obstructs efforts to provide care and support. Stigma, manifesting in various forms – internalised or self, public, and structural (See Table 1) – imposes significant barriers to the wellbeing of people with dementia and their carers. The different aspects of stigma are discussed more in depth in Jess Young et al's essay in Chapter 1.

At the individual level, stigma undermines life goals, diminishes participation in meaningful activities, and deteriorates quality of life. People with dementia often internalise societal stereotypes, leading to self-stigma, which can manifest as shame, social withdrawal, and secrecy. This internalised stigma can be as debilitating as the symptoms of dementia itself, further isolating individuals and preventing them from seeking help and support. Public stigma can also extend to carers, who may also face stigma by association.

Stigma can also influence public policy and the allocation of resources for dementia care. Negative perceptions and widespread misinformation about dementia contribute to a lack of funding for essential services and support systems. This underinvestment exacerbates existing inequalities, leaving individuals with dementia and their carers without the necessary resources to manage the condition effectively. Consequently, societal stigma perpetuates a cycle of neglect and inadequate care, exacerbating the challenges faced by individuals with dementia and their families.

Table 1. Definitions and examples of different types of dementia-related stigma

Type of stigma	Definition	Example
Public stigma	The reaction that the general public has towards people with dementia, often characterised by negative stereotypes, prejudice, and discrimination.	"People with dementia are like children, incapable of making decisions." "People with dementia are like the living dead."
Internalised or self-stigma	When individuals with dementia internalise societal stereotypes and turn them against themselves, resulting in feelings of shame, reduced self-esteem, and social withdrawal.	"I have dementia so I can no longer contribute meaningfully to my family or community." "Because of my dementia, I avoid social events to avoid embarrassment."
Structural stigma	Systemic policies, practices, and regulations that disadvantage people with dementia. This includes institutionalising discrimination and perpetuating inequality.	Insurance policies that exclude coverage for dementia care. Nursing homes refusing to admit individuals with dementia due to additional care requirements.
Affiliate stigma	The stigma experienced by carers and family members of individuals with dementia. This occurs when they internalise public stigma and face discrimination or social exclusion due to their association with someone who has dementia. This can lead to feelings of guilt, shame, and social isolation among carers.	"People stopped inviting us over to their house after they found out about my family member's dementia." "I feel embarrassed to talk about my spouse's dementia with my friends. People avoid inviting us over."

1.1 Changes since the 2019 report and the current landscape

The 2019 World Alzheimer's Report represented the first and largest global survey on dementia stigma. The 2019 survey findings provided a detailed description of the nature of dementia-related stigma, how it is experienced by people living with dementia, and its detrimental impacts across diverse contexts. Much has changed since the publication of the 2019 report. The COVID-19 pandemic, in particular, has amplified existing structural discrimination and highlighted the need for more robust support systems. The pandemic has strained healthcare resources, making it even more challenging for people with dementia to access essential care and support. Geopolitical conflicts, economic crises, and the ongoing impact of climate change have created regional pockets devoid of basic services and patchy access to dementia medications.

Despite these challenges, there have been notable advancements. The Global action plan on the public health response to dementia, launched by the World Health Organization in 2017, has inspired a number of countries to devise national dementia plans that enhance the quality of life of individuals living with dementia and their carers by improving access to diagnosis, treatment, and support services. While the Global action plan has so far fallen short of its set ambitions, it remains a powerful tool, which has led ADI to advocate for its extension past its scheduled 2025 end date.

The 2024 survey's aim was to capture the current global knowledge, attitudes, and behaviours towards dementia-related stigma, comparing these findings with those from 2019. This report seeks to understand the changes in dementia stigma over the past five years and to explore how these insights can inform effective strategies to reduce stigma globally. Emphasising the theme of change, this report highlights initiatives and progress in combating dementia stigma, including case studies and examples of stigma reduction efforts. These initiatives, together with the findings from our survey, can highlight areas that need more attention and provide examples of tools to enact change.

We must collectively seek to create environments where people with dementia and their carers can live meaningful, inclusive, and stigma-free lives. By addressing stigma at multiple levels, we strive to foster a more equitable and supportive society for those affected by dementia. This requires a concerted effort to challenge societal norms, implement inclusive policies, and provide support systems that enable the wellbeing of people with dementia and their carers. Through collaborative efforts, we can dismantle the barriers imposed by stigma and work towards a future where every individual affected by dementia can experience dignity, respect, and inclusion.

> **“We must collectively seek to create environments where people with dementia and their carers can live meaningful, inclusive, and stigma-free lives.”**

2. Comparative analysis: 2019 vs. 2024

In the 2019 World Alzheimer Report, we explored the issue of stigma across three key areas that contribute to it: 1) knowledge (problems of ignorance and misinformation), 2) attitudes (problems of prejudice), and 3) behaviour (problems of discrimination).[1] These issues are interlinked and influence one another in complex ways. We repeat the exercise here, but through the lens of how these have changed since 2019. Building on this theme, we first present survey findings regarding stigma-related knowledge.

For our comparisons, we group countries according to World Bank income groups, allowing us to capture differences and similarities across countries with similar levels of resources and economic development. Additional comparisons between countries are included in the appendices at the end of this chapter. Detailed information about our sample and the methods we used for comparisons over time are included in Section 7 on methodology.

2.1 Changes in stigma-related knowledge about dementia

The vast majority of general public respondents (96 to 97% depending on World Bank income group) believe in the value of a medical diagnosis (Figure 1) and that there are things we can do to improve the lives of people with dementia, and this is relatively consistent across countries and seemed to remain relatively stable between 2019 and 2024 (Figure 2). There is also a high agreement that social support can help improve the lives of people with dementia, though agreement decreased in low-/lower-middle income countries and increased in high-income countries between 2019 and 2024 (Figure 3).

However, between 24% and 37% of survey respondents still think that there is nothing we can do to prevent dementia (Figure 4). This belief increased across all country income groups between 2019 and 2024, with a particularly significant rise in low-/lower-middle income countries, where it increased from 20% to 37%. This suggests a growing gap in awareness of dementia risk reduction, potentially leading to missed opportunities for prevention in lower-income settings.

Figure 1. Percentage of the general public agreeing with the statement 'It's useful to receive a formal diagnosis' by World Bank country income group in 2019 and 2024

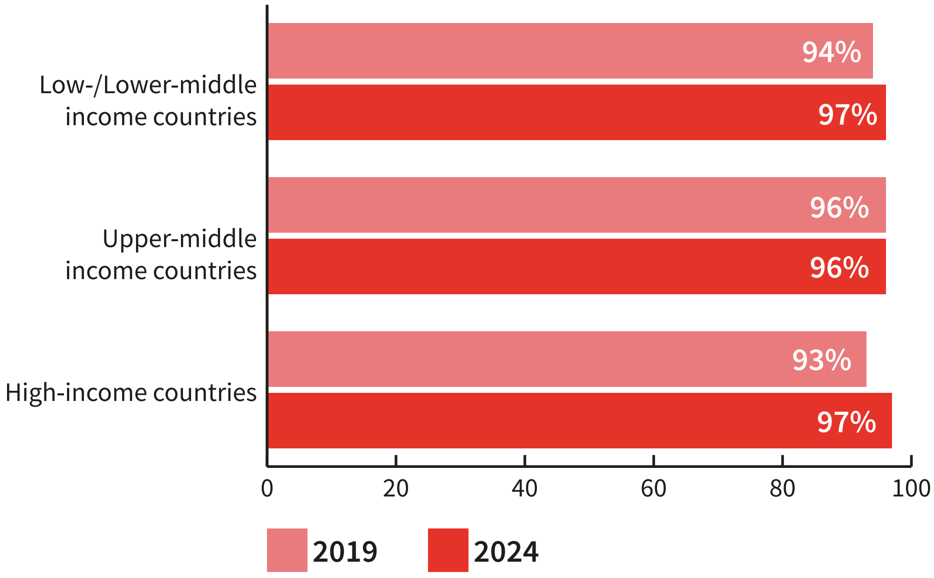


Figure 2. Percentage of the general public agreeing with the statement 'There are things we can do to improve the lives of the people with dementia' by World Bank country income group in 2019 and 2024

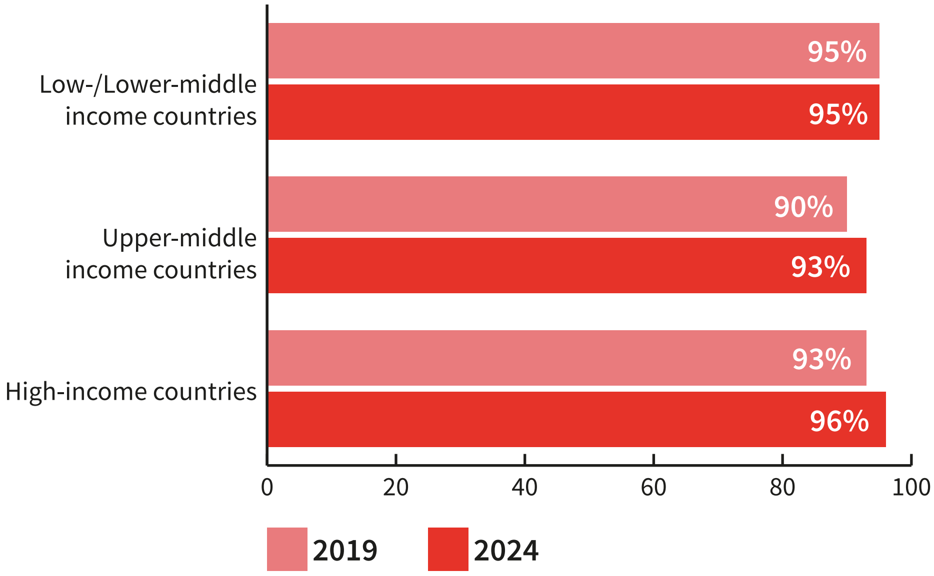


Figure 3. Percentage of the general public agreeing with the statement 'A person with dementia's situation is likely to improve with social support' by World Bank country income group in 2019 and 2024

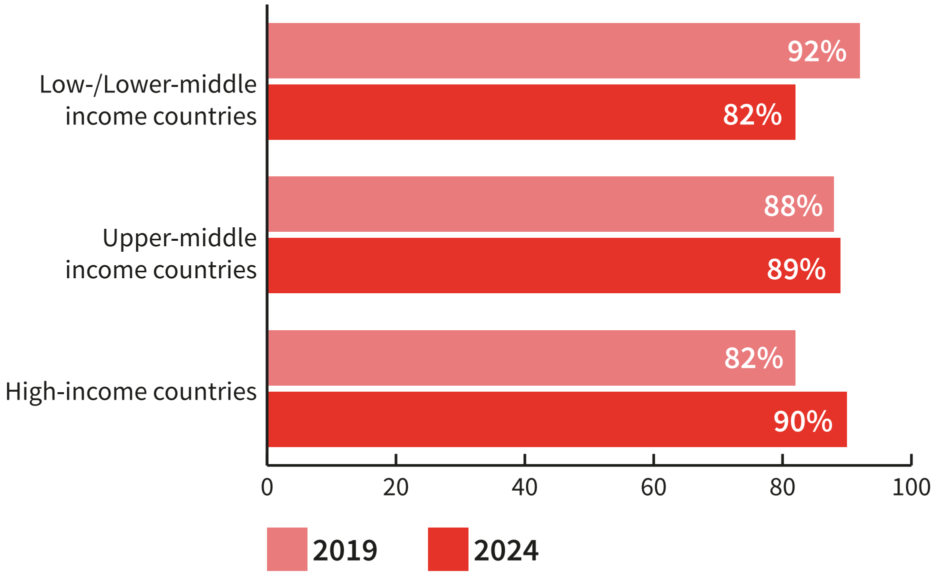
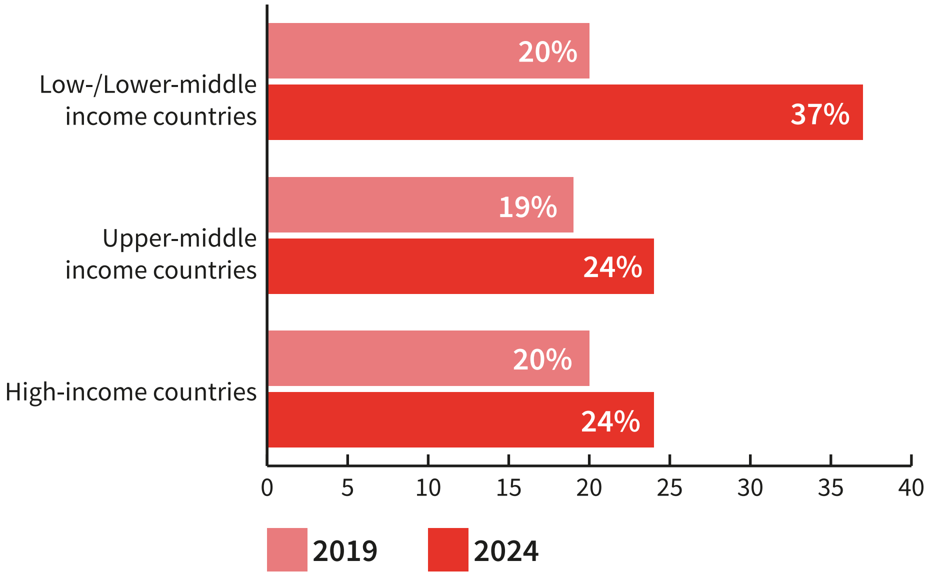


Figure 4. Percentage of the general public agreeing with the statement 'There is nothing we can do to prevent dementia' by World Bank country income group in 2019 and 2024



Public perceptions about the causes of dementia

Causal attributions – how people explain the causes of dementia – play a crucial role in shaping public attitudes, behaviours, and policy responses. Understanding these perceptions can help us identify areas where misinformation may be influencing the stigma surrounding dementia. In this section, we explore public beliefs about the causes of dementia, including views on whether it is attributed to bad luck (Figure 5), an unhealthy lifestyle (Figure 6), lack of family support (Figure 7), or simply a normal part of ageing (Figure 8 and 9).

In terms of a fatalistic view that dementia is caused by bad luck, perceptions remained relatively stable in low-/lower-middle income countries. In high-income countries, however, fewer people agreed that dementia was caused by bad luck in 2024 compared to 2019 (27% to 23%). Conversely, in upper-middle income countries, agreement increased from 11% in 2019 to 17% in 2024.

In 2024, more people in high-income countries believed that dementia was caused by an unhealthy lifestyle (61% vs 51%), suggesting that messaging around risk reduction is gaining traction. However, this belief remained relatively stable in upper-middle income countries and decreased in low-/lower-middle income countries (78% to 58%).

The increase in agreement that dementia is caused by a lack of family support suggests a growing tendency to place responsibility for dementia on the social environment, particularly families. This could reflect a cultural shift towards moral or social attributions, where the family is viewed as failing in their duty of care, or reflect societal norms where the role of the family in caregiving is becoming more pronounced. In relation to stigma, this view can lead to blame and guilt directed at carers and families, contributing to family members internalising feelings of shame (Figure 7).

Figure 5. Percentage of the general public agreeing with the statement 'Dementia is caused due to bad luck' by World Bank country income group in 2019 and 2024

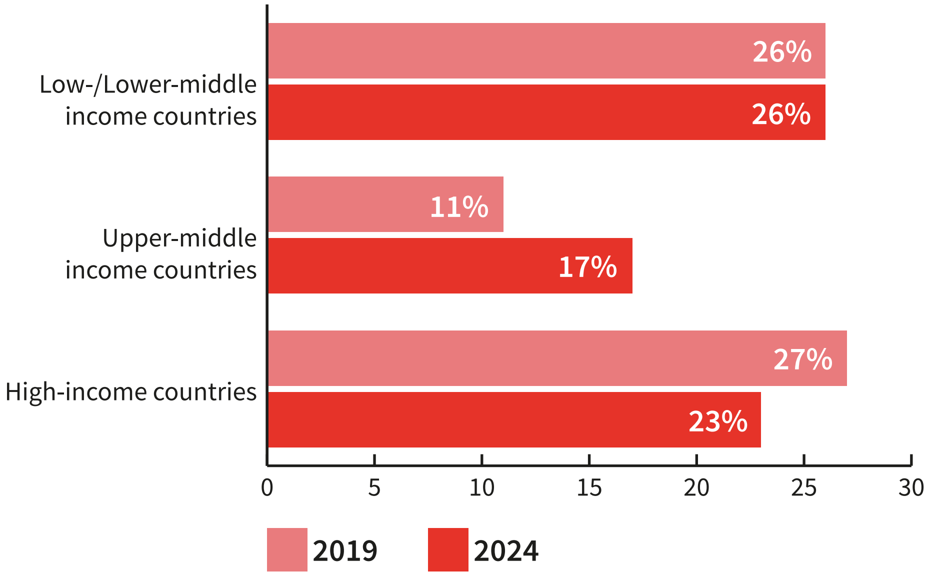


Figure 6. Percentage of the general public agreeing with the statement 'Dementia is caused due to unhealthy lifestyle' by World Bank country income group in 2019 and 2024

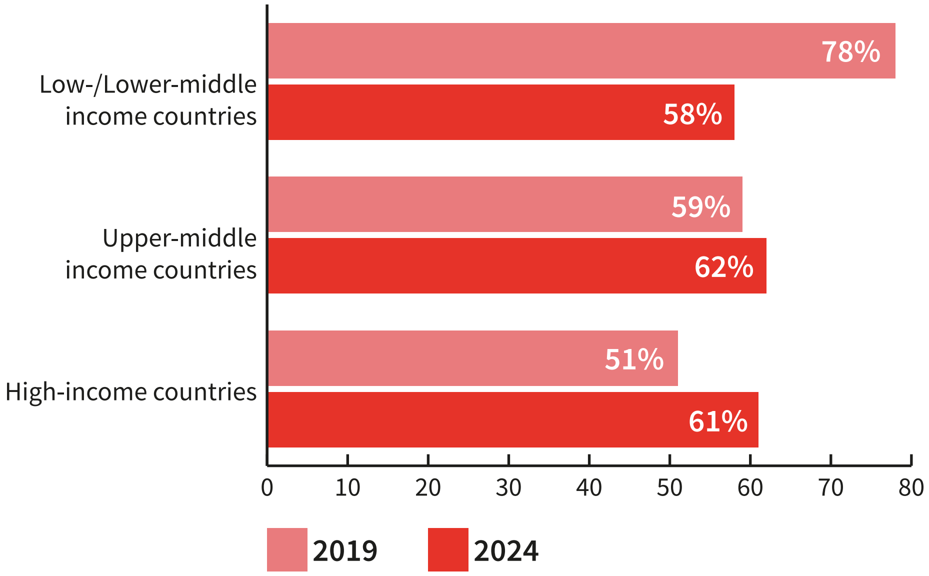
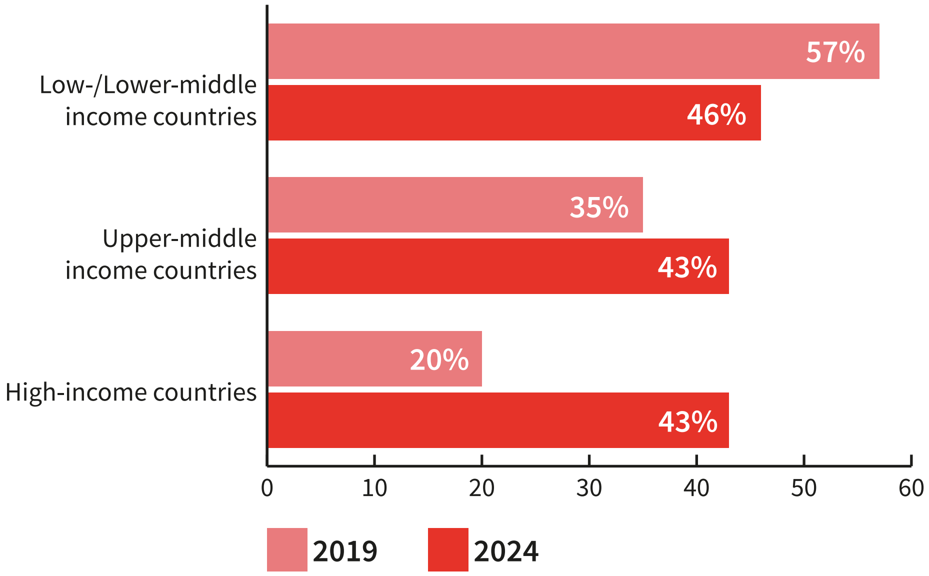


Figure 7. Percentage of the general public agreeing with the statement 'Dementia is caused due to lack of family support' by World Bank country income group in 2019 and 2024



Dementia as a normal part of ageing?

The view that dementia is a normal part of ageing can hinder recognition that there is something wrong, discourage people from seeking a diagnosis, and ultimately inhibit the types of support and treatment received. In the 2019 report, we found that this misconception was widespread internationally. In this report, we see that this view has become even more prevalent across most income groups and participant categories (Figure 8). The most notable increase was among people living with dementia in high-income countries (from 63% to 74%) and low-/lower-middle income countries (from 74% to 84%). Perhaps more concerningly, in 2024, the proportion of health and care professionals who agreed with this misconception ranged from 62% to 68%. This compares with a broader range of 53% to 78% in 2019. This misperception is more common in low-/lower-middle income countries compared to upper-middle income and high-income countries. For example, 84% of people with dementia in low-/lower-middle income countries felt that it was likely dementia was a normal part of ageing, compared to 74% of those in high-income countries.

However, an exception to this trend was observed among health and care professionals in low-/lower-middle income countries, where the belief that dementia is a normal part of ageing decreased from 78% in 2019 to 68% in 2024. Despite this decline, the overall perception remained strong across regions, highlighting ongoing challenges in addressing this misconception. The continued prevalence of this belief among health and care professionals is concerning, as it could significantly impact the diagnosis, treatment, and support provided to people living with dementia.

Figure 8. Agreeing with the statement 'Dementia is a normal part of ageing', % very or somewhat likely by World Bank country income group in 2024

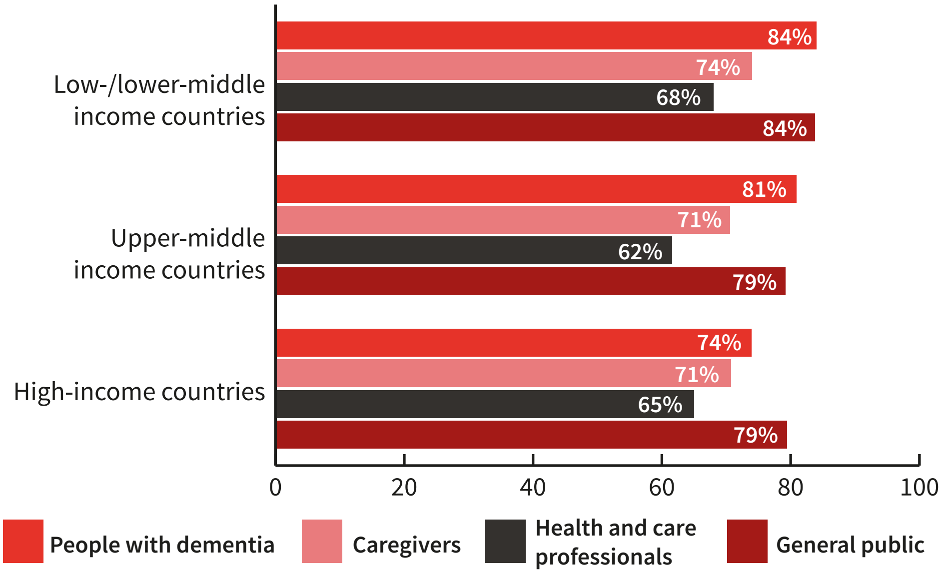
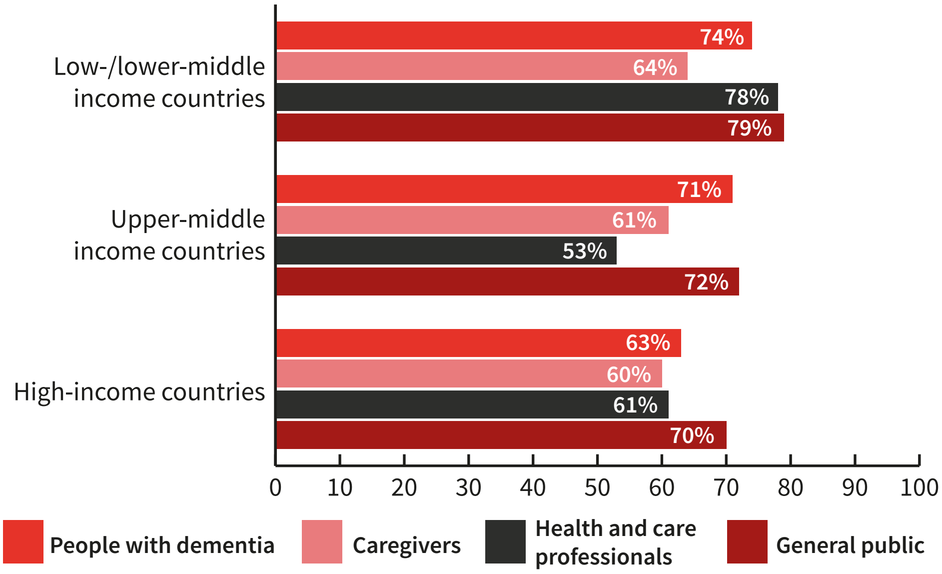


Figure 9. Agreeing with the statement 'Dementia is a normal part of ageing', % very or somewhat likely by World Bank country income group in 2019



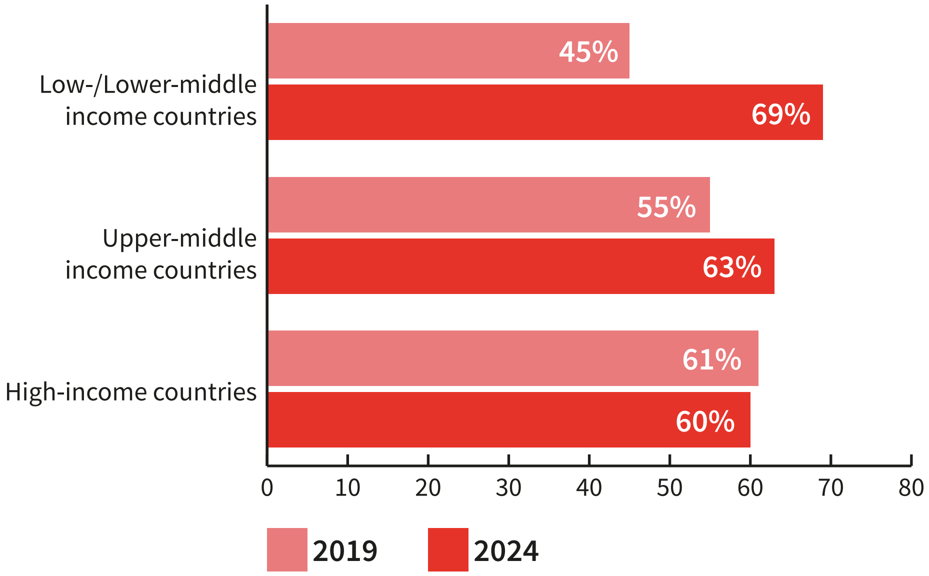
2.2 Changes in stigma-related attitudes

There were some changes in stigma-related attitudes around perceptions between 2019 and 2024, though the patterns differed by item and according to country income groups (See Figures 10-12). Dementia does not affect everyone in the same way, but it is a progressive condition, which means that the symptoms can be relatively mild at first and people can continue to lead a relatively normal life, but this will change over time. It is important to note that in lower- and middle-income countries, people with dementia are likely to be diagnosed when they are at more advanced stages of dementia and this may affect the perception people have of the capabilities of people with dementia.

Family responsibilities:

- In 2024, between 60% and 69% of the general public believed it was important to remove family responsibilities from people with dementia to avoid stressing them.
- There was an increase in people who agreed with this statement from 2019 to 2024 in upper-middle income and low-/lower-middle income countries.

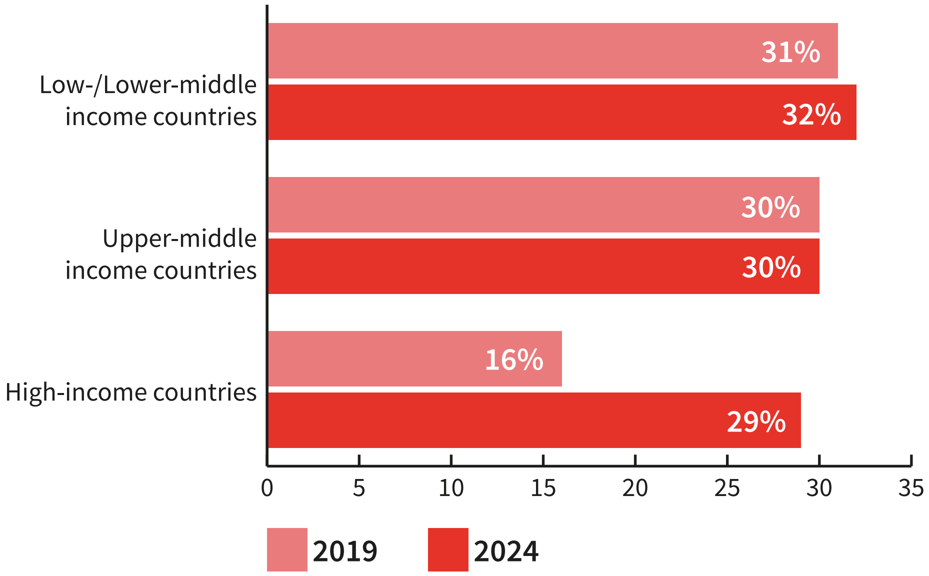
Figure 10. Percentage of the general public agreeing with the statement 'It is important to remove family responsibilities from people with dementia so as not to stress them' by World Bank country income group in 2019 and 2024



Dangerousness:

- In 2024, between 29% and 32% of the general public felt that people with dementia were dangerous more often than not.
- There was an increase in agreement from 2019 to 2024 in high-income countries from 16% to 29%.

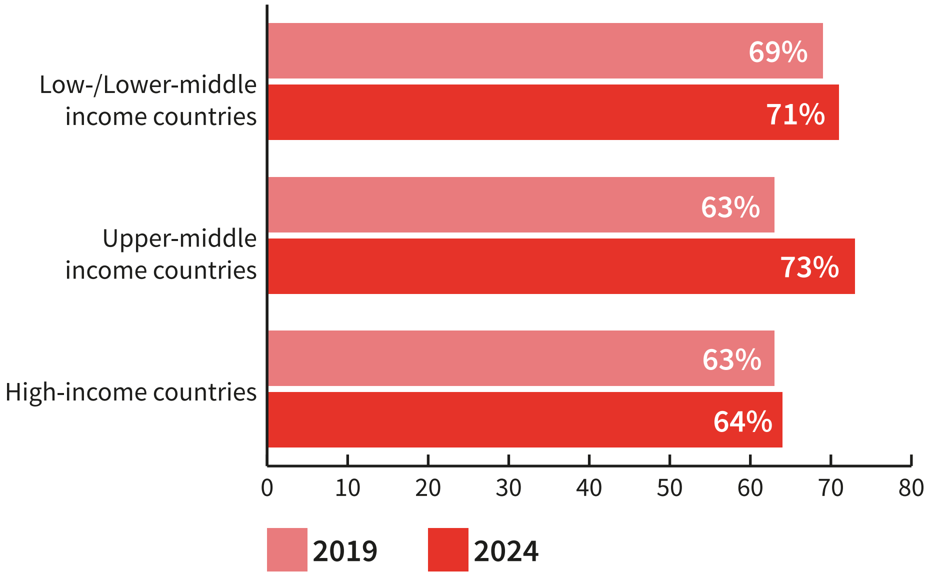
Figure 11. Percentage of the general public agreeing with the statement 'People with dementia are dangerous more often than not' by World Bank country income group in 2019 and 2024



Impulsivity and unpredictability:

- In 2024, between 64% and 71% of the general public perceived people with dementia as impulsive and unpredictable.
- There was an increase in agreement with this statement from 2019 to 2024 in upper-middle income countries from 63% to 73%.

Figure 12. Percentage of the general public agreeing with the statement 'A person living with dementia is impulsive and unpredictable' by World Bank country income group in 2019 and 2024



2.2.1 General public perceptions of personal risk of developing dementia

Here, we explore public and personal perceptions of the risk of developing dementia, dementia treatment (See Figures 13–16), and discuss how these may be linked with hopes for a cure and the reality of treatment limitations across contexts and cultures.

- In 2024, the vast majority of respondents across all income groups acknowledged the likelihood of developing dementia and expressed concern about it. Across country income groups, there was also strong interest in genetic profiling,[2] with between 80–89% of respondents indicating a willingness to take a genetic test, reflecting both a desire for proactive health management and a fear of the unknown. However, it raises important considerations about the public's understanding of the limitations of genetic testing – namely, that there isn't a conclusive genetic test to determine whether someone will develop dementia. Additionally, there could be potential implications of such testing, including how insurance companies might use this information to raise premiums.
- In 2024, high-income countries showed higher perceived likelihood of developing dementia (89%) compared to lower-income countries (79%). This was a slight decrease since 2019.

Figure 13. Percentage of the general public agreeing with the statement 'I would take a genetic profiling test to learn whether I am at risk of developing dementia' by World Bank country income group in 2019 and 2024

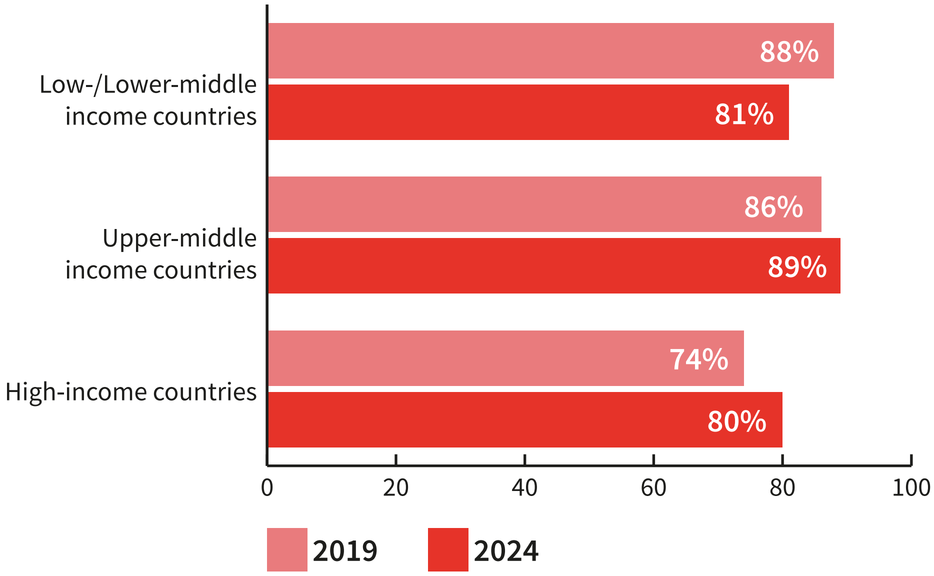


Figure 14. Percentage of the general public agreeing with the statement 'I am concerned about developing dementia at some point in my lifetime' by World Bank country income group in 2019 and 2024

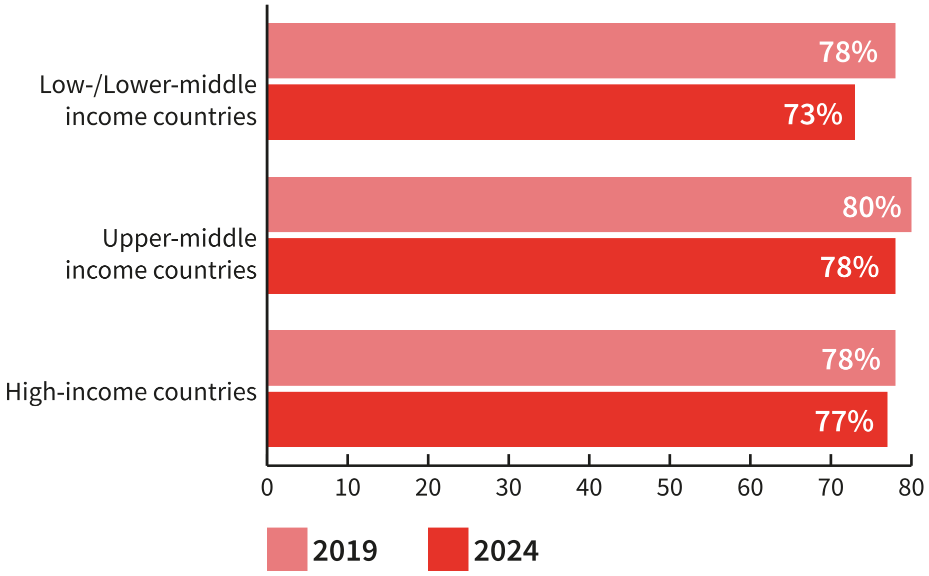
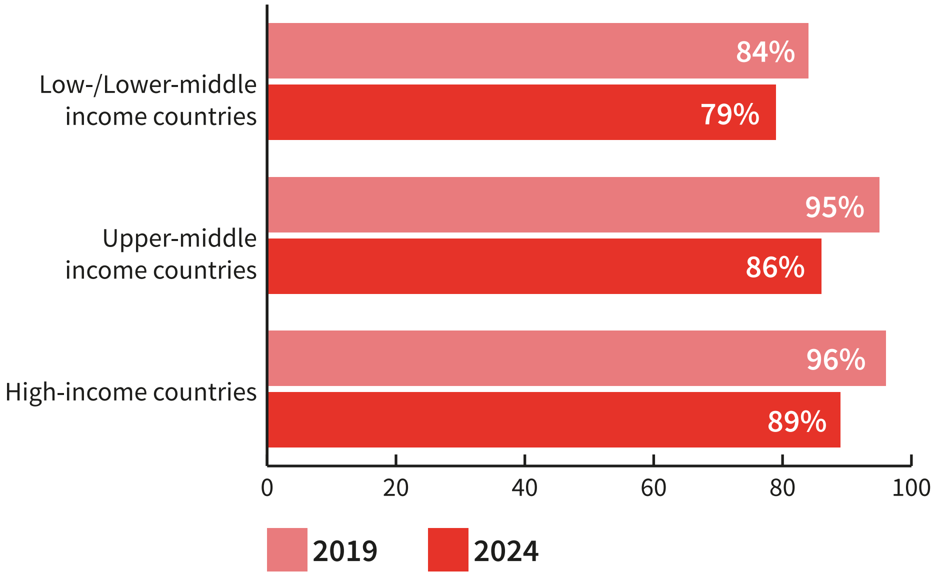


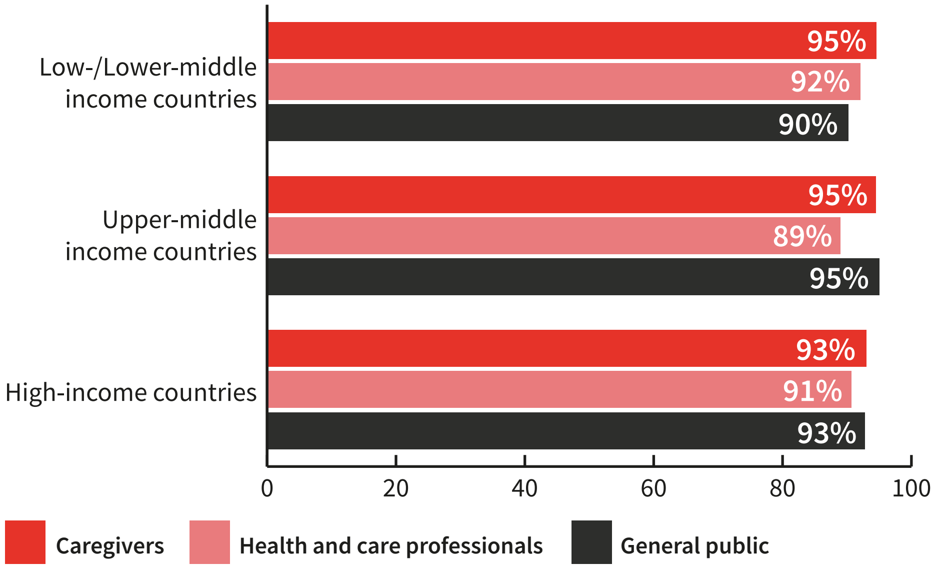
Figure 15. Percentage of the general public agreeing with the statement 'I could develop dementia at some point in my lifetime' by World Bank country income group in 2019 and 2024



In 2024, we introduced an additional item assessing people's willingness to seek a diagnosis if a treatment that could prevent or slow the progression of dementia was available.

- Among carers and the general public, more than 90% of respondents said they would be encouraged to get a diagnosis if such a treatment was available.
- Among health and care professionals, 91%, 89%, and 92% of respondents from high-income, upper-middle income and low-/lower-middle income countries, respectively, expressed a willingness to seek a diagnosis.

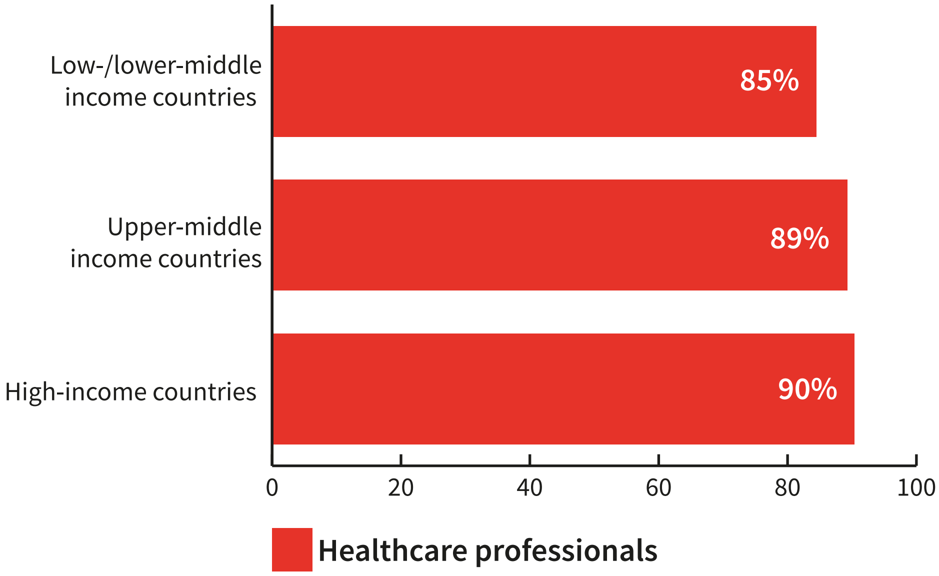
Figure 16. Agreeing with the statement 'If I knew there was a medicine or treatment that could prevent or slow the progression of dementia, it would encourage me to get a diagnosis' by World Bank country income and respondent group in 2024



The second question assessed the willingness of health care professionals to give a diagnosis if there was a treatment that could prevent or slow the progression of dementia.

Across all World Bank country income groups, health and care professionals indicated that access to such a treatment would encourage them to provide a diagnosis, with percentages ranging between 85% in low-/lower-middle income countries to 90% in high-income countries.

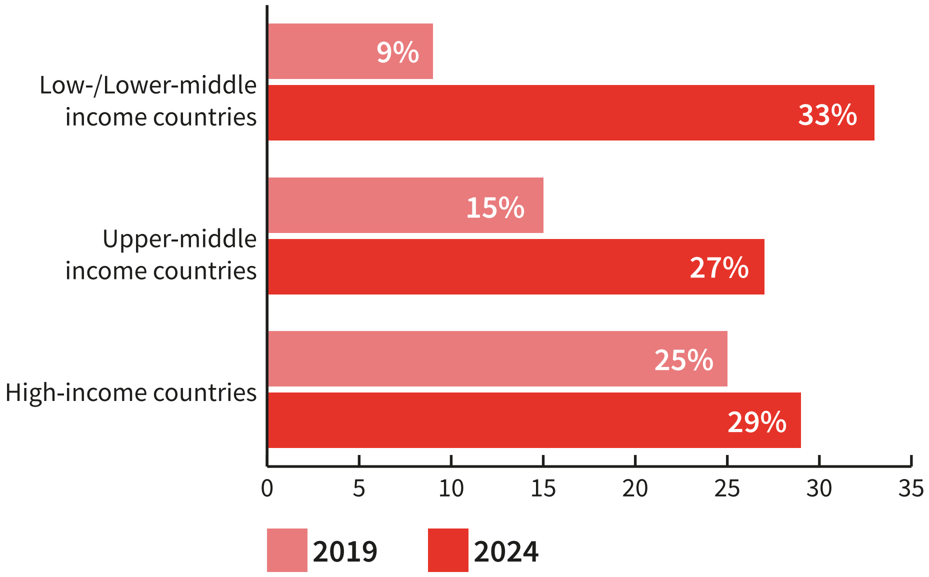
Figure 17. If I knew there was a medicine or treatment that could prevent or slow the progression of dementia, it would encourage me to give a diagnosis (%, agree)



2.2.2 Attitudes towards moving a family member with dementia to a care home even if they didn't want to go

- In 2024, a larger proportion of respondents across all income groups expressed a belief that moving a family member with dementia to a care home, even against their wishes, would be the best option.
- There was a substantial increase among low-/lower-middle income respondents, with the belief that care homes would be the best option, with the percentage rising from 9% in 2019 to 33% in 2024 – and this despite the fact that a majority of low-/lower-middle income countries do not have a strong care home sector. Upper-middle income country respondents increased from 15% to 27% and high-income country respondents increased from 25% to 29%.

Figure 18. Percentage of the general public agreeing with the statement 'If I had a family member with dementia it would be best to move them to a care home even if they didn't want to go' by World Bank country income group in 2019 and 2024



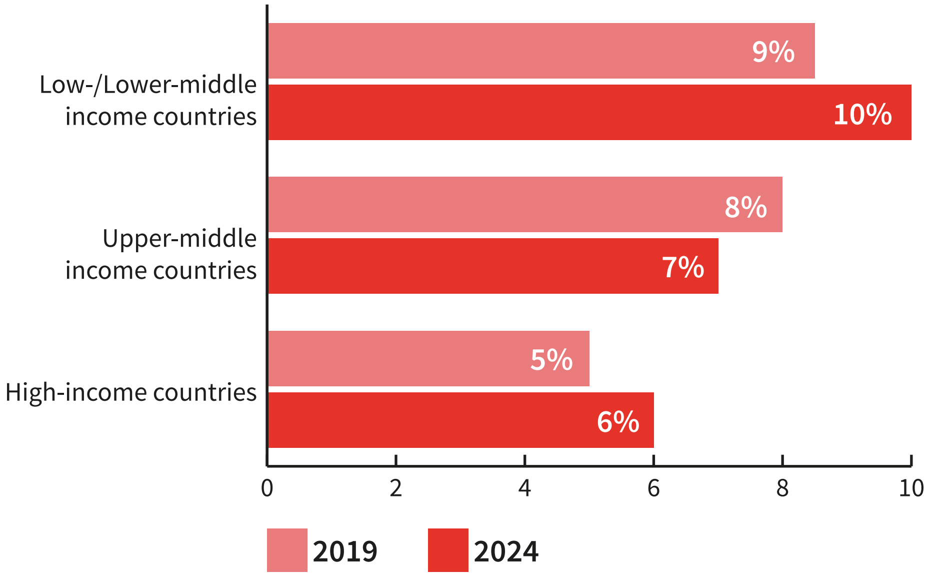
2.3 General public changes in stigma-related behaviour

Understanding stigma-related behaviour is essential to fully grasp the impact of stigma on the lived experiences of people with dementia and their carers. These behaviours, which stem from public and structural stigma, can manifest as discriminatory actions that undermine the autonomy, dignity, and wellbeing of those affected by dementia. By examining these behaviours, we can gain insight into the real-world impact of stigma and identify strategies to reduce its harmful effects. In this section, we first explore the behaviours of the general public, as they significantly influence societal norms and attitudes. We then examine the actions of health and care professionals, whose professional conduct plays a key role in shaping the care environment for people with dementia. Finally, we focus on the experiences of people with dementia and their carers, highlighting the discrimination they face as a result of stigmatising behaviours and ensuring their voices are at the forefront of our discussion.

2.3.1 Secrecy and concealment of dementia among the general public

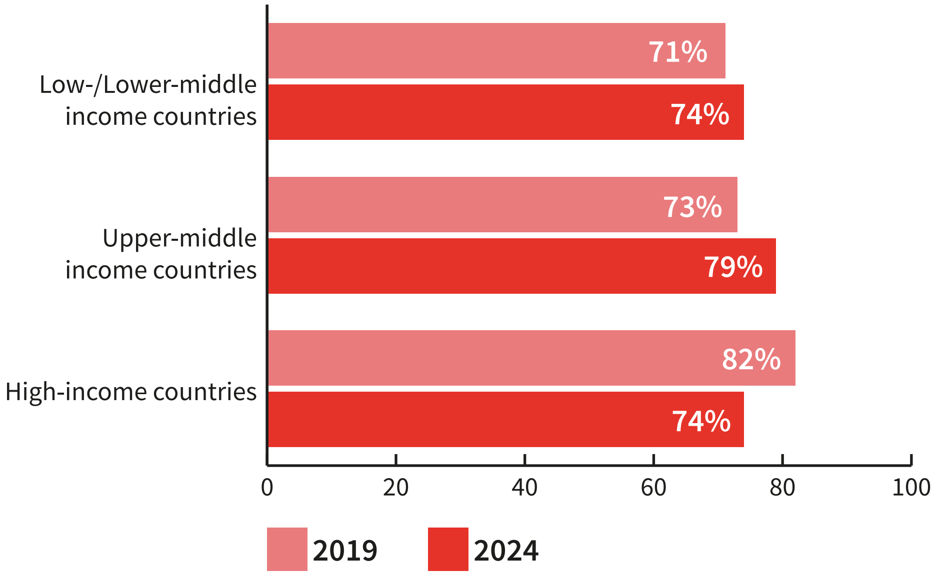
- The vast majority of people would not feel embarrassed when going out with a person with dementia. There were no differences between 2019 and 2024 in terms of the general public reporting feeling embarrassed when going out with a person with dementia. Agreement remained low and stable at between 6% and 10% in 2024.

Figure 19. Percentage of the general public agreeing with the statement 'Feel embarrassed going out in public with relative or friend with dementia' by World Bank country income group in 2019 and 2024



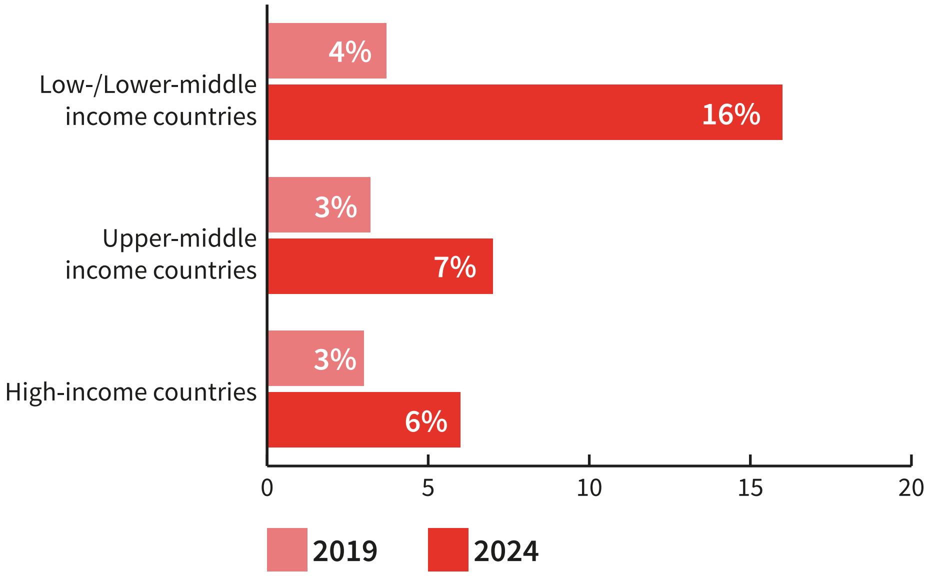
- Compared to 2019, in high-income countries, there was a decrease in the proportion of general public respondents feeling comfortable spending an afternoon with someone with dementia. In 2019, 82% of people were comfortable to spend an afternoon with a person with dementia, compared to 74% in 2024.

Figure 20. Percentage of the general public agreeing with the statement 'Feel comfortable to spend an afternoon with someone who has dementia' by World Bank country income group in 2019 and 2024



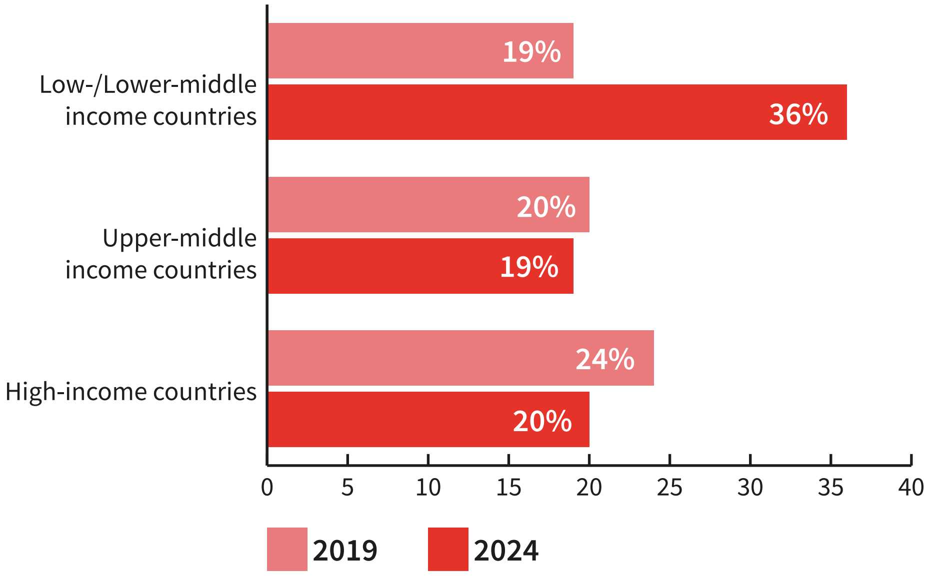
- Among the general public, in low-/lower-middle income countries, there was also an increase among the general public in willingness to keep their dementia a secret from the doctor, rising from 4% in 2019 to 16% in 2024. While still low, this indicates a growing tendency to conceal dementia when consulting health and care professionals.

Figure 21. Percentage of the general public agreeing with the statement 'I would keep my dementia a secret from the doctor' by World Bank country income group in 2019 and 2024



- In low-/lower-middle income countries, the general public was more willing to keep their dementia a secret when meeting people in 2024 (36%) compared to 2019 (19%).

Figure 22. Percentage of the general public agreeing with the statement 'If I had dementia, I would make an effort to keep my dementia a secret when meeting people' by World Bank country income group in 2019 and 2024



2.3.2 Secrecy among health and care professionals

- Fewer health and care professionals said they would hide their dementia when meeting people compared to the general public.
- Among health and care professionals in upper-middle income countries, people were less inclined to hide their dementia compared to 2019.

Table 2. Changes in agreement with the statement 'If I had dementia, I would make an effort to keep my dementia a secret when meeting people' among health and care professionals % by World Bank country income group in 2019 and 2024

Health and care professionals	2019	2024
	Agree	Agree
Higher-income	16	16
Upper-middle income	19	10
Low-/Lower-middle income	11	13

2.3.3 Changes in experiences of discrimination and unfair treatment due to one's dementia

We asked people living with dementia to indicate whether they had experienced any form of discrimination across 14 life areas, ranging from making/keeping friends to being avoided or shunned (see Table 3). From 2019 to 2024, there was a significant increase in the percentage of people with dementia reporting discrimination in all 14 life areas. The largest increases were observed in making or keeping friends, dating and intimate relationships, and having rights or responsibilities unfairly taken away. The overall percentage of individuals experiencing discrimination in at least one area also increased significantly from 83% to 88%.

Table 3. Changes[3] in experienced discrimination[a] reported by people living with dementia between 2019 and 2024, overall and by life area (% reporting discrimination)

	2019	2024	Direction of change	p-value[b]
Making or keeping friends	37.7	53.8	*Increased	<0.001
Treatment whilst dating and intimate relationships	24.7	53.7	*Increased	<0.001
Housing	9.3	18.0	*Increased	<0.001
Treatment by children/family members	28.3	37.7	*Increased	0.001
Rights or responsibilities unfairly taken away	23.9	36.6	*Increased	<0.001
Denied a choice to do something	42.5	59.7	*Increased	<0.001
Social life	26.7	33.2	Increased	0.0140
Not taking your opinions seriously	50.2	65.5	*Increased	<0.001
Jokes about your dementia symptoms	32.8	44.2	*Increased	<0.001
Levels of privacy	13.5	19.9	*Increased	0.0029
Personal safety and security	13.3	18.2	Increased	0.0179
Treatment by health or medical staff	18.6	24.5	Increased	0.0121
People doing things for you	51.3	57.7	Increased	0.0274
Avoided or shunned	29.1	40.7	*Increased	<0.001
Experienced discrimination in at least one area	82.8	87.6	Increased	0.0196

[a] Includes responses 'A lot/ moderately/ a little'

[b] p-values indicate the likelihood that the observed changes occurred by chance. Lower p-values indicate stronger evidence that the changes are real and not due to random variation. A p-value of <0.05 is considered statistically significant suggesting there is less than a 5% probability that the result is due to chance. A p-value of <0.01 is considered highly significant

*Statistically significant change after Bonferroni correction for p-value for 15 comparisons: 0.05/15=0.003

3. Anticipated discrimination among people with dementia and carers in 2024

Building on the changes in experienced discrimination among people living with dementia between 2019 and 2024, we now turn our attention to the anticipated discrimination faced by both people living with dementia and their caregivers. Anticipated discrimination refers to the expectation that one will be treated unfairly or unjustly because of their dementia. This expectation can shape the behaviour of both people with dementia and their carers, often leading them to avoid situations where they fear they may be stigmatised. Our summary highlights key areas and how they differ based on World Bank income categories. Both people living with dementia and their caregivers experienced significant levels of anticipated discrimination. More than half of people with dementia and their caregivers reported anticipated discrimination in at least one of the life domains; but the specific issues and their frequency vary between these groups and by country income groups.

3.1 People living with dementia

Workplace discrimination concerns:

- Across all income groups, 36% of people living with dementia reported stopping themselves from applying for or continuing work due to concerns about employer or coworker treatment.
- This concern was consistent across low-/lower-middle income countries (36%), upper-middle income countries (37%), and high-income countries (35%).
- As advanced diagnostic techniques enter the market, people can receive a diagnosis earlier than before – meaning that the issue of discrimination in the workplace will feature more prominently when it comes to dementia, as more people are expected to be diagnosed younger and still of working age.

Personal relationships:

- Concerns about reactions from partners or family led 29% of people living with dementia to avoid or discontinue close personal relationships.
- Higher avoidance rates were identified in low-/lower-middle income countries (46%) compared to upper-middle income (33%) and high-income countries (24%).

Healthcare and treatment avoidance:

- 24% of people living with dementia avoided seeking help, care, or treatment due to concerns about treatment by pharmacists or other customers.
- Avoidance rates were highest in low-/lower-middle income countries (29%) compared to upper-middle income countries (16%).

Financial management:

- 22% of people living with dementia avoided visiting banks due to fears of judgment from staff or clients.
- Avoidance rates varied by country income group, with 38% in low-/lower-middle income countries, 13% in upper-middle income countries, and 19% in high-income countries.

Social situations:

- 31% of people living with dementia avoided social situations due to concerns about reactions from others.
- Avoidance was consistent across income groups, with 32% in low-/lower-middle income and high-income countries, and 27% in upper-middle income countries.

Table 4. Anticipated discrimination among people living with dementia, by World Bank country income group (2024) (% reporting anticipated stigma)

Life domain	High-income	Upper-middle income	Low-/Lower-middle income
Stopped yourself from applying for or continuing to work because of worrying about how your employer or coworkers might treat you due to having dementia	35	37	36
Stopped yourself from having or continuing a close personal relationship because of worrying about how your partner or family might react to you having dementia	24	33	46
Avoided getting help, care, or treatment (including, for example, going to the doctor or to the pharmacy to get your medications) because of worrying about how the pharmacist or other customers might treat you due to having dementia	24	16	29
Avoided visiting a bank to manage your finances because of worrying about how the bank staff or other clients might judge you due to having dementia	19	13	38
Avoided social situations (for example, eating at a restaurant, attending parties or festive events) because of how others might react to you having dementia	32	27	32

3.2 Caregivers

The experiences of caregivers suggest similar patterns of anticipated discrimination to people living with dementia, often reflecting concerns about how their loved ones with dementia might be treated in various social contexts.

Social invitations:

- Overall, 43% of caregivers stopped inviting friends or family over due to concerns about how they might treat the person with dementia.
- This concern was highest in low-/lower-middle income countries (51%) compared to high-income (43%) and upper-middle income countries (40%).

Accepting invitations:

- Almost half (47%) of caregivers stopped accepting invitations to visit friends or family, consistent across all income groups with slight variation (46–47%).

Participation in social groups:

- 40% of caregivers avoided joining or participating in social groups or activities due to concerns about reactions to the person with dementia.
- This concern was slightly higher in high-income countries (42%) compared to upper-middle income (37%) and low-/lower-middle income countries (38%).

Public places:

- 34% of caregivers avoided going out in public places with the person they care for due to worries about public perception.
- This concern was highest in low-/lower-middle income countries (42%) and lowest in upper-middle income countries (29%).

Travel and vacations:

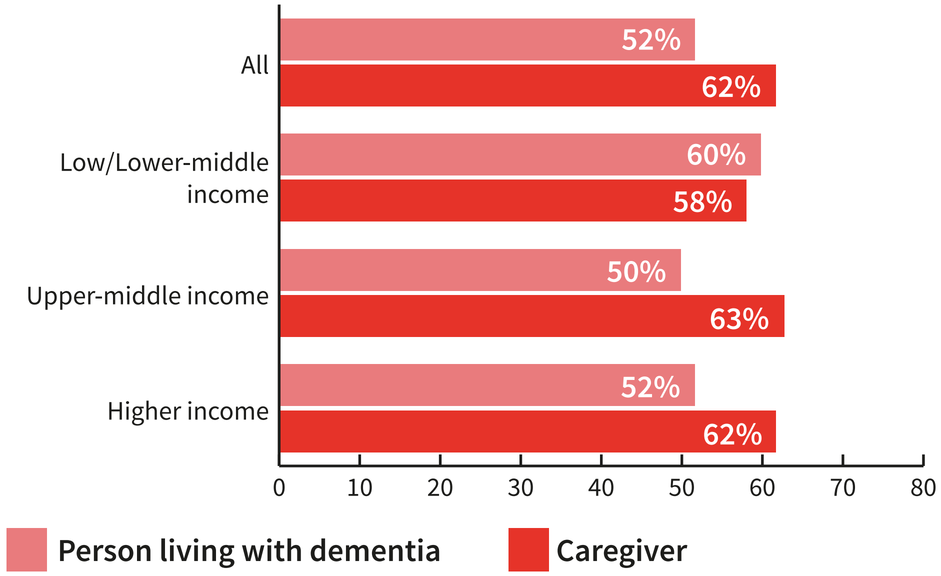
- 41% of caregivers avoided travelling or taking vacations with the person they care for due to potential negative treatment by staff or other travellers.
- This concern is consistent across high-income (43%) and low-/lower-middle income countries (43%), but lower in upper-middle income countries (36%).

Table 7. Anticipated discrimination among dementia caregivers, by World Bank country income group (% reporting anticipated stigma)

Life domain	High-income	Upper-middle income	Low-/Lower-middle income
Stopped yourself from inviting friends or family over to your home because of worrying about how they might treat the person you care for who has dementia	43	40	51
Stopped yourself from accepting invitations to visit friends or family because of worrying about how they might react to the person you care for who has dementia	47	47	46
Avoided joining or participating in social groups or activities (such as clubs, hobbies, or volunteering) because of worrying about how the group members or organisers might deal with or react to the person you care for who has dementia	42	37	38
Avoided going out in public places (such as parks, malls, or cinemas) with the person you care for who has dementia because of worrying about how the public might perceive the person you care for	35	29	42
Avoided travelling or taking vacations with the person you care for with dementia because of how staff, or other travellers might treat them	43	36	43

- Anticipated discrimination among caregivers and people with dementia
  - More than 60% of caregivers in higher-income and upper-middle income countries reported anticipated discrimination.
  - Similarly, 58% of caregivers in low-/lower-middle income countries have reported anticipated discrimination.
  - Around 50% of people with dementia in higher-income and upper-middle income countries have reported anticipated discrimination, while almost 60% have reported anticipated discrimination in low-/lower-middle income countries.

