Alzheimer's Disease International

The global voice on dementia

World Alzheimer Report 2019

Attitudes to dementia



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Carers / caregivers / care providers / care partners
Healthcare practitioners / healthcare providers / healthcare professionals



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The global voice on dementia

World Alzheimer Report 2019

Attitudes to dementia

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Alzheimer's Disease International
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ADI Global survey on **attitudes to dementia**

Almost 70,000 respondents from 155 countries



2 in **3** people think that dementia is caused by normal ageing

1 in **4** people think that there is nothing we can do to prevent dementia

95% of the general public think they could develop dementia at some point in their lifetime

Just under **40%** of the general public think that there are adequate community services in place for people living with dementia and carers

54% of respondents think lifestyle factors play a part in developing dementia

91% of respondents say that people should not hide the fact they have dementia

♂ **Men are more likely to hold stigmatising views about dementia than women** ♀

Although they were more likely to let a relative with dementia move in with them

Attitudes of healthcare practitioners to dementia

62% of healthcare practitioners still believe that dementia is part of normal ageing



Around **40%** of the public think healthcare practitioners ignore people with dementia



"My neurologist ignored my presence when my diagnosis was discussed with my husband."

"Neurologist diagnosed me with Alzheimer's at 56, telling me to go home and get my final affairs in order and wait until my premature death."

"They sometimes talk to my wife about things like I'm not even there, but I'm sitting right there."

"Many healthcare practitioners often do not believe I have dementia - which is abusive and offensive. But, also, they then talk over me, about me, and never to me..."

Experiences of carers

Over 50% of dementia carers expressed positive sentiments about their role

Over 50% of dementia carers said their health suffered as a result of their caring responsibilities

35% of carers globally have hidden the diagnosis of a person with dementia

Over 60% of dementia carers said their social life suffered as a result of their caring responsibilities

Dementia: not a laughing matter?

63% of respondents living with dementia in South-East Asia said their dementia symptoms were joked about by others

67% of respondents living with dementia in Africa said their dementia symptoms were joked about by others

Carers of people with dementia said:

"So-called Alzheimer's humour does much more than annoy and hurt those who work hard to make life better for the 50 million plus people in the world living with dementia. It trivialises the disease."

People with dementia said:

"It is 100% offensive, and inexcusable to joke about my symptoms (unless it is me joking about it)."

"When others who also have a dementia diagnosis joke this is just an expression that we are able to maintain a sense of humour and is a great stress reliever."

"Laughter is good for the soul and if you can laugh about your circumstances it can reduce anxiety. So we laugh from time to time when something incoherent comes out of my mouth."

Dementia, intimacy and relationships

Between 35% in high income and 57% in low and lower-middle income countries reported being treated unfairly in dating or intimate relationships



People with dementia said:

"To be honest, NO ONE wants to date a 58-year-old guy with Alzheimer's."

"I call it the friendship divorce. I have lost a fair amount of people in my life that at one time considered friends."

"... my wife and I divorced due to my Alzheimer's... her decision."

"I don't date at all now. As soon as I mention I have dementia, they presume the worst... My last boyfriend wanted to hide me away and I spoke openly about my dementia. Hence why that relationship didn't work... "

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Foreword

Paola Barbarino, CEO



Time to roll our sleeves up (again, and again!)

I cannot express enough pride at being able to introduce this year's World Alzheimer Report on global attitudes to dementia. This report belongs to all the 70,000 of you who replied to our survey, so first of all, **thank you**.

When you look back at our international movement, which started in 1984, you see how a group of committed and energetic doctors and of professional and family carers, decided they had had enough of Alzheimer's being hidden in society and that the time was right to bring the disease to the attention of governments, politicians and the public at large.

Behind the foundation of an International Non-Governmental Organisation like ADI there is always the feeling that things could be much better and a sense that if we campaign strongly enough, if our voice is loud enough, we **will** be heard, and things **will** change.

At times I wonder why we did not start sooner. Alzheimer's disease was first described in 1906 but ADIwas only founded in 1984. If we look at the Union for International Cancer Control (UICC), which is the equivalent of ADI, that was founded in 1933, about 50 years before us. The UICC is now a multimillion-pound organisation and the driving force behind cancer de-stigmatisation.

We, on the other hand, are running 50 years behind and still have a mountain to climb. In the words of one of our survey respondents:

"Shunned by hundreds in my home town. People would sooner have stage 4 breast cancer than my diagnosis. (They) couldn't look me in the eye."

Today people march together against cancer and support each other through cancer. We all talk about it as the last frontier. We talk of battles and of survivors. We appropriate a military language which, whilst not quite suitable to the people going through the disease (who can resent the idea of having to fight the inevitable), it certainly works from an awareness raising perspective. It also gives people a sense that they can be proactive and not just passive victims of the disease.

If society feels that they play a positive role then they will demand a solution. Last year's World Alzheimer Report[1] – which focused on research – stated unequivocally that for every 12 studies on cancer there is only one on neurocognitive disorders (not just on Alzheimer's disease!). This is the size of the research gap - but there still isn't enough funding in Alzheimer's and dementia research - despite civil society's collective efforts.

Going back to the genesis of this report, one of my biggest challenges, as I stepped into my role at ADI, was my Board and my members' desire to see a decrease in stigma and heightened awareness. The thinking was that if we manage to raise awareness, then we will have a more determined grassroots movement. People will understand that Alzheimer's is a disease, not just old age, and ask their governments to acknowledge that we have a crisis on our hands. This in turn could mean the creation of dedicated services for those going through the disease and for their carers, for better diagnostic and post-diagnostic support, as well as an increased focus on finding a disease-modifying treatment. In short, all the actions described in the World Health Organization (WHO) Global action plan on dementia[2], which we fought so hard for but that is so difficult to implement.

ADI already runs World Alzheimer's Day and Month awareness campaigns, which get a lot of traction in the public and in the press, and it publishes the World Alzheimer Report, which is possibly the most quoted and trusted source of information on Alzheimer's and dementia globally. But, for all this output, there isn't a corresponding measurement that can tell us how well we are doing at changing attitudes to dementia, and not just globally but nationally and locally.

In Alzheimer's and dementia there has undoubtedly been a great increase in awareness in higher income countries - certainly in the last 10 years - pretty much since ADI promoted the global figures on prevalence and incidence of the disease for the first time[3-4]. However, in low- and middle- income countries there are still reports of stigma felt by people with dementia and by carers – I need only recount the appalling stories of physical restriction and murder in Africa, as reported by our members there.

Even in high income countries (and this really comes into sharp focus in the survey) the general public, healthcare professionals, our members and other advocacy organisations report widespread shortages of services as well as noticeable differences in service provision between rural areas and urban areas. Also, despite high-profile awareness campaigns people still delay seeking out help, advice and support when they first start to worry about their memory or that of a family member. If this was a physical or visible ailment, how much more quickly would people react?

Back in 2018 however, our problem was that because much of this evidence was anecdotal, we did not know

how we could measure whether these issues were sporadic or consistent throughout the world, or peculiar to a particular region; whether some issues were real for everyone or just perceptions; and, crucially, whether anything was getting better as a result of our advocacy efforts.

This report was borne out of a resounding need to establish a strong baseline so we could start measuring whether we really are doing better and making a difference once and for all. But we did not want to focus just on those countries where there are resources and means of taking action. In the spirit of solidarity and love that is the bedrock of ADI, we wanted to know more about those countries where there is little or nothing.

A prior survey on stigma by ADI in 2012[5] had 2,500 participants. A laudable effort (and a first) but statistically a very low sample to consider it as a strong baseline for global attitudes. Looking at other diseases and how they had addressed stigma was also interesting and frankly a bit disheartening. I remember some of my early conversations about HIV/AIDS and cancer with professionals who had been working in those areas at the time of greatest stigma, and almost everyone pointed out that the real change in attitudes (both from the point of view of people seeking a diagnosis and from the point of view of the general public acknowledging the disease) had happened when a drug-based treatment and a cure started appearing on the horizon. Well, we still don't have a cure and have had no treatment breakthrough for almost 20 years for Alzheimer's and dementia. We are yet to have that light at the end of the tunnel, but this is not a good reason to let go and do nothing.

As the Dementia Friendly Community[6-7] movement has demonstrated, time and time again, there is so much we can do to make life for those who have dementia and their carers immensely better by making them feel supported, loved and understood by our society and wherever possible by empowering them in every aspect of dementia activity, including advocacy. This makes a marked contrast to feeling shunned, hidden or ashamed, as in the quote above.

Indeed, the word love is something that comes out strongly from one of this report's essays, the one focusing on Canada's First Nation's attitudes to dementia:

"… Reminds us that the person with dementia, who is being cared for, is in need of a lot of love. He urges the use of 'loved one' to refer to the person with dementia so that we remember that they are loved. He shared that using the words 'loved one' serves as a reminder of how care providers should be treating and respecting the person with dementia".

Ironically, and sadly, the enormous swelling of population with the disease is on our side. When people ask me what I do for a living, and we start a conversation, it's rare they don't have a case in the family, wherever I am in the world.

When we commissioned this ambitious survey, we asked several universities and I am delighted that the London School of Economics and Political Science (LSE) was enthusiastic to pick up the gauntlet. They share our vision and our passion and as the numbers for our survey went up and up, there was a shared sense of joy undeterred by the enormity of the analytical task ahead.

I should not underestimate the size of the challenge faced by ADI and its members and partners in distributing the survey globally to so many different audiences. Nobody had ever attempted such a large survey in this field, and we were not sure whether we would have the capacity to mobilise our network to a whole new level.

A smidgen under 70,000 people later we can say that we certainly did! But it did take a huge amount of work on the part of everyone involved and I would particularly like to thank Australia, Brazil, Canada, China, India, Indonesia, Italy, Mexico, the Netherlands, New Zealand, TADA Chinese Taipei, Vietnam, the UK and USA who really went for it and helped us drive the numbers up globally. This survey, and its dataset, will now form part of the freely available shared resources we can use from now on to measure our performance on attitudes and hopefully make stigma a thing of the past – in all countries. It is our intention to repeat this research process after 5 years.

I know if you have picked this up that you will read the report in detail and I don't want to pre-empt it, but I leave you with a few thoughts.

- **Almost 80% of the general public are concerned about developing dementia at some point and 1 in 4 people think that there is nothing we can do to prevent dementia.** Clearly the messages on the importance of risk reduction highlighted recently by a WHO report are not getting through.[8] People don't know what to do. We need to do more to spread this message at every level.
- **35% of carers across the world said that they have hidden the diagnosis of dementia of a family member from at least 1 person**. Our next target will be to get to 0%.
- **75% carers globally say "I am often stressed between caring and meeting other responsibilities" even whilst expressing positive sentiments about their role and over 50% of carers said their health suffered as a result of their caring responsibilities.** Are we doing enough for carers? Obviously not. Help and support for carers should be a fundamental lynchpin of any national dementia plan and we will continue to advocate towards it and empower our members to do so at national level. In the report it is clear that even in high income countries, most categories of survey respondents felt there were not enough services available.

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- **Health Care Professionals in lower income countries were most positive about their willingness to work with a colleague with dementia. However, the public (most of whom will not work in a health setting) were least willing to work with a colleague with dementia.** We need to change that, and we will work in the next few years both on the issue of the rights for carers in the workplace and the issue of disability rights for people living with dementia.
- **Almost 62% of healthcare providers worldwide think that dementia is part of normal aging.** Our message that dementia is NOT part of normal aging but a disease, is loud and clear, but is clearly not getting through. We must work much harder at this with all our members.
- I see a worrying trend developing with **36% of all respondents saying they would seek help on the internet**. There is so much unreliable information over the web, and it is an area with exponential growth, so we do need to be proactive and create trusted repositories of real information. We give the example with our website where all resources are freely available and so do our members.
- And last but not least around **40% of the general public think doctors and nurses ignore people with dementia** – time for primary healthcare practitioners to look closely at their practice and for governments to increase dementia training.

In the enthusiasm to include the views and voices of the people with dementia we must never forget the family carers. This extract of the Mexican essay is a sobering reminder of that:

"After about ten days I made the decision that I was going to take my husband who has dementia to the federal highway and I was going to throw myself under the wheels of a trailer, the biggest one I saw pass by, together with my husband, because I was not going to be able to bear everything that was coming. I woke up that day very early with my decision taken, to clean the house and leave everything ready, so they could hold vigil over us afterwards that day."

It is a relief that the person in this stark story lived to tell the tale, but these stories are happening all over the world and we must do something to stop this. It is terrible that a human being should contemplate suicide because they cannot cope caring for another human being by themselves. Respite and care must be made available globally, it is a matter of social justice.

As you have gathered from above, alongside the survey results you will read expert essays and case studies that highlight the scope and scale of the global challenge and the often spirited and galvanising response from people, like us, trying to affect change. Amongst many topics we look at:

- the double stigma attached to both age and dementia
- the challenges experienced by some indigenous populations around the world
- stigma in marginalised or lesser heard from communities including prison settings, people with learning disabilities and the LGBTQ community
- the media's role in helping raise awareness or exacerbating stigma
- the history and influence of working groups of people living with dementia and carers
- a philosophical question about the introduction and evolution of dementia friendly communities

I would like to thank the founders of ADI and the hundreds of thousands of you who work so hard day in day out on all aspects of the disease. You are doing so much, but we need to do more. This is just the beginning.

Ultimately, reality is not what governments tell us it is, it is not what experts like us tell us it is; reality is what people on the ground are feeling. Reality is what people feel every morning when they wake up and every night when they go to sleep. We must never forget that, and this is why this World Alzheimer Report is for all of you.

References

1 Patterson, C. 2018. *World Alzheimer Report 2018: The state of the art of dementia research; New frontiers*. London: Alzheimer's Disease International.

2 World Health Organization. *Global action plan on the public health response to dementia 2017–2025*. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0. online: <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1> Last accessed 20 August 2019.

3 Alzheimer's Disease International. 2009. *World Alzheimer Report 2009: The Global Prevalence of Dementia*. London: Alzheimer's Disease International.

4 Prince, M., Wimo, Guerchet, 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.* London. Alzheimer's Disease International.

5 Batsch, N. L., Mittelman, M. S. 2012. *World Alzheimer Report 2012: Overcoming the Stigma of Dementia*. London: Alzheimer's Disease International.

6 Alzheimer's Disease International. 2016. *Dementia Friendly Communities: Key Principals* (1st Edition) online: <https://www.alz.co.uk/dementia-friendly-communities/principles> Last accessed 20 August 2019.

7 Alzheimer's Disease International. 2017. *Dementia Friendly Communities: Global developments* (2nd Edition) online: <https://www.alz.co.uk/adi/pdf/dfc-developments.pdf> Last accessed 19 August 2019.

8 World Health Organisation 2019. *Risk reduction of cognitive decline and dementia: WHO guidelines*. Geneva: World Health Organization; 2019.

Executive summary



In 2019 ADI estimates that there are over 50 million people living with dementia globally, a figure set to increase to 152 million by 2050. Someone develops dementia every three seconds and the current annual cost of dementia is estimated at US $1trillion, a figure set to double by 2030.

In the World Alzheimer Report 2012 *'Overcoming the stigma of dementia'* we explored the nature of dementia related stigma. The core of the report focussed on the results of a survey of 2,500 people; people living with dementia and carers, in a limited number of countries around the world. The report helped define dementia related stigma and offered recommendations to tackle it, alongside a series of case studies and practices aimed at stigma reduction.

In this 2019 World Alzheimer Report, we revisit attitudes to dementia and stigma to better understand the role they play and to set a baseline against which we can gauge future changes. This report details the scale of the challenge we face where attitudes to dementia, and specifically stigma, are still a major barrier to people seeking out information, help, advice, support and even a diagnosis; preventing or delaying people from putting plans in place; progressing to a stage of acceptance and being able to adjust to live with dementia. Stigma may be overt; in some countries it is still associated with witchcraft resulting in people being restrained and isolated. Or it can be more subtle; even in countries with national dementia plans and profile awareness campaigns, many people still delay seeking help when they first become aware that something is wrong.

The 2019 World Report:

At the core of the 2019 report are the results of a global survey, commissioned by ADI and undertaken by the London School of Economics and Political Science (LSE). Almost 70,000 people globally engaged with the survey, making it the biggest of its kind ever undertaken.

LSE developed the survey to target four key groups, (1) people living with dementia, (2) carers, (3) healthcare practitioners and (4) the general public, with analysis being provided in three categories: knowledge, attitudes and behaviour. In the survey analysis we highlight the behavioural element first, giving prominence to the voices and experiences of people living with dementia as direct assessment of actual behaviour is central to discrimination and is the closest representation of the true impact of stigma on people living with dementia.

The report also poses the question *"what is stigma?"*, looking to define dementia related stigma and to better understand the component parts based on power, stereotypes, prejudice and discrimination. Then, through

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a series of expert essays, case studies and programmes, the report sheds light on the nature and complexity of attitudes and stigma; it looks to other sectors for guidance and inspiration; showcases examples of the different challenges and responses at global, regional, national and local levels; and offers some examples of programmes developed to improve awareness and to tackle stigma.

Key findings

Knowledge

- 95% of the public think they will develop dementia in their lifetime
- 78% are concerned about developing dementia at some point
- 1 in 4 people think that there is nothing you can do about dementia
- 2 out of 3 think dementia is caused by normal ageing
- 62% of healthcare practitioners think that dementia is a normal part of ageing
- 82% of people would take a genetic test to learn about their risk
- 54% of respondents think that lifestyle factors play a part in developing dementia
- Just under 40% of the general public think that there are adequate community services for people living with dementia and for carers
- Just under 70% of the general public think there are adequate competent physicians for the diagnosis and treatment of dementia

Two years into the WHO Global action plan on dementia, 35 years into the life of ADI, and longer for many associations around the world, should we be surprised at these findings? There is evidently underlying fear in global populations about developing dementia - 78% expressing concern – and some media portraying dementia as the most feared illness. Journalist Pippa Kelly, in this report, articulates that *"Stigma stems from fear. Fear breeds silence, which in turn perpetuates ignorance and misunderstanding".*

A key reason for developing this survey and establishing a baseline for future review is to help us understand the scale of the challenge in informing and educating the 2/3rds of people who still think that dementia is a normal part of ageing, rather than a neurodegenerative disease and a leading cause of death; in some countries the leading cause of death.

Perhaps an even bigger challenge, and more worrying, is the staggering 62% of healthcare practitioners that think dementia is a normal part of ageing.

With an increasing focus on risk reduction research and messaging, and in the continued absence of a disease modifying treatment, we now have a clear understanding of how important people think that lifestyle factors are. The stark finding of this survey reveals that currently just over 50% of people think that lifestyle factors are influential. These figures form a baseline from which we can measure the impact of future global risk reduction efforts.

Behaviour

- Over 85% of respondents living with dementia stated that their opinion had not been taken seriously
- Around 40% of the general public think doctors and nurses ignore people with dementia
- 67% of people living with dementia in Africa, and 63% in South East Asia, said their dementia symptoms were joked about by others
- Between 35% in high income countries and 57% in low-middle income countries reported being treated unfairly in dating and intimate relationships
- Around 30% of people in Europe are willing to have a person with dementia move in with them, rising to 62% in South East Asia and 71% in the Eastern Mediterranean region

We wanted to better understand the stigma and discrimination experienced by people living with dementia, and particularly, what kinds of treatment they felt were unfair and the outcomes associated with these negative experiences. Unfair treatment can be experienced in many ways – at home, in the community, even in healthcare settings – and include things like being denied choice, being ignored, unfair treatment in dating and intimate relationships, lack of privacy, joking about dementia, and of particular interest, inappropriate treatment by healthcare practitioners.

Respondents reported feeling "avoided", "ignored" and "ostracized" in their social life due to having dementia where many of them "no longer get invited to social gatherings". Poignantly, one respondent captures this with:

"I call it the friendship divorce. I have lost a fair amount of people in my life that at one time considered friends".

Half of the respondents living with dementia from lower-middle income countries reported that they had

experienced their rights or responsibilities taken away from them unfairly.

Over 85% of respondents living with dementia stated that their opinion had not been taken seriously. One respondent reported being told *"your opinion no longer matters".*

Unfair treatment by health or medical staff is an area of concern, as are the attitudes of some healthcare practitioners – with around 40% of the general public thinking doctors and nurses ignore people with dementia. *"My neurologist ignored my presence when my diagnosis was discussed with my husband".*

Joking and humour around dementia is a very sensitive subject. Respondents in the African region (66.7%) and South-East Asia (62.5%) reported the highest prevalence of their dementia being joked about. However, this is a tricky area, humour can be therapeutic, but it is often permission based. The challenge is evidently how difficult it is to judge appropriateness. *"It is 100% offensive and inexcusable to joke about my symptoms, unless it is me joking about it!"*

Attitudes

- 91% of respondents say that people should not hide the fact they have dementia and the vast majority of carers never hide the person with dementia
- However, around 20% of respondents would keep their own dementia a secret when meeting people
- Concealment of dementia varied regionally - with the general public in Europe (25.7%) and the Americas (24.5%) reporting they would keep their dementia a secret. Healthcare practitioners also reported higher levels of concealment in Europe (19%) and the Americas (17.4%)
- Respondents stating they would hide their dementia when meeting people was highest in Russia (66.7%), Poland (57.9%), and Puerto Rico (51.1%),
- 45% of people living in South-East Asia and 48% of healthcare practitioners in the region feel that people with dementia are dangerous.
- 60% of people felt it was important to remove responsibilities of people living with dementia

Dating and intimate relationships are another sensitive area. Respondents with dementia reported unfair treatment in relationships, the highest figures in low / lower middle-income countries (57.1%) and upper-middle countries (50%). "*To be honest, NO ONE wants to date a 58-year old guy with Alzheimer's".*

A very high proportion believe that people should not hide the fact that they have dementia, supported by a high number of people (80%) agreeing that people with dementia can participate in a variety of activities. Attitudes to concealment, however, varied regionally – in Europe and the Americas around 25% saying they would keep their dementia a secret, with Healthcare practitioners also reporting higher levels of concealment in Europe (19%) and the Americas (17.4%).

Concealment and secrecy are key examples of stigma surrounding dementia and some specific country level figures warrant attention – with people in Russia (66.7%), Poland (57.9%), Puerto Rico (51.1%) saying they would hide their dementia when meeting people.

In relation to attitudes and views around danger 45% of people living in South-East Asia, and 48% of healthcare practitioners, think that people with dementia are dangerous, however, this is interesting considering relatively high proportions of people living in the South-East Asia region are willing to have a family member living with dementia to move in with them.

Around 60% of people felt it was important to remove responsibilities of people living with dementia which is interesting in the context that many of the experiences of discrimination reported by people living with dementia pertain to loss of status and loss of roles.

Around 40% of the general public think that healthcare practitioners (physicians and nurses) ignore people with dementia (38% in high-income, 49% in upper-middle income and 32.5% in low/lower middle-income countries).

Ironically, respondents had a vastly more negative opinion of the behaviours of others than about their own behaviour. Both healthcare practitioners and the general public believe that other people are likely to engage in stigmatising behaviours.

Carers

- Majority of carers expressed positive sentiments about their caring role
- 52% of carers said their health had suffered
- 49% of carers said their work had suffered
- 62% of carers said their social life had suffered
- Over 35% of carers globally have hidden the diagnosis of a person with dementia

Although just over half of carers expressed positive sentiments about their caring role, and found it fulfilling,

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52% of carers said their health, 49% their work and 62% their social life suffered because of their caring responsibilities. This raises key questions about formal support services for carers and brings into perspective the importance of a resilient response to action area 5 of the WHO Global action plan on dementia. Attitudes to caring vary by region, by socio-economic grouping and by culture and expectation.

The extent to which work is affected by the provision of care may be influenced not only by the amount of care that is provided and the support available to the carers, but also by differences in the propensity for women (who are most likely to be carers) and older people to work, and by policies to support the employment of people with caring responsibilities.

Recommendations

Stigma and knowledge issues around dementia are evidently still major barriers, not only to people seeking out more information, advice, support and a diagnosis but also in the basic understanding of Alzheimer's disease and related dementias as a medical conditions, that require treatment, support, even rehabilitation. By default, stigma thus also impacts negatively on research and research participation as we strive for a disease modifying treatment breakthrough.

Therefore, it is essential to take action, to improve awareness, to help dispel lingering myths around dementia and ultimately aim to reduce or even eradicate stigma.

Recommendations

1 Targeted public health awareness campaigns

2 Promotion of timely diagnosis and better post diagnostic support

3 Global evolution of dementia friends programmes and dementia friendly/inclusive communities - with people living with dementia and carers at the heart of their design, implementation and evaluation

4 Increased public advocacy of people living with dementia – amplifying the voice of lived experience

5 Increase advocacy focused on carers experiences – whilst improving the understanding of first-hand experience

6 Specialised education about dementia-related stigma and person-centred care practice for healthcare practitioners

7 Call for local governments to increase the funding, range and quality of community services for people living with dementia

8 Changes to public policy relating to employment, health and insurance for both people living with dementia and their carers

9 Full adoption of a rights-based approach to dementia including full compliance with the Convention of Rights of Persons with Disabilities (CRPD)

10 Increase funded research – for both a disease-modifying drug as well as further understanding of stigma. We know from other high stigma illnesses, including cancer and HIV-AIDS, that medical treatment breakthroughs can be a catalyst to stigma reduction – and we also need to better understand the complex role stigma plays throughout society in order to tackle it and change hearts and minds.

CHAPTER 1

What is stigma?

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"Diagnosis has changed our world forever. Our lives become limited by the stigma we face in the world around us. It's like we have a target painted on our foreheads shouting out 'dementing' for all the world to see. People become awkward in our presence, are unsure of our behaviour, and our world becomes circumscribed by the stigma of our illness". Christine Bryden, Dementia Activist[1]

For persons living with dementia, full and equitable engagement in everyday life activities often is compromised by the stigma associated with dementia[2&3]. But what is *stigma* exactly? Here we introduce the concept of stigma and describe its relationship to the concepts of 'stereotype', 'prejudice', 'discrimination' and 'power'. We provide context for later discussions of stigma in this report and form a foundation for initial recommendations to reduce dementia-related stigma.