Figure 23. Any anticipated discrimination a among people living with dementia and caregivers, overall and by World Bank country income group (% reporting anticipated stigma)



[a] Includes responses 'A lot/ moderately/ a little'

3.3 Examples of anticipated and experienced discrimination among people with dementia

Experienced discrimination among people with dementia

As part of the survey, we asked people with dementia to provide examples of their experiences of discrimination. We provide some examples in Table 7, but overall we found that:

- People with dementia report experiences of discrimination in many domains of their personal lives, especially within their families and other people in general
- Many people with dementia think that family members might not believe their dementia diagnosis and/or find it difficult to understand what having dementia means
- People with dementia are often excluded from family gatherings and/or outings with old friends
- People with dementia also report being ignored in conversations as people often do not talk to them directly, but instead refer to them when speaking with their carers and/or partners
- Not feeling understood is described as a major issue by people living with dementia

First, we describe examples of experienced discrimination reported by people living with dementia in their social life.

Table 6. Examples of experienced discrimination reported by people living with dementia in social life (i.e., with family, friends, and other people in general)

I was the only family member not invited to a granddaughter's birthday party. It was hurtful to be excluded. I have never exhibited behaviour or conversation that would have warranted that.	*Female, USA, 56–65*
Whispering behind my back and thinking I won't notice.	*Female, Germany, 46–55*
Friends, at first, when they saw me on the street with my partner, would ask him how he was doing instead of asking me, that bothered me a lot.	*Female, Spain, 66–75*
I use my dementia as an excuse, one family member said.	*Female, UK, 56–65*
They don't bother me because they have to explain a lot.	*Female, Iran, 36–45*
Some people think that I choose the moment to have or not to have Alzheimer's.	*Male, Not specified, 56–65*
One family member said I couldn't have dementia, too young and I use so-called dementia to my advantage.	*Female, UK, 56–65*
My son did not believe and still does not believe that I am sick. He calls me an actor. It hurts me a lot.	*Male, Ukraine, 66–75*
Family member refused to understand my diagnosis and cut off contact.	*Female, Dutch, 56–65*
Friends don't want to know I'm getting worse from dementia.	*Female, Brazil, 56–65*
They make me not talk.	*Female, Ecuador, 46–55*
Treated unfairly because I was accused of not being diagnosed and lying about it.	*Male, Namibia, 66–75*
They didn't ask me questions that they thought I couldn't answer, asked my partner instead.	*Female, Australia, >85*
They make me feel that I'm incapable of remembering anything.	*Female, Bahamas, 56–65*
They hardly ever believe what I am telling them.	*Female, South Africa, 56–65*
They sometimes make jokes, I feel belittled.	*Female, South Africa, 56–65*

Experienced discrimination in health and care settings

People with dementia also reported some common experiences of discrimination in health and care settings.

- People with dementia reported feeling dismissed by doctors and health and care professionals.
- People with dementia also feel that their symptoms are dismissed or minimised.

Table 7. Examples of experienced discrimination in healthcare settings among people with dementia

The attending doctor was insensitive to my concerns and brushed it off with a hurting remark – I don't see there is a problem with your language.	*Female, Singapore, 56–65*
Does a doctor telling me that I am too young to have dementia count? I have Lewy Body. I have good days and bad days. On good days, medical staff treat me like I am making it up. On bad days, some doctors don't allow me to be part of the conversation, talking at me rather than with me.	*Male, USA, 56–65*
When the doctor talks to my husband about me and I being together, without taking into account my presence.	*Female, Brazil, 76–85*
They may just nod their heads, but really don't believe a word of it. Unless I have a printed official document!	*Male, New Zealand, 76–85*
In the healthcare arena, nurses and doctors speaking to my daughter, not me or, comments like 'you're too young, you haven't got it.'	*Female, UK, 56–65*
Some doctors or health and care providers don't know how to interact with people with Alzheimer's.	*Female, Ecuador, 56–65*

Anticipated discrimination among caregivers of people living with dementia

- Carers want to prevent people living with dementia from being mistreated and experiencing unfair treatment by others
- Carers are worried about others making fun of or disrespecting the person living with dementia because of their behaviours
- Carers think that lack of understanding from others is a key factor, which drives them to not participate in social activities nor go to public places with people with dementia

Examples of anticipated discrimination among people with dementia

- People living with dementia feel that people keep their distance from them, they are talked to differently, and they feel like they are not trusted by others in the way they used to be
- People living with dementia express that other family members think less of them and for this reason, they prefer to exclude themselves

Table 8. Examples of anticipated discrimination reported by caregivers and people living with dementia

I don't make her participate because she often says things that make me feel very uncomfortable and I think others do too.	*Carer, Female, Argentina, 66–75*
Above all, I am ashamed in advance. Few people even in my family put up with my mother's possible behaviour.	*Carer, Female, France, 46–55*
I knew they don't understand and don't include my mother so I prefer to not go sometimes.	*Carer, Male, Zimbabwe, 46–55*
I am embarrassed or uncomfortable that my mother is present in social situations.	*Carer, Female, Argentina, 36–45*
There are still many people who do not understand dementia, especially at a young age. My husband does not want to be treated and spoken to as if he were a child. It is quieter to just stay at home.	*Carer, Female, Netherlands, 56–65*
Because my wife's ability to do some things has decreased, I prefer not to participate in these gatherings so that she will not be humiliated.	*Carer, Male, Iran, 56–65*
I'm not sure "unfairly" describes my experience. I feel a wariness, a tendency to keep me at arm's length.	*Person living with dementia, Female, USA, 76–85*
If we express that we can't remember. Other people will have unusual reactions, so we have to try to say little and conceal that we don't remember.	*Person living with dementia, Female, Thailand, 36–45*

4. Impacts of stigma on life satisfaction, loneliness, and quality of life

4.1. Life satisfaction

- Overall, a larger proportion of health and care professionals (68%) and general public (69%) reported being satisfied with life every day or almost every day, compared with people living with dementia (46%) and caregivers (43%).
- Importantly, 9% of people living with dementia and 11% of caregivers did not feel satisfied with life at any point in the past month, compared with 3% among health and care professionals and 4% of the general public.
- Daily or almost daily satisfaction with life was most frequently reported by health and care professionals in upper-middle income countries (76%) and the general public in high-income countries (71%). The lowest proportions of daily or almost-daily life satisfaction were among people living with dementia in upper-middle and low-/lower-middle income countries (30% and 31%, respectively).
- Among caregivers, those in upper-middle income countries reported the highest proportion of daily or almost daily life satisfaction (54%), compared with 38% in low-/lower-middle income and 40% in high-income countries. Notably, 12% of people with dementia and 18% of carers in low-/lower-middle income countries reported not feeling satisfied with life at any point in the past month.

Figure 24. Life satisfaction (%) by participant group.

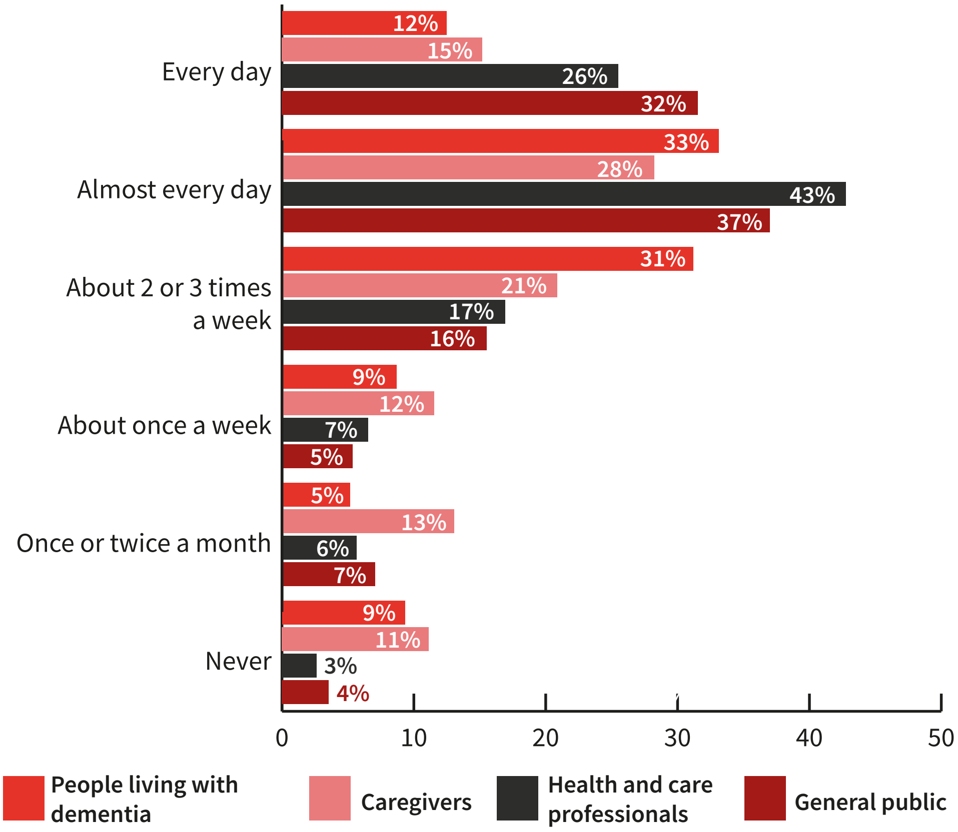
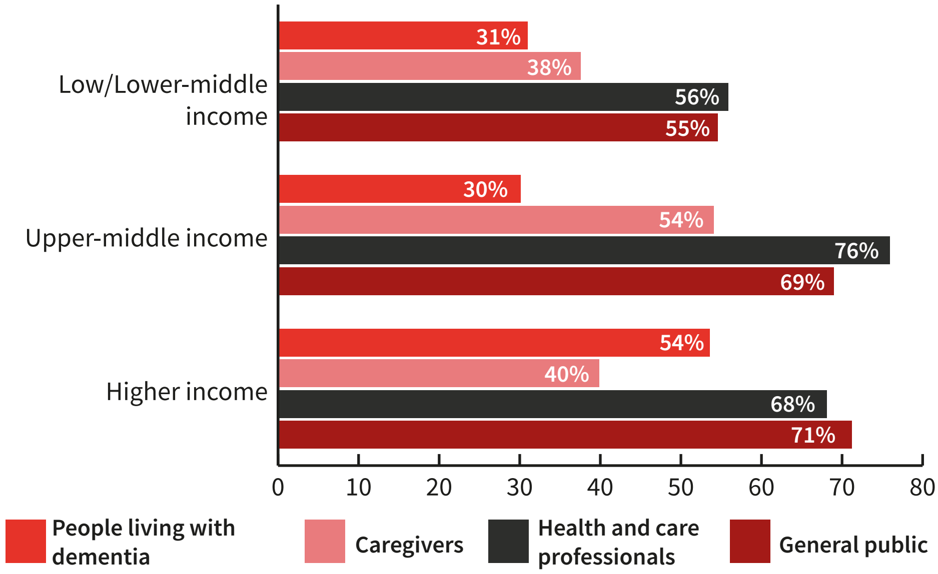


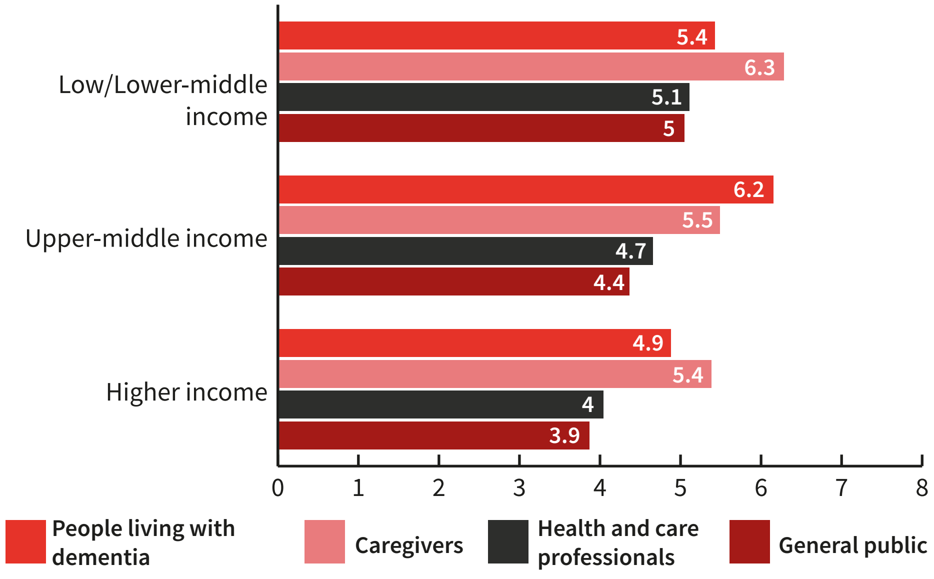
Figure 25. Satisfied with life every day or almost every day (%) by World Bank country income group.



4.2 Loneliness[4]

- We found that carers (mean=6, standard deviation=2.02) and people living with dementia (mean =5.1, standard deviation =1.86) tended to report higher levels of loneliness compared to health and care professionals (mean =4.3, standard deviation= 1.69) and the general public[5] (mean =4.1, standard deviation = 1.62).
- There was some variability between countries in terms of loneliness score, though there did not appear to be a clear pattern (e.g., loneliness scores were not consistently higher in a given group).
- Feelings of loneliness can be explained by a number of factors, outside of population grouping and geographic locale. Females tended to report being lonelier. This was true for females who were living with dementia, carers, and the general public. Among health and care professionals, males tended to report greater loneliness. In addition, individuals with more education (i.e., attaining a university degree or higher) were less likely to be lonely across groups.

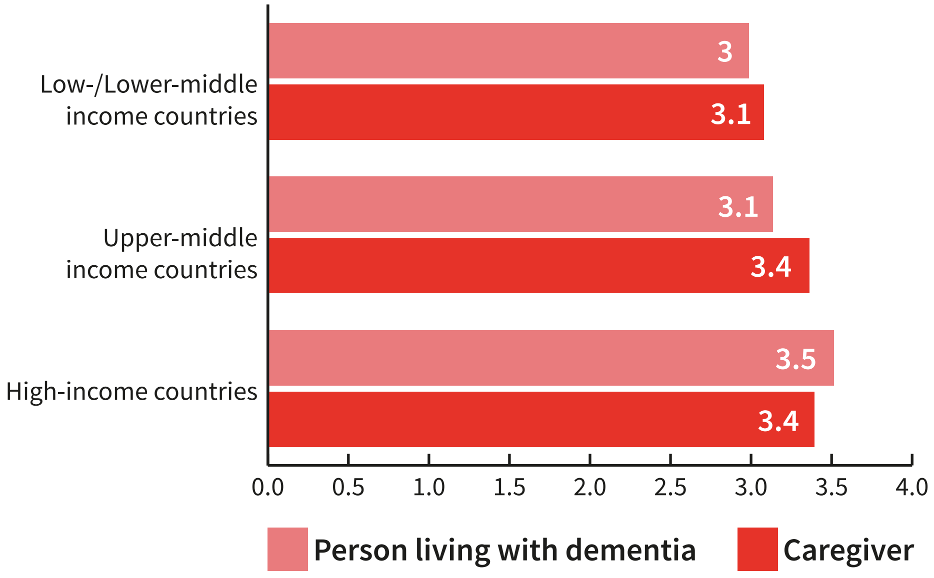
Figure 26. Loneliness (UCLA Loneliness Scale) by World Bank country income group.



4.3 Quality of life[6]

- Although overall people living with dementia (mean=3.4, standard deviation=0.81) and carers (mean=3.4, standard deviation= 0.76) showed similar levels of quality of life[7], carers in low- and middle-income countries reported higher quality of life compared to people living with dementia, whereas in higher-income countries the pattern was opposite.
- Quality of life tended to be lower among people with dementia in low-/lower-middle income countries (mean= 3.0, standard deviation=0.73), and highest in high-income countries (mean =3.5, standard deviation =0.81). A similar pattern was observed for carers, although the difference between upper-middle and higher-income countries was small.

Figure 27. Quality of life in caregivers and people living with dementia by World Bank country income group.



5. Perceptions of change since 2019

5.1 Perception that people's attitude has changed since 2019 by participant group and World Bank country income group

Overall, around half of all respondents, across all the different groups, seemed to think that there was more awareness of dementia and that people were more supportive since 2019, with higher agreement among caregivers and health professionals in higher-income countries.

People living with dementia

Table 9. Do you feel that in general people's attitude towards dementia has changed in the last five years? (% agree by World Bank income groups)

	Yes, people are more aware and supportive of dementia than before	Yes, people have less awareness and more negative attitudes about dementia than before	No, people's attitudes towards dementia have not changed much	I don't know or I don't have an opinion
Low-/Lower-middle income countries	56	7	15	21
Upper-middle income countries	55	5	31	9
High-income countries	51	7	19	23
Total	**53**	**7**	**20**	**21**

Caregivers

Table 10. Do you feel that in general people's attitude towards dementia has changed in the last five years? (% agree by World Bank income groups)

	Yes, people are more aware and supportive of dementia than before	Yes, people have less awareness and more negative attitudes about dementia than before	No, people's attitudes towards dementia have not changed much	I don't know or I don't have an opinion
Low-/Lower-middle income countries	45	10	27	19
Upper-middle income countries	55	7	23	15
High-income countries	65	4	20	12
Total	**60**	**5**	**21**	**13**

Health and care professionals

Table 11. Do you feel that in general people's attitude towards dementia has changed in the last five years? (% agree by World Bank income groups)

	Yes, people are more aware and supportive of dementia than before	Yes, people have less awareness and more negative attitudes about dementia than before	No, people's attitudes towards dementia have not changed much	I don't know or I don't have an opinion
Low-/Lower-middle income countries	51	5	25	19
Upper-middle income countries	55	10	27	7
High-income countries	68	4	22	6
Total	**64**	**5**	**23**	**8**

General public

Table 12. Do you feel that in general people's attitude towards dementia has changed in the last five years? (% agree by World Bank income groups)

	Yes, people are more aware and supportive of dementia than before	Yes, people have less awareness and more negative attitudes about dementia than before	No, people's attitudes towards dementia have not changed much	I don't know or I don't have an opinion
Low-/Lower-middle income countries	47	7	23	23
Upper-middle income countries	49	11	20	20
High-income countries	56	5	21	17
Total	**53**	**7**	**21**	**19**

5.2 Participation and awareness of dementia related activities

- Across all target groups and income levels, a significant proportion of respondents reported seeing dementia-related posts or articles on social media or news platforms. This awareness was relatively consistent in upper-middle and high-income countries, with 40% to 48% of people living with dementia, carers, and the general public reporting such exposure. Levels were lower (34% to 48%) in low-/lower-middle income countries.
- Notably, health and care professionals tended to show higher levels of awareness than the other participant groups. The highest awareness was in high-income countries, with 52% of health and care professionals reporting seeing dementia-related posts or articles, compared to 44% of people with dementia, 48% of carers, and 42% of the general public.
- People living with dementia in high-income countries and carers and health and care professionals in high-income and upper-middle income countries had the highest levels of participation in activities to support or learn about dementia, with around one-third reporting participation. The general public in low-/lower-middle income countries had the lowest levels of participation (8%).
- The general public reported the lowest levels of exposure to dementia-related activities. Almost half of those in low-/lower-middle income countries (46%) reported no exposure, followed by upper-middle income countries (35%) and high-income countries (31%).

Figure 28. Among people living with dementia – are you aware of any dementia-related activities on social media, news, awareness campaigns? (% agree by World Bank income groups)

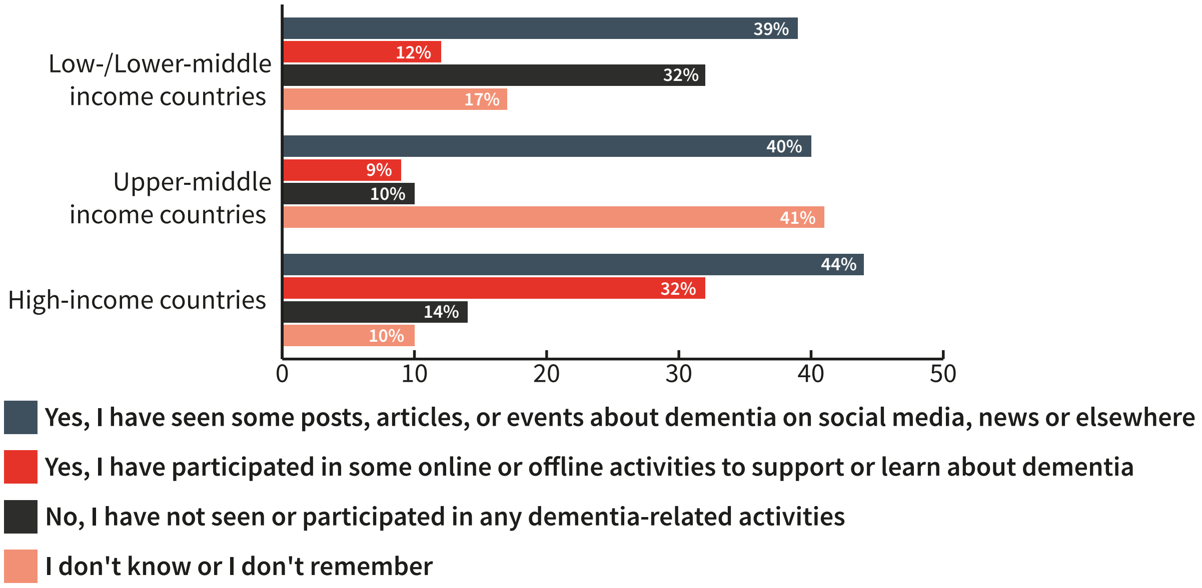


Figure 29. Among carers – are you aware of any dementia-related activities on social media, news, awareness campaigns? (% agree by World Bank income groups)

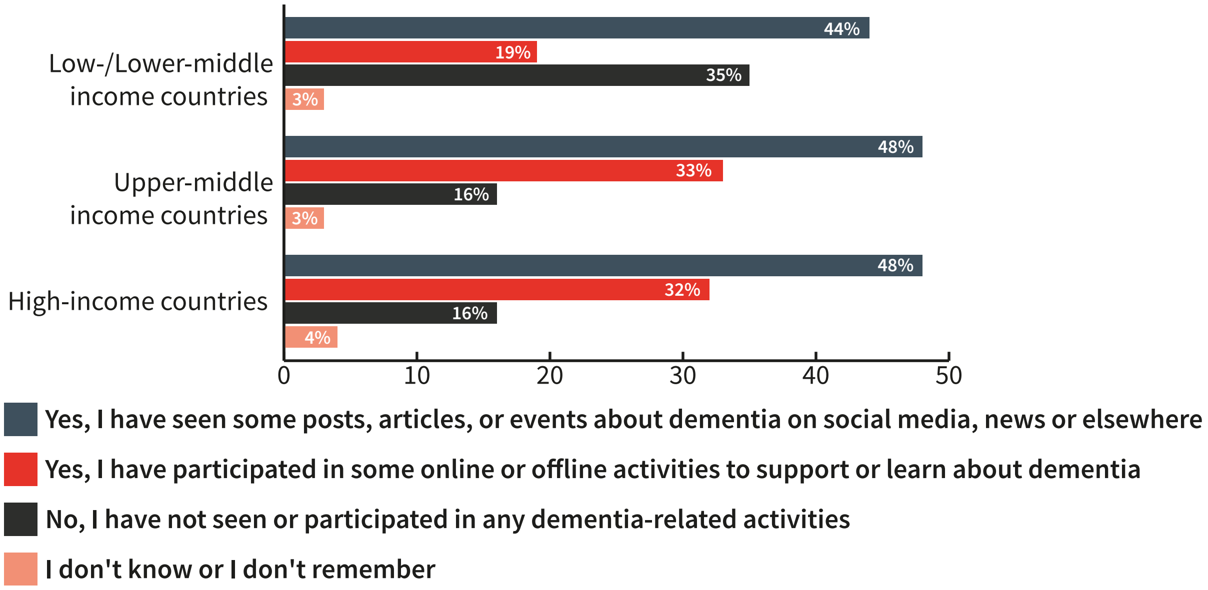


Figure 30. Among health and care professionals – are you aware of any dementia-related activities on social media, news, awareness campaigns (% agree by World Bank income groups)

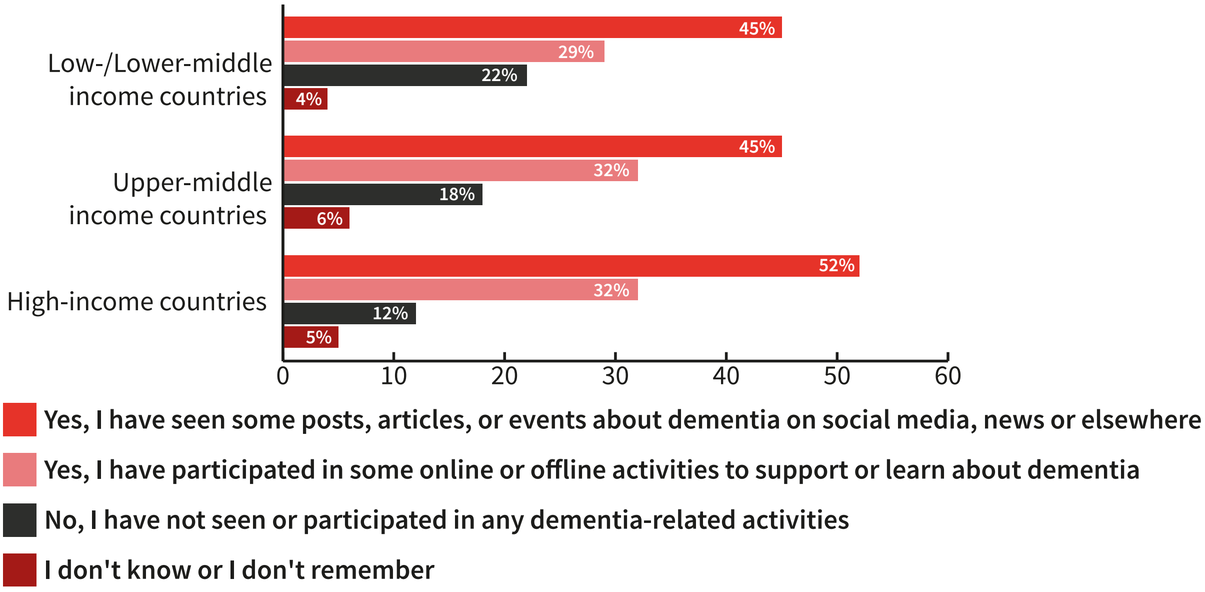
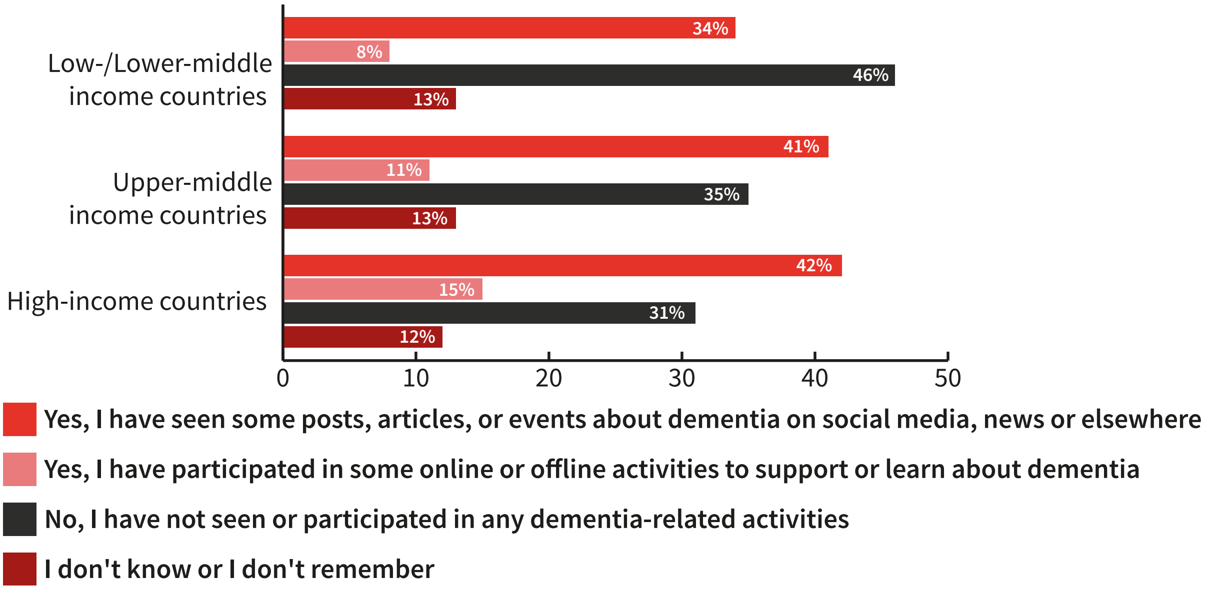


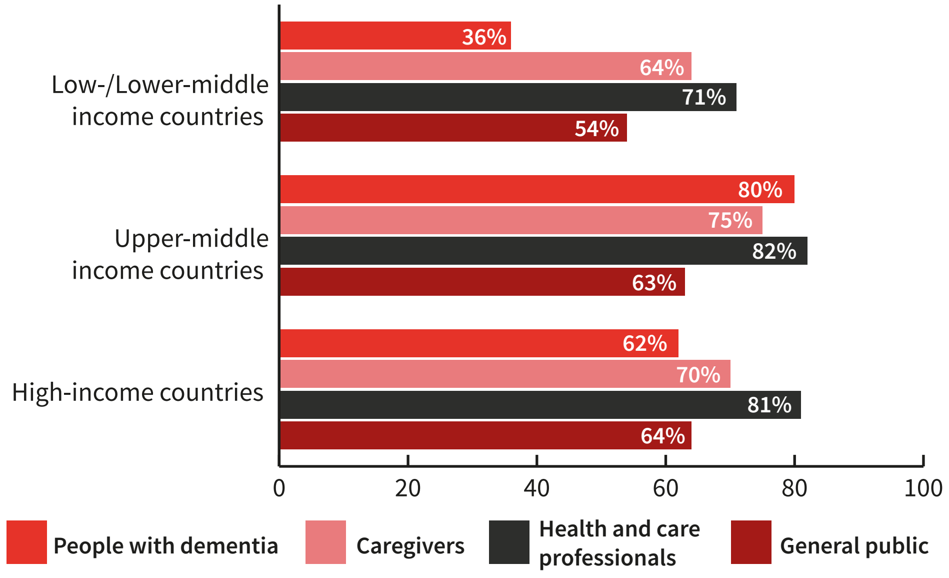
Figure 31. Among the general public – are you aware of any dementia-related activities on social media, news, awareness campaigns? (% agree by World Bank income groups)



5.3 Confidence to challenge stigma and discrimination

- Among the general public group, most respondents feel more confident to challenge stigma and discrimination than they did in 2019, especially in high-income countries (64%).
- Health and care professionals living in high-income and upper-middle income countries and people living with dementia in upper-middle income countries tended to feel most confident relative to 2019 (80–82%), while only 36% of people living with dementia in low-/lower-middle income countries felt more confident.

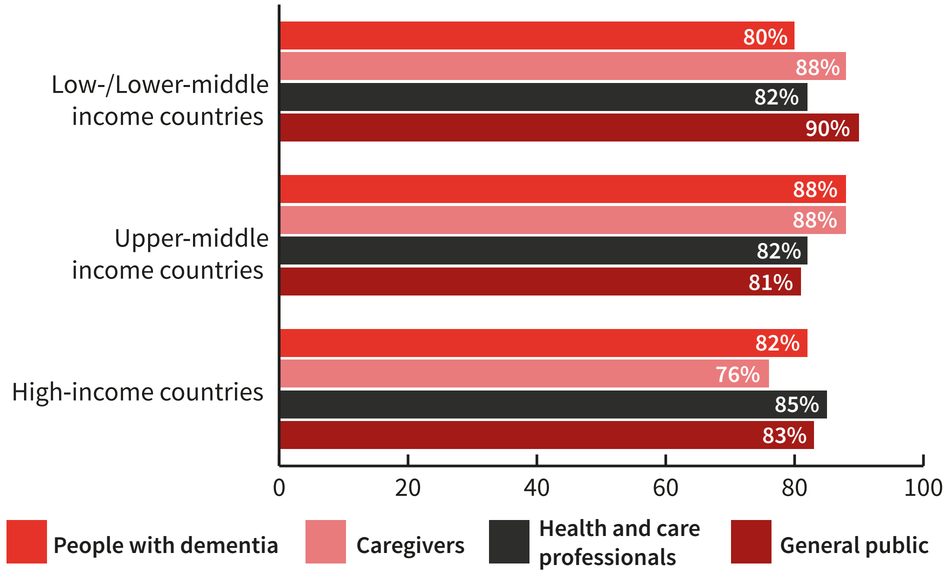
Figure 32. Compared to five years ago, do you feel more confident now in challenging stigma and discrimination related to dementia when you see it? % responding 'Yes' by World Bank country income group



5.4 Perceptions that one's vote can change support for people living with dementia

Another new question we introduced in the 2024 survey explored the perceived influence of one's own vote on the support provided to people living with dementia. Here we sought to understand the extent to which respondents believe that their vote can impact dementia care policies in their respective countries. The findings, presented in Figure 33, are analysed across different World Bank income groups to highlight variations in perceived electoral influence on dementia support. Interestingly, across all countries, more than 80% of the general public believes that they can change the support provided to people with dementia through their vote. It is encouraging to see such a high proportion of respondents believe they can influence dementia care through their vote. This suggests there is a strong foundation of civic engagement that can be harnessed to drive meaningful change.

Figure 33. I feel that I can change the support provided to people living with dementia in my country through my vote, % responding 'Yes' by World Bank country income group



6. Reducing dementia-related stigma

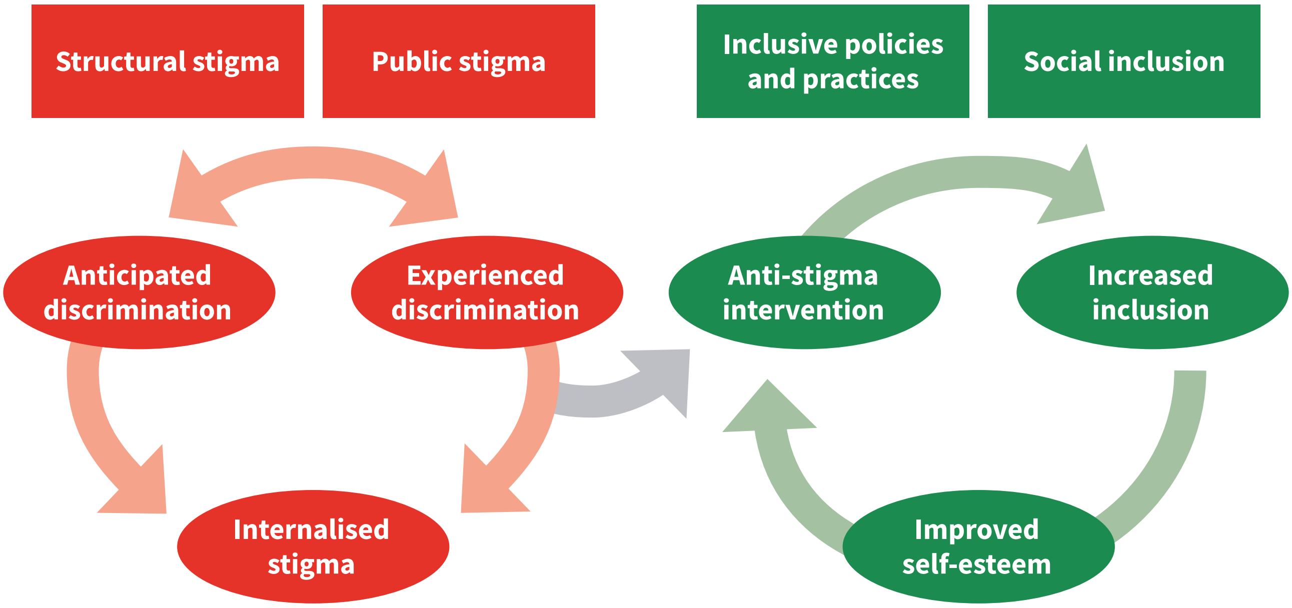
The findings from this report highlight the persistence of stigma-related challenges faced by people living with dementia and their carers across the world. Despite some progress and high levels of awareness, significant barriers remain in the form of public, structural, and internalised stigma. The increase in experienced discrimination underscores the need for targeted interventions that go beyond raising awareness. Efforts to reduce stigma need to integrate multifaceted approaches at the individual, societal, and structural levels and consider the experiences of people living with dementia and their carers.

The conceptual figure presented below illustrates the complex cycle of stigma and exclusion faced by people living with dementia and their carers. This cycle is perpetuated by interrelated forms of stigma: public, structural, internalised, experienced, and anticipated. These forms of stigma collectively contribute to the challenges encountered by people living with dementia and their carers, leading to social exclusion and marginalisation. Living in a context where stigma is prevalent can lead to more experienced discrimination, heightened anticipation of future discrimination, internalised stigma, and diminished self-worth. This can perpetuate the cycle of exclusion and marginalisation.

To counteract this cycle, it is crucial to address both public and structural stigma. Reducing public stigma can foster a more inclusive environment, while tackling structural stigma can promote equitable policies, and increase comprehensive and inclusive support systems. By reducing stigma at these levels, we can enhance the self-esteem and quality of life of people living with dementia and their carers, promote social inclusion, and improve overall wellbeing.

This report underscores the importance of a multifaceted approach to stigma reduction, integrating efforts at individual, community, and systemic levels. Such an approach is vital for dismantling the barriers imposed by stigma and working towards a future where individuals affected by dementia can experience dignity, respect, and inclusion.

The vicious cycle of stigma and virtuous cycle of inclusion for people with dementia and carers



7. Methodology

The 2024 dementia stigma survey aimed to capture the current global knowledge, attitudes, and behaviours towards dementia-related stigma. We replicated the methodology from the 2019 survey to ensure consistency and comparability, while introducing a few new items to address emerging areas of interest.

The survey questions for 2024 were based on the comprehensive framework established in 2019.[8] We continued to target three stigma domains: knowledge and causal attribution of dementia; attitudes and beliefs about people living with dementia; and behaviours towards persons living with dementia and their carers. The survey was tailored for four target groups: people living with dementia, their carers, health and care professionals, and the general public, ensuring overlap in questions where possible and including items specific to each group's experiences.

Changes in survey items since 2019

The 2024 survey maintains consistency in methodology with 2019 report, ensuring comparability while introducing new items important for better understanding dementia-related stigma. For the 2024 survey, we introduced new items to better capture the experiences and perceptions of people with dementia and their carers. These new items focus on anticipated discrimination among people living with dementia and their carers, perceptions of treatments, knowledge of dementia activities, changes in attitudes towards people with dementia in the past five years, and confidence to challenge stigma and discrimination related to dementia. All new items were reviewed by experts, including consultations with people living with dementia, carers, and NGO representatives.

We also aimed to keep the survey concise to ensure high completion rates while capturing critical data.

Efforts to ensure accessibility and inclusivity

To ensure the survey was accessible to a diverse global audience, it was made available in 35 languages. Most translations were done by volunteers and staff from ADI member associations, following the WHO guidelines for forward-translation, back-translation, and concept checking. This process helped ensure that translations were accurate and culturally relevant.

The survey was administered both online and in-person to accommodate different access levels. The online survey was conducted using the Qualtrics platform, which allowed for wide distribution and easy access. In regions with limited internet access, the survey was distributed in-person using paper forms, with data later entered online by volunteers.

We used snowball sampling for the online survey and targeted recruitment for in-person data collection to ensure a representative sample across different demographics. Webinars were conducted for ADI member associations to discuss recruitment strategies and encourage diverse participation.

Data security and consent

Participants were informed that their responses would be anonymous and that survey data would be securely stored without personal identifiers. All data was treated as confidential and kept on secure networks, complying with GDPR privacy legislation. Participants provided informed consent before participating in the survey.

Analysis

Because our sample was a convenience sample, we performed a series of adjustments to allow for comparisons across countries, country groups and survey years. First, we developed survey weights which account for sample selection.[9] Weights were developed to match characteristics of the sample recruited to the nationally representative characteristics in each country according to gender, age and educational level and were used in all analyses. To calculate the weights, we created a dataset for population estimates and sample estimates for each characteristic used for weights, in this case gender, age and education based on existing administrative sources of data as described below. All these weight indicators were dichotomous:

- Proportions of women vs. men for gender
- Proportions of those aged 15–46 vs. 65+
- Proportions of those who have either completed or partially completed tertiary education (higher education degree) vs. less than this in the population aged 25 to 65 years.*

We used year 2021 for gender, year 2024 for age and projection for year 2025 (the closest to 2024) for education for population estimates sourced from Our world in data website.[10]

*Notice that the age group used for higher education population estimates was 25–65, whereas the table from the same source which was used for calculating 2019 weights was based on 15+ population (these tables are not anymore available). In the current 2024 sample, about 8% were 18–25 and 16% aged 65+.

There were some countries/territories which did not have population estimates available. In most cases, the estimate for educational level was missing (the largest entities were Hong Kong (*n* = 615) and Ethiopia (*n* = 590). Because of the difficulty in finding matching groupings, these estimates were not possible be retrieved from other sources. The only exception was the gender ratio for Chinese Taipei, which was not available in the above-mentioned source. However, it could be found for 2021.[11] There were 5,384 participants who did not indicate their country/entity. Moreover, some participants did not provide information on their gender, age or education, and therefore weight for them was missing. Responses with weights greater than 20 (less than 0.02% of the sample) were excluded due to their non-representativeness.

For country comparisons, we also performed a pooled estimation technique (the meta-proportion command which is available in the statistical programme Stata)[12] to compare across countries with at least 100 participants per target group (caregivers, health and care professionals and general public). The best estimate of the response was represented by a box and a horizontal line that represents the 95% confidence interval. Those groups with a greater number of participants/respondents tend to have a narrower confidence interval and a smaller line. Confidence intervals provide a range within which we can be reasonably confident that the true value lies. For example, a 95% confidence interval means that we are 95% certain that the true value lies within that range. The country-specific mean proportions (point estimates of the proportion) were compared using confidence intervals: if the confidence intervals overlap, it indicates there is no significant difference between the countries, if they do not overlap, it suggests a significant difference between the countries. In addition, p-values are used to determine the variation around the mean proportions.

The survey responses were analysed to understand global trends and regional variations in dementia-related stigma. Data were aggregated by World Bank income categories. We developed survey weights to adjust for imbalances in gender, age, and education based on nationally representative figures. The comparison across survey years (2019 vs. 2024) was done by testing the difference between the reported value in 2019 and the respective sample value in 2024 with chi-square test.

Description of the 2024 sample participants

Of about 40,000 people who engaged with the survey, 34,619 answered at least one question on stigma-related knowledge, attitudes, and beliefs in relation to dementia. This included 789 people living with dementia (2.3% of our total sample), 10,605 carers for a person living with dementia (30.6%), 8,797 health and care professionals (25.4%) and 14,428 members of the general public (41.7%).

Respondents came from 166 countries or semi-autonomous regions/territories and answered the survey in one of 35 different languages. Responses were aggregated by World Bank income category and World Health Organization (WHO) geographical region. The majority of participants resided in high-income countries (57.7%). Individuals from low-income and lower-middle income economies represented 2.6% and 11.7% of respondents, respectively. The remaining 28.1% resided in upper-middle income countries. Because of the small numbers of respondents from low-income countries, we combined respondents from low and lower-middle income countries, creating three World Bank categories. In relation to WHO regions, most respondents were from the Region of the Americas (33.9%), the European Region (29.8%), and the Western Pacific Region (17.9%). A lower proportion of respondents came from the Eastern Mediterranean Region (3.0%), South-East Asia Region (5.6%) and the African Region (9.9%).

Compared to 2019, there were proportionally more respondents from lower- and middle-income countries (25.3% in 2019 vs. 42.3% in 2024) and fewer from higher-income countries (74.7% in 2019 vs. 57.7% in 2024) in 2024. This was mainly due to a smaller proportion of respondents from the European Region (42.4% in 2019 vs. 29.8% in 2024) and a larger proportion from the Regions of Americas (25.7% in 2019 vs. 33.9% in 2024) and the African Region (1.7% in 2019 vs. 9.9% in 2024) participating in 2024.

Our recruitment resulted in a large and diverse sample; however, respondents over-represented females and individuals with university education: more females (78.9%) than males (20.4%) completed the survey, and 75.6% of respondents had completed college/university or post-graduate studies.

References

1. Thornicroft G, Rose D, Kassam A, Sartorius N. 2007. 'Stigma: ignorance, prejudice or discrimination?' Br J Psychiatry 190: 192–93.
2. This is despite evidence that 45% of dementia cases are potentially preventable. Livingston G, Huntley J, Liu KY, Costafreda SG, Selbæk G, Alladi S, Ames D, Banerjee S, Burns A, Brayne C, Fox NC, Ferri CP, Gitlin LN, Howard R, Kales HC, Kivimäki M, Larson EB, Nakasujja N, Rockwood K, Samus Q, Shirai K, Singh-Manoux A, Schneider LS, Walsh S, Yao Y, Sommerlad A, Mukadam N. Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. Lancet. 2024 Jul 30:S0140–6736(24)01296–0. doi: 10.1016/S0140–6736(24)01296–0. Epub ahead of print. PMID: 39096926.
3. Question wording was: If it were available, I would take a genetic profiling test to learn whether I am at risk of developing dementia
4. Experiences of discrimination were measured using the DISCUS, a scale validated among people living with dementia from diverse countries and contexts using the 2019 survey data: Bhatt J, Brohan E, Blasco D, Oliveira D, Bakolis I, Comas-Herrera A, D'Amico F, Farina N, Knapp M, Stevens M, Thornicroft G, Wilson E, Salcher-Konrad M, Yang LH, Evans-Lacko S. The development and validation of the Discrimination and Stigma Scale Ultra Short for People Living with Dementia (DISCUS-Dementia). BJPsych Open. 2023 Aug 31;9(5):e164. doi: 10.1192/bjo.2023.551. PMID: 37650126;.
5. To assess loneliness, we used a short three-item version of the revised UCLA Loneliness Scale (Hughes et al., 2004). The measure is summed to create a scale from 3 (not lonely) to 9 (very lonely).
6. The fact that carers, might be lonelier compared to the general public is unsurprising. The English Longitudinal Study of Aging (ELSA) identified that partners of those age 50 years and older who cared for someone with dementia (M=5.1, SD=1.7, n=48) were lonelier than non-caregiving partners (M=3.9, 1.4, n=4,251) and care partners without dementia or functional impairments (M=4.0, SD=1.4; n=195) (Saadi et al., 2021). Unfortunately, there is less relevant data for people with dementia, as there is a tendency to focus on loneliness as a risk factor, rather than a consequence of dementia. We can however observe that people who screen positive for dementia in Kenya reported the very similar level of loneliness as our global survey (M=5.1, SD=1.86; n=652) (Musyimi et al., 2024).
7. We assessed quality of life using the EUROHIS-QOL 8-item index which is scored between 1 and 5, with higher scores representing better quality of life.
8. The quality of life scores reported here appear to be slightly lower compared to a cohort of European and Israeli adults (M=3.7, SD=0.62; n=4,849)(Schmidt et al., 2006), though higher than an international cohort of depressed adults (M=2.8, SD=0.66; n=1,193)(Rocha et al., 2012) and Kenyan older adults that have screen positive for dementia (M=2.4, SD=0.65, n= 652)(Musyimi et al., 2024).
9. Evans-Lacko, S, Bhatt, J., Comas-Herrera, A., D'Amico, F., Farina, N., Gaber, S., Knapp, M., Salcher-Konrad, M., Stevens, M., and Wilson, E. (2019). Attitudes to dementia survey. World Alzheimer Report 2019, Attitudes to dementia. (pp. 21–87). London: Alzheimer's Disease International.
10. Lavallée, P. & Beaumont, J.-F. (2015), 'Why We Should Put Some Weight on Weights. Survey Insights: Methods from the Field, Weighting: Practical Issues and 'How to' Approach,' Invited article, Retrieved from https://surveyinsights.org/?p=6255 Last accessed 30 August 2019.
11. https://ourworldindata.org/grapher/share-population-female
12. https://ourworldindata.org/grapher/population-by-age-group-with-projections https://ourworldindata.org/grapher/share-of-the-population-with-completed-tertiary-education
13. https://www.globaldata.com/data-insights/macroeconomic/the-gender-ratio-of-taiwan-325448/
14. Nyaga VN, Arbyn M, Aerts M. 2014. 'Metaprop: a Stata command to perform meta-analysis of binomial data.' Archives of Public Health volume 72

8. Appendices

Appendix 1

Map 1. World Health Organization (WHO) Regions

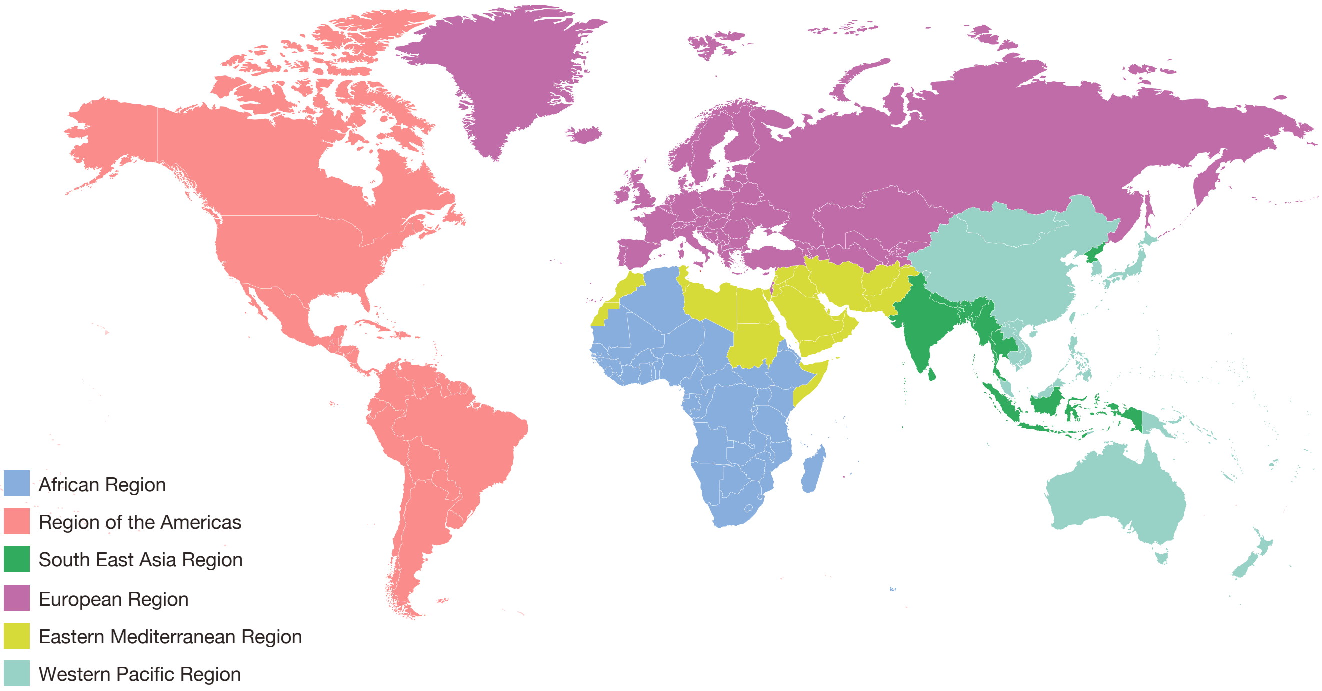


Chart 1. World Bank Income Groups 2024

1. Low-income countries

- Afghanistan
- Burundi
- Chad
- Democratic Republic of the Congo
- Ethiopia
- Madagascar
- Mali
- Mozambique
- Sierra Leone
- Somalia
- Syria
- Uganda
- Yemen

2. Lower-middle income countries

- Angola
- Benin
- Bhutan
- Bolivia
- Cameroon
- Republic of the Congo
- Côte d’Ivoire
- Egypt
- Ghana
- Haiti
- Honduras
- India
- Jordan
- Kenya
- Lebanon
- Lesotho
- Micronesia
- Nicaragua
- Nigeria
- North Korea
- Pakistan
- Philippines
- Samoa
- Sri Lanka
- Swaziland
- Tanzania
- Uzbekistan
- Vietnam
- Zambia
- Zimbabwe

3. Upper-middle income countries

- Albania
- Algeria
- Argentina
- Armenia
- Azerbaijan
- Belarus
- Bonaire
- Bosnia and Herzegovina
- Botswana
- Brazil
- China
- Colombia
- Costa Rica
- Cuba
- Dominica
- Dominican Republic
- Ecuador
- Georgia
- Grenada
- Indonesia
- Iran
- Jamaica
- Libya
- Malaysia
- Maldives
- Mauritius
- Mexico
- Moldova
- Montenegro
- North Macedonia
- Palestinian Territories
- Saint Lucia
- Saint Vincent and the Grenadines
- South Africa
- Suriname
- Thailand
- Tonga
- Turkey
- Ukraine
- Venezuela

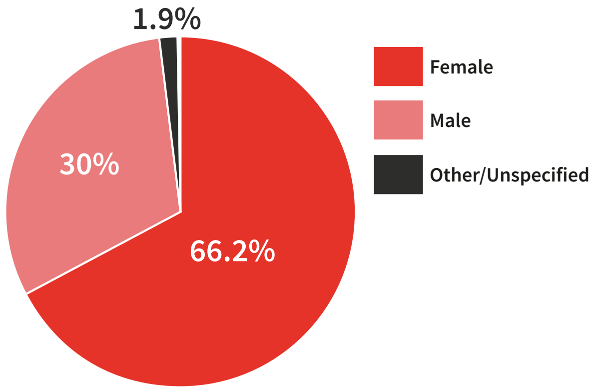
4. High-income countries

- Andorra
- Antigua and Barbuda
- Australia
- Austria
- Bahamas
- Barbados
- Belgium
- Bermuda
- British Virgin Islands
- Brunei Darussalam
- Canada
- Cayman Islands
- Chile
- Curacao
- Cyprus
- Czech Republic
- Denmark
- Estonia
- Finland
- France
- Germany
- Greece
- Hong Kong SAR
- Hungary
- Ireland
- Israel
- Italy
- Japan
- Lithuania
- Luxemburg
- Macau SAR
- Netherlands
- New Zealand
- Norway
- Oman
- Panama
- Poland
- Portugal
- Puerto Rico
- Qatar
- Romania
- Russian Federation
- Saint Kitts and Nevis
- Saudi Arabia
- Seychelles
- Singapore
- Sint Marteen
- Slovakia
- Slovenia
- South Korea
- Spain
- Chinese Taipei
- Trinidad and Tobago
- United Arab Emirates
- United Kingdom
- United States
- Uruguay

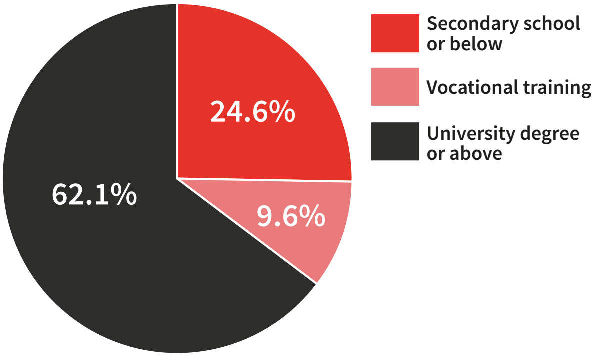
Appendix 2 – Characteristics of survey respondents

People living with dementia (n = 789)

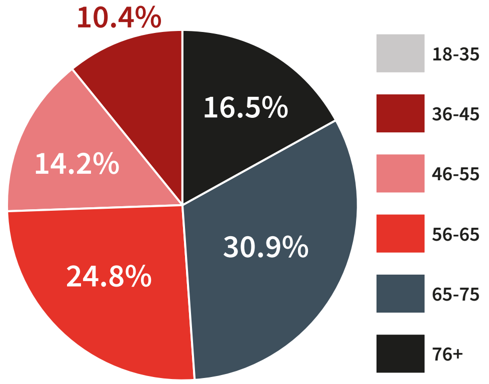
Gender



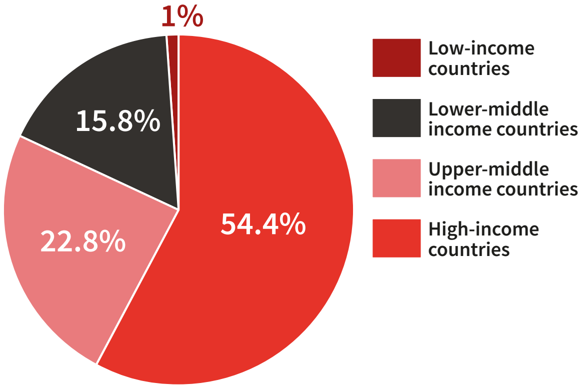
Education



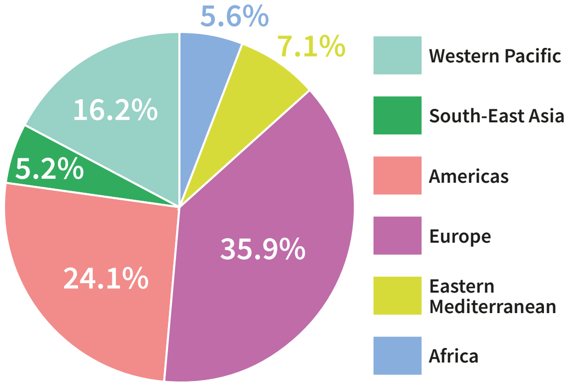
Age



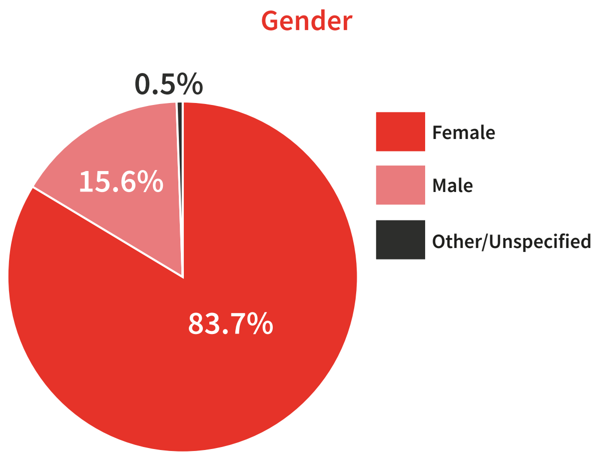
World bank income groups

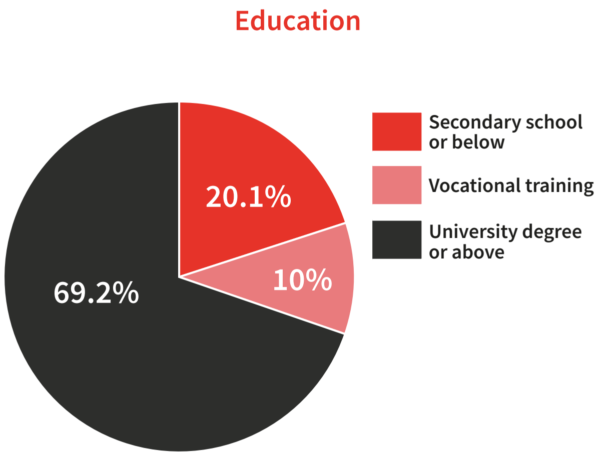


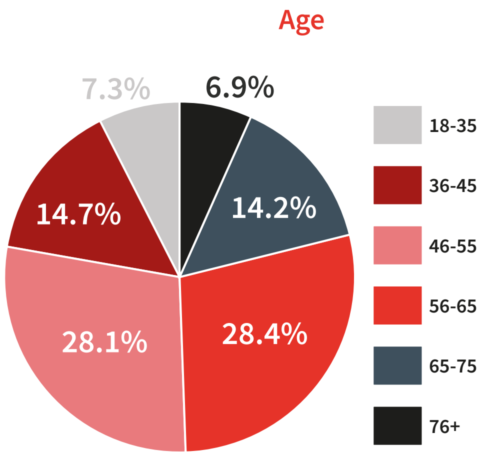
WHO Regions

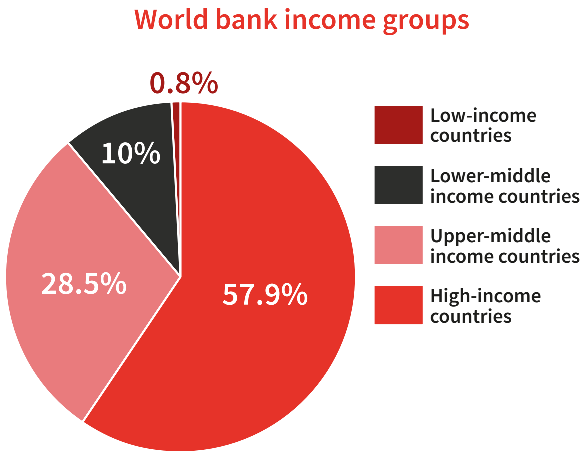


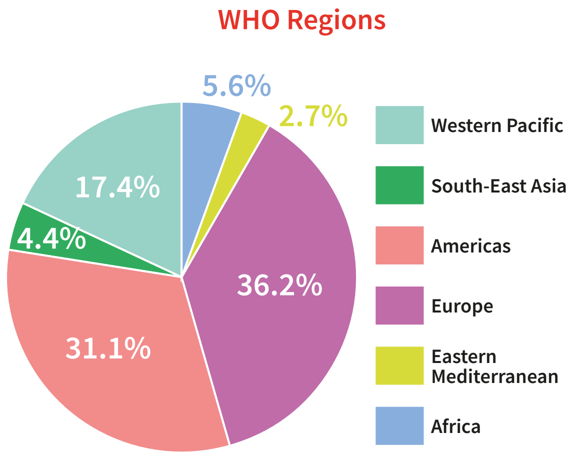
Carers (n = 10,605)





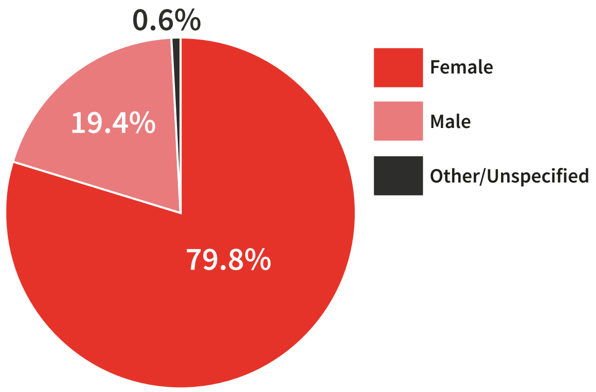




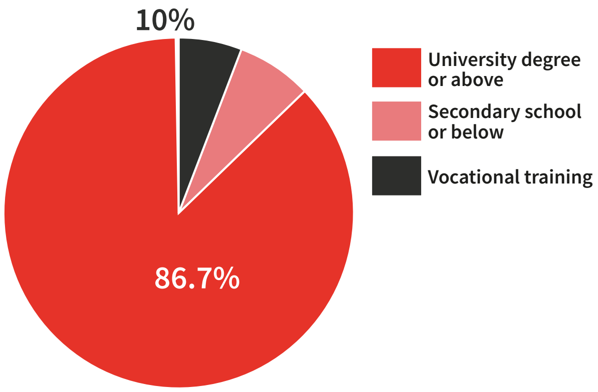


Health and/or care professionals (n = 8,797)

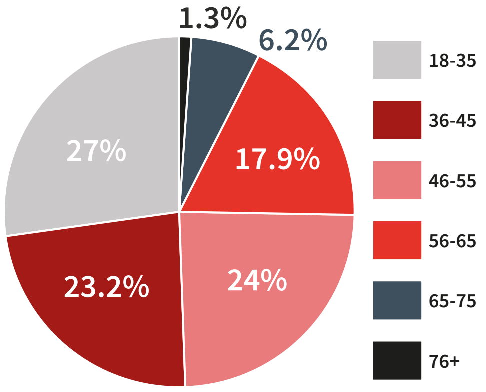
Gender



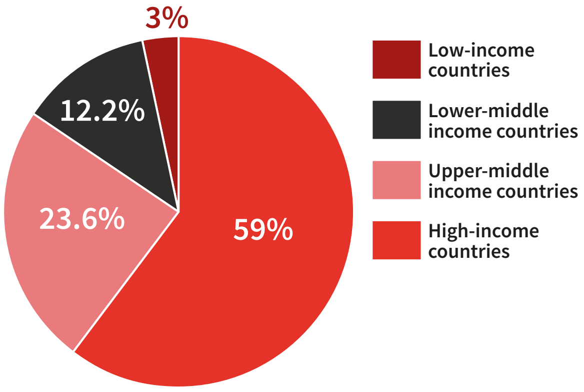
Education



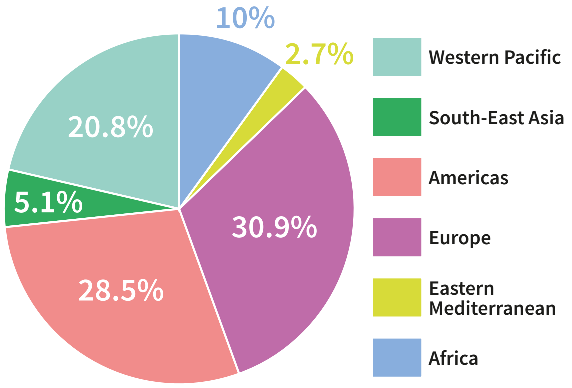
Age



World bank income groups

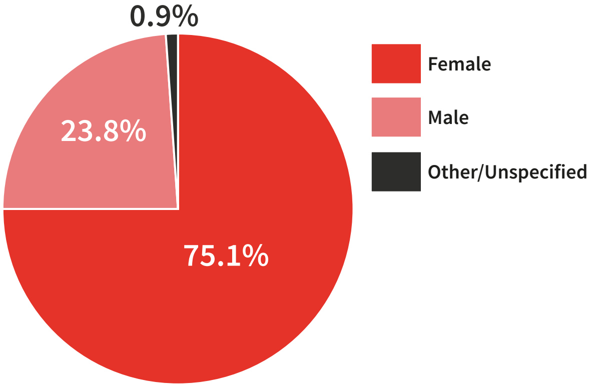


WHO Regions

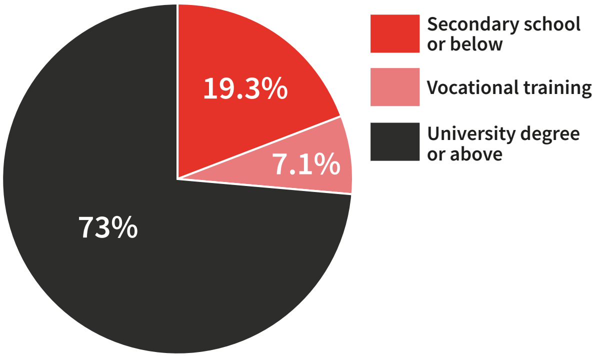


General Public (n = 14,428)

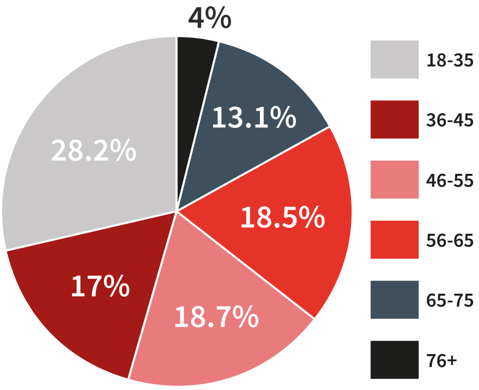
Gender



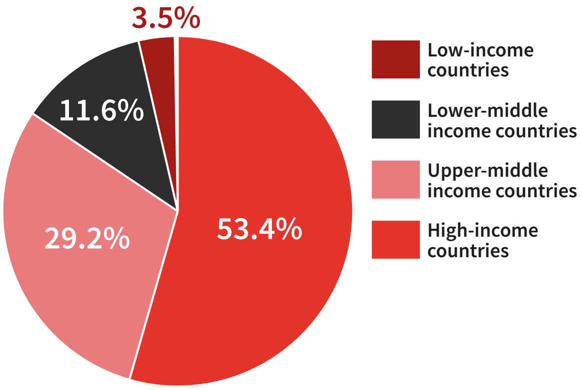
Education



Age



World bank income groups



WHO Regions

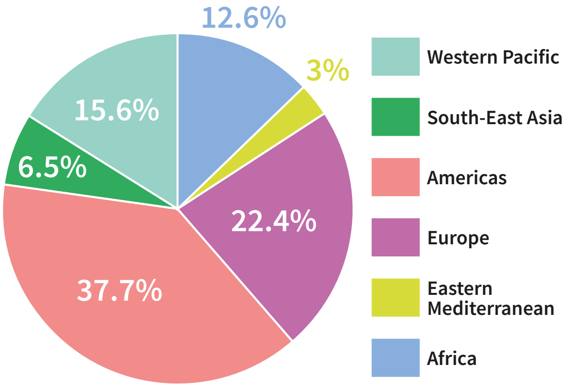


Table 1. Numbers of participants with missing weights. Notice that when population estimates were not missing, the missing cases were due to incomplete information of participant's education, age, or gender or identifying gender other than female/male, which were used for population estimates.

		Population estimates missing for		
	n	Education	Gender	Age
Country missing	5,384	Yes	Yes	Yes
Afghanistan	5			
Albania	4			
Algeria	3			
Andorra	7	Yes		
Angola	4	Yes		
Antigua and Barbuda	8	Yes		
Argentina	16			
Armenia	2			
Australia	13			
Austria	13			
Azerbaijan	9	Yes		
Bahamas	388	Yes		
Barbados	6			
Belarus	1	Yes		
Belgium	7			
Benin	1			
Bermuda	352	Yes		
Bhutan	11	Yes		
Bolivia	15			
Bonaire	5	Yes	Yes	Yes
Bosnia and Herzegovina	4	Yes		
Botswana	12			
Brazil	43			
British Virgin Islands	6	Yes		
Brunei Darussalam	304	Yes	Yes	Yes
Burundi	6			
Cameroon	7			
Canada	20			
Cayman Islands	64	Yes		
Chad	1	Yes		
Chile	9			
China	15			
Colombia	12			
Costa Rica	2			
Cuba	1			
Curacao	6	Yes		
Cyprus	1			
Czech Republic	21	Yes	Yes	Yes
Côte d'Ivoire	1	Yes	Yes	Yes
Democratic Republic of the Congo	46	Yes	Yes	Yes
Denmark	2			
Dominica	252	Yes		
Dominican Republic	15			
Ecuador	13			
Egypt	6			
Estonia	2			
Ethiopia	590	Yes		
Finland	2			
France	27			

		Population estimates missing for		
	n	Education	Gender	Age
Country missing	**5,384**	**Yes**	**Yes**	**Yes**
Georgia	44	Yes		
Germany	18			
Ghana	1			
Greece	12			
Grenada	16	Yes		
Haiti	1			
Honduras	1			
Hong Kong	615	Yes	Yes	Yes
Hungary	1			
India	10			
Indonesia	21			
Iran	18			
Ireland	6			
Israel	22			
Italy	18			
Jamaica	2			
Japan	11			
Jordan	3			
Kenya	13			
Lebanon	71	Yes		
Lesotho	1			
Libya	1	Yes	Yes	Yes
Lithuania	13			
Luxembourg	1			
Macau SAR	166	Yes	Yes	Yes
Madagascar	121	Yes		
Malaysia	22			
Maldives	2			
Mali	2			
Mauritius	2			
Mexico	44			
Micronesia (country)	2	Yes		
Moldova	1	Yes	Yes	Yes
Montenegro	7	Yes		
Mozambique	1			
Netherlands	14			
New Zealand	20			
Nicaragua	1			
Nigeria	81	Yes		
North Korea	1	Yes		
North Macedonia	10		Yes	Yes
Norway	43			
Oman	36	Yes		
Pakistan	4			
Palestine	6	Yes	Yes	Yes
Panama	49			
Philippines	7			
Poland	2			
Portugal	8			
Puerto Rico	96	Yes		
Qatar	4			
Romania	11			
Russia	4	Yes	Yes	Yes

		Population estimates missing for		
	n	Education	Gender	Age
Country missing	**5,384**	**Yes**	**Yes**	**Yes**
Saint Kitts and Nevis	179	Yes		
Saint Lucia	13	Yes		
Saint Vincent and the Grenadines	87	Yes		
Samoa	1	Yes		
Saudi Arabia	1			
Seychelles	73	Yes		
Sierra Leone	2			
Singapore	5			
Sint Maarten	1	Yes	Yes	Yes
Slovakia	1			
Slovenia	3			
Somalia	1	Yes		
South Africa	26			
South Korea	1			
Spain	24			
Sri Lanka	2			
Suriname	99	Yes		
Swaziland	5	Yes	Yes	Yes
Switzerland	2			
Syria	2	Yes	Yes	Yes
Chinese Taipei	57			
Tanzania	1	Yes	Yes	Yes
Thailand	32			
The former Yugoslav Republic of Macedonia	10	Yes		
Tonga	1			
Trinidad and Tobago	3			
Turkey	1			
Uganda	6			
Ukraine	36			
United Arab Emirates	1			
United Kingdom	46			
United States	28			
Uruguay	2			
Uzbekistan	1	Yes		
Venezuela	10			
Vietnam	80	Yes	Yes	Yes
Yemen	3			
Zambia	26			
Zimbabwe	8			
Total	**4,917**			

Appendix 3

Figure 1. Intended secrecy and concealment of dementia among health and care professionals by country. "I would make an effort to keep my dementia a secret when meeting people agree or strongly agree with", agree or strongly agree (%). Countries with 100+ participants included.

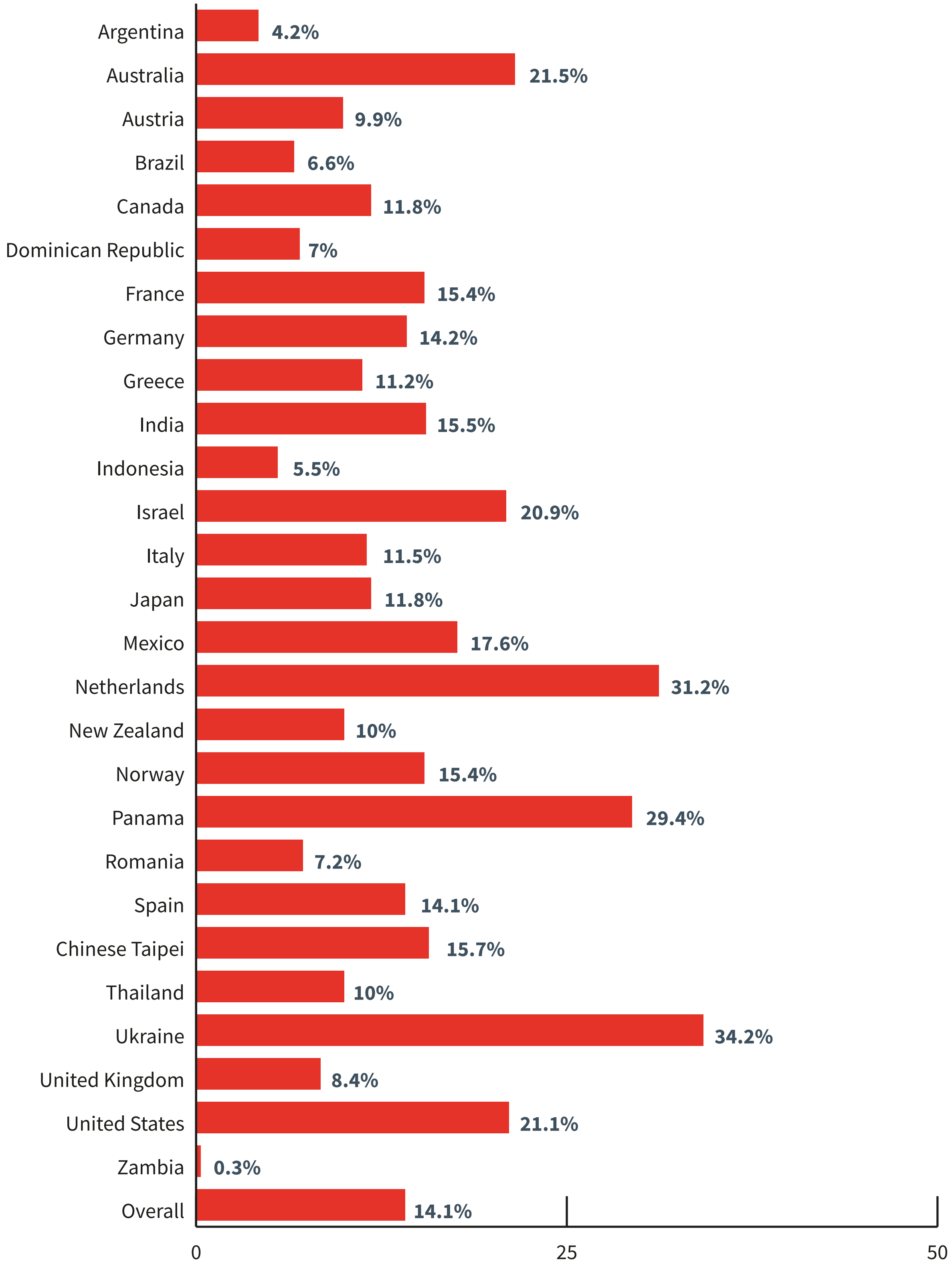


Figure 2. Intended secrecy and concealment of dementia among general public by country. "I would make an effort to keep my dementia a secret when meeting people agree or strongly agree with", agree or strongly agree (%). Countries with 100+ participants included.

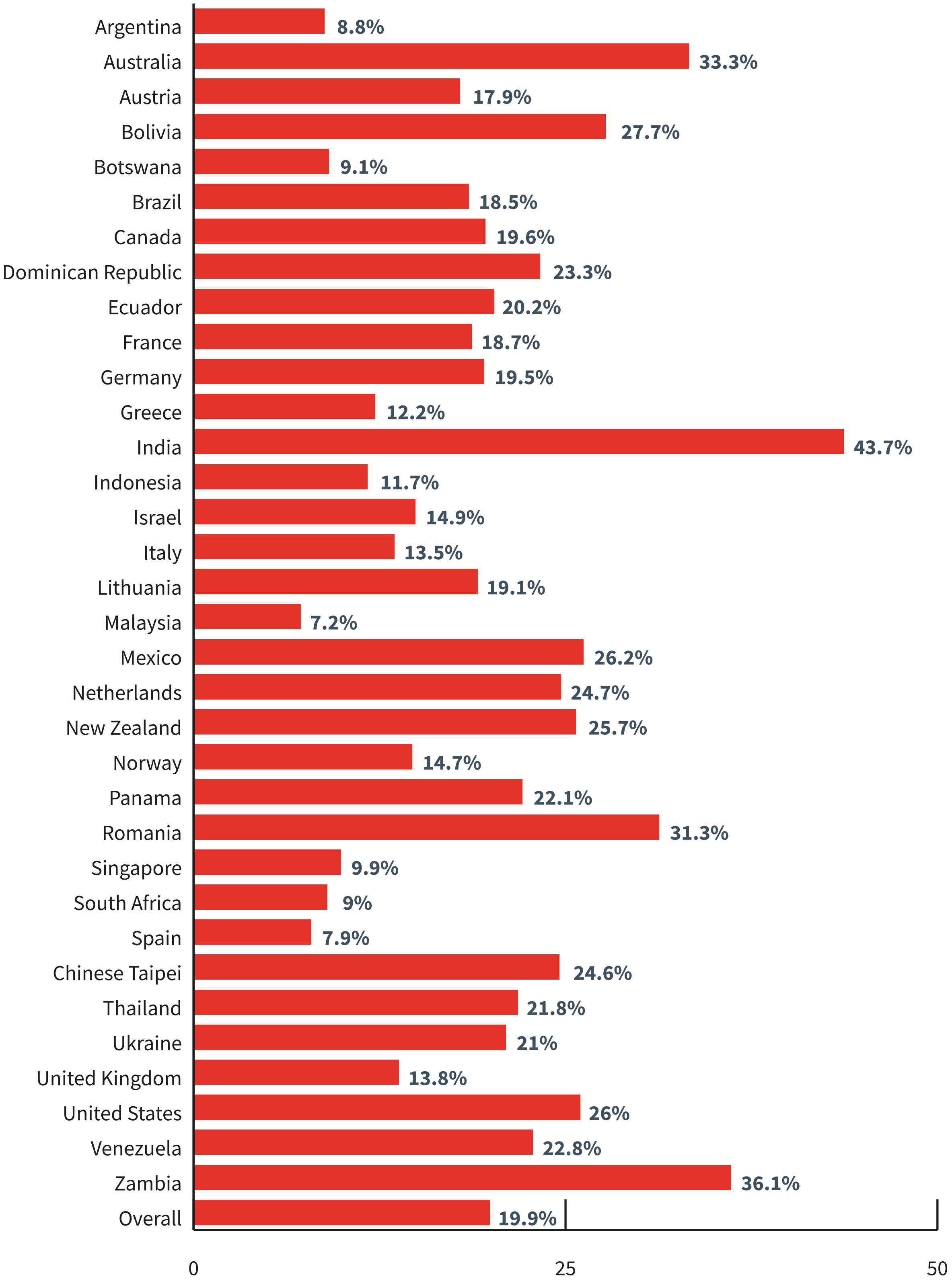


Figure 3. Agreement that there are adequate community services for people with dementia among caregivers by country. % agree or strongly agree. Countries with 100+ participants included.

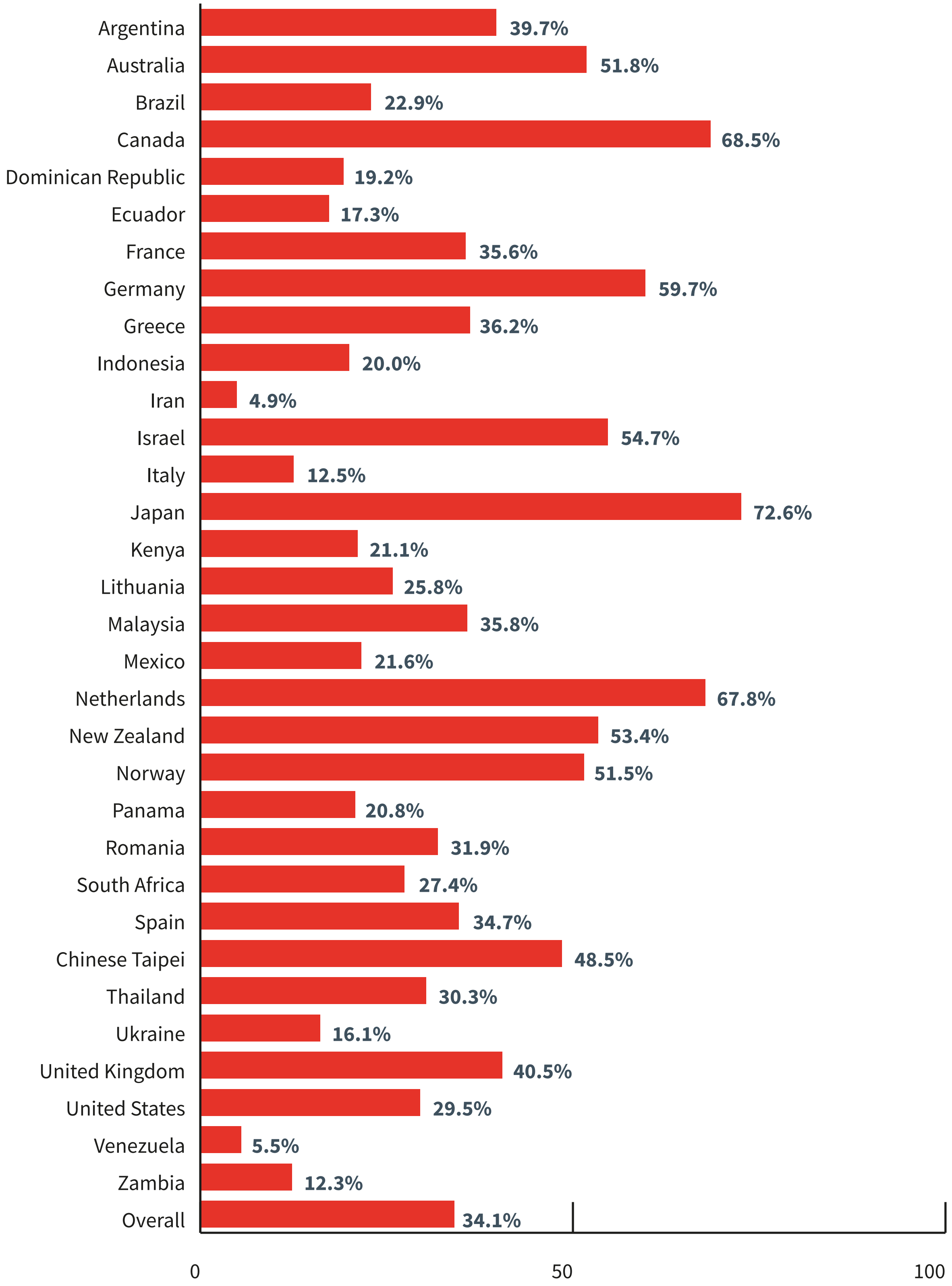


Figure 4. Agreement that there are adequate community services for people with dementia among health and care professionals by country. % agree or strongly agree. Countries with 100+ participants included.

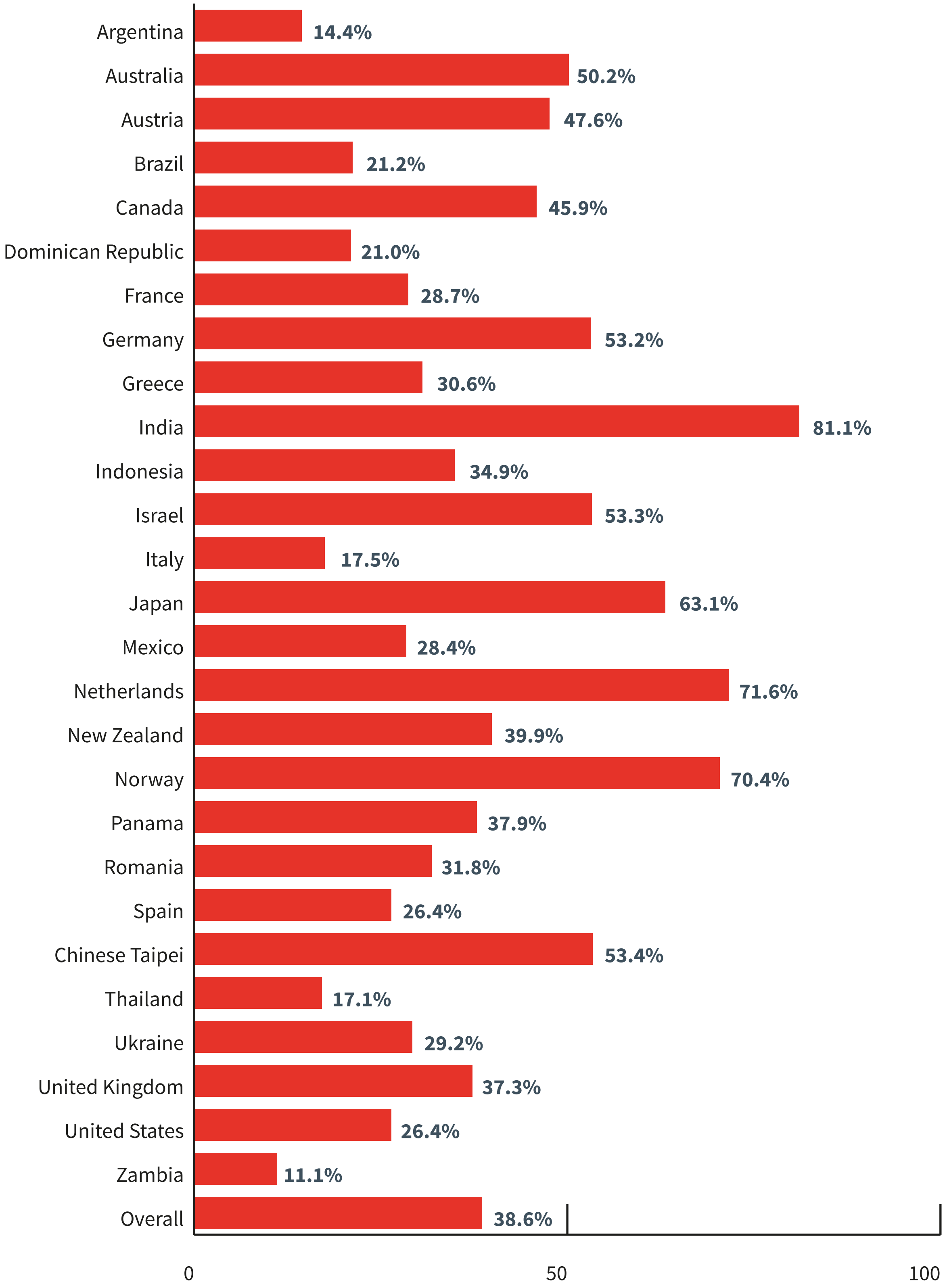


Figure 5. Agreement that there are adequate community services for people with dementia among general public by country. % agree or strongly agree. Countries with 100+ participants included.

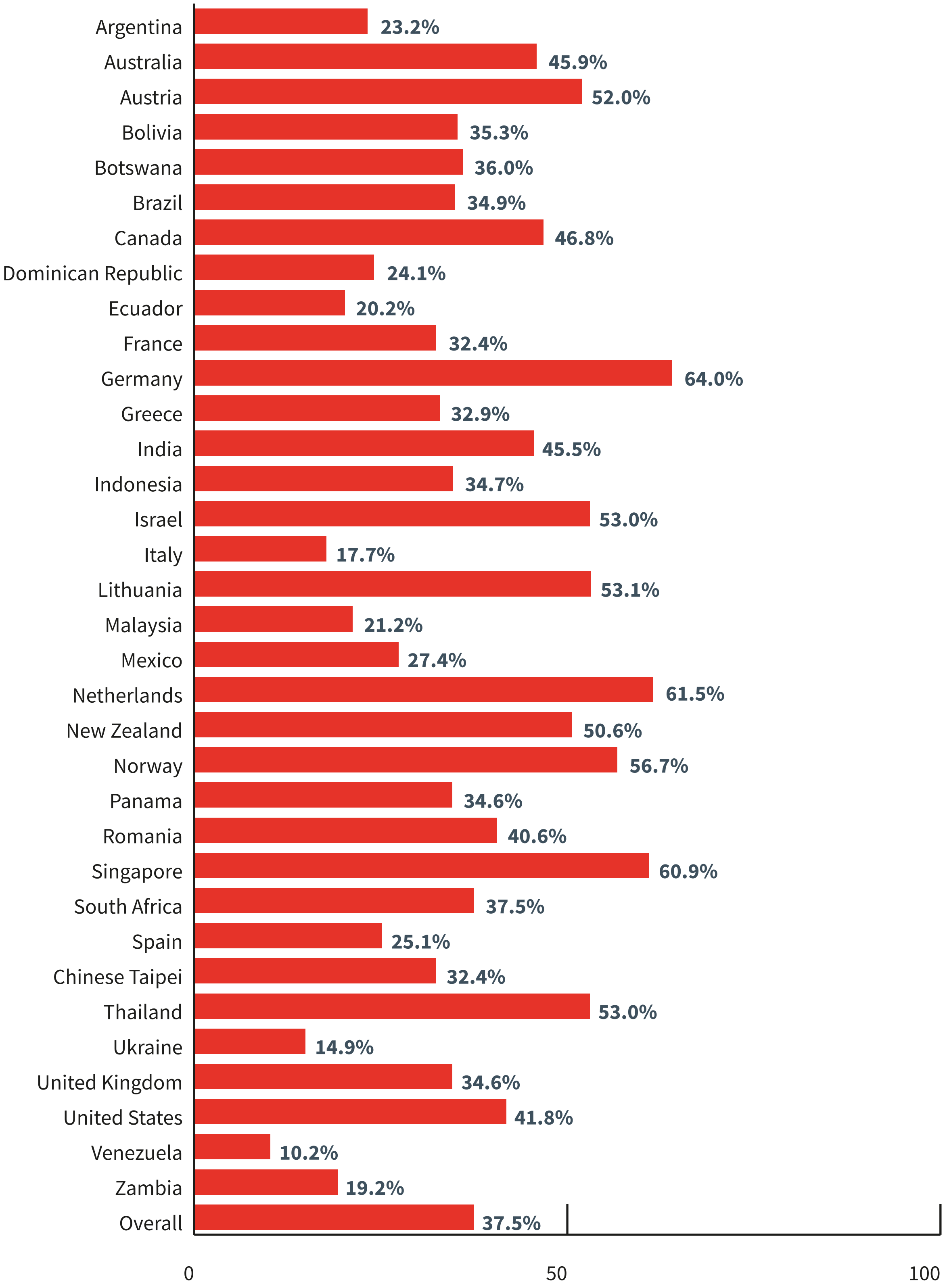


Figure 6. Agreement that health professionals ignore the person with dementia among caregivers by country, % agree or strongly agree. Countries with 100+ participants included.

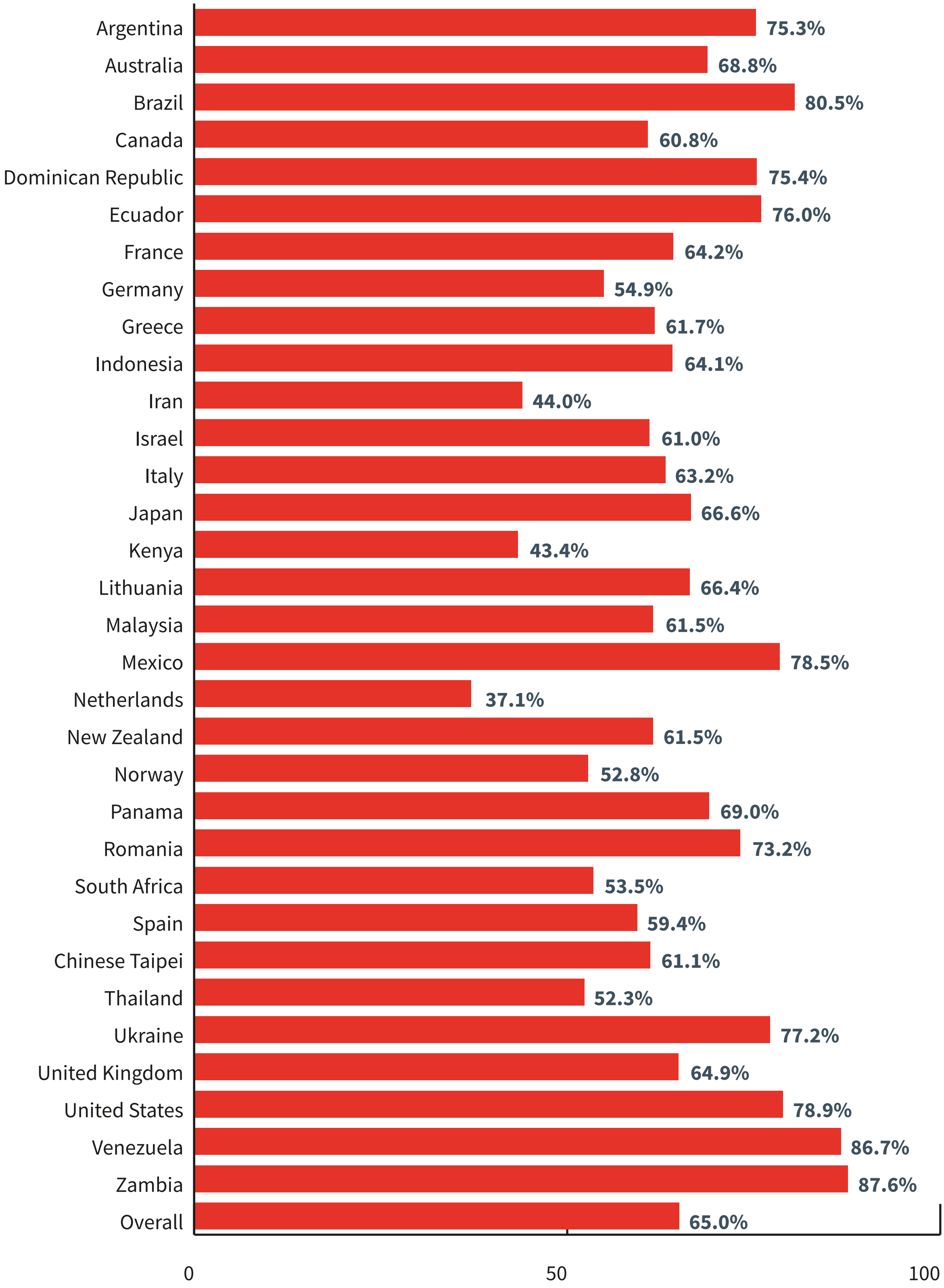


Figure 7. Agreement that health professionals ignore the person with dementia among health and care professionals by country, % agree or strongly agree. Countries with 100+ participants included.

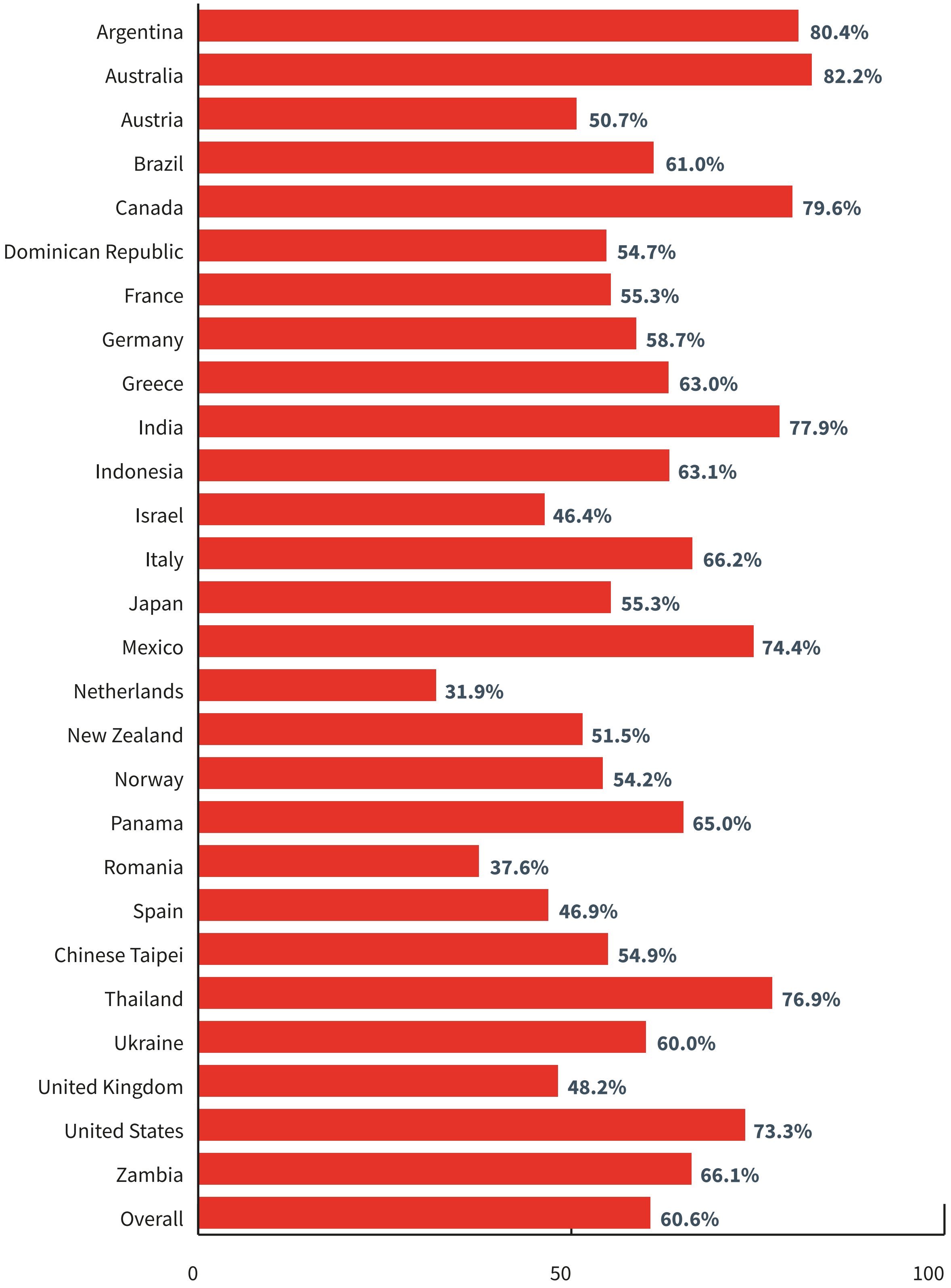


Figure 8. Agreement that health professionals ignore the person with dementia among general public by country, % agree or strongly agree. Countries with 100+ participants included.

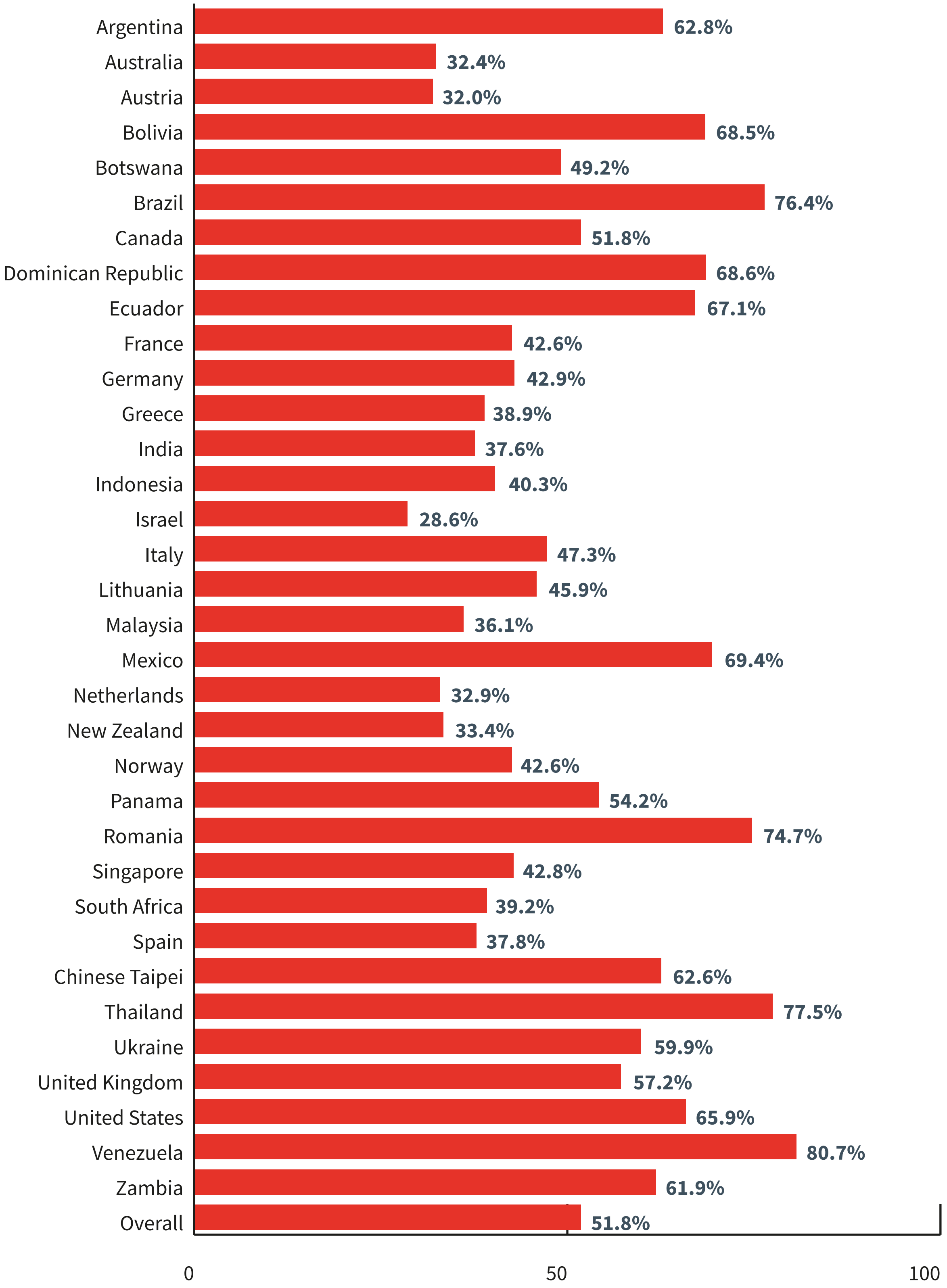


Figure 9. Agreement among the general public that 'I would take a genetic profiling test to learn whether I am at risk of developing dementia', by country (% agree or strongly agree). Countries with 100+ participants included.

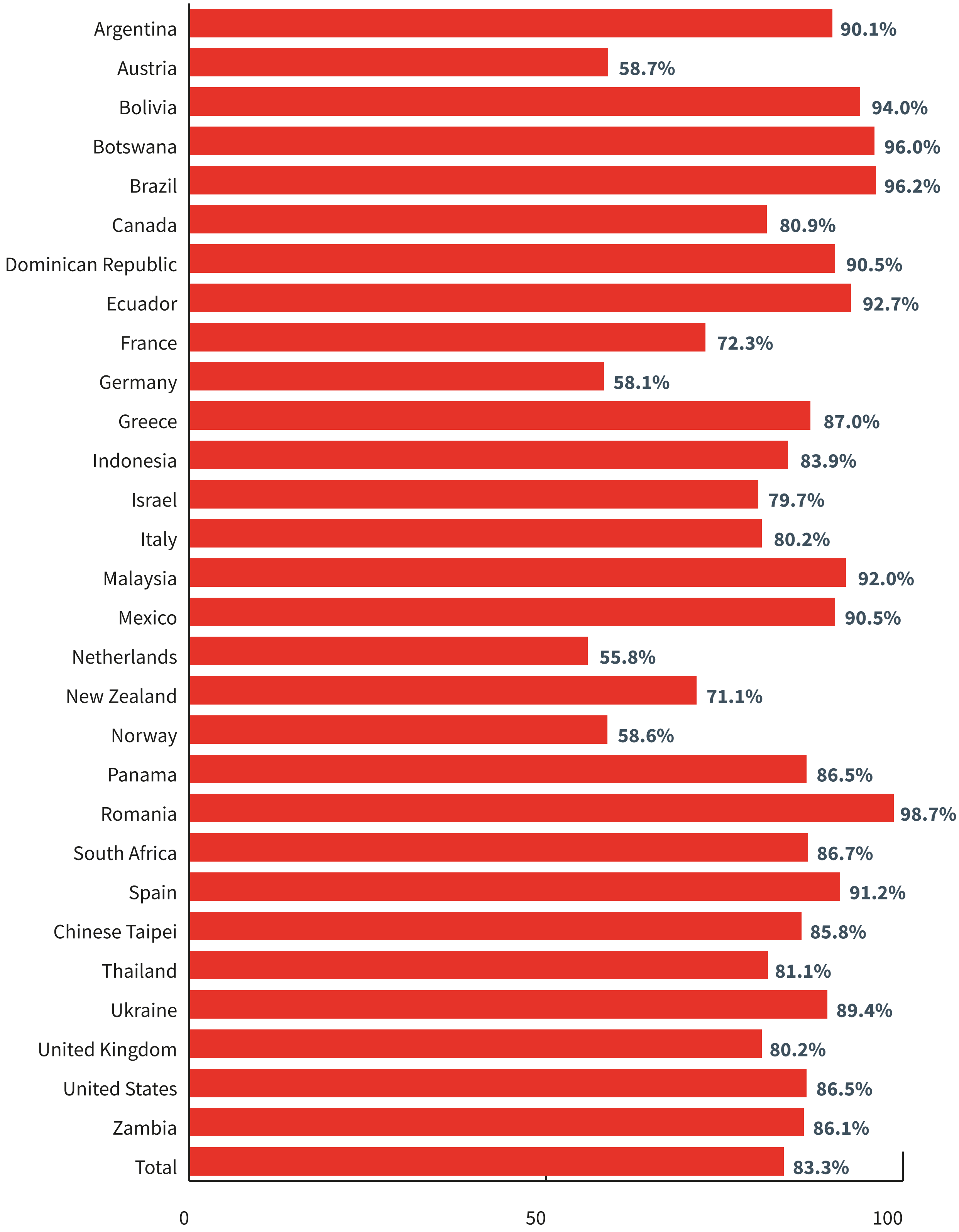


Figure 10. Agreement among health and care professionals that people with dementia are perceived as dangerous, by country (% agree or strongly agree). Countries with 100+ participants included.

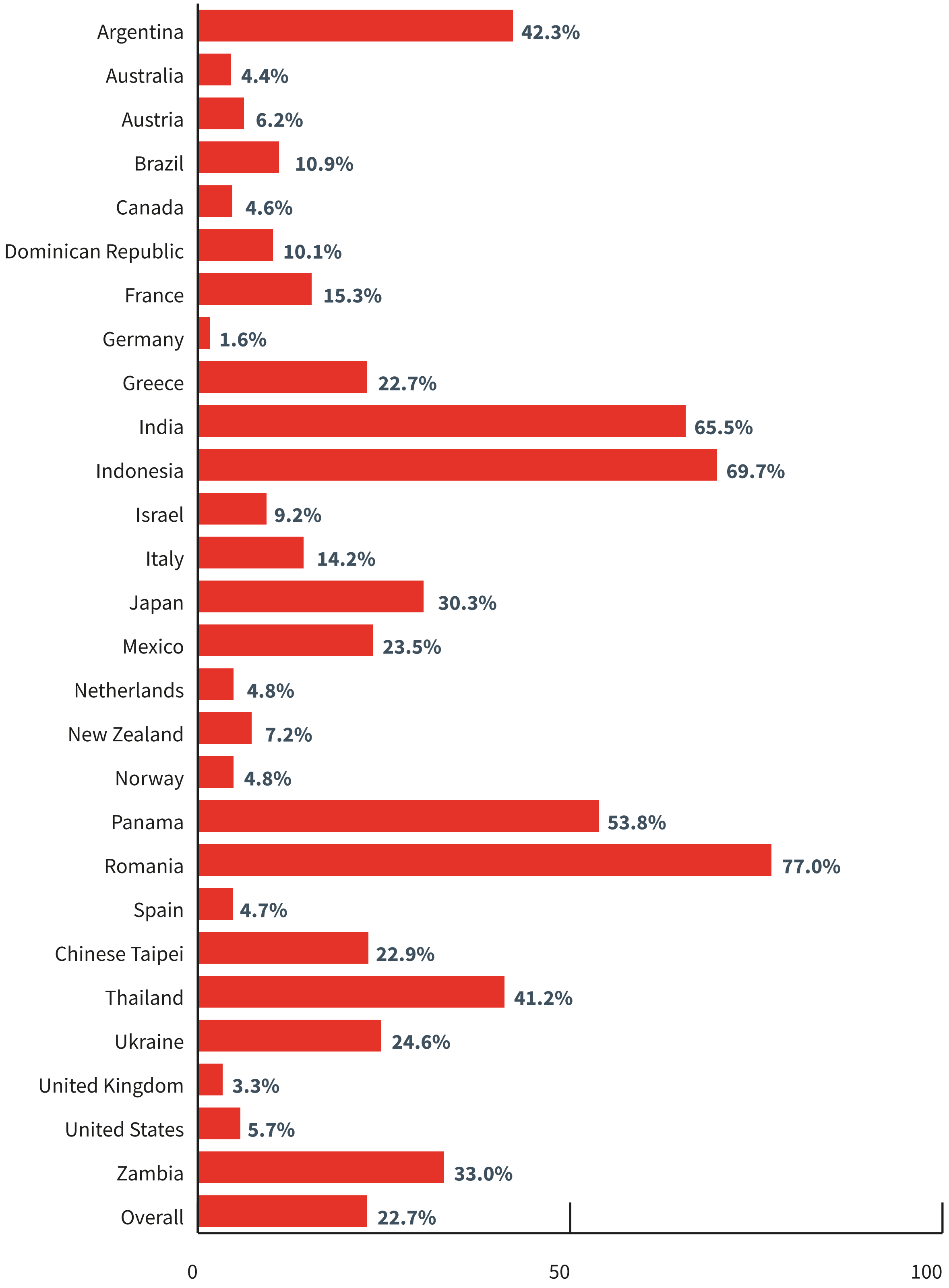


Figure 11. Agreement among general public that people with dementia are perceived as dangerous, by country (% agree or strongly agree). Countries with 100+ participants included.

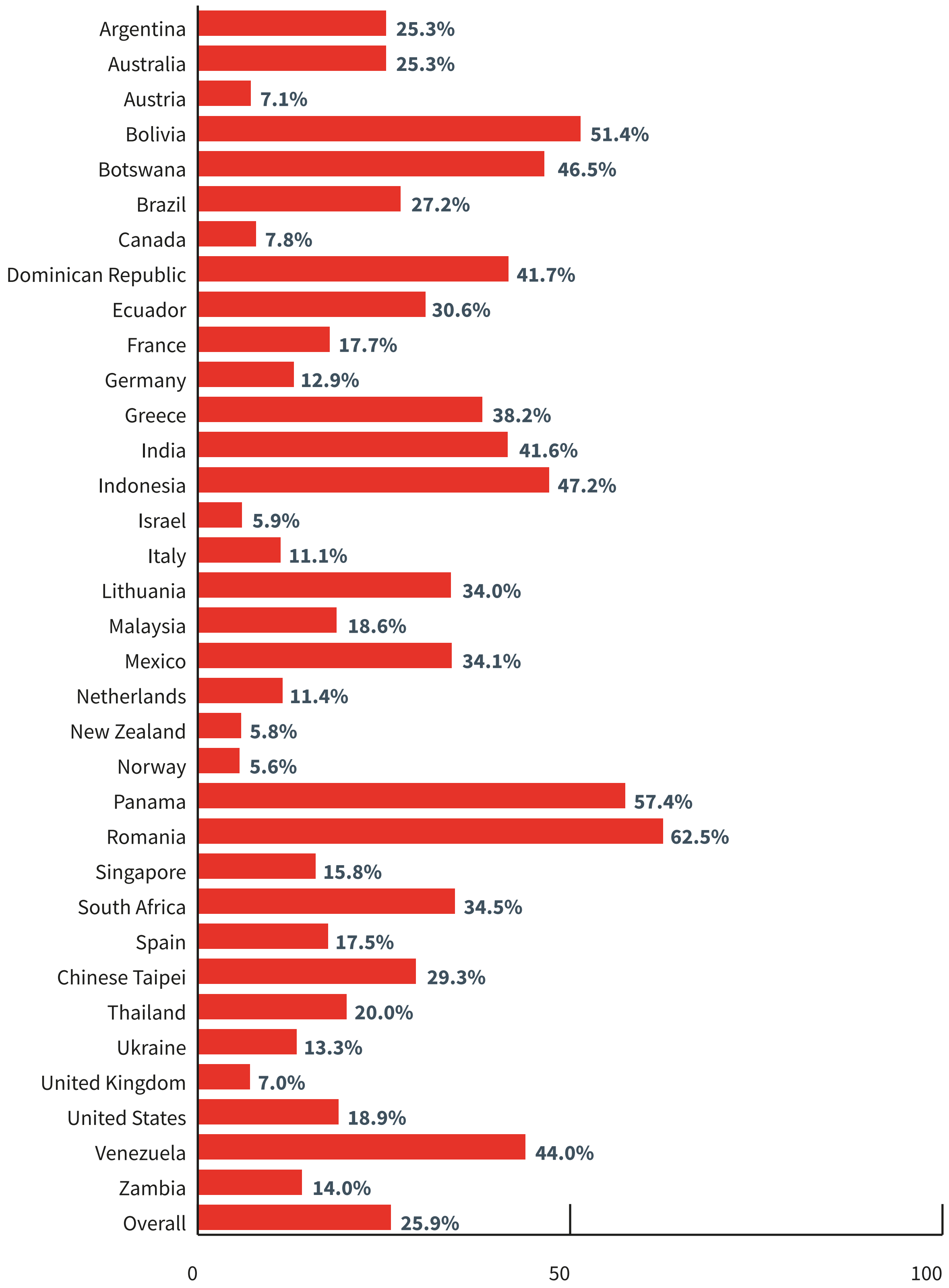
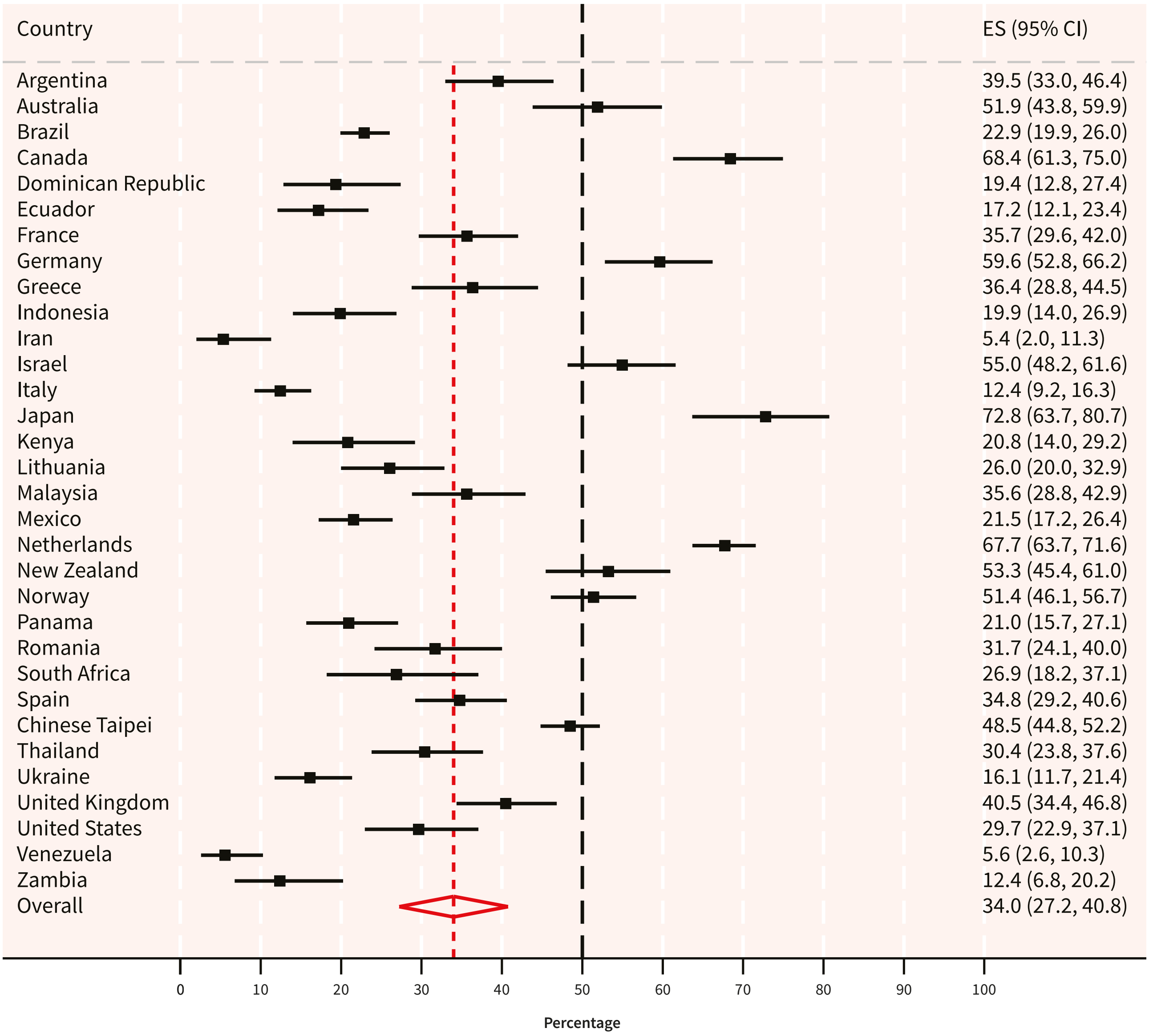


Figure 12. Percentage of carers agreeing with the statement 'There are adequate community services for people living with dementia'



Note: The forest plots summarise the responses for each group. The best estimate of the response is represented by the box and the horizontal line represents the 95% confidence interval. Those groups with a greater number of respondents have a narrower confidence interval and a smaller line. All analyses incorporated survey weights as described in the methodology section.