The word 'stigma' originates from Greek language, meaning a 'mark' or 'brand'. In the social sciences, the term 'stigma' refers to marked differences from what is 'normal' for a group of people, and to negative emotional and/or behavioural responses to those differences. Sociologist Erving Goffman[4] has been influential in our understanding of stigma as a social phenomenon. Goffman described stigma as the marginalisation of persons in response to traits they exhibit, such as ethnicity, religious beliefs, physical disability, skin scarring, or 'weaknesses' of character (e.g., represented by imprisonment or addiction). He showed how being 'marked' with any of these traits could have negative consequences in a given social context.

Four key components

Contemporary stigma research adds clarity to our understanding of what stigma is, what outcomes it creates, and who it affects. This research advances our understanding of how people labelled as somehow abnormal (i.e., those being stigmatised) experience their everyday lives. Recently, researchers, clinicians, policy makers, care providers and persons living with dementia have used the concept of stigma to explain how *dementia* often is seen as a socially undesired trait, leading to discrimination, social isolation, and disenfranchisement.

There are many contemporary models of stigma[5-7]. One model[8], which has proven particularly useful in understanding dementia-related stigma[9-11], identifies four critical components essential for stigma to have its effect: *power, stereotypes, prejudice,* and *discrimination*. 'Stigma' is said to occur when persons with relative social, economic, or political power internalise generalised negative beliefs (stereotypes) which then manifest as negative emotional responses (prejudice) and negative behavioural responses (discrimination). Below we describe each component in greater detail and consider how each contributes to dementia-related stigma.

Component 1: Power

Stigma is dependent on social, economic, or political *power*[8]. The type and severity of stigma can differ depending on who holds relative power over another[7]. For example, persons living with dementia may form stereotypes of medical professionals, yet often lack the power to discriminate against them (e.g., they may lack the social, economic or political resources required to exclude that individual from decision-making about their care).

Examples of stereotypes

All persons living with dementia are:

- a burden to family,
- a burden on the healthcare system,
- delirious,
- hopeless,
- incapable of speaking for themselves,
- incompetent,
- invariably old,
- on a path to inevitable death,
- unable to contribute to society,
- unaware of their abilities or limitations,
- unreliable, and
- untrustworthy.

Figure 1. Dementia-related stereotypes [13-18]

Component 2: Stereotypes

Stereotypes refer to the generalised beliefs, often negative, about what it means to have a certain trait. According to common dementia stereotypes, having dementia is an inherently negative experience (see Figure

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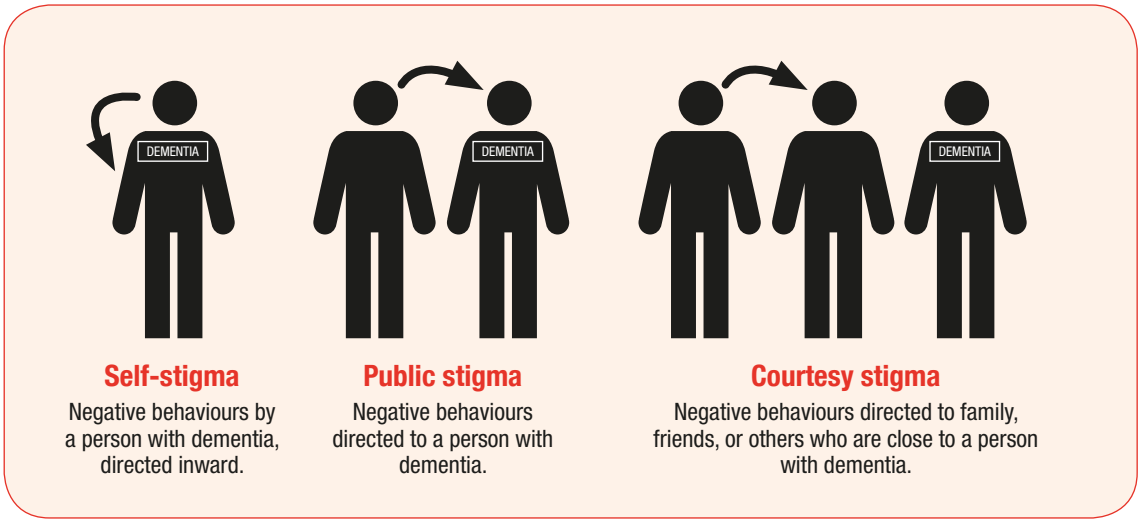


Figure 2. Three types of stigma [2,23]

1). Stereotypes are powerful because they are created and perpetuated in many different ways[11]. They:

1 are perpetuated through the language used to talk about persons living with dementia (e.g., by referring to them as "'demented' 'sufferers', 'subjects', 'victims', and 'not all there'"[12]);

2 are perpetuated through the prevailing medical model of dementia, which portrays dementia as an inexorable decline in all aspects of human functioning including loss of personhood and self;

3 are compounded with other stereotypes (such as stereotypes about older adults or about persons who are institutionalised); and

4 are shaped by cultural beliefs about the cause of dementia (e.g., karma, lack of religious or spiritual adherence).

Component 3: Prejudice

Prejudice refers to the uptake of stereotypes and negative emotional reactions to those stereotypes. Adopting these stereotypes often is subconscious but can have real, significant impacts on our emotions and behaviours. Within the context of dementia, negative emotional reactions most often include *fear*, *shame*, *revulsion* or *disgust*[19-21]. The severity of prejudice is shaped by age, gender, profession, ethnicity, culture and understandings of dementia prognosis, among other factors[22].

Component 4: Discrimination

Discrimination refers to negative behavioural responses to prejudice[8]. These responses include behaviours such as avoiding, ignoring, or actively excluding persons living with dementia. At the most extreme, discrimination may result in the denial of basic human rights including, for example: the choice of where to live, deciding what and when to eat, and access to medical care.

Who does stigma affect?

It is important to note that: (1) both persons *with* dementia and persons *without* dementia can exhibit discriminatory behaviours, and (2) discriminatory behaviours can be directed toward the person living with dementia or to persons close to them. To demonstrate these two points, a useful distinction can be drawn among three types of stigma: *self-stigma*, *public stigma*, and *courtesy stigma* (See Figure 2).

In the context of *self-stigma*, stereotypes and prejudice may lead to discrimination of persons living with dementia, with many possible negative outcomes. These include a person living with dementia being reluctant to seek help, presenting late to health services, disbelieving the diagnosis, and/or social isolation caused by avoidance of, or total withdrawal from, interactions with others[2,24,16].

In the context of *public stigma*, persons living with dementia may experience discrimination in the form of: loss of quality social interactions, social roles, and relationships; exclusion from decision-making; delayed or withheld disclosure of dementia diagnosis[25,26]; and limited or delayed referral to dementia-appropriate services or treatment[27,28].

In the context of *courtesy stigma*, also known as 'stigma by association', stereotypes and prejudice lead to discrimination of persons close to an individual with dementia[29]. Courtesy stigma is expressed in the form of social isolation or exclusion of family members or friends of persons living with dementia[13,30], or by staring at or by talking about formal caregivers and friends behind their backs[31], for example.

Reducing stigma

There are many approaches to reducing dementia-related stigma, but limited evidence for or consensus about which are the most effective[22,23]. To date, the most promising approaches to reducing stigma include:



1 Specialised education about dementia-related stigma[32,33].

2 Social contact with persons living with dementia[34,35,36].

3 Targetted public health awareness / messaging / education[37], through:

- public advocacy by persons living with dementia[38];
- arts-based approaches, such as musical performance by persons living with dementia[39]; and
- short film[40,41], for example.

4 Changes to public policy (e.g., relating to employment, health insurance)[42].

We also suggest that interventions aimed at any of the four components described above (i.e., power, stereotype, prejudice or discrimination) may break the cycle of stigma. For example, combatting dementia-related stigma may involve:

- challenging negative stereotypes, assisted by increased awareness of specific stereotypes and of the ways they are perpetuated;
- challenging prejudices and attitudes by exposing where these come from (i.e., from stereotypes);
- mediating behavioural enactment of prejudices (discrimination); and/or
- acknowledging and adjusting power imbalances, achieved by promoting active involvement of persons living with dementia in research, advocacy, and care.

Only when active measures are taken to reduce stigma can we begin to uphold for persons with dementia the human right to full and equitable engagement in, and access to, meaningful activities of everyday life.

References

1 Bryden, C.2015. *Nothing about us, without us!: 20 years of dementia advocacy*, Jessica Kingsley Publishers, London, UK, p. 40.

2 Ashworth, R 2017. 'Perceptions of stigma among people affected by early- and late-onset Alzheimer's disease', *Journal of Health Psychology* Epub ahead of print. Available at: https://doi.org/10.1177/1359105317720818 Last accessed: 7 August 2019.

3 Lion, KM, Szczesniak, D, Bulinska, K, Evans, SB, Evans, SC, Saibene, FL, d'Arma, A, Farina, E, Brooker, DJ, Chattat, R, Meiland, FJM, Droes, RM & Rymaszewska, J 2019. 'Do people with dementia and mild cognitive impairments experience stigma? A cross-cultural investigation between Italy, Poland and the UK', *Aging and Mental Health* Epub ahead of print. Available at: https://doi.org/10.1080/13607863.2019.1577799 Last accessed: 7 August 2019.

4 Goffman, E 1963. *Stigma: Notes on the management of spoiled identity*, Simon and Schuster, New York, NY.

5 Corrigan, PW 2000. 'Mental health stigma as social attribution: Implications for research methods and attitude change', *Clinical Psychology: Science and Practice*, 7(1) 48-67.

6 Link, BG, Cullen, FT, Struening, E, Shrout, PE & Dohrenwend, BP 1989. 'A modified labeling theory approach to mental disorders: An empirical assessment', *American Sociological Review*, 54 (3), 400-23.

7 Link, BG & Phelan, JC 2001. 'Conceptualising stigma', *Annual Review of Sociology*, vol. 27, 363-85.

8 Rüsch, N, Angermeyer, MC & Corrigan, PW 2005. 'Mental illnes s stigma: Concepts, consequences, and initiatives to reduce stigma', *European Psychiatry*, 20(8), 529-39.

9 Blay, SL & Peluso, ETP 2010. 'Public stigma: The community's tolerance of alzheimer disease', *American Journal of Geriatric Psychiatry*, 18 (2), 163-171.

10 Gove, D, Small, N, Downs, M & Vernooij-Dassen, M 2017. 'General practitioners' perceptions of the stigma of dementia and the role of reciprocity', *Dementia*, 16 (7), 948-64.

11 Young, JA, Lind, C, Orange, JB & Savundranayagam, MY 2019. 'Expanding current understandings of epistemic injustice and dementia: Learning from stigma theory', *Journal of Aging Studies*, 48 (76-84).

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12 Swaffer, K 2014. 'Dementia: Stigma, language, and dementia-friendly', *Dementia*, 13(6): p. 709-16.

13 AboJabel, H & Werner, P 2016, 'Exploring family stigma among caregivers of persons with Alzheimer's disease: The experiences of Israeli-Arab caregivers', *Dementia*, 18(1): p. 391-408.

14 Ballenger, JF 2017, 'Framing confusion: Dementia, society, and history', *AMA Journal of Ethics*, 19(7): p. 713-719.

15 Beard, RL 2017, 'Dementia and the privilege of growing old', *Dementia*, 16(6): p. 685-688.

16 Stites, SD, Rubright, JD & Karlawish, J 2018, '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 and Dementia*, 14(7): p. 925-32.

17 Werner, P & Doron, I 2017, 'Alzheimer's disease and the law: Positive and negative consequences of structural stigma and labeling in the legal system', *Aging and Mental Health*, 21(11): p. 1206-13.

18 Werner, P, AboJabel, H, Reuveni, Y & Prilutzki, D 2017, 'Stigmatic beliefs toward a person with Alzheimer's disease among high-school students: Does majority–minority status make a difference?', *Educational Gerontology*, 43(12): p. 609-18.

19 Behuniak, SM 2011, 'The living dead? The construction of people with Alzheimer's disease as zombies', *Ageing and Society*, 31(1): p. 70-92.

20 Casado, BL, Hong, M & Lee, SE 2018, 'Attitudes toward Alzheimer's care-seeking among Korean americans: Effects of knowledge, stigma, and subjective norm', *Gerontologist*, 58(2): p. e25-e34.

21 Lopez, RP, Rose, KM, Kenney, L, Sanborn, V & Davis, JD 2019, 'Managing shame: A grounded theory of how stigma manifests in families living with dementia', *Journal of the American Psychiatric Nurses Association* Epub ahead of print. Available at: https://doi.org/10.1177/1078390319832965 Last accessed: 7 August 2019.

22 Herrmann, LK, Welter, E, Leverenz, JB, Lerner, A, Udelson, N, Kanetsky, C & Sajatovic, M 2018, 'A systematic review of Alzheimer's disease and dementia stigma research: How might we move the stigma dial?', *American Journal of Geriatric Psychiatry*, 26(3): p. 316-331.

23 Werner, P 2014, 'Stigma and Alzheimer's disease: A systematic review of evidence, theory, and methods', in PW Corrigan (ed), *The stigma of disease and disability: Understanding causes and overcoming injustices,* p. 223-244. American Psychological Association, Washington, DC.

24 Livingston, G, Baio, G, Sommerlad, A, de Lusignan, S, Poulimenos, S, Morris, S, Rait, G & Hoe, J 2017, 'Effectiveness of an intervention to facilitate prompt referral to memory clinics in the United Kingdom: Cluster randomised controlled trial', *PLoS Medicine*, 14(3): p. e1002252.

25 Low, LF, McGrath, M, Swaffer, K & Brodaty, H 2018, 'Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners', *Dementia* Epub ahead of print. Available at: https://doi.org/10.1177/1471301218761911 Last accessed: 7 August 2019.

26 O'Connor, D, Mann, J & Wiersma, E 2018, 'Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship', *Journal of Aging Studies*, 44: p. 45-51.

27 Johnson, R, Harkins, K, Cary, M, Sankar, P & Karlawish, J 2015, 'The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment', *Social Science & Medicine*, 143: p. 117-27.

28 Mukadam, N & Livingston, G 2012, 'Reducing the stigma associated with dementia: Approaches and goals', *Aging Health*, 8(4): p. 377-86.

29 Werner, P & AboJabel, H 2019, 'Who internalizes courtesy stigma and how? A study among Israeli Arab family caregivers of persons with dementia', *Aging and Mental Health* Epub ahead of print. Available at: https://doi.org/10.1080/13607863.2019.1584790 Last accessed: 7 August 2019.

30 Greenwood, N, Mezey, G & Smith, R 2018, 'Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness', *Maturitas*, 112: p. 39-45.

31 Werner, P & Hess, A 2016, 'Examining courtesy stigma among foreign health care workers caring for persons with Alzheimer's diseas: A focus group study', *Home Health Care Services Quarterly,* 35(2): p. 69-85.

32 Herrmann, LK, Udelson, N, Kanetsky, C, Liu, H, Cassidy, K, Welter, E & Sajatovic, M 2018, 'A new curriculum to address dementia-related stigma: Preliminary experience with Alzheimer's Association staff', *Dementia* Epub ahead of print. Available at: https://doi.org/10.1177/1471301217752706 Last accessed: 7 August 2019.

33 Kim, S, Werner, P, Richardson, A & Anstey, KJ 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, art. 100351.

34 Cheston, R, Hancock, J & White, P 2018, 'Does personal experience of dementia change attitudes? The Bristol and South Gloucestershire survey of dementia attitudes', *Dementia* Epub ahead of print. Available at: https://doi.org/10.1177/1471301217752707 Last accessed: 7 August 2019.

35 Goldman, JS & Trommer, AE 2019, 'A qualitative study of the impact of a dementia experiential learning project on pre-medical students: A friend for Rachel', *BMC Medical Education*, 19:127.

36 Kane, A, Murphy, C & Kelly, M 2018, 'Assessing implicit and explicit dementia stigma in young adults and care-workers', *Dementia* Epub ahead of print. Available at: https://doi.org/10.1177/1471301218804727 Last accessed: 7 August 2019.

37 Lawlor, B 2018, 'The local and global imperative to raise public awareness and knowledge about dementia', *Arquivos de Neuro-Psiquiatria*, 76(11): p. 729-30.

38 Phillipson, L, Hall, D, Cridland, E, Fleming, R, Brennan-Horley, C, Guggisberg, N, Frost, D & Hasan, H 2018, 'Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project', *Dementia* Epub ahead of print. Available at: https://doi.org/10.1177/1471301218754455 Last accessed: 7 August 2019.

39 Reynolds, L, Poyner, C, Innes, A & Hambidge, S 2017, ''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*, 16(2): p. 219-25.

40 Hand, MD 2019, 'Every three seconds: A review of an innovative documentary on research and stigma surrounding dementia across the globe', *Journal of Gerontological Social Work*, 62(3): p. 369-373.

41 Prins, M, Veerbeek, M, Willemse, BM & Pot, AM 2019, 'Use and impact of the Alzheimer Experience: a free online media production to raise public awareness and enhance knowledge and understanding of dementia', *Aging and Mental Health* Epub ahead of print. Available at: https://doi.org/10.1080/13607863.2019.1579781 Last accessed: 7 August 2019.

42 Stites, SD, Johnson, R, Harkins, K, Sankar, P, Xie, D & Karlawish, J 2018, '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 Communication*, 33(3): p. 264-73.

CHAPTER 2

Attitudes to dementia survey results

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Attitudes to dementia survey results

This section of the report summarises the findings from the largest ever global survey of people living with dementia, carers(i), healthcare practitioners and the general public. A more detailed, technical report will be made available online. We aimed to understand stigma-related knowledge, attitudes and behaviours around dementia and to understand how stigma affects people living with dementia. The consequences of stigma are often described as being as important as the condition itself. At the individual level, stigma can undermine life goals, reduce participation in meaningful life activities and lower levels of well-being and quality of life. At the societal level, structural stigma and discrimination can influence levels of funding allocated to care and support. Currently, there is very little information about how stigma manifests in relation to people with dementia and how this may vary around the world. A better understanding of knowledge, attitudes and behaviour towards people with dementia and how these link with consequences for people living with dementia could help us to understand where we might focus our efforts to reduce stigma in order to improve the lives of people living with dementia and their families.

Almost 70,000 people from 155 countries and territories(ii) engaged with the survey and this chapter summarises findings from 60,860 complete responses to questions on stigma-related knowledge, attitudes and behaviour in relation to people living with dementia. Some survey questions were asked among all respondents while others were tailored for a particular group (for example carers). This enabled us to compare findings across groups but also understand the specific experiences of certain groups. We generally categorise our findings in two ways: (1) by WHO Region (geographical location) and (2) by World Bank income groups (see Appendix 1). These categories capture broad cultural and economic variations in relation to stigma towards people living with dementia. In addition, we provide a break-down of selected questions by countries with more than 100 respondents.

(i) Throughout the survey analysis the word 'carers' also refers to caregivers and care partners.

(ii) Throughout the report, the word 'countries' also refers to countries and territories/regions together.

Further information on the study methodology including the survey development, data collection and analysis are described in detail in the methodology section (See Methodology Section page 61).

Survey findings

We present survey findings according to three areas which contribute to stigma: (1) knowledge (problems of ignorance and misinformation), (2) attitudes (problems of prejudice) and (3) behaviour (problems of discrimination, e.g. social exclusion)[1]. In this report, we highlight the behavioural element first, as direct assessment of actual behaviour is central to discrimination and is the closest representation of the true impact of stigma on people living with dementia. Additionally, stigma surveys tend to focus on knowledge and/or awareness, assuming that these are linked with discrimination; however, it is essential that we assess true behaviour and experiences from the perspective of people living with dementia in order to validate these links[2]. Additionally, this gives prominence to the voices and reported experiences of people living with dementia so that we can understand the main areas in relation to which they feel society treats them unfairly as this should be the focus of any anti-stigma effort.

Behaviour

Experiences among people living with dementia

We wanted to understand the stigma and discrimination experienced by people living with dementia, in particular what kinds of treatment they felt were unfair and the outcomes associated with these negative experiences. In terms of outcomes, we looked at quality of life, life satisfaction, well-being and self-esteem, hypothesising that individuals experiencing greater levels of stigma and discrimination might have worse outcomes.

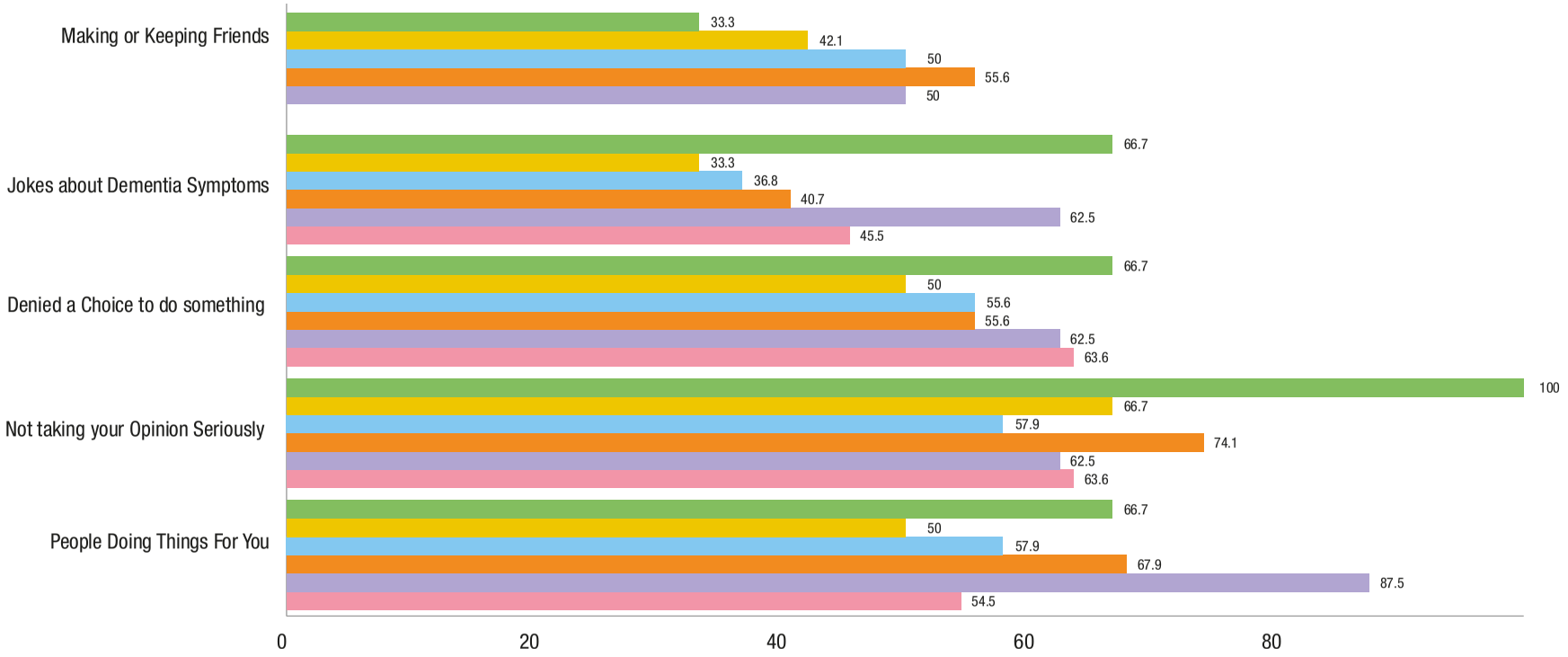
Unfair treatment experienced by people living with dementia

Unfair treatment can be felt across many life domains such as being treated unfairly in hospitals or by family members, having jokes made about one's dementia symptoms or being denied the opportunity to do things by others because of a diagnosis of dementia. We present the reported prevalence of unfair treatment by respondents living with dementia according to different types of life domains and compare these responses across World Bank income groups and across WHO regions in Figures 1-2. Alongside each domain, we contextualise participant responses with quotes from

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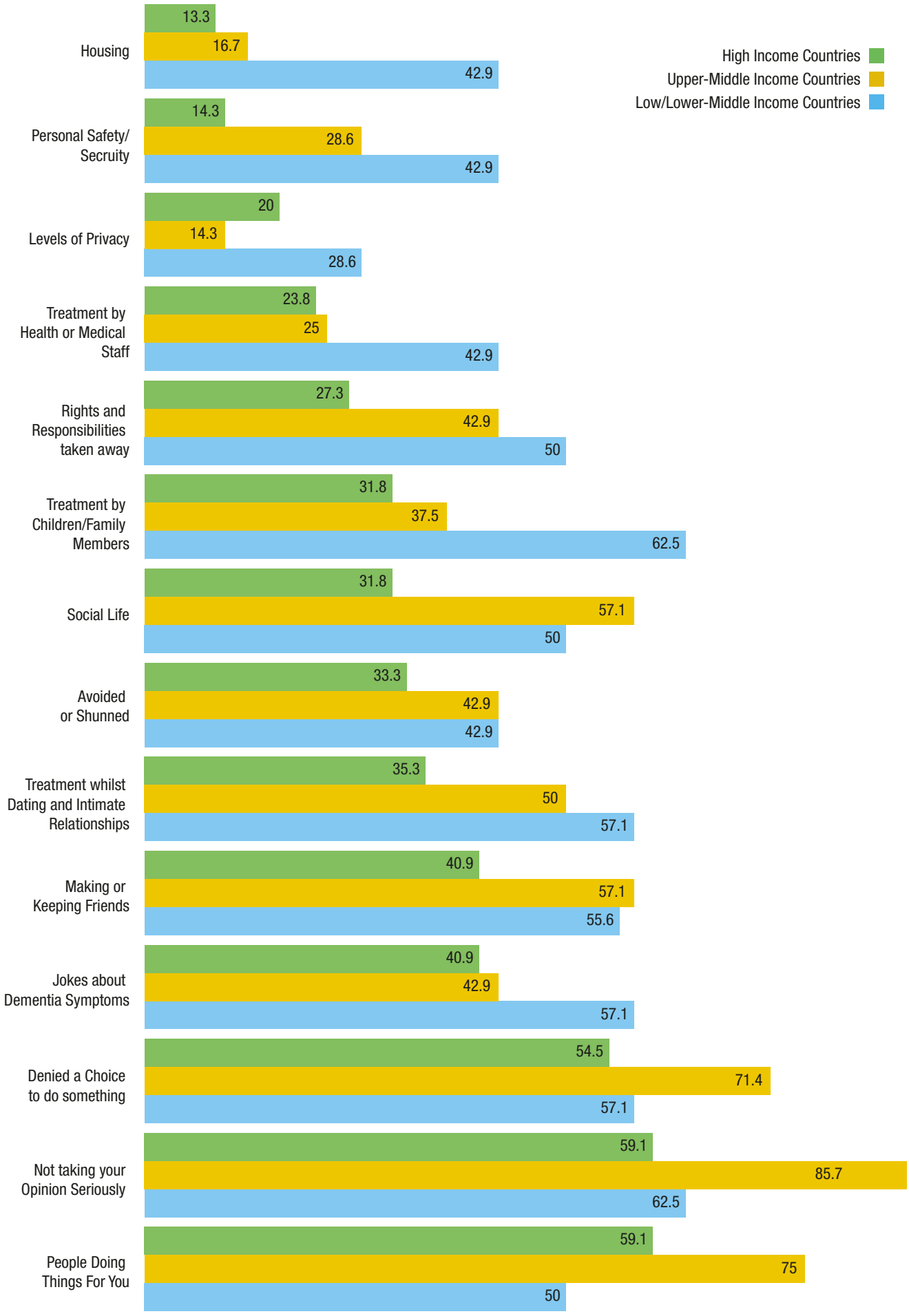
Figure 1. Domains in which respondents living with dementia have experienced unfair treatment across world regions (% of respondents)



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Figure 2. Domains of unfair treatment experienced by people living with dementia by World Bank income category (% of respondents)



individuals living with dementia who have experienced being treated unfairly across different global regions.

Global comparisons of unfair treatment according to life domain and / or experience

Social life

When asked about being treated unfairly in social life, such as being excluded from socialising, hobbies or attending events, respondents living with dementia in high (38.1%), upper-middle (57.1%) and low/lower-middle income (50%) countries reported experiencing this form of unfair treatment because of their dementia and this was highest in upper-middle income countries (see Figure 2). Respondents reported feeling "avoided", "ignored" and "ostracized" in their social life due to having dementia where many of them *"no longer get invited to social gatherings"* (71 year old female from the United States (US)).

Being avoided or shunned

A further 42.9% of respondents living with dementia in upper and low/lower-middle income countries experienced being avoided or shunned, whereas this was lower in high-income countries (33.3%). The greatest experience of avoidance or shunning was in the Region of the Americas (40.7%, see Figure 1).

Personal safety and security

Respondents in low/lower-middle (42.9%) income countries experienced the greatest amount of unfair treatment in personal safety and security compared to respondents in high (14.3%) and upper-middle (28.6%) income countries. Respondents living with dementia said they had been *"pushed and verbally abused"* (66 year old male from the US) and *"emotionally abused"* (62 year old female from the US).

Privacy

When asked have you been treated unfairly in your levels of privacy? Respondents living with dementia in low/lower-middle (28.6%), high (20%) and upper-middle (14.3%) income countries all reported this form of unfair treatment. For example, one respondent said, *"I know my health records have been shared without my consent"* (60 year old female from Australia). Another respondent spoke of a lack privacy across many different situations: *"I have 3 caretakers. One of them will open packages I get in the mail, even after I have asked her not to. It is impossible for me to have a private phone call and privacy with visitors. They usually go into my doctor visits, so I have no privacy there"* (75 year old female from the US).

Housing

When respondents living with dementia were asked have you been treated unfairly in housing? those living in lower-middle income countries reported the greatest amount of unfair treatment (42.9%, see Figure 2).

However, respondents from high (13.3%) and upper-middle (16.7%) income countries had also had this experience, saying things such as *"when the place reference to housing knew I had dementia they showed me the door… I was not welcome"* (73 year old female from the United Kingdom (UK)).

Dementia symptoms being joked about by others

Fifty-seven percent of respondents living with dementia in low/lower-middle income countries reported that their dementia symptoms were joked about by others. This form of unfair treatment was also experienced by respondents living with dementia in high (40.9%) and upper-middle (42.9%) income countries. Respondents in the African (66.7%) and South-East Asia Regions (62.5%) reported the highest prevalence of their dementia being joked about often by others (see Figure 1).

Having responsibilities taken away unfairly

Half of the respondents living with dementia from lower-middle income countries reported that they had experienced their rights or responsibilities taken away from them unfairly (see Figure 2), this was also experienced in high (27.3%) and upper-middle (42.9%) income countries. For example, one respondent said their *"spouse wants to do most of the work around the house, because she doesn't want me to get tired"* (57 year old female from the US), and one *"I feel I have little say in making a decision to move house"* (67 year old female from the UK).

Been told you couldn't do something that you still thought you could do

When asked about being told that they couldn't do something that they still thought they could do because of their dementia, respondents living with dementia in upper-middle (71.4%), high (54.5%) and low/lower-middle (57.1%) income countries all experienced this form of unfair treatment with the greatest regional prevalence being in the African (66.7%), Western Pacific (63.6%) and South-East Asia (62.5%) regions of the world (see Figure 1).

People do things for you that you could do yourself

When asked about whether people do things for you that you could do yourself because they know you have dementia, respondents living with dementia in upper-middle income countries (75%) reported higher rates of others doing things for them, in comparison to high-income (59.1%) and low/lower-middle income (50%) countries (see Figure 2). The highest prevalence of others doing things for respondents living with dementia that they can do themselves was in the South-East Asian region (87.5%). It may be possible that in some cultures doing things that people can do for themselves corresponds to a wish to show deference, particularly towards older people.

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People do not take your opinions seriously because of your dementia

To the question, Because of your dementia have some people not taken your opinions seriously?, 85.7% of respondents living with dementia in upper-middle income countries reported that some people have not taken their opinion seriously, and this was also commonly reported in low/lower-middle (62.5%) and high (59.1%) income countries (see Figure 2). Respondents reported being told *"but you have dementia, so what would you know"* (60 year old female from Australia) and *"your opinion no longer matters"* (60 year old male from the US).

Unfair treatment by health or medical staff

Unfair treatment by health or medical staff was most commonly reported by people living in low/lower-middle income countries (42.9%) compared to high (23.8%) or upper-middle income countries (25%, see Figure 2). The highest prevalence being in the Africa region (33.3%) and in the region of the Americas (29.6%). Respondents living with dementia in the African region said *"my neurologist ignored my presence when my diagnosis was discussed with my husband"* (59 year old female from South Africa) and *"they tell me that I am not sick but too old"* (86 year old male from Zambia). Respondents living with dementia in the region of the Americas said *"my primary care doctor said to my face, too bad that euthanasia is illegal here"* (65 year old female from the US) and *"doctors don't talk to you but your caregiver"* (60 year old male from the US).

Dating or intimate relationships

To the question Have you been treated unfairly in dating or intimate relationships, respondents living with dementia in low/lower-middle income countries reported the greatest prevalence (57.1%), compared to upper-middle (50%) and high (35.3%) income countries (see Figure 2). Respondents have reported difficulties and negative experiences while dating: *"As soon as I mention I have dementia, they presume the worst. I walk with a stick and that doesn't help either. My last boyfriend wanted to hide me away and I spoke openly about my dementia. Hence why that relationship didn't work"* (49 year old female from the UK).

Making or keeping friends

When asked about being treated unfairly in making or keeping friends because of dementia, respondents from upper-middle (57.1%) income countries reported the greatest prevalence compared to high (40.9%) and low/lower-middle (55.6%) income countries (see Figure 2). Respondents living with dementia in the Americas reported the highest prevalence of unfair treatment when making or keeping friends (55.6%). Respondents added, *"People tend to run when they learn you have dementia"* (60 year old male from the US), or *"cannot cope with the different me"* (69 year old male from Australia). Respondents from the South-East Asia region said *"others are not able to comprehend the out of situation behaviour"* (62 year old male from India) and *"some friends do not talk or share information with me"* (64 year old female from Thailand).

Treated unfairly by children or family

Being treated unfairly by children or other family members was most prevalent in low/lower-middle (62.5%) income countries rather than in high (31.8%) or upper middle (37.5%) income countries. Unfair treatment by children or family members was greatest in the Western Pacific region (41.7%) and the region of the Americas (40.7%). Respondents from Western Pacific regions said: *"my parents, siblings and many other family members have completely abandoned me"* (60 year old female from Australia) and *"I was excluded by over half of them. Told I was attention seeking"* (66 year old female from Australia). Respondents in the region of the Americas said: *"I have just one sister. Thinks I am making it all up"* (60 year old female from Canada) and *"My suggestions or comments are sometimes ignored"* (77 year old male from the US).

Key themes

Key areas of participation relevant to people with dementia in all cultures and countries include social relationships and interactions with healthcare staff. These interactions represent meaningful relationships where many people reported being treated unfairly. Respondents articulated different ways in which they felt they were treated unfairly because of their dementia in social life including: no longer being invited out, being ostracised, losing contact with previous contacts, feeling they could no longer contribute and a lack of support to make interactions accessible. (See Figures 3-4, Tables 1-3)

Table 1. Respondent examples of being treated unfairly in social life because of dementia, categorised by theme

Themes	Respondent examples
Accessibility	I rely on people to get me places, they often forget me or they are too busy – 59, female, United Kingdom
	They control what they think I can do. They say they will take me for a drive and then make excuses that they can't – 57, female, United Kingdom
	Having to always use a walker (rollator type) causes me to miss out on socialising and attending events. I can't even go to the movies now. Just recently missed out on attending a good concert which my son and daughter-in-law attended. They did not even try to include me. That hurt me – 75, female, United States
	I was not able to attend an event because I didn't have a caregiver to accompany me. I live by myself and don't need one yet – 65, female, United States
	Sometimes I am not included. Also because of physical disabilities (as an effect of the dementia) accessibility at a given venue makes it impossible for me to attend – 56, female, United Kingdom
'Feel I can no longer contribute'	Feel I can no longer contribute – 68, female, Europe
	To a family reunion because there are people who get annoyed or feel uncomfortable – 46, female, Panama
	I exclude myself, because I can't keep up – 58, male, the Netherlands
Loss of contact	Some work colleagues do not contact me any longer – 63, female, Finland
	Fewer people call to socialize – 58, female, United States
	After going to a social function with friends, those friends have all but disappeared – 56, female, United States
	Old friends do not call – 72, male, United States
Not being invited	Sometimes friends don't ask me to shindigs as often as they used to, because I don't drive anymore. That hurt to start with, not so much now – 49, female, United Kingdom
	Except for a couple of very close friends I no longer get invited to anything – 57, female, United States
	I'm no longer invited to do things with my friends. If I do something, it's usually by myself or with my ex-wife. I have very few close friends now – 58, male, United States
	Too many to tell. My daughter have me babysit while they go out with her in-laws. I'm never invited. My son's present girlfriend would not have me in their home. I am no longer allowed visitation with my five year old grandson who were her most of the time from birth to three and a half. The new girlfriend is in charge – 64, female, United States
	Not invited to family birthdays which hurt. Slowly changing but both my husband and I weren't on the invitations anymore – 66, female, Australia
	I am excluded from social get-togethers with in-laws or friends – 57, female, Suriname
'You are ostracized'	People treated me like a freak in our church meals. Neighbours avoid me – 69, female, United States
	Kicked out of book club – 69, female, United States
	I used to be active in a club, but now I am a non person – male, United States
	I used to volunteer in helping immigrants learn English until they found out I had dementia – 60, female, Canada
	First time at new resident clubhouse lunch function, after being accepted previously at their board meeting, they shunned my effort to help volunteer to prepare & serve the meal as they previously stated I would be helping – 77, female, United States
	They treat me like I don't exist. They move away from me. I feel alone – 65, female, Argentina
	The organizer denied a person living with dementia participation in the care training session and stopped sending the information about the session – 55, male, Japan

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Figure 3. Social life and family relationships. Themes based on textual responses of people living with dementia when asked 'Have you been treated unfairly in your social life? (for example, being excluded from socialising, hobbies, attending events, leisure activities)'

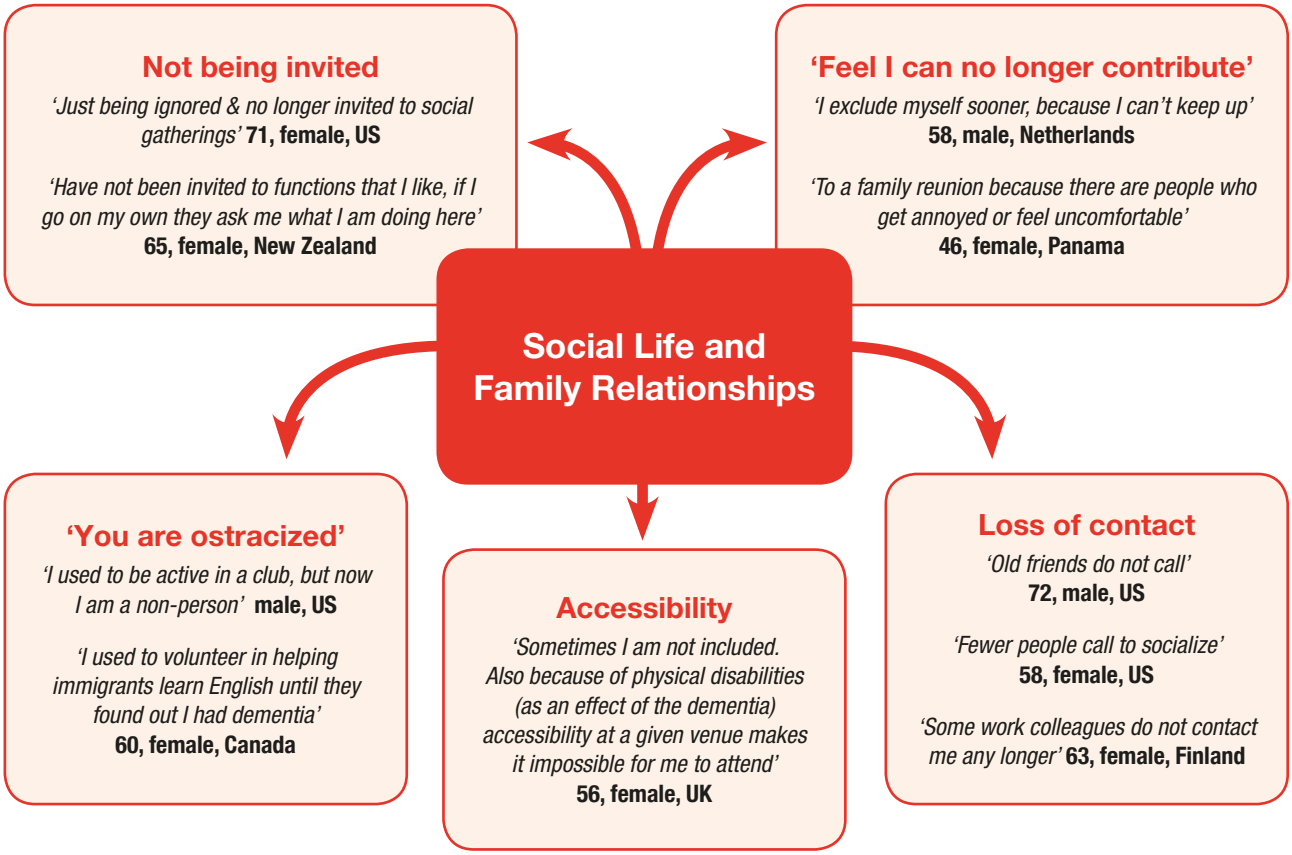


Figure 4. Unfair treatment within healthcare. Themes based on textual responses of people living with dementia when asked 'Have you been treated unfairly health or medical staff? (for example, did a health care professional suggest that you disengage from daily activities or social situation)'

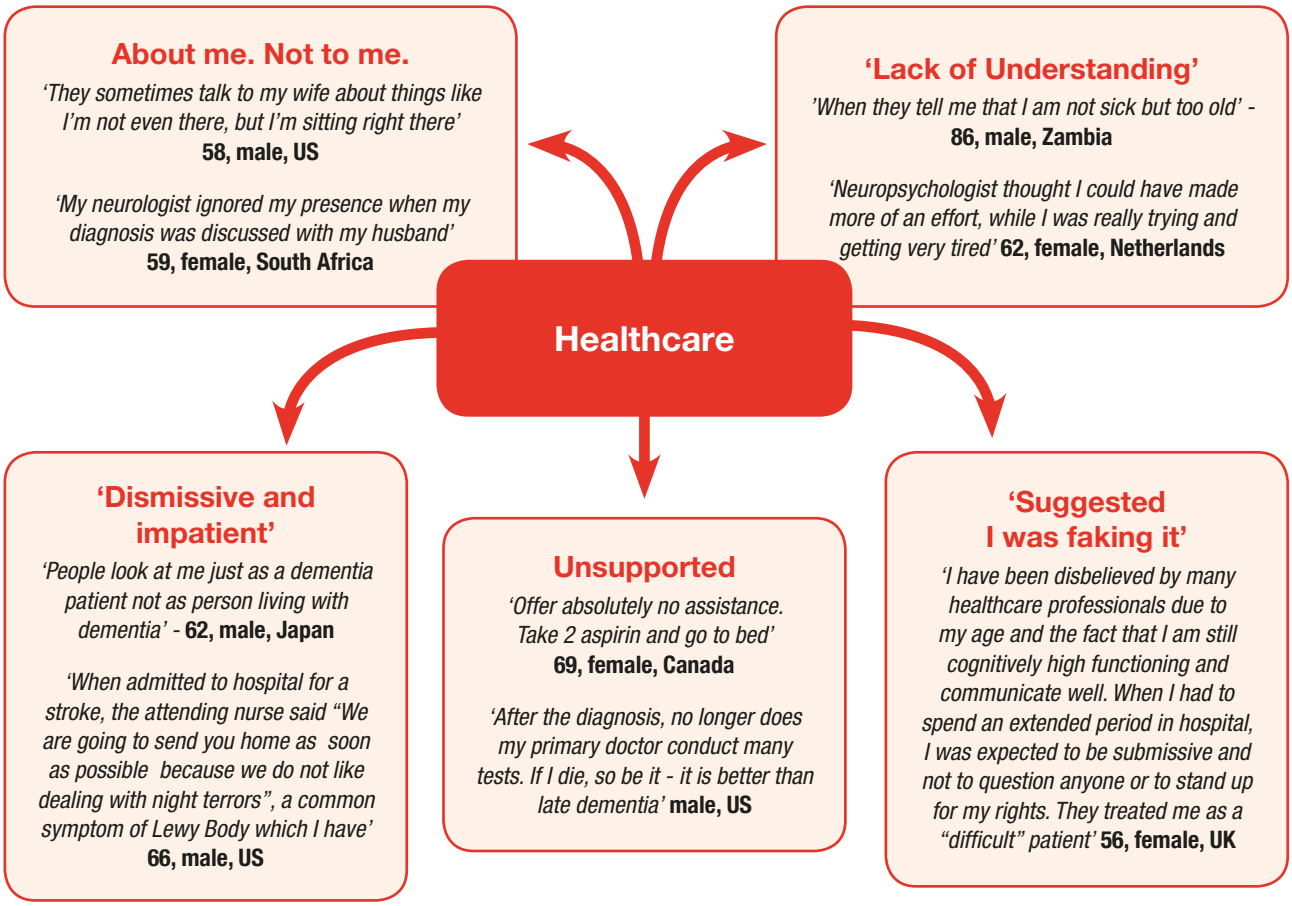


Table 2. Respondent examples of being treated unfairly in healthcare because of dementia, categorised by theme

Themes	Respondent examples
About me. Not to me.	They sometimes talk to my wife about things like I'm not even there, but I'm sitting right there – 58, male, United States
	My neurologist ignored my presence when my diagnosis was discussed with my husband – 59, female, South Africa
	Being talked about not being talked too I sometimes feel invisible in a room I think a lot of health care officials need to retrain in dementia awareness skills – 56, male, United Kingdom
	Case manager who just wants to arrange things instead of talking about the difficulties I'm dealing with – 68, female, Netherlands
Dismissive and impatient	I was advised I should no longer scuba dive without any reason other than I have dementia. Not any specific symptom to drive this decision and I am in very early stage of disease – 57, female, United States
	One medical provider advised me to stop my social engagements because I am old – 70, male, Canada
	Doctor advised me not to cook anymore, not to drive. And some doctors totally ignored me and talked to my daughter in law only – 76, male, Malaysia
	My doctor told me that I shouldn't be able to continue with my voluntary activities – female, Australia
	Primary care doctor said to my face, "too bad that euthanasia is illegal here" – 65, female, United States
	Neurologist diagnosed me with Alzheimer's at 56, telling me to go home and get my final affairs in order and to wait until my premature death – 60, male, United States
Lack of Understanding	People including health professional ignoring what I am saying – 86, male, Zambia
	When admitted to hospital for a stroke, the attending nurse said, "We are going to send you home as soon as possible because we do not like dealing with night terrors", a common symptom of Lewy Body dementia which I have – 66, male, United States
	People look at me just as a dementia patient not as person living with dementia – 62, male, Japan
	The bluntness of the first neurologist and his diagnosis - without any additional examination – 78, male, Netherlands
	Not spending enough time, only showing me once how to use a gadget to read diabetes readings. I need shown a few times for me to remember how to use it – 73, female, New Zealand
'Suggested I was faking it'	While I was in hospital a nurse was moaning about a noisy patient with dementia - made me feel like what are they saying about me – 70, female, United Kingdom
	A primary care doctor told me that I wanted to be sick! – 69, female, United States
	When they tell me that I am not sick but too old – 86, male, Zambia
	Neuropsychologist thought I could have made more of an effort, while I was really trying and getting very tired – 62, female, Netherlands
	Suggested I was faking it – female, United Kingdom
Unsupported	Not in the ways you have asked for examples of, but many HCPs (healthcare professionals) often do not believe I have dementia - which is abusive and offensive. But, also, they then talk over me, about me, and never to me, if an inpatient, due to me having dementia. Very ironic indeed, and who's the level of IGNORANCE about dementia in HCPs – 60, female, Australia
	I have been disbelieved by many healthcare professionals due to my age and the fact that I am still cognitively high functioning and communicate well. When I had to spend an extended period in hospital I was expected to be submissive and not to question anyone or to stand up for my rights. They treated me as a "difficult" patient – 56, female, United Kingdom
	I am finding that health care professionals do not listen to me, or know how to ask the questions that I can answer...and they always say - who told you have this...and then discredit the diagnosis or say they don't believe that is the problem...when I try to explain the level of life change I have recently experienced, they blow me off – 56, female, United States
	One Doctor refused to believe what I said, implying I was making it up – 73, female, United Kingdom
	Some of my doctors don't pay much attention to what I tell them, and therefore they are unable to help me. I am now looking for a 3rd GI specialist, because the first 2 did nothing for me and both just dismissed me without treatment or relief of symptoms – 75, female, United States

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Table 3. Examples of unfair treatment reported by people living with dementia according to life domain

Domain of unfair treatment	Quote from respondents living with dementia
People doing things for you that you could do yourself because they know you have dementia	My partner has taken over all our finances - I think I could manage some of the – 63, female, South Africa Sometime people try to speak for me, but I insist I am still able to do this – 56, female, United Kingdom People mean well, but I am not an invalid. My family can be like that hence why I live alone. If I offer to help when I go to their house they don't often let me – 49, female, United Kingdom Giving a shower to the persons with dementia instead of assist and let them shower themselves because they don't have time and have to go to work – 50, female, Thailand Spouse reminds me of things that I can remember on my own, i.e. Don't forget your keys. Do you have your phone? All in voice that sounds like she is reminding a child – 57, female, United States A close friend sometimes finishes my sentence as I take time to find my words. I am in very early stage and aphasia is my major problem – 75, female, United States A lot of things I feel I may still be able to do others do for me in the name of helping – 62, female, United States Always volunteering to do stuff not wanted by me. Tiresome – 60, female, Malaysia I was excluded from the rotating duty of the neighbourhood association – 87, female, Japan
Not taking your opinion seriously because of your dementia	Sometimes in open conversations in groups of friends, I feel my opinion is "sidelined" – 63, female, South Africa They simply think I am dumb. Especially since I look 10+ years younger than my age – 48, female, Uganda Some people have the impression that should be less vocal in my opinions. When speaking to carers (of others) in order to spread awareness of the dementia experience I have been shouted down and told I don't understand the situation, even though I have also been a carer for a family member with dementia – 56, female, United Kingdom It's as if invisible, if I ask my husband to do something, he totally ignores it causing arguments all the time – 57, female, United Kingdom I love a good debate. I have a debating back ground throughout my life. I remember attempting a debate with someone on a topic of interest to me. Her reply was you are very argumentative. That is the dementia talking – 61, male, Canada People just don't listen when I talk – 69, female, United States I have even been told, "but you have dementia, so what would you know!" – 60, female, Australia
Denied a choice to do something that you still thought you could because of your dementia	I can't do anything anymore without asking someone, but no one cares if I want to do it or not. People seem to forget, I'm still a real person with real feelings and very real emotions – 59, female, United Kingdom Volunteering for Alzheimer's Association ESAG requires me to have a travel partner even for local events where I am the better of us at navigating. No exceptions just because I have Alzheimer's. I was also denied access to an Alzheimer's seminar because I have the disease and when insisted and raised the Americans with Disabilities Act, was allowed to attend but only if I didn't tell anyone I had dementia. This was a well-known hospital providing this seminar – 57, female, United States Taking away carrying credit cards, cash – 81, male, United States I still live on my own. I feel doctors are rushing to convince me to go into a care facility. I'd rather have discussions on how I can live on my own longer and what, if any, services are available to prolong my independence – 69, male, United States Driving, finances, and especially payments for consulting or other usually funded advice from ALL Alzheimer's advocacy organisations. Curiously, organisations outside of the dementia sector have NO problem paying me for advice, consulting or appropriate disability support - it has been exclusively the dementia sector which has systematically denied me this, and I have had to fully or partially self-fund to even have a voice or be included – 60, female, Australia Taking away my car key; disconnect my house gas supply and drive away my car and said thieves stole it after I refused to close the gate – 76, male, Malaysia