Figure 13. Percentage of the general public agreeing with the statement 'There are adequate community services for people living with dementia'

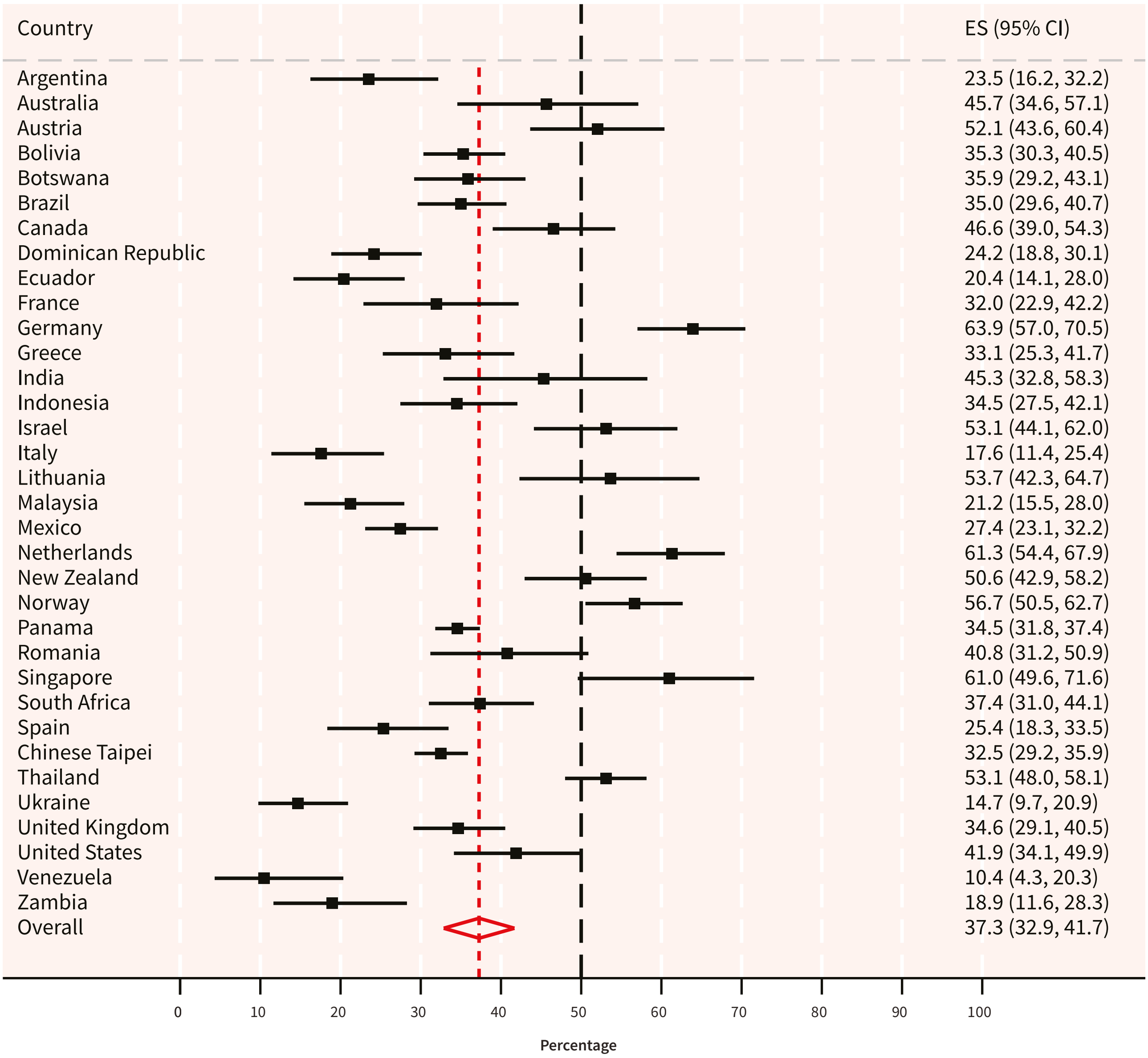


Figure 14. Percentage of health and care professionals agreeing with the statement 'There are adequate community services for people living with dementia'

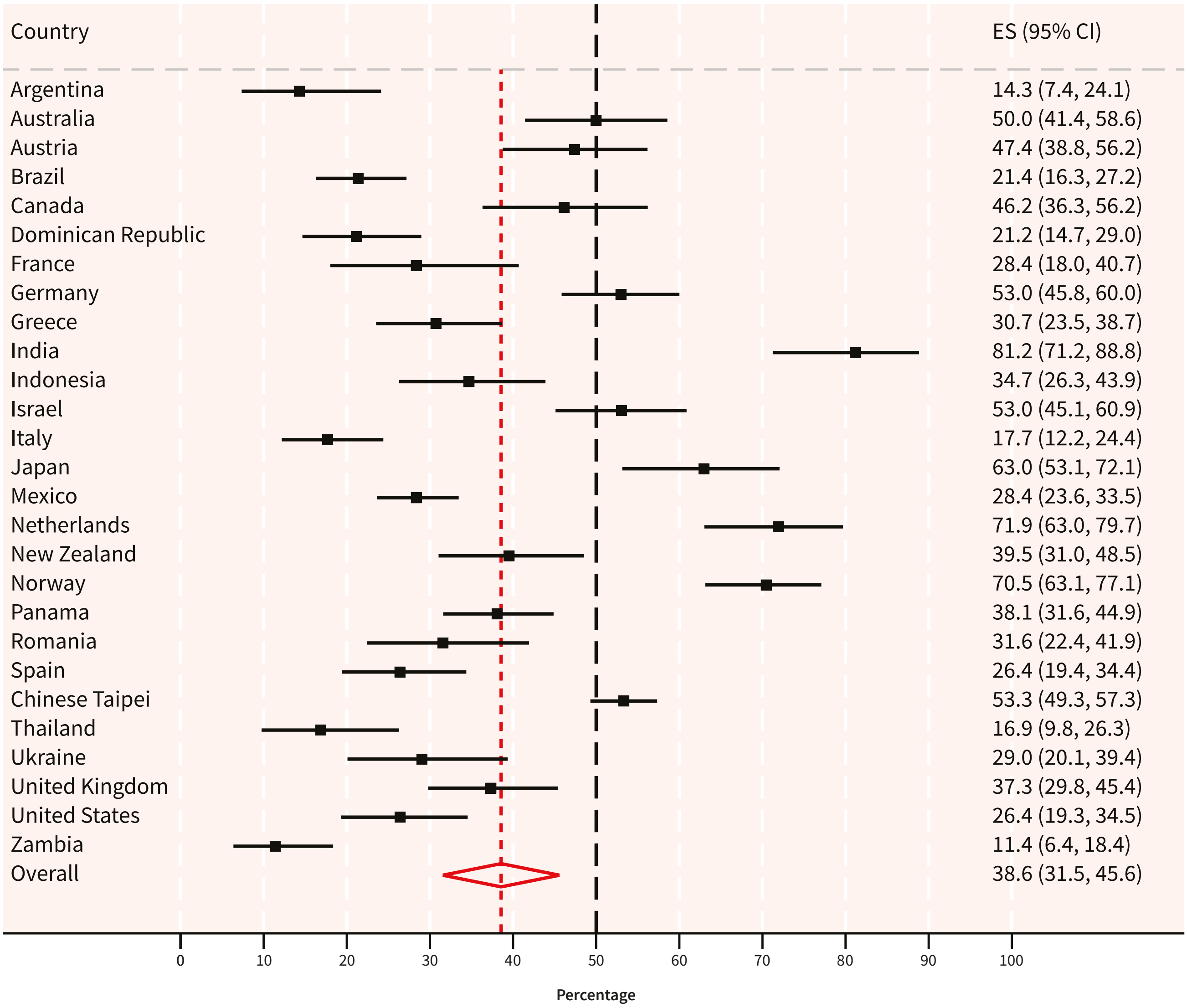


Figure 15. Percentage of the general public agreeing with the statement 'It would be best to move a family member living with dementia to a care home even if they didn't want to go'

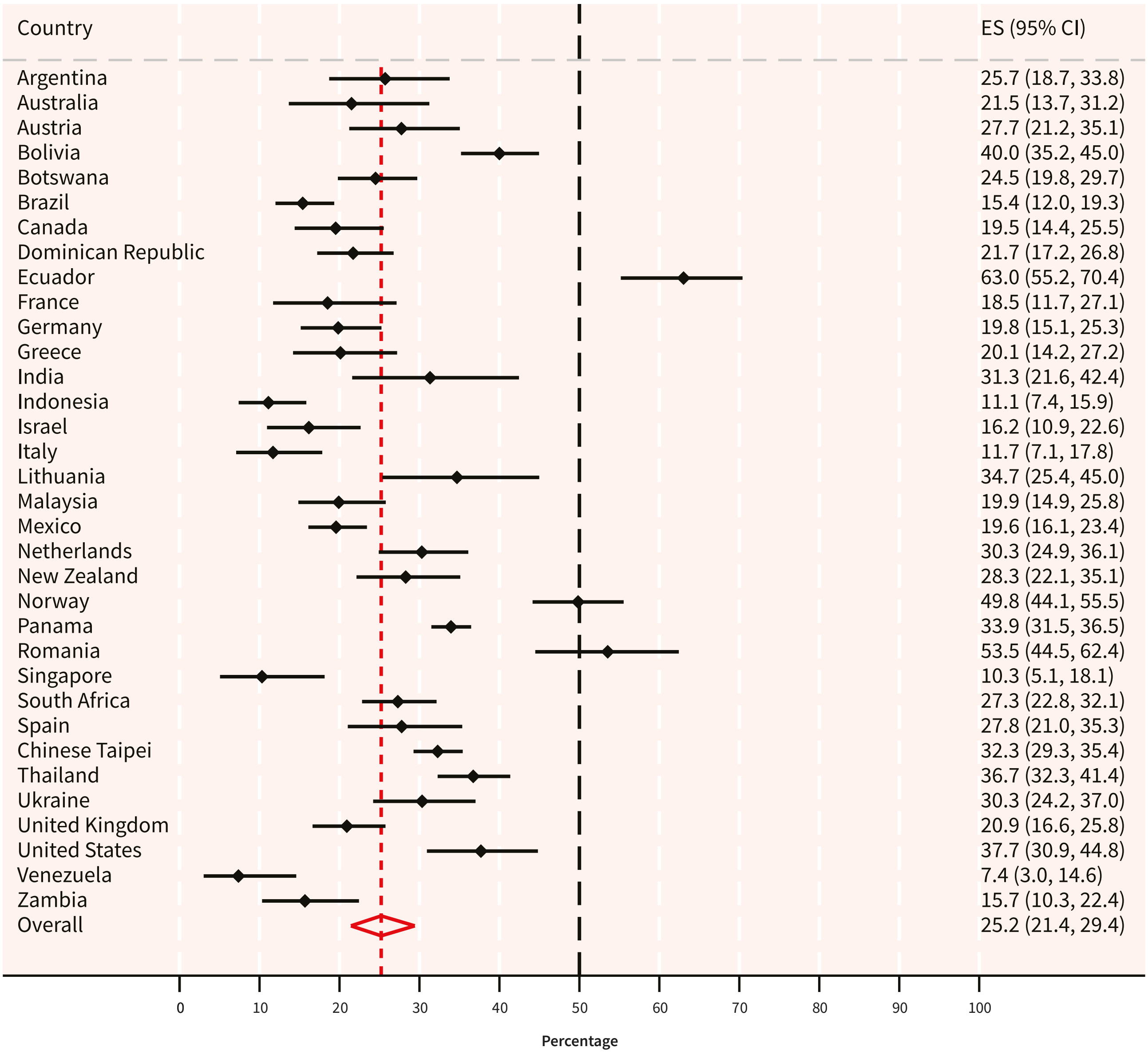


Figure 16. Percentage of carers agreeing with the statement 'Health professionals ignore the person with dementia'

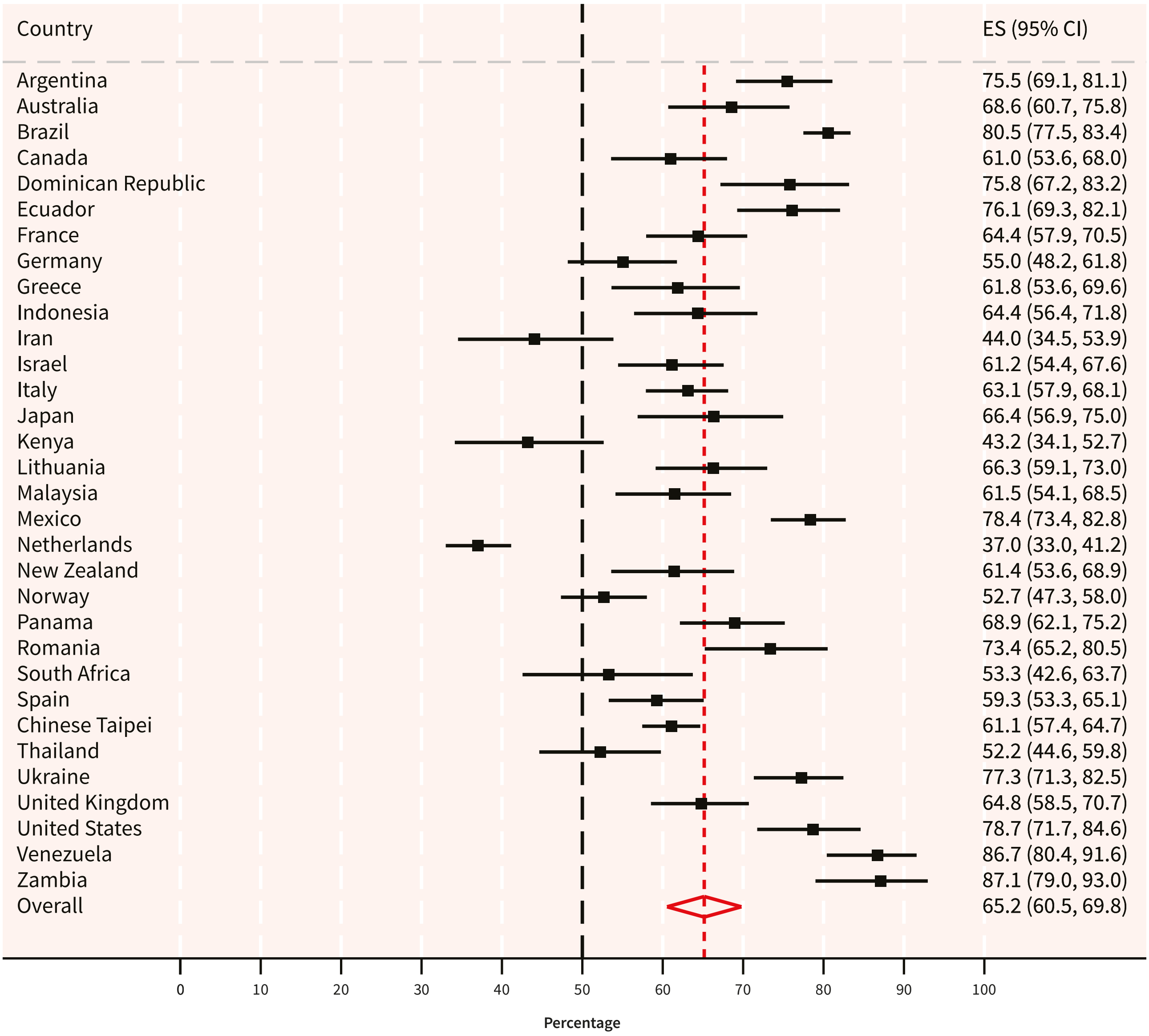


Figure 17. Percentage of the general public agreeing with the statement 'Health professionals ignore the person with dementia'

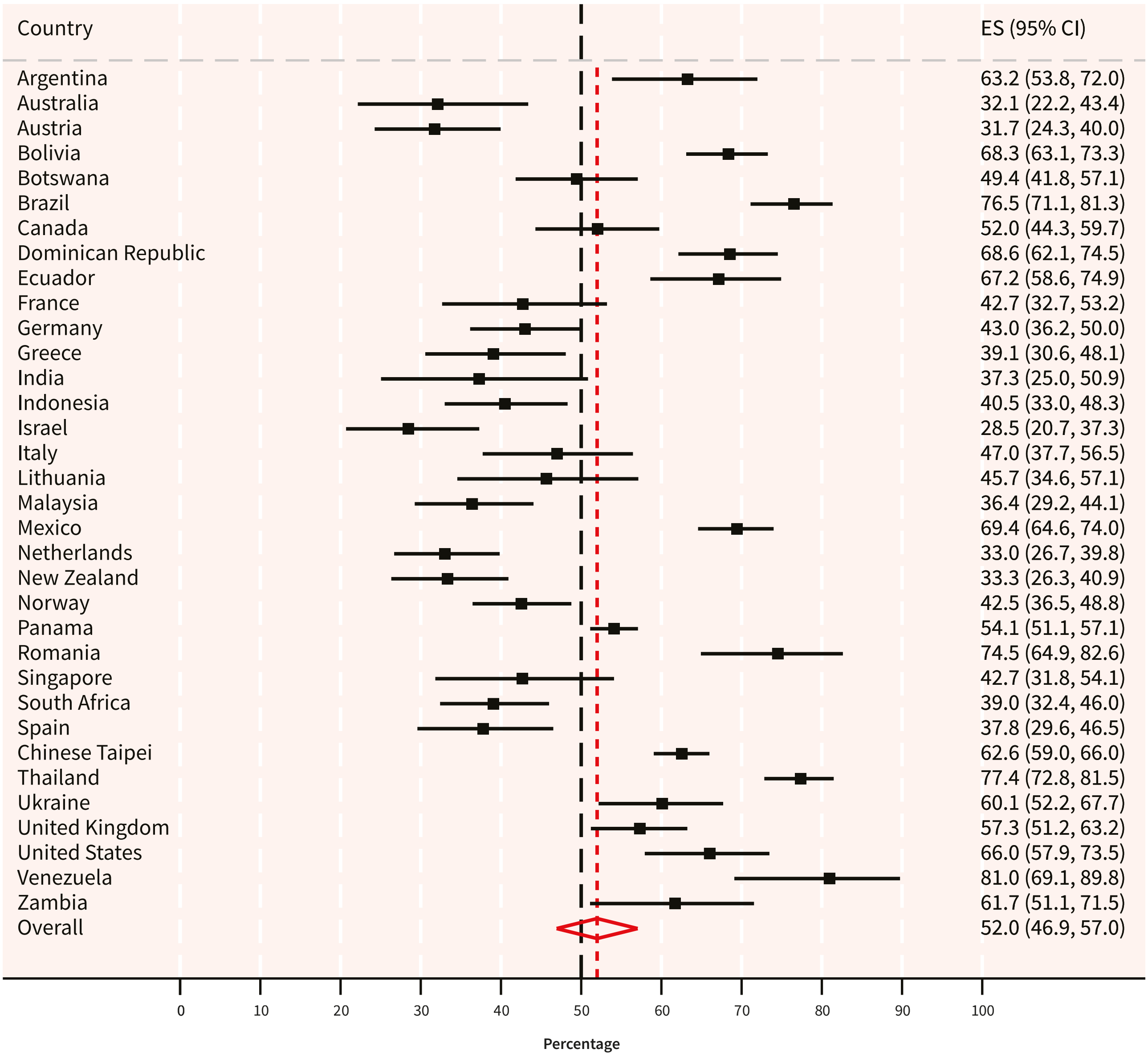


Figure 18. Percentage of health and care professionals agreeing with the statement 'Health professionals ignore the person with dementia'

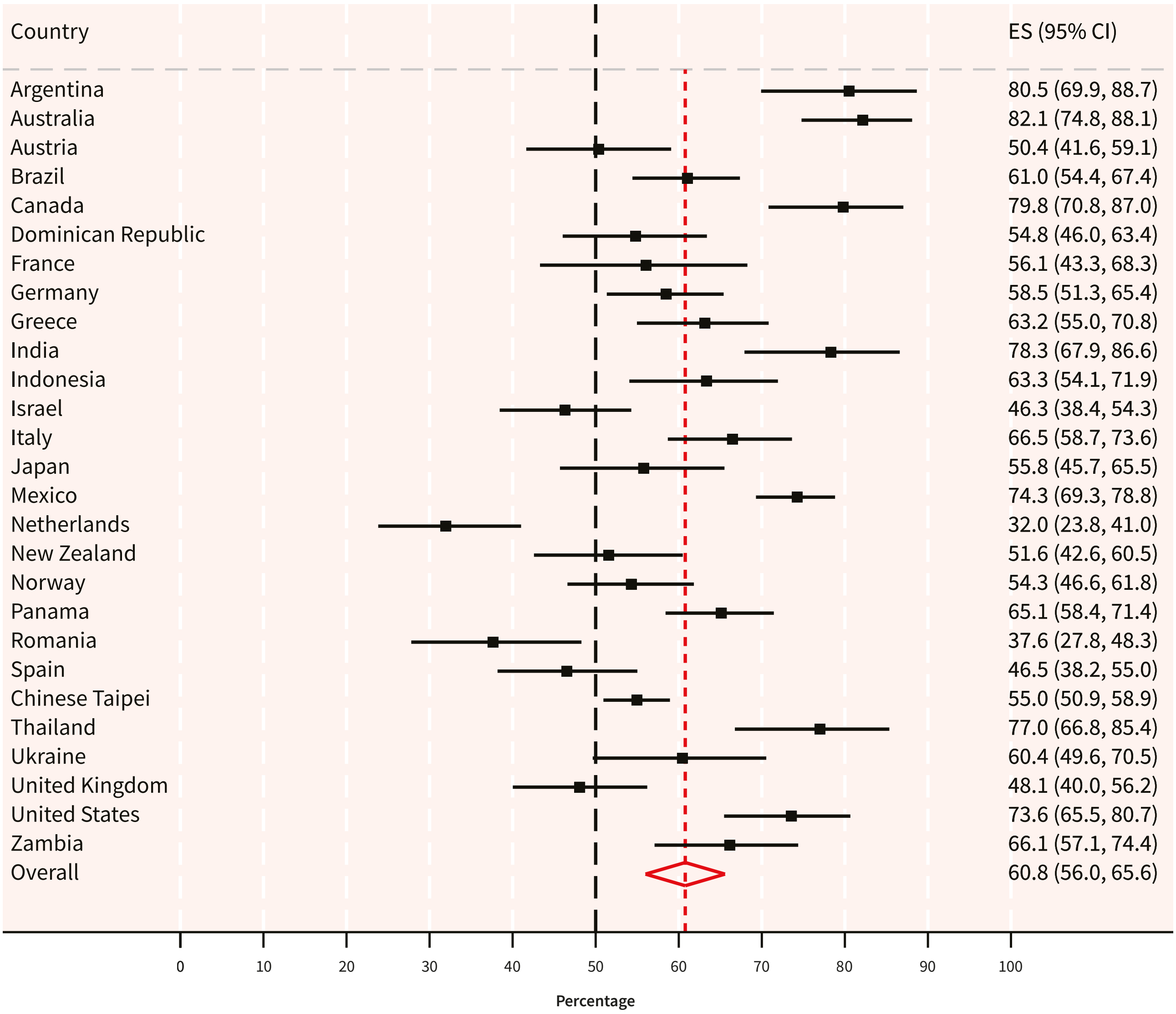


Figure 19. Percentage of the general public agreeing with the statement 'If I had dementia, I would make an effort to keep it a secret when meeting people'

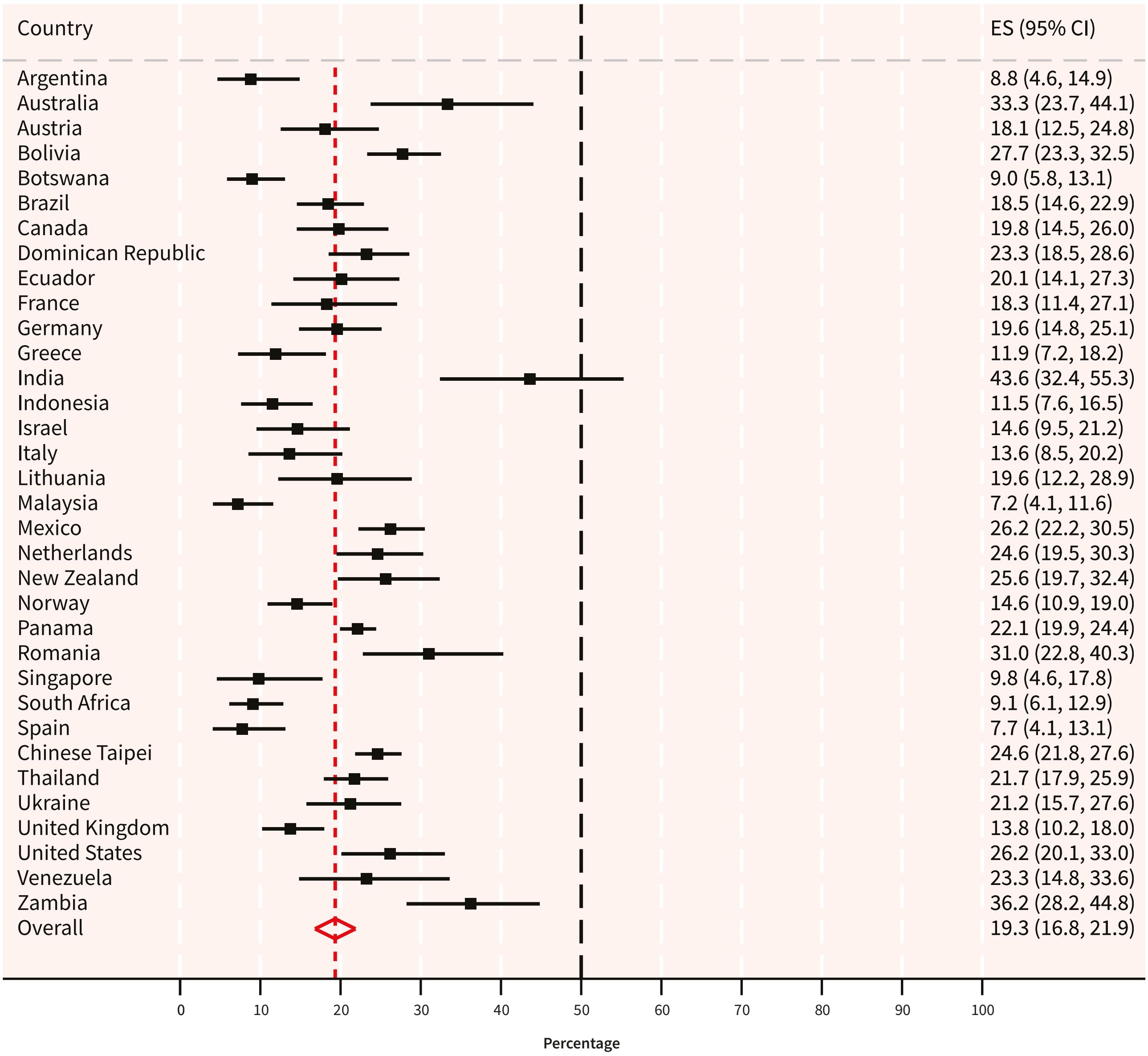


Figure 20. Percentage of health and care professionals agreeing with the statement 'If I had dementia, I would make an effort to keep it a secret when meeting people'

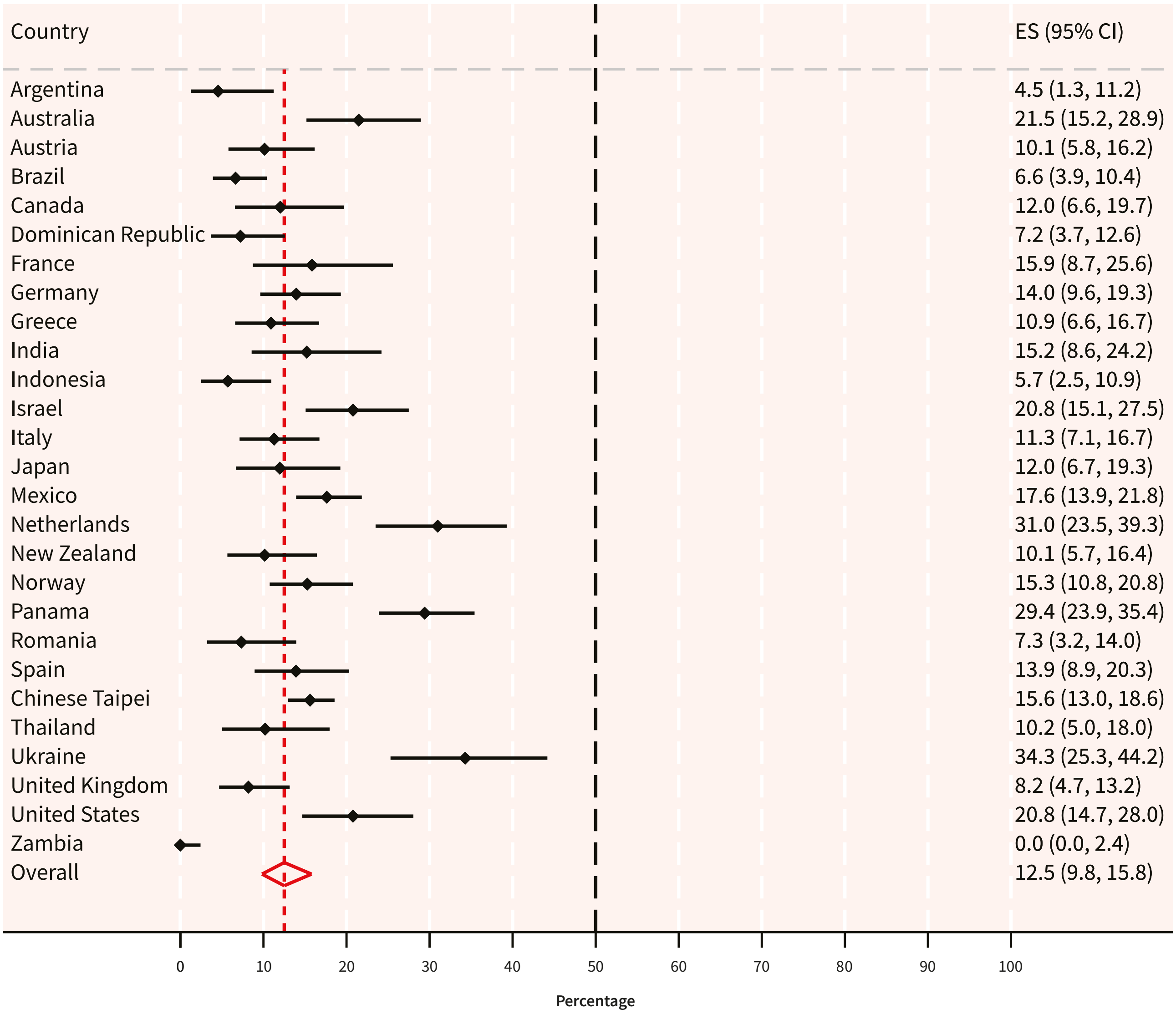
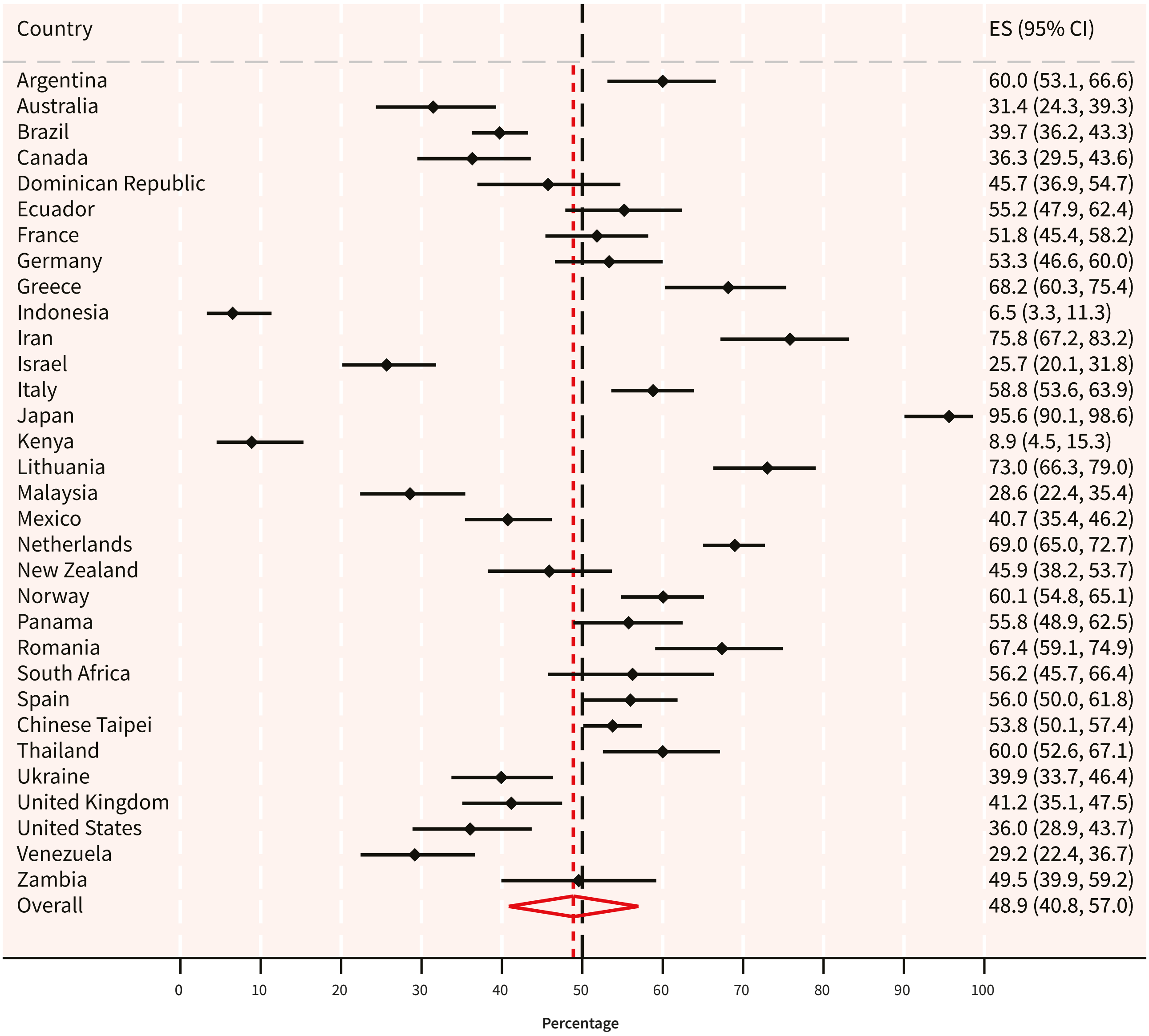


Figure 21. Percentage of carers agreeing with the statement 'It is important to remove family responsibilities from people living with dementia'



Country	ES (95% CI)
Argentina	60.0 (53.1, 66.6)
Australia	31.4 (24.3, 39.3)
Brazil	39.7 (36.2, 43.3)
Canada	36.3 (29.5, 43.6)
Dominican Republic	45.7 (36.9, 54.7)
Ecuador	55.2 (47.9, 62.4)
France	51.8 (45.4, 58.2)
Germany	53.3 (46.6, 60.0)
Greece	68.2 (60.3, 75.4)
Indonesia	6.5 (3.3, 11.3)
Iran	75.8 (67.2, 83.2)
Israel	25.7 (20.1, 31.8)
Italy	58.8 (53.6, 63.9)
Japan	95.6 (90.1, 98.6)
Kenya	8.9 (4.5, 15.3)
Lithuania	73.0 (66.3, 79.0)
Malaysia	28.6 (22.4, 35.4)
Mexico	40.7 (35.4, 46.2)
Netherlands	69.0 (65.0, 72.7)
New Zealand	45.9 (38.2, 53.7)
Norway	60.1 (54.8, 65.1)
Panama	55.8 (48.9, 62.5)
Romania	67.4 (59.1, 74.9)
South Africa	56.2 (45.7, 66.4)
Spain	56.0 (50.0, 61.8)
Chinese Taipei	53.8 (50.1, 57.4)
Thailand	60.0 (52.6, 67.1)
Ukraine	39.9 (33.7, 46.4)
United Kingdom	41.2 (35.1, 47.5)
United States	36.0 (28.9, 43.7)
Venezuela	29.2 (22.4, 36.7)
Zambia	49.5 (39.9, 59.2)
Overall	48.9 (40.8, 57.0)

Figure 22. Percentage of the general public agreeing with the statement 'It is important to remove family responsibilities from people living with dementia'

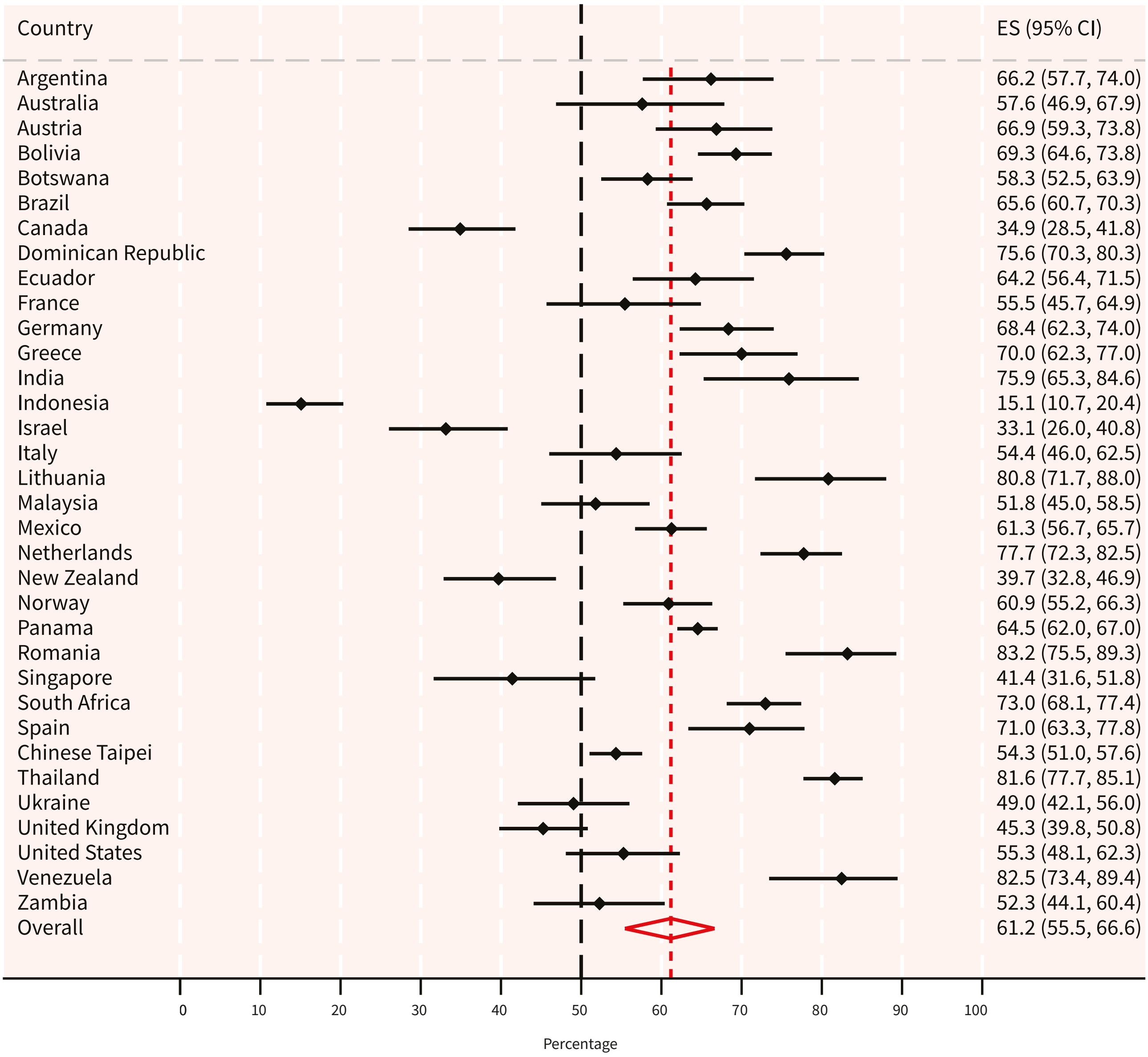


Figure 23. Percentage of the general public agreeing with the statement 'People living with dementia are dangerous'

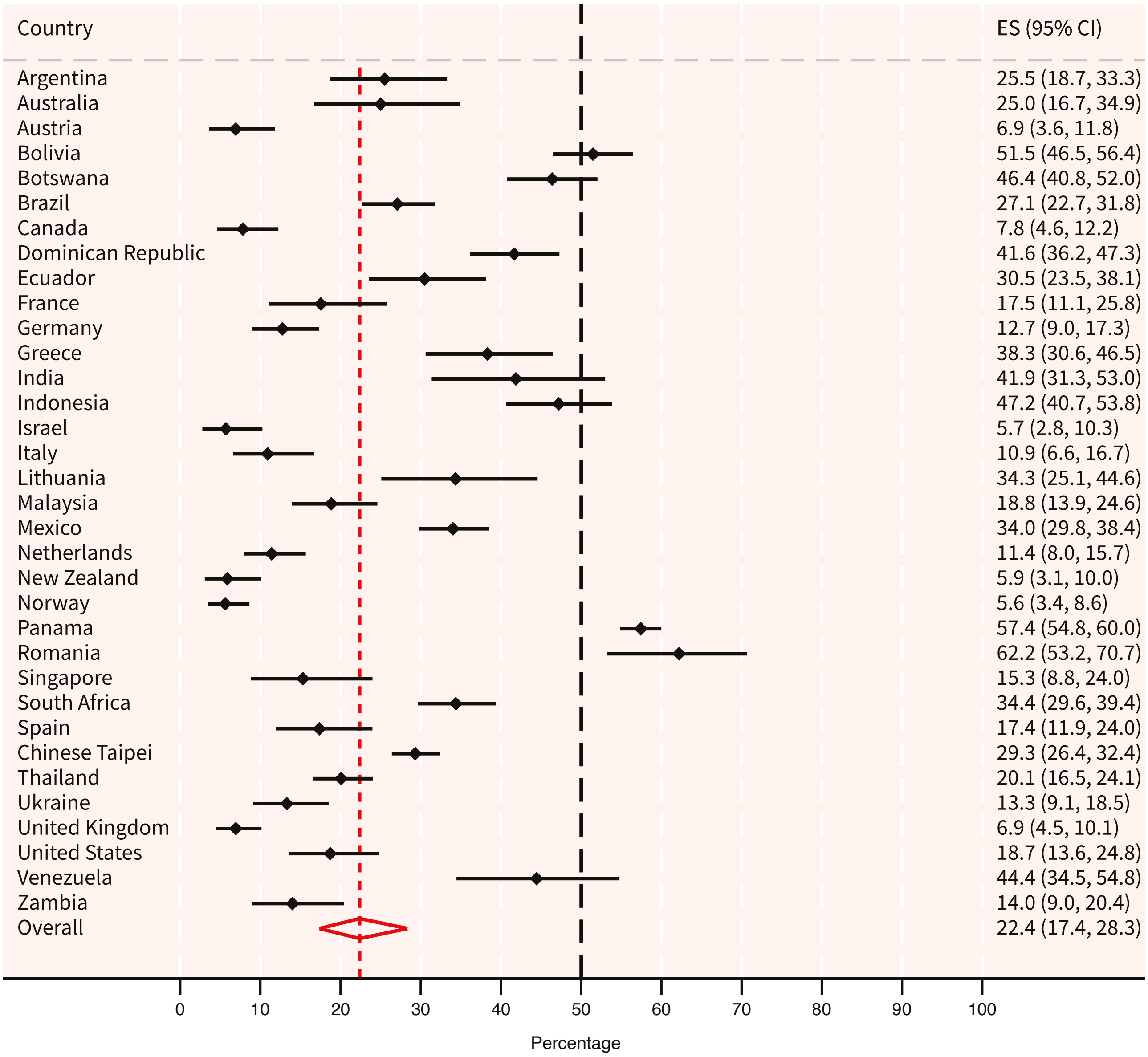


Figure 24. Percentage of health and care professionals agreeing with the statement 'People living with dementia are dangerous'

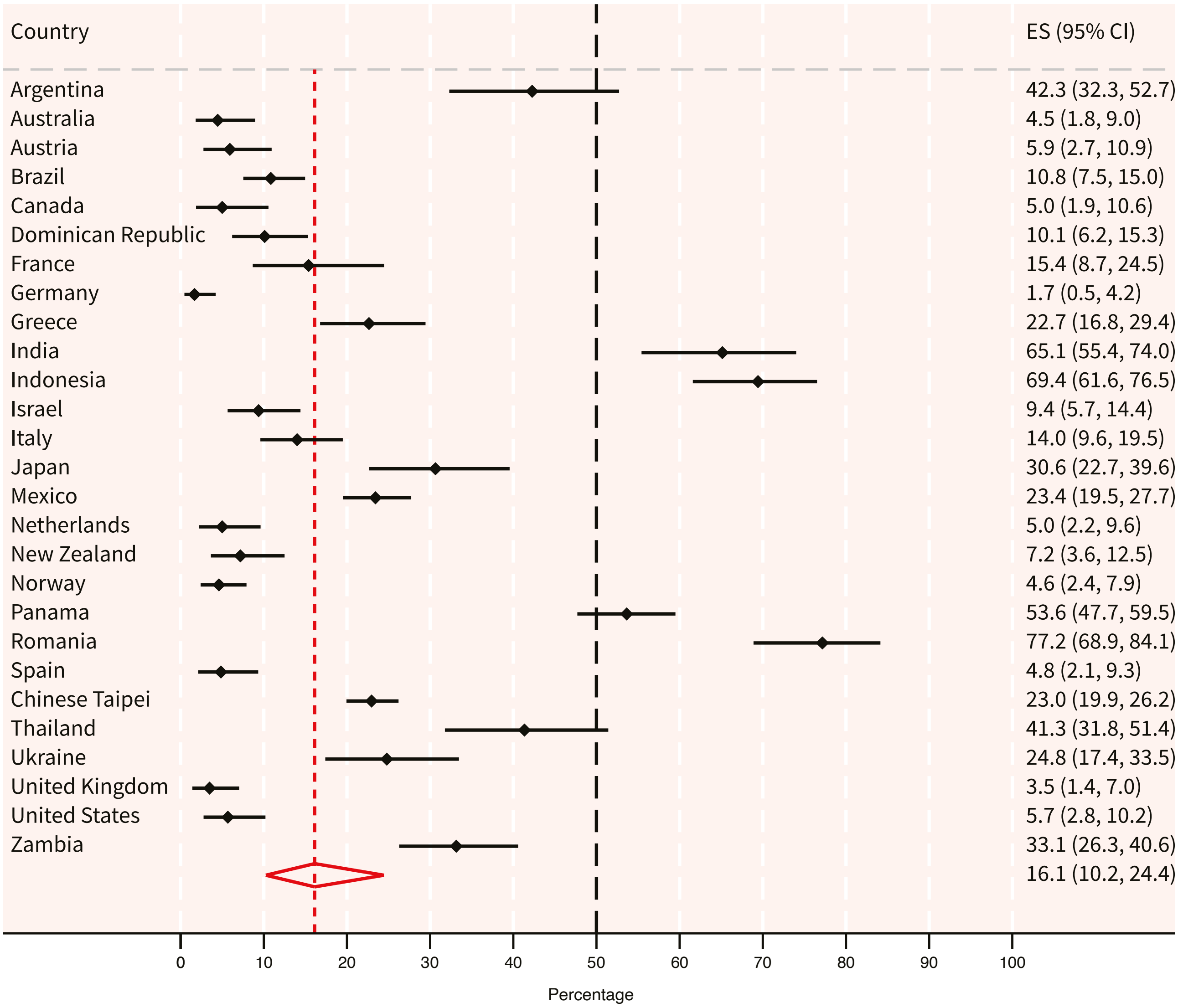


Figure 25. Percentage of the general public agreeing with the statement 'People living with dementia are impulsive and unpredictable'

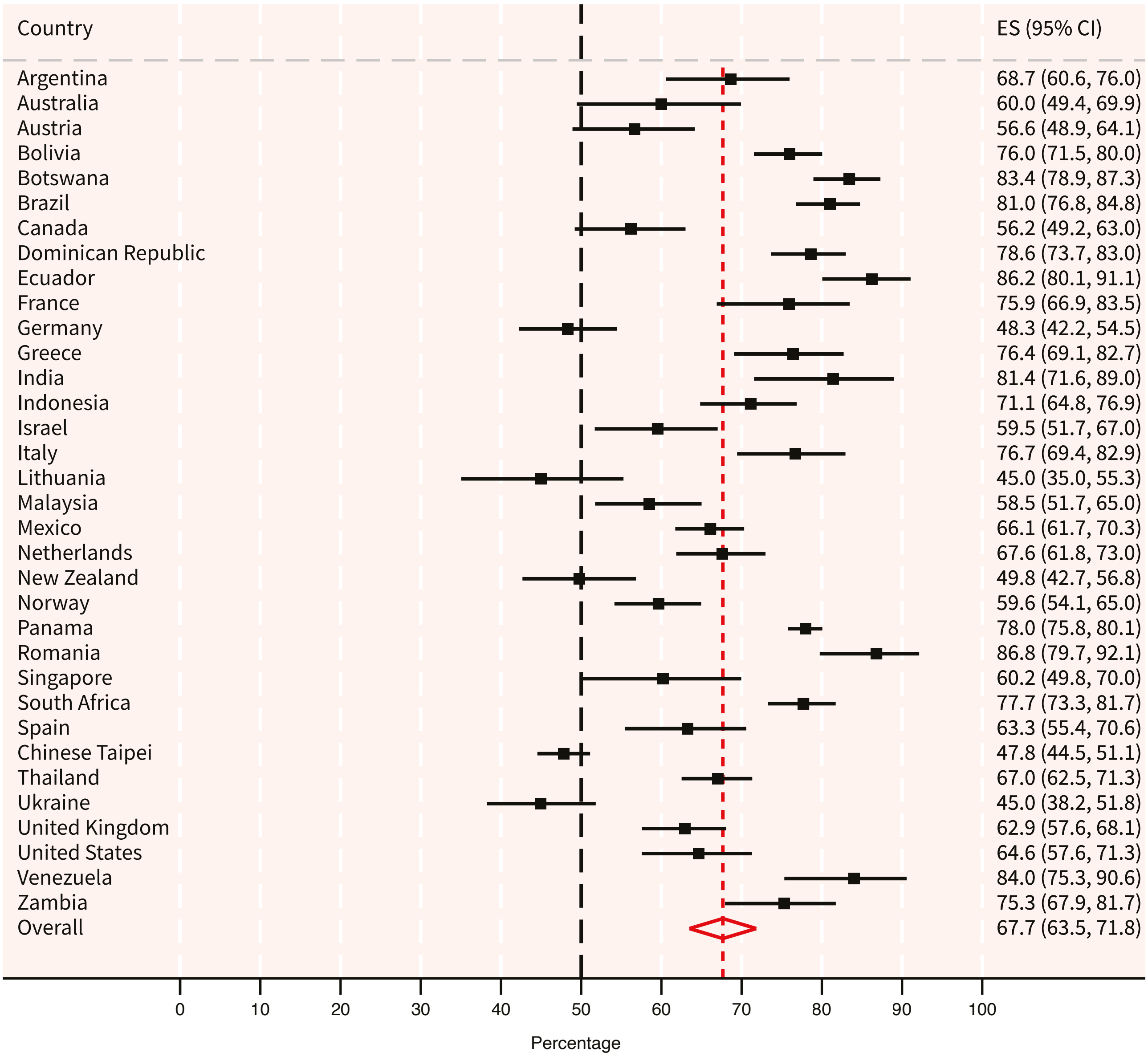
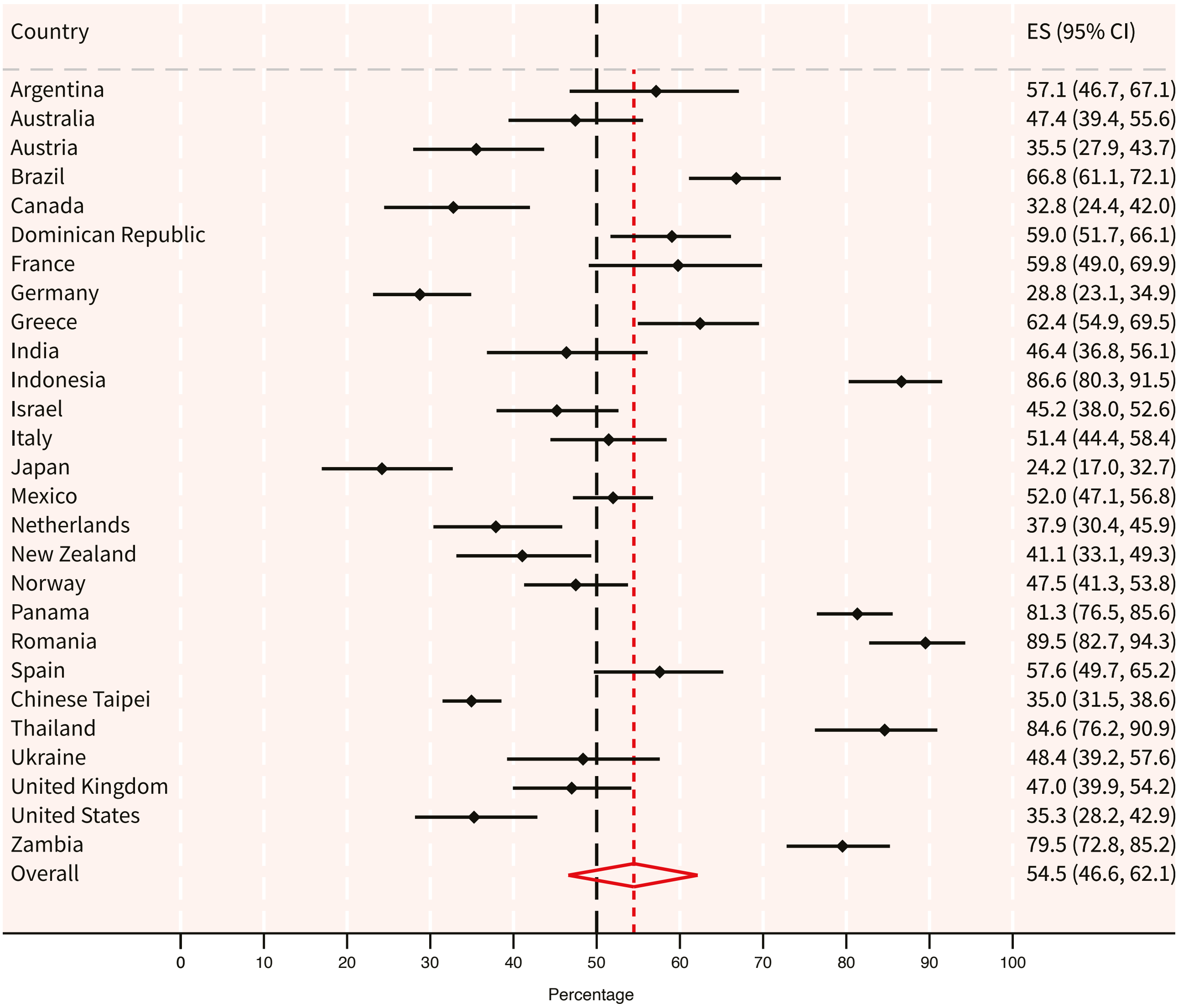


Figure 25. Percentage of health and care professionals agreeing with the statement 'People living with dementia are impulsive and unpredictable'



Country	ES (95% CI)
Argentina	57.1 (46.7, 67.1)
Australia	47.4 (39.4, 55.6)
Austria	35.5 (27.9, 43.7)
Brazil	66.8 (61.1, 72.1)
Canada	32.8 (24.4, 42.0)
Dominican Republic	59.0 (51.7, 66.1)
France	59.8 (49.0, 69.9)
Germany	28.8 (23.1, 34.9)
Greece	62.4 (54.9, 69.5)
India	46.4 (36.8, 56.1)
Indonesia	86.6 (80.3, 91.5)
Israel	45.2 (38.0, 52.6)
Italy	51.4 (44.4, 58.4)
Japan	24.2 (17.0, 32.7)
Mexico	52.0 (47.1, 56.8)
Netherlands	37.9 (30.4, 45.9)
New Zealand	41.1 (33.1, 49.3)
Norway	47.5 (41.3, 53.8)
Panama	81.3 (76.5, 85.6)
Romania	89.5 (82.7, 94.3)
Spain	57.6 (49.7, 65.2)
Chinese Taipei	35.0 (31.5, 38.6)
Thailand	84.6 (76.2, 90.9)
Ukraine	48.4 (39.2, 57.6)
United Kingdom	47.0 (39.9, 54.2)
United States	35.3 (28.2, 42.9)
Zambia	79.5 (72.8, 85.2)
Overall	54.5 (46.6, 62.1)

Appendix 4: Qualitative examples from the survey: people with dementia and carers

Key themes qualitative analysis of people living with dementia responses:

1. Issues with family members and friends

- Being dismissed/talked down/disrespected/discredited in daily life activities
- They do not believe and/or understand dementia
- Being told what they can and cannot do
- Lost contacts
- Being excluded from social gatherings and events
- Not being visited at home anymore
- Opinions and inputs are rejected
- Feeling isolated due to them having stopped receiving invitations
- Financial responsibilities are taken away (willingly but also unwillingly)
- Being undermined due to hurtful jokes
- Talked about versus talked with
- Family members being in charge of their bank accounts/ finances/payments
- Being told that they lie about having dementia
- Having their dementia minimised

2. Issues with other people

- Others are described as being afraid of people living with dementia
- Lack of trust in people living with dementia when speaking in general
- People keep their distance due to being scared or frightened
- People do not know and/or understand dementia well enough
- Others pity people living with dementia and do not treat them as people anymore
- Excluded in conversations

3. Negative experiences with health and care professionals

- Doctors or health and care professionals don't know how to interact with people living with dementia
- Health and care professionals treat people living with dementia badly and can be dismissive if they don't show clear signs of dementia
- Health and care professionals staff might refuse to give a diagnosis and/or can be very difficult to receive one
- Health and care professionals are said to be not prepared
- People living with dementia have been humiliated by health and care professionals

4. Career

- Lost their jobs and stopped career abruptly

5. Self-consciousness

- Self-exclusion from social environments
- People living with dementia are highly affected by self-consciousness and self-awareness
- They use jokes about their own dementia as a coping mechanism
- People living with dementia are afraid of behaving inappropriately in public and being judged by others
- They prefer for their diagnosis not to be disclosed
- Many people living with dementia are self-conscious and fear that others will know about them having dementia

Examples from the survey: quotes from people with dementia's experiences of stigma and discrimination

- The other person didn't know how to deal with me/behave towards me... They didn't talk to me openly and at eye level... it was communicated about me, but not with each other.
- I use my dementia as an excuse, one family member said.
- Some people think that I choose the moment to have or not to have Alzheimer's.
- Family members treat me like I am making it up, like I have not progressed fast enough so I must be faking.
- People gave me a giant calendar and whiteboard for Christmas. I was so humiliated. Today, people want to carry things for me or to do things for me without me asking for help. Some days are better than others.
- My bank accounts were blocked because they believe that I am not allowed due to my dementia.
- I could still drive but they took my license. I would have been prepared to have a formal assessment. They took my career (job) within three weeks of my disclosing. This was despite being told I was doing a fantastic job in my role.
- I was the only family member not invited to a granddaughter's birthday party. It was hurtful to be excluded. I have never exhibited behaviour or conversation that would have warranted that.
- I have excluded myself.
- One comment I will never forget. 'Dementia, oh that explains a lot'!
- 'You don't look like you have got dementia' – profoundly offensive as who would ever claim they had it if they didn't.
- Friends, at first, when they saw me on the street with my partner, would ask him how he was doing instead of asking me, that bothered me a lot.
- Does a doctor telling me that I am too young to have dementia count? I have Lewy Body. I have good days and bad days. On good days, medical staff treat me like I am making it up. On bad days, some doctors don't allow me to be part of the conversation, talking at me rather than with me.
- I was astonished at how little help or support I've been offered by anyone. I've had to push relentlessly for diagnosis every step of the way. The first time I raised my concern that my cognition was impaired, the nurse practitioner I told responded, "Don't worry. People with dementia are too impaired to notice or even ask about their cognition." That was in 2018 after I learned I had one copy of the ApoE4 genetic variant. Every step of the way, I have had to push for diagnosis.
- We have lost some friends since diagnosis because they are uncomfortable around me since I am not the same as I once was.
- I'm not going anywhere so people don't notice, I'm ashamed.
- I feel anxious about meeting girlfriends for lunch at a restaurant. Afraid I'll make a mistake or embarrass myself. Tired of having friends argue that I don't have dementia because they don't see me in challenging situations. They say something like "Oh, I forget where I put things too." They don't acknowledge how it impacts me every day, all day, in contrast to their occasional incident.

Key themes qualitative analysis of carer responses

1. Issues with other people

- Guests ignore/talk down to people with dementia
- Guests ask the caregiver about the person with dementia and do not speak directly to the person with dementia
- Friends and family members stopped visiting them and the person with dementia
- Others do not have a good understanding and/or knowledge of dementia (i.e., they do not know how to behave with a person with dementia)
- People with dementia are sometimes mistreated by guests/others in general
- Some people think that people with dementia are crazy
- Guests and visitors often become uncomfortable in the presence of a person with dementia
- Carers are afraid that others will make fun of the person with dementia or they will make comments or ask inappropriate questions
- People with dementia might be discriminated against by visitors due to their lack of understanding of the situation

2. Feeling embarrassed of the person being cared for

- Carers often express feeling embarrassed and/or ashamed of the person with dementia due to their unpredictable behaviours in front of others
- Carers worry about what others think, fearing judgment and others' preconceptions
- They worry that the person with dementia will do things that they are not supposed to in front of others

3. Self-exclusion

- Carers avoid visits to 'protect' others from seeing the person with dementia and their cognitive decline
- Carers do not invite guests 'to avoid judgement'
- People with dementia are 'hidden' from friends due to carers willingness to avoid others feeling sorry for the person with dementia
- Carers do not want for people with dementia to attend social gatherings with others because of their inappropriate behaviour (i.e., spitting up food)
- Invitations are refused by carers as people with dementia do not comply to table manners and rules
- Carers claim that they want to protect people with dementia from others' pity

4. Self-consciousness

- Caregivers are unwilling to disclose dementia diagnosis to others to avoid becoming uncomfortable and being embarrassed

5. Quality of life

- Carers do not have time nor the energy to pay attention to the person with dementia and guests, hence, they do not invite guests and they do not accept invitations either
- Caring duties prevent carers from attending social activities and social gatherings
- Carers are more concerned about the person with dementia's comfort rather than what others think

Examples from the survey: Quotes from carers on experiences of stigma and discrimination

- We are worried that interactions from outsiders who have little understanding of dementia can be horrible for all parties involved, so plans are often tempered to adjust for this.
- They do not understand what my parent is going through. Most think she has been bewitched or is part of the witches.
- They think she's crazy.
- I feel he gets ignored by certain people as he doesn't join in with group conversations, normal banter. I don't like it. He gets ignored so I don't invite them anymore.
- Others do not always see that my dementia father still wants to 'belong'. They start talking about him in front of him, instead of involving him in the conversation.
- Most people do not know how to relate to a patient with Alzheimer's condition.
- In truth, I don't make her participate because she gets confused on one hand and she often says things that make me feel very uncomfortable and I think others do too.
- People are uncomfortable with dementia, and don't know how to converse and act around a person who has the disease.
- I can only invite people who already know the situation, family and/or close friends.
- I am embarrassed or uncomfortable that my mother is present in social situations.
- We avoid exposing her to the public.
- They are either condescending or making fun of him unintentionally. Some are embarrassed to talk to him and don't know how to reply. Others are not interested and ignore him. Others show their pity.
- To avoid judgement.
- They feel uncomfortable not knowing how to treat someone with dementia.
- There are many people who are so unsure about how to deal with someone suffering from dementia that they simply ignore them.
- Above all, I am ashamed in advance. Few people even in my family put up with my mother's possible behaviour.
- Some people laugh secretly, some don't understand, some don't care.
- There are friends and family who, due to their ignorance of this disease, do not understand the situation. I prefer to avoid it.
- Some people look uncomfortable when they see the person they knew has changed.
- Some people do not understand the condition because he presents well and don't look sick per se.
- It is feared that people with dementia will show inappropriate symptoms, such as eating food messily, farting, burping, or searching things in other people's homes. This may cause you to be shunned and may receive expressions that you don't understand/disrespectful from others, causing the patient to lose confidence, worry, or be sad.
- My biggest concern is that my husband is often overlooked or left out of the conversation because he can't follow the give and take in a group and I think that undermines his confidence so I try to avoid these situations.
- I feel as if I have to apologise for her potential behaviour, then feel really bad about saying it.
- They avoid visiting her because they don't know how to deal with the situation or because they preserve good memories of her, as they don't like seeing her at that level of weakness.
- I know most people feel uncomfortable with the situation.
- Not everyone understands so I tend not to make them feel uncomfortable.
- I know they don't understand and don't include my mother so I prefer to not go sometimes.
- I don't like that they don't talk to her and that they sadly tell me how bad it is.
- In my country, there is little or no knowledge about dementia so they are considered as witches or wizards.
- People who look with pity, don't talk to the person, it seems that the person is invisible.
- I'm not worried about the perception of the public, or other people. The priority is for the patient to feel well. I try to go on short outings, in pleasant places and comfortable environments.
- People stare at and/or avoid us. It is very intimidating and isolating.
- Some people who used to talk to us, no longer do, as if they are fearful, they will catch dementia. They are so uninformed.
- There is misinformation and rudeness from people who don't know the disease. People are invasive and ask questions that expose the caregiver and the patient (Ex: Does she have Alzheimer's? Can she understand what I'm saying?! Does she know me?! Does she know you?!) There are also looks of pity.

Chapter 3:

Expert essays

In this chapter, we have gathered essays that address the issue of attitudes to dementia from overarching perspectives. Instead of focusing on specific local contexts, the authors in this chapter have looked at aspects of dementia attitudes and stigma that play a role no matter where one is in the world.

Looming large over the past five years is the COVID-19 pandemic, which has had a disproportionate impact on how people living with dementia, as Aida Suárez-González and Manuel Rico explain. Bianca Brijnath and Lee-Fay Low look at the role of popular culture in shaping perceptions of dementia, while Annemarie Schumacher Dimech covers the intersection of gender and dementia stigma and its impact on women. Paola Barbarino and Alireza Atri discuss how dementia science, policy, and awareness influence one another; Cristiano S. Aguzzoli, Emmanuel Epenge, Beniam Daniel Darge, Charles Windon, and Bruce L. Miller look at how rarer forms of dementia can be overshadowed by Alzheimer's disease; and Gill Livingston reflects on how greater understanding of risk reduction in recent years has affected dementia awareness. Finally, James Rupert Fletcher challenges the reader to rethink prevailing conceptions of and approaches to dementia awareness. This year's survey certainly highlights the need to address the multifaceted challenge of fostering truly dementia-inclusive societies in fresh ways.

A young woman reads in Islamabad, Pakistan in 2023 (Saiyna Bashir)

The impact of COVID-19 on people with dementia: discriminated, neglected, isolated

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In this article, we examine the unfair treatment faced by people with dementia during the COVID-19 pandemic, highlighting issues concerning excess deaths, restricted access to healthcare, and isolation measures.

Excess deaths

In August 2020, six months after the World Health Organization (WHO) declared the COVID-19 pandemic, the first international report on the impact of COVID-19 on people with dementia was published, revealing stark facts and figures[1]. This report showed that deaths of people with dementia ranged from 29% (e.g., Ireland) to 75% (e.g., Spain) of all deaths in care homes internationally.[1] This high death toll is linked to the fact that most COVID-19 deaths happened in care homes, where a large proportion of residents have dementia. Significant barriers in accessing accurate statistics and data about people with dementia living in long-term care (LTC) were identified in this study and in many others.[2,3] Most countries lacked basic up-to-date data about care homes resident in general (e.g., the number of people living in LTC facilities) and those with dementia in particular (e.g. how many residents have dementia, what their health and disability status are). People with dementia were invisible in national datasets. Where data did exist, it was fragmented, inconsistently collected across regions, and impossible to merge, compare, and use. We know that tens of thousands of people with dementia lost their lives in LTC facilities during the first months of 2020 across Europe and North America (where most data come from), but the precise figures will never be known. The absence of timely and reliable statistical data during the pandemic emerged as a tangible sign of the low priority given to people with dementia in national political agendas worldwide.

How did these deaths happen?

Discriminatory policies and practices against people with dementia during the pandemic have been documented extensively in reports by humanitarian organisations such as Doctors without Borders,[4] Human Rights Watch,[5] and Amnesty International.[6] Below, we describe four policies or practices that constituted human rights breaches with deadly consequences.

Discharge policies

Several governments across Europe and North America allowed the discharge of untested patients from hospitals to care homes to free up hospital beds (e.g. UK, Italy, and USA).[7,8,9] This policy exposed the very vulnerable population in care homes to high risk of COVID-19 outbreaks, which eventually led to high rates of mortality among residents, many of them with dementia.[10] It is estimated that each admission of a COVID-19 positive case was associated with approximately six additional infections and 1.5 additional deaths among residents in the 15 weeks after the admission.[10] Amnesty International has called for official enquiries into COVID deaths in care homes in some of these countries.[11]

Do not resuscitate orders and deny transfer to hospital

In the UK, the Care Quality Commission (the regulatory body ensuring safety and quality of health and social care services in England) found illegal use of "blanket do not resuscitate (DNR) orders" being issued by local authorities and imposed on care homes residents without their consent or the consent of their families during the pandemic.[12] Due to the existence of DNR orders, ambulances or doctors were not being called when needed. Beyond blanket use of DNR orders in the UK, blockage of hospital transfers has been documented in many other countries, such as Italy, Belgium, Spain, and Canada. This practice impeded many people with dementia from accessing hospital care, even when they met criteria to benefit from it and when hospital beds were available.

Failure to medicalise care homes

Care homes were often unsupported and left to face outbreaks on their own in regions with high rates of infections, leading to well-documented cases of neglect in different countries. Examples of care homes where people with dementia and other frail, very sick residents died from severe dehydration, malnourishment, and neglect were reported in countries like the USA,[13] Australia,[14] and Canada.[15]

Isolation and ban on visits in care homes

In addition to the practices described above, sustained bans on visits have been in force in care homes from the beginning of the pandemic and lasted for many months. Isolation is extremely damaging for people with dementia[16]; it worsens all dementia-related symptoms, induces depression, leads to cognitive decline, and causes physical deterioration. It is somewhat incomprehensible that, after lockdowns, care home staff were allowed to enter the care homes daily for work, but families were not. It is also difficult to understand why, when the rest of society was no longer confined, different rules applied to this population segment, which paradoxically was the most vulnerable to the pernicious effects of isolation. Suárez-González and Storr[17] denounced these measures and called for the production dementia-specific infection prevention and control protocols that guarantee the human rights of people with dementia and their families.

Why it was so easy to discriminate against this vulnerable part of society?

According to the WHO, living in an institution is a risk factor for experiencing abuse. Discriminating against vulnerable people is easier because they are less capable of protecting themselves from injustice and abuse. A combination of well-accepted ageism and the normalisation of negative attitudes towards people with dementia (e.g., the belief that their lives have less value than others) permeates public policies. This makes it very easy to disregard the rights of people with dementia and for injustices to occur without any legal consequences. Impunity is a critical cog in the wheel that perpetuates discrimination against people with dementia. To illustrate this point, we will analyse the case of Spain, which is very well-documented thanks to extensive and rigorous journalistic research.