Domain of unfair treatment	Quote from respondents living with dementia
People joke about your dementia symptoms	They call me names – 55, female, Zambia I put humour in my own situation to let other people feel comfortable – 56, female, South Africa My grandchildren mock me that my decisions are not sound – 86, male, Zambia Becoming a joke / joked about – 69, male, Indonesia Bullying, speaking about dementia as a funny joke – 40, female, Thailand I have been told, "Well my memory is better than yours!" or "Don't forget to wear the same type of shoes" – 57, female, United states You can't remember anything! – 70, female, United States How long before you become fully demented – 60, female, Canada When I make a mistake they just say oh it's a senior moment but they don't really know that I have dementia because I haven't told them – 80, female, United States It is 100% offensive, and inexcusable to joke about my symptoms (unless it is me joking about it). It also means I will not engage with these people afterwards. Asking people not to joke about us, always means they take offense, rather than accept they may be offending or upsetting us – 60, female, Australia My child said that I looked like an alpaca when I dribbled saliva – 53, female, Japan People said that I did not look like someone with dementia – 58, male, Japan
Treated unfairly in making or keeping friends because of your dementia	They tend to visit less often avoid visits – 74, female, South Africa Forgetting their names or when to meet...makes them think I do it intentionally – 48, female, Uganda With some friends they became distant on finding out about my diagnosis. I am not always included in the plans of friends I have kept and I put this down to my diagnosis – 56, female, United Kingdom My siblings don't talk to me or ask how I am anymore – 62, male, United Kingdom Barred from my Sister's house because they said I have used abusive and obscene language – 70, male, Canada People tend to run when they learn you have dementia – 60, male, United States When I make statements that are out of character some friends and family have taken it personally and stopped talking to me – 58, female, United States I feel isolated – 65, female, Argentina Many have told me they are not at all interested in "the dementia journey" – 60, female, Australia Some friends don't like to talk to me because I repeat – 87, female, Singapore I have a few people say don't talk to her she has no idea what she is talking about – 65, female, New Zealand Some people cannot cope with the different me – 69, male, Australia
Avoided or shunned by people who know that you have dementia	Because they think that they cannot cope up to their standard of thinking – 55, female, Zambia They avoid socialize – 74, female, South Africa Close friend doesn't call at all anymore – 60, male, United states In my faith community, avoiding me – 66, male, United States No one comes to my house but one neighbour (who wants my furniture when I am moved away) and my adult children visit rarely - when they come they avoid me most of the time and go out to have fun. My in-laws posture was always like backing away from dangerous animal. My mother in law harassed and insulted me and threatened to call police on me for telling her to back off – 69, female, United States

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Domain of unfair treatment	Quote from respondents living with dementia
Treated unfairly by your children or other family members	My children are more distant and are not acknowledging my condition, refusing to talk about it – 56, female, United Kingdom I have a daughter who has distanced her and her family since I was diagnosed – 55, female, United Kingdom Not being included in conversations. I stopped attending family gatherings for the last 9 years since diagnosis – 70, male, Canada Too much expected of me sometimes. Irritation that I don't remember things – 70, female, United States Family frustrated, angry, and in denial themselves – 69, female, Canada Children sometimes seem to dismiss my decisions regarding my future – 79 female, United States [being told] "You're a crazy mother" – 52, female, Brazil Excluded by over half of them. Told I was attention seeking, they didn't believe I had dementia. It was easier to believe the wrong diagnosis of hypomanic depression late onset bi/ polar schizophrenia. These aren't terminal diseases. Just didn't want it for me as not familial Dementia – 66, female, Australia My daughter insists that I should go for day care, my daughter in law took photos of the pots I have burnt and told me to look at what I have done – 76, male, Malaysia I am blamed for my mistakes due to my disease as if it were laziness - Japan People don't expect anything from me because I have dementia – 53, female, Japan My child dislikes me because I am slow and cannot clearly articulate my question – 65, male, China Since they cannot tolerate my behaviours, they do not want to contact me – 58, male, Chinese Taipei
Rights and Responsibilities unfairly taken away from you because of your dementia	The right to work and at times to think for myself – 63, male, UK My wife handles all finances even though I think I am capable – 79, male, Canada We are buying a second home. My wife assumes roles she is unfamiliar with because she fears (justifiably) I am incompetent – 77, male, United States Forced to apologize for my behavior – 67, female, United States Mother brother and sister cheated me out of large share of inheritance – 69, female, United States Rating at work was decreased – 59, female, United States
Treated unfairly in your levels of privacy because of your dementia	In hospital, psychiatric doctor did not give me my medical records – 60, female, Czech Republic Hospital lack of dementia protocols – 67, male, United States I have 3 caretakers. One of them will open packages I get in the mail, even after I have asked her not to. It is impossible for me to have a private phone call and privacy with visitors. They usually go into my doctor visits, so I have no privacy there – female, United States Financial info, asking neighbours about me without telling me – 69, female, United States I know my health records have been shared without my consent... and I have also felt the need to share them to prevent public defamation of the possibility of me faking dementia – 60, female, Australia Hospital moving from bed to bed. Manager does not understand dementia – total lack of training – 68, female, Europe

Domain of unfair treatment	Quote from respondents living with dementia
Treated unfairly in your personal safety and security because of your dementia	People harangue me cos I get things wrong or say something they don't like – 62, male, United Kingdom I have been verbalized in the past by people not understanding about my dementia. Like people saying that my dementia is "Gods punishment to me for something I have done in my life" And other things like that – 49, female, United Kingdom I feel that my husband will do something, get rid of something for example and when I approach him about it, he will say it never existed or it's all in my head, he will say I don't know what you're talking about or I'm starting an argument which normally happens – 57, female, United Kingdom Elder verbal abuse by the society – 50, female, India In the face of some crisis, as I have mild cognitive impairment.... my oldest son threw me on the floor – 55, female, Argentina At first my kids would yell and so would my partner. He seemed to know I was weaker – 60, female, United States Don't ask her as she has lost it – 65, female, New Zealand Husband speaks badly. Children do not take into account what I say – 65, female, Argentina Verbal abuse ... the maid my daughter employed. Physical abuse ... the nursing home nurse restraining me to my bed by tying me to the bed railing as they said I kept removing my diapers and mess up the bed and floor with urine and shit – 76, male, Malaysia
Treated unfairly in housing because of your dementia	When the place knew I had dementia they showed me the door and was told I was not welcome – 76, female, United Kingdom I have lived in the country[side] for many years and after diagnosis I have been put in a town – 58, female, Ireland Wants to live in his/her own home, but live in the kid's home instead – 68, female, Indonesia Moving into independent senior facility when I mentioned I had short term memory loss I was told I'd have to be in a dependent section by their rules. I had to get a Dr.'s letter stating I was competent – 77, female, United States

Impact of stigma on intimate relationships among people living with dementia

Feeling loved and intimacy is considered an essential part of interpersonal relationships. Whilst an intimate relationship could imply sexual activity, conceptually an intimate relationship fulfils the desire for closeness and warmth from another person. The need for intimate relationships exists across cultures. Dementia may, however, negatively impact the maintenance of these relationships and could also impede the formation of new ones (e.g. dating).

As mentioned earlier, in the survey, people with dementia from low/lower-middle income countries more frequently reported that they had been treated unfairly in dating or intimate relationships (57.1%) compared to upper-middle-income countries (50%), and high-income countries (35.3%). Irrespective of region, the responses were quite variable.

Open text responses commonly described how the person with dementia felt they were treated differently within their existing intimate relationships. This included feelings that they are being ignored, others being less attentive to what they say, or even neglected.

"In conversations when sharing my opinions. They are often ignored or put down." (Female, 60, Canada).

"There is no longer an equal dialogue with my partner" (Female, 54, Netherlands)

"Since they (friends) realized that I have dementia, they are not so intimate with me." (Male, 58, Vietnam)

Generally, respondents did not openly report changes to sexual habits, and were more likely to discuss changes to sleeping arrangements (e.g. sleeping in separate beds). However, some did report a reduction in sexual contact, which resulted in conflict.

"My husband does not understand my mood. He thinks that I do not want to have relations for other reason and is angry." (Female, 65, Argentina)

In some cases, the diagnosis of dementia appeared to lead to a breakdown in the intimate relationship. It was not always clear the reason for this breakdown, though it was not always due to the partner leaving the person with dementia.

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"…. my wife and I divorced due to my Alzheimer's … her decision." (US)

"my husband would yell at me, refused to comfort my panic, refused to help me more. He also threatened me and I divorced him" (Female, 69, US)

Respondents also described that dementia prevented the formation of new intimate relationships, through dating. Respondents either were self-stigmatizing in the belief that others would not want to date someone with dementia or had previous negative and stigmatizing experiences whilst dating in the past.

"To be honest, NO ONE wants to date a 58-year-old guy with Alzheimer's." (Male, 58, US)

"I haven't dated in years. Had my confidence blown out of the water towards this. I met a nurse…on our second date I mentioned I had Alzheimer's. Thought I should get that out of the way. She said, 'I have met some losers in my time but you take the cake'. I asked why she said that. She said, 'everyone knows anyone with dementia should be locked up' and went on to say that I couldn't have dementia. I asked her why? She said, 'because you make sense when you talk.'" (Male, 61, Canada)

"I don't date at all now. As soon as I mention I have dementia, they presume the worse. I walk with a stick and that doesn't help either. My last boyfriend wanted to hide me away and I spoke openly about my dementia. Hence why that relationship didn't work. That was in 2016." (Female, 49, UK)

Concealing the diagnosis and life satisfaction

When asked about how comfortable they feel talking about their dementia, for example, telling others you have a dementia diagnosis and how it affects you, 14.1% of respondents living with dementia reported being 'not at all' comfortable when talking to a friend and 13% when talking to a family member. The highest rates of discomfort were felt in upper-middle income countries. Just under one- third of respondents living with dementia agreed that when meeting people for the first time I try to keep my dementia a secret, with higher rates of secrecy found in respondents who were from high-income and low/lower-middle income countries. Nonetheless, a significant majority of respondents living with dementia (86.3%) think that people should not hide their diagnosis.

Further analysis suggested that higher levels of secrecy were related to a greater experience of unfair treatment and negative quality of life factors such as loneliness, frustration and anger. Whereas being comfortable in disclosing to others was associated with higher levels of self-esteem and positive quality of life factors such as happiness, hopefulness and content. When respondents were asked How often in the past month did you feel satisfied with your life? 23.5% of people living with dementia reported they were at most satisfied 'about once or twice' in the last month. Respondents in low/lower-middle (55.5%) and upper-middle reported being satisfied less often than respondents in high-income countries.

Behaviour among the general public, healthcare practitioners and carers

In addition to experiences of people living with dementia highlighting the unfair treatment that they face, understanding behaviours of the general public, healthcare practitioners and carers can help us understand the context in which people live.

Intended behaviour in relation to allowing a person with dementia to move in

- As well as specific attitudes towards people living with dementia, the question of whether people would allow a person with dementia to move in with them, may reflect other cultural differences, as in some regions of the world multigenerational households are much more common than in others. When looking by World Bank income group, 40.6% of the general public living in high-income countries were willing or extremely willing to allow a person living with dementia to move in with them, compared to 58.4% of upper- and 64.1% low/lower-middle income countries (see Figure 5A).
- When looking at WHO Regions, those living in the Eastern Mediterranean (71.1%) and South East Asia (62%) were mostly likely to agree to have a person with dementia move in with them while those living in Europe were least likely to agree (30.6%) (see Figure 5B).

Beliefs about secrecy and disclosure of dementia

- On the whole, attitudes strongly support openness about dementia, with 91% of respondents saying that people should not hide the fact that they have dementia.
- However, around 20% of respondents would keep their own dementia a secret when meeting people. Only a small proportion of respondents (4.2%) would advise a close relative to keep their dementia a secret from everyone. This figure was higher for male than for female respondents (see section below on gender differences, page 50)
- Individuals living in high-income countries were most likely to say they would make an effort to keep their dementia a secret when meeting people (24.2%) compared to those living in low or lower-middle income countries (18.8%). A preference for secrecy was more common among the general public compared to healthcare practitioners, where 16.2% of those living in high-income and 10.9% of those living in low or lower-middle income countries agreed with the statement (see Figure 6A).

Figure 5A. Willingness to have a person with dementia move in with them among the general public by World Bank income group

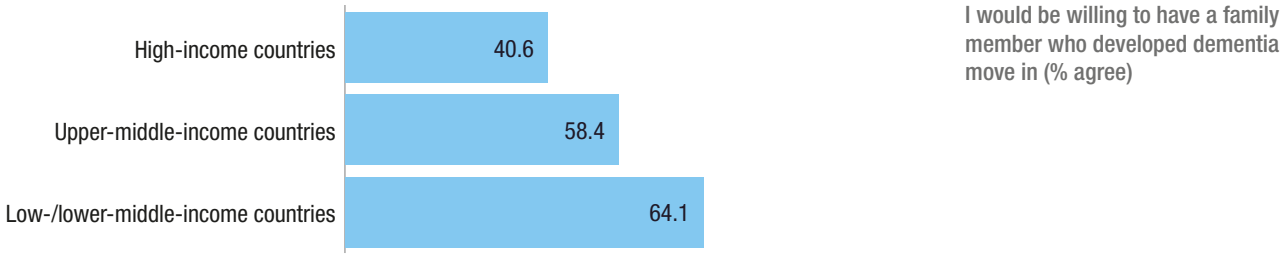


Figure 5B. Willingness to have a person with dementia move in with them among the general public by WHO Region

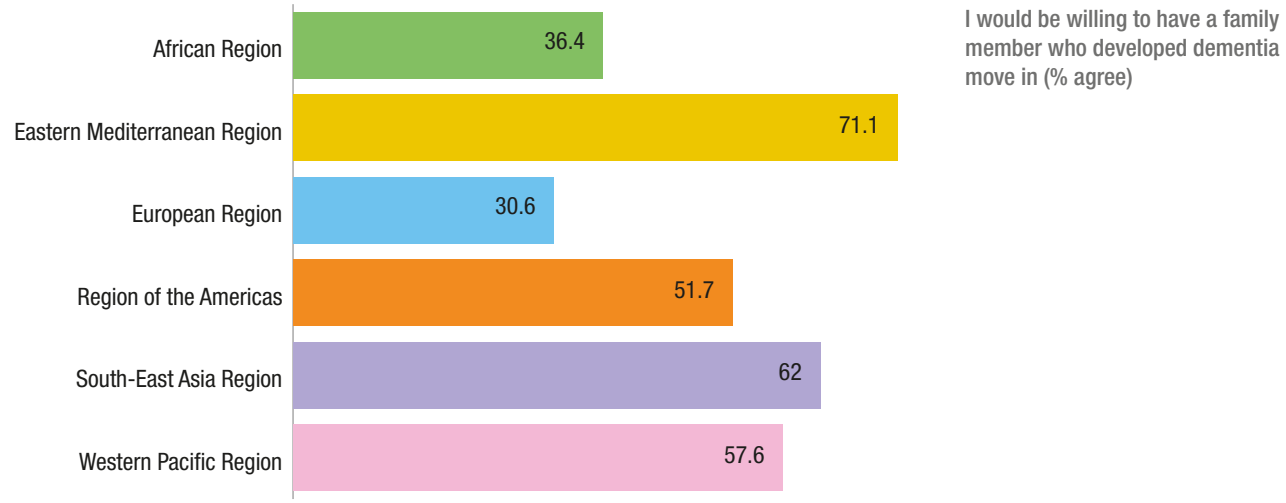
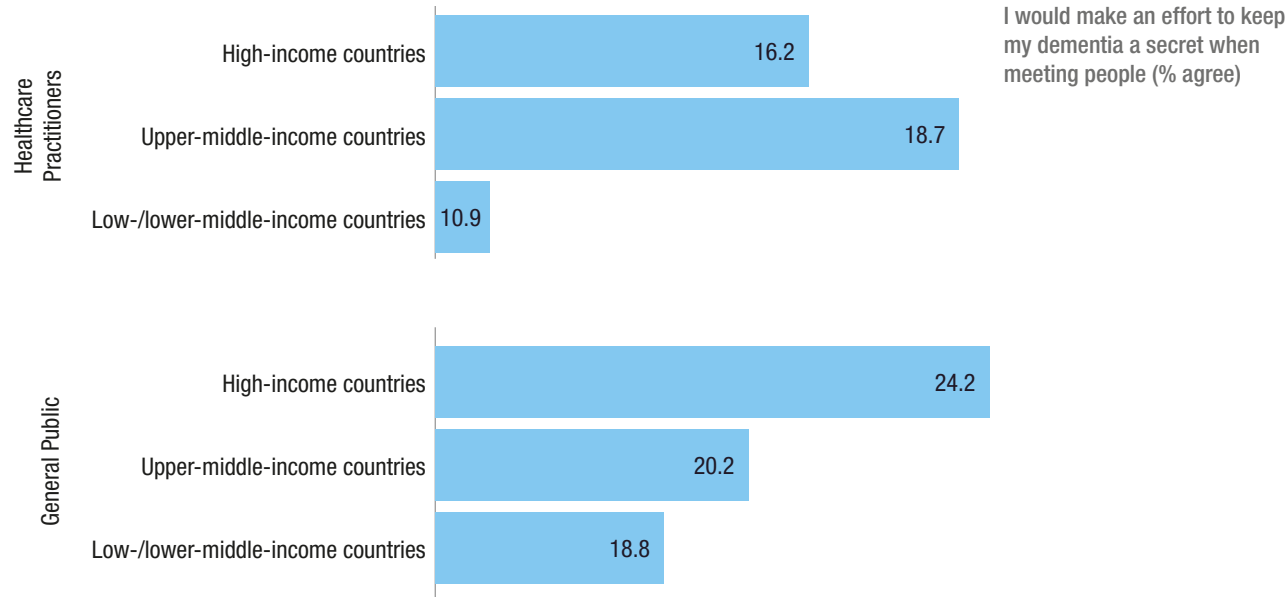


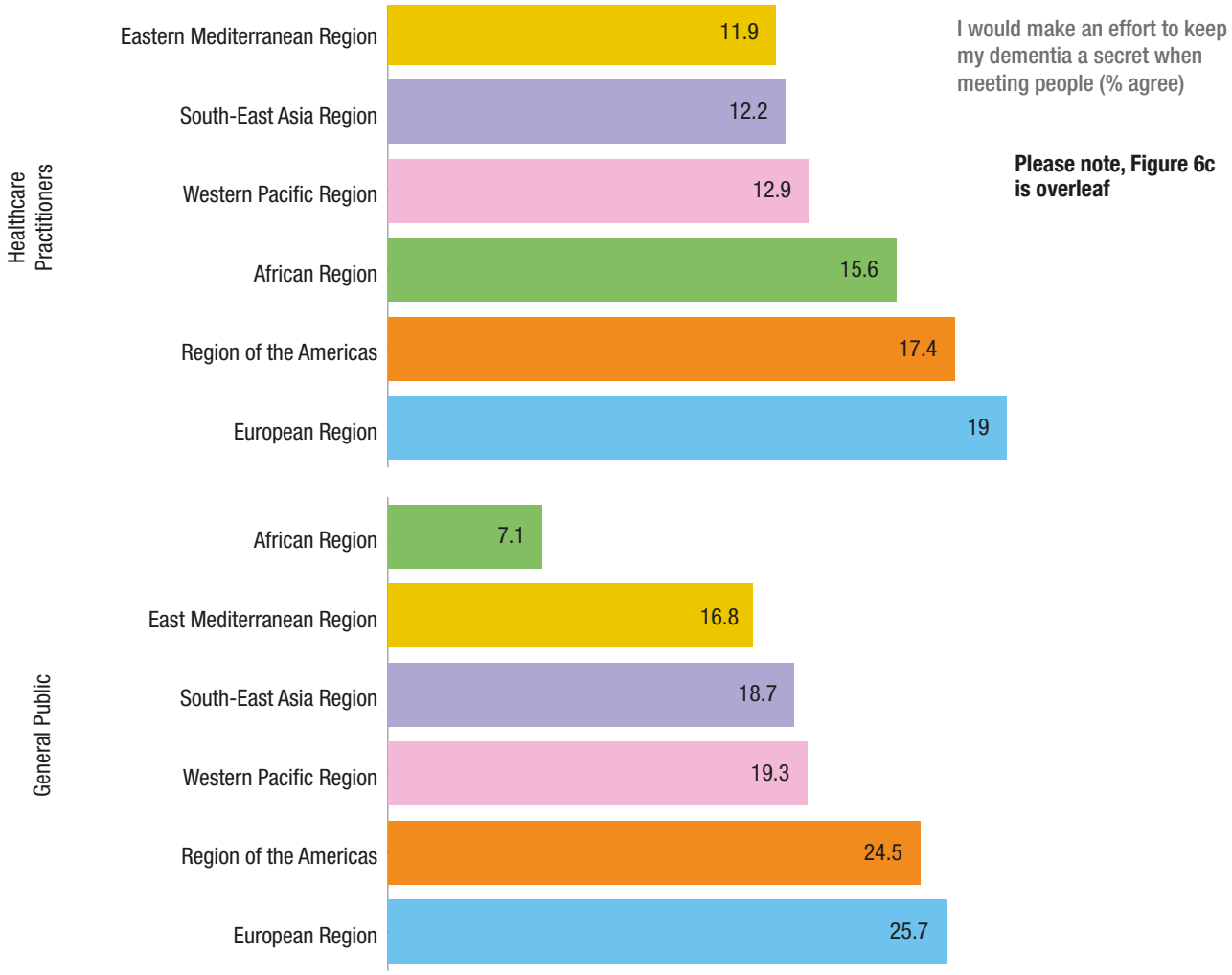
Figure 6A. Intended secrecy and concealment of dementia among healthcare practitioners and the general public by World Bank income group



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Figure 6B. Intended secrecy and concealment of dementia among healthcare practitioners and the general public by WHO Region



- Concealment of dementia varied regionally, with roughly a quarter of the general public in Europe (25.7%) and the Americas (24.5%) reporting they would keep their dementia a secret when meeting others compared, for example, to only 7% in Africa. Healthcare practitioners also reported higher levels of concealment in Europe (19%) and the Americas (17.4%) compared to other regions (see Figure 6B).
- Among countries/territories with more than 100 respondents, the countries with the highest proportion of respondents stating they would hide their dementia when meeting people were: Russia (66.7%), Poland (57.9%), Puerto Rico (51.1%), and Romania (36.7%), and the countries with the lowest proportion were: Iran (2.3%), Portugal (2.6%), Kenya (2.7%) and Singapore (3.4%) (see Figure 6C)
- Although a minority of respondents preferred secrecy, nearly a quarter of carers reported keeping a low profile while with the person they care for, and 37.3% report cutting down their contacts with friends and relatives, although this may be due to the other aspects of their caring role.

Comparing own personal attitudes with perceptions of the general public

Respondents have a vastly more negative opinion of the behaviours of others than they do about their own behaviour. Both healthcare practitioners and the general public believe that other people are likely to engage in stigmatising behaviours. The general public responded, however, that they themselves were unlikely to engage in these behaviours. For example, 4.4% of the general public agreed that if someone they knew developed dementia they felt there would be no point in talking to people living with dementia, while 29.8% thought that others would behave in this way.

Intended sources of support

Respondents were asked about where they would seek help if they were concerned they had early signs of dementia. They could choose as many options as they wished and were also given the option of providing a free text entry.

- Healthcare practitioner was the most commonly chosen source of support, selected by 87% of respondents, followed by a partner and a family

member.

- Most of those who said they would seek help from a healthcare practitioner would also seek help from a family member or spouse, with only 18% saying they would seek help from a healthcare practitioner but not a spouse, family member or friend.
- 36% of people answered they would seek help online/internet.
- Although the vast majority of respondents answering this question would seek help, 1% replied that they would not seek help from any source.

Carers experiences and behaviours

Just over half of the carers who answered the questionnaire expressed positive sentiments about their caring role and found it fulfilling. However, providing care is also challenging; particularly if lack of support from formal services or other family members or the wider community results in negative impacts for the carers.

We found that 52% of carers said their health, 49% their work and 62% their social life suffered because of their caring responsibilities.

Impact on health of providing care to people with dementia

Carers in low/lower-middle income countries were more likely to answer that their health had been impacted by providing care (55.0%), compared to 49.9% of carers in high income countries. The highest proportion of carers reporting that caring had affected their health were those living the Eastern Mediterranean region at 64.9%, whereas the lowest was in the European region, 47.5%. These differences would be consistent with a relationship between the availability of formal services and the impact of providing care the health of carers.