Spain and the "Protocols of Shame"

Around 60–76% of care home residents in Spain have dementia.[18] Four Spanish regions – Madrid, Catalonia, Castile and Leon, and Castile-La Mancha – contributed to 78% of the 18,102 total national deaths in care homes with confirmed or suspected COVID between March and April 2020.[19] Under normal circumstances, less than 20% of care home residents die in the care home where they live. Between March-April 2020, this figure rose to 70–77% in these regions, greatly influenced by unlawful age and disability-based protocols that prevented transfers of care home residents to hospitals.[19] In the region of Madrid, these protocols are now popularly known as "Protocols of Shame." As a result, 7,291 care home residents, many of them with dementia, died in Madrid without having received medical care. The regional government of Madrid in particular, could have taken several measures to protect people in care homes (but failed to do so):

- Facilitate referrals to public hospitals, including the field hospital purposely built for COVID-19 (but the "Protocols of Shame" impeded the transfers).
- Refer to private hospitals, which were at the time under the control of the regional government and had free beds. However, only care home residents with private insurance were eventually transferred to private hospitals, introducing a second discriminatory factor based on economic status.
- Medicalise care homes to provide hospital-like care. Madrid's government did not send sick residents to the hospital, nor did it bring the hospital to the care homes, despite having 1,400 health professionals at its disposal who had been freed up after the closure of multiple primary care centres due to the confinement that went into effect on March 14, 2020.

Despite these sobering facts, the three investigations opened in the parliaments of Madrid, Catalonia, and Castile and Leon were closed before completion. Moreover, even though hundreds of criminal complaints were filed to the Prosecutor Office, around 90% were closed without investigation. It is extremely disturbing to see a public investigation concerning possible homicide through a neglect of duty not to be treated with due diligence by the judicial system[20] – so much so that Amnesty International produced a report denouncing the poor performance of the Spanish Prosecutor's Office and the General Council of the Judiciary.[21]

In response to the lack of action by Spanish authorities, relatives of the victims formed in Madrid a Citizens' Commission for Truth, inspired by the Russell Tribunal, to investigate the "Protocols of Shame." The report published by this Commission in March 2024 concluded that 4,000 residents could have been saved if they had received hospital care.[22] To be precise, analysing official regional data, the Citizens' Commission found that 65% of care home residents that were transferred to hospital survived, and the remaining 35% died with dignity while receiving adequate palliative care to alleviate their suffering. When asked in a parliamentarian session, the president of the Madrid government responded that these people were going to die anyway. Not only is this not true, as the Commission's inquiry revealed, but in the cases where death was inevitable, palliative care would have made a significant difference in how these people died. A care worker from a care home in Madrid that was refused transfer to hospital and lost nearly 40% of its residents declared before the Commission: "They (the sick residents with COVID) died clinging to the bars of their beds, trying to breathe."[23]

What measures helped in the past and what changes we would like to see in the future

The most important and effective measure adopted in most countries during the COVID-19 pandemic was giving people with dementia priority for vaccination as soon as vaccines became available. This contributed to reducing both the number and severity of infections. It also contributed to slowly containing the pandemic and allowed care homes to reopen to visitors. However, this is the only instance where people with dementia were prioritised.

Investigations into the deaths and discriminatory policies against people with dementia during COVID-19 are being conducted in many countries, and this is important. It is unclear, however, whether those investigations are being carried out with appropriate quality and independence standards. Moreover, will governments ever be held accountable and sentenced for their unlawful practices affecting people with dementia, their rights, and their lives? Will those sentences set a precedent for real change? Human rights acts and laws are of little value if governments can break them without consequences. The LTC system should be elevated from the bottom to the top of the political agenda across countries, and this should be evidenced with real change, not promises. Since 2020, we have heard many good intentions, but no change in the lives of people with dementia living in LTC or their private homes. Ageism should be fought and eradicated and taken as seriously as racism and sexism. Discrimination based on age is unlawful, but there seems to be little societal and political awareness about this. Minimum national datasets on dementia, transparency, research and ensuring that investigations about the impact of COVID-19 on people with dementia continue are moral imperatives long ignored.

The COVID-19 pandemic taught us that real change requires a strong civil society that actively holds governments accountable. In response to governments' failure to protect the rights of people with dementia, we have seen the rise of civil society. In many countries, relatives of people with dementia who faced discrimination and died in care homes are joining forces with NGOs, lawyers, journalists, and other social agents to seek justice and advocate for change. Alzheimer's Disease International has led this advocacy worldwide by defending the rights of people with dementia at the World Health Assembly in 2022, campaigning relentlessly, and producing many resources to educate the public.[24]

We dedicate this piece to those who passed away in care homes during COVID-19, to those who lost loved ones, those who provided care and assistance, and to those who are tirelessly working to ensure that the tragic events described in this essay are neither forgotten nor repeated.

References

1. Suárez-González A, Livingston G, Low LF, Cahill S, Hennelly N, Dawson WD, Weidner W, Bocchetta M, Ferri CP, Matias-Guiu JA, Alladi S, Musyimi CW, Comas-Herrera A. (2020) *Impact and mortality of COVID-19 on people living with dementia: cross-country report*. LTCcovid.org, International Long-Term Care Policy Network, CPEC- LSE, 19 August 2020
2. Burton JK, Goodman C, Guthrie B, Gordon AL, Hanratty B, Quinn TJ. Closing the UK care home data gap – methodological challenges and solutions. Int J Popul Data Sci. 2021 May 12;5(4):1391. doi: 10.23889/ijpds.v5i4.1391.
3. Comas-Herrera A, Zalakaín J, Lemmon E, Henderson D, Litwin C, Hsu AT, Schmidt AE, Arling G, Kruse F and Fernández J-L (2020) Mortality associated with COVID-19 in care homes: international evidence. Article in LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 1st February 2021
4. Médicos sin Fronteras. Too little too late: the unacceptable neglect of the elderly in care homes during the Covid-19 epidemic in Spain. https://www.msf.es/sites/default/files/documents/msf-full-report-about-the-situation-in-nursing-homes-eng.pdf. August 2020.
5. Human Rights Watch. Covid-19 exposed need to protect older people's rights. https://www.hrw.org/news/2021/03/04/covid-19-exposed-need-protect-older-peoples-rights. March 2021.
6. Amnesty International. United Kingdom: as if expendable : The UK government's failure to protect older people in care homes during the Covid-19 pandemic. https://www.amnesty.org/en/documents/eur45/3152/2020/en/. October 2020.
7. Gardner, C. The Guardian. Covid care homes discharge policy was unlawful, says court. https://www.theguardian.com/world/2022/apr/27/covid-discharging-untested-patients-into-care-homes-was-unlawful-says-court. April 2022.
8. Amnesty International. Italy: violation of the human rights of older residents of care homes during the Covid-19 pandemic. https://www.amnesty.org/en/latest/news/2020/12/italyviolations-of-the-h-uman-rights-of-older-residents-of-care-homes-during-covid-19-pandemic/. December 2020.
9. Barker K and Harris AJ. The New York Times. Playing Russian roulette: nursing homes told to take the infected. https://www.nytimes.com/2020/04/24/us/nursing-homes-coronavirus.html. March 2021.
10. Goodwin JS, Xu H. COVID-19 in Nursing Homes—Learning the Hard Way. *JAMA Intern Med.* Published online June 03, 2024. doi:10.1001/jamainternmed.2024.1087.
11. BBC. Covid: care homes policies violated human rights, says Amnesty. https://www.bbc.co.uk/news/uk-54408723. October 2020.
12. Taylor D. The Guardian. Blanket 'do not resuscitate' orders imposed on English care homes, finds CQC. https://www.theguardian.com/society/2021/mar/18/blanket-do-not-resuscitate-orders-imposed-on-english-care-homes-finds-cqc . March 2021.
13. Human Rights Watch. US: concerns of neglect in nursing homes. https://www.hrw.org/news/2021/03/25/us-concerns-neglect-nursing-homes. March 2021.
14. UN Human Rights Office. A human rights analysis of the impacts of Covid-19 on persons in Australian residential aged care facilities. https://www.ohchr.org/sites/default/files/Documents/HRBodies/SP/COVID/Academics/Castan_Centre_and_Prof_Joe.pdf. February 2021.
15. Cecco, L. The Guardian. Canada: neglected residents and rotten food found at care homes hit by Covid-19. https://www.theguardian.com/world/2020/may/26/canada-care-homes-military-report-coronavirus. May 2020.
16. Suárez-González A, Rajagopalan J, Livingston G, Alladi S. The effect of COVID-19 isolation measures on the cognition and mental health of people living with dementia: A rapid systematic review of one year of quantitative evidence. EClinicalMedicine. 2021 Jul 31;39:101047.
17. Suárez-González A, and Jules Storr. Enforced restrictions to care homes access – unfair, unnecessary and harmful. https://blogs.bmj.com/bmj/2021/07/15/enforced-restrictions-to-care-home-access-unfair-unnecessary-and-harmful/. July 2021.
18. Suarez-Gonzalez A, Jordi A Matias-Guiu and Comas-Herrera A (2020) Impact and mortality of the first wave of COVID-19 on people living with dementia in Spain. LTCcovid, International Long-Term Care Policy Network, CPEC-LSE, 9 August 2020.
19. Rico, Manuel. *¡Vergüenza! El escándalo de las residencias*. Planeta, 2021.
20. Carreño and Allen. Spain opens 200 criminal probes into care home pandemic failings. https://www.reuters.com/article/idUSKBN29Q28U/ . January 2021.
21. Amnesty International. Residencias: la deficiente investigación sobre lo sucedido extiende impunidad y obstaculiza el acceso a la verdad a las familias. https://www.es.amnesty.org/en-que-estamos/noticias/noticia/articulo/residencias-la-deficiente-investigacion-sobre-lo-sucedido-extiende-la-impunidad-y-obstaculiza-el-acceso-a-la-verdad-a-las-familias/. January 2022.
22. Informe de la comisión ciudadana por la verdad en las residencias de Madrid. https://comisionverdadresidenciasmadrid.wordpress.com/wp-content/uploads/2024/04/summary_en_02042024.pdf. March 2024.
23. Kassam A. Over 4,000 Covid victims at Madrid care homes 'could have been saved'. https://www.theguardian.com/world/2024/mar/28/over-4000-covid-victims-madrid-care-homes-could-have-been-saved. March 2024.
24. https://www.alzint.org/news-events/news/covid-19-deaths-disproportionately-affecting-people-with-dementia/

Challenging dementia stigma in popular culture: why we need media guidelines

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Where and when did you first become aware of the idea of 'dementia?' What feelings did 'dementia' invoke in you?

Unless we have a family member or close friend affected by dementia, our understanding of dementia is derived from popular culture including mass media – i.e., news, books, movies and social media.[1] In our survey of Australians aged 45 and older, most people heard about dementia from family and friends, TV/radio and the internet (see Figure 1).

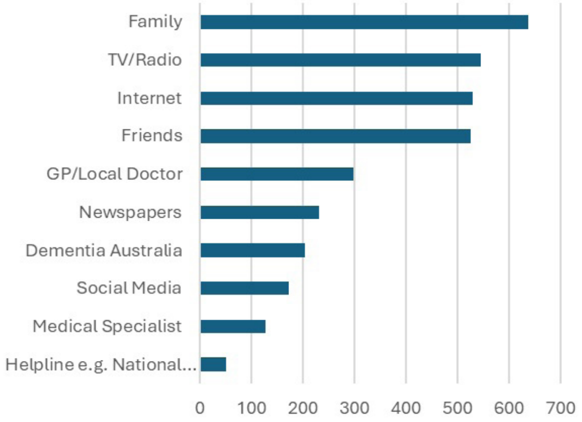
Many representations of dementia in popular culture reinforce stereotypes around ageing and care. Terms used in different languages to describe dementia are often pejorative, and loosely translate as "memory loss," "tired brains," "senility," and "madness." Such terminology creates the false impression that people living with dementia are diminished as people, cannot be trusted to make decisions for themselves, are dangerous and unruly, and may need sequestration from society. Cumulative impressions of dementia absorbed from popular culture can have a powerful impact on public knowledge and beliefs about dementia and dementia stigma. In this essay, we present some of the common dementia stereotypes in popular culture, their consequences on stigma, and ways we can counter these inaccurate narratives.

News depicts dementia as a biomedical disease, reporting breakthroughs and the need for lifestyle risk reduction

Most news stories frame dementia as a biomedical disease focusing on brain biology, with people living with dementia described as "patients" or "sufferers" rather than having agency. When stories of people with dementia are told, this tends to be through the views of professionals or carers.[2,3] For example, in Irish newspapers between 2011–2017 there were 3,669 articles on dementia; of these, only 13 included the voice of the person with dementia themselves.[2]

The good news is that, more recently, the depiction of dementia in the media may be changing, albeit differently by region. For example, in English language newspapers the number of stories with a negative tone has decreased (from 31% in 2014 to 19% in 2019). Similarly, in Norwegian newspapers, personhood framing is accompanying the biomedical lens and the number of articles on dementia in newspapers has increased from 1995 to 2015.[4] In contrast, while there has been an increase in the number of articles on dementia in Chinese newspapers from 2005 to 2020, the most common word for dementia is still *lao nian chi dai* (年痴呆), which literally translates as "senile retardation" or "older person dummy disease."[5]

Figure 1. From what main sources have you seen or heard about dementia and Alzheimer's Disease (n = 1379)



There have been increases in German, English, and Chinese news stories on dementia prevention. These stories place a strong emphasis on individual responsibility through promoting risk reduction through a healthy lifestyle – e.g. by following a Mediterranean diet, being physically active, socialising, challenging your brain, and consuming only small amounts of alcohol,[3,5,6] example in Figure 2.

The news frequently reports on advances in drug treatments for Alzheimer's disease, often heralding them as "groundbreaking," "momentous," and offering "new hope."[7] However, most treatments are not yet available publicly and may have narrow eligibility criteria. For example, anti-amyloid monoclonal antibodies such as Lecanemab remove beta-amyloid from the brain and slow cognitive decline but are only for people with very early Alzheimer's disease, are expensive and complicated to deliver, and can lead to brain bleeds and brain swelling.[8]

中国老年痴呆人数全球第一，竟是喝茶惹的祸?

39健康网
39健康网官方澎湃号

2024-02-06 11:04 上海 澎湃号 · 湃客 >

顾大爷今年76岁，去年被确诊为老年痴呆症，这事对他打击很大。他从年轻就喜欢喝茶，后来看到专家科普，喝茶有益于预防老年痴呆症，于是就把每天喝的量又翻了一倍。

可没想到，还是在75岁时被查出老年痴呆，顾大爷可能怎么想也想不明白，他患上老年痴呆的原因，有可能就是在他给自己加上去的几杯茶里。

Figure 2

Similarly, pseudo-medicines without evidence, such as dietary supplements (e.g. Vitamin E) and other treatments (e.g. stem cell treatments), are advertised in mass media and through health blogs as being able to "cure" or "slow" dementia onset.[9] Unrealistic expectations are subsequently created among people with dementia and carers, and frontline health providers may have the added workload of managing questions and expectations around new treatments and pseudo-medicines.

Dementia on social media includes voices of carers, but 'dementia' is also used as an insult

Social media allows for connection, information sharing and communication with others with similar interests or values. On X (formerly known as Twitter), dementia is mentioned in posts seven times more often than other neurological conditions (e.g. headache Parkinson's disease, epilepsy).[10] Of 398 tweets on dementia between Jan-Feb 2018, 9.2% were by a carer or a person living with dementia, 14.3% by advocacy organisations, 10.3% by health professionals, and 61.4% by the general public.[11] Studies suggest that 9–40% of tweets are stigmatising (e.g. used negatively to denigrate).[11,12] Dementia is often used as a political insult – e.g. to put down Donald Trump or Joe Biden.[12,13,14]

Of the 100 most popular TikTok videos tagged with #dementia in June/July 2023, 65% were posted by family members, 18% by health professionals, and 2% by people living with dementia themselves.[15]

Social media can be actively used to balance the depictions of dementia – for example, Canadian tweets posted during Canada's Alzheimer's Awareness Month 2022 related to dementia education and advocacy, fundraising and promotion, experiences of dementia – though there were also cursory – and negative or misinformative messages.[16]

Dementia in fiction is associated with old age, decline, and negative emotions

Our review of depictions of dementia, including analyses of 39 books and film, found that people with dementia were almost always portrayed as being old and sad, often juxtaposed against their younger happier self (examples in Figures 3, 4, 5).[17] Almost all books and films had a narrative of progressive decline, institutionalisation and/or death, and were associated with feelings like fear and shame.[17]

Meaningful relationships of people with dementia tend to be situated in the past, with the plotline focusing on recounting, then resolving a past trauma. Current relationships are characterised by power imbalances as people with dementia have memory difficulties, are confused, disoriented, and acting outside social norms.[17] Future relationships and stories are rarely discussed, with the implicit assumption that there is no future, as the person's dementia advances, the protagonist living with it will only experience profound anomie and alienation.

Figure 3: In the popular Polish soap opera Klan (4,000+ episodes), Wladek, the clan's father, develops Alzheimer's disease. His family initially keeps the diagnosis from him. He is devastated when he finds out, and asks to be put into a nursing home when he becomes disabled.

Figure 4: The American romance movie The Notebook (2004) intersperses flashbacks between present-day Noah and Allie, who is living with dementia and does not know who she is, with their heyday in the 1940s when they fell in love.

Figure 5: In the 2022 Hindi-language film The Three of Us, the protagonist Shailaja decides to go on a trip to revisit her childhood before her memories ebb away due to dementia.

The depiction of dementia in popular culture may develop and reinforce stigma

The depiction of dementia in news, fiction, and social media may all contribute to ongoing stigma by modelling fear, shame, and avoidance of dementia, minimal inclusion of voices of people living with dementia, and dehumanising depictions of them, reinforcement of the stereotype of dementia as late-stage dementia. Dementia prevention coverage is often individualistic and Western-centric, without considering cultural, environmental, and socioeconomic barriers to risk reduction and may lead to lifestyle stigma, where it's the individual's fault if they develop dementia.[18]

It has been asserted that raising awareness of dementia is crucial for tackling stigma.[19] However, the proliferation of dementia awareness campaigns, including fear-based campaigns, may be increasing dementia worry and fear.[20] Fear may in turn lead to greater social distancing from people with dementia as we try to avoid situations that make us feel uncomfortable.[21]

Media guidelines may improve depiction of dementia

There are guidelines for media professionals on reporting sensitive subject matter such as mass shootings, terrorism, mental illness, and court cases. Media adherence to these guidelines can deliver positive social benefits. For example, the Mindframe national implementation of the suicide media guidelines in Australia is estimated to have reduced suicides and saved $596M over five years.[22]

We need to co-develop and implement media guidelines for dementia as one of a range of strategies to decrease dementia stigma. This starts by shining a light on stigmatising narratives and unintended consequences. It should no longer be acceptable to solely frame dementia as an epidemic, a killer that needs to be fought, and people with dementia as "the living dead" looked after by overburdened families.[17]

Researchers and advocacy organisations putting out media releases need to consider the framing of dementia in the story. We all have a responsibility to support the inclusion of voices of people living with dementia and family, and to think more deeply about how collective media coverage of dementia may contribute to public stigma. The lived experiences of people with dementia and their families must be incorporated into stories to ensure accurate and balanced representations of dementia in everyday life. Thanks to Maria Maćkowiak and Zihan He for the examples of dementia depictions.

References

1. Huisman, M., Joye, S., & Biltereyst, D. (2022). The Alzheimer case: perceptions, knowledge and the acquisition of information about Alzheimer's disease by middle-aged and older adults in Flanders. *Ageing and Society*, *42*(4), 918–937. https://doi.org/10.1017/s0144686x20001221
2. O'Malley, M.-P., Shortt, O., & Carroll, C. (2022). Representations of the experiences of people with dementia in Irish newspapers. *Dementia*, *21*(4), 1343–1362. https://doi.org/10.1177/14713012221077526
3. Sm-Rahman, A., Lo, C. H., & Jahan, Y. (2021). Dementia in Media Coverage: A Comparative Analysis of Two Online Newspapers across Time. *International Journal of Environmental Research and Public Health*, *18*(19), 10539. https://doi.org/10.3390/ijerph181910539
4. Siiner, M. (2019). Let me grow old and senile in peace: Norwegian newspaper accounts of voice and agency with dementia. *Ageing and Society*, *39*(5), 977–997. https://doi.org/10.1017/s0144686x17001374
5. Chen, L., Tian, F. F., Fu, Y., & Kahana, E. (2024). Dementia Knowledge in Chinese Newspapers (2005–2020): A Topic Modeling Analysis. *Journal of Aging & Social Policy*, 1–17. https://doi.org/10.1080/08959420.2024.2348966
6. Petersen, N., & Schicktanz, S. (2021). The Experts' Advice: Prevention and Responsibility in German Media and Scientific Discourses on Dementia. *Qualitative Health Research*, *31*(11), 2005–2018. https://doi.org/10.1177/10497323211014844
7. Bailey, A., Dening, T., & Harvey, K. (2021). Battles and breakthroughs: representations of dementia in the British press. *Ageing and Society*, *41*(2), 362–376. https://doi.org/10.1017/s0144686x19001120
8. Rubin, R. (2023). Who Should—and Can—Get Lecanemab, the New Alzheimer Disease Drug? *JAMA*, *330*(15), 1411. https://doi.org/10.1001/jama.2023.14443

9. Hellmuth, J., Rabinovici, G. D., & Miller, B. L. (2019). The Rise of Pseudomedicine for Dementia and Brain Health. *JAMA*, *321*(6), 543. https://doi.org/10.1001/jama.2018.21560

10. Domingo-Espiñeira, J., Fraile-Martíne et al. (2024). Navigating the Digital Neurolandscape: Analyzing the Social Perception of and Sentiments Regarding Neurological Disorders through Topic Modeling and Unsupervised Research Using Twitter. *Information*, *15*(3), 152. https://doi.org/10.3390/info15030152

11. Cheng, T. Y.-m., Liu, L., & Woo, B. K. P. (2018). Analyzing Twitter as a Platform for Alzheimer-Related Dementia Awareness: Thematic Analyses of Tweets. *JMIR Aging*, *1*(2), e11542. https://doi.org/10.2196/11542

12. Creten, S., Heynderickx, P., & Dieltjens, S. (2022). The Stigma Toward Dementia on Twitter: A Sentiment Analysis of Dutch Language Tweets. *Journal of Health Communication*, *27*(10), 697–705. https://doi.org/10.1080/10810730.2022.2149904

13. Bacsu, J.-D., Fraser, S., et al. (2022). Using Twitter to Examine Stigma Against People With Dementia During COVID-19: Infodemiology Study. *JMIR Aging*, *5*(1), e35677. https://doi.org/10.2196/35677

14. Roveta, F., Grassini, A., Marcinnò, et al. (2023). The political discourse on Alzheimer's disease and related dementias: a Twitter content analysis. *Neurological Sciences*, *44*(9), 3319–3320. https://doi.org/10.1007/s10072-023-06799-5

15. Lukić, S., & Petrović, J. (2023). The quality of information provided by the most popular dementia videos on TikTok. *Frontiers in Public Health*, *11*. https://doi.org/10.3389/fpubh.2023.1266415

16. Bacsu, J.-D., Cammer, A., Ahmadi, S., et al. (2022). Examining the Twitter Discourse on Dementia During Alzheimer's Awareness Month in Canada: Infodemiology Study [Original Paper]. *JMIR Form Res*, *6*(10), e40049. https://doi.org/10.2196/40049

17. Low, L., & Purwaningrum, F. (2020). Negative stereotypes, fear and social distance: a systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatrics*, *20*(1). https://doi.org/10.1186/s12877-020-01754-x

18. Wilson, N.-A., & Anstey, K. J. (2024). Dementia Prevention and Individual and Socioeconomic Barriers: Avoiding "Lifestyle" Stigma. *The Gerontologist*, *64*(5). https://doi.org/10.1093/geront/gnad130

19. Brai, E., Tonacci, A., Brugada-Ramentol, V., et al. (2021). Intercepting Dementia: Awareness and Innovation as Key Tools. *Frontiers in Aging Neuroscience*, *13*. https://doi.org/10.3389/fnagi.2021.730727

20. Kessler, E.-M., Bowen, C. E., Baer, M., et al. (2012). Dementia worry: a psychological examination of an unexplored phenomenon. *European Journal of Ageing*, *9*(4), 275–284. https://doi.org/10.1007/s10433-012-0242-8

21. Cheston, R., Dodd, E., Christopher, G., et al. (2022). The Development and Validation of the Threat of Dementia Scale. *The International Journal of Aging and Human Development*, *94*(4), 496–514. https://doi.org/10.1177/0091415020957388

22. Flego, A., Reifels, L., Mihalopoulos, C., et al. (2022). Cost-effectiveness of media reporting guidelines for the prevention of suicide. *Suicide and Life-Threatening Behavior*, *52*(5), 1048–1057. https://doi.org/10.1111/sltb.12902

Women's experience of stigma and bias around Alzheimer's and related dementias: access to information, diagnosis, treatment, care, and research

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Alzheimer's disease and related dementias (ADRD) present a significant global public health challenge, with prevalence doubling every 20 years and lower- and middle-income countries being the most impacted.[1] Women are disproportionately represented among those affected, both as patients and as caregivers.[2,3] This disparity is influenced by biological factors such as hormonal changes post-menopause and the genetic risk factor APOE4, which has a stronger association with Alzheimer's in women.[4] Additionally, women generally live longer than men, increasing their likelihood of developing age-related diseases like dementia.[5] Socioeconomic factors further impact women living with ADRD and female caregivers, such as lower education levels and higher caregiver burden.[6,7]

Understanding stigma and its impact

A major challenge encountered by those living with ADRD and their networks is dementia-related stigma and bias. Stigma has been described as a fundamental cause of health inequalities and added burden.[8] Stigma and bias are interrelated phenomena that often reinforce and perpetuate each other, leading to discrimination and social exclusion.[9]

Apart from public stigma, self-stigma influences a person's own beliefs and decisions about their condition, such as concealing information about their diagnosis and refraining from seeking help and support.[8,10,11,12,13]

These forms of stigma affect individuals with ADRD, particularly women, by creating barriers to accessing care and leading to greater social isolation.[14,15] The intersection of ageism, sexism, and ableism contributes to the heightened stigma faced by women with ADRD. Women are often stereotyped as more fragile and dependent, exacerbating negative perceptions when they develop ADRD. This compounded stigma leads to greater social isolation and reduced access to care compared to men with similar conditions.[16,17]

Traditional gender roles and related bias complicate the situation for women living with ADRD. Women are typically expected to be caregivers, not care recipients, leading to additional stigma and guilt. Studies show that women with ADRD often receive less support and are more likely to be institutionalised than men. Cultural perceptions of gender and ageing play a significant role in the stigma associated with dementia. Ageing women are often viewed less favourably than ageing men, compounding the stigma of having a cognitive disorder.

Structural bias, benevolent sexism, and ADRD

In its 2019 survey, Alzheimer's Disease International reported that 62% of healthcare practitioners believe that dementia is part of normal ageing, leading to false beliefs about the condition. In 2024, that percentage remained largely the same. Moreover, in this same survey, nearly half of the public expressed the view that healthcare professionals tend to ignore persons with ADRD in 2019. In 2024, more than half of the general public agreed with that statement.

This bias in the healthcare system, coupled with bias related to gender stereotypes and ageism, particularly affect the quality of care women receive.[18] Medical professionals may unconsciously hold stereotypes about women being more emotional or less rational, influencing diagnosis and treatment decisions. Women are also less likely to receive timely diagnoses and appropriate interventions for dementia compared to men.[5]

A specific type of gender bias is benevolent sexism. Benevolent sexism in healthcare settings refers to attitudes and behaviours that, although seemingly positive or protective, ultimately reinforce traditional gender roles and contribute to gender inequality. This type of bias is characterised by the perception that women need to be cared for and protected, which can lead to patronising behaviour and decisions that undermine women's autonomy and competence.[19] In healthcare, benevolent sexism can manifest in several ways:

- **Overprotection**: Healthcare providers might be overly cautious with female patients, assuming they are less capable of understanding complex medical information or making informed decisions about their health. This can result in women being excluded from participating fully in their treatment plans or being shielded from information that is deemed too distressing or complicated for them to handle.
- **Stereotyping**: Assumptions that women are naturally more nurturing and emotional can lead to their symptoms being dismissed or misdiagnosed as psychological rather than physical. For example, women's complaints of pain are often taken less seriously than men's, attributed to emotional distress rather than legitimate medical conditions.[20]
- **Patronising communication**: Healthcare professionals may use condescending language or tone when communicating with female patients, reflecting an underlying belief that women need simpler explanations or more reassurance than men. This can undermine women's confidence in managing their health and contribute to feelings of inadequacy.[21]
- **Decision-making**: Benevolent sexism can lead to healthcare providers making decisions on behalf of female patients, based on the belief that they are acting in the women's best interests. This can limit women's autonomy and their ability to exercise agency over their health choices.[22]

Addressing this issue requires increased awareness and training among healthcare providers to recognise and counteract these biases, ensuring that women receive equitable care.

Stigma and inequity in access to health: education, health literacy, and income

Education and health literacy play pivotal roles in combating stigma and bias associated with ADRD.[12] Better-informed communities and individuals can foster more inclusive and supportive environments.[23]

Educational disparities limit the understanding of health issues and access to resources, particularly among women.[24] Additionally, the income gender gap, particularly in lower- and middle-income countries, impacts women's access to quality care and support services.[25,26] Lower education levels and low income have been identified as risk factors for ADRD.[23,27]

Adequate health literacy empowers patients and caregivers to find and utilise resources, communicate effectively with healthcare professionals, and advocate for necessary services. Higher health literacy levels enable better management of ADRD and reduce stigma by promoting informed decision-making and understanding of the condition.[28]

Access to accurate and timely information is crucial for managing ADRD effectively. However, women often encounter significant barriers in obtaining such information due to sociocultural factors and educational disparities.[29] In many societies, women have less access to education compared to men, limiting their understanding of health issues and available resources. These economic and social disadvantages further contribute to the heightened stigma faced by women living with ADRD, limiting their ability to access care, a timely diagnosis, and early intervention.[1,10]

Diagnosis and stigma

Stigma around ADRD can negatively affect help-seeking behaviour and delay diagnosis, increasing the risk of social isolation.[30,31] Moreover, gender biases in the medical community can lead to underdiagnosis or misdiagnosis of dementia in women, with symptoms incorrectly attributed to emotional or psychological factors. Societal expectations and internalised beliefs about their roles lead women to delay seeking medical advice, often resulting in more advanced disease stages at diagnosis.

Furthermore, stigma around ADRD may lead persons living with the condition to conceal their diagnosis, thus creating a barrier to receiving help and support. In the Alzheimer's Disease International 2019 survey, around 25% of respondents said they would keep their dementia diagnosis a secret. In some countries, an even higher percentage stated they would not disclose their dementia diagnosis when meeting people. In 2024, between 19% and 36% of respondents (from higher- to lower- and middle-income countries) said they would keep their dementia diagnosis secret.

ADRD treatment and clinical trials

Women face distinct challenges in accessing and receiving treatment and care for ADRD. The stigma associated with dementia can lead to social isolation and discrimination, more pronounced for women due to their roles within families and communities. Women with dementia may receive fewer formal care services. Financial barriers also play a role, as women generally have lower incomes and savings, making it difficult to afford necessary treatments and care services.[25]

Closely linked to stigma surrounding treatment and care is the gender bias observed in ADRD research and clinical trials. Women are often underrepresented in dementia research and clinical trials, leading to a lack of gender-specific data crucial for developing effective interventions.[32] Daitsch et al. (2022)[33] also reported old age as a potential barrier for recruiting women in clinical trials in general, thus highlighting the compounded bias related to gender and age. Rosende-Roca et al.'s (2021)[34] study investigating the role of sex and gender in the selection of Alzheimer patients for clinical trial pre-screening observed that women were less likely to be deemed eligible for screening and identified education – or lack thereof – as the decisive criterion for this exclusion.[34] Other studies mentioned challenges for older women's participant in clinical trials, including lack of support/caregiver and cultural barriers.[32,33]

Recruitment strategies for clinical trials may not adequately consider gender differences, and there is a historical bias in medical research that prioritises male subjects, resulting in a significant knowledge gap in understanding how ADRD manifests and progresses differently in women.[5]

Addressing stigma and bias for women living with ADRD

Addressing these intersecting stigmas and related bias requires a comprehensive strategy involving policy changes including gender-transformational dementia policies, public health initiatives, and shifts in societal attitudes. Public health campaigns should focus on raising awareness about ADRD, reducing stigmatising attitudes, and being gender-sensitive and accessible.[12,14] Healthcare providers should receive training on gender-specific aspects of dementia to reduce biases and improve diagnosis and treatment accuracy.[35] Chrisler and colleagues (2016)[18] specifically recommend further qualitative studies with healthcare providers to investigate biases in healthcare decision-making, which would also prompt reflection on the reasons behind treatment decisions for patients.

Inclusive research practices should prioritise the collection and analysis of sex-disaggregated data to better understand women's unique needs and experiences with ADRD.[1] Research is essential to explore disparities in health and healthcare related to age, gender, and other factors, with a focus on how these aspects intersect and interact with stigma.[8]

Recognising and addressing the unique experiences of women with ADRD can improve outcomes and quality of life for this disproportionately affected population and their support network.

Conclusion

Women face significant stigma and barriers in relation to ADRD, impacting their access to information, diagnosis, treatment, care, and participation in research. Addressing these challenges requires a comprehensive and person-centred approach that includes educational public campaigns as well as gender sensitive curricula for healthcare professionals, gender-sensitive healthcare policy and practices, accessible support, and information for caregivers, as well as inclusive research practices.

References

1. Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Yu-Tzu, W., & Matthew, P. (2019). *World Alzheimer Report: World Alzheimer Report 2015. The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends.* Alzheimer's Disease International.
2. Ferretti, M., Iulita, M., Cavedo, E., Chiesa, P., Schumacher Dimech, A., Santuccione Chadha, A., . . . al., e. (2018). Sex differences in Alzheimer disease—the gateway to precision medicine. *Nature Reviews Neurology*, 457–469.
3. Lupu-Stănescu, R. (2018). Why Are Women More Vulnerable in Developing Alzheimer Disease Dementia? The Effect of Gender on Incidence, Risk Factors, and Results. *Journal of Research in Gender Studies*, 134.
4. O'Neal, M. A. (2024). Women and the risk of Alzheimer's disease. *Frontiers in Global Women's Health.*
5. Mielke, M., Vemuri, P., & Rocca, W. (2014). Clinical epidemiology of Alzheimer's disease: assessing sex and gender differences. . *Clinical epidemiology*, 37–48.
6. Schoenhofen Sharp, E., & Gatz, M. (2011). The Relationship between Education and Dementia An Updated Systematic Review. *Alzheimer Disease & Associated Disorders*, 289–304.
7. Swinkels, J., Tilburg, T., Verbakel, E., & Broese van Groenou, M. (2019). Explaining the gender gap in the caregiving burden of partner caregivers. *The Journals of Gerontology: Series B*, 309–317.
8. Hatzenbuehler, M., Phelan, J., & Link, B. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, 813–821.
9. Sing Raj, S., Peters, R., Syurina, E., Irwanto, I., Naniche, D., & Zweekhorst, M. (2020). Intersectionality and health-related stigma: insights from experiences of people living with stigmatized health conditions in Indonesia. *International Journal for Equity in Health*, 206.
10. Alzheimer's Disease International. (2019). *World Alzheimer Report 2019: Attitudes to dementia.* London: Alzheimer's Disease International.
11. Corrigan, P., & Watson, A. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, 16.
12. Herrmann, L., Welter, E., Leverenz, J., Lerner, A., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A systematic review of dementia-related stigma research: Can we move the stigma dial? *The American Journal of Geriatric Psychiatry*, 316–331.
13. Tolhurst, E., Weicht, B., & Runacres, J. (2023). Sustaining relational subjectivity: The experience of women with dementia. *Sociology of Health & Illness*, 503–521.
14. Weidner, W., Barbarino, P., & Lynch, C. (2021). Women and dementia policy: redressing imbalance through gender transformative policies. In M. Ferretti, A. Schumacher Dimech, & A. Santuccione Chadha, *Sex and Gender Differences in Alzheimer's Disease* (pp. 439–468). Cambridge: Elsevier.
15. Wiersma, E., Harvey, D., & Caffery, P. (2023). "I'm still the queen and I'm still on my throne…": Women's reflections on gender and living with dementia. *Journal of Women and Aging*, 113–127.
16. Barnes, L. e. (2019). Racial Differences in the Association of Education With Physical and Cognitive Function in Older African Americans and Whites. *Annals of Epidemiology.*, 354–363.
17. Alzheimer's Association. (2021). *2021 Alzheimer's disease facts and figures.* Alzheimer's Association.
18. Chrisler, J., Barney, A., & Palatino, B. (2016). Ageism can be hazardous to women's health: Ageism, sexism, and stereotypes of older women in the healthcare system. *Journal of Social Issues*, 86–104.
19. Leaper, C., & Gutierrez, B. (2024). Sexism and gender-based discrimination. In W. Troop-Gorden, & E. Neblett, *Encyclopedia of Adolescence (Second Edition)* (pp. 543–561). Academic Press.
20. Samulowitz, A., Gremyr, I., Eriksson, E., & Hensing, G. (2018). "Brave men" and "emotional women": A theory-guided literature review on gender bias in health care and gendered norms towards patients with chronic pain. *Pain research and management*, 6358624.
21. FitzGerald, C., & Hurst, S. (2017). Implicit bias in healthcare professionals: a systematic review. *BMC Medical Ethics*, 1–18.

22. Gustafsson Sendén, M., Lindqvist, A., & Löfgren, S. (2020). Benevolent Sexism and Reactions towards Women's Subordination: Does Benevolent Sexism Encourage Women to Be Submissive? *Frontiers in Psychology*, 556545.

23. Livingston, G., & et al. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*, 413–446.

24. Kim, S., Anstey, K., & Mortby, M. (2023). Who displays dementia-related stigma and what does the general public know about dementia? Findings from a nationally representative survey. *Aging and Mental Health*, 1111–1119.

25. Landmesser, J., Orlowski, A., & Rusek, M. (2020). Gender Pay Gap Across the Income Distribution: Analysis for the EU. *Acta Physica Polonica*, 138.

26. Schwab, K., Samans, R., Zahidi, S., Leopold, T., Ratcheva, V., Hausmann, R., & Tyson, L. (2017). *The global gender gap report 2017.* World Economic Forum.

27. Wang, A., Hu, A., Ou, Y., Wang, Z., Ma, Y., Tan, L., & Yu, J. (2023). Socioeconomic status and risks of cognitive impairment and dementia: a systematic review and meta-analysis of 39 prospective studies. *The Journal of Prevention of Alzheimer's Disease*, 83–94.

28. Nguyen, T., & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia*, 148–181.

29. Arai, Y., Arai, A., & Zarit, S. (2008). What do we know about dementia?: a survey on knowledge about dementia in the general public of Japan. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences*, 433–438.

30. Vernooij-Dassen, M., Moniz-Cook, E., Woods, R., De Lepeleire, J., Leuschner, A., Zanetti, O., . . . et al. (2005). Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma. *Geriatric Psychiatriy*, 377–386.

31. Harper, L., Dobbs, B., Royan, H., & Moorth, T. (2018). The experience of stigma in care partners of people with dementia – results from an exploratory study. *Innovation in Aging*, 865.

32. Martinkova, J., Quevenco, F., Karcher, H., Ferrari, A., Sandset, E., Szoeke, C., & et al. (2021). Proportion of women and reporting of outcomes by sex in clinical trials for Alzheimer disease: a systematic review and meta-analysis. *JAMA Network Open*, e2124124-e2124124.

33. Daitsch, V., Turjeman, A., Poran, I., Tau, N., Ayalon-Dangur, I., Nashashibi, J., & et al. (2022). Underrepresentation of women in randomized controlled trials: a systematic review and meta-analysis. *Trials*, 1038.

34. Rosende-Roca, M., Abdelnour, C., Esteben, E., Tartari, J., Alarcon, E., Martínez-Atienza, J., & et al. (2021). The role of sex and gender in the selection of Alzheimer patients for clinical trial pre-screening. *Alzheimer's Research & Therapy*, 95.

35. Gove, D., Downs, M., Vernooij-Dassen, M., & Small, N. (2016). Stigma and GPs' perceptions of dementia. *Aging & Mental Health*, 391–400.

"We need to row in the same direction": a dialogue on dementia science, policy, and awareness

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Dementia awareness plays a big role in other aspects of the condition – from access to diagnosis, care, and treatment all the way to research and policy. Alzheimer's Disease International (ADI) CEO Paola Barbarino and Dr Alireza Atri, the chair of ADI's Medical and Scientific Advisory Panel (MSAP), sat down to discuss about how awareness and stigma intersect with their respective fields – and how the discourse around dementia needs to change so the advances in dementia research can have a more concrete impact on advocacy and the lives of people living with dementia and their carers.

Can you briefly introduce yourself in terms of what you do and what motivates you to dedicate your career to dementia?

Alireza Atri: I'm Alireza Atri, I'm a cognitive neurologist, the chief medical officer for Banner research and director of the Banner Sun Health Research Institute, where I direct the aspects of clinical care, research training, education at Banner Alzheimer's Institute. I'm involved with a lot of clinical trials and therapeutics on Alzheimer's disease, and best practices trying to translate what we're doing into early detection and accurate diagnosis, advancing treatments and care into clinical practice.

As far as why I'm doing this, this is a life purpose for me. There's an imaginary line between the clinician and being on the other side and being impacted by Alzheimer's disease and related disorders. I've been a primary caregiver twice – once to my aunt, who was like a mother and grandmother to us, and once to my dad, who lived with us for 10 years. It's very difficult, even as a specialist and somebody who has the information and knowledge at their fingertips. I want to do something that impacts the next generation, and I think we're on our way to do that.

Paola Barbarino: I'm Paola Barbarino, and I'm the chief executive officer of Alzheimer's Disease International (ADI). I have come to dementia, not by having had an experience in my family, but having had a lot of experience of it through my friends. I would say that three things motivate me. One is the unfairness of it, which is very related to stigma. This is a massive problem – we all know friends and family who have an experience with it, so why are we not doing anything about it? I have a very strong sense of justice, so for me that is really powerful. The second thing is that I have met amazing and inspiring people committed to this issue. There is a real sense of community and family and of helping each other, and that is extremely powerful. And the third is perhaps more selfish: because I want to feel useful. That motivates me to go forward, take risks, and do things that need to get done because nobody else is doing them.

Paola, your work involves trying to change policy around the world around dementia. Ali, you are very invested in the research and scientific side. How does dementia awareness or dementia stigma relate to your respective work?

Paola Barbarino: In my case, the major problem is that government officials around the world often don't know about dementia, they don't want to talk about it, or they underplay the role of Alzheimer's and dementia in their population. But this is changing; now I meet a lot more government officials who want to talk about it because they have it in their family. Nevertheless, there is still great stigma attached around care, this feeling that care is too big, or too expensive, that their country doesn't have the resources. For me, it's about getting people back to the lowest common denominator. For example, risk reduction doesn't cost so much and can help people have better lifestyle habits that will eventually reduce their risk of developing the condition. But it can be difficult to apportion all my knowledge on the issue into small things that people can do, rather than trying to tackle the whole problem at once.

Alireza Atri: The root cause of stigma is in many ways a combination of lack of knowledge, understanding, and appreciation. It's fear and a lack of confidence that dementia can and should be tackled proactively. There are many factors involved that can probably be overcome to give patients the autonomy to make choices at the height of their abilities about how they want to approach things. It doesn't always mean they need to get this drug or this treatment. It really means understanding the things we know, the things we don't know, the uncertainties like everything in life, and being able to put that together.

There really is ageism and dementia-ism within the clinician community, and nihilism about what can and should be done. Again, out of fear, lack of knowledge of health systems, not prioritising dementia. So there are multiple stakeholders going all the way from social services to the government, and at each level that stigma impacts the fact that people don't get diagnosed until late, or they don't get an accurate diagnosis. and this is incredibly sad, wasteful, and destructive. It affects all these other aspects of health for people who have dementia as well as their family members, because people's spiralling health conditions might get attributed to other things like out-of-control diabetes, heart failure... not appreciating that the root cause for a person who'd managed all these conditions for many years could actually be cognitive or behavioural impairment. And so it really affects the health and well-being of a whole network of people.

There's also the economics of it. There are the direct costs that are measured, but those are only a small fraction when considering the indirect and hidden costs. We did a paper on this called "The Tip of the Iceberg"[1] looking at the social economic cost back in 2019. Stigma affects all this, including people coming in to the doctor very, very late, when their organs have already failed, and not getting appropriate care and treatment.

We've seen giant strides in the last few years when it comes to dementia research, including the emergence of new drugs that can slow down the progression of Alzheimer's disease and are starting to come on the market, mostly in higher-income countries. Beyond the impact on people who are able to access these treatments, what do you think are the consequences of these news headlines on the wider public? Does it have an impact on changing attitudes around dementia?

Alireza Atri: I think it's important to put this news in perspective and not sensationalise it. This is really important news, but we're at the end of the beginning, not the beginning of the end. We're not curing Alzheimer's right now. But we've gained this incredible understanding over the last 10, 15, 20 years with the advent of biomarkers, being able to measure these processes, and having models about the complexity of Alzheimer's disease. What we do for Alzheimer's is going to be a key for how we approach other related conditions, such as Lewy Body disease and other pathologies. And with emerging blood biomarkers – not to overplay it, but it's putting us on a path towards much more individualised precision medicine that we can test out even in prevention in earlier years.

Drugs are part of the equation, but we're not going to be able to beat dementia with one drug. It's going to take a combination of things, because we understand the dementia process starts 20 to 25 years before people show symptoms. So it's a long road where we can intervene at a non-clinical, less symptom-related phase.

Now, the new drugs that are getting in the headlines are a foundational step that we're going to build upon. For example, the very first drugs for multiple sclerosis were slowing down plaques by about 20, 25% or so. And I remember when this was happening, people said: "We don't know, we don't believe this." And then, lo and behold, over the next 20, 25 years, we got 13 more drugs that were much more effective at slowing things down.

The important thing is that people should be able to get a more accurate diagnosis in a timelier way, and then decide what they want to do. That doesn't mean just taking these new drugs – the symptomatic drugs that we have had for 20 years, including cholinesterase inhibitors and memantine, are underutilised and undervalued.

So it is a really exciting time in our field. We shouldn't oversell it, we are far from a cure, but it's important that we make progress in all these stages in combination with accurate diagnosis, lifestyle interventions, and care. This is imperative. The economic and the social impact of dementia over the next 25 years just cannot be ignored.

Paola Barbarino: For 40 years, ADI has been an organisation that promotes care ahead of cure. Care is what people really need at every stage. From post-diagnostic support to palliative care, it is all critical while we're waiting for a cure. We obviously are interested in everything from diagnostics to inclusivity to data-sharing, but whenever I post anything around new treatments, there's been a lot of negativity in the community. We are trying to converse and understand everybody's opinion. We don't do biomedical research; we leave questions of efficacy to regulators and to medical researchers. What is really important for us is that people must have the right to choose. If there is something available, we know that the vast majority of people want to be able to choose. We are also concerned about what could happen if you start approving drugs in certain constituencies but not others. You could end up with wealthy people going for those drugs – and then what happens to poorer people, what happens to people in lower-income countries? So, we are worried from the point of view of justice. And then throughout we have continued to say, care, care, care. Maybe in the future will have a cure, but not now, so we can't pull the brakes on care. It has to be supported and financed, and there's got to be more research on care.

I've been involved in discussions with a few governments this year where they have said: "Now we got a cure, fabulous, let's increase our diagnostic capacity and take away money from care." We have had to go back quietly behind closed doors and say, "no, you should increase diagnostic capacity and continue to finance care because the two things are not mutually exclusive, they are two facets of the same coin." That has been really fascinating, this is partially ignorance and partially different places pulling different strings. We are an advocacy organisation. We need to be able to pull all the strings together to advance the whole cause of dementia, which is difficult enough because of the stigma, but at the same time making sure that it's not just about diagnosis, it's not just about risk reduction, it's not just about care, it's not just about medical research, it's about everything.

Looking at the data, it's only in the last few years that we have realised that dementia is among the first causes of mortality in some countries – and I always wonder whether that is the case in many more countries where they're not reporting those numbers properly. We are only now really understanding the scale of the issue, and it's only going to get bigger as the population grows older.

It's interesting to hear from the both of you that what people read in the headlines can still lead to misunderstandings. More information entering public consciousness doesn't necessarily translate to more awareness overall. How do you break things down in a way that doesn't feel too overwhelming to laypeople?

Alireza Atri: You always try to tailor things to your audience, whether it's for a seminar, whether you're talking to patients, or whether you're talking to other types of stakeholders like Paola does... but in general, dementia is a problem that is absolutely growing and it's going to impact all countries. And we have ways of approaching it now that are going to cost money, but if you don't do it, we know exactly where this train is heading: it's going off the tracks and off the cliff, and it's going to be more difficult and costlier to do it later.

As far as patients go, I try to explain the significance of getting a timely and accurate diagnosis, and to empower them. It comes down to autonomy and justice, that people should have the ability to determine their own course based on accurate and honest information. I explain to them that we have a greater ability to have accurate diagnoses and we have a multi-pronged, comprehensive approaches to care that includes non-pharmacological and pharmacological options together. And if you do this early enough, it could really change your trajectory based on odds. We all live our lives with no certainty other than all of us are going to die someday. Before that, though, we play the probabilities, and we make decisions based on our own priorities.

The importance of the new drugs is what we call disease modification. This is a well-established principle in medicine, where you have something that's impacting the underlying driving pathophysiology, and you can slow down the course of the condition. Clinical trials give us an average appreciation of whether the drugs are doing something that's generally beneficial. Of course, on the other side there are the side effects, the burdens, and the costs that you have to think about. There is also an implementation gap between what we've done in research and getting the resources for our health systems, our clinicians, which are important to address. Patients should be empowered to make those decisions. So I would say to people that these drugs come with risks, benefits, and burdens, and we would talk about the potential side effects that can occur and how we would monitor or mitigate that. But it is an important stepping stone, and people should have this information and be counselled so they can do the right thing for them.

What is interesting listening to the both of you, whether we're talking about raising awareness at the patient or policy level, is having to walk a fine line between raising the very real individual, economic, and societal costs of this condition and trying to have an empowering perspective. How do you navigate that?

Paola Barbarino: We at ADI took the decision many years ago that the way we approach dementia isn't about creating fear, but about creating hope, a sense of community, and a sense that we can overcome if we work together. We don't like the idea of fearmongering – however oftentimes the only way we get the attention of the press is by employing a different kind of language, which alludes to "going into battle" or "fighting." Nobody's battling anything here, but it sometimes seems to be the only language the press understands – that and the language of clinical trials or of miracle pills that, when you read into the details, you discover have only been tested on mice. There is so much out there that is totally off the wall, and it confuses people. This is why we have tried our uttermost best to demystify, to clarify, to explain, to make complicated concept easier, and to be objective.

This brings me to another point, which is that we in the Western world have demanded the development of new drugs and treatments from the pharmaceutical industry, for better or worse, with some funding allocated by governments to university and researchers – but the vast majority of investments are coming from the industry. The reason I am not happy to see people be so negative about new treatments is that it can only scare investors, and we need people to invest in Alzheimer's disease. From the point of view of people living with dementia, the years during which clinical trials were failing and closing felt desperate. People didn't have anything to hope for. In 2017, we realised that for every study on neurological diseases – so not just dementia or Alzheimer, but any neurological disease, including migraine or epilepsy – there were 12 studies on cancer. If there is so little funding, we won't have what we need to produce new ideas, theories, hypotheses.

When I then look at the fearmongering and negativity, I think this is not helping anyone. If there are little steps, as Ali said, we have to celebrate those little steps. We have to be conscious, honest, and open about how small those steps are – but we do need to celebrate them, because at one point we had nothing.

Alireza Atri: You make so many good points, Paola, about misinformation, misunderstanding, misrepresentation, fear, and how it affects everything. It's also about scientific and medical literacy in general. It's not just about there being studies, but about the quality of the studies, and whether they could actually answer the question being posed. This is how people leap to believing that we've already cured Alzheimer's because researchers gave mice plaques and tangles then pulled them out, and now they're doing so much better at finding their way out of mazes. Humans are much more complex than that. It's interesting, because researchers may do a negative study and say, "such and such thing doesn't work," for example. But what if the study is not designed well? It's not just the general public, clinicians can also have a lack of understanding of science. So where you get your information from is very important.

I learned a really important lesson in the last few years during these monoclonal trials. I can't tell you how many times in my life I heard people, even our own field, who are naysayers about X, Y, and Z. And then I'll look them in the eye and say: "Would you give this to your dad?" They say yes, and yet they're publicly speaking otherwise. There is just so much nuance here, and you don't want fear and sensationalism to be the things that grab attention and drive people.

We can't go from zero to a cure. We cure very few cancers still, right? But we've made incredible progress. When you go on TV, they don't say: "Take this drug for breast cancer." They'll say: "If you are this and this, and have already been on X, Y, and Z, then this could be an option for you." Which means they've used precision biomarkers to figure out if this drug will work for this segment of people with breast cancer. But imagine if they gave the same drug 10 years ago to a large population, what would happen? Probably a negative study, right? And this is where we are in Alzheimer's. We need voices of reason to advocate. The solutions aren't going to come from somewhere else, they're going to have to come from us, so we need to row in the same direction.

People with dementia are usually older, and they're not valued as much, unfortunately, by systems and governments. The moral and economic impact on society, including on caregivers and care partners, the health of the spouse, the health of the adult children – usually women – who are working, raising kids, and trying to take care of things, missing work... is not appreciated. Could I have published a hundred more papers and written more grants if I wasn't taking care of my dad at home for all those years? Yes, I probably could have done that. But it comes at a cost when you caregive, and it's going to affect all of us.

Governments can't hope this is going to go away by ignoring it. Dementia is an incredible societal problem that we all need to make our own. When you look at the progress that we've already made in other fields, and that we're now making with Alzheimer's disease and related dementias, it's important to understand that, collectively, we can do this and it's important to do it.

Paola Barbarino: My philosophy is that we're all in the same boat here, even if everybody's different and everybody has different ambitions and hopes, and we have to be more empathetic with those ambitions and those hopes. I would like our community to remember that unity is what we get us there. Since starting World Alzheimer's Month, we're now reaching 74 million people worldwide.[2] But we are seven billion people on this planet, 74 million is still a drop in the ocean. It's not us, the people in the dementia community, who we have to worry about – it's the vast majority of people who still don't understand dementia. So we need to remember that we are all in it together.

References

1 El-Hayek YH et al. Tip of the Iceberg: Assessing the Global Socioeconomic Costs of Alzheimer's Disease and Related Dementias and Strategic Implications for Stakeholders. J Alzheimers Dis. 2019;70(2):323–341. doi: 10.3233/JAD-190426. PMID: 31256142; PMCID: PMC6700654.

2 "World Alzheimer's Month 2023: Tangible Steps to Risk Reduction," *Alzheimer's Disease International*, https://www.alzint.org/news-events/news/world-alzheimers-month-2023-tangible-steps-to-risk-reduction/.

Valuable initiatives to understand and address stigma in rarer forms of dementia

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Alzheimer's disease (AD) is the most common cause of dementia, but other important neurodegenerative disorders, such as frontotemporal dementia (FTD)[1] and dementia with Lewy bodies (DLB),[2] tend to receive less attention. Non-AD dementias, particularly behavioural variant FTD (bvFTD), are underdiagnosed and undertreated. Exacerbating this divide, good biomarkers can be used to confirm an AD diagnosis, while they are still lacking for bvFTD, diminishing certainty as to the underlying aetiology of the clinical syndrome. In this review, we discuss non-AD dementias with a focus on bvFTD, emphasising the stigma associated with bvFTD, which in turn increases the burden for caregivers and patients living with this condition. We also propose strategies to improve diagnosis and diminish the burden of bvFTD.

While AD presents with prominent memory and other cognitive deficits, the most common early manifestations of bvFTD are neuropsychiatric and behavioural symptoms dominating all stages of bvFTD. These can include disinhibition, addiction, crime, apathy, overeating, spitting, compulsive collecting of objects, diminished empathy or sympathy for others, uncontrollable itching, and psychosis. Traditionally, such symptoms and behaviours are considered under the broad rubric of psychiatry. When a patient with a neurodegenerative disease manifest with these symptoms, they are usually classified as having a psychiatric disorder. Therefore, it is no surprise that in one study 50% of patients with bvFTD (and 70% of the women with bvFTD) were first misdiagnosed as having a primary psychiatric disorder.[3] Lack of awareness that these socially unacceptable behaviours are caused by a neurodegenerative condition will increase hostility to the patient from their families, friends, and people in their social and work environments.

Research by Levenson, Merrilees, and colleagues outlines how a cascade of behaviours associated with bvFTD drives poor outcomes for the patients and for their caregivers. bvFTD caregivers show greater strain and distress, more depressive symptoms, and lower perceived control compared to AD caregivers.[4] Others suggest that the two neurodegenerative disorders with the greatest caregiver burden are bvFTD and Jakob-Creutzfeldt disease, likely due to the high level of psychiatric symptoms associated with both conditions.[5] Some of the behaviours characteristic of bvFTD drive worse outcomes in their caregivers. In one study, lower linkage in couples' daily somatic activity (e.g., synchronised movement measured from wrist sensors), was associated with higher caregiver anxiety.[6] Further, in dementia, decreased ability to detect emotions in their caregivers' is associated with greater depression in caregivers. In turn, depression in caregivers is significantly associated with increased emergency department use, "revealing a key caregiver vulnerability, which, if addressed with patient- and caregiver-centred dementia care, could improve health outcomes and lower costs for this high-risk population."[7] In summary, the symptoms associated with this non-AD dementia strongly drive bad outcomes. In the next sections, we describe diminished diagnosis of bvFTD and other non-AD dementias, poor societal responses to the clinical syndrome of bvFTD, and potential solutions to improve diagnosis, diminish stigma and improve care for bvFTD and other non-AD early-age-of-onset dementias with prominent behavioural symptoms.

Challenges in diagnosing bvFTD and other non-AD dementias

Behavioural variant frontotemporal dementia presents significant diagnostic challenges, particularly in non-Western countries and underserved communities. Effective diagnosis is complicated by various factors, including the prominence of behavioural and neuropsychiatric symptoms. Studies worldwide have identified several issues that make diagnosing bvFTD difficult, such as the overlap of symptoms with other neurodegenerative diseases, non-specific diagnostic criteria, early onset of symptoms, lack of specific biomarkers, and scarcity of specialists and trained professionals.[3]

Figure 1: Connections series. Postcards received from cognitively impaired and unimpaired individuals were used as canvases in painting activities.

Delays in diagnosis and lack of access to care and biomarker testing contribute to underestimation of bvFTD and non-AD dementias among diverse groups. Underdiagnosis and delayed diagnosis of bvFTD is even more pronounced in lower- and middle-income country settings.[8] Although limited research exists from such settings, growing evidence, particularly coming out of Latin American countries, highlight significant gaps in the diagnosis of bvFTD. Studies indicate a higher likelihood of misdiagnosis of patients with bvFTD[9] and surveys among health professionals providing care for individuals with memory and other cognitive complaints, suggesting that a majority of the professionals from different specialties have difficulties in detecting bvFTD.[10]

Research on the diagnosis and detection of bvFTD from sub-Saharan Africa, however, is shockingly non-existent. Our literature review found few studies specifically addressing non-AD subtypes of dementia, including bvFTD, in this region, highlighting a significant gap in the evidence base.[11] Some studies from South Africa have reported that most dementia cases were diagnosed as Alzheimer's disease (AD), with only a fraction of the patients identified as FTD, 3 (n=165) and 2 (n=305) cases.[12,13] Nevertheless, several studies conducted in different regions of the continent including Central Africa, Tanzania, Uganda, and Nigeria indicate that more than 90% of dementia patients exhibit behavioural and psychological symptoms of dementia (BPSD), including as irritability, apathy, and psychotic symptoms as their most prominent presentations. These figures suggest a potential misclassification and underdiagnosis of non-AD dementias.[14,15] Another possibility is that some of these patients do have AD but are diagnosed later in the course of their condition when behaviour changes are increased.

There is an urgent need for increased training, awareness, research, and interventions to improve the diagnosis and management of bvFTD in low- and middle-income settings including Sub-Saharan Africa. Developing and adopting culturally appropriate diagnostic tools and enhancing healthcare infrastructure are critical steps towards addressing this challenge

Stigma and poor societal responses to the clinical syndrome of bvFTD in Africa

Alzheimer's disease and other dementias are often the subject of stigma and discrimination in developed countries but with higher severity in middle- and lower-income countries, linked to the absence or poor knowledge surrounding neurodegenerative diseases. In some instances, these patients are identified as witches.

bvFTD often presents unique challenges for individuals and their families, particularly in the African context, a region marked by limited access to healthcare, socioeconomic disparities, and cultural stigma. Although comprehensive prevalence data on dementia in Sub-Saharan Africa is severely lacking, existing estimates suggest that the burden of the disease is significant and growing, with the region expected to see a dramatic increase in the number of individuals affected in the coming years.[16] Unfortunately, the true burden of the disease may be underestimated due to factors such as poor access to medical care, reluctance to seek assistance, and defective case-finding techniques.

The impact of bvFTD on individuals, families, and communities in Africa is exacerbated by the pervasive stigma surrounding the condition. Despite the significant impact on patients and caregivers, there is a limited understanding of and poor societal response to this condition, due to a lack of awareness and understanding of dementia as a biological brain disorder. In some cases, where cultural beliefs attribute the condition to supernatural or spiritual causes, leading to the marginalisation and social isolation of those affected. Low-resource settings are often characterised by a reliance on family members as the primary source of support and care for individuals with dementia, as formal healthcare and social services may be limited or inaccessible. This can lead to significant caregiver burden and distress, particularly when behaviours associated with bvFTD emerge. Caregivers, often family members, may face significant social, emotional, and financial strain, yet be reluctant to seek support due to fears of being perceived as perpetrators of abuse or neglect.

Addressing the complex challenges posed by bvFTD in Africa will require a multifaceted approach that combines efforts to increase public awareness, improve access to healthcare and support services, and tackle the deep-rooted stigma that continues to hinder the well-being of those affected.[16,17,18] Researchers have highlighted the pressing need for studies to be conducted to estimate the prevalence and burden of the disease, particularly within the South African context.[16,17] Additionally, there is a need for tailored psychoeducational interventions that target specific population groups, aiming to increase awareness and reduce the stigma associated with the condition.[16,17,18,19] By addressing the social and cultural barriers that impede access to care and support anywhere, these interventions can empower individuals and their families to navigate the challenges of bvFTD more effectively.

Hospitals, schools, and the media can play a crucial role in disseminating information and raising awareness about dementia, while also fostering a more inclusive and supportive environment for those affected. Furthermore, a participatory health model that engages all stakeholders within the community, including caregivers, healthcare providers, and policymakers, can help to identify and address the unique needs of individuals living with bvFTD.

Potential solutions

Remarkably, some patients with FTD develop a new interest in artistic activities.[20] This is particularly true in patients in whom the disease begins in the dominant (language) side of the brain. All FTD subtypes tend to be relatively sparing of visuospatial abilities, making this an ideal population to work within visual artistic modalities. In the current landscape of unavailable disease-modifying treatments for bvFTD and other non-AD dementias, art can play an important role in the management of these patients. Previous studies show the positive impact of art on the quality of life, neuropsychiatric symptoms, and cognition in patients with dementia.[21] Engaging these individuals in art activities facilitates communication and expression, and strengthens the emotional, perceptual, conceptual, and motor systems.[22] Furthermore, art offers a unique space for social engagement with other community members, which is key to addressing social isolation.

An example of involving patients in art activities includes the *Connections* series of paintings exhibited at Gallery 190 at the University of California San Francisco's Memory and Aging Center in 2022.[23] This project uses postcards received from cognitively normal and impaired individuals as the background canvas. These postcards share experiences, connect people, and become physical memories reflecting how, in real life, humans are made from memories (Figure 1).

Creative activities also provide an opportunity for social inclusion accessible to all individuals, thereby supporting the potential of art in promoting equity in brain health and mitigating stigma. All types of dementia trigger discrimination and stigma. However, younger-onset presentations and behavioural-predominant dementia syndromes such as bvFTD are at higher risk of eliciting stigma and diagnostic delays.[24] These less common types of dementia are often misdiagnosed for psychiatric conditions. The stigma surrounding dementia is a worldwide phenomenon associated with, but not limited to, poor education, false beliefs, and a lack of awareness of dementia syndromes among citizens and healthcare professionals.[25] It creates barriers to early diagnosis and care, harms the dignity of people with dementia, and exacerbates the burden for patients and caregivers.[26] In conclusion, education and art have the potential to improve earlier diagnosis and to provide an opportunity for social inclusion, which are cornerstones for addressing the stigmatisation of dementia.

Art is beneficial for patients with neurodegenerative diseases, although is not always triggered by conscious planning. Some individuals who develop a neurodegenerative disease experience an enhanced drive to create art, particularly through drawing and painting.[27] This phenomenon is more common in FTD and has been proposed as a type of paradoxical functional facilitation. In this process, atrophy in an eloquent brain region unleashes neuronal activity in otherwise suppressed regions associated with visuospatial and executive functions.[28] Considering the potential of art in hampering cognitive decline and reducing the stigma associated with dementia, the emergence of creativity intrinsic to neuropathology may paradoxically be a consequence of the disease and a part of its healing. Unfortunately, this type of behaviour is often not recognised as being caused by a neurodegenerative disease due to a lack of awareness among family members and healthcare professionals. Therefore, this manifestation may be more frequent than we expect, and further research is needed to reveal its accurate prevalence. Understanding this is crucial, as individuals who develop creative behaviours could benefit from art interventions and incentives tailored to their artistic abilities. Moreover, this understanding could lead to a shift in the narrative, focusing on abilities rather than cognitive decline. Such a cultural shift is important to maximise the quality of life of people affected by dementia. In conclusion, art plays a key role in the quality of life of individuals with dementia by enhancing cognitive abilities and reducing stigma.

References

1. Llibre-Guerra, J. J., Iaccarino, L., Coble, D., et al. (2023). Longitudinal clinical, cognitive and biomarker profiles in dominantly inherited versus sporadic early-onset Alzheimer's disease. *Brain Commun*, *5*(6), fcad280. https://doi.org/10.1093/braincomms/fcad280
2. Agarwal, K., Backler, W., Bayram, E., et al. (2024). Lewy body dementia: Overcoming barriers and identifying solutions. *Alzheimers Dement*, *20*(3), 2298–2308. https://doi.org/10.1002/alz.13674
3. Woolley, J. D., Khan, B. K., Murthy, N. K., et al. The diagnostic challenge of psychiatric symptoms in neurodegenerative disease: rates of and risk factors for prior psychiatric diagnosis in patients with early neurodegenerative disease. *J Clin Psychiatry*, *72*(2), 126–133. https://doi.org/10.4088/JCP.10m06382oli
4. Wong, C., Merrilees, J., Ketelle, R., et al. (2012). The experience of caregiving: differences between behavioral variant of frontotemporal dementia and Alzheimer disease. *Am J Geriatr Psychiatry*, *20*(8), 724–728. https://doi.org/10.1097/JGP.0b013e318233154d
5. Uflacker, A., Edmondson, M. C., et al. (2016). Caregiver burden in atypical dementias: comparing frontotemporal dementia, Creutzfeldt-Jakob disease, and Alzheimer's disease. *Int Psychogeriatr*, *28*(2), 269–273. https://doi.org/10.1017/S1041610215001647
6. Chen, K. H., Casey, J. J., Connelly, D. E., et al. (2022). Lower activity linkage between caregivers and persons with neurodegenerative diseases is associated with greater caregiver anxiety. *Psychophysiology*, *59*(8), e14040. https://doi.org/10.1111/psyp.14040
7. Guterman, E. L., Allen, I. E., Josephson, S. A., et al. (2019). Association Between Caregiver Depression and Emergency Department Use Among Patients With Dementia. *JAMA Neurol*, *76*(10), 1166–1173. https://doi.org/10.1001/jamaneurol.2019.1820
8. Franzen, S., Nuytemans, K., Bourdage, R., et al. Disparities, P. I. A. (2023). Gaps in clinical research in frontotemporal dementia: A call for diversity and disparities-focused research. *Alzheimers Dement*, *19*(12), 5817–5836. https://doi.org/10.1002/alz.13129
9. Zapata-Restrepo, L., Rivas, J., Miranda, C., et al. (2021). The Psychiatric Misdiagnosis of Behavioral Variant Frontotemporal Dementia in a Colombian Sample. *Front Neurol*, *12*, 729381. https://doi.org/10.3389/fneur.2021.729381
10. Castro-Suarez, S., Guevara-Silva, E., Caparo-Zamalloa, C., et al. (2021). Knowledge and Attitudes for the Management of Behavioral Variant of Frontotemporal Dementia. *Front Neurol*, *12*, 786448. https://doi.org/10.3389/fneur.2021.786448
11. Guerchet, M. M., R; Lloyd-Sherlock, P; Prince, M; et al. (2017). Dementia in sub-Saharan Africa Challenges and opportunities. *Alzheimer's Disease International*.
12. Kalula, S. Z., Ferreira, M., Thomas, K. G., et al. (2010). Profile and management of patients at a memory clinic. *S Afr Med J*, *100*(7), 449–451. https://doi.org/10.7196/samj.3384
13. Ssonko, M., Hardy, A., Naganathan, V., et al. (2023). Dementia subtypes, cognitive decline and survival among older adults attending a memory clinic in Cape Town, South Africa: a retrospective study. *BMC Geriatr*, *23*(1), 829. https://doi.org/10.1186/s12877-023-04536-3
14. Paddick, S. M., Kisoli, A., Longdon, A., et al. (2015). The prevalence and burden of behavioural and psychological symptoms of dementia in rural Tanzania. *Int J Geriatr Psychiatry*, *30*(8), 815–823. https://doi.org/10.1002/gps.4218
15. Yoro-Zohoun, I., Houinato, D., Nubukpo, P., et al. (2020). Severity of Neuropsychiatric Symptoms and Distress in Dementia among Older People in Central Africa (EPIDEMCA Study). *J Am Geriatr Soc*, *68*(1), 180–185. https://doi.org/10.1111/jgs.16234
16. Rizzi, L., Rosset, I., & Roriz-Cruz, M. (2014). Global epidemiology of dementia: Alzheimer's and vascular types. *Biomed Res Int*, *2014*, 908915. https://doi.org/10.1155/2014/908915
17. Mahomed, A., & Pretorius, C. (2022). Up-Close and Personal: Conceptualizing the Self as Dementia Caregiver: a Study in Soweto, South Africa. *J Cross Cult Gerontol*, *37*(4), 355–374. https://doi.org/10.1007/s10823-022-09460-4
18. Shaji, K. S., Arun Kishore, et al. (2002). Revealing a hidden problem. An evaluation of a community dementia case-finding program from the Indian 10/66 dementia research network. *Int J Geriatr Psychiatry*, *17*(3), 222–225. https://doi.org/10.1002/gps.553
19. de Jager, C. A., Msemburi, W., et al. (2017). Dementia Prevalence in a Rural Region of South Africa: A Cross-Sectional Community Study. *J Alzheimers Dis*, *60*(3), 1087–1096. https://doi.org/10.3233/JAD-170325
20. Friedberg, A., Pasquini, L., Diggs, R., et al. (2023). Prevalence, Timing, and Network Localization of Emergent Visual Creativity in Frontotemporal Dementia. *JAMA Neurol*, *80*(4), 377–387. https://doi.org/10.1001/jamaneurol.2023.0001
21. Fancourt, D., & Steptoe, A. (2018). Cultural engagement predicts changes in cognitive function in older adults over a 10 year period: findings from the English Longitudinal Study of Ageing. *Sci Rep*, *8*(1), 10226. https://doi.org/10.1038/s41598-018-28591-8
22. Emblad, S. Y. M., & Mukaetova-Ladinska, E. B. (2021). Creative Art Therapy as a Non-Pharmacological Intervention for Dementia: A Systematic Review. *J Alzheimers Dis Rep*, *5*(1), 353–364. https://doi.org/10.3233/ADR-201002
23. Owen, T. (2022). Connections. *Gallery 190 from UCSF Memory and Aging Center*. https://memory.ucsf.edu/about/art-mac/gallery190
24. Velilla, L., Acosta-Baena, N., Allen, I., et al. (2022). Analysis of family stigma and socioeconomic factors impact among caregivers of patients with early- and late-onset Alzheimer's disease and frontotemporal dementia. *Sci Rep*, *12*(1), 12663. https://doi.org/10.1038/s41598-022-16400-2
25. Rewerska-Jusko, M., & Rejdak, K. (2020). Social Stigma of People with Dementia. *J Alzheimers Dis*, *78*(4), 1339–1343. https://doi.org/10.3233/JAD-201004
26. Ibanez, A., Pina-Escudero, S. D., Possin, K. L., et al. (2021). Dementia caregiving across Latin America and the Caribbean and brain health diplomacy. *Lancet Healthy Longev*, *2*(4), e222-e231. https://doi.org/10.1016/s2666-7568(21)00031-3
27. Miller, B. L., & Hou, C. E. (2004). Portraits of artists: emergence of visual creativity in dementia. *Arch Neurol*, *61*(6), 842–844. https://doi.org/10.1001/archneur.61.6.842
28. Kapur, N. (1996). Paradoxical functional facilitation in brain-behaviour research. A critical review. *Brain*, *119 (Pt 5)*, 1775–1790. https://doi.org/10.1093/brain/119.5.1775

Dementia risk reduction and stigma: a complex relationship with hopeful potential

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In many ways we live in good times, where death in childhood, early adulthood, and midlife has thankfully become less common, and a much greater proportion of the population now lives until, and often many years past, retirement. Recently, with COVID-19 leading to higher mortality, this extension of lifespan has stopped, but there are still huge increases in life expectancy within living memory. While many people live to older age with excellent cognition, the risk of dementia increases with age and there are more older people alive. Despite the increase in those at risk, the age-related incidence has reduced in some, but not all, countries. This is linked to reduction in potentially modifiable risk factors[1], with our recent work for The Lancet Commission synthesising and adding to knowledge about potentially modifiable risk factors and suggesting that 14 factors account for nearly half of all risks for dementia. In theory, removing these modifiable risk factors might lead to prevention of or later presentation of dementia.[2] This suggests that dementia may potentially be avoidable but is not inevitably so.

Dementia is underdiagnosed, despite diagnosis being the gateway to treatment and services and key to future planning and for relationships. One of the reasons why people do not ask health professionals about a diagnosis even when they are aware of some symptoms is the stigma attached to having dementia.[3] This may be even more evident in lower- and middle-income countries (LMIC), where dementia is not always recognised as an illness or can be stigmatised as a mental health condition and therefore often hidden.[4]

A new source of stigma is to blame individuals themselves for developing dementia because they failed to live a healthy enough life, such as their lifestyle including potentially modifiable risk factors. Projected or self-shame around having the condition can potentially be widened to prevention, to blame people for the illness and to justify restriction of help and information. I was recently astounded to be told socially of a London-based carer who said her friends had told her it was her mother's own fault that she had developed dementia. This cruel and misinformed blame was because her mother had not taken hormone replacement therapy to treat her menopause symptoms. Thus, blaming neither relies on accurate information about risks,[2] nor on assessing the ability to change your life decades before anyone knew that avoiding dementia might be possible, nor on considering the differential difficulties in making changes according to resources, and certainly not on normal human empathy.

Another concern about stigma was shared by an anonymous referee on an (ultimately successful) grant application, who said we should not try to give people the information and tools to reduce their risk of dementia, as asking people if they want to change their behaviour as a form of censure. Similarly, I have heard colleagues say that we should not suggest individuals could take measures to prevent traumatic brain injury like using helmets on cycle rides, as this was about making individuals feel guilty, and change should only be made through legislation.

I do not see prevention as a choice between individual and public health measures.[2] This stigma is of course not only wrong but also counterproductive, and we know that the stigma associated with obesity and diabetes reduces the chances of people being able to make changes or seek help.[5,6]

However, the more hopeful side of knowing of the possibility of prevention or risk reduction is that the possibility of positive interventions to prevent and alleviate dementia can lead to positive attention to the condition and a sense of optimism where before there was therapeutic nihilism. Our work and the work which we have built on in the Lancet commissions on dementia prevention, intervention, and care[7] has been associated with numerous media articles telling people there is hope, which in some cases lead individuals to make changes, although we cannot quantify these numbers. At the first presentation, I heard a prominent academic saying the commission had changed his view of dementia and given him hope. Many people have told me personally or on social media that they have had their hearing tested and started wearing hearing aids building on the commission's work. One person tweeted that acting on the 2017 commission meant he had his hearing tested and been able to hear birds sing since then and possibly contributed to him avoiding dementia. In addition, I have seen posters in audiology clinics explaining the link.

The commissions' accessible and summarised explanations of risk have informed changes in policy in many countries to reduce risk factors. They have also had over 15,000 citations to date, as scientists around the world build on the work and there is a consequent and positive explosion of knowledge.

In addition to leading to a reduction in dementia, addressing risk can also lead to dementia occurring later in life. People who exercise regularly, do not smoke or drink too much alcohol, and remain cognitively active in late life have a lower risk of dementia than those with less healthy lifestyles.[8] Importantly, those who have such a healthy lifestyle not only live longer but have a compression of morbidity – meaning that they can live healthier for longer, and if they develop dementia, they have it for fewer years than the number of years by which their life has been extended.[8]

I would like to conclude by talking about how the awareness of the stigma paradox informs us about how to implement health advice and policy. Hopeful knowledge about prevention can transform our understanding and view of dementia positively and make us talk more openly about avoiding dementia and thus reduce stigma. Lifestyle blame and humiliation are potential problems for dementia risk reduction. It is therefore essential to focus on the positives of giving people information while acknowledging that lifestyle is often not a choice for people in disadvantaged positions. People with more social, economic, time, and education resources find choosing a healthy lifestyle more possible, such as having the time and possibly money to socialise more, the option of living in a place where there is low air pollution, and access to safe spaces to exercise. They (or we) can find and weigh up information and avoid false claims of miracle cures while acting on new, credible findings. A home where there is reasonably priced healthy food nearby makes it easier to avoid obesity, and resources that in some countries are only available to the wealthy include healthcare for hearing, high cholesterol, smoking cessation, blood pressure, diabetes, and vision. It can enable individuals, families and government to act to reduce the number of people developing dementia.

References

1. Naaheed Mukadam; Frank J. Wolters; Sebastian Walsh; Lindsay Wallace; Carol Brayne; Fiona Matthews; Simona Sacuiu; Ingmar Skoog; Sudha Seshadri; Alexa Beiser; Saptaparni Ghosh; Gill Livingston Changes in prevalence and incidence of dementia and risk factors for dementia an analysis from cohort studies The Lancet Public Health, Volume 9, Issue 7, July 2024, Pages e443-e460
2. Gill Livingston, Jonathan Huntley, Kathy Y Liu, Sergi G Costafreda, Geir Selbæk, Suvarna Alladi, David Ames, Sube Banerjee, Alistair Burns, Carol Brayne, Nick C Fox, Cleusa P Ferri, Laura N Gitlin, Robert Howard, Helen C Kales, Mika Kivimäki, Eric B Larson, Noeline Nakasujja, Kenneth Rockwood, Quincy Samus, Kokoro Shirai, Archana Singh-Manoux, Lon S Schneider, Sebastian Walsh, Yao Yao, Andrew Sommerlad, Naaheed Mukadam Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission 31st July 2024
3. Parker M, Barlow S, Hoe J, Aitken L. Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. Int Psychogeriatr 2020; 32: 1–24.
4. Nwakasi CC, de Medeiros K, Bosun-Arije FS. "We are doing these things so that people will not laugh at us": caregivers' attitudes about dementia
5. Batterham RL. Weight stigma in healthcare settings is detrimental to health and must be eradicated. Nat Rev Endocrinol 2022; 18: 387–88.
6. Nikki-Anne Wilson and Kaarin J. Anstey, Dementia Prevention and Individual and Socioeconomic Barriers: Avoiding "Lifestyle" Stigma. The Gerontologist, 2024, 64, 1–5 https://doi.org/10.1093/geront/gnad130
7. Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimaki, M., Larson, E. B., Ogunniyi, A., & Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet, 396(10248)
8. Dhana K, Franco OH, Ritz EM, et al. Healthy lifestyle and life expectancy with and without Alzheimer's dementia: population based cohort study. BMJ 2022; 377: e068390.

Stigma and awareness: some critical questions

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Twenty-first century psychiatric public health has sought to challenge the stigmatisation of mental disorders by promoting greater public awareness. Government and third-sector campaigns, fronted by celebrities and advocates, repeatedly implore us to better understand and open up about mental health and other health conditions. Dementia illustrates the trend. Over the past two decades, related organisations have produced campaigns to assess and change how publics, both affected and not affected by dementia, including healthcare practitioners, think about and act toward dementia, focussing on raising awareness to tackle stigma.[1,2] Here, I want to critically reflect on two questions: is stigma a problem? And is awareness a solution?

Is stigma a problem?

Between 2000 and 2020, the number of academic publications on dementia and stigma increased 600% as a proportion of all publications.[3] Such work has repeatedly suggested that some people or institutions have problematic dispositions, characterised as *prejudice*, *discrimination,* and *ignorance*,[4] toward dementia and those affected by it. Stigma is argued to degrade the circumstances of people affected by dementia, most obviously when they are treated worse than they might be if dementia was not stigmatised.[5,6]

Prejudice speaks to attitudes that frame dementia negatively without just cause. Perhaps no controversy characterises this bad-attitude problem more than contentions regarding the word "suffer." The language of "suffering" has been criticised by many dementia advocates – including people living with dementia – as stigmatising, because it depicts dementia in an excessively negative light.[7,8] However, many people affected by dementia do say that they experience suffering and would prefer that their lives were untouched by dementia.[9,10] Many who have not experienced dementia feel similarly.[11,12] When does such sentiment become prejudicial? Ultimately, the concept of anti-dementia prejudice depends on our ability to distinguish between justified and unjustified negativity toward dementia. Such distinguishing strikes me as neither desirable nor possible.

The concept of *discrimination* is when "bad thought" turns into "bad action" against people with dementia. In my own work with people diagnosed with dementia, it is discrimination that most typically resonates. Many participants express concerns that others will treat them as lesser, and therefore often work to conceal their diagnoses.[13,14] Participants regularly use the word "stigma" when expressing fear of discrimination. Far less frequent, however, are examples of discrimination having happened to them directly.

This observation echoes Graham Scambler's distinction between felt and enacted stigma.[15] Working on epilepsy, Scambler challenged dominant notions of stigma, arguing that for his participants, their fear of potential discrimination worsened their lives beyond direct discrimination from others.

Two caveats are crucial here. First, there are very real instances of direct discrimination against people with dementia. Felt stigma merely reminds us that such instances of direct discrimination can be subordinate to fear of discrimination itself. Second, felt stigma is no less real or problematic than enacted stigma. It can ruin people's lives, as I have documented in heartrending examples.[3] For Brian, a retired engineer with mixed dementia, the worst aspect of his condition was the fear of being judged when he spoke. His wife and children assured me that this did not happen, but nonetheless, Brian tearfully told me that he self-isolated to avoid others' judgement.

A related issue with stigma work is an underlying moralisation of personal failing. Researchers assess the attitudes of various groups (e.g., older people, healthcare workers) and judge those attitudes as stigmatising or not. This moral personalisation of stigma risks obscuring the structural conditions that generate potential for stigma.[19] For instance, growing wealth and health inequality puts older people at risk of the kinds of abjection and desolation that typify stigmatic depictions.[20] As older people with impairments are pushed into poverty and disability,[21] it seems misguided to moralise people for negatively interpreting those negative circumstances.

In work that does consider structural stigma, operationalisations often conflate the institutional contingencies of services (e.g., funding, eligibility, accessibility) and healthcare worker attitudes.[16,17] This focus on staff attitudes perpetuates criticisms of carer attitudes that were common in early personhood scholarship and have since been critiqued for decontextualising structural problems and blaming individuals.[18] Practitioners are often unable to implement their desired standards of care because of difficult institutional circumstances, and are regretful of the constrained nature of their practice and its consequences for people with dementia. Practitioner attitudes are not irrelevant, but the material impoverishment of dementia care (e.g., two year waits for memory services) leaves little scope for individual staff to transform structural inequities.

The most troubling example of this moralisation of stigma, attributing structural phenomena to individuals or groups, attends to ethnicity. A significant subfield of stigma work measures various ethnicity-associated inequalities (e.g., diagnosis rates) and attributes those inequalities to ethnicity-associated stigma. Without acknowledging various forms of institutional racism that undermine service engagement, such work blames prejudice and ignorance, purportedly endemic to those minoritised populations.[22,23] The danger here is that the injustices faced by minoritised communities are oversimplified and attributed to them, or some aspect of their being, rather than underlying social and political forces.

I see stigma as a political problem in the dementia economy. Focussing on bad attitudes risks obscuring, if not perpetuating, the structural determination of stigmatising circumstances (e.g., poverty, racism). For example, Aelwyn Williams' recent exploration of British dementia policy during the 2010s documented the long-term cutting of support, materially worsening people's circumstances and ultimately leaving services vulnerable to a pandemic that disproportionately killed people with dementia.[24] In such contexts, people's lives can be worsened by understandable fears of abjection and discrimination in environments hostile to people living with dementia.

Is awareness a solution?

The 2012 edition of this report stated that "it is very important that there is better public awareness and understanding to reduce the stigma associated with dementia."[1] Awareness campaigns have a long history of contributing to public health improvements (e.g., lung cancer and sexually transmitted infections). In response to dementia, the benefits of awareness are articulated as reducing stigma by making people think about and act toward dementia in less stigmatising ways.[25] Here, *ignorance* is important, grounding convictions that making people more knowledgeable will address stigma.

The first issue with an awareness approach to stigma is the matter of whether and how ignorance equates to stigma. Across life, non-expert ideas differ from expert ideas in many ways, and this does not intuitively warrant accusations of stigma. However, stigma-related work can appraise lay (including families and staff) knowledges against institutional knowledges, and can conflate incongruencies with evidence of stigma. The more nuanced challenge is determining what particular types of ignorance are harmful, but such judgement is difficult given the uncertainty of contemporary knowledge-claims about dementia.

This is the second issue with awareness – the question of how one appraises knowledge of dementia. In stigma work, knowledge is often assessed against certain claims regarding dementia, particularly that it has discrete neurophysiological aetiologies, is distinct from normal ageing, and necessitates technical interventions, e.g., diagnosis. These claims form correct dementia knowledge, but, in my view, none is settled. Briefly:

1. Older brains are commonly characterised by varied overlapping senescence and neuropathologies, poorly correlated with cognitive function.
2. Claims distinguishing dementia and ageing (e.g., "dementia is not a normal part of ageing") contradict some clinical, pathological, and epidemiological evidence that indicates that a) ageing is typified by pronounced physiological, cognitive, and functional heterogeneity, and b) the common dementias significantly overlap that heterogeneity.[26,27,28,29]
3. Despite huge resourcing, promised technical interventions have not materialised, and emerging drugs are mired in controversy, including several deaths. A thorough appraisal of these issues is beyond the scope of this essay – see chapter four of *The Biopolitics of Dementia*[3] for a detailed discussion.

A third issue is that awareness and stigma are not inversely correlated. Research related to awareness efforts around psychiatric disorders, such as schizophrenia, which attribute them to physiology in order to elicit public sympathy, found that that such messaging can depict those affected as being beyond self-control, and therefore more dangerous.[30] In a similar fashion, some survey evidence has suggested that the growing public profile of dementia over recent decades has correlated with increasing public fear.[31] There are several potential explanations for this. For example, the rejection of normal ageing leads to stakeholders arguing that dementia is not normal in order to destigmatise it. The Lancet commission on mental health stigma suggests social contact as the most effective stigma reduction strategy.[32]

Alongside rejections of normal ageing and appeals to neuropathology, much awareness work promotes positive depictions of dementia.[33,34] These positive publicity efforts risk *benevolent othering*, whereby well-meaning attentions are focussed on a population and demarcate them as exceptional and in need of special treatment.[35] Such campaigning can single out people with dementia as a particular societal problem. Ultimately, the relative positiveness or negativeness of messaging may be incidental. Efforts to draw public attention to dementia do the same basic work of emphasising its noteworthiness. Awareness may intensify stigma.

Conclusion

Over the past decade, I have become uncomfortable with approaches to stigma as a leading dementia problem. Substantial growth in efforts to assess stigma and intervene via increasing awareness have inflated the public profile of dementia, and panic has risen accordingly,[31] without corresponding improvements in care. Care quality may have even declined over recent years in some respects, e.g., cholinesterase inhibitor defunding in France,[36] increased antipsychotic use in the UK,[37] anti-amyloid licensing in the U.S.[38,39] Such awareness work exemplifies a broader trend of institutional responses to dementia as an information issue. In some instances, focussing on awareness has facilitated the conflation, and even substitution, of practical support with information provision, e.g. the UK's dementia friends scheme under austerity.[3,24]

Stigma-related work should explicitly emphasise that materially improving the circumstances of people affected by dementia – through things like respite facilities, financial transfers, admiral nurses, etc. – would generate conditions in which life with dementia was less fear-worthy. Situating bad experiences of dementia in corresponding material circumstances provides a tangible and generalisable aspiration for meaningful interventions that offer practical applied support for people in need. People affected by dementia are not going to awareness or anti-stigma their way out of the challenges of cognitive impairment amidst harsh political economies of care. Awareness-raising would be more productive if corresponding material conditions were in place that supported people to act on the information provided to achieve positive ends.

References

1. ADI (2012). World Alzheimer Report 2012: Overcoming the stigma of dementia.
2. ADI (2019). World Alzheimer Report 2019: Attitudes to dementia.
3. Fletcher, J.R. (2024). The Biopolitics of Dementia: A Neurocritical Perspective. Routledge.
4. Thornicroft, G., Rose, D., Kassam, A., and Sartorius, N. (2007). Stigma: ignorance, prejudice or discrimination? The British Journal of Psychiatry, 190, 192–193.
5. Werner, P., and Kim, S. (2021). A Cross-National Study of Dementia Stigma Among the General Public in Israel and Australia. Journal of Alzheimer's Disease, 83, 103–110.
6. Herrmann, L.K., Welter, E., Leverenz, J., Lerner, A.J., Udelson, N., Kanetsky, C., and Sajatovic, M. (2018). A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial? The American Journal of Geriatric Psychiatry, 26, 316–331.
7. Swaffer, K. (2014). Dementia: Stigma, Language, and Dementia-friendly. Dementia, 13, 709–716.
8. Putland, E., and Brookes, G. (2024). Dementia stigma: representation and language use. Journal of Language and Aging Research, 2, 5–46.
9. Shiba, T., Yamakawa, M., Endo, Y., Konno, R., and Tanimukai, S. (2022). Experiences of families of people living with frontotemporal dementia: a qualitative systematic review. Psychogeriatrics, 22, 530–543.
10. Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., and Moniz-Cook, E. (2016). Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic review. The British Journal of Psychiatry, 208, 429–434.
11. Corner, L., and Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. Journal of Aging Studies, 18, 143–155.
12. Marhánková, J.H., and Honelová, M. (2024). Making sense of dementia: Older adults' subjective representations of dementia and Alzheimer's disease. The Journals of Gerontology: Series B, 79, gbae056.
13. Fletcher, J.R. (2020). Distributed selves: Shifting inequities of impression management in couples living with dementia. Symbolic Interaction, 43, 405–427.
14. Fletcher, J.R. (2019). Discovering deviance: The visibility mechanisms through which one becomes a person with dementia in interaction. Journal of Aging Studies, 48, 33–39.
15. Scambler, G. (1989). Epilepsy. Tavistock.
16. Nguyen, T., and Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. Dementia, 19, 148–181.
17. Mantzorou, M., Economou, M., Kalokerinou, A., Sourtzi, P., Zyga, S., Politis, A., and Koukia, E. (2020). Exploration of the relationship between stigma and burnout among Greek nurses in dementia care. Journal of Nursing Management, 28, 615–624.
18. Fletcher, J.R. (2020). Renegotiating relationships: Theorising shared experiences of dementia within the dyadic career. Dementia 19, 708–720.
19. Stuart, H., and Sartorius, N. (2022). Paradigms Lost, Paradigms Found: Lessons Learned in the Fight Against the Stigma of Mental Illness. Oxford University Press.
20. Bambra, C. (2024). The u-shaped curve of health inequalities over the 20th and 21st centuries. International Journal of Social Determinants of Health and Health Services, 54, 199–205.
21. Barnes, M. (2022). Longer-Term Pensioner Poverty and Poverty Transitions. City, University of London.
22. Fletcher, J.R., Zubair, M., and Roche, M. (2022). The neuropsychiatric biopolitics of dementia and its ethnicity problem. Sociological Review, 70, 1005–1024.
23. Fletcher, J.R. (2020). Positioning ethnicity in dementia awareness research: does the use of senility risk ascribing racialised knowledge deficits to minority groups? Sociology of Health and Illness, 42, 705–723.
24. Williams, A. (2022). Looking for Dementia Friendly Communities: Towards an Interdisciplinary Understanding Using a Case Study, Fragments and Cut-Ups. Swansea University.
25. WHO (2017). Global Action Plan on the Public Health Response to Dementia 2017–2025. https://www.who.int/publications-detail-redirect/global-action-plan-on-the-public-health-response-to-dementia-2017---2025.
26. Boyle, P.A., Wang, T., Yu, L., Wilson, R.S., Dawe, R., Arfanakis, K., Schneider, J.A., and Bennett, D.A. (2021). To what degree is late life cognitive decline driven by age-related neuropathologies?. Brain, 144, 2166–2175.
27. Gonzales, M.M., Garbarino, V.R., Pollet, E., Palavicini, J.P., Kellogg, D.L., Kraig, E., and Orr, M.E. (2022). Biological aging processes underlying cognitive decline and neurodegenerative disease. The Journal of Clinical Investigation, 132, e158453.
28. Habes, M., Grothe, M.J., Tunc, B., McMillan, C., Wolk, D.A., and Davatzikos, C. (2020). Disentangling heterogeneity in Alzheimer's disease and related dementias using data-driven methods. Biological Psychiatry, 88, 70–82.
29. Yu, L., Boyle, P.A., Wingo, A.P., Yang, J., Wang, T., Buchman, A.S., Wingo, T.S., Seyfried, N.T., Levey, A.I., De Jager, P.L. and Schneider, J.A., 2022. Neuropathologic correlates of human cortical proteins in Alzheimer disease and related dementias. Neurology, 98, e1031–e1039.
30. Larkings, J.S., and Brown, P.M. (2018). Do biogenetic causal beliefs reduce mental illness stigma in people with mental illness and in mental health professionals? A systematic review. International Journal of Mental Health Nursing, 27, 928–941.
31. Fletcher, J.R. (2021). Destigmatising dementia: The dangers of felt stigma and benevolent othering. Dementia, 20, 417–426.
32. Thornicroft, G., Sunkel, C., Aliev, A.A., Baker, S., Brohan, E., El Chammay, R., Davies, K., Demissie, M., Duncan, J., Fekadu, W., and Gronholm, P.C. (2022). The Lancet Commission on ending stigma and discrimination in mental health. The Lancet, 400, 1438–1480.

33. Quinn, C., Pickett, J.A., Litherland, R., Morris, R.G., Martyr, A., and Clare, L. (2022). Living well with dementia: What is possible and how to promote it. International Journal of Geriatric Psychiatry, 37, 1–7.

34. Smith, G., and Simkhada, B. (2019). Co-Creating the living well with dementia message. Issues in Mental Health Nursing, 40, 825–826.

35. Grey, F. (2016). Benevolent othering: Speaking positively about mental health service users. Philosophy, Psychiatry and Psychology, 23, 241–251.

36. Walsh, S., King, E., and Brayne, C. (2019). France removes state funding for dementia drugs. BMJ, 367, l6930.

37. Howard, R., Burns, A., and Schneider, L. (2020). Antipsychotic prescribing to people with dementia during COVID-19. The Lancet Neurology, 19, 892.

38. Digma, L.A., Winer, J.R., and Greicius, M.D. (2024). Substantial doubt remains about the efficacy of anti-amyloid antibodies. Journal of Alzheimer's Disease, 97, 567–572.

39. Thambisetty, M., and Howard, R. (2024). Conveying risks of harm in Alzheimer disease by amyloid lowering. JAMA, doi:10.1001/jama.2024.7548.

Chapter 4:

Case studies of stigma

Stigma takes on many forms, as laid out in Chapter 1. In this chapter we compile essays that look at how stigma plays out concretely through specific examples. The case studies in this section do not seek to shame, but to understand where stigmatic beliefs may come from so that it can be addressed at the root.

The chapter opens with essays by John-Richard Pagan and Natalie Ive, two people living with dementia who describe their first-hand experiences of stigma, beginning even before they received their diagnoses. Shana D. Stites then explores how recent strides in diagnostic tools for Alzheimer's disease may see their impact stunted by pervasive stigma. In Australia, Sarang Kim, Moyra E. Mortby, and Kaarin J. Anstey seek to understand who is more likely to hold stigmatic beliefs and how this information can help tackle it – while Esra Hassan and Nicolas Farina explore perceptions of dementia among British adolescents. After years of reporting from Ghana, Namibia, and Madagascar, Lee-Ann Olwage paints a moving picture of how some persistent cultural beliefs about dementia, such as its association with witchcraft, impact people living with the condition, especially women. On the other side of the globe, Pamela Roach and Jennifer D. Walker explain the particularities of Canadian Indigenous Peoples' experiences of dementia. Iryna Shevchenko, meanwhile, lays bare how the ongoing war with Russia has left people living with dementia especially vulnerable in Ukraine. Finally, Maha El Akoum looks at how the conversation around palliative care for people living with dementia in the Middle East has to adapt to cultural needs.

Residents of Okinawa, Japan, engage in exercises at the community centre (Reina Ogawa Clarke)

Speaking up for change: the long road to a Lewy body diagnosis in the U.S.'s veteran healthcare system

Brother John-Richard Pagan

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My name is Brother John-Richard Pagan, and this is my story. I am of Puerto Rican descent and grew up in the United States in the 1960s, 70s, and 80s in a society that would challenge me for being gay, even to the point of having me discharged (albeit honourably) from the US Navy. But from the very beginning, I showed determination to succeed in life against all odds, spending another 20 years fighting addiction, living on the streets, and being a victim of many of my own foolish choices in demanding to belong.

That's why it was no surprise when I went from working at a local gas station, to getting a job for a local deli food delivery company, to working for a large wholesale travel company, to managing a travel consulting company and doubling its gross sales, to working for the travel reservation software creators, which in turn would lead me into the amazing world of computer technology at a time when the fears of a Y2K (Year 2000) bug in technology was leaving many companies across the globe racing to find solutions to a problem they could not quite fathom.

After 10 years in the computer industry, I left technology behind to start successfully running a coffee shop for another four years, before returning to school to earn my master's degree in clinical psychology with a specialisation in marriage and family therapy. It was this journey that would lead me to want to help others after finding courage, strength, and hope in getting myself clean and sober. Even now, as I sit here and contemplate my story, I see the gifts I have gained that led me to become the man I am today. My faith has led me to accept the walk of a monastic life, and I am able to share real compassion with the suffering of those I speak to, understanding their struggles even as I have learned to heal from my own.

In 2013, I was in my 40s and working on my PhD in clinical psychology. I was excited to be continuing my education in this amazing field. Only I began to seriously struggle in a couple of my classes. My advanced statistics instructor would tell me that on exams I could answer advanced questions well enough, but I would get basic formulas wrong, even as they were needed to get to more advanced solutions. I was also being told that I was misinterpreting lectures and notes. I studied hard, but nothing seemed to improve. Having had between a 3.5 and a 3.73 grade point average since my bachelor's degree, this was not my norm. I went to my dean for help, only to be told I was overreacting and perhaps should consider seeing a therapist to work on my anxiety. Instead, I went to the veteran's hospital for help.

Between 2013 and 2014, I received many neuropsychological assessments as well as behavioural tests. Initially, I was told that I had an attention deficit disorder (no earlier history) and a cognitive language expressive-receptive disorder. A month or so later, my diagnoses was elevated to mild cognitive impairment (MCI).

My school acted as though I was making it all up. One professor cornered me and demanded to know exactly what I was diagnosed with, so I told him. He was a neuropsychology assessment specialist, yet he insisted there was no such thing as an expressive-receptive language disorder. That, and the dismissal letter I would receive for not being committed enough to my programme, would be just the start of my challenges in getting a diagnosis, care, and support.

In 2014, I was told by my neurologist in California that I should consider moving closer to my family, as he did not believe I was going to get better. So, I had to uproot myself and my dog on a very tight veteran's disability check and move across the country to Virginia. I was now struggling from issues with balance and weakness on my left side as well as the MCI. I made the trip and checked into their local veteran's hospital and clinics to receive care. How was I to know that they would make me start all over again and get a referral from my new primary care provider to see a neurologist? In turn, the neurologist wanted to carry out a whole new neuropsychological assessment on me. Meanwhile, I was complaining of dizzy spells and zoning out suddenly. So, they decided to prove to me that nothing was wrong by connecting me to a heart monitor for 30 days. On that first evening, the monitoring station was calling for an ambulance to my home. My heart had stopped, first for four seconds and then for six seconds: my zoning out turned out to be an autonomic issue with my heart. A pacemaker went in after testing showed that

I also had low blood pressure with sudden drops occurring at unexpected times. I was also put on a medication to keep my heartbeat regular.

I say all of this because I want it to be clear that the biggest challenge for me was getting people to believe me when I said there was a problem. Ageism is rampant in the West. People assume that if you are under the age of 65, there is no way that you can be having issues with cognitive impairment. They just don't take you seriously. Every symptom I shared was met with doubt and suspicion – a story that seems to resonate with a lot of other people. When a doctor was finally willing to say I had a neurodegenerative disease, dementia, he told me that we could talk more about it in three to six months and disconnected the telehealth video call, leaving me standing in an empty room, at my primary clinic, with no support whatsoever.

I spent two more years trying to get a specific diagnosis. One doctor told me that he only knew how to evaluate for Alzheimer's disease, and as it did not appear to be Alzheimer's, I should simply go on and live my life until more symptoms presented and could help them identify what type of dementia I had. Other veteran doctors wanted to prove the first doctors wrong, so they insisted I was fine. One neuropsychologist put a giant five-piece puzzle in front of me and told me to put it together. When I did, she said I did not have MCI.

I had to do my own research, find my own support group, and figure out for myself what type of dementia this might be. I then took all the paperwork about dementia with Lewy body to a Parkinson's specialist at my veteran's hospital and begged her to review my case. She sent me to a civilian (non-veteran) neurologist who specialises in certain types of movement disorder, who, initially told me again that I was too young to have Lewy body. They say that dementia with Lewy body is like a rollercoaster with symptoms all over the place. Well for me, the rollercoaster was simply getting diagnosed.

But my persistence paid off, and my bold willingness to face doctors and tell them that they were practicing ageism or simply brushing off a condition because they weren't willing to look deeper, taught me that I was in control of my care, and no one was going to simply rule me out. In 2018, I was finally diagnosed with Lewy body dementia. This was the cause of my cognitive changes, issues with attention, mood swings (increased anxiety, depression, and agitation), loss of balance, and autonomic dysfunction. I also learned that my REM sleep behaviour disorder, which had been ongoing for over 10 years, was probably one of the early symptoms that had been overlooked. The non-veteran specialist is now my regular doctor, but only after I had him apologise to me for his ageist remark.

Today, I am an advocate for those living with dementia and their care partners. As a gay man, I don't have children to go to for support, nor do I have a spouse. I instead go to my parents, who are more than 20 years older than me. They are also going through their own physical and cognitive changes while trying to be there for mine. It is an exceedingly difficult challenge, as at times roles get switched and care receiver becomes care partner. We worry all the time about what will happen to me if I need greater care and they are unable to provide it, or worse, they are no longer around to give it.

A question I repeatedly ask is: Where do I go if I need assisted living or memory care? In my country, I cannot file for federal health insurance, Medicare, until I am 65 years old. There are veteran facilities that offer these services, but I was kicked out of the US Navy for being gay, and so I don't feel safe going to a veteran facility. I don't want to return into the 'closet,' living a secret and never able to be true to myself, just to receive the same kind of care others receive. I worry about being treated with dignity. There are a few LGBTQIA-friendly places, however, they tend to cost a lot of money that I do not have. I sit with a knot in my stomach worrying about this every day.

> **"They say that dementia with Lewy body is like a rollercoaster with symptoms all over the place. Well for me, the rollercoaster was simply getting diagnosed."**

All of these are reasons why I feel the need to advocate and speak my truth. I know there are others struggling out there. Some are in much darker places than myself. I, at least, have a couple of support systems that many don't have when they first get diagnosed, like my 12-step programme. Having been sober for more than 10 years now, I have been taught tools that I use like living one day at a time and staying in the present moment. I have learned to work on things I am concerned about and can change, but to let go of things I have no control over, for which I seek a higher power than myself to take on. Finding acceptance in a higher power helped me in my darkest hours when I was angry and bitter. It reminded me of the importance of community and faith and led me to an Episcopal family that would support my journey. That same community gave me purpose as I became more involved in leadership and spirituality.

Finding purpose and a place to be needed has helped my ability to advocate for myself and others. It has allowed me to become more involved in dementia discussions and change at the state, federal, and even global level. But what I have seen and done still does not amount to enough. Many people out there do not receive the care they need or deserve. Many in the LGBTQ community have minimal support or are less trusting of medical professionals, as are other cultural minorities in my country. Low-income individuals are less likely to receive the care that I receive to make life easier. In the U.S., veterans are eight times more likely to develop dementia, and yet it is a struggle for people under the age of 65 to even get seen by a neurologist. Even if someone is lucky enough to have a doctor willing to truly assess for cognitive impairment and give a diagnosis, many continue to be overlooked by their medical professionals, who talk to their spouse or care partner instead. Both the medical and social communities dumb down what they say, thinking that it is necessary to get their point across to someone living with dementia, or else they speak slowly and very loud as though we are deaf. Many in society also continue to assume that a dementia diagnosis means I need a giant whiteboard and calendar to get what thoughts I still have across to others. As new tests are developed to make the diagnosis process easier, access and costs still prevent low-income communities, minority communities, and lower-income countries from receiving them.

There is still much to be done to advocate for dementia, and to be honest, I can only continue for so long. It will be up to new voices to speak up and demand change, to share their story, whatever it might be, and to wake people up to what good is happening and what challenges need to be faced with courage and determination. I pray that someone will read this and say: "I am ready to be that voice!"

"You don't look like you have dementia!": what I wish people knew about living with primary progressive aphasia

Natalie Ive

Person living with primary progressive aphasia, Australia

My name is Natalie. I live in Melbourne, Australia, and I was diagnosed with Primary Progressive Aphasia (PPA) in 2021. I'm an educator in special education and freelance between universities, working with teams on research projects. I am on the board directors of the Australian Aphasia Association and sit on the Dementia Australia Advisory Committee. I was also recently appointed to represent Australia on the ADI Global Dementia Expert Panel (GDEP). I also chair Hobsons Bay Dementia Soaring Falcons, an alliance that my cofounders and I created as a call to action for those living with dementia and their carers in our municipality. These roles have enabled me to keep working and advocate for all people living with dementia.

In my experience, very few people have heard of aphasia and even fewer about Primary Progressive Aphasia, a language-led dementia that affects all aspects of communication: talking, understanding, speech, reading, writing, and using numbers. Mobility and swallowing challenges can arise for people as the disease advances. It is crucial to highlight that symptoms vary from person to person and intelligence is unaffected. Still, people with PPA can face negative attitudes from others who do not understand the condition or know how to support communication.

I first knew something was different with me when I would have trouble finding words to say or think. Now this was different for me as an educator; I used to talk academically and write abstracts with relative ease. I started using Google or asking my daughters to help me when I had word blanks. At work, I was not able to recall some of the students' names in the classroom and schoolyard to bring them to attention, so I would use workarounds to find out their names. As if that wasn't enough, I forgot how to fill out student progress reports, which is something I did every day with relative ease. I did unfortunately lose my job and the students I adored.

My GP has been supportive of me throughout my journey so far; however, when I first went to the hospital, I felt alone in my journey when I lost my ability to speak and did not know my surroundings nor the names of my family members. I felt I wasn't being heard or trusted by the medical sector, which was looking after me and supposed to help. Even if they didn't believe me at the time, some of the doctors needed a course in sympathy and effective communication.

I had to search for a solution myself. In those unsure, dark times, I would be sitting in my lounge alone, crying and thinking: What I am going to do? How do I deal with all my symptoms happening to me? But underneath, I had this burning tenacity that I was going to find a way, no matter what it took. As luck would have it, a good friend of mine – also an advocate – suggested I contact the advocate's programme at Dementia Australia, which is why I am an advocate today.

I also reached out to my friends at the Dementia Alliance International (DAI) online Zoom support group, who encouraged me to see my trusted GP for a referral to see a speech pathologist. I followed through with their recommendations and soon found out what was happening to me. After lengthy tests and appointments, I was finally diagnosed with primary progressive aphasia.

It should be understood that no two people living with dementia are the same, and everyday symptoms will vary. For instance, some days I wake up and my speech is fine. That's when I run for dear life to complete all my written tasks, because I don't know what tomorrow will bring. Life is unpredictable, just like this condition. On other days, I have limited speech. This is a frightening place to be in, especially if I have scheduled meetings where things can change spontaneously if agendas are not followed. It can be quite overwhelming for me to find words for my thoughts on the spot.

People often don't understand how difficult it is for me to listen during a conversation and take all the information in. This can be disappointing as by the time I do, sometimes the conversation has moved on, and my thoughts are no longer relevant. This is disempowering. As if that wasn't enough, I can no longer multitask. My cognitive processing speed is slower, resulting in confusion and difficulty navigating between different actions, causing me to lose track of what I want to say.

I once had an online meeting scheduled and needed to share documents on Zoom. I knew this was going to be difficult for me as it requires lots of different actions while listening to people at the same time. I explained this was no longer in my skill set and if someone else could share the slides for me instead. One member sent me a YouTube tutorial video and said to follow that. That was admirable of them, however, this was not the issue – not to mention I would forget the instructions after watching it.

This is an example of some people not understanding just how much difficulty I have doing multiple actions at once. People just don't understand because they see it as something simple, because they do it and so should everyone else. But living with a degenerative condition means I have lost some of my abilities and need the support of those around me, and that little support makes a big difference to me. Some people do not see my PPA or acknowledge it at times, and this is very frustrating and hurtful.

Due to the stigma surrounding dementia, I have unfortunately not been able to secure any contracts within the education system. However, the great news is that I have now found purpose through my advocacy work to be able to freelance between universities and work with teams on research projects, such as a PPA guide for the Australian Aphasia Association, which has been translated into Greek, as well as a research project with the University of Melbourne looking into the importance of eye checks for people living with dementia. The PPA guide was co-developed by Cathy Taylor, Deborah Hersh, Jade Cartwright and me. I approached Professor Jade to discuss a much-needed PPA strategy as too many people are missing out on services. After robust conversation and brainstorming, this led to the PPA guide.

Personally, my eyesight and communication are a vital part of my life. Vision and communication are a key priority for everyone, but they hold even greater significance for those of us living with dementia as they can significantly impact our quality of life and ability to maintain our independence, perform daily tasks, and be able to navigate the world around us. Imagine if you will, waking up one morning and not being able to communicate as well as having vision changes starting to happen. A frightening prospect you might say. I heavily rely on my glasses to ascertain visual cues when I don't understand conversation or words. I am uncertain about the future effects of my dementia as daily symptoms vary, but I am aware of the impact on my speech and eyesight.

When engaging with people living with PPA, it is essential to follow these respectful guidelines:

- Speaking slowly.
- Pausing between sentences.
- Confirming understanding.
- Utilising visual cues, such as images or written words, to facilitate communication. This approach can be useful both for verbal and nonverbal persons.
- Requesting email feedback if a response cannot be provided immediately.
- Utilising assistive technology during a conversation where appropriate can enhance communication outcomes.
- Always fostering a sense of: "We're in this together!"

My greatest appreciation goes to my daughters, family, friends, Limitless Adventures support workers, Dementia Australia staff, Dementia Alliance International friends, Alzheimer's Disease International staff and friends, work colleagues at the University of Tasmania and the University of Melbourne, and finally my Hobsons Bay Dementia Soaring Falcons alliance members. All these people are so generous and support me without a thought.

I will leave you with this one last thought:

Many have told me: "You don't look like you have dementia, Natalie." I had such an experience at a recent dementia research conference. I was asked about my affiliation, and I explained that I'm a person living with dementia, and I'll be speaking on a panel shortly. He proceeded to say: "You don't look like you have dementia." I asked: "What does dementia look like?" and his response was: "Not you!" This came from a professor.

It is deplorable that people living with dementia face discrimination in all aspects of their lives and this stigma continues, whether intentionally or through ignorance by some within the dementia medical sector. Unfortunately, this common phrase unintentionally perpetuates stigma and stereotypes. The words we use affect how people with dementia are perceived and treated and impact the support and empowerment they feel within society.

Alzheimer's stigma: a gamut of social group attitudes affecting healthcare access, diagnosis confidence, and caregivers' efforts

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Advances in technology and science are identifying biological underpinnings to dementia, which is a syndrome of cognitive and functional impairments. These discoveries are revolutionising diagnosis and treatment of Alzheimer's disease (AD) and other types of dementia. However, AD stigma is impeding the benefits of this revolution, which hinge on early diagnosis and diagnostic confidence.

AD stigma contributes to underdiagnosis, misdiagnosis, and late diagnosis. AD stigma contains false information, either wrong or exaggerated, that discourages people – patients, clinicians, or both – from wanting to address matters related to the condition. People living with AD stigma report feelings of lowered self-worth, incompetence, social exclusion, and isolation.[1] They also describe experiences of AD stigma in healthcare, such as physicians not wanting to communicate a diagnosis and physicians not talking directly to the person with dementia but to the caregiver.[2] Such testimonies from patients have been substantiated by clinicians. A 2020 report found, for example, that 39% of primary care physicians reported they were «never» or only «sometimes comfortable» making an AD diagnosis, and 27% reported similar discomfort when answering patient questions.[3]

Addressing AD stigma in order to promote early diagnosis has taken on greater urgency with United States (U.S.) Food and Drug Administration approval of new disease-modifying therapies. It had been hypothesised that AD stigma might lessen when treatments that could improve the disease course became available. A recent study shows, however, that the arrival of disease-modifying treatments, in and of itself, is unlikely to change stigma associated with AD. In a vignette experiment with a U.S. sample, the availability of a treatment had no detectable effect[4] on any of the seven domains of AD stigma that were examined, while both a positive (versus negative) AD biomarker result and clinical symptoms (versus no clinical symptoms) heightened AD stigma. Reducing AD stigma as a barrier to early diagnosis will require deliberate intervention as it is unlikely to occur as a consequence of medical innovation.

> **"Addressing AD stigma in order to promote early diagnosis has taken on greater urgency with United States (U.S.) Food and Drug Administration approval of new disease-modifying therapies."**

Attitudes towards healthcare

Stigma can have wide-ranging effects that are barriers to diagnosis and care.[5,6] AD stigma can centre on feelings of antipathy, include acts of discrimination and social exclusion, and other negative attitudes, beliefs, and behaviours toward people with AD. One group of people may face one set of stigma related barriers to AD diagnosis, while a different group may contend with another set.[7]

Black Americans, as one key social group in the U.S., might experience AD stigma in distinct ways, given the disproportionately high burden of AD in Black communities.[8] In a comparison of AD stigma in reaction to a description of an initial visit at a memory centre, which is the major entry point for accessing advances in AD diagnosis and treatment, Black Americans reported higher stigma than their White counterparts.[9] Specifically, they worried more about structural discrimination and made harsher judgments about dementia symptoms. This is consistent with the accounting that many Black adults encounter structural racism and healthcare disparities, including in memory care and caregiving.[10,11]

In that study comparing reactions of Black and White Americans, the largest difference between the racialised groups was for the measure of AD stigma related to *Negative Severity Attributions*; Black participants were twice as likely as White participants to attribute greater severity to dementia symptoms.[9] These findings align with research that shows Black Americans meet clinical criteria for dementia at higher rates but are less likely to be diagnosed, are diagnosed at later stages of the condition, and receive lower quality of care than their White counterparts.[12,13] Racial equity and anti-stigma efforts are needed and these efforts need to include addressing detrimental attitudes in and around healthcare.

Korean Americans have experiences in healthcare that are distinct from that of other racialised groups. They comprise a social group that can face consequential language barriers, tends to underutilise healthcare, and is underdiagnosed when they have AD.[14] AD stigma among Korean Americans emphasises patterns of pity, antipathy, and social distance. Characteristics that ground or mediate these patterns of AD stigma among Korean Americans have been shown to include being younger and more proficient in English, being less socially engaged, and knowing less about AD risk factors.[15] These characteristics parallel those that describe barriers to healthcare utilisation among this group, showing how AD stigma can correspond to underutilisation of healthcare and underdiagnosis of AD.

Beyond the U.S., connections between AD stigma, AD diagnosis, and healthcare are also widely observable. In Jaza, a province of Saudi Arabia, awareness about AD diagnosis was found to be low and co-occur with stigmatising attitudes and misconceptions.[16] In their reporting of the findings, the authors stress the important role of healthcare professionals in improving public education, especially for higher-risk groups.[16] They understand healthcare professionals as being integral in educating the public to address misconceptions and promote social inclusion for those with dementia.[16]

Data from Brazil, China, Spain, Chile, and Nigeria prominently feature AD stigma as a barrier to diagnosis.[17] Structural discrimination, also called institutional discrimination, is a prominent feature of AD stigma in each of these countries.[17] In Spain, Brazil, and China, the structural problems included healthcare systems poorly equipped to appropriately meet patient needs, while in Nigeria and Chile the issues pertain to cultural and individual beliefs that impede access to care. To support diagnosis, it will be essential to address stigma embedded in practices and policies that limit the availability and accessibly of clinical programs to diagnosis, treat, and care for persons with AD. This necessitates strengthening healthcare systems with social resources and patient centred policies to mitigate institutional stigma.

Diagnosis confidence

In healthcare systems across many countries, the journey to an AD diagnosis can be difficult and uncertain for patients and their families. Individuals must overcome barriers to accessing care and, even then, diagnosis can take months or even years, and patients are sometimes misdiagnosed. A major hope is that advances in clinical testing, including AD biomarkers, are improving accuracy and timeliness of an AD diagnosis, and thereby increasing public confidence.

With higher confidence in an AD diagnosis, individuals and their families may not seek out multiple clinical evaluations to feel comfortable that they have received the correct diagnosis. Instead, patients and families may begin to address current care needs, future life planning, and consider available treatment options. Simultaneously, fewer diagnostic visits may in turn reduce healthcare spending. Moreover, improved diagnosis confidence may help ameliorate the most common reason given by patients for not discussing cognitive issues during medical visits: incorrect diagnosis.[18]

Consistent with the idea that improved AD diagnostics could raise confidence in an AD diagnosis, the study that found Black Americans reported higher AD stigma than their White counterparts also found confidence ratings in an AD diagnosis increased in both groups with the number and type of diagnostic tests used to determine that diagnosis. The study also showed, unfortunately, that diagnosis confidence and elevated AD stigma are related; Black Americans, who reported higher confidence than their White counterparts in three of the four conditions that were evaluated, also reported higher AD stigma in response to a memory centre visit. The link between higher diagnosis confidence and greater AD stigma reflects the salience of the disease model among the public, whereby certainty in the presence of a disease increases confidence in consequences of that disease.[19]

Caregivers and early diagnosis

The experiences of caregivers with early diagnosis, including AD stigma and navigating complex healthcare structures, are not yet well known. However, it is important to understand the experience of AD caregivers as they are pillars supporting the health and wellbeing of persons with dementia. In fact, it is often the efforts of caregivers that help individuals with dementia pursue a diagnosis, suggesting they seek out diagnosis for their loved one despite AD stigma.

Research that exists suggests caregivers' experiences with diagnosis and stigma may be a distinct social experience; one which may be particularly informative to developing interventions that mitigate barriers to early diagnosis while also being one warranting attention and care post-diagnosis. Research with Arab Israeli caregivers, for example, has shown that the access to resources that can accompany a diagnosis can ease the contribution of stigma to caregiver burden.[20] Concernedly, however, another study found, contrary to the hypothesis, that AD stigma was universally higher among prior or current AD caregivers than among persons who did not have this experience.[21]

In sum, AD stigma affects diagnosis in multifactorial and, sometimes, unexpected and far-reaching ways. Innovation in diagnosis and treatment of AD is unlikely to mitigate the effects of this stigma on its own. We need to develop policies and programmes that are effective at lowering the stigma that impedes the access and availability of diagnosis, treatment, and care. We also need patient-centred practices that address AD stigma at the individual and family levels. These interventions need to focus on attitudes towards healthcare and internalised AD stigma. There also remain notable gaps in what we understand about AD stigma. One major gap is what we do not know about caregivers' experiences; these support persons are pillars in helping individuals with dementia pursue a diagnosis and access treatment and care. If we are to address AD stigma as a barrier to early AD diagnosis, we must better understand the factors that affect it.

References

1. Alzheimer's Disease International. *World Alzheimer Report 2019: Attitudes to Dementia*. Alzheimer's Disease International; 2019. https://www.alzint.org/u/WorldAlzheimerReport2019.pdf
2. Public Health Agency of Canada. *A Dementia Strategy for Canada: Together We Aspire*. Public Health Agency of Canada; 2019. Accessed June 18, 2024. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html
3. Alzheimer's Association. Primary Care Physicians on the Front Lines of Diagnosing and Providing Alzheimer's and Dementia Care. Alzheimer's Association. Published March 11, 2020. Accessed June 18, 2024. https://alz.org/news/2020/primary-care-physicians-on-the-front-lines-of-diag
4. Stites SD, Gill J, Largent EA, et al. The relative contributions of biomarkers, disease modifying treatment, and dementia severity to Alzheimer's stigma: a vignette-based experiment. *Social Science & Medicine*. 2022;292:114620. doi:10.1016/j.socscimed.2021.114620
5. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health*. 2013;103(5):813–821. doi:10.2105/AJPH.2012.301069
6. Herrmann LK, Welter E, Leverenz J, et al. A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial? *Am J Geriatr Psychiatry*. 2018;26(3):316–331. doi:10.1016/j.jagp.2017.09.006
7. Stites SD, Johnson R, Harkins K, Sankar P, Xie D, Karlawish J. Identifiable characteristics and potentially malleable beliefs predict stigmatizing attributions toward persons with Alzheimer's disease dementia: results of a survey of the U.S. general public. *Health Commun*. 2018;33(3):264–273. doi:10.1080/10410236.2016.1255847
8. Barnes LL. Alzheimer disease in African American individuals: increased incidence or not enough data? *Nat Rev Neurol*. 2022;18(1):56–62. doi:10.1038/s41582–021–00589–3
9. Stites SD, Largent EA, Schumann R, Harkins K, Sankar P, Krieger A. How reactions to a brain scan result differ for adults based on self-identified Black and White race. *Alzheimer's & Dementia*. 2024;20:1527–1537. doi:10.1002/alz.13558
10. Kiselica AM, Johnson E, Lewis K, Trout K. Examining misdiagnosis of mild cognitive impairment among Black/African American older adults. *Alzheimer's & Dementia*. 2021;17(S6):e049776. doi:10.1002/alz.049776
11. Coe NB, Lee C. Racial and Ethnic Disparities in Dementia Care: Next Steps. *JAMA Network Open*. 2022;5(6):e2216267. doi:10.1001/jamanetworkopen.2022.16267
12. Lines LM, Wiener JM. *Racial and Ethnic Disparities in Alzheimer's Disease: A Literature Review*. Research Triangle Institute International; U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy; 2014. https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//138596/RacEthDis.pdf
13. Lennon JC, Aita SL, Bene VAD, et al. Black and White individuals differ in dementia prevalence, risk factors, and symptomatic presentation. *Alzheimer's & Dementia*. 2021;18(8):1461–1471. doi:10.1002/alz.12509
14. Li J, Maxwell AE, Glenn BA, et al. Healthcare Access and Utilization among Korean Americans: The Mediating Role of English Use and Proficiency. *Int J Soc Sci Res*. 2016;4(1):83–97. doi:10.5296/ijssr.v4i1.8678
15. Lee SE, Hong M, Casado BL. Examining public stigma of Alzheimer's disease and its correlates among Korean Americans. *Dementia (London)*. 2021;20(3):952–966. doi:10.1177/1471301220918328
16. Hakami F, Madkhali MA, Saleh E, et al. Awareness and Perception Toward Alzheimer's Disease Among Residents Living in the Jazan Province, Saudi Arabia: A Cross-Sectional Study. *Cureus*. 2023;15(9):e44505. doi:10.7759/cureus.44505
17. Kerwin D, Abdelnour C, Caramelli P, et al. Alzheimer's disease diagnosis and management: Perspectives from around the world. *Alzheimers Dement (Amst)*. 2022;14(1):e12334. doi:10.1002/dad2.12334
18. Alzheimer's Association. 2023 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*. 2023;19(4):1598–1695. doi:10.1002/alz.13016
19. Stites SD, Lee BN, Largent EA, et al. Double-Edged Sword: A Positive Brain Scan Result Heightens Confidence in an Alzheimer's Diagnosis But Also Leads to Higher Stigma Among Older Adults in a Vignette-Based Experiment. *J Gerontol B Psychol Sci Soc Sci*. 2024;79(8):gbae109. doi:10.1093/geronb/gbae109
20. AboJabel H, Werner P. The mediating effect of social support and coping strategies on the relation between family stigma and caregiver burden among Israeli Arab family caregivers of people with Alzheimer's disease (AD). *Aging Ment Health*. 2022;26(8):1597–1603. doi:10.1080/13607863.2021.1916881
21. Stites SD, Largent EA, Johnson R, Harkins K, Karlawish J. Effects of self-identification as a caregiver on expectations of public stigma of Alzheimer's disease. *ADR*. 2021;5(1):31–39. doi:10.3233/ADR-200206

Understanding and reducing dementia stigma in Australia: who holds it and how to mitigate it?

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By 2050, it is expected that over 139 million people will be living with dementia globally. With the rapidly growing prevalence of dementia, it is essential that awareness and understanding about the condition amongst the general public is improved. This is particularly important as a more well-informed public is more likely to challenge misconceptions of dementia, detect dementia symptomatology, and support help-seeking.[1,2] Fear and negative perceptions of dementia may lead to denial of changes in memory and behaviour and prevent individuals from seeking medical help and treatment.[3] Understanding how negative and stigmatising attitudes to dementia influence service use can assist in developing nuanced and effective strategies to educate the general population as well as health professionals about dementia, and to reduce dementia stigma in Australia.

To evaluate the level of dementia stigma in Australia, a nationally representative survey of 1,000 Australians aged 18–93 years was conducted in 2017.[1] The survey showed that dementia knowledge amongst the general population was broad, with only 26% of people surveyed demonstrating good dementia knowledge, while 23% of participants had poor dementia knowledge.[1] In general, respondents associated dementia with memory loss, with people stating that dementia is *"a degenerative brain condition that typically effects the elderly, which causes breakdown in memory and personality,"* or that it has *"to do with the brain, losing your memory, not thinking correctly, issues with memory."* Furthermore, almost half of the people surveyed expressed uncertainty and a mixed understanding of the causes of dementia[1], with views being expressed that *"old people, at some age 70–80 percent of people who work hard get dementia, they lose their new memories and they've only got their old memories, they think they're still young, their kids are still young, things like that."*

Interestingly, this study found that those aged 70+ had the poorest dementia knowledge, while those aged 18–29 years had the best dementia knowledge.[1] Better dementia knowledge was also found amongst women, English speakers, people born in Australia and those who identified as being exclusively Australian. The survey also revealed that the population sampled held somewhat stigmatising beliefs around dementia, with people stating that they believed dementia related to *"someone that's getting old and the brain's not working quite as well,"* that it is *"a horrible disease,"* that dementia is *"very sad, hard to describe it, losing your faculties and making decisions, not being with it,"* or that *"it is a sickness of the mind, I think it's from too low activity when they're old and they're alone."*

> **"Understanding how negative and stigmatising attitudes to dementia influence service use can assist in developing nuanced and effective strategies to educate the general population as well as health professionals about dementia, and to reduce dementia stigma in Australia."**

Higher dementia stigma was also found amongst older, non-English speakers, people with low education, those who know someone with dementia, and those with better dementia knowledge. However, dementia knowledge was significantly associated with stigmatising beliefs, but not with behavioural reactions towards people living with dementia. This finding might be due to the stigma scale used in this survey. Some items measuring stereotypes, such as "people with dementia do not remember recent events" and "people with dementia do not recognise their family members," are accurate for those in the advanced stages of dementia, although these characteristics should not be generalised.