Impact on work of providing care to people living with dementia

People living in upper-middle income countries reported the highest rates of their work having been impacted by their caring role (52.8%), compared to 47.9% in high income countries and 44.1% in low/lower-middle income countries. The extent to which work is affected by the provision of care may be influenced not only by the amount of care that is provided and the support available to the carers, but also by differences in the propensity for women (who are most likely to be carers)

Figure 7A. Carers report of the impact of caring on their health, by World Bank income group

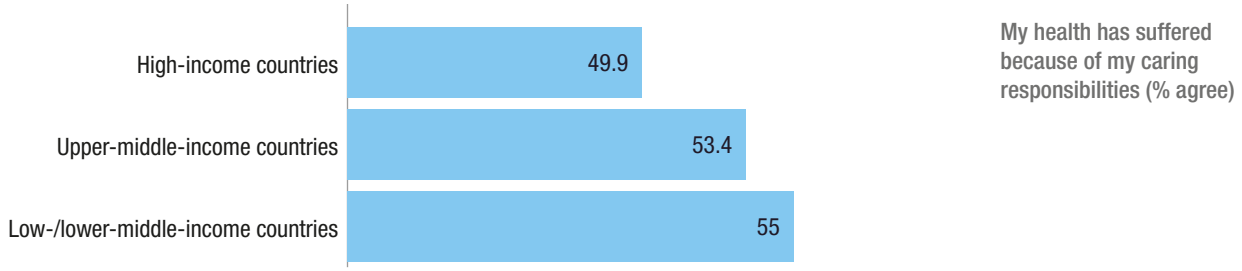
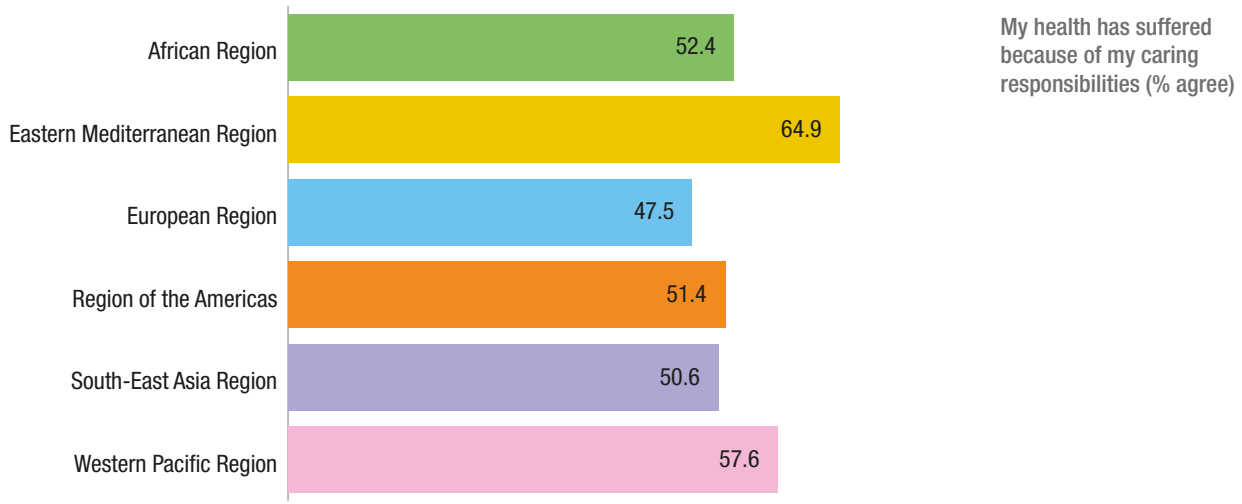


Figure 7B. Carers report of the impact of caring on their health, by WHO Region



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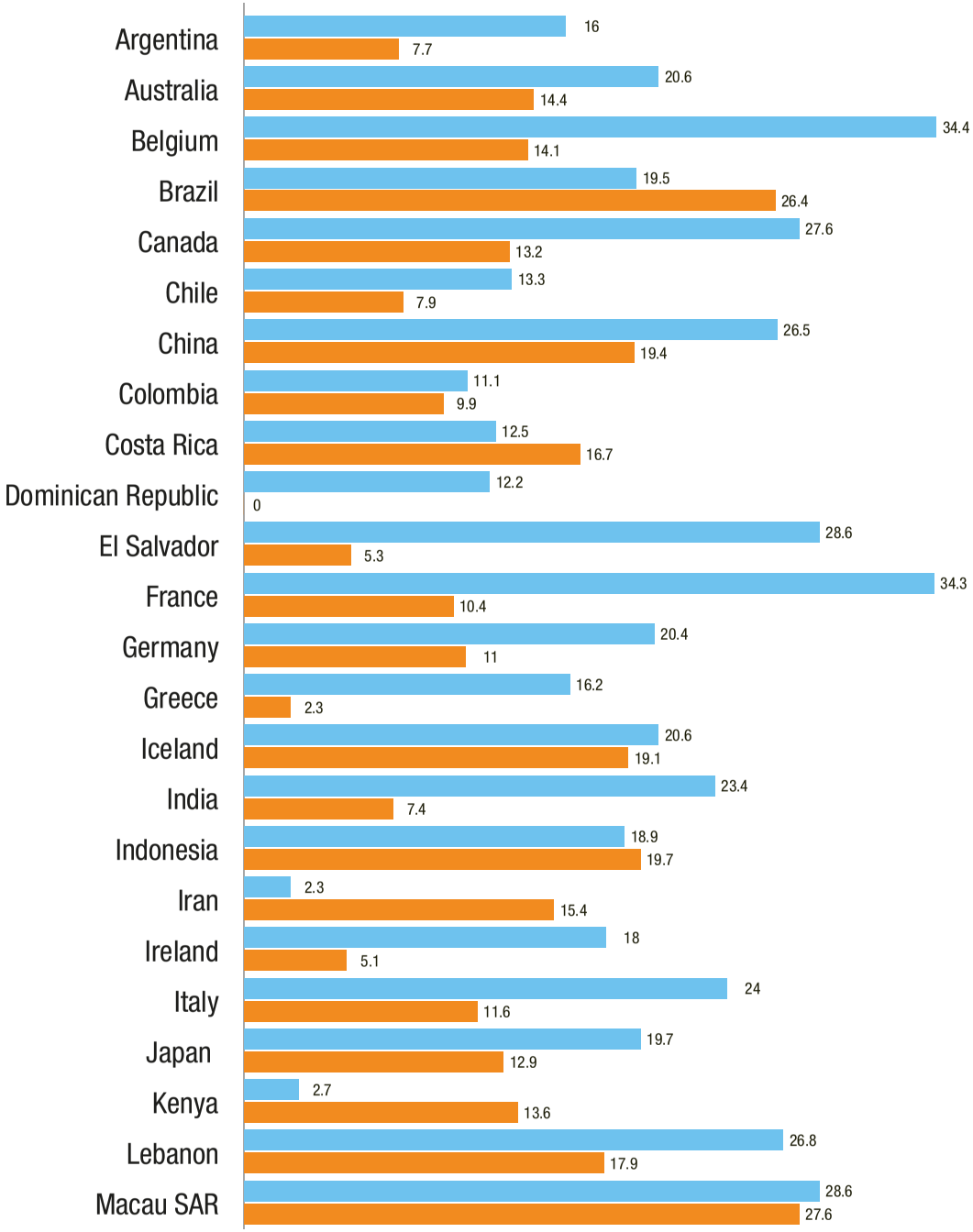
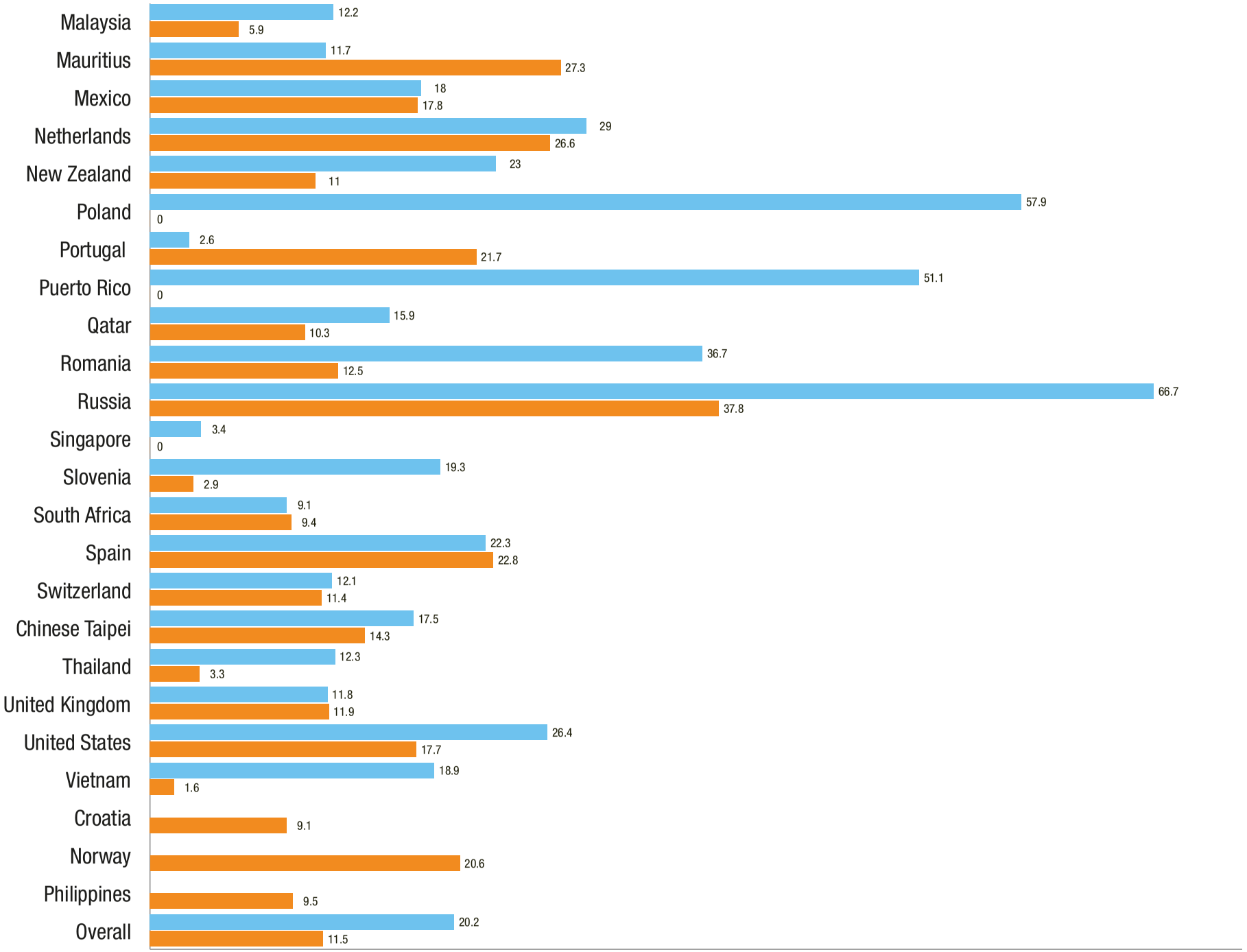


Figure 6C. Intended secrecy and concealment of dementia among healthcare practitioners and the general public by country

Note: Croatia, Norway, and the Philippines were excluded due to low sample size (n<100) for this particular item/ target group



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Figure 8A. Carers report of caring impact on work, by World Bank income group

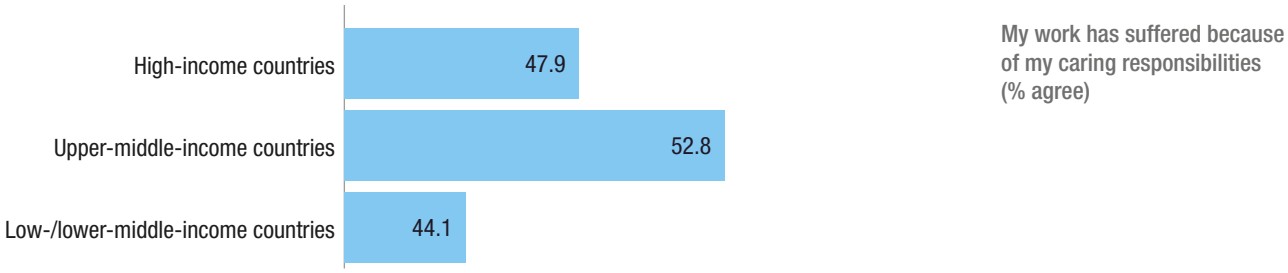
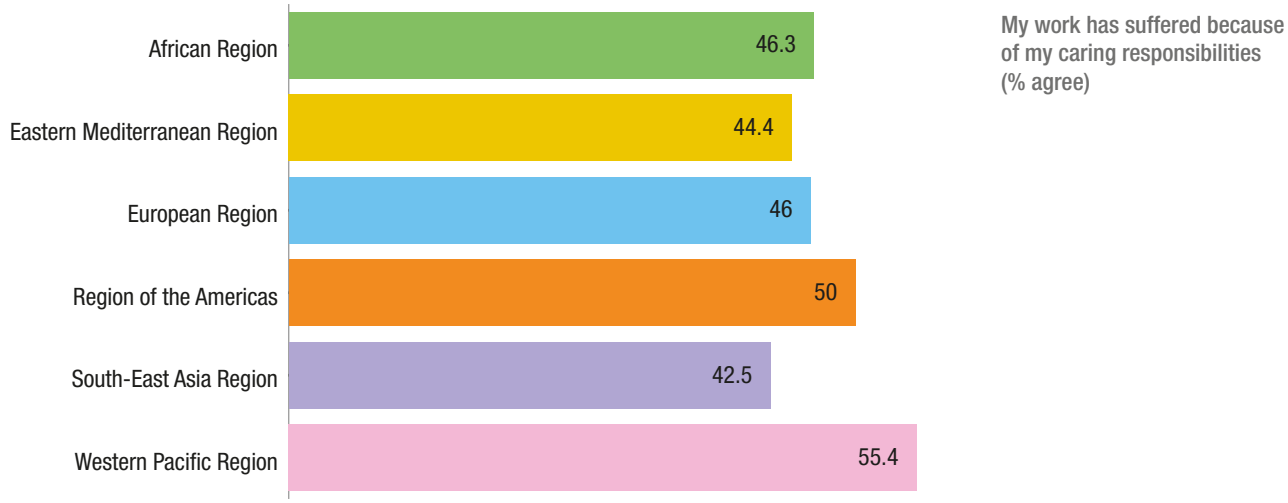


Figure 8B. Carers report of caring impact on work, by WHO Region



and older people to work, and by policies to support the employment of people with caring responsibilities.

Impact of providing care to people with dementia on social life

More than half of all carers reported that their social life had been affected by their role, the highest rates were found in upper-middle countries (64.6%) and in the African region (69.0%) and the lowest in low/lower-middle income countries (55.9%) and in the South-East Asia region (49%).

Carers' views on disclosure

Carers were asked in a separate question about the extent to which they hide the person they care for with dementia. The vast majority of carers never hide the person with dementia. There are some differences by geographical region but only small numbers responding to this question in some areas. Carers in South East Asia (16.3%) and the African Region (7.1%) are most likely to hide the person with dementia.

Carers were also asked whether they had ever concealed the diagnosis of the person they care for with dementia. 35% of carers said they had concealed the diagnosis of the person they cared for with dementia from at least one person.

Perceptions about health and care resources for people with dementia and carers

The availability of services for people with dementia may be affected by structural stigma, meaning that, because of stigma, people with dementia are disadvantaged by the health and care systems. While our survey did not set out to analyse this, it did include questions on the perceptions about the availability and adequacy of health and care resources for people with dementia and carers.

Adequate community services for people living with dementia and for carers

Just under 40% of the general public (37.8% in high-income, 37.3% in upper-middle income and 34.7% in low/lower middle-income countries) thought that there were adequate community services for people living with dementia and for carers. Healthcare practitioners and carers were slightly more likely to think there were adequate community services than the general public. There are interesting differences between countries (or territories) that do not always seem to correspond to what would be expected in terms of income levels, or levels of public spending on health and long-term care services. For example, over 50% of all three groups of

Figure 9A. Carers report of caring impact on social life, by World Bank income group

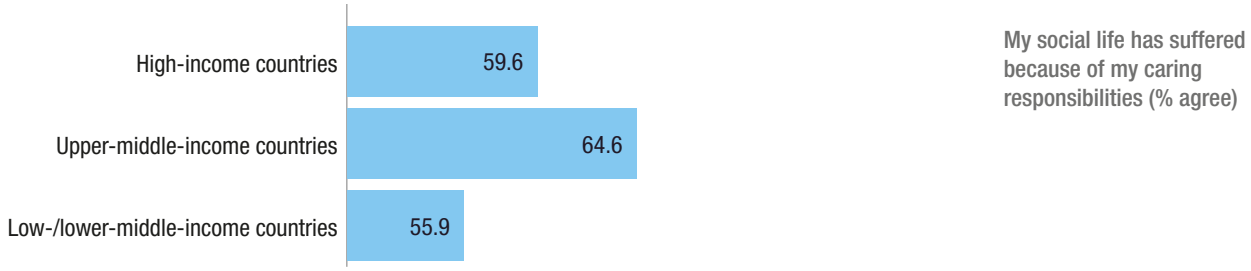


Figure 9B. Carers report of caring impact on social life, by WHO Region

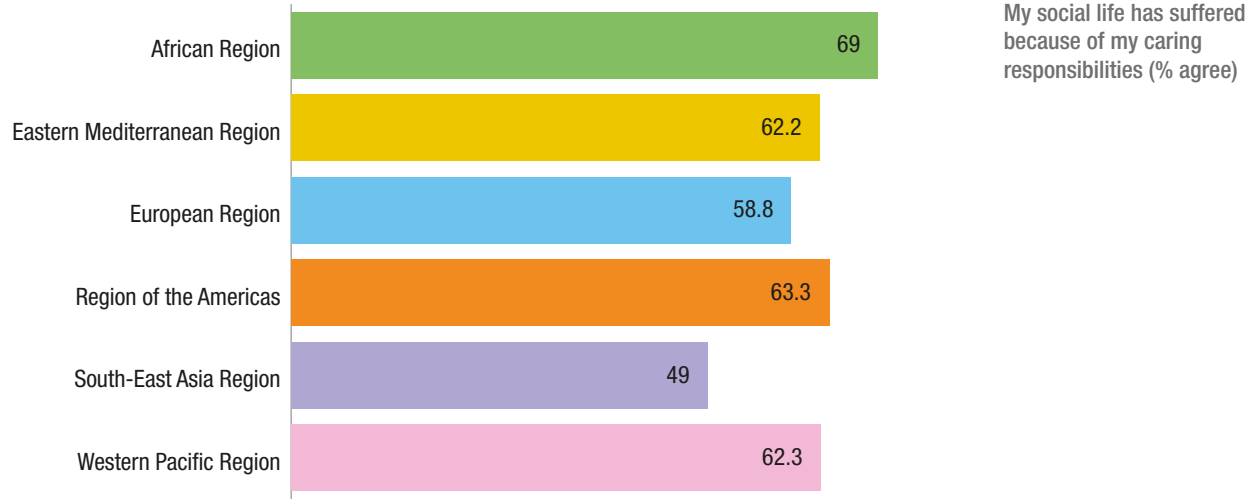


Figure 10A. Carers agreement they 'would hide the person I care for when out of the home', by World Bank income group (% agree)

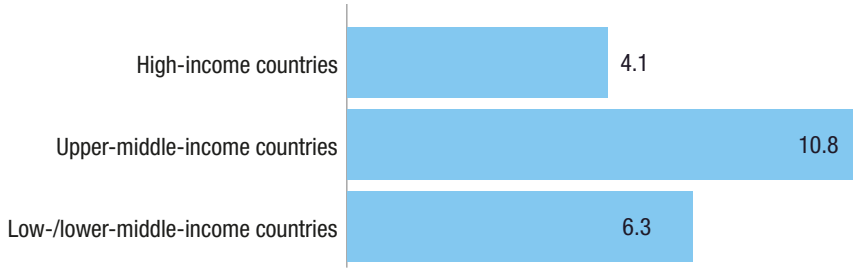
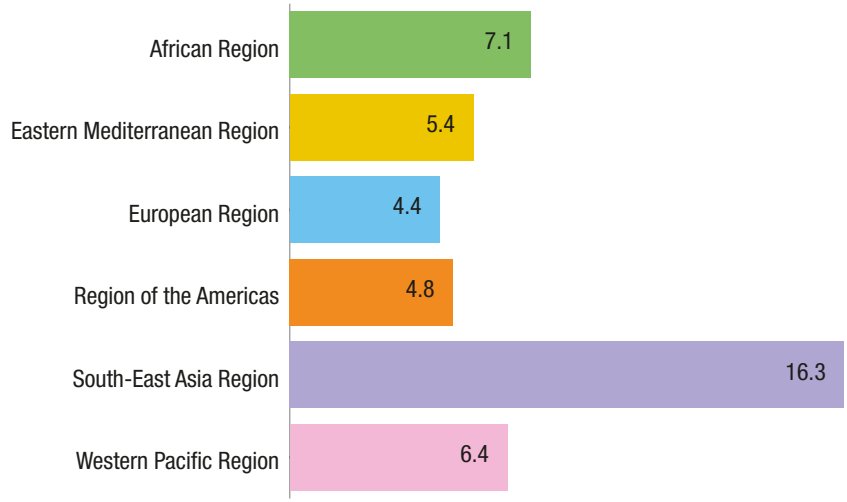


Figure 10B. Carers agreement they 'would hide the person I care for when out of the home', by WHO Region (% agree)



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respondents (general public, healthcare practitioners and carers) in China, Germany, Macau, Chinese Taipei and Vietnam thought that there are adequate services. Additionally, 50% or more of the general public also thinks there are adequate services in Chile, Iceland, Singapore, Spain and Switzerland. There are some countries (Indonesia, the Netherlands and Slovenia) where over 50% of the carers and the healthcare practitioners also think there are adequate services.

Enough competent physicians for the diagnosis and treatment of dementia

Just under 70% of the general public (71.6% in high-income, 69.9% in upper-middle income and 63.7% in low/lower middle-income countries) thought that there were enough competent physicians for the diagnosis and treatment of dementia. These rates were highest in the European and Western Pacific regions (76% in both) and lowest in the Eastern Mediterranean (44.7%) and Africa (42.9%). There were striking differences between countries too and, remarkably, in the United Kingdom (where there is a strong policy emphasis on increasing diagnostic rates), only 38.8% of carers and 53.3% of

Figure 11A. Agreement that there are adequate community services for people living with dementia, by World Bank income group (% agree)

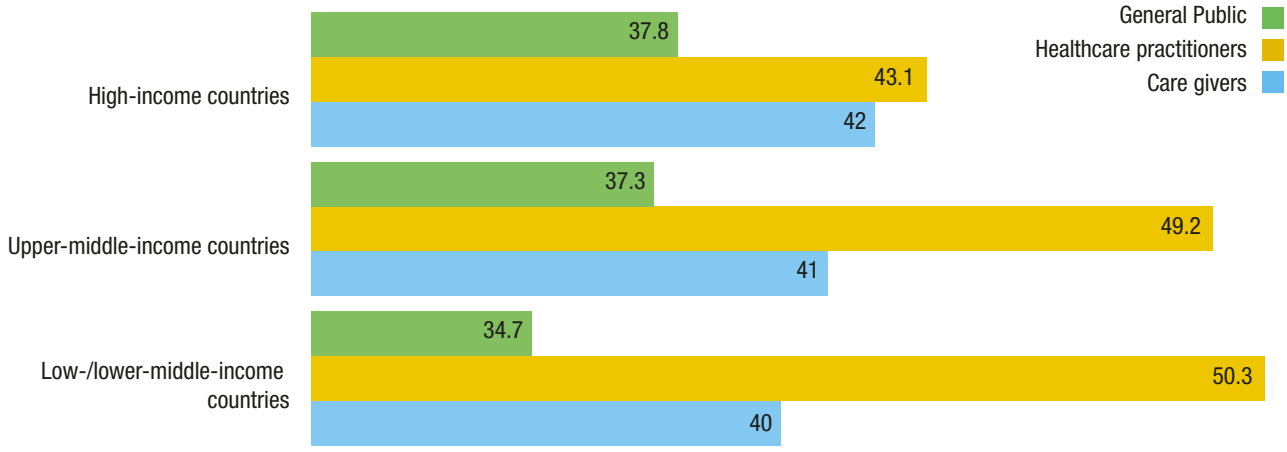


Figure 11B. Agreement that there are adequate community services for people living with dementia, by WHO Region (% agree)

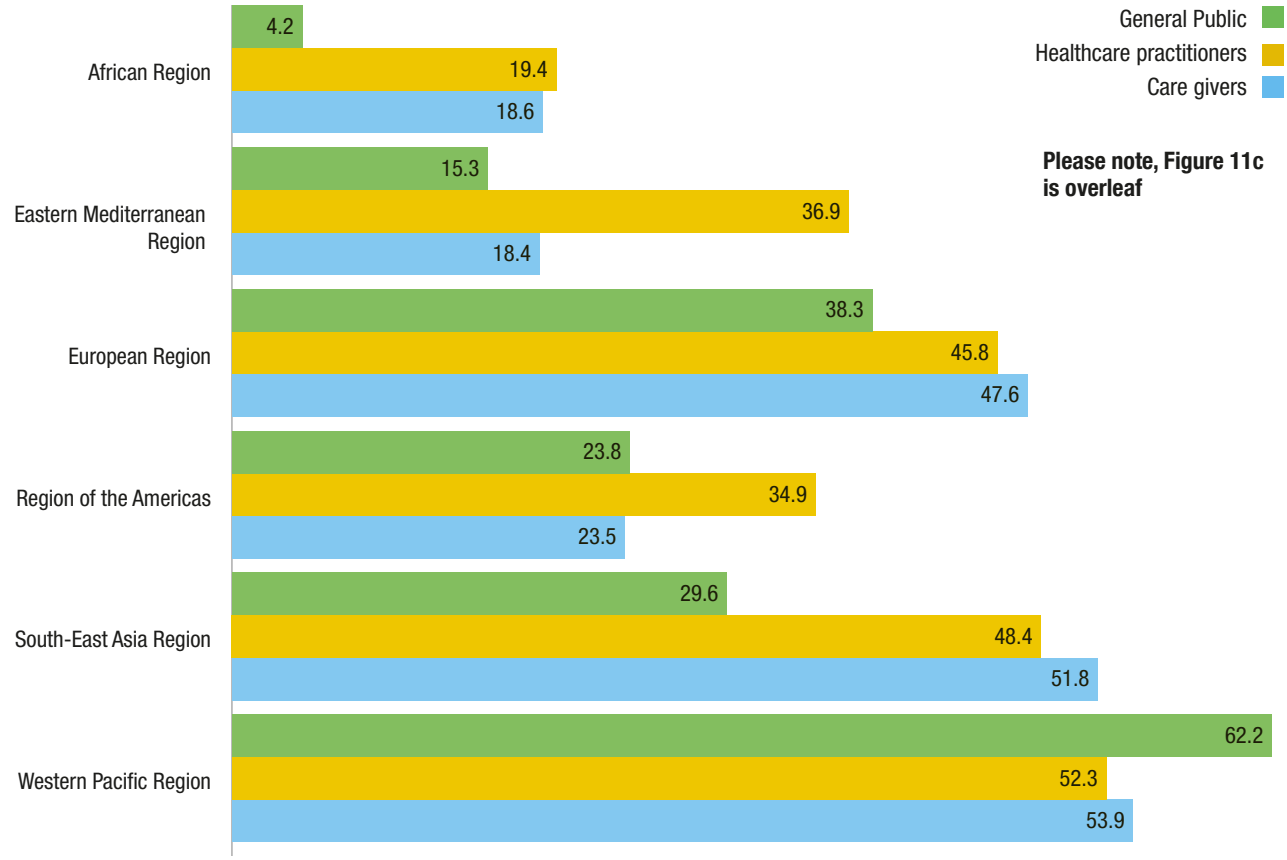


Figure 12A. Agreement that there are competent healthcare practitioners for the diagnosis and treatment of people living with dementia, by World Bank income group (% agree)

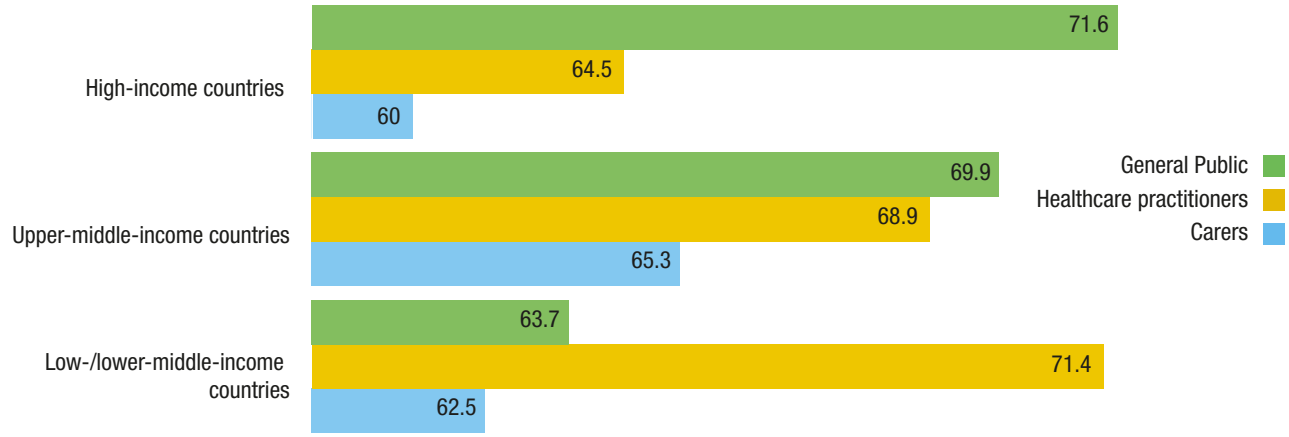
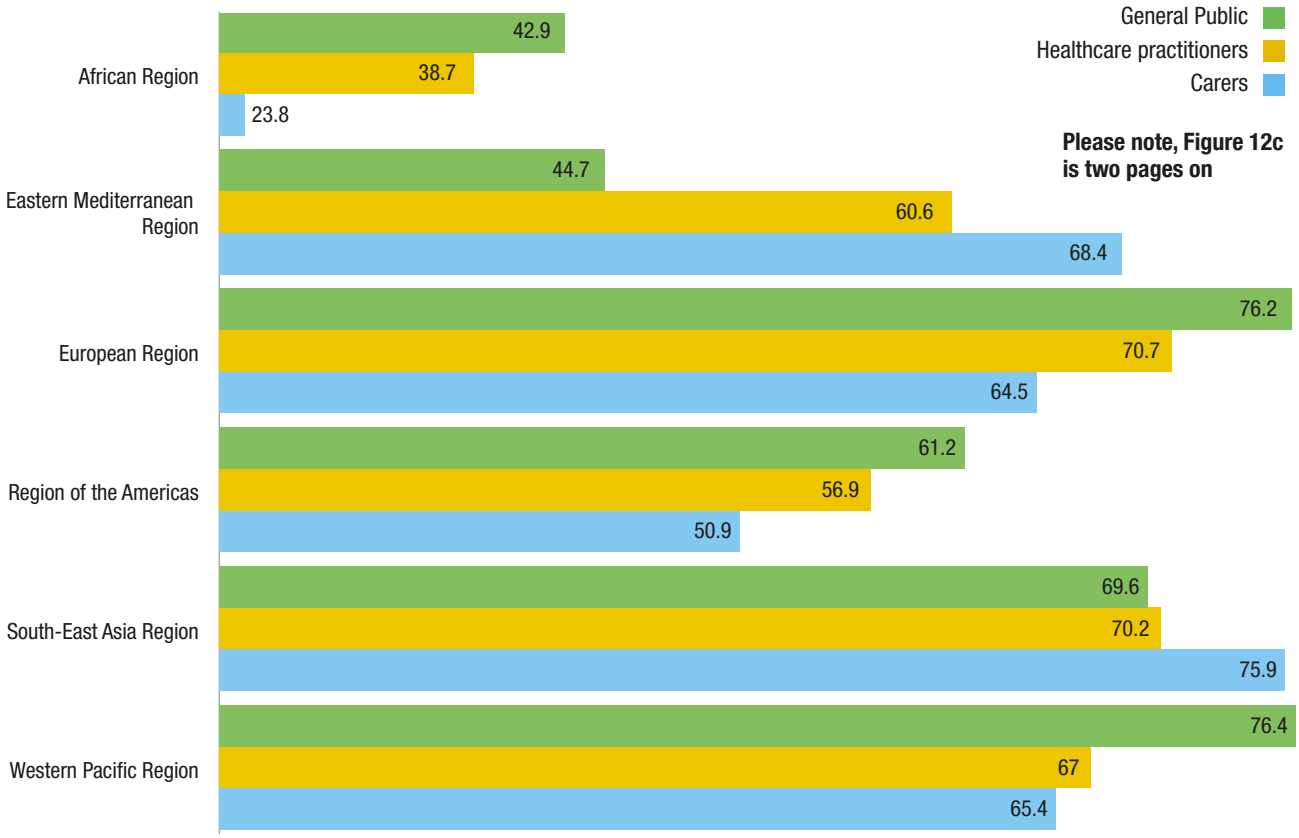


Figure 12B. Agreement that there are competent healthcare practitioners for the diagnosis and treatment of people living with dementia, by WHO Region (% agree)



healthcare practitioners thought there enough competent physicians. Other countries might have elevated views of healthcare professionals, because they have limited first-hand experience of them.

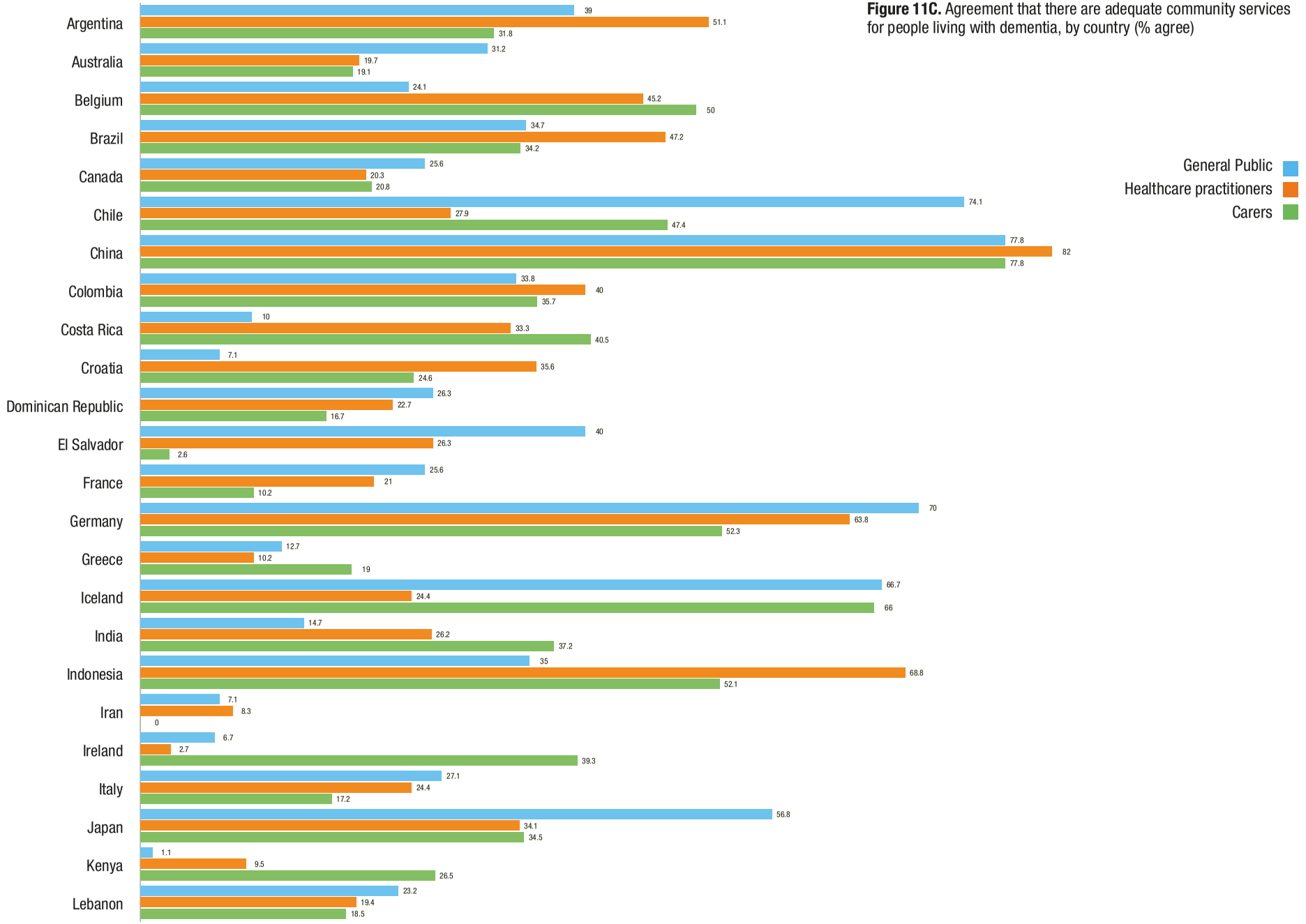
Healthcare practitioners (physicians and nurses) ignoring people with dementia

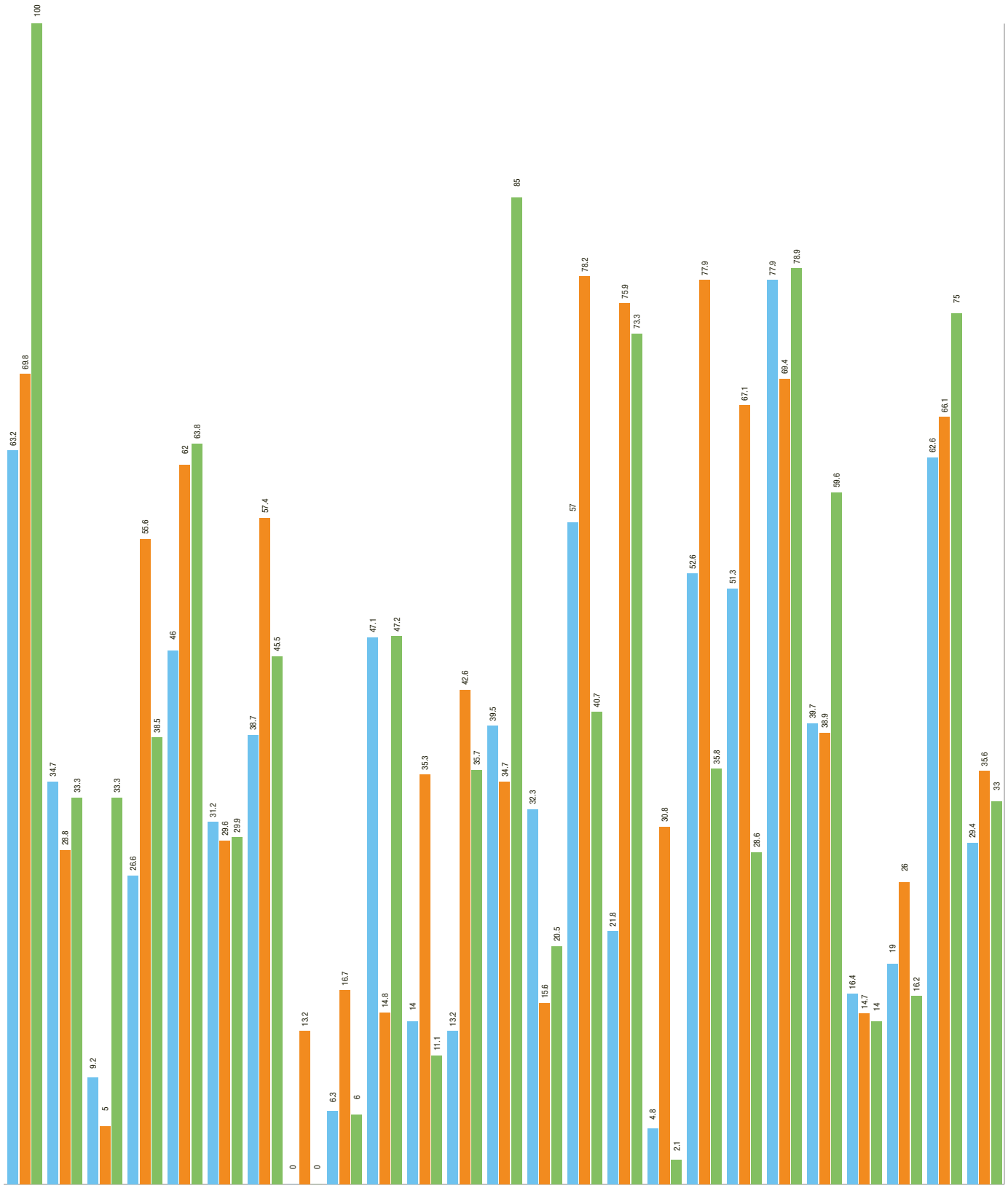
Around 40% of the general public think that healthcare practitioners (physicians and nurses) ignore people with dementia (38% in high-income, 49% in upper-middle income and 32.5% in low/lower middle-income countries). Similarly, as per the question about competence, the highest rates of thinking that healthcare practitioners ignore people with dementia were in the Eastern Mediterranean and the African regions (59% and 55.7% respectively, among the general public) and lowest in Europe (29.2%). However, there were high rates of concern (among the general public) about healthcare practitioners ignoring people with dementia in some European countries (59.3% in Iceland, 57.8% in

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Figure 11C. Agreement that there are adequate community services for people living with dementia, by country (% agree)

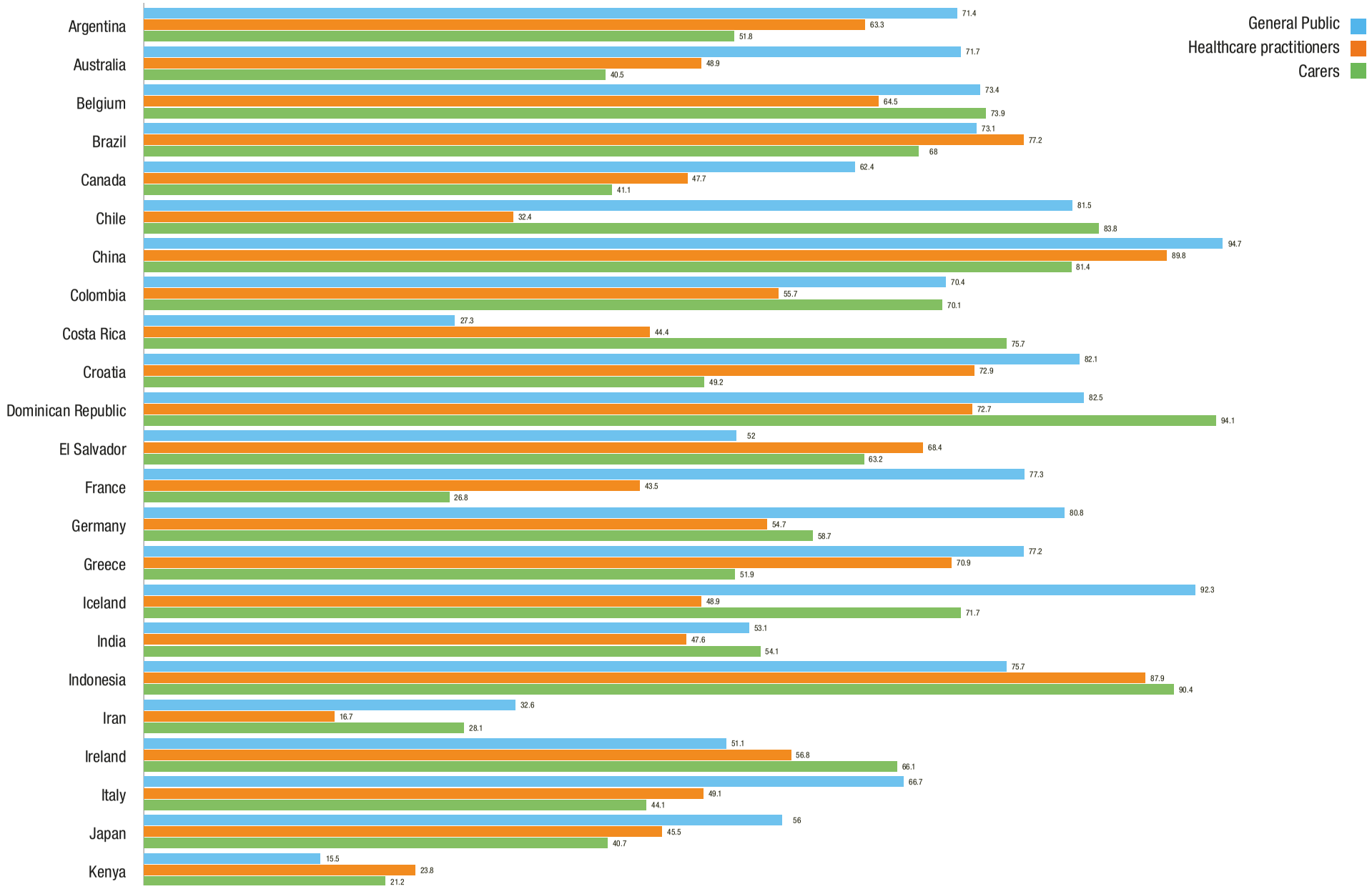


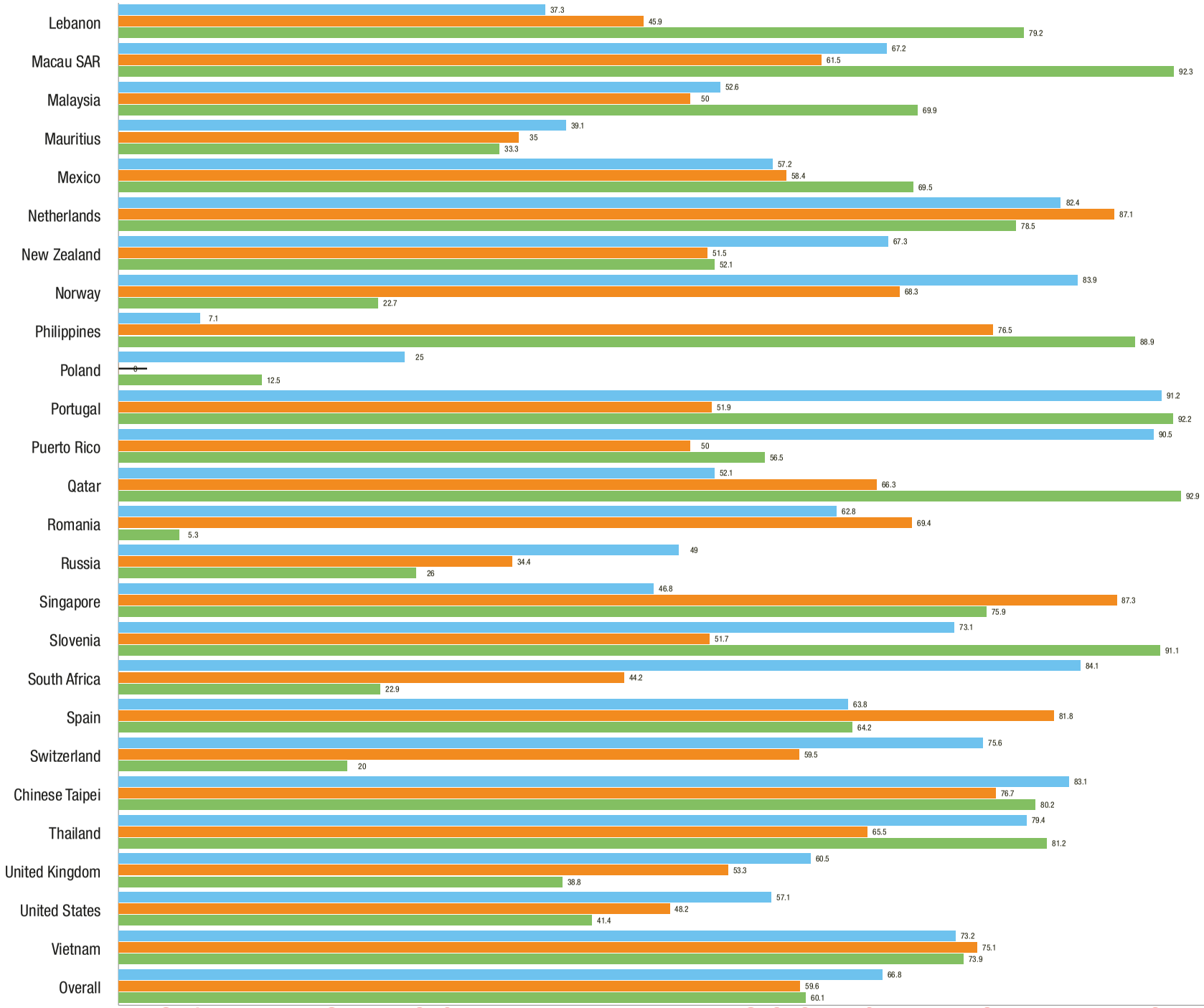


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Figure 12C. Agreement that there are competent healthcare practitioners for the diagnosis and treatment people living with dementia, by country (% agree)