In 2023, a second nationally representative survey, the 'Dementia Awareness Survey' (DAS), was conducted in Australia by the Australian Institute of Health and Welfare.[4] Over 5,400 Australian adults from all states and territories were surveyed to assess 1) knowledge of dementia and dementia risk factors, and 2) community attitudes towards dementia and people living with dementia. This survey was primarily conducted online and included the Dementia Public Stigma Scale,[5] which measures cognitive (dementia-related stereotypes), emotional (negative prejudices and emotional reactions), and behavioural (discriminatory behaviours) aspects of stigma. The survey showed that over 60% of Australians believed people with dementia should always be supervised and that Australians perceived people with dementia as being unpredictable. Only about half of Australians reported that they felt confident or relaxed around people living with dementia, and less than 5% reported that they would ignore people with dementia. This demonstrated that Australians hold relatively high levels of stigmatic beliefs, moderate levels of negative emotions, and lower levels of discriminatory behaviour.

Furthermore, this survey found differences in dementia stigma across different sociodemographic groups. Findings included that women and those identifying as non-heterosexual were found to have significantly lower levels of dementia-related stigma than men and those identifying as heterosexual. Also, compared with those born in culturally dissimilar countries and who spoke language other than English at home, those born in Australia or in countries that were culturally similar (e.g. the UK and New Zealand) and who spoke English at home were less likely to hold stigmatic beliefs, emotions, and behaviours towards dementia and people living with dementia. Exposure to dementia also played a crucial role, with those who had a family member or friend with dementia, or those who had worked with people with dementia, appearing to have lower levels of dementia stigma than those without any personal experience with people with dementia. Additionally, Australians with greater knowledge about dementia demonstrated lower levels of dementia stigma, emphasising the importance of public education to enhance awareness and reduce dementia-related stigma among the general population. This contradicts the findings from our previous survey. However, a direct comparison of the two surveys may not be appropriate, as different methods were used to measure dementia knowledge and stigma. The DAS used a scale that measured dementia knowledge through recognition, while our 2017 survey measured it through recall. Additionally, dementia stigma in the DAS was assessed using a scale specifically developed to measure public stigma of dementia, whereas the previous survey used a modified family stigma in Alzheimer's scale.

In summary, these two nationally representative surveys in Australia have shown that despite increasing awareness around dementia, dementia-related stigma still prevails. Addressing this need, the Dementia Stigma Reduction (DESeRvE) intervention was developed to target public dementia-related stigma using 'education' and 'contact' approaches.[6,7] Over 1,000 Australians aged between 40 and 87 years old participated in this study and were randomly assigned to one of four conditions: 1) an online education programme (ED), 2) contact through simulated interactions with people with dementia and their carers (CT), 3) a combination of education and contact (ED+CT), and 4) an active control group. Participants in the ED group received information about dementia, including its definition, symptoms, pathology, treatments, and the impacts of dementia-related stigma. Those in the CT group watched video clips featuring people with dementia and informal carers, creating the sensation of having a virtual conversation with real people affected by dementia. All four groups showed significant improvement in dementia-related stigma from baseline to week 12, with stronger effects observed in participants who initially had higher levels of stigma.

The reduction in dementia-related stigma was mainly found to be due to a decrease in cognitive-related stigma, indicating that the interventions were effective in changing perceptions of people living with dementia. The intervention could potentially reduce emotional and behavioural aspects of stigma over a longer period, as stereotypes can lead to negative emotions and discriminatory behaviours.[8,9] However, long-term follow-up is needed to evaluate whether reductions in stigma due to interventions have persistent effects.

In conclusion, our national studies of dementia stigma provide a benchmark for measuring aspects of dementia stigma in Australia over time. The findings that dementia stigma was reduced after an intervention also demonstrates that stigma is modifiable within a short period of time, at least in terms of survey responses. Nevertheless, significant gaps in our knowledge remain and many areas of dementia stigma still need to be addressed. There is a need for more information on different types of stigma, such as lifestyle stigma associated with dementia risk factors.[10] We need to learn more from the many diverse cultural and ethnic groups in Australia how specific cultural factors influence the experience of dementia, and perceptions of dementia symptoms.[11] Not speaking English is a known barrier to help seeking, which can be compounded by stigma. Longitudinal data is needed to evaluate whether levels of stigma are changing over time. There is also a need to better understand how people with dementia and their care givers experience stigma.

With the introduction of novel treatments for Alzheimer's disease such as monoclonal antibodies, there will be a further need to address stigma as a potential barrier to accessing treatment and funding. Challenging and reversing negative stereotypes is essential for improving the quality of life of people living with dementia and enabling them to participate fully in society. Taking a human rights approach to dementia is also essential for prioritising the need for inclusion, optimal care and social participation. In Australia, we hope that the renewed focus on dementia with the release of the National Dementia Action Plan in late 2024[12] will highlight the importance of addressing dementia stigma.

References

1. Kim S, Anstey KJ, Mortby ME. Who displays dementia-related stigma and what does the general public know about dementia? Findings from a nationally representative survey. Aging Ment Health. 2023;27(6):1111–9.
2. Rimmer E, Wojciechowska M, Stave C, Sganga A, O'Connell B. Implications of the Facing Dementia Survey for the general population, patients and caregivers across Europe. International Journal of Clinical Practice. 2005;59(s146):17–24.
3. Allam, I., Gresham, M., Phillipson, L. Brodaty, H., & Low, L-F. (2023). Beliefs around help-seeking and support for dementia in the Australian Arabic speaking community. *Dementia*, Jul;22(5):995–1009.
4. Australian Institute of Health and Welfare. (2024). *Dementia Awareness Survey.* Retrieved from https://www.aihw.gov.au/reports/dementia/dementia-awareness-survey
5. Kim S, Eccleston C, Klekociuk S, Cook PS and Doherty K (2022) 'Development and psychometric evaluation of the Dementia Public Stigma Scale- external site opens in new window', *International Journal of Geriatric Psychiatry,* 37(2), doi:10.1002/gps.5672.
6. Kim, S., Werner, P., Richardson, A., & Anstey, K. J. (2019). Dementia Stigma Reduction (DESeRvE): Study protocol for a randomized controlled trial of an online intervention program to reduce dementia-related public stigma. Contemporary Clinical Trials Communications, 14, 100351. DOI: 10.1016/j.conctc.2019. 100351.
7. Kim S, Richardson A, Werner P, Anstey KJ. Dementia stigma reduction (DESeRvE) through education and virtual contact in the general public: A multi-arm factorial randomised controlled trial. Dementia (London). 2021 Aug;20(6):2152–2169. doi: 10.1177/1471301220987374. Epub 2021 Jan 31. PMID: 33517746.
8. Corrigan, P., Markowitz, F. E., Watson, A., Rowan, D., & Kubiak, M. A. (2003). An attribution model of public discrimination towards persons with mental illness. Journal of Health and Social Behavior, 44(2), 162–179.
9. Werner, P., Kalaitzaki, A. E., Spitzer, N., Raviv-Turgeman, L., Koukouli, S., & Tziraki, C. (2019). Stigmatic beliefs towards persons with dementia: comparing Israeli and Greek college students. International Psychogeriatrics, 31(10), 1393–1401. DOI: 10.1017/S104161021900070X
10. Wilson, N-A., Anstey, K.J. Dementia Prevention and Individual and Socioeconomic Barriers: Avoiding "Lifestyle" Stigma, 2024 May 1;64(5)
11. Siette, J., Meka, A., Antonides, J. Breaking the barriers: overcoming dementia-related stigma in minority communities, Frontiers in Psychiatry, 2023 Dec 20:14:1278944.
12. Department of Health and Aged Care. (2024). National Dementia Action Plan. Retrieved from National Dementia Action Plan | Australian Government Department of Health and Aged Care

Dementia attitudes in British adolescents

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As the number of people living with dementia grows, it impacts not only those living with the condition, but also their families and society. Identifying demographic groups most susceptible to stigmatising attitudes and those receptive to attitude-changing initiatives is crucial. The dementia attitudes of younger generations are particularly critical, as they shape future societal responses and policies. Adolescents represent a significant demographic with potential experience of dementia, yet their attitudes towards it have been explored to a limited extent. Despite their potential to influence societal perceptions and behaviours, young people are often neglected in dementia strategies and policy.

Why are adolescents an important demographic to focus on?

Adolescents are not immune from the impact of dementia. The number of grandchildren of people living with dementia is growing.[1] This is unsurprising given the estimated 1.8 million multigenerational households in the UK.[2] Prior research has indicated that nearly a quarter of British adolescents have provided some form of care for someone with dementia (23.2%, n=901; 13–18-year-olds) and a greater proportion have spent time with someone with dementia. However, these experiences are not formally contextualised since dementia does not feature in most school curriculums,[3] with over 66% of secondary schools surveyed in England having never taught dementia in schools.[4] This is despite young people expressing an interest in learning about dementia.[5,6] Adolescents typically acquire their dementia-related information from sources like parents, grandparents, and TV.[3,7,8]

In 2020, then-UK Prime Minister Boris Johnson updated the national dementia challenge policy to include increasing dementia awareness in schools.[9] Schools can serve as an effective setting for delivering national and widespread interventions, particularly since positive attitudes should be held by all members of society, not just a select subgroup. Adolescents are thought to be more responsive to anti-stigma education during early adolescence, when stereotypes are more malleable.[4] Intergenerational initiatives, where people living with dementia and young people engage in activities together, show promise but are limited by small sample sizes and lack of validated outcomes.[10,11] More research is needed to ensure these initiatives are effective.[12] By understanding the factors that influence dementia attitudes, we can better support young people and improve societal perceptions of dementia.

A study on the 'factors associated with dementia attitudes in British adolescents' (Hassan et al., in review): a summary of findings

In this essay, we will report complementary data to the World Alzheimer's Report, by highlighting knowledge, attitudes, and experiences of dementia in a British adolescent cohort. Our research, funded by the Alzheimer's Society, provides a cross-sectional survey of adolescents (aged 11–18 years) in England, currently in mainstream secondary education. Nine schools across six regions of England took part in the study.

Knowledge

From a total of 1,625 adolescents, 6.1% (n=81) had never heard of either "dementia" or "Alzheimer's disease" before. Overall, adolescents (n=1,371) could only correctly answer just under half of the knowledge items (48%). This is in line with prior studies on adolescents' level of knowledge in England.[13] The item adolescents were most able to answer correctly was "dementia is a disease of the brain" (72.1%, n=989).

Overall, adolescents in our study held common misconceptions about dementia that may feed into stigma. While we observed some demographic differences, the level of knowledge across various demographic groups did not significantly differ. Our findings highlight the need for more awareness-raising initiatives that target adolescents.

Experiences of dementia

A common misconception is that the populations of young people and dementia are unconnected, with only a minority having first-hand experience of dementia. This misconception is perhaps amplified through the lack of data on the topic. Within our study of 1,209 adolescents, 69% of adolescents (n=834) had indicated that they had come across people living with dementia, whilst 30% of adolescents (n=362) indicated that they had looked after someone with dementia. As such, these experiences, alongside the previously reported knowledge gaps, may mean that adolescents in England are experiencing dementia without formal contextualising of what dementia is. Whilst this is concerning, it is important to note that the majority of adolescents who had spent time with someone with dementia or looked after someone with dementia reported to have generally positive experiences of these interactions.

Adolescents most frequently came across dementia through TV (75%, n=905) and coming across adverts about dementia (75%, n=903), though 54% (n=648) of adolescents had previously spoken to their family and friends about dementia. Interestingly, females were associated with higher levels of contact with dementia, which perhaps could be laying the foundation for cultural and gender norms of dementia care later in life.

Of the adolescents who indicated that they had seen a person with dementia in TV or film, over half reported that dementia was represented in the media as generally negative (54%). This can also be observed in a prior focus group conducted with British adolescents:[4]

> **"[The media] doesn't portray a good, like, equal-sided opinion of it [dementia]...it can still be negative on the media."**
>
> *British adolescent, Female*

Dementia attitudes in adolescents: can we move the dial?

Overall, dementia attitudes were generally positive. Within our sample (n=1,044), the mean score of dementia attitudes was 48 out of a possible score of 65 (74%). This indicates that on average, adolescents' attitudes towards dementia were relatively positive, given that higher scores reflect better attitudes. These findings are in line with previous studies in British adolescents.[14,15] In previous focus groups with British adolescents, we can observe this[4]:

> **"They're just normal people, they have dementia but there's no, like, they're not different and people with dementia should be treated the same way, and they should be treated with care because obviously they can forget stuff, and they're just people so they're just the same as us, there's nothing different with them."**
>
> *British adolescent, Female*

Understanding what factors are associated with dementia attitudes in young people is valuable because it can provide insights into potential future interventions. In our study, the strongest factors predicting dementia attitudes in the models were modifiable factors.[16] In the structural equation model (SEM) – a statistical modelling technique used to analyse the interrelationships between factors – contact, empathy, and ageism were strongly associated with dementia attitudes. However, it is important to consider how these factors are interlinked, and potentially mediate other associations. The fact that higher levels of empathy were strongly associated with positive dementia attitudes could indicate that interventions that stimulate empathetic responses might be the most effective route to improving dementia attitudes.

Willingness to work with people with dementia in the future

Linked with attitudes are behavioural intentions. For adolescents, we recognise that they are future health practitioners and formal carers, and they are in the midst of choosing subjects at school that align with their developing interests in future careers. Career preferences formed in early educational and training years can be predictive of future career choices.[17] A prior study highlighted that some adolescents would consider working with people with dementia in the future and even displayed positivity towards this after a Dementia Friends session.[4,15]

> **"…I would definitely work with people who have dementia, like, more because I realise that they are just normal people… although they may forget things, although you may have to tell them a few times, like, it's worth it, because you make, like, new friends…"**
>
> *British adolescent, Male*

Our current research highlights that the majority of adolescents are unsure or unwilling to work with people with dementia. Though certain groups are more willing to work with people with dementia, males are notably less likely to be willing to work with people with dementia. In addition, there also may be an erosion of willingness over time; for every year older there is a 22% decrease in the odds of willingness to work with people with dementia. However, similar to attitudes, it appears that increased contact with people with dementia may be one such solution; adolescents who have had more contact with people with dementia are associated with a greater willingness to work with people with dementia.

Conclusion

Adolescents are a pivotal demographic, both in terms of their current interactions with those living with dementia and their potential future roles as caregivers and healthcare professionals. Our research reaffirms that British adolescents already experience dementia in their communities, including as people that provide care. For the most part, experiences of dementia in adolescents come through media sources, and therefore dementia has not formally been contextualised. This is perhaps evident through some gaps in adolescent knowledge.

It is promising that dementia attitudes were generally positive in our cohort, though there is still scope for improvement. Stimulating empathy, potentially through intergenerational contact, may be one such solution. Ultimately, by improving dementia attitudes among adolescents, we can build a more compassionate society, better equipped to support individuals with dementia and their families. This approach will not only improve the quality of life for those affected but also inspire future generations to engage in dementia care and related fields, addressing the growing need for dedicated professionals in this area.

References

1. Celdrán M, Triadó C, Villar F. "My Grandparent Has Dementia" How Adolescents Perceive Their Relationship With Grandparents With a Cognitive Impairment. Journal of Applied Gerontology. 2011 Jun;30(3):332–52.
2. CBRE. Multi-generational housing. [Online]. (2021). Available from: https://www.cbre.co.uk/research-and-reports/our-cities/multi-generational-housing [Accessed 2023 Aug 04].
3. Farina N, Hughes LJ, Griffiths AW, Parveen S. Adolescents' experiences and perceptions of dementia. Aging & Mental Health. 2020 Jul 2;24(7):1175–81.
4. Farina N, Hughes LJ, Jones E, Parveen S, Griffiths AW, Galvin K, Banerjee S. Evaluation of a dementia awareness programme in UK schools: A qualitative study. Public health. 2020 Aug 1;185:348–55.
5. Parveen S, Farina N, Shafiq S, Hughes LJ, Griffiths AW. What do adolescents perceive to be key features of an effective dementia education and awareness initiative?. Dementia. 2020 Aug;19(6):1844–54.
6. Baker JR, Goodenough B, Jeon YH, Bryden C, Hutchinson K, Low LF. The Kids4Dementia education program is effective in improving children's attitudes towards dementia. Dementia. 2019 Jul;18(5):1777–89.
7. Cahill S, Pierce M, Werner P, Darley A, Bobersky A. A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. Alzheimer Disease & Associated Disorders. 2015 Jul 1;29(3):255–75.
8. Olsen V, Taylor L, Whiteley K, Ellerton A, Kingston P, Bailey J. Exploring public perceptions and understanding of dementia: Analysing narratives from the Mass Observation Project. Dementia. 2020 Nov;19(8):2804–20.
9. National Children's Bureau [online]. Young people caring for adults with dementia in England (2016). Report on NCB's survey findings and internet research. Available from: https://www.ncb.org.uk [Accessed 2023 Aug 04].
10. Di Bona L, Kennedy S, Mountain G. Adopt a care home: An intergenerational initiative bringing children into care homes. Dementia. 2019 Jul;18(5):1679–94.
11. Skropeta CM, Colvin A, Sladen S. An evaluative study of the benefits of participating in intergenerational playgroups in aged care for older people. BMC geriatrics. 2014 Dec;14:1–1.
12. Galbraith B, Larkin H, Moorhouse A, Oomen T. Intergenerational programs for persons with dementia: A scoping review. Journal of Gerontological Social Work. 2015 May 19;58(4):357–78.
13. Isaac MG, Isaac MM, Farina N, Tabet N. Knowledge and attitudes towards dementia in adolescent students. Journal of Mental Health. 2017 Sep 3;26(5):419–25.
14. Farina N, Griffiths A, Hughes L, Parveen S. Measuring Adolescent Attitudes towards dementia: The validation of the Brief A-ADS. Journal of Health Psychology. 2020 Sep 10.
15. Farina N, Hughes LJ, Jones E, Parveen S, Griffiths AW, Galvin K, Banerjee S. The effect of a dementia awareness class on changing dementia attitudes in adolescents. BMC geriatrics. 2020 Dec;20:1–9.
16. Hassan E, Hicks B, Tabet N, Farina N. Factors associated with dementia attitudes in an adolescent cohort: structural equation modelling. Cogent psychology. 2023 Dec 31;10(1):2235125.
17. Hebditch M, Daley S, Wright J, Sherlock G, Scott J, Banerjee S. Preferences of nursing and medical students for working with older adults and people with dementia: A systematic review. BMC medical education. 2020 Dec;20:1–1.

The Big Forget: perceptions of dementia across Africa

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Our memories are deeply tied to our identity, our history and our stories. It's the thread that connects us to society and ourselves and it makes us who we are. So, what happens when we lose our memories?

There has been a growing trend in longevity, but living longer does not mean we are living healthier lives. An increase in global population ageing means that more people are at risk of developing dementia. According to the World Health Organization (WHO), around 55 million people have dementia worldwide, and there are nearly 10 million new cases every year, with over 60% living in lower- and middle-income countries. In nearly every country, there has been an increase in the number of older people in the population, and as a result dementia has become a global health crisis.

Due to lower life expectancy than other regions, African countries are often not included in these discussions, but the population of Africa is ageing, which means more people are at risk of developing dementia. Yet localised attitudes toward dementia and cultural perceptions about the disease are still largely overlooked when it comes to global discussions about dementia.

In some African countries, symptoms of dementia that may lead to out-of-the-ordinary behaviour and memory dysfunction are associated with madness as well as witchcraft. This often leads to fear and stigma, leaving the elderly in an extremely vulnerable position.

A major challenge preventing people with dementia from accessing appropriate services is the absence of the word 'dementia' in most African languages. Instead, words such as "madness" and "confusion" are used, which immediately attaches a stigma to the condition.

Another barrier to getting a diagnosis and appropriate care is a lack of old age specialists. There simply aren't many geriatricians in many parts of Africa, especially in rural areas.

For many people from rural areas and indigenous communities, traditional medicine is the main or only form of treatment, because it is accessible and culturally accepted. Sometimes, doctors will refer mental health matters to traditional healers if they are unable to heal the condition.

Over the years, I have been to countries such as Ghana, Namibia, and Madagascar in order to understand how people living with dementia are perceived and treated. While some traditional beliefs lead to people with dementia being ostracised and isolated, the answers to issues of stigma could also lie in local cultural practices and values.

Ghana's Gambaga witch camp

The sun is blazing down in the northern town of Gambaga in Ghana, home of the Mamprusi people. The bright sun and heat haze colour the town in washed-out hues and the smell of dust fills the air.

In the late 18th century, a camp for those accused of witchcraft was established on the outskirts of Gambaga. The town has since swallowed the camp and is now surrounded by the homes of the local community.

Ghana appears to be the only country with established 'witch' camps. There are six official camps in the North, although some sources say that there are possibly more.

Ageing women in rural Ghana are sometimes accused of witchcraft because of mental health issues, menopausal symptoms, and signs of dementia. Although both men and women can be accused of witchcraft, most accusations are levied against women, especially the elderly.

As of February 2022, the Gambaga camp housed 88 women, one man, and 26 children, with 95% of the women in the camp above 60 years of age. The camp is bursting at its seams, with two or three residents occupying each mud hut and numbers on the rise. In 1960, Ghanaians lived to 45 years old on average; today, it is 64.

In Ghana, traditional beliefs are still widespread and the connection to the world of spirits and ancestors is very important – much like religion, shamanism, paganism, and other spiritual beliefs are widespread throughout the world.

Mohammed Iddurusu is a traditional healer who works in Tamale, Northern Ghana, and consults the spirits before treating his patients with medicinal plants. In recent years, he has seen an increase in patients who seek help with memory problems and "confusion," many of whom have never seen a medical doctor.

Health-seeking behaviour of individuals will be governed by their beliefs, which means that traditional healers and faith healers can play an important role in identifying people with dementia and should be included in awareness campaigns.

Within Gambaga camp, those who have been accused of witchcraft experience a certain level of protection. The belief is that the spirit of the chief controls the alleged "witches" and they are unable to practice witchcraft, therefore the local community does not fear them. The situation is however very complex. Despite being safe from threats of violence in the camp, many live in dire conditions far away from the familiarity of home. Some were banished to the camp because no one wanted a suspected witch in the family, and others fled there in search of safety from physical harm.

Although the residents live far from their familiar surroundings, they have found some form of social cohesion and community within the camp, albeit under undignified living conditions. Those who are younger and healthier find themselves providing care for older residents and spend their days together in the small courtyards between the huts, cooking and sharing stories.

In countries like Ghana, there are limited resources and funding focused on understanding mental illness and dementia, along with a lack of public understanding about these conditions, especially in rural areas. Coupled with a lack of geriatricians, this means that many cases of dementia remain undiagnosed, leaving the elderly at risk and unsupported.

The Go Home Project

During my first visit to the witch camp in February 2022, I met Konduuk Labik, who had been living in the camp for approximately 12 years. I photographed her in front of the hut she was sharing with another resident wearing an old Beatles t-shirt. At the end of the day, as I was about to leave, I felt someone touch my hand. I turned around to find Labik with a big smile dressed in a beautiful green dress. I instantly knew that she wanted me to take another picture of her wearing her beautiful dress. Despite her declining cognitive abilities, she wanted to look her best for the photographs.

This moment made such an impression on me that when I returned to the camp in October 2022, I immediately looked for Labik to give her a printed photograph from my first visit. I was disappointed to find someone else living in her hut. My initial disappointment soon turned into joy, however, when I learnt that something very rare had happened to Labik – she had gone home.

This momentous achievement was orchestrated by one of the camp volunteers, Obed Yobe, and his team as part of The Go Home Project. First, the chief of the village needs to be consulted. If he agrees, the family of the accused witch and the family of her alleged victim meet to discuss the case. This is often done in consultation with a doctor or nurse and a traditional or faith healer, who help to ease worries on both sides. Labik is one of the lucky ones who have successfully been reintegrated into their communities. These days, she sits in the same spot she had left empty for 12 years – overlooking the courtyard of her home. Her children are happy to have her back home where she belongs and to help take care of the 82-year-old after she suffered a stroke.

Konduuk Labik, a woman who had lived in Gambaga witch camp in Ghana for over 12 years, is one of a rare number of people who was able to return home (Lee-Ann Olwage)

Kahimbi Mushanana often wanders away from her homestead in the village of Ikoma, Namibia. (Lee-Ann Olwage)

Obed Yobe knows that education in the villages is key to raising public awareness about dementia. Where possible, they have done this in collaboration with a nurse who teaches the community about the symptoms of dementia and ageing from a medical perspective. This has led to a reduction in witch trials, he said, but funding is needed to maintain momentum. Unfortunately, aid organisations and churches remain apprehensive about getting involved in the sensitive topic of witchcraft.

Localised solutions to global problems: community care in Namibia

In the far northeast Zambezi region of Namibia lies the village of Ikoma. The long grass, dry after a blistering summer, crunches underneath the feet of Kahimbi Mushanana as she wanders away from her homestead to collect firewood. Mushanana, who is in her eighties, often wanders away from the village and has on occasion been brought back home by neighbours because she was unable to find her way back. Her granddaughter, Kahundu Mushanana, emerges from the village to keep an eye on her.

Irvine Mushanana recognised that his mom was becoming more forgetful, and he started noticing behavioural changes, but the doctors assured him that this was a normal part of ageing. When she forgot him, Irvine knew something else was wrong and continued his search for answers. He contacted Alzheimer's Dementia Namibia (ADN), which explained that his mom was probably living with dementia. ADN assisted the family with practical knowledge on how to care for Kahimbi and understand her symptoms. These days, Kahimbi Mushanana is able to age in the familiar environment of her home while she is supported and cared for by various family members and her extended village community.

Nurses from local communities can act as educators and play a key role in supporting education and screening initiatives. Understanding cultural beliefs about dementia is key in providing person-centred care for those living with dementia and their families.

Andrias Mangundu, a nurse from Rundu, Namibia, is passionate about community education about dementia. Mangundu is aware that a lack of medical specialists, especially in rural areas, prevents many people from receiving a formal diagnosis. He uses an infographic by Alzheimer's Disease International to screen those at risk in rural communities in Rundu in the Kavango-East Region in northern Namibia.

Mangundu's approach to community education stems from a deep-rooted respect for his own culture. He understands the cultural beliefs of the people he works with, but also introduces new information about dementia as a condition that affects the brain. This new generation of nurses may be the answer to dementia education as they balance their cultural beliefs with science and medicine in a way that can empower communities with information.

The concept of Valim-babena in Madagascar

In Madagascar, I was introduced to the concept *Valim-babena* by Muriel Yolande Rason-Andriamaro from Masoandro Mody, the only Alzheimer's organisation on the island nation. Loosely translating to "we are because of our parents," Valim-babena is seen as an expression of love, the repayment of a moral debt for the care parents put into raising their children. In this way, dementia care is shared by the person, their immediate family, and between generations of the community at large.

Masoandro Mody run a daycare centre in Antananarivo for the elderly, where family members can take their loved ones to participate in exercises, games, and socialise as a way to add meaning to their lives and give family caregivers a break.

Stigma is not only limited to the women who find themselves living in witch camps but can be seen in every corner of the world. Many people living with dementia across the globe are ostracised and are no longer given the opportunity to contribute to society in a meaningful way. One of the most basic human needs is the desire to belong and to feel like we are part of something bigger.

Only when stakeholders work together to empower communities with information about dementia can culturally congruent care and support be given to people living with dementia and their families.

Canadian Indigenous experiences of and attitudes to dementia

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Dementia currently directly impacts 55 million people across the globe with an expected increase to 139 people by 2050.[1] Across countries that have experienced settler colonialism, there is evidence of increased prevalence and incidence of dementia within Indigenous communities, along with earlier ages of onset in many communities.[2,3,4,5] When assessing the impact of dementia within Indigenous communities, especially stigma, it is important to understand and engage with different Ways of Knowing and conceptualisations of health and wellness. Indigenous Peoples may not speak directly to having experienced dementia but instead speak to cognitive changes that are part of a natural life cycle where one grows closer to returning to Creator.[6] However, as communities experience longer life expectancies and an increase in rates of dementia and lower ages of onset, more and more communities are prioritising self-determined approaches, services, and solutions to improving dementia care with Indigenous people.

How colonialism impacts the Indigenous dementia experience

The differences in experiences of dementia are impacted by many factors, and most importantly, the ongoing colonialism present in all of these countries that have similar shared experiences of colonisation. However, within most systems, and notably the healthcare system, there remains a lack of understanding of the present-day impacts of colonialism on the health of Indigenous Peoples. This means that many dementia care services are not culturally safe or cognisant of the cultural connections to identity, knowledge, and traditional approaches to wellness that have been shown to enhance health for Indigenous people.[7] Culturally safe healthcare, including dementia care, are grounded in Indigenous worldviews and values and should not support any actions that undermine individual wellbeing. A commitment to advances for Indigenous health broadly is included in the Truth and Reconciliation Commission of Canada's Calls to Action 18–24.[8,9]

Indeed, there is a large body of evidence demonstrating the racism, discrimination, and stigma that Indigenous people face when accessing healthcare,[10,11] and the resulting direct impacts to physical and mental health. It can be daunting to seek help or to openly disclose a diagnosis of dementia because of the expectation of mistreatment. Stigma of dementia compounded with stereotypes may mean that Indigenous people living with dementia are assumed to be intoxicated or may even be blamed for the diagnosis because of 'risk factors associated with lifestyle.' This makes the journey to seek help or talk openly as an attempt to reduce the stigma surrounding dementia more difficult because of the anticipation of discriminatory and harmful behaviours and attitudes. For many Indigenous people living with dementia in home communities, no matter what country they live in, there can often be additional barriers to accessing health and social supports due to funding policies that limit access to some services.[12] This means that appropriate and culturally safe peer support relationships are necessary for Indigenous Peoples to mitigate the harm experienced when they encounter stigma, racism, and continued marginalisation within western healthcare systems.[10] One potential direction to find these kinds of supports may actually be virtual healthcare or mobile clinics for Indigenous people living in rural areas that have proven successful in other contexts.[13,14]

There has been a significant amount of progress developing person-centred care from earlier iterations to broader and more inclusive models,[15] including the movement toward relationship-centred care.[16] However, person-centred care is not always culturally appropriate or culturally safe for Indigenous people living with dementia, their families, or their communities. This is compounded by the underservice of healthcare broadly for Indigenous people and low referral rate for Indigenous people to specialist services. These low referral rates are likely due to a variety of reasons that may include, but are not limited to, lack of knowledge within primary healthcare and other referring healthcare professionals, a growing crisis in access to primary care for the general population that cannot meet demand, availability of appropriate primary care services for Indigenous people, and often a lack of service availability or appropriate screening and assessment. This often means that Indigenous people living with dementia are without specialist support but small populations in rural and remote areas can mean that advocating for specialist services may be unsuccessful and difficult to financially sustain.[17]

Indigenous community-centred care as the antidote to dementia stigma

The summative evidence clearly indicates the need for increased and improved Indigenous dementia care services and supports, with additional competency building in strengths-based, trauma-informed and Indigenous-centred approaches to dementia care. While this shift is in line with the principles of person-centred care, it shifts the lens from being focused on an individual (or in many cases a dyad including the person living with dementia and a care partner), to a collective. This means that living well with dementia is now not only an individual or dyadic activity but encompasses supports for a family and an entire community that is living with dementia. Previous research pushed the concept of family to include the person living with dementia and pushed the lens toward family-centred care,[18] so the further step to move to community-centred care inclusive of Indigenous worldviews is a natural one. This step must also be done along with health services decision makers and providers to integrate cultural safety, cultural humility, and anti-racism in its design in a self-determined manner. Strengthening care in the community, led by Indigenous people and informed by Indigenous worldviews, is a way to have an impact on attitudes to dementia and reduce stigma. Connection of traditional understandings of dementia to biomedical risk reduction and treatment may improve attitudes by creating space for people to come together and understand the impact of dementia on their own community.

Collective Indigenous self-determination has been evidenced as a critical factor for the maintenance of health and wellbeing with Indigenous Peoples that leads to improved health outcomes at both community and individual levels.[19] The impact of self-determination is so fundamental as an Indigenous determinant of health, in fact, that it has been enshrined in international law as adopted by the United Nations in 2008.[9] This provides clear guidance for healthcare systems around the world to consider Indigenous sovereignty and Indigenous-led approaches to healthcare design, delivery, and evaluation of health systems and services. This becomes particularly important with the connection to resourcing appropriate structures so that the right supports are provided for Indigenous people who are living in their home communities and those residing outside of these communities.[20] Sovereignty over health systems and services also means that health promotion and support materials can be made in culturally relevant ways that are strengths-based and made for specific communities to break down stigma in these settings.

To this end, there are many emerging examples of good practice for dementia care with Indigenous people. One such example is the Indigenous-led and community-based clinic, Maamwesying.[21] Maamwesying North Shore Community Health Services is a First Nations-governed health centre in Ontario, Canada. Based on the findings of self-determined research, Maamwesyng partnered with surrounding health services to develop a community-based memory clinic that aims to implement and deliver culturally safe and accessible services that are adapted from primary care-based models for increasing access to dementia diagnosis and care. Maamwesying also works in partnership with communities to ensure the work done with researchers is driven by the needs and values of the communities that are served by the clinic. Attending to working in ethical, relational ways allows the clinic to participate in healthcare design and service delivery that is led by those accessing care, ultimately improving cultural safety for Indigenous people navigating the health system. In addition to direct service delivery, there are many other aspects of a patient's journey that are important when considering what it means to provide culturally safe care with Indigenous people living with dementia. Substantial work has been done to develop Indigenous-specific cognitive screening and functional assessment tools[22] to support better diagnosis of dementia and respond to community-identified priorities internationally. In addition to these crucial improvements in assessment and diagnosis within health services, work is continuing to expand and improve culturally relevant and culturally safe dementia prevention and knowledge exchange with Indigenous communities. Prioritisation of this type of work will contribute to ongoing efforts to mitigate the effects of stigma with Indigenous people living with dementia.

Dementia supports for Indigenous people, like all healthcare services for Indigenous people, must be designed to respond to intergenerational trauma, the legacy of colonisation on lived experience and cognition, and Indigenous ways of knowing and being. Strengths-based dementia care that is trauma-informed and supports connections to culture, when desired, is important part of reconciliation to enhance Indigenous cognitive health outcomes internationally. Many countries are recognising that there are diverse needs and experiences of Indigenous Peoples and Indigenous communities and that these needs are an urgent priority in health systems. This includes addressing the needs of all Indigenous people, including those in urban areas and shifting towards community-centred, or Indigenous-centred, models of dementia care that go beyond person-centred care in order to impact attitudes to dementia.

References

1. CanAge (2022) Dementia in Canada, Cross Country Report. CanAge, Canada. https://alzheimer.ca/sites/default/files/documents/CanAge-Dementia-Report-2022-EN-OCT-18-2022-compressed.pdf
2. Alzheimer's New Zealand. (2020) *Dementia Economic Impact Report 2020*. https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf
3. Mayeda, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016) Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & dementia*, *12*(3), 216–224. https://doi.org/10.1016/j.jalz.2015.12.007
4. Jacklin, K.M., Walker, J.D. and Shawande, M. (2013) The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. *Canadian Journal of Public Health*, 104(1): pp.39–44.
5. Smith, K., Flicker, L., Lautenschlager, N. T., Almeida, O. P., Atkinson, D., Dwyer, A., & Logiudice, D. (2008) High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology*, *71*(19), 1470–1473. https://doi.org/10.1212/01.wnl.0000320508.11013.4f
6. Jacklin, K. and Walker, J.D. (2020) Cultural Understandings of Dementia in Indigenous Peoples: A Qualitative Evidence Synthesis. *Canadian Journal on Aging*, 39(2):220–234. doi: 10.1017/S071498081900028X. PMID: 31179965.
7. Hulko, W., Camille, E., Antifeau, E., Arnouse, M., Bachynski, N. and Taylor, D. (2010) Views of First Nation elders on memory loss and memory care in later life. *Journal of Cross-Cultural Gerontology*, 25(4): pp.317–42.
8. Truth and Reconciliation Commission of Canada. (2015) *Honouring the Truth, Reconciling for the Future: Summary of the Final Report of the Truth and Reconciliation Commission of Canada.* Truth and Reconciliation Commission of Canada. Winnipeg, Canada.
9. UN General Assembly. (2008) United Nations Declaration on the Rights of Indigenous Peoples. Resolution/adopted by the General Assembly, 2 October 2007, A/RES/61/295.
10. Roach, P., Ruzycki, S.M., Hernandez, S., Carbert, A., Holroyd-Leduc, J., Ahmed, S. and Barnabe, C. (2023) Prevalence and characteristics of anti-Indigenous bias among Albertan physicians: a cross-sectional survey and framework analysis. *BMJ Open* 13: pp.e063178.
11. Allan, B. and Smylie, J. (2015) *First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada.* Toronto, ON: the Wellesley Institute.
12. Standing Committee on Indigenous and Northern Affairs. (2018) *The Challenges of Delivering Continuing Care in First Nations Communities*. House of Commons. Ottawa, Canada.
13. Fitzpatrick, K.M., Ody, M., Goveas, D., Montesanti, S., Campbell, P., MacDonald, K., Crowshoe, L., Campbell, S. and Roach P. (2023) Understanding virtual primary healthcare with Indigenous populations: a rapid evidence review. *BMC Health Services Research*, 23(1): pp.1–13.
14. Roach, P., Ody, M., Campbell, P., Bablitz, C., Toth, E., Murry, A., Henderson, R., Kennedy, A., Montesanti, S., Barnabe, C. and Crowshoe, L. (2022) Access, relationships, quality and safety (ARQS): a qualitative study to develop an Indigenous-centred understanding of virtual care quality. BMJ Open Quality, 11(4): pp.e002028.
15. Vernooij-Dassen, M. and Moniz-Cook, E. (2016) Person-centred dementia care: moving beyond caregiving. *Aging & Mental Health,* 20(7): pp. 667–668.
16. Nolan, M.R., Davies, S., Brown, J., Keady, J. and Nolan J. (2004) Beyond 'person-centred' care: a new vision for gerontological nursing. *International Journal of Older People's Nursing* in association with *Journal of Clinical Nursing,* 13(3a): pp.45–53.
17. Morgan, D., Crossley, M., Stewart, N., Kirk, A., Forbes, D., D'Arcy, C., Dal Bello-Haas, V., McBain, L., O'Connell, M., Bracken, J., Kosteniuk, J. and Cammer, A. (2014) Evolution of a community-based participatory approach in a rural and remote dementia care research program. *Progress in Community Health Partnerships: Research, Education, and Action*, 8(2): pp337–345.
18. Roach, P., Keady, J. and Bee, P. (2012) 'It's easier just to separate them' practice constructions in the mental health care and support of younger people with dementia and their families. *Journal of Psychiatric and Mental Health Nursing,* 19: pp.555–562.
19. Chandler, M.J. and Lalonde, C.E. (2008) Cultural Continuity as a moderator of suicide risk among Canada's First Nations. In: Kirmayer, L. and Valaskakis, G. (Eds) *Healing traditions: The mental health of Aboriginal peoples in Canada*, pp 221–248. University of British Columbia Press. Vancouver, Canada.
20. Browne, C.V., Ka'opua, L.S., Jervis, L.L., Alboroto, R. and Trockman, M.L. (2017) United States Indigenous Populations and Dementia: Is there a case for culture-based psychosocial interventions? *The Gerontologist,* 57(6): pp.1011–1019.
21. Maamwesying. (2021) *Annual Report 2020–2021*. North Shore Community Health Services Inc. Ontario, Canada.
22. Walker, J.D., O'Connell, M.E., Pitawanakwat, K., Blind, M., Warry, W., Lemieux, A., Patterson, C., Allaby, C., Valvasori, M., Zhao, Y. and Jacklin, K. (2021) Canadian Indigenous Cognitive Assessment (CICA): Inter-rater reliability and criterion validity in Anishinaabe communities on Manitoulin Island, Canada. *Alzheimer's & Dementia*, 13: pp.e12213.

Stigma in times of crisis: how war compounds the struggle for people living with dementia in Ukraine

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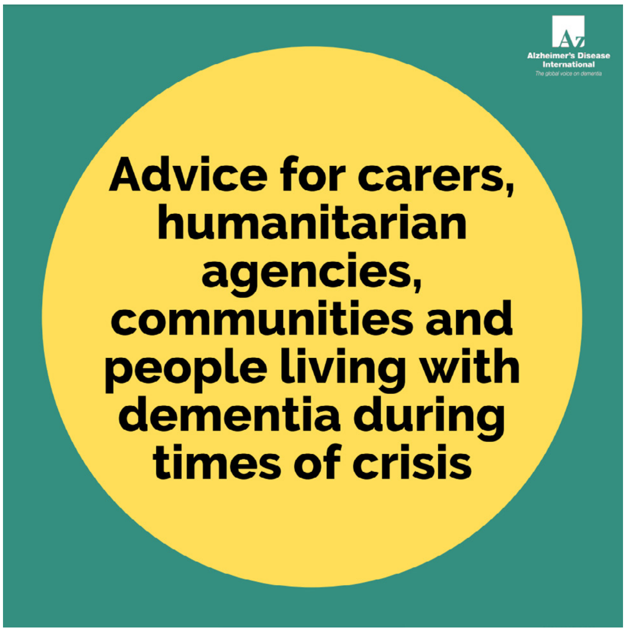
In Ukraine, dementia has not yet become a major concern or priority for society or policymakers, with public awareness and understanding of the condition remaining limited. However, there is growing recognition that this needs to change. The Russian war in Ukraine since February 2022 has highlighted the urgent need to prioritise dementia as a public health issue.

The situation in Ukraine can be described as the "oldest" humanitarian crisis in the world, as 8.9 million people, or 24% of the population, are over 60 years old. Older Ukrainians face disproportionate barriers to accessing essential items and support due to poverty and the limited accessibility of assistance, services, and information.[1]

There are no publicly available statistics on the number of people with dementia in Ukraine, but according to global burden of disease calculations, 651,773 Ukrainians had dementia in 2019, with this number expected to rise to one million by 2050.[2]

Traditionally, dementia has been viewed through a stigmatised lens in Ukraine, with many people believing it is an inevitable part of ageing, rather than recognising it as a medical condition that requires specialised care and support. This is a legacy of Soviet-era systems and practices that have undergone minimal change since Ukraine became independent in 1991.

Pre-existing misinformation and prejudice have caused longstanding major challenges for people with dementia and their caregivers, which have only taken on more dramatic proportions in wartime. In the past two-and-a-half years, we have seen volunteer drivers sometimes refuse to help people with dementia evacuate from Russian-occupied territories because they were behaving "abnormally"; people with dementia facing complaints and incomprehension from others taking refuge in shelters during air raids; refugees and internally displaced people struggling to find housing and being asked to leave after being told they "do not behave properly." Other people living with dementia have also been abandoned by their own relatives because they didn't know how to safely flee with them or how to arrange suitable accommodations elsewhere.



Alzheimer's Disease International
The global voice on dementia

Advice for carers, humanitarian agencies, communities and people living with dementia during times of crisis

Despite these dramatic instances, the war has not so much highlighted the actions of society as its inaction. Key challenges include low societal awareness about dementia and fear of diagnosis, which lead to stigmatisation and delays in seeking professional help.

Biomedical approaches, especially in inpatient psychiatric departments, dominate the field, which exacerbates the institutionalisation and stigmatisation of individuals with dementia. There is a noticeable lack of preventive measures, early detection, psychosocial methods, primary medical care-level dementia care, and person-centred and community-based services.[3]

Despite these challenges, there have been positive shifts in the last several years, driven by both non-governmental organisations and the government.

> **"The war has not so much highlighted the actions of society as its inaction."**

Since 2021, the Nezabutni Charitable Foundation, which is the Alzheimer's disease association in Ukraine, has been working to raise awareness, provide education, and support families affected by dementia. There are various programmes to train caregivers, offer psychological support, and advocate for better healthcare policies, such as the "Dementia Cafes" initiative running in five cities of Ukraine in 2024 and spreading further. Nezabutni has participated in the World Alzheimer's Month campaign every September since 2021 with wide media coverage, PR activities, and events to raise awareness and change attitudes towards dementia. Nezabutni is also providing training on dementia for caregivers, social workers, and the personnel in nursing homes in Ukraine.

Since the Russian invasion of Ukraine, Nezabutni launched humanitarian response programmes such as providing medications, generators, and support with evacuation. These programmes highlighted a strong need for guidance on how to act and communicate with people living with dementia situations of crisis. In consultation with ADI, advice cards for carers, humanitarian agencies, communities, and people living with dementia during times of crisis were put together and disseminated in a number of languages including Ukrainian.[4] This practical and much-needed information was distributed by Nezabutni all over the country and played an important role in supporting caregivers, volunteers, and community services who provide assistance to people with dementia.

At the governmental level, there has also been major progress, as the government has committed to developing the first Ukrainian National Dementia Plan by the end of 2025.[5]

While there is recognition among Ukrainian government officials that people with dementia face particular risks and stigmatisation, and there are certain national initiatives targeting them, assistance remains insufficient, particularly in efforts to reach the most at risk.

References

1. Help Age International (2022) report. "I've Lost The Life I Knew" Link to the report
2. The Lancet Public Health, 7(2), e105-e125. Link to the article
3. Richard Fleming, Iryna Shevchenko, Anna Grygorieva (2024). Practical approaches to Care in Ukraine
4. ADI, Advice for carers, humanitarian agencies, communities and people living with dementia during times of crisis Link to the Card
5. Resolution of the Cabinet of Ministers of Ukraine (2024) Link to the resolution

Palliative care access for people living with dementia in the Middle East: navigating cultural barriers

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Dementia is a growing public health concern, particularly in the Middle East, with an estimated 1.3 million people affected in the region in 2021.[1] The projected increase in the number of cases by 2050 is anticipated to be much higher in the Middle East and North Africa regions when compared to Asia Pacific and Western Europe.[1] In the Middle East region, sociocultural and political factors play an integral role in shaping the concept of health.[2] As such, these factors directly impact the intricacies of accessing care. In the case of dementia, it is generally believed that it is part of the natural ageing process, and, given that is it thought to be linked to the concept of "fate," people living with dementia tend not to seek medical care. Instead, they often seek advice from religious or traditional healers to treat dementia, further exacerbating the issue at hand.[3] In addition, due to perceived cultural and religious beliefs and obligations, people with dementia living in the Middle East are often taken care of at home until the last stages of disease progression.[4]

The importance of palliative care for people living with dementia

As people living with dementia approach the end of their lives, their care needs become more complex. As such, palliative care can help improve both the experiences and outcomes of this population.

Palliative care is a holistic type of care that is patient-centred and focuses on meeting the physical, psychosocial, and spiritual needs of patients with life-limiting illnesses.[5] It aims to alleviate suffering and improve overall quality of life and encompasses symptom management and treatment, including around pain and agitation, both of which become increasingly common as dementia progresses. Pain is the highest reported symptom among elderly people living with dementia. However, this often goes untreated, given that the assessment of pain becomes more challenging as the condition progresses and the ability of these patients to self-report it becomes more difficult.

Although these symptoms become worse towards the end of life, palliative care can be initiated early in the disease trajectory, simultaneously with other therapies.[6] This would allow more dementia patients to remain in their place of residence and reduce prolonged hospital stays, particularly towards the end of life. Using a palliative care approach to dementia care could also potentially enhance and ease the end-of-life experience by allowing individuals with dementia and their families and caregivers to plan and make decisions about their care and treatment in advance.

However, despite its proven effectiveness, access to palliative care in the Middle East remains a major challenge, as it is estimated that only 5% of adults who need these services are receiving them.[7]

Barriers to accessing palliative care services in the Middle East

Access to palliative care for people living with dementia in the Middle East varies across countries, with some having more developed services than others. Generally, the level of palliative care that is provided tends to be quite basic, with some countries having no known palliative care services available.[8] Even in countries where palliative care services are advanced, barriers to access still exist. These challenges can sometimes be systemic and include a lack of integration of palliative care into the healthcare system; a shortage of palliative care professionals, coupled with insufficient training and education for healthcare professionals and volunteers; lack of public awareness; and/or strict regulations that limit the accessibility and use of analgesics.[9]

It is often the case that for the small proportion who people with dementia who access palliative care services, this is usually triggered by a crisis or imminent death.[10] This can be due to a number of reasons, including high out-of-pocket costs for care, or a general lack of understanding of what palliative care is and how it can improve quality of life.[11] However, it is well documented that a timely referral to palliative care for those with dementia can help better prepare patients and caregivers for the trajectory of the condition and can facilitate proactive discussions and decision-making through advance care planning by the patient, their family, and healthcare professionals.[12]

Sociocultural barriers

Sociocultural and religious beliefs play a major role in influencing how people with dementia seek access to care, particularly in the Middle East where the majority of the population is Muslim. In a study on palliative care conducted in Qatar, Arab culture and Islamic religion were the most reported influencers of patients' healthcare decisions.[13] From an Islamic perspective, Muslims are expected to take care of their parents entirely and to ensure their dignity is maintained when they reach old age.[14] Therefore, placement in care facilities or anywhere outside the family home is considered an abandonment of duty and is unacceptable.[14] The social stigma associated with having a mental illness in the Middle East can also have a negative impact on patients and carers seeking appropriate care and treatment.[15] Stereotyping and stigma are therefore associated with an increased caregiver burden, stress, and social isolation.[16]

A study looking at the perspectives of dementia caregivers when asked about the quality of care provided to their loved ones described this care as "passive" and "lacking individualisation."[17] Caregivers who experienced home care services reported that these services often lacked reliability and predictability.[17] The study participants also reported that healthcare services generally failed to meet their needs or the needs of the person they are caring for, both when it came to diagnosis and personalised care plans. Palliative care was also not commonly offered.[17]

Education and training

Given than palliative care is crucial to improving the quality of life of people living with dementia and their families, healthcare professionals must be adequately trained on how to provide palliative care to these individuals using a holistic, patient-centred approach. Given that palliative care education is not covered in depth in medical and nursing curricula, very few qualified palliative care specialists exist.[18] Healthcare professionals worldwide, as well as the general population, also lack advanced knowledge of dementia care. As such, enhanced dementia education could expedite the implementation of preventative measures at an earlier stage and could help solve the issue of under-referrals of people with dementia to palliative care.

Procedural barriers

> "Through understanding the culture and religious beliefs, better healthcare outcomes can be achieved by providing religiously and culturally appropriate care to the patient and caregiver from the diagnosis to end of life."

Given that it is generally thought that family members are the primary caregivers for people with dementia, governments in the Middle East seldom have guidelines or policies related to care and support provision to individuals with dementia and their carers.[19] As such, healthcare workers often struggle to find the relevant policies and guidelines that govern aspects related to end of life such as resuscitation orders, pain management, and the insertion of feeding tubes. Particularly in the case of advanced dementia, where individuals cannot communicate their care needs, a surrogate (often a family member) is ultimately involved in the decision making. However, they might be reluctant to make decisions due to religious beliefs, fear of blame from family members, or feelings of guilt. Therefore, there is a need for policies that support patients and caregivers in critical circumstances towards the end of life.[19]

The way forward

Governments worldwide have a responsibility to improve health outcomes for conditions such as dementia. Culturally and religiously sensitive national campaigns are needed to raise awareness on dementia, shed light on its life-limiting aspects, and encourage the utilisation of palliative care services to improve health outcomes and quality of life. This can be done using social media and other accessible media channels and should include specific messaging that portrays dementia as one of the chronic diseases, encouraging patients with dementia and their caregivers to express their concerns and access care without fear of stigma.

There is also a need for building capacity within the health workforce around dementia and palliative care.[13] Palliative care training should be integrated into the undergraduate curriculum across various healthcare professions (nurses, physicians, and allied healthcare professionals) and offered as continuous professional development for different specialisations, including primary care, home care, geriatrics and long-term care, specialist medical care, and rehabilitation. Awareness campaigns that target healthcare professionals and address the ethical challenges related to palliative care from the angle of various religions are also recommended and can help overcome difficult situations and aid with important care-related decision making towards the end of life.

On a national level, policies and guidelines that provide support to people with dementia and their families should be developed and circulated to help ease otherwise difficult care decisions towards the end of life. There is also a need for the formulation of national palliative care strategies and dementia strategies that align on policy, education, service provision, caregiver and family support, advance directives, and advocacy and awareness raising.

The Middle East provides a unique context given the values and beliefs that are specific to this region's population. Through understanding the culture and religious beliefs, better healthcare outcomes can be achieved by providing religiously and culturally appropriate care to the patient and caregiver from the diagnosis to end of life.

References:

1. T, Q. *et al.* Prevalence and economic burden of dementia in the Arab world.
2. Lakey, L., Chandaria, K., Quince, C., Kane, M. & Saunders, T. Dementia 2012: A national challenge. *Alzheimer's Soc.* (2012).
3. Okasha, T. & Boutros, N. N. A synopsis of recent influential papers published in psychiatric journals from the Arab World. (2010).
4. Zaidi, A. *et al.* Dementia in Pakistan. (2018).
5. L, S. *et al.* Empowering Better End-of-Life Dementia Care (EMBED-Care): A mixed methods protocol to achieve integrated person-centred care across settings.
6. Yorganci, E. & Sleeman, K. E. Palliative care can benefit people with dementia. *BMJ* **380**, p754 (2023).
7. Connor, S. *et al. Global Atlas of Palliative Care*. *The Worldwide Palliative Care Alliance* (2020).
8. Sánchez-Cárdenas, M. A. *et al.* Palliative care in the Eastern Mediterranean: comparative analysis using specific indicators. *BMC Palliat. Care* **21**, 168 (2022).
9. Fadhil, I., Lyons, G. & Payne, S. Barriers to, and opportunities for, palliative care development in the Eastern Mediterranean Region. (2017).
10. Sampson, E. L. *et al.* Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliat. Med.* **32**, 668–681 (2018).
11. University College London. Nine in 10 Brits underestimate impact of dementia. Available at: https://www.ucl.ac.uk/news/2022/dec/nine-10-brits-underestimate-impact-dementia. (Accessed: 4th August 2024)
12. Deschepper, R. *et al.* Truth-telling at the end of life: a pilot study on the perspective of patients and professional caregivers. (2008).
13. Demachkieh, F. *et al. Integrating palliative care for older adults : A needs assessment for Hamad Medical Corporation ' s geriatric services older adults : A needs assessment for Hamad Medical Corporation ' s geriatric services*. (World Innovation Summit for Health (WISH), 2022).
14. Hammad, S., Daher-Nashif, S., Kane, T. & Al-Wattary, N. Sociocultural insights on dementia caregiving in Qatar: The perspectives of family caregivers. *Ageing Soc.* (2020).
15. Ciftci, A., Jones, N. & Corrigan, P. W. Mental Health Stigma in the Muslim Community. *J. Muslim Ment. Health* **7**, (2013).
16. LA, S., Combes H FAU – Stokes, G. & Stokes, G. Understanding the dementia diagnosis: the impact on the caregiving experience.
17. Granbo, R., Boulton, E., Saltvedt, I., Helbostad, J. L. & Taraldsen, K. My husband is not ill; he has memory loss – caregivers´ perspectives on health care services for persons with dementia. *BMC Geriatr.* **19**, 75 (2019).
18. Kolmar, A., Jordan, M., Amy Lee, Y.-L., Turner, D. & Kamal, A. A SYSTEMATIC REVIEW OF PROVIDER EXPERIENCES WITH PALLIATIVE CARE IN MUSLIM PATIENT POPULATIONS. *Crit. Care Med.* **47**, (2019).
19. Silbermann, M. & Berger, A. *The Impact of Culture and Faith in Dementia Care: Psycho-Social-Spiritual Healing*. (Cambridge Scholars Publishing, 2023).

Chapter 5:

Case studies in addressing stigma

While discussions of stigma can lead to despair, it is important to highlight the numerous existing initiatives around the world that seek to improve the treatment and inclusion of people living with dementia. Many of the essays in this section stand in conversation with those in previous chapters, and will hopefully inspire others to follow suit in their respective communities.

This chapter opens with a poignant testimony by Patrick Kitana Ettenes, whose difficult experience with early-onset dementia has led them to become an advocate for LGBTQI+ people living with the condition. In Japan, Noriyo Washizu explores the successful campaign to replace pervasive stigmatising terminology for dementia. Mataa Mataa and Primrose Nyamayaro reflect on the lessons that can be learned from efforts to destigmatise HIV in Africa – a condition that, much like dementia, has long been associated with fear, shame, and discrimination – while Déborah Oliveira and Carolina Godoy present the effects of their interventions with healthcare workers in Brazil. Lucas Cose and Will Dean discuss their personal experiences as teenagers and young adults with a parent living with young-onset dementia, while Martin A. Bruno, Luciana Vita, Mariana Zanino, and Laura Noguera highlight efforts to promote brain health and healthy ageing among young children in Argentina. Manka Nkimbeng meanwhile looks at the impact of outreach efforts aimed at African immigrants in the United States to increase dementia awareness.

Last and not least, Ingrid Wellington, Kago G. Paledi, and Faraneh Farin – representing ADI member associations in Panama, Botswana, and Iran respectively – speak of the importance of the 2024 attitudes to dementia survey for their advocacy and awareness-raising efforts, in a context where lower- and middle-income countries remain far too often overlooked in research.

Pam Andrew, 76, who lives with dementia, works on a puzzle with her granddaughter Christiane, 2, and her daughter-in-law Julie Hau in June 2023 in Alameda, California. (Jason Andrew)

Becoming an advocate and a force for change as an LGBTQ+ person with early-onset dementia

Patrick Ettenes

Lived experience advisor, co-founder of Bring Dementia Out, Manchester, UK

My name is Patrick Kitana Italo Ettenes and I am 41 years old. I was born in Barbados, my mother is from Trinidad of East Indian descent, while my father is Dutch of Swiss descent. I also have a brother, who's older, odd, and complicated – but then he could definitely say the same about me. I currently reside in Manchester, in the United Kingdom. I identify as trans and non-binary, I use both he and she pronouns, and I have early-onset dementia.

Being diagnosed with dementia in your early thirties

My story began a decade ago. I was in an abusive relationship, which resulted in me having a nervous breakdown and some form of stroke. I went to sleep and woke up basically paraplegic, and as a result I had to learn to walk, talk, and write again.

I knew something more was wrong with my brain when I started to hear voices. I started experiencing short-term memory loss, but most upsettingly, I was not able to remember my childhood. I had no emotional memory whatsoever. The last straw came when I took over an hour to put pages 1 to 5 of a printed document in order.

The doctor who told me I had frontal lobe atrophy never explained to me that my condition was a form of dementia, just that I had more brain wastage than anyone they have ever seen, and that my brain was 20 years older than it should be.

Google became my best friend, and I realised that early-onset frontotemporal lobar degeneration (FTLD) was a rare form of dementia (please note that I took this as a compliment). I stumbled across a thesis that touched on the theory that Frontal Lobe Atrophy can be caused by high amounts of trauma to the brain. Well, my former partner did a number on my brain, that's for sure.

When I was eventually diagnosed with dementia in my early thirties, it was the support worker from the Alzheimer's Society, not the clinical psychologist I had an appointment with, who explained to me that I had early onset. That same psychologist later denied that we had had that conversation – despite the support worker having been there – and never let me address the abuse my ex-partner put me through. Do you know what its like to have PTSD, with past memories of abuse coming forward, and as you sit in the room with someone who's meant to help you, they try to change the topic?

Little did I know I was facing another form of abuse. I remember going to the leading neurologist in Manchester, to whom I told all the struggles I was facing. I even had printed out the results of my own research to show him.

He took one look at the paper, threw it to the side, and said to me that I couldn't have dementia because of how I was dressed and how articulate I was. He even added: "I bet you anything you just don't have it."

I finally snapped. "Listen here, I am a gay man who has always been fashionable and colour-coordinated – since when does wearing Zara head to toe mean anything about not having dementia?"

The process to get my diagnosis has been one of the most shameful experiences I've ever had with the NHS. What happened to me has left other healthcare professionals upset and baffled as to why and how these people could still be out there helping others.

At the time of my diagnosis, very little was known about FTLD. After a few years, I heard about a support group for people living with FTLD. As you can imagine, I was so excited to attend. Little did I know that it would be so comforting, reassuring, emotional, and extremely triggering all at once.

I broke into tears when I heard stories from others with my condition, which confirmed what I had tried to explain to the know-it-all neurologist. I was so relieved, but at the same time it triggered pain and hardship that someone of my age had to face this.

Because I was in my early thirties, people knew I had the condition but didn't empathise with me when I had to explain that I couldn't do certain things, hold down a full-time job, or why I wasn't the same person anymore. Everyone just thought I was exaggerating or making excuses.

My father, who passed away in June 2024, also had dementia. About a year ago, I was in Spain with him and my mother, who used to be an NHS nurse for over 30 years, when she sat me down to say: "For the first time, I can see that your dementia is affecting you." I could feel the pain it caused her to say this, but she could see the similarities between my father and myself.

"Like father, like son," as my father would say.

Advocating for dementia in the LGBTQ+ community

There were also misunderstandings with other people living with dementia. I attended a conference with a fellow dementia activist who had written a book that got a lot of praise for having a very positive outlook on dementia.

When I was asked to speak, I explained the struggles I had to face as a single LGBTQ+ person living alone with the condition, and how I suffered with the condition. She got so upset that I said that I *suffer* with dementia, telling me that she was trying to educate people into using correct phrases so they wouldn't fear the condition.

I had to kindly explain to her that I do suffer with my condition. I had no career, I was still trying to learn how to manage myself, it was hell on earth for me. Not remembering my childhood, not been able to carry on with basic organising and functioning made my life as a single person even more isolating.

When you face others with the condition, you realise that you are facing another person's reality that is perhaps different than your own, and that's okay. This is when I learned that my voice and my situation were unique, and they needed to be shared.

When I was diagnosed with this condition, my mentor looked at me one day and said: "Only you have the gift to turn your issues into a way to help other people. I don't know how you will do it, but only you can."

And he was right. I took those words and started to build a new road from scratch. I was an amazing writer, but I now needed to be seen and heard. With great effort, my mentor taught me public speaking. I guess he knew I had a gift that needed to be nurtured, and I'm so grateful he did.

In all honesty, it has taken 10 years or so to finally have friends who understand my situation as best as they can, who adapt and care for me on so many levels when I'm around them. I am grateful for them every day. After a couple years of friendship, I turned to a friend and asked if she would be my carer. It's not every day you ask that of someone, but it came to that point. So now I don't feel alone, and I have to remind myself of that.

However, the sheer loneliness and lack of empathy from others in the LGBTQ+ community has sometimes been phenomenal. Many gay men don't like to think about getting older, so anything that shows the harsh possibility that they could get dementia gets thrown to the side because it is too frightening.

I have learned that a lot of single people do not receive treatment or access care – simply because they are ignored. My life with this condition has caused me to be suicidal and self-destructive for days, weeks, months on end – all because I was alone. I craved my family more than I craved drugs. I wanted to be loved, but who wants to date someone who already has dementia?

This is why I set up Bring Dementia Out back in 2018, the world's first LGBTQ+ support group for people living with dementia. My work is now to ensure that LGBTQ+ people and people of colour are included in dementia work at the local and international levels.

The more I fell out of love with my community, the more I wanted to help it. It's an odd statement, so I'll explain. The way I was treated by so many in the LGBTQ+ community, one wouldn't be able to recover from that anytime soon – but that made me work more, because one day, one of them will develop my condition, and they will need the services I am trying to develop. I know in my heart that a lot of them would struggle much more than I did, and I just don't want them to suffer that much.

My illness made me see the world differently. I have the unique perspective of having an older person's condition at a very young age. Those circumstances have made me empathise more with individuals that I never would have thought about. Because of this, I realised that there are so many people from different religious backgrounds and ethnic minorities that have also been overlooked.

I am facing the fears and struggle of my future living with dementia and worrying about what services and care I would receive in the foreseeable future. It's so important that people from my community feel accepted, because you have no idea the struggles we face day in and day out trying to be accepted within our own minds, within our families, our environment, and at work. Then comes a time when we are sick, and it's another battle we face, alone, because the world still sees us as taboo.

I've not had the chance to develop long-time connections and romantic partnerships like my heterosexual counterparts. I am so frightened of the shame and prejudice that could befall me in a care home, because I want to wear my heels around all day when I am perceived as a man. Will my care staff, nurses, and residence understand why that pair of heels mean so much to me?

Person-centred care is about understanding this one golden rule: you were born into the norm, I wasn't, and I was told every day that I was different. As a result, I may have different coping mechanisms, social structures, stories, or habits. Nevertheless, just be open to how they lived their life.