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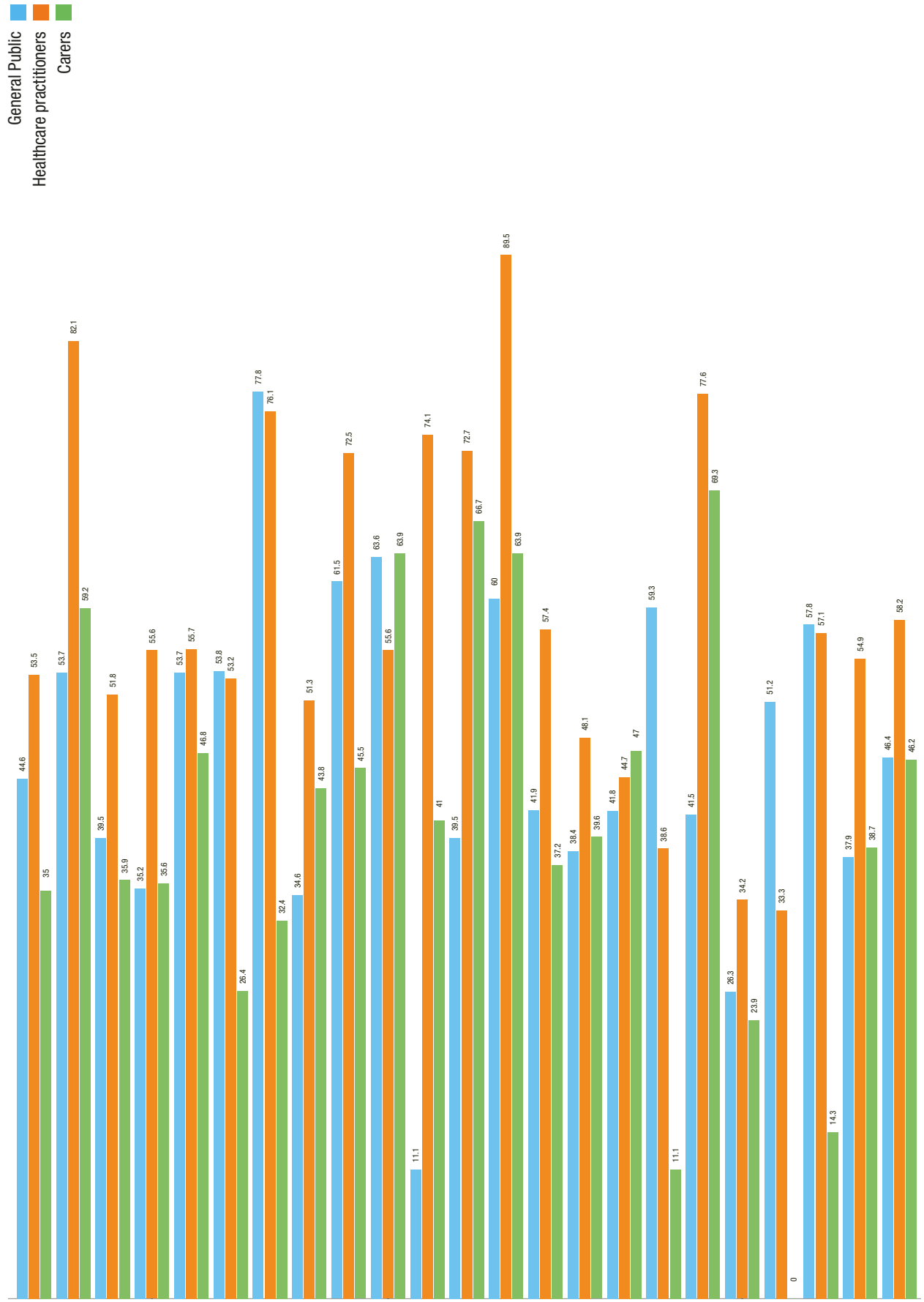
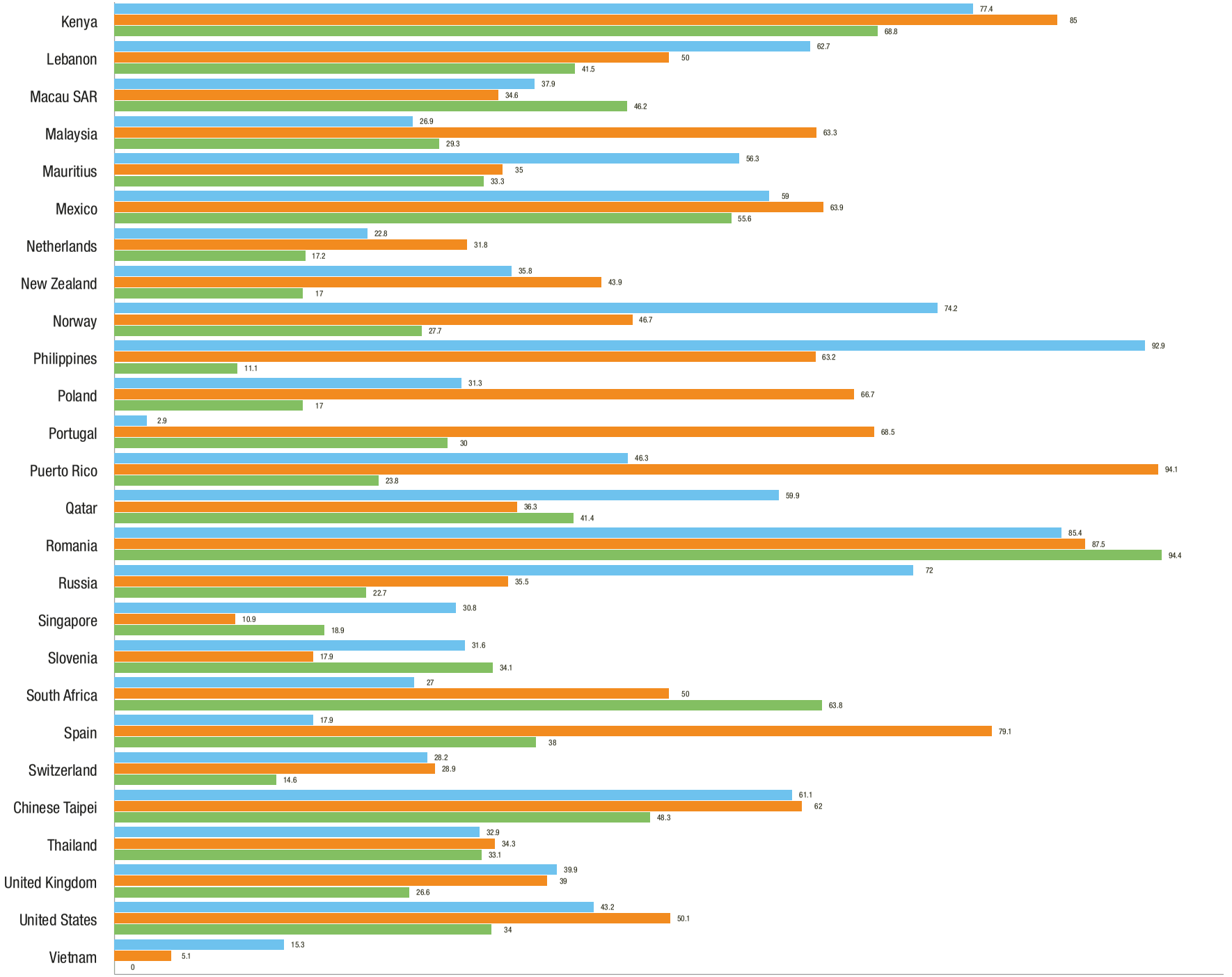


Figure 13A. Agreement that healthcare practitioners ignore the person living with dementia, by country (% agree)



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Figure 13B. Agreement that healthcare practitioners ignore the person living with dementia, by World Bank income group (% agree)

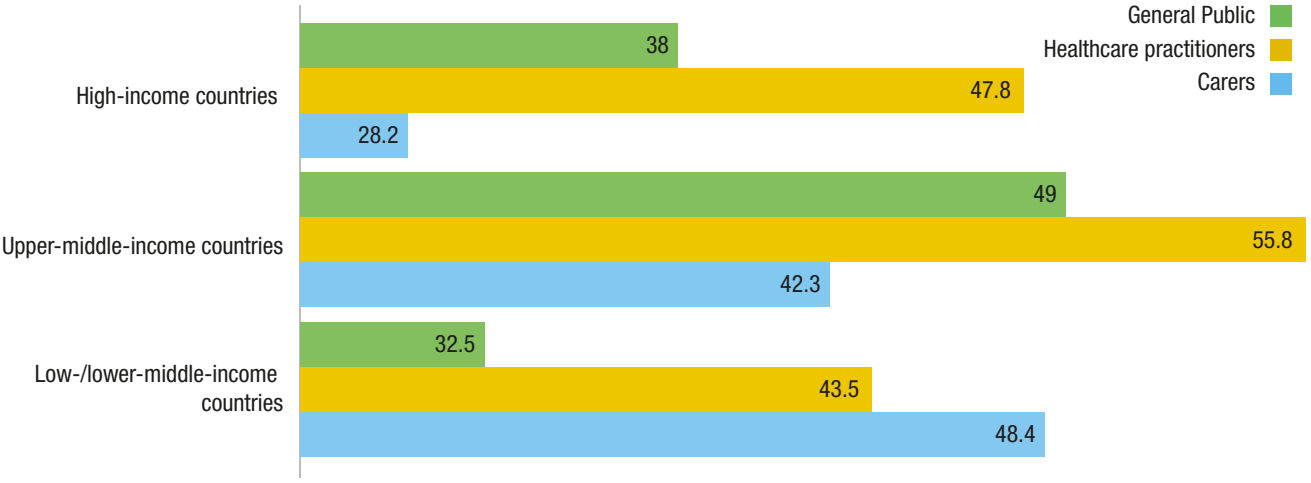
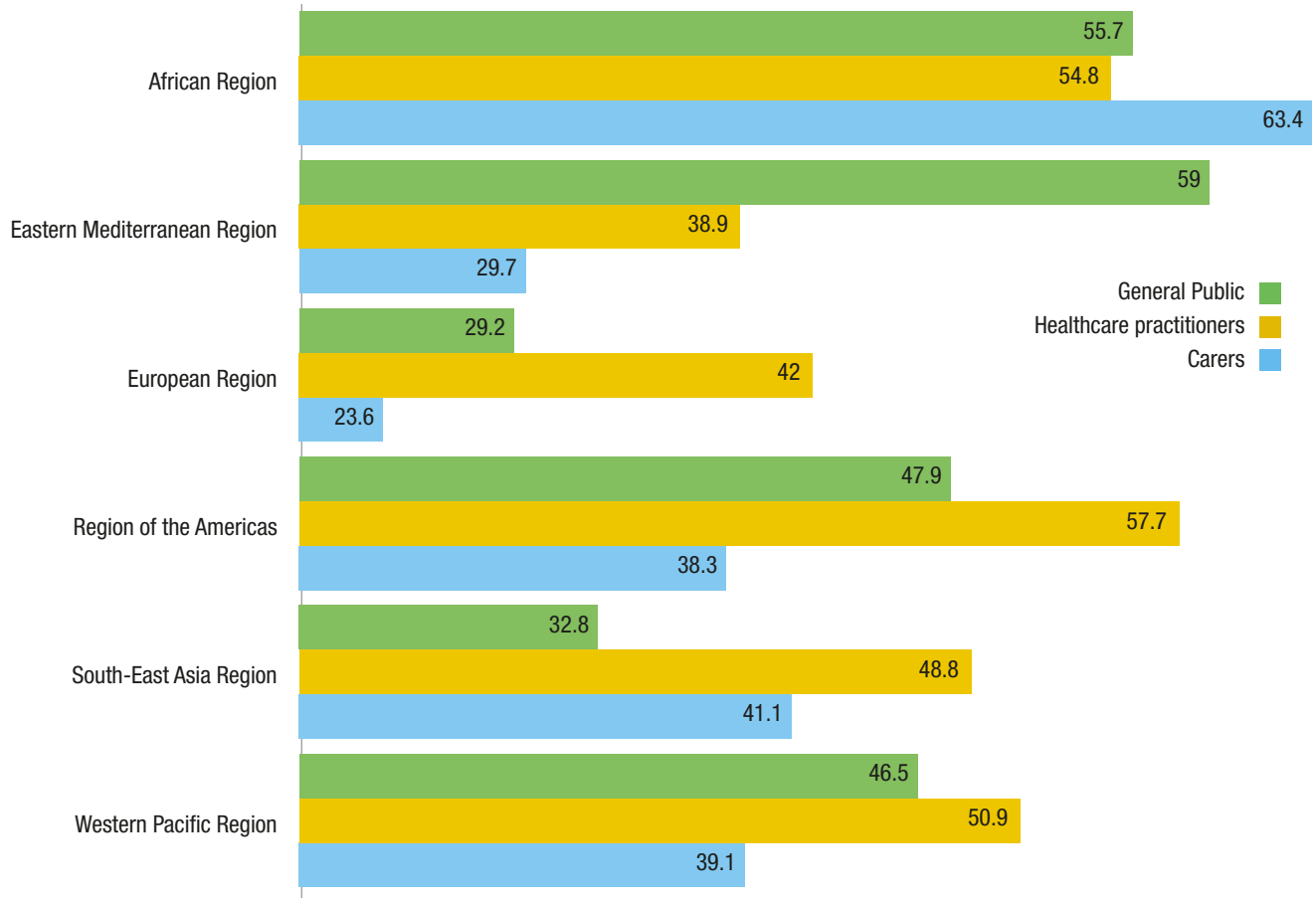


Figure 13C. Agreement that healthcare practitioners ignore the person living with dementia, by WHO Region (% agree)



Ireland, 74.2% in Norway, 85.4% in Romania and 72% in Russia).

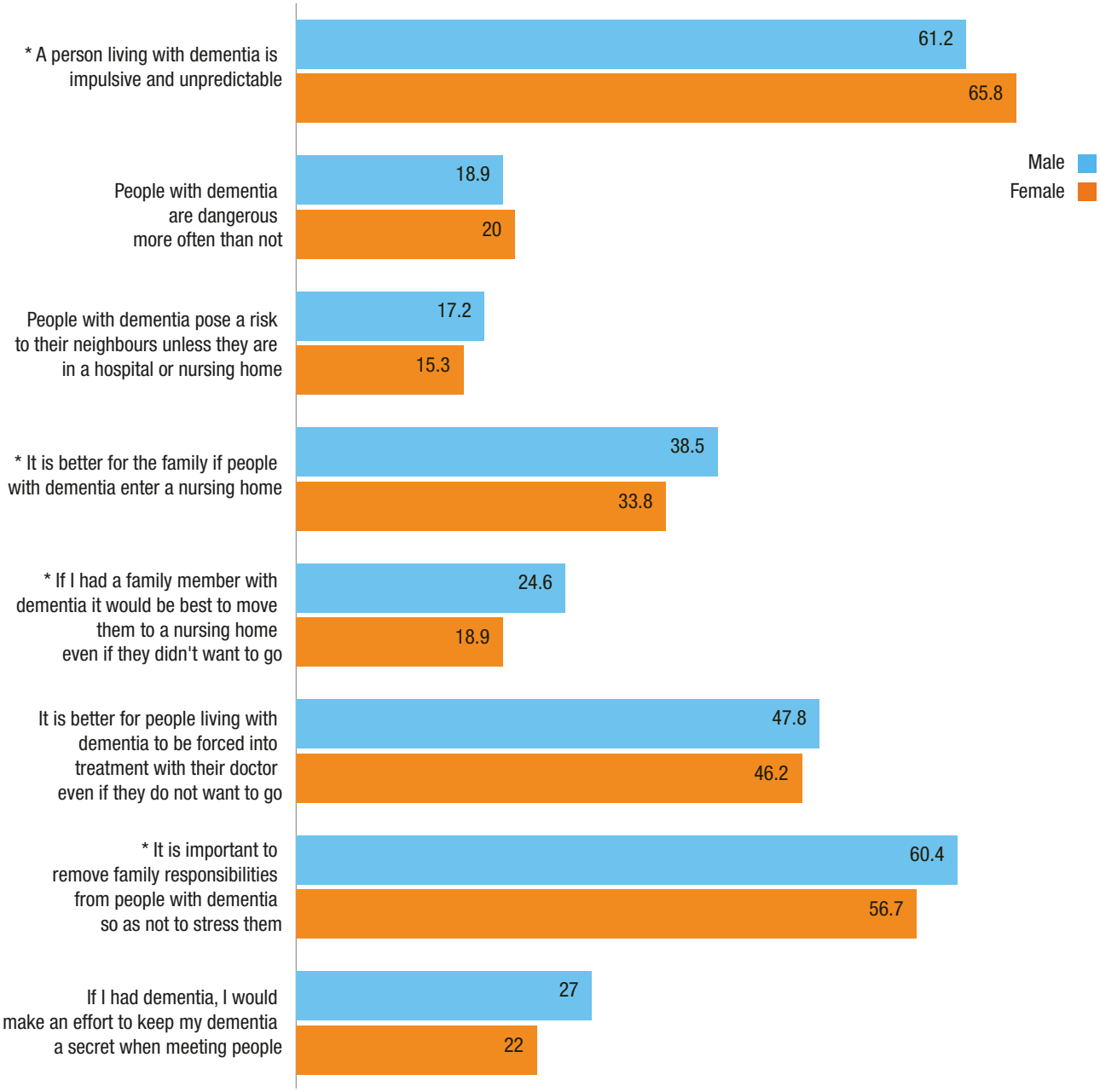
- The respondents who identified as healthcare practitioners were slightly more critical of their colleagues, with 47.8% in high-income, 55.8% in upper-middle income and 43.5% in low/lower-middle countries responding that healthcare practitioners ignore people with dementia.
- 33% of people think that if they had dementia, they would not be listened to by healthcare practitioners.

Gender differences

The majority of survey respondents (nearly 80%) were women. (See description of survey respondents, page 63). Looking at the differences[iii] in responses between male and female respondents, male

(iii) We controlled for age, education, knowing someone with dementia, country.

Figure 14. Percentage of women and men agreeing with each statement – all statements represent responses from the general public except for the first one which refers to carers only
**Indicates statistical significance*



respondents tended to be somewhat more stigmatising in their views of people living with dementia compared to female respondents. Males were more likely to think that people living with dementia were impulsive or unpredictable, that it is better for the family if the person is in a nursing home and that they should be forced into a home or forced to accept treatment. They are more likely to think family responsibilities should be removed from someone with dementia so as not to stress them, and they are more likely to want to keep dementia a secret (see Figure 14). Males are also less likely to be stressed by their caring and other responsibilities. It is possible, particularly given the suggestion above, that male respondents are less likely to be the sole or primary carer[iv].

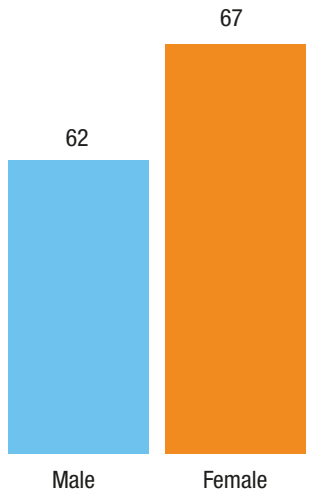
Males are less likely to say they would seek help from a healthcare practitioner if they thought they might have dementia. Males are, in fact, less likely to seek support from any of the alternative sources offered by the questionnaire (friend, family member, online/internet, healthcare practitioner or other) with one exception. Men are markedly more likely to seek help from their partner than are women. 75.5% of male respondents would seek help from their partner compared to only

(iv) Differences statistically significant at the P<.001 level.

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Figure 15. Percentage of respondents agreeing that they are 'often stressed between caring and meeting other responsibilities', by gender*
**Indicates statistical significance*



62.1% of women. People answering these questions were members of the public who have not identified as carers on the questionnaire. It may be that women are more likely than men to be acting as gatekeepers to informal and formal health and social care networks. Unfortunately, we do not have information on the marital status of respondents, so we don't know if this is due to a greater proportion of single female respondents. Given that our sample is skewed towards older ages, we looked to see if this finding held true at younger ages (when people would be less likely to be widowed). The difference remains large for under-60s (67% versus 74%) but is much smaller for under-50s (68% versus 72%). While it's possible this reflects something about marital status, it could also be that younger respondents have different gender relations which affect their answers to this question.

There was not much variation in healthcare practitioner attitudes towards people living with dementia according to gender. However, male healthcare practitioners were

Figure 16. Healthcare provider attitudes towards dementia, by gender (% agree)
**Indicates statistical significance*

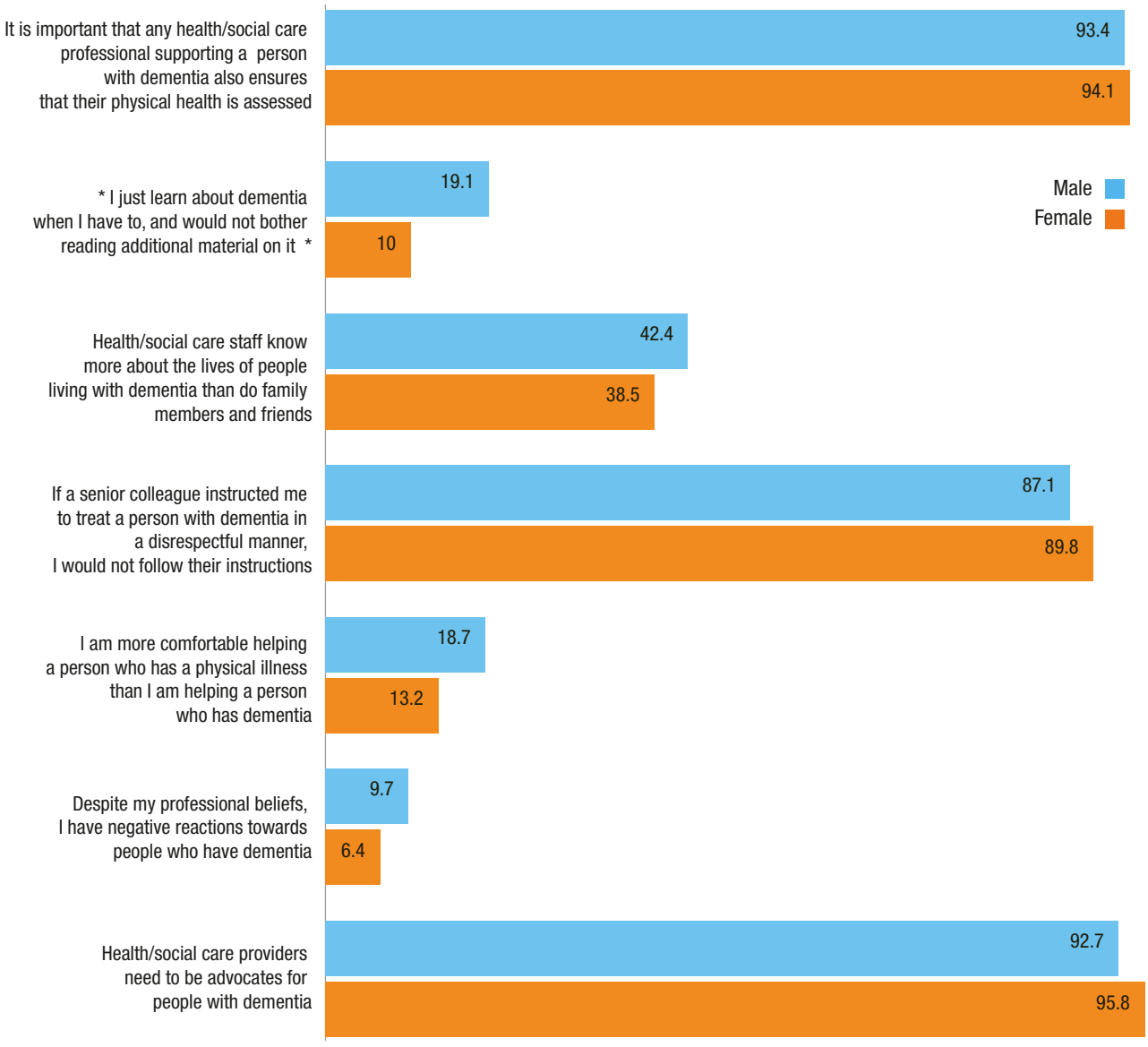
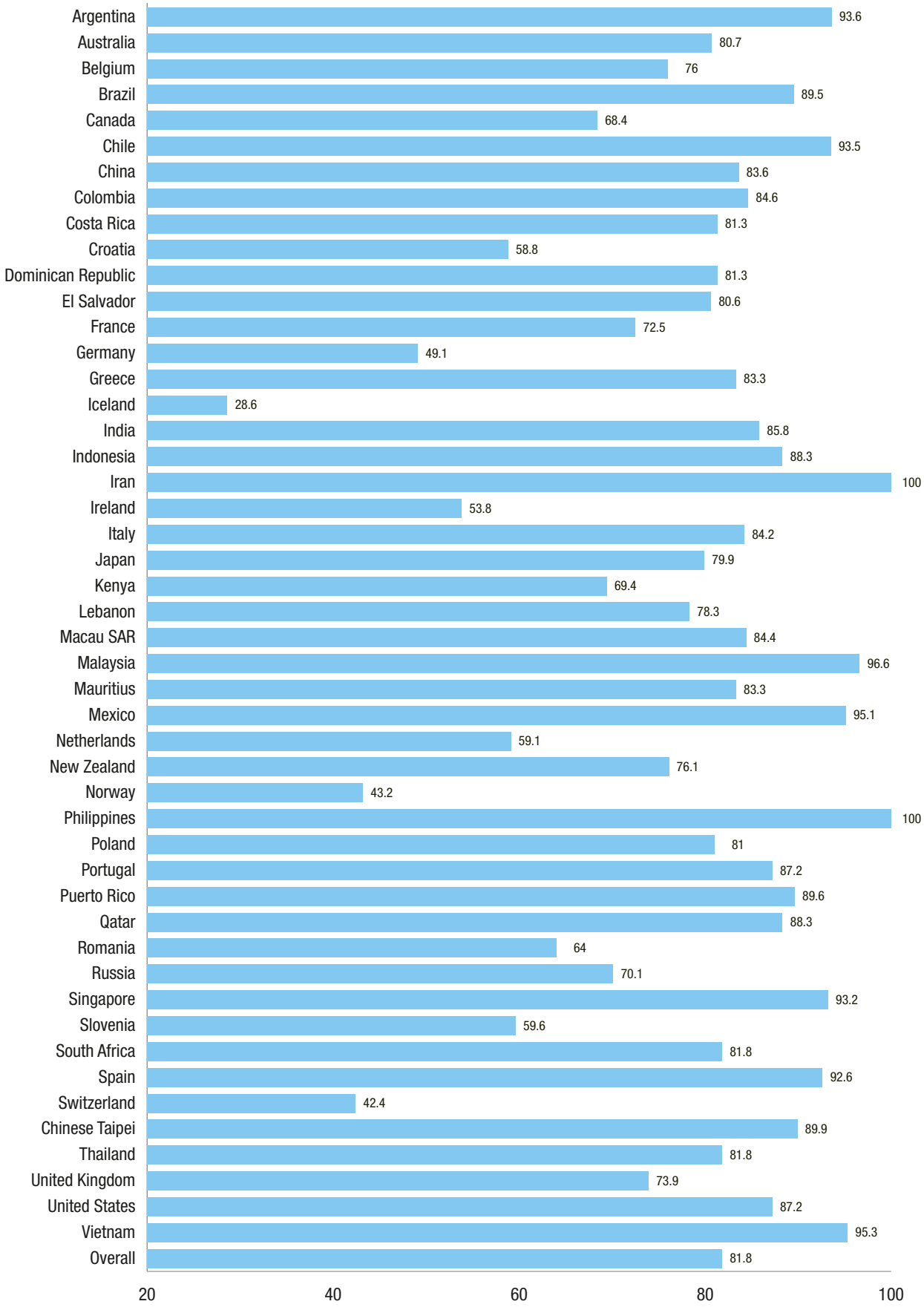


Figure 17. Agreement among the general public that 'I would take a genetic profiling test to learn whether I am at risk of developing dementia', by country (% agree)



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more likely to say they would just learn about dementia when they have to and would not bother reading additional material on it (19.1% vs. 10.0%). 18.7% of male healthcare practitioners said they agreed to feeling more comfortable helping a person who has a physical illness than helping a person who has dementia.

Attitudes

Personal risk

The vast majority of the general public think they could develop dementia at some point in their lifetime (95.2%) and are concerned about developing dementia at some point (78.2%). Although there are currently no disease modifying treatments for dementia, over two-thirds of respondents (81.8%) would take a genetic profiling test to learn whether they are at risk.

Attitudes among the general public and healthcare practitioners about people living with dementia by country income groups and regions

When comparing attitudes about people living with dementia it is important to note that, because in many parts of the world there are low rates of diagnosis, it is likely that those who are known to have dementia in areas with low diagnostic rates are at more advanced stages. This may shape the perceptions of respondents.