The work I am doing is vital, because voices that are brave and open and honest about their experiences are rare. I don't believe I was punished by having this condition. I believe it was a gift, a painful one, but I believe the universe wanted me to do something with this condition: to educate as many people as possible and open their eyes hearts and minds to the needs and requirements of my community, so that another generation of LGBTQ+ people with dementia doesn't have to feel alone or abandoned.

As my condition progresses, I've now found myself identifying more and more as transgender, and I see the world through another lens. As a 41-year-old person who has lived their life as a gay man, as a result of my dementia I have unshackled the restraints I had in place around my feminine side and embraced a new era in my life where the divine feminine in me shapes the very essence of my work.

As I find myself more and more, I see where others trans and non-binary people need change and acceptance today. As I become whatever I am meant to be, I continue to shape this broken world into a richer and more caring one, so no one has to feel scared that they wouldn't be cared for properly if they are diagnosed with dementia. A world where trans women can embrace a future in which, if they were to be diagnosed with dementia, they can choose a care home and carer without worry, instead of ignoring the future like I did. A world where they can be themselves no matter where they are.

When I started to see the effects of my work and how it has impacted others, that fuelled me more. A friend was a student of mine at the University of Manchester, where I was a guest lecturer. To this day, she says this lecture changed her career path to become a ward manager in a dementia care unit. That student is one of my best friends now, and a major support in both my personal and professional life.

I've been humbled by the feedback of people who have heard me speak, to know that my experiences in life haven't been in vain, even as I sit here distraught by the passing of my father, crumbling in ways I can't express. It does something to you when you watch your father pass of the same condition as yourself.

Writing this article wasn't easy, I haven't been in a good place since my father's passing, but it has given me perspective, and I believe it will do the same for others. I just want to leave a legacy behind so the day I finally close my eyes, I know I've done right by the world, for others – until they find the few thousand skeletons in my closet (a little bit of humour to break the ice).

Take these last words from me please. In any given moment, a memory can stay forever or fade away. Wouldn't it be amazing you were part of someone's forever memory? That you made them smile, feel safe, and maybe even loved?

Try to be someone's forever moment, because I'll need you one day to remind me.

Changing terminology to change attitudes: the Japanese experience

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Words influence the activities and thoughts of individuals and societies. People initially identify things by their labels, and stigmatic and inappropriate terms create discrimination and prejudice. These terms as they relate to dementia impact the person living with dementia themselves, but also their families, their carers, and contribute to fostering negative attitudes to dementia in society as a whole, becoming a grave impediment to an inclusive society.

Japan is a rare example of a country that changed the word for dementia from a discriminatory one to a symptoms-based explanatory term. This essay explores the background, process, and impact of the name change and dementia-related terms in Japanese society.

The need for a name change

The word *chiho* (痴呆), meaning "fool" and "blockhead," first appeared in Japanese medical literature in 1909 to refer to dementia. For a century, the word *chiho* was widely used in Japan, both in the medical field and in everyday language.

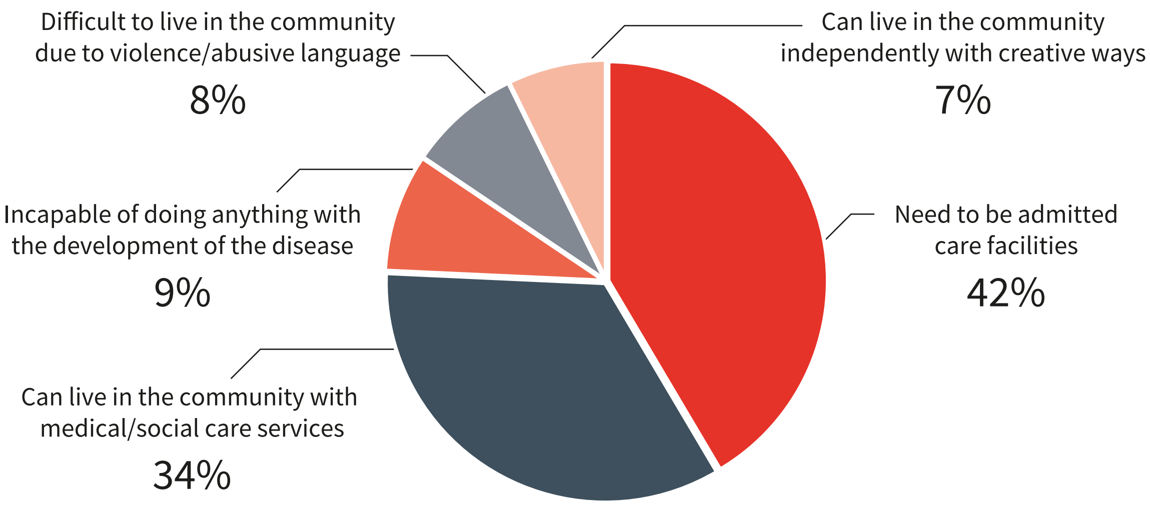
But around the turn of the 21st century, the growing need for a government strategy to address Japan's ageing society, the development of medical and social care, and awareness raising around dementia all contributed to the realisation that things needed to change.

In the early 2000s, the Ministry of Health, Labour, and Welfare (MoHLW) discussed with medical and nursing care specialists changing the stigmatic name *chiho*. They firmly believed that the term formed a crucial barrier to correctly understanding the condition and creating a dementia-inclusive society.

The government set an exploratory committee formed of medical and social care professionals, as well as linguists to find a new term to replace *chiho*. The government then conducted a national survey about new terminology and publicly announced in 2004 the introduction of a new term, *ninchisho* (認知症), meaning "cognition syndrome."[1]

National opinion survey on dementia 2021

Japan's Government Cabinet Office 2021 – https://survey.gov-online.go.jp/hutai/r01/r01-ninchisho.pdf



Universalising a new word

The central and local governments promoted the establishment of the new term *ninchisho* through various strategies, including by collaborating with academia and stakeholder associations. All related medical and academic fields such as medicine, psychology, rehabilitation, and nursing, announced they would use the new word and changed their associations' names accordingly. All stressed the importance of decreasing stigma and promoting better understanding of dementia.

Another driving force was the increasing number public and private qualifications in dementia care, all including the word *ninchisho* in their titles.

The Dementia Supporter (Dementia Friends) campaign, which started in 2006, also significantly contributed to disseminating the new name to the public nationwide. A person who completes a 90-minute course on basic knowledge and how to support people living with dementia qualifies as a dementia supporter. This ongoing campaign has reached more than 15 million people as of 2023, ranging in age from six-year-old children to 90-year-old elderly.

The development of medical/social dementia care and the voices of people living with dementia themselves from the early 2000s onwards significantly advanced the acceptance of the new term.

Of course, there were some adverse comments against the new term and suggestions for other options at the beginning of the reform, but the multilayered strategies succeeded in steadily and incrementally spreading the word *ninchisho* into society.

The aftermath

It has been 20 years since the name changed; we rarely see and hear the former name *chiho* in the media, documents, or daily conversation. If someone uses the former term, most people feel that it is strange and inappropriate. It seems that the discriminatory name for dementia has almost disappeared, and perception have improved to a certain extent.

But while the term *chiho* has almost disappeared, discrimination and misunderstandings still exist. Sometimes, we find inappropriate usage of expressions that lead to negative attitudes toward dementia, even in government documents and textbooks. For example, some of people living with dementia's behaviours are still described as "agitation," "attacks," etc.

According to a government survey conducted in 2021, 42% of respondents think "people living with dementia need to be admitted to care facilities," and 8% of them answered that it was "difficult for people living with dementia to live in the community due to violence and abusive language."

The goal of a fully dementia-inclusive society is still far away. However, there is a significant difference between 20 years ago and now. People living with dementia, their carers, and attentive professionals have started to point out inappropriateness, and those voices are gradually impacting society. For example, major newspaper companies now use words related to dementia carefully to be politically correct. These actions are making a difference and help to create a society without discrimination and prejudice.

Terminology predisposes people's minds. It is a label by which people identify things. Therefore, the name for dementia, in any language, should not include implications of prejudice, discrimination, or contempt.

The Japanese government implemented the name change as a top-down strategy, while medical and nursing care professionals, researchers, and frontline practitioners significantly contributed to its establishment.

The name change was essential to build towards an inclusive society without prejudice and discrimination. While Japan has taken a step forward, continuous and multilayered efforts are essential in order for us to live in an inclusive society without discrimination.

We want to share our experiences and learn from other countries to reach our goal. A journey of a thousand miles begins with a single step. Let's walk together.

References

1 https://www.mhlw.go.jp/shingi/2004/12/s1224-17.html

Stigma in dementia: lessons from HIV care in Africa

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Is a world without stigma towards people living with dementia possible? Is such a goal too aspirational? What would such a world look like, and what needs to happen now for us to achieve this?

When we think about stigma and its consequences for people living with dementia and their carers, we must look critically at the drivers of stigma. By reflecting on these drivers, we can develop better strategies to address stigma, asking ourselves what has worked and what has not. Many lessons can be learned from how stigma is being tackled in other conditions, such as HIV, especially in low-resourced settings. It is these same regions that will have the most people living with dementia shortly.[1]

Understanding and overcoming stigma

In their landmark paper on conceptualising stigma, Link and Phelan[2] defined stigma as the "co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination – further indicating that for stigmatisation to occur, power must be exercised." Stigma is not unique to people with dementia. It occurs in people living with the human immunodeficiency virus (HIV) as well.

HIV-related stigma refers to negative beliefs, feelings, and attitudes toward people living with HIV.[3,4] While significant progress has been made to address it, stigma in HIV continues to be one of the critical drivers of late presentation to health facilities to receive treatment, even though treatment is now available. Stigma continues to affect engagement in care and treatment outcomes in people living with HIV.[4] Similarly, the stigma associated with dementia is lived in several ways, impacting individuals, families, and communities, leading to different behaviours by the person experiencing the stigma and those perpetrating it.[4,5]

This stigma is essentially driven by fear. There is the fear of the unknown, fear of losing physical and cognitive abilities, fear of loss of familial and societal roles, and of becoming a burden. At a community level, there is fear about what causes dementia and what risks it poses to the rest of the community. Communities are misinformed about the causes, progression, and impact of dementia., often fuelled by outdated beliefs and a lack of public education. Many still view dementia as a natural part of ageing[6] or as the consequence of witchcraft practices.[7] Traditional and religious leaders often perpetuate these beliefs.[7]

Similar themes have been seen throughout the HIV pandemic. Engagement with communities and robust awareness campaigns have been effective in raising community-level knowledge of what causes HIV and the availability of effective treatments. This has been important in reducing the stigma of HIV. Similar community-level and national awareness campaigns must be implemented as a national priority to help reduce stigma toward persons with dementia.

Unlike conditions that have early, clearly visible symptoms, dementia is often a private condition. What people know about dementia dictates their help-seeking behaviour. How they have seen dementia discussed and how people with dementia have been treated by their families and communities plays a part in how likely someone is to come forward with symptoms; this self-stigma is problematic because only the person going through it can fully express its impact. Discrimination against individuals with dementia can affect employment opportunities, access to healthcare, and social interactions. These fears must be addressed in campaigns aiming to reduce stigma.

At the same time, there must be national-level protections for persons with dementia driven by national dementia plans. Laws that were enacted to protect people living with HIV from discrimination in workplaces, healthcare, and communities at large had a vital part to play in reducing the stigma experienced by people living with HIV. This further emphasises the need for national dementia plans as part of efforts to eliminate the stigma of dementia.

People living with HIV have been effective champions for campaigns that address issues to do with HIV. Having someone living with HIV at the forefront has been and is still a critical component of addressing HIV-related stigma. Working with local dementia advocates and organisations will be essential to overcoming stigma. There is impact when people can look at someone who lives as they have lived, speaking to their situation, and say: "I am living through what you are living, and I am here to support you." People living with dementia and caregivers must be given space to be the voice of dementia. Political, religious, and other community leaders must be encouraged to be visible supporters of people with dementia.

Overcoming the stigma associated with dementia must be multisectoral, involving education, advocacy, and compassionate support. Dementia education must be integrated into school curricula and professional training programmes for primary health workers; these health workers who engage directly at the community level play a crucial role in dispelling myths. Increasing the knowledge of primary healthcare workers can serve to reduce the stigma that persons with dementia will face as they access healthcare, increasing the likelihood they will seek care and be retained in care.

Some of the interventions that are in place for addressing HIV-related stigma include offering routine testing of HIV to the general public, ensuring there are information leaflets and posters educating the public about HIV, having educational programmes on HIV on the radio, having HIV education in schools as part of sexual health lessons and widespread mass media campaigns with the "Undetectable= Untransmittable" message.[3,4]

Inexpensive, reliable, and accessible tests for dementia must be developed and applicable in all settings. We must also be mindful of how likely these tests are to be accepted in the communities they are intended to serve. The more complicated, misunderstood, and expensive a medical procedure is, the more it discriminates against those it is intended to help. For example, lumbar punctures may face significant resistance and failure as a diagnostic approach.[8] At the same time, blood-based testing may be more acceptable in communities, as this is already done routinely for conditions like HIV with high levels of acceptance.

Prior to the advent of antiretroviral therapy (ART), people living with HIV had a lower life expectancy compared to people without HIV; however, with ART, people living with HIV are living longer, and people diagnosed with HIV can start treatment soon after diagnosis. The availability of antiretroviral therapy has played a pivotal role in tackling HIV-related stigma. Treatment of HIV with ART decreases mortality and morbidity, prevents HIV transmission, and improves quality of life.[3] Therefore, continued awareness of ART and its benefits is continuing to yield results. Community and public engagement programmes bring to the fore awareness of the benefits of being tested and treated early and consequently address HIV-related stigma.

While there are as yet no comparable medications for dementia, education campaigns must continue to show the importance of early diagnosis and care. Education campaigns must focus on a life-course approach to risk reduction and integrate messages on dementia into already existing care systems. In HIV, the elimination of mother-to-child transmission has become an achievable goal because screening for HIV was added to already existing antenatal services.

The lived narrative in HIV has changed over time, from one in which an HIV diagnosis was seen as a death sentence to one in which people with HIV are living lives that are no different in quality and length from those who are HIV negative. Similarly, campaigns for dementia need to begin to message information in life-affirming ways and show that there are things that can be done to improve the quality of life of the person with dementia and their carers, even in low-resource settings.

> **"The lived narrative in HIV has changed over time, from one in which an HIV diagnosis was seen as a death sentence to one in which people with HIV are living lives that are no different in quality and length from those who are HIV negative. Similarly, campaigns for dementia need to begin to message information in life-affirming ways."**

As long as people feel there is no help for them in formal healthcare systems, they are unlikely to continue seeking care.[7] Education about the management of behavioural symptoms associated with dementia, which is the cause of most caregiver distress, and equipping caregivers and health workers with tools to address these will have a more achievable impact on patient and caregiver quality of life. We need to be mindful that we often compete with other traditional and religious care systems. These alternative systems usually offer what is perceived as more practical solutions to the challenges faced by people with dementia and caregivers. Engaging with traditional leaders and religious leaders can be influential in reducing the stigma against those with dementia.[7]

At the same time, medicines currently used in dementia care must be made more readily accessible by encouraging national governments to include them in national essential medicines lists. As newer therapies become available, considerations must be made as to how these will be made available to all those who need them. A lack of access to available therapies is a cause of stigma that must be addressed.

In conclusion, we must routinely measure our success or lack thereof and revise our efforts as part of routine practice, adjusting our efforts as required so that a world without dementia stigma is no longer just an aspiration, but something we can look forward to and hold each other accountable to.

References

1. *Global Action Plan on the Public Health Response to Dementia*. http://apps.who.int/bookorders.
2. Link BG, Phelan JC. *CONCEPTUALIZING STIGMA*.; 2001.
3. *UNAIDS Data 2020*.
4. Bonnington O, Wamoyi J, Ddaaki W, et al. Changing forms of HIV-related stigma along the HIV care and treatment continuum in sub-Saharan Africa: A temporal analysis. *Sex Transm Infect*. 2017;93. doi:10.1136/sextrans-2016–052975
5. Nguyen T, Li X. Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia*. 2020;19(2):148–181. doi:10.1177/1471301218800122
6. Alzheimer's Disease International. *World Alzheimer Report 2019: Attitudes to Dementia; World Alzheimer Report 2019: Attitudes to Dementia*.
7. Kehoua G, Dubreuil CM, Ndamba-Bandzouzi B, et al. People with Dementia in Sub-Saharan Africa: From Support to Abuse by Caregivers: Results of EPIDEMCA-FU Program in Congo. *Dement Geriatr Cogn Dis Extra*. 2019;9(1):163–175. doi:10.1159/000489846
8. Saylor D, Elafros M, Bearden D, et al. Factors Associated with Lumbar Puncture Performance in Zambia. *American Journal of Tropical Medicine and Hygiene*. 2021;105(5):1429–1433. doi:10.4269/ajtmh.21–0091

Development and feasibility testing of the Changing Attitudes and Reducing Discrimination in Dementia (CARD) intervention with community healthcare workers in Brazil

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Brazil has approximately 1.8 million people living with dementia,[1] of whom over 75% are currently undiagnosed.[2] Among the general public, as well as among healthcare workers and carers, it is common for dementia to be seen as a natural part of the ageing process and that nothing can be done to support people with dementia to live a life of quality.[3,4] Such negative views linked to dementia not only hinder help seeking and contribute to delaying timely diagnoses, but they also limit progress in terms of service quality development and family support.[5] Further, they lead to discriminatory behaviours towards people living with dementia, compromising their rights and life opportunities.[3,4] As well as in other middle-income countries, anti-stigma initiatives are desperately needed to fight negative views and practices towards people living with dementia.

As part of the STRiDE initiative (Strengthening Responses to Dementia in Middle-Income Countries), we have developed and evaluated the first ever dementia-related anti-stigma intervention for Brazil, named **CARD – Changing Attitudes and Reducing Discrimination in Dementia**.[6] It is a group intervention developed for and implemented with community healthcare workers (CHW) with the aim of improving their knowledge and attitudes and reducing stigma and discrimination related to dementia. CARD was informed by and developed through an international and local multistakeholder participatory process involving people living with dementia, care partners, research experts, policymakers, and healthcare workers. A theory of change was created through a series of online discussion meetings and qualitative enquiries on broader aspects related to dementia care, as well as on dementia-related stigma specifically.[4–9] The intervention was then tested with CHW of the public primary healthcare units in São José dos Campos, São Paulo, Brazil. We decided to focus on CHW because these individuals are members of the communities where they work

Illustration of the CARD anti-stigma intervention (Courtesy of Carolina Godoy)

and are involved with multiple activities aimed at strengthening community healthcare delivery, awareness, and education. Their work helps enhance healthcare access and utilisation among diverse population groups.[10] Also, resources and capacity building initiatives are limited in low-resource settings and in remote/disadvantaged communities, making anti-stigma strategies involving CHW a potentially cost-effective and scalable option, and therefore key to promote equity in healthcare.[11,12]

Design and content of the CARD intervention

The content was strategically created and organised to be delivered sequentially in three sessions of three hours each, spread over three days, to allow for time of reflection in between sessions/days. However, after discussions with the city administration, we had to join days one and two to ensure that all the intervention components could be delivered whilst protecting the service routines and healthcare delivery. The intervention was then carried out in a day and a half, over nine hours. A total of 132 individuals took part: 70 in the intervention group and 62 in the control group. The intervention group was sub-divided into three separate groups to allow for small group work (n=19, n=21, n=30). Individuals in the control group did not receive any intervention but completed the baseline and follow up measures for comparison.

A crucial concern for us was to ensure the use of accessible language to facilitate understanding by CHW, as well an approach that was as participatory (less passive) as possible. We also sought to build content that reflected as much as possible their real work experiences, so as to make sense to them and to be as applicable as possible in their future practice.

In **Session 1**, we aimed to identify and challenge the current views and attitudes to dementia among participants so that we could build positive attitudes targeting the prevailing understandings of the group. We encouraged participants to get in touch with their own individual and shared beliefs, feelings, and questions related to dementia, and then provided them with an evidence-based understanding of the condition, whilst helping them see the "person behind the disease." Using participants' responses, we aimed to deepen their understanding of what dementia is, what dementia is not, and what treatment and care options are available. It was also an opportunity to debunk misconceptions about this condition.

We used a secret box containing the pictures of two unknown people, and the participant had to describe these people to the wider group of participants (e.g., how they look like, how they might live or feel), and then how their lives would change if they developed dementia. This helped to bring to the surface common experiences of discrimination faced by people living with dementia (e.g., they would be discredited, socially excluded, shunned). After this, participants were given another box with a mirror inside, and each of them had to answer similar questions – describe how this person looks like, how this person lives, and how this person's life would change if they had dementia – whilst others did not know that they were referring to themselves with a mirror. This not only helped individuals to put themselves in the shoes of people living with dementia, but also to reflect about how their own coworkers in the room would think of and act towards them if they had dementia.

In **Session 2**, we presented evidence-based content on dementia-related stigma and encouraged participants to recognise how thoughts, feelings, beliefs, and behaviours of other people affect the lives of people living with dementia, and that experiencing stigma and discrimination can be as detrimental for the quality of life of people with dementia as the condition itself. Participants were stimulated to reflect on the power of language as a mechanism of prejudice and discrimination and to identify how they could be promoting stigma in their day-to-day interactions. After, we re-read and held a debate on the answers participants gave on the first day regarding their views and beliefs related to dementia and encouraged them to share how they felt that these had changed since then.

Following that, we presented videos of individuals living with dementia sharing their personal experiences, desires, preferences, feelings, and aspirations; fostering empathy and raising awareness about the everyday social challenges faced by individuals living with dementia. Building on this, we facilitated discussions about the profound impacts of prejudice, discrimination, and negative language on the lives of people with dementia and their families. We then used vignettes in which we depicted two cases of people who found out they had dementia, and participants had to read them in the first person as if the story described were theirs. This was followed by a group discussion about how they felt in reading those vignettes and how they would have liked to be treated in those situations.

In **Session 3**, we sought to develop compassion and empathy by strengthening communication and behavioural skills. We discussed the importance of the CHW's work in combating stigma related to dementia whilst introducing positive verbal and non-verbal communication strategies, which we then applied in group dynamics. We presented real-life-based short stories of daily issues faced by people living with dementia, highlighting how CHW could manage them in a positive way in their day-to-day work. This was aimed at helping participants to develop self-awareness by actively recognising any inappropriate behaviours and attitudes of their own and to notice any transformation in their beliefs, attitudes, and behaviours related to people living with dementia compared with the beginning of the intervention. Finally, we reflected as a group on appropriate ways of delivering healthcare for people living with dementia.

Experiences and impact

The strategies and content we used were essential to optimise engagement and positive feedback from participants, who were mostly pleased with taking part. In particular, the third day's activities with real-life situations generated the highest engagement across all three sessions. Several participants commented about how close the situations presented were to their own day-to-day experiences. As researchers, it was interesting to observe how participants had incorporated the content covered in the three sessions in their speech, demonstrating how these had made sense to them. Some CHW asked questions and shared similar stories with the group, enriching the discussions.

Compared to the control group, the intervention group had a significant improvement in attitudes and intended behaviours towards people living with dementia both at 30- and 90-day follow up (*unpublished data*). This was noticeable during the intervention as well as in their feedback comments provided in the follow up. In Session 1, one participant mentioned several times during the discussions that she would rather die than know that she has dementia. In Session 2, after having watched the videos of people living with dementia telling their stories, she felt differently and said, "there can indeed be life after diagnosis and that there are many things to be done." She had never heard someone with dementia talk prior to the intervention and felt this was very impactful. The group agreed, and others mentioned that it would be vital that more people had access to these videos. Another participant was moved by the case vignette – she reported that reading the first-person account stirred her feelings and made her imagine herself in this reality. She was tearful whilst saying that she had not been able to stop reflecting about the video narratives since she had watched them.

Multiple CHW believed this type of intervention should be delivered to all healthcare workers as they do not feel empowered enough to change their reality, whilst other professional groups working at the primary care units (i.e., nurses, medical doctors) maintained their current views. Findings and experiences with the CARD intervention therefore revealed that group-based anti-stigma interventions can be well received by CHW and can have long-lasting effects on their attitudes and behavioural intentions towards people living with dementia, and therefore should be implemented widely. The type of strategies used appears to be key to reach optimum results, particularly empathy-producing elements and social contact components, even if indirectly via video narratives.

References

1. Bertola L, Suemoto CK, Aliberti MJR, Gomes Gonçalves N, Pinho PJ de MR, Castro-Costa E, et al. Prevalence of Dementia and Cognitive Impairment No Dementia in a Large and Diverse Nationally Representative Sample: The ELSI-Brazil Study. Lipsitz L, editor. J Gerontol Ser A. 2023 Jun 1;78(6):1060–8.
2. Nakamura AE, Opaleye D, Tani G, Ferri CP. Dementia underdiagnosis in Brazil. The Lancet. 2015 Jan;385(9966):418–9.
3. Godoy C, Oliveira D, Da Mata FAF, Weidner W, Evans-Lacko S, Ferri CP. Dementia-related stigma among health professionals, family carers, people with dementia, and the general public in Brazil. Stigma Health [Internet]. 2023 Oct 26 [cited 2024 Jun 24]; Available from: https://doi.apa.org/doi/10.1037/sah0000488
4. Oliveira D, Da Mata FAF, Mateus E, Musyimi CW, Farina N, Ferri CP, et al. Experiences of stigma and discrimination among people living with dementia and family carers in Brazil: qualitative study. Ageing Soc. 2021 May 20;1–22.
5. Figueiredo Da Mata FA, Oliveira D, Mateus E, Franzon ACA, Godoy C, Salcher-Konrad M, et al. Accessing Dementia Care in Brazil: An Analysis of Case Vignettes. Dementia. 2024 Apr;23(3):378–97.
6. Oliveira D, Godoy C, da Mata FAF, Mateus E, Franzon ACA, Farina N, et al. Reducing dementia-related stigma and discrimination among community health workers in Brazil: protocol for a randomised controlled feasibility trial. BMJ Open. 2022 Jul;12(7):e060033.
7. da Mata F, Oliveira D, Mateus E, Lorenz K, Comas-Herrera A, Ferri C. In-depth situational analysis of the current state of care for dementia in Brazil. 2020.
8. Breuer E, Freeman E, Alladi S, Breedt M, Govia I, López-Ortega M, et al. Active inclusion of people living with dementia in planning for dementia care and services in low- and middle-income countries. Dementia. 2022 Feb;21(2):380–95.
9. Breuer E, Comas-Herrera A, Freeman E, Albanese E, Alladi S, Amour R, et al. Beyond the project: Building a strategic theory of change to address dementia care, treatment and support gaps across seven middle-income countries. Dementia. 2022 Jan;21(1):114–35.
10. Van Iseghem T, Jacobs I, Vanden Bossche D, Delobelle P, Willems S, Masquillier C, et al. The role of community health workers in primary healthcare in the WHO-EU region: a scoping review. Int J Equity Health. 2023 Jul 20;22(1):134.

Old before our years: a conversation between two sons of younger-onset dementia from across the pond

Lucas Cose[1] and Will Dean[2]

[1] *Son of a dad with younger-onset Alzheimer's, Lorenzo's House, US*

[2] *Son of a mother with early-onset Alzheimer's, UK*

Lorenzo's House is a purpose-built, youth-led virtual global organisation for youth of a parent affected by younger-onset dementia of any form to come together to heal in community and help advocate for dementia justice. Will Dean and Lucas Cose are among the young people brought together by this organisation. The two had a candid conversation about what it is like to be a son of a parent with younger-onset dementia.

Brothers through experience

Will: I am Will, 25 years old, from the UK. My Mum is my rock. She was diagnosed with younger-onset Alzheimer's nine years ago at age 49. I was 16. I am on a mission to try to shift the narrative of dementia and make life after diagnosis less painful for everyone in the family and beyond. Today, I facilitate global youth advocacy sessions at Lorenzo's House and am the digital marketing manager at Race Against Dementia.

Lucas: I'm Lucas, and I'm 19 years old from Chicago in the United States. I was in sixth grade when my Dad was diagnosed with younger-onset Alzheimer's. I think changes were going on in our home before that. I am now a sophomore in college.

Finding out

Will: I was 16, and after years of friction with education, I was now free and old enough to pursue anything I wanted. What was vital was that no one was telling me what to do. I wanted

Will Dean (left) and Lucas Cose meet in Chicago, IL.

independence. My Mum, the 'work hard, mum hard' force of nature who always encouraged me to dream, began changing. She fell out of love with work and, like a blur, I received the news that Mum had younger-onset Alzheimer's. This didn't make sense to us. Suddenly, a life-changing phone call with a tone of "Here you go, you have dementia, live with it." Or as Max Lugavere says, "Diagnose and adios."

Lucas: When my dad was diagnosed with younger-onset Alzheimer's, I was 11. My parents got the family together and explained it to us. I didn't really understand, and so I took time for granted. I had no idea of the damage it was going to cause all of us. I remember my Dad – he became quiet and low-spirited when he was usually playful and positive. At first it seemed like things stayed the same. My Dad would still drive me to practice, walk me to school, and ask me a bunch of questions. But then going into seventh grade, I saw a big difference.

Will: Had you heard of the word dementia before?

Lucas: Never had. We used the word Alzheimer's, so I sort of heard about that, but assumed it was something grandparents get. I've learned that the word dementia is a more universal term.

Will: The doctors thought Mum was depressed, they said "you're too young to have dementia." Mum had to fight for tests and for a diagnosis that would change her life. All I wanted to know was how long do we have? How do we beat this? What is one thing you would have liked to have had as information to prepare you for what was to come?

Lucas: I am not sure that I would have wanted to know anything. I didn't want to have no hope. I did not want to know what was going to happen. I would have hated knowing what was coming. There were days I was talking to him as if he was going to get better. Making him smoothies in the morning. Hoping he would get better. I did not know how bad it could actually get. I thought he was going to forget my name, forget the simple stuff. I did not think it would change our whole family and our everyday.

Stigma starts at home, and not 'fitting in'

Will: What we are left with after the diagnosis is the stigma, the assumptions that the world has taught us about dementia: it's for older people, it's loss of memory. I see it like the family are the custodians of hope despite learning on the job. How did you hold onto hope? How do we own this new identity with what we don't know?

Lucas: I always wanted to go over to other people's houses and not have friends over to my house. I was super embarrassed of him. He would sit in this one chair. I would try to hide him from them. I didn't want them to see him. When I got older, I was more secure. I got more mature. That embarrassment sort of faded. I started to understand things.

Will: Because of the romantic I am, on our first date with my girlfriend, I asked: "What is the worst thing that you can imagine dying from?" She said "dementia." I did not share my story with her until much later. But what could be scarier than losing who you are?

Lucas: Sounds like a great first date. I don't know, but there is stigma around so much of it. People think it's about losing memory, and it's really about losing a person. Losing the family that was there before.

Will: So much changes. My Mum would not let anyone but immediate family know because she saw people in her church being treated differently. She did not let them know for two or three years… for fear of being treated differently. Her closest friend went distant for a while. There is a certain weight with loved ones. There is an initial impact response. Some people get closer but so many people don't know how to cope, treating you differently and judging your family. For us kids, we are trying to fit in as teens, in our daily lives…what you wear, your taste in music, you just try to fit in.

Lucas: And it's like we are the exact opposite, given this condition.

Will: Yes, and I also felt isolated within my family. I was sheltered from the news. They isolated me from it. That pushed me away from conversations like power of attorney and what's next? I maintained a relationship; I was and am a bit of an escape for Mum.

Lucas: Maybe stigma starts at home. We have to figure it out ourselves to change it for other people.

Telling someone and coping

Will: Who is the first person you remember telling?

Lucas: I told a close friend that Dad had Alzheimer's. The friend said: "He is going to forget your name. So what?" I was upset. That was super ignorant, but also, that was all he knew.

Will: What could he have said at that moment?

Lucas: That is a hard question. Being sincere in whatever you say. Not being phony at all. Asking if I need any help or, "I'm sorry" – and being really sincere.

Will: When speaking with another young person at Lorenzo's House, they wished that their friend would just listen. We came up with an idea based on Jinx, that old childhood game. Call 'Jinx' and that friend has to be quiet, "I just want to talk at you for a moment." And I hate that they say you are so strong, amazing, heroic. The first time you tell someone, their reaction will shape everything. The friend was probably trying to help calm you down, replying from a nice place, but often saying "it will be okay" is the last thing we want to hear. Did you ever lose your temper?

Lucas: High temper is not really how I am, but I had to reset. I did not tell anyone. I had everything bottled up in my head, I would try writing things out. I wanted to move on with my life. Let's get on with it and not worry anymore. Basketball was my escape. Music was like therapy. My place to calm down and be myself – find me, be me.

Will: It was skating for me. I was a sort of runaway kid. Not at school or at home. Always away. Being busy all day … to not think about it at all. My Mum's diagnosis was the one thing in my life that could pull the rug from under me.

Lucas: Mom had me live with my uncle and finish out my two years of high school in Madison, about two hours from home. So, I did not have to worry about the day-to-day with Dad. I felt guilty. And bad for my Mom – she had a full-time job, was a full-time carer and mom to me and my brother.

Will: That's tough. There is no time off. My dreams are on hold. Why dream about the outside world while I am living this? And my sister, who people recognise as my Mum's primary carer, is really in my eyes, my hero. She loves to escape into the world of a book. With younger onset, the progression is much faster. You have to learn on the job that is far faster. Relinquishing the role of a daughter for that of the enforcer. How do you hold onto the love and roles that we once knew? How does reliving all of this make you feel?

Lucas: To be real, I hate talking about it. This is a really powerful conversation. Glad I am having it with you. The trust is here. It is hard. It's good.

Sons and daughters connected, and ending dementia stigma

Will: It sounds strange saying brothers and sisters, but when you are in a Lorenzo's House session or space, you immediately feel a sense of family. Because we share this identity.

Lucas: The fact that it's for the kids of a parent with younger onset helps make it that way. It breaks the stigma that dementia is a condition for older people. How did you find Lorenzo's House?

Will: Patri, a researcher from Wales, told me about it. I had a Zoom with Diana, Lorenzo's House founding executive director, and then went to last year's Youth Summit. I was no longer a sceptic! Very big for me. I was inclined to be a part of the movement, to help and heal. Then I met Alisha through the one-on-one MATCH program. She is like a sister to me now. Her mum had younger onset from the time she was 11 until she was 21. She can brace me for things to come. She could unpack things that she had never talked about. It's as if Alisha is preparing me and healing herself. Lucas, the Summit was your idea. You actually suggested a camp or summit concept, right?

Lucas: Yeah, I told my mom that if we were going to start Lorenzo's House that there should be a place for the kids where we, can meet up to do what we are doing now. The first year, there were about 20 of us at Summit and this year over 200 from all over the world.

Will: What I find particularly important is that Summit is created and led by the young people, us … the sons and daughters of a parent with younger onset.

Lucas: The second year I shared a part of my story. It took a lot and was good at the same time. It's a cool space to open up. I could only do that because I knew I wasn't going to be judged.

Will: And I was fortunate to be involved in the stigma focus groups. They led to creating the EmpowermentPlus model to end dementia stigma.

During this year's Summit, Jessica broke down the steps. She was incredible. At 14 years old, from Idaho in the US. She shared personal examples of challenging times/social moments. I found the breakout rooms so helpful where we used the model to practice with examples of our own. To leave Youth Summit with a tool to manage the stigma that is a part of the journey is really great for us all.

Lucas: It helps me recognise that stigma is around me that I guess was blind about in a lot of ways. I am more conscious now and more prepared.

New paradigms in dementia: promoting brain health and healthy ageing from childhood

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The increase in life expectancy and associated pathologies has led to a shift towards a paradigm of healthy ageing that aims not only to extend life, but also to improve its quality, promoting brain health and functionality throughout the years in a more empathetic and holistic manner. Despite decades of medical and psychological research on this subject, the stigma surrounding dementia remains a significant issue that affects both those diagnosed and their families and caregivers. This stigma, born from a lack of information, is based on misconceptions and fear of the unknown. Essential to combating this are education, awareness, positive narratives, caregiver support, and inclusive policies.

Our group in Argentina decided to tackle this problem through a creative and unprecedented approach in the field of dementia, including early childhood education on brain care and concepts of brain health, crucial for eliminating these limiting beliefs. These actions are also supported by activities prioritising playful interactions between children and grandparents, ensuring the humanisation of ageing, and promoting the inclusion of individuals with cognitive impairments in family and community contexts.

Although many years have passed since clear and consensual discoveries about the neurophysiology underlying the development of dementia, only recently have links with other factors and the cumulative processes they involve begun to be clarified. This context underpins the paradigm shift in understanding dementia.

Paradigms guide perspectives and, ultimately, actions. If we look at the progression of knowledge about dementia, we can initially identify theories emphasising a deterministic genetic influence, focusing on describing pathological changes and better understanding the brain's neurobiology. This progressed through various hypotheses that led to pharmacological therapies, culminating in the present with multidimensional approaches that include combinations of therapies and personalised interventions, considering the individual within their sociocultural context, with a health history and various habits that determine how the brain ages and becomes ill. However, there is a lack of unified, innovative, and effective actions that go beyond the personal and encompass the community dimension, including political and legislative realms, among others.

Recently, science has demonstrated that a high percentage of dementia cases can potentially be prevented by addressing modifiable risk factors.[1] In this context, the concept of brain health, which allows for a more positive approach to dementia, has been consolidated. This construct, still in development, is dynamic and spans the life cycle, extending beyond the presence or absence of disease and being influenced by eco-bio-psycho-social determinants.[2]

Maintaining brain health is undoubtedly one of the greatest challenges to global health in the 21st century, as few other issues will have a similar impact on humanity.[3] This situation is even more problematic for Latin American and Caribbean (LAC) countries, where the cumulative burden of brain health disorders is among the highest in the world.[4] This is due to the impact of various relevant risk factors, such as genetic heterogeneity and social determinants of health,[5] leading to a high and growing prevalence of dementia.

Fortunately, alongside the development of this concept, brain health specialists from various parts of the world are engaging in discussions and actions, raising awareness about the need for resources to promote equitable outcomes,[4] and urging mitigation of the threats posed by brain health care at individual, community, national, and international levels.[6] It has been proposed that brain health interventions be culturally sensitive and region-specific, addressing the unique needs of vulnerable populations. Such interventions are believed to influence both micro-level empowerment of individuals

The Universe of Brains puppet show has raised awareness of dementia among children in San Juan, Argentina (Sydelle Willow Smith/Atlantic Institute)

regarding their own future and macro-level commitment to enacting public policies centred on the brain or investing in brain-related research and care.[3]

With this change of approach in mind, we formed an interdisciplinary team in San Juan, Argentina to address dementia with a focus on this multidimensional aetiological approach, aiming to empower communities as key players in shaping their brain capital, understood as a form of capital prioritising brain skills and health.[7]

It is important to note that San Juan, like many other places in Argentina, has structural inequalities that present us with challenges similar to the rest of the region, while also offering opportunities for action that were previously overlooked. In these regions, dementia has historically been stigmatised, with the condition being seen as a natural part of ageing and isolation as a familial solution, highlighting a lack of knowledge and support from key players, who do not offer other ways to age and navigate the condition, undermining the population's wellbeing.

For this approach, we designed actions to optimise detection and prevention, supported by a more accessible and positive vision. Fear of the condition creates real and psychological barriers. Creating outreach spaces with prevention tools based on scientific evidence reduces these fears and social biases, fostering dialogue among different sectors of the population. This facilitates the appropriation of knowledge and the adoption of healthy behaviours, presenting feasible actions backed by science. Speaking openly about preventive factors allows for addressing the disease without fear.

Thus, our actions, based on the sociodemographic knowledge of the population, include a range of tools to reach various age groups, communities across the province, and key stakeholders (patients, families, caregivers, health professionals, and policymakers).

Within the framework of a Provincial Dementia Prevention Plan developed in collaboration with public and private entities, we implemented a technological tool called Neuromentia for dementia screening, alongside the training of primary healthcare professionals throughout the province. Simultaneously, we conducted awareness talks on brain care and health for the general community, targeting both urban and rural areas, to ensure equitable access to knowledge. Currently, Neuromentia is being used for population screening by healthcare personnel across the province of San Juan, reaching remote areas that have never been assessed before. Thanks to its implementation, vulnerable and at-risk individuals are identified, diagnosed, and receive appropriate treatment. Additionally, the team actively participates in media and social networks to publicise these actions.

As a result, there was a significant public demand that required joint actions. This same local team is part of an international consortium researching dementia in Latin America, providing equitable access to accurate and, in many cases, early diagnosis. This set of actions consolidates us as leaders in the community on the topic, aiming to initiate a generational change in the conceptual transformation implied by brain health.

Regarding the aforementioned goal, we dared to expand our scope and chose an age group almost neglected in dementia prevention. Inspired by a European initiative called My Brain Robbie that sparked our imagination, we took on the challenge of overcoming geographical barriers and promoting equitable access to scientific information, facilitating its understanding and application in daily life. Thus, we created a narrative device in the form of a puppet show to be presented in schools. Puppetry is considered an excellent educational tool that offers, as a distinguishing feature from traditional audiovisual formats, an immersive, experiential engagement and empathetic identification with the puppet, enabling a meaningful interaction between the character and the audience, making the spectator a co-creator of the performance. The central idea is that participation in this playful and artistic situation facilitates the activation of reflective mechanisms and habit modification through a low-cost tool and shared language.

The objective of the project named "Universe of Brains," is to promote brain health habits in children to foster behaviours that support a healthy lifestyle, protecting their brains throughout the life cycle and generating a public health impact.

The puppet show is a highly versatile resource that adapts in real-time to the audience's age range without deviating from its core script. It requires no adaptation to different sociocultural contexts as it represents a universal language and can easily scale to other populations and topics. Indeed, a performance was held where children were invited to bring an elderly companion, clearly enjoying the joint experience. A new show is currently being developed, with the main character being an older adult in various contexts of human relationships and age-friendly cities. Ultimately, these actions actively promote generational connections between children, adults, and grandparents. "Universe of Brains" conducted 17 performances in the first few months of 2024, reaching over 22 public schools and other nonprofit organisations, such as senior centres and sports clubs. Over 3,000 children, along with their parents and other elderly adults, engaged with the concept of brain health.

This initiative aims to position the project as an entry point for global actions, supported by an interdisciplinary alliance among neuroscience, puppetry, research, stage production, technology, narrative, and pedagogy, with community impact. It can be envisioned as an integral proposal that goes beyond the artistic presentation, with Art and Science serving each other.

Reference

1. Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A., Orgeta, V., Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet (London, England), 396(10248), 413–446. https://doi.org/10.1016/S0140-6736(20)30367-6
2. Chen, Y., Demnitz, N., Yamamoto, S., Yaffe, K., Lawlor, B., & Leroi, I. (2021). Defining brain
3. health: a concept analysis. International journal of geriatric psychiatry, 37(1). https://doi.org/10.1002/gps.5564.
4. Dawson, W. D., Bobrow, K., Ibanez, A., Booi, L., Pintado-Caipa, M., Yamamoto, S., ... & Eyre, H. A. (2020). The necessity of diplomacy in brain health. The Lancet Neurology, 19(12), 972–974.
5. Parra, M. A., Baez, S., Sedeño, L., Gonzalez Campo, C., Santamaría-García, H., Aprahamian, I., ... & Ibanez, A. (2021). Dementia in Latin America: paving the way toward a regional action plan. Alzheimer's & Dementia, 17(2), 295–313.
6. Santamaria-García, H., Moguilner, S., Rodriguez-Villagra, O. A., Botero-Rodriguez, F., Pina-
7. Escudero, S. D., O'Donovan, G., ... & Ibanez, A. (2023b). The impacts of socialdeterminants of health and cardiometabolic factors on cognitive and functional aging in Colombian underserved populations. GeroScience, 45(4), 2405–2423. https://doi.org/10.1007/s11357-023-00755-z
8. Dawson, W. D., Booi, L., Pintado-Caipa, M., de Oliveira, M. O., Kornhuber, A., Spoden, N., ... & Ibáñez, A. (2023). The Brain Health Diplomat's Toolkit: supporting brain health diplomacy leaders in Latin America and the Caribbean. The Lancet Regional Health–Americas, 28.
9. Eyre, H. A., Ayadi, R., Ellsworth, W., Aragam, G., Smith, E., Dawson, W. D., Ibanez, A., Altimus, C., Berk, M., Manji, H. K., Storch, E. A., Leboyer, M., Kawaguchi, N., Freeman, M., Brannelly, P., Manes, F., Chapman, S. B. Cummings, J., Graham, C., . . . Hynes, W. (2021). Building brain capital. Neuronview, 109(9), 1430–1432. doi:10.1016/j.neuron.2021.04.007

Awareness in action: dementia education for African immigrants in the United States

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African immigrants based within the United States (U.S.) have observed the negative impact of dementia in their community. In search of a more comprehensive understanding of dementia and what could be done to improve health outcomes for these families, the African Career Education and Resources Inc. (ACER; a local non-profit organisation), approached our team of dementia researchers at the University of Minnesota. Together, we've built a strong community-university partnership and collaborated on multiple projects to improve dementia care outcomes for the African immigrant community in the United States.

A conversation about dementia, dementia care, and caregiving in the African immigrant community must start from the beginning: terminology. There is no word for "dementia" in many African languages. Efforts to find culturally appropriate terms for "dementia" in various languages often result in using words with negative connotations, reinforcing existing stigmas. Therefore, to enhance engagement and reception and to avoid any negative mental schemas, we chose the phrase "memory loss," a symptom that many in the community already know.

The African Immigrant Memory Loss Project[1], was the first project of this partnership. Its goal was to develop culturally informed tools and use those to explore dementia care needs and assets with African immigrants in Minnesota. We would like to acknowledge Dr Posa Aswani, Restoration for All Inc., Progressive Individuals Resources Inc., Masjid Al-Ansar, and the many community organisations that opened their doors to us for their important contributions to the project.

As a community-based participatory research project, we worked with ACER and the project advisory board to develop these tools. We used these tools to host community conversations and conduct a community survey to explore dementia care experiences. Findings from this project highlighted an urgent need for dementia education and outreach for the community.

In the course of this work, several explanations of community dementia stigma and myths have become evident. These explanations are interconnected, sustained by social determinants of health, and compounded by the challenges that immigrants face when engaging with the U.S. healthcare system. However, I will only describe three below:

1) When African immigrants recognise that dementia is a medical condition.

Several African immigrants report that they had seen some signs and symptoms of dementia in older relatives and persons in their communities while growing up in Africa but had not heard the word dementia. In referring to when they first heard about dementia, one community conversation participant noted: "*About six or seven years ago when I started doing this CNA, PCA (certified nursing assistant/ personal care assistant) job. Back home in Africa, I know some of our elders suffered from this disease, but it is not evident and not visible.*" They remembered the signs and symptoms but stigmatised the person. "*As kids, we would just say they are crazy or just lost their minds.*" It wasn't until they began working in a health-related job in the U.S. that they understood that what they saw might have been dementia and/or symptoms of the disease. Furthermore, the limited healthcare infrastructure with severe shortages of practitioners and facilities, especially for dementia care,[2] left many African immigrants with limited exposure to dementia in their countries of origin.

2) Community attitudes and beliefs about dementia.

African immigrants hold numerous beliefs and perceptions that have been described as possible reasons for stigma in the community. Starting with the avoidance of bad news or death, many in the community fear negative health information and avoid it at all costs. Those who are religious attribute everything to their supreme being and thus believe they have no personal control over their health. Likewise, the culture of secretiveness, especially about health information, does not help.[3] Families prefer to keep their medical problems private and there have been stories of families hiding relatives with dementia away from others during social functions. Also, caregiving attitudes, such as the preference for family care, impact health outcomes for all. Some families choose to send their relatives back home to their country of origin because there are more relatives there who can support their care, which is in alignment with the idea of transnational ageing and filial piety.[4,5] Also, aligned with the notion of filial piety, others choose to support their relatives in the U.S., but this can affect health outcomes for the care partners both positively and negatively.[5]

3) Limited knowledge about mental health and dementia, specifically.

Limited awareness of mental health and dementia has been identified by community members as the principal reason why stigma and myths about dementia persist. Dementia is a condition of the brain, and as such many African immigrants often lump it in with mental health conditions. Memory loss is the one symptom that many African immigrants know, but often cannot differentiate memory loss that interferes with daily activities from age-related memory loss. As such, early symptoms of dementia often go unrecognised. Many are not aware of other symptoms and only recognise these symptoms as problematic late in the disease process, when something significant "such as a person getting lost during their normal walk" occurs, highlighting the fact that racial/ethnic minorities are often diagnosed with dementia at later stages of the condition.[6,7]

Dementia education outreach with the African immigrant community

Therefore, in developing the dementia outreach programme, the goal was to decrease stigma, debunk myths, and improve dementia awareness. Also, conversations with the project advisory board informed the inclusion of dementia in our project name and materials to introduce the African immigrant community to the appropriate medical terminology. The African Immigrant Dementia project also used community engagement to develop a culturally tailored dementia education programme and booklet for the community. Titled "African MaDE," (Memory and Dementia education) by and for the African community was recently piloted in the community. Utilising a cultural lens, African MaDE identified various myths and stigmas and debunked them while offering accurate information about dementia, its causes, current burden, risk factors, diagnosis and management, and prevention. We also identified cultural care and caregiving expectations and current challenges in accessing care. In addition to distributing dementia booklets, we brought resources into the community, such as brochures from the Alzheimer's Association, Area Agency on Aging, and many other local resources, and encouraged other organisations to be present to answer questions.

Our education sessions were organised by community partners and the research team at places where participants normally access such as churches, mosques, community centres, and fairs. Pre-and post-surveys were collected from these participants and findings showed an increase in dementia knowledge immediately after the education session. Attendees at these sessions had the following to say: "*Very well interactive, very informative, great presentation. Loved how the doctor used simple terms and words to explain.*"; "*This was so educative. We are so glad we came. I will be sharing the knowledge I gained today with friends and family regarding the topic of dementia*" about these sessions. Many planned to share this knowledge with family back home in their countries of origin since many are currently providing distance care to persons living with dementia there.

The burden of dementia is projected to grow, especially in lower- and middle-income countries[8,9] and there is great societal misunderstanding and stigma surrounding dementia and dementia care. Studies show that people wrongly believe that dementia is an inevitable part of ageing[10] and close to two-thirds of healthcare professionals attribute dementia to normal ageing in ADI's 2024 Attitudes to dementia survey. There is a great need for societal dementia education and outreach. Now that we've understood the feasibility and change in knowledge from African MaDE, our goal is to continue the dissemination of this programme. We appreciate all the funders of this work for supporting it thus far and are currently seeking funding to enhance content and delivery for large-scale dissemination, with African immigrants in the diaspora and Africa. Finally, we hope this model of community-university partnership(s) could inform the cultural tailoring of dementia education and outreach for other minoritised cultural groups disproportionately burdened across the world.

References

1. Nkimbeng, M., Rosebush, C. E., Akosah, K. O., Yam, H., Russell, W. N., Bustamante, G., Albers, E. A., Shippee, T. P., Sasikumar, A. P., & Gaugler, J. E. (2022). The Immigrant Memory Collaborative: A Community-University Partnership to Assess African Immigrant Families' Experiences with Dementia. *International Journal of Environmental Research and Public Health*, *19*(7), 4075. https://doi.org/10.3390/ijerph19074075
2. World Health Organization. (2012). *Health Systems in Africa: Community Perceptions and Perspectives*. The World Health Organization Regional Office for Africa Brazzaville Republic of Congo. https://www.afro.who.int/sites/default/files/2017-06/english---health_systems_in_africa---2012.pdf
3. Nkimbeng, M., Yam, H., Aswani, T., Russell, W. N., Shippee, T. P., & Gaugler, J. E. (2024). Perceptions of dementia and dementia care among African immigrants in Minnesota: Insights from community conversations. *The Journals of Gerontology: Series B*, gbae094. https://doi.org/10.1093/geronb/gbae094
4. Nkimbeng, M., Akumbom, A., Granbom, M., Szanton, S. L., Shippee, T. P., Thorpe, R. J., & Gaugler, J. E. (2022). Where to Retire? Experiences of Older African Immigrants in the United States. *International Journal of Environmental Research and Public Health*, *19*(3), Article 3. https://doi.org/10.3390/ijerph19031040
5. Nkimbeng, M., & Parker, L., J. (2021). Diverse, Culturally Rich Approaches to Family Care in the United States. In *Bridging the Family Care Gap* (p. 325). Academic Press.
6. Bieber, A., Nguyen, N., Meyer, G., & Stephan, A. (2019). Influences on the access to and use of formal community care by people with dementia and their informal caregivers: A scoping review. *BMC Health Services Research*, *19*. https://doi.org/10.1186/s12913-018-3825-z
7. Lines, L., M., & Wiener, J., M. (2015, April 28). *Racial and Ethnic Disparities in Alzheimer's Disease: A Literature Review*. ASPE. https://aspe.hhs.gov/report/racial-and-ethnic-disparities-alzheimers-disease-literature-review
8. Akinyemi, R. O., Yaria, J., Ojagbemi, A., Guerchet, M., Okubadejo, N., Njamnshi, A. K., Sarfo, F. S., Akpalu, A., Ogbole, G., Ayantayo, T., Adokonou, T., Paddick, S.-M., Ndetei, D., Bosche, J., Ayele, B., Damas, A., Coker, M., Mbakile-Mahlanza, L., Ranchod, K., … Consortium (AfDC), the A. D. (2022). Dementia in Africa: Current evidence, knowledge gaps, and future directions. *Alzheimer's & Dementia*, *18*(4), 790–809. https://doi.org/10.1002/alz.12432
9. Prince, M. J., Wimo, A., Guerchet, M. M., Ali, G. C., Wu, Y.-T., & Prina, M. (2015). *World Alzheimer Report 2015 – The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*. https://kclpure.kcl.ac.uk/portal/en/publications/world-alzheimer-report-2015%E2%80%94the-global-impact-of-dementia(ae525fda-1938-4892-8daa-a2222a672254).html
10. Crawley, S., Moore, K., Vickerstaff, V., Fisher, E., Cooper, C., & Sampson, E. L. (2022). How do factors of sociodemographics, health literacy, and dementia experience influence carers' knowledge of dementia? *Dementia*, *21*(4), 1270–1288. https://doi.org/10.1177/14713012221074219

The importance of data in addressing dementia attitudes: lower- and middle-income countries' perspectives

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Surveys capture important data for researchers to analyse, interpret, and use to inspire recommendations or to better understand key issues – but efforts like ADI's Attitudes to dementia survey are also created with advocacy in mind. After 12 years of World Alzheimer's Month campaigns and over 40 years of efforts by Alzheimer's and dementia organisations worldwide, are attitudes to the condition changing? What erroneous or stigmatic beliefs and practices persist, and what factors could affect them? Most importantly, how can we use what we learn to change things for the better?

While such information is important for many dementia advocates around the world, for those in lower- and middle-income countries the 2024 World Alzheimer Report survey has been all the more significant. In many of these countries, there are far fewer resources to support scientific research as a whole, let alone for dementia. Because attitudes to dementia are so deeply informed by societal, economic, and cultural circumstances, beliefs, and norms, it is vital to obtain local data that countries can use to support awareness efforts tailored to their specific context. Advocates from Alzheimer's and dementia associations in Panama, Botswana, and Iran – all of which are ADI member associations – explain here what this survey could mean for their efforts to improve the lives of people living with dementia and their carers in their respective countries, whether through policy, care provision, or awareness efforts. Getting people to respond to the survey was not always straightforward, and they had to adapt to particular hurdles in their countries – but all hope that their efforts will bear fruit, both in terms of addressing the views of the general public and making their case to their respective governments.

> **"After 12 years of World Alzheimer's Month campaigns and over 40 years of efforts by Alzheimer's and dementia organisations worldwide, are attitudes to the condition changing? What erroneous or stigmatic beliefs and practices persist, and what factors could affect them? Most importantly, how can we use what we learn to change things for the better?"**

Panama

Pushing this survey in Panama was crucial for many reasons: We do not have a national dementia plan, there is a lack of understanding about dementia withing our society, and families and caregivers often navigate complex challenges without adequate support from the healthcare system.

The survey gave us a sense of urgency to improve quality of life for people living with dementia and the opportunity to gather information on the specific needs and experiences of caregivers (formal and informal), as well as the number of barriers they face to access care and support services.

In other words, pushing the survey in Panama not only let us collect data, but also amplify the voices of those affected by dementia and to advocate for policies that uphold their dignity and rights.

We took advantage of 2024 general elections in Panama and invited political candidates to take part in the survey and to share it with their supporters. We employed a combination of in-person interactions, digital outreach, and community partnerships with vegetable sellers, healthcare facilities, community centres, and educational institutions to distribute surveys and engage directly with people living with dementia, caregivers, healthcare professionals, and the general public. We also sent letters of invitation to local government, public institutions, and private companies explaining why it was important to participate in the survey. Every single week, we shared the survey link and QR codes through WhatsApp groups. We also prepared some flyers and stickers with the QR code of the survey and distributed to people in parks and markets. Last but not least, we received wonderful support from geriatricians who invited their patients to take part in the survey.

However, the journey was not without its challenges. We have limited resources and logistical constraints to effectively reach remote communities and marginalised groups. Recognising those barriers, we adapted our strategy by explaining the importance of brain health and how important the survey results would be to Panama. We navigated these challenges through creativity, humanism, and persistence.

In Panama, as in many other countries, dementia remains misunderstood and stigmatised. For that reason, understanding the current level of awareness and the extent to which there is stigma surrounding dementia in Panama will allow us to tailor our advocacy efforts effectively. Our goal with the data is to use it in educational campaigns to raise awareness in schools and universities and to improve practical guidance to caregivers and families. Moreover, understanding the challenges faced by people living with dementia and their families and caregivers will enable us to advocate for improvement in healthcare services such as inclusive dementia-friendly healthcare settings and training healthcare professional in dementia care.

Stigma often prevents individuals from seeking help and a timely diagnosis, leading to isolation and inadequate support and treatment. Having more information about dementia awareness and stigma empowers communities to take action. By working together with healthcare professionals, communities, families, and people living with dementia, we can create a future where everyone impacted by dementia receives the support and dignity they deserve.

We aim to engage policymakers, healthcare providers, and the public in a constructive dialogue to bring about a national dementia plan. We seek to influence policy decisions that prioritise dementia care, advocate for increased funding for research and support services, and foster a more compassionate and inclusive society for those affected by dementia. The survey's results will guide us in developing and creating inclusive, dementia-friendly environments to improve quality of life for individuals living with dementia.

Botswana

In Botswana, there is a lack of understanding of dementia. Increasing awareness helps communities recognise the symptoms and understand that dementia is a medical condition and not just a part of ageing. Dementia often carries significant stigma, which can lead to social isolation for those affected. Changing attitudes can reduce stigma, encouraging people to seek help and support without fear of discrimination. With better attitude and awareness, there can be improved care and support for people with dementia and their families. This can include better access to healthcare services, support groups, and educational resources.

Positive attitude towards dementia can also influence policymakers to allocate resources and create supportive policies. This can lead to better infrastructure for dementia care and research. In Botswana, like many other countries, cultural beliefs and practices significantly influence health perceptions and behaviours. Addressing dementia with sensitivity to local culture ensures that interventions are more effective and accepted by community.

We distributed the survey in person on paper but struggled to get people to take part. We ended up getting an influencer to post the survey link on her Facebook page, advertising that 20 participants would win some of her services. Despite having to rely on participation incentives, we realised that most of them were happy to have taken part on the survey and learned about dementia. Most importantly, some shared that they were living with dementia, while others said they were caregivers. We are now engaging with them and providing help.

We hope to use the survey data to highlight the prevalence and impact of dementia in Botswana. This can drive public awareness campaigns to educate communities. Sharing survey results can also help normalise conversations about dementia, reduce stigma, and encourage more people to seek help.

We hope to present the findings to policymakers to demonstrate the need for targeted dementia strategies and policies, including the establishment of a national dementia plan, with informed decision-making that will protect the rights of people with dementia and ensure their access to necessary services. This data can be used to advocate for better funding and resources for dementia care and research and helps us to make a stronger case for financial support.

With regards to healthcare providers, the survey results may be used to identify gaps in knowledge and training among healthcare providers and help develop training programmes to improve the quality of care, as well as create or enhance support services tailored to the specific needs of people with dementia and caregivers, such as counselling, respite care, and community support groups.

We also plan to publish the survey results in accessible formats, such as reports and articles, and share these through various media channels to reach wide audiences.

Iran

Disseminating the ADI survey in Iran was no simple feat. The survey launched during Nowruz celebrations (Iranian new year), which also coincided with the Muslim holy month of Ramadan, meaning that many people in Iran were on holiday, and many more were fasting. The challenge of slow and filtered internet in Iran also hindered people's ability to take the survey. It took great efforts on the part of people who participated in the survey, as they had to use unpredictable VPNs to access the survey platform, leading some to give up partway. The challenges were numerous, but a good number submitted the completed survey.

Iran Dementia & Alzheimer's Association (IDAA) reached out to people via WhatsApp groups, Instagram, Telegram channels, our website, and word of mouth. A QR code linking to the survey was also used on banners in our clinic and day centre. Many friendly reminders were sent to the target groups, emphasising the importance of participation. Through this engagement, we were actively responding to questions raised by our audience.

The ADI survey was very important to Iran Dementia & Alzheimer's Association, as no such survey on dementia of this scale has been implemented in Iran to date. The information collected could help us to initiate a conversation with the Ministry of Health about a national dementia action plan, which was endorsed by the former health minister in 2021. We hope presenting this data could show the new minister the vital need to address dementia in the country. One of the pillars of our dementia action plan is raising awareness among our communities. The information collected by ADI can enhance our endeavours in raising public awareness and reach our goal of reducing stigma.

We ultimately hope that awareness-raising will shift people's attitude towards seeking timely help for diagnosis. The results of this survey can support IDAA in its advocacy with different sections of the government, emphasising the urgency of implementing a dementia action plan knowing full well that more than one million people are living with the condition in this moment in time in Iran. Attentions must be diverted to developing effective care policy for different environments. IDAA has a long way to go to make sure that we are on the right path for people with dementia and their carers to receive the care and support they need. But even if the project is funded step by step, we would know that dementia is being included and can become a priority.

Conclusion

As this report aimed to show, being aware of dementia isn't just about knowing basic scientific facts about the condition or memorising statistics; it is about understanding how dementia impacts many aspects of life in complex ways, with consequences that extend far beyond the immediate inner circle of people living with the condition – and acting in accordance with that knowledge.

Awareness is the first, essential step; as ADI's 2024 Attitudes to dementia survey has shown, while people worldwide are more knowledgeable about dementia than in 2019, this does not automatically translate into a decrease in stigmatising attitudes and behaviours towards people living with dementia and their carers.

The 2024 survey therefore raises the question: Should we rethink how we raise awareness of dementia? How do we strike the right tone, raising the alarm about the increasing economic, societal, and personal costs of dementia if nothing is done, without falling into fearmongering that alienates and stigmatises those currently living with the condition? How do we make complex scientific and medical discoveries about risk reduction, diagnosis, and treatment easily digestible to the wider public, healthcare practitioners, and the policymakers who can enact change? How do we ensure that people living with dementia and their carers have access to the best treatment, care, and support possible now, regardless of where public opinion stands?

The last five years have seen seismic events on the global stage. The devastating COVID-19 pandemic, severe economic crises, and political upheaval around the world have left millions of people vulnerable, the elderly among them. Meanwhile, the great strides made in dementia research have also meant that people can now be diagnosed with dementia earlier than ever, which requires a change in the way the condition has been portrayed as a disease of old age. Headline-grabbing breakthroughs in disease-modifying treatments are progressing at a faster pace than healthcare systems' ability to deliver such treatments in an equitable manner, further exacerbating inequalities that must be meaningfully addressed.

While ADI has long made clear that governments and national and international institutions need to take on the challenges of dementia at a structural level, addressing dementia stigma and awareness is within reach for compassionate and caring individuals wherever they may be across the globe. Befriending someone living with dementia, getting involved with a local dementia association, or reaching out to one's political representatives are only a few examples of how people can take tangible steps towards creating dementia-inclusive societies.

In 2019, ADI said it was time to break the taboo and talk about dementia. Five years on, we can – and should – acknowledge the progress that has been made in demystifying dementia, but our work does not end there. Now is the time to act.

> **Addressing dementia stigma and awareness is within reach for compassionate and caring individuals wherever they may be across the globe.**

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