- All regions had over 80% agreement that people living with dementia can participate in a variety of activities.
- Overall, the people living in South-East Asia were most likely to think that people with dementia are dangerous: 45.4% of respondents said 'people living with dementia are dangerous more often than not', compared to 25.7% in the Western Pacific, 17.2% in Africa, 14.6% in Americas, 15% in the European region, and 13.9% in the Eastern Mediterranean. This is interesting considering relatively high proportions of people living in the South-East Asia region are willing to have a family member living with dementia to move in with them.
- Views among healthcare practitioners showed a similar trend and agreement that people living with dementia are dangerous: by WHO Region: South-East Asia (48.1%), Eastern Mediterranean (31%), Western Pacific (18.4%) European Region (10.5%), Americas (8.9%).
- When answering whether they agreed 'a person living with dementia is impulsive and unpredictable' by WHO Region: African Region (70.5%), South-East Asia (70.1%), Europe (68.8%), Eastern Mediterranean Region (64.5%), Americas (62%), Western Pacific Region (49.5%).
- The majority of respondents felt it was important to remove responsibilities of people living with dementia as it might stress them. Agreement tended to be lower among carers (47.5%) compared to the general public (60%). In terms of region, those among the general public in the African region had the highest agreement (72.1%) followed by Europe (71.2%), Eastern Mediterranean Region (57.1%), Western Pacific Region (54.8%), Americas (46.6%) and South-East Asia (38.1%).
- This is interesting given that many of the experiences of discrimination reported by people living with dementia pertain to loss of status and loss of roles (See section below on experiences of discrimination among people living with dementia).

Attitudes about treatment for people living with dementia

Results suggest that people living in high income countries are more likely to agree that people living with dementia should be moved into a nursing home even if they don't want to go (25%). This is higher than those living in upper middle-income (14.6%) or low / lower-middle income countries (8.6%). Respondents were also more likely to force someone living with dementia to a nursing home if it was not a member of their family.

When looking at the WHO Regions, the European Region had the highest proportion of respondents agreeing that 'If I had a family member with dementia it would be best to move them into a nursing home even if they didn't want to go (27.5%) compared to Western Pacific Region (22.7%), the Americas (17.5%), Africa (16.3%), Eastern Mediterranean Region (11.4%), South-East Asia (11.2%). There are important differences, worldwide, in both the availability of nursing homes and cultural and religious beliefs that may influence these attitudes. It is interesting that people living in South-East Asia had the lowest number agreeing that people living with dementia should be moved into a nursing home even if they didn't want to go and that they should have responsibilities removed from them; however, they had the highest feelings of fear because people living with dementia are dangerous.

Knowledge

Knowledge and causal attribution of dementia

- The vast majority of the general public think that dementia has biological roots, for example agreeing that dementia is in part a brain disease (93.7%), that it is due to a head or brain injury (71.3%) or is due to APOE[v] (87.5%)
- Significantly fewer respondents think that lifestyle factors play any part in the development of dementia, for example due to an unhealthy lifestyle (54.5%) or lack of family support (26%)

(v) Apolipoprotein e (APOE) is a gene which is associated with a higher risk of developing Alzheimer's disease.

Figure 18A. Attitudes among the general public towards people living with dementia by World Bank income group (% agree)

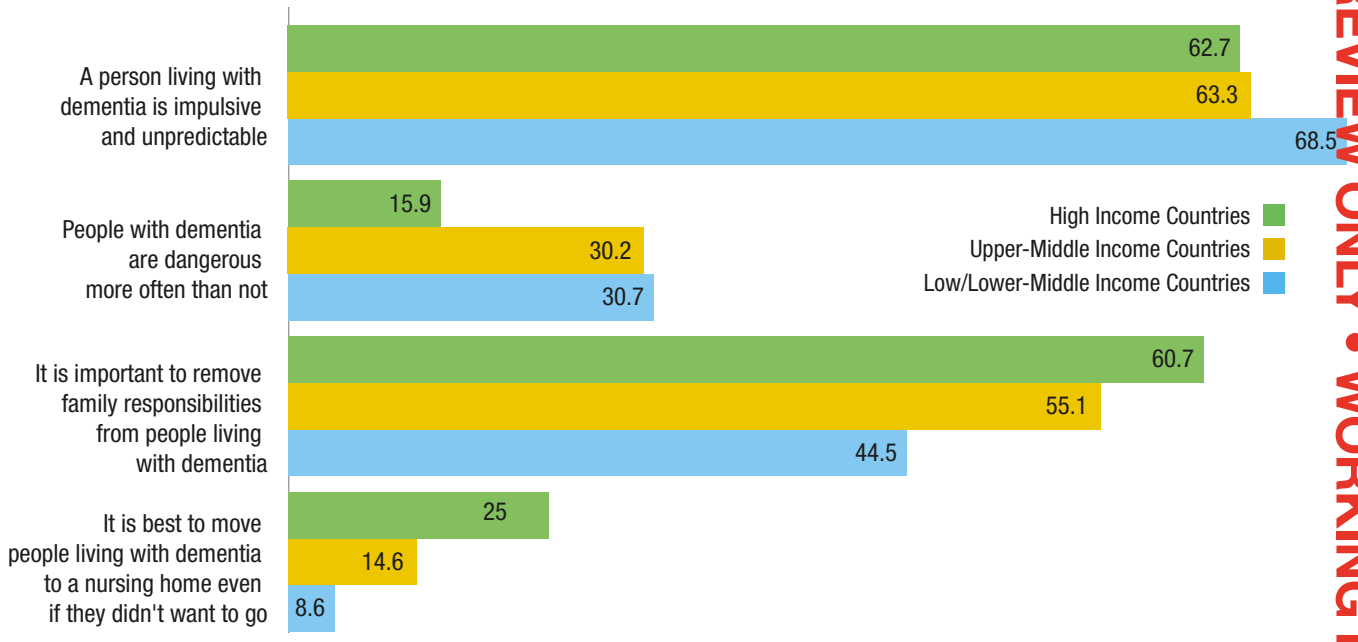
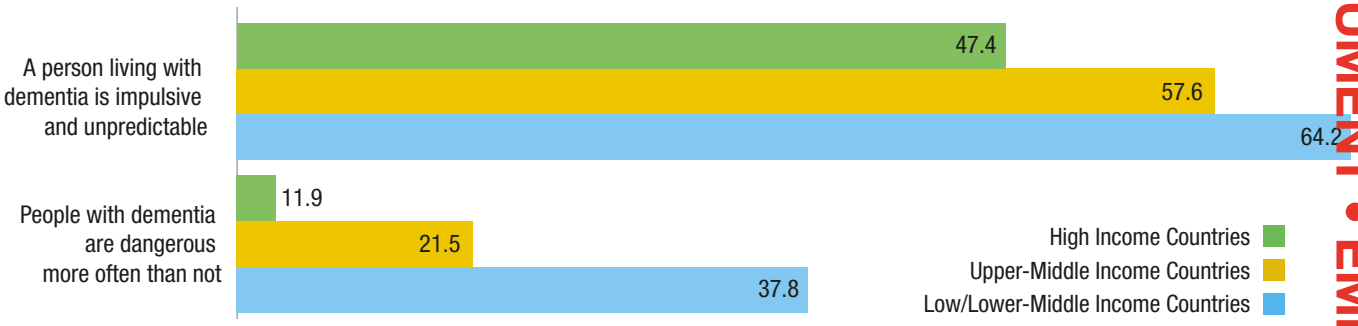


Figure 18B. Attitudes among healthcare practitioners towards people living with dementia by World Bank income group (% agree)



- More than two-thirds of respondents still feel that dementia is caused by normal ageing (70.1%). This is an important result considering global awareness raising efforts which position dementia as not being a natural part of ageing, and this area is explored further in the expert essays and case studies later in the report.
- More than one-fifth of people think that dementia is a result of external forces like bad luck (21.7 %), God's will (8.7%) or witchcraft (1.9%). Witchcraft and being "bewitched" are considered in a number of the report case studies, looking at how such beliefs impact on seeking out information, advice, treatment and support.
- Carers (60.6%) were less likely than the general public to agree that dementia is part of normal aging. Although less likely than the general public, almost 62% of healthcare practitioners that responded to the survey feel that dementia is part of normal ageing. This opens up for discussion the need for increased levels of awareness and training amongst healthcare practitioners and perhaps the figure is exacerbated by the fact there have been no disease modifying treatment breakthroughs for over 15 years and the current medical treatments available have limited long-term effectiveness.

Knowledge of treatment and risk factors

- The vast majority of the general public think that it is useful to receive a formal diagnosis (88.1%).
- The vast majority of respondents from the general public also think that people living with dementia can enjoy life (87%) and that there are things we can do to improve the lives of people with dementia (90%). For example, most people think that a person with dementia's situation is likely to improve with social support (79.3%) and that people with a healthy lifestyle have a lower risk of dementia (64.3%).
- However, almost half think that a person with dementia's memory will never improve even with medical treatment (47.9%).
- About a quarter (25.2%) think that there is nothing

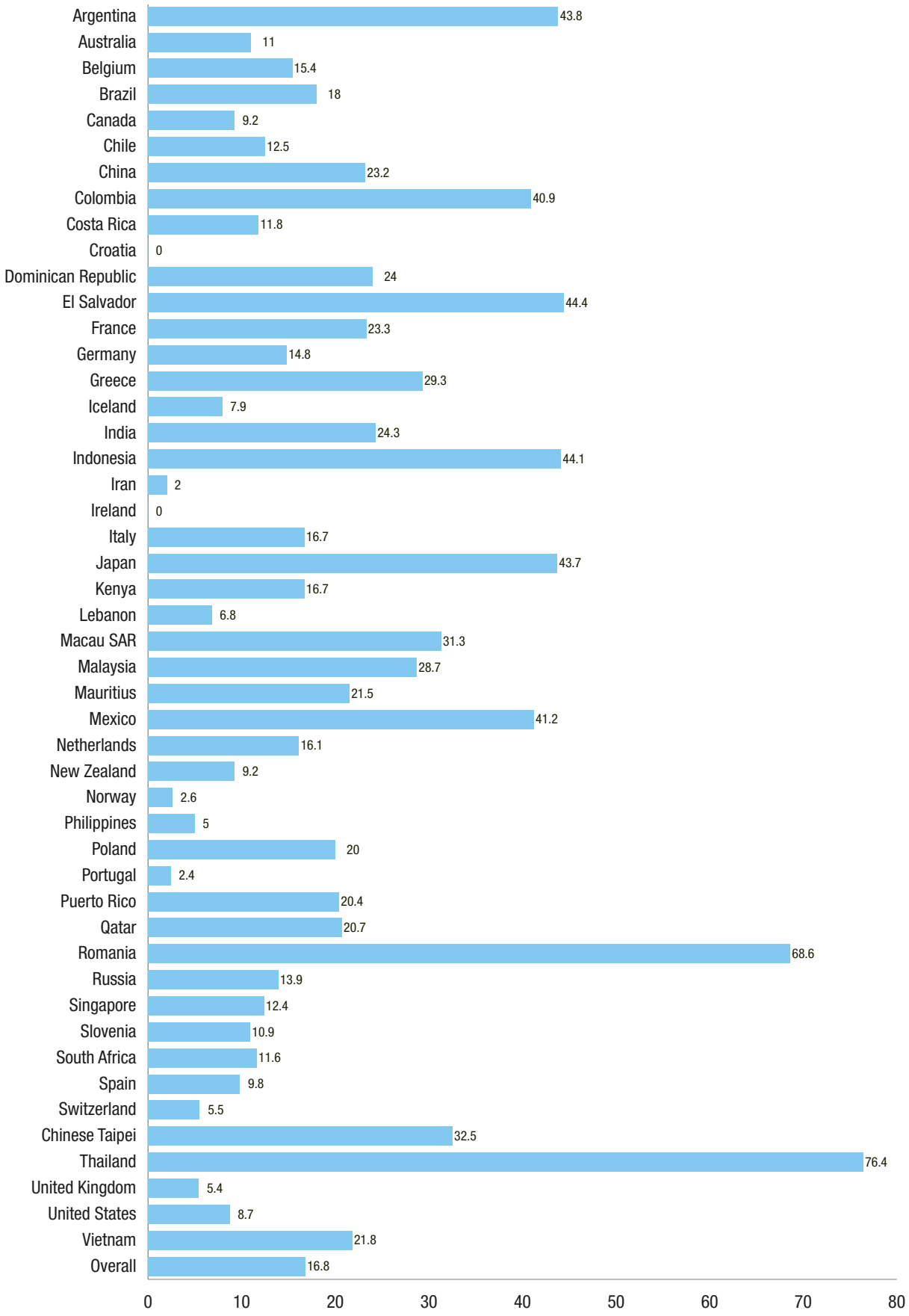
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Figure 18C. Attitudes among the general public towards people living with dementia by WHO Region (% agree)

Figure 19. Attitudes among healthcare practitioners towards people living with dementia by WHO Region (% agree)

Figure 20. Agreement among the general public that people with dementia are perceived as dangerous, by country (% agree)



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Figure 21. Agreement among healthcare practitioners that people with dementia are perceived as dangerous, by country (% agree)

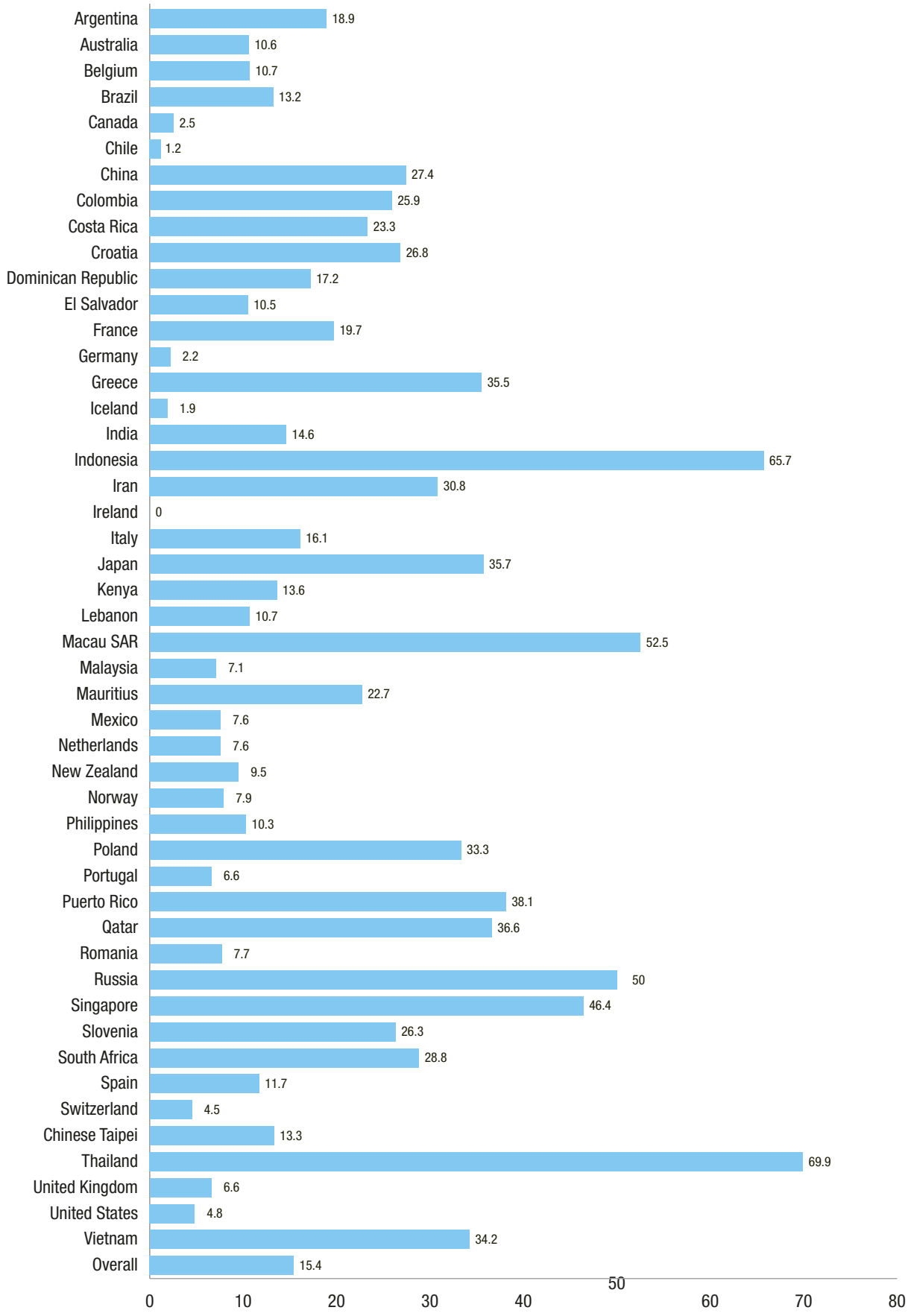
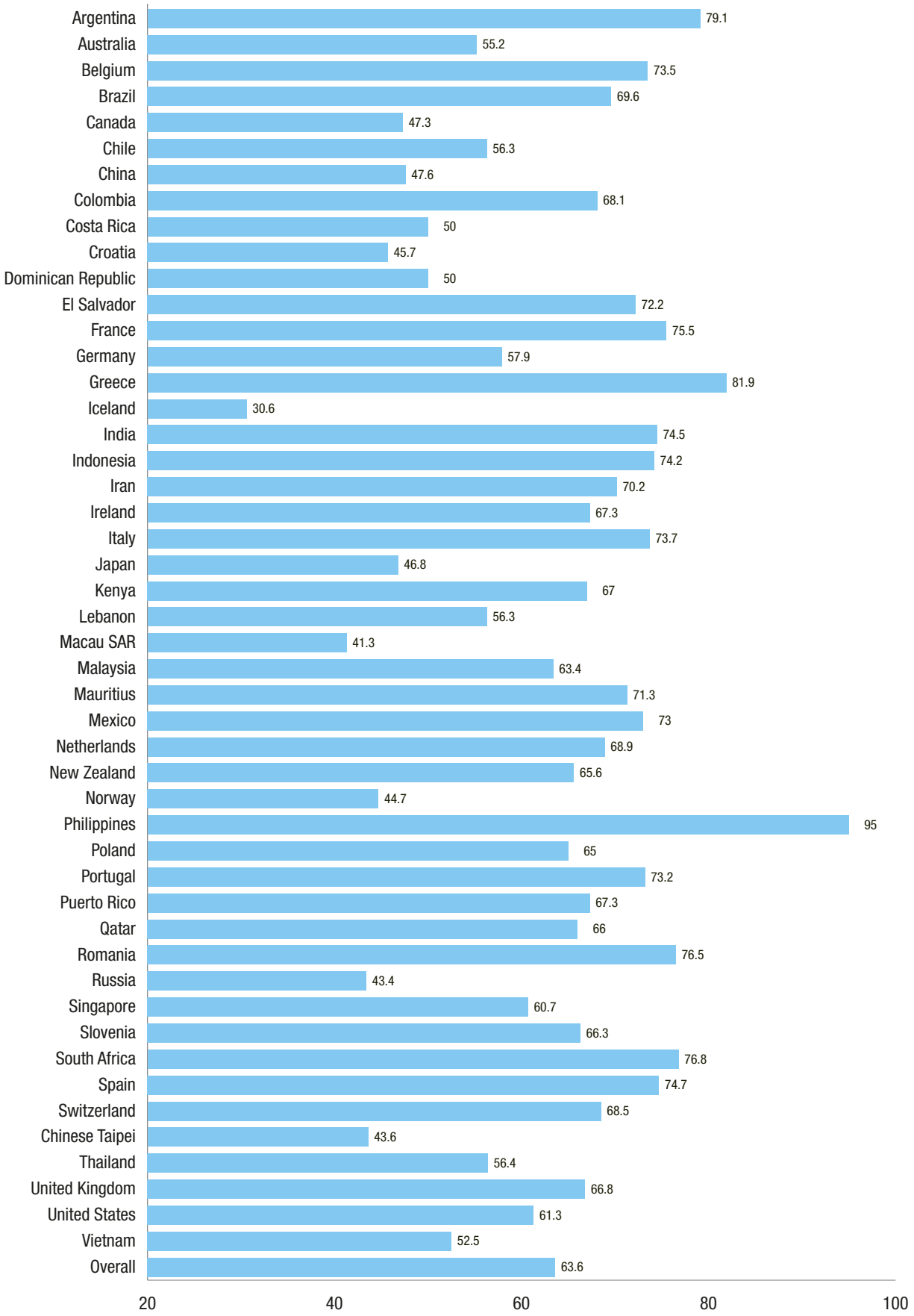


Figure 22. Agreement among the general public that people living with dementia are impulsive and unpredictable, by country (% agree)



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Figure 23. People living with dementia are / the person I care for is a good source of knowledge (% agree)

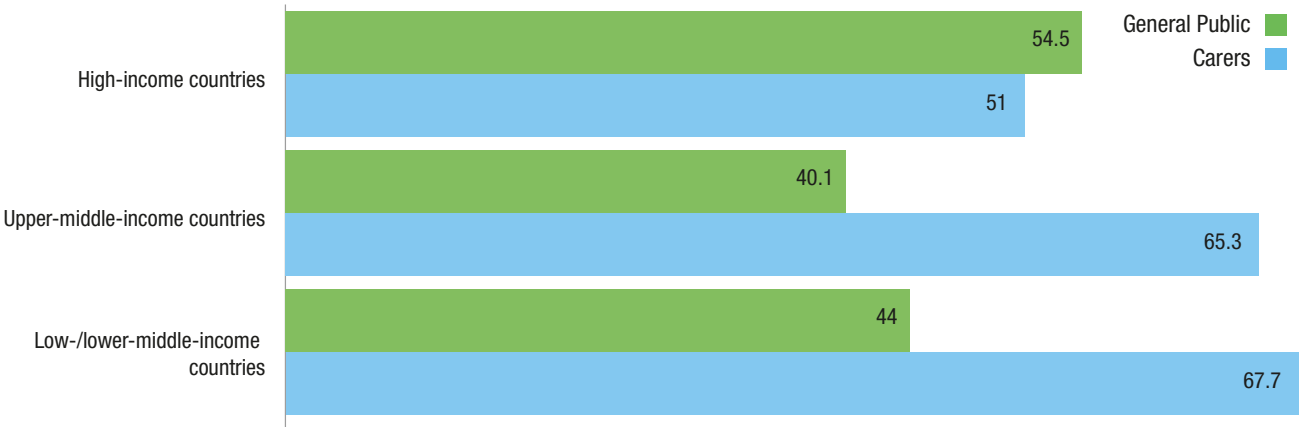
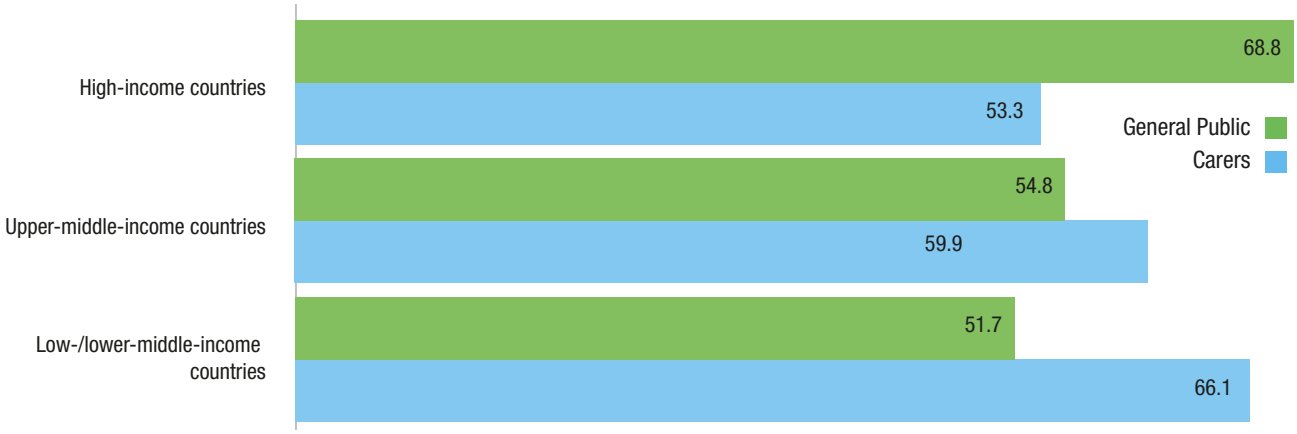


Figure 24. People living with dementia / the person I care for can pass on valued traditions (% agree)



we can do to prevent dementia. This presents an important opportunity for public health interventions as there are actions we can take to reduce the risk of developing dementia. The WHO dementia risk reduction guidelines published in 2019 strongly recommend public health interventions to help people cease smoking, increase physical activity, treat high blood pressure and manage diabetes. It also recommended interventions to manage cholesterol, hearing loss, depression, weight and diet, as well as interventions that reduce harmful drinking, enable social activity and provide cognitive training.

Consequences of stigma and discrimination for people living with dementia

As we collected data from people living with dementia, this provided an opportunity to directly link public views of people living with dementia to experiences of people living with dementia. As respondents came from a number of diverse countries, this allowed us to examine whether living in a country with a higher level of stigma was associated with lower wellbeing, quality of life, concealment of dementia and reported experienced stigma among people living with dementia. We also looked at how individual factors (age, gender and education) were related to outcomes for people living with dementia.

Findings suggest public attitudes and behaviour are associated with consequences for people living with dementia.

- At the individual level females living with dementia and those with university education had higher levels of wellbeing. At the country level, those living in a country where the public felt more embarrassed going out with a friend or relative with dementia or where the public felt it is important to remove family responsibilities from people living with dementia had lower levels of wellbeing.
- At the individual level females living with dementia had lower levels of self-esteem. At the country level, individuals living with dementia who resided in a country where the public felt more embarrassed going out with a friend or relative with dementia had lower self-esteem.
- At the individual level females living with dementia were less likely to conceal their dementia. At the country level, those living with dementia who resided

in a country where healthcare practitioner felt as comfortable talking to a person with dementia as talking to a person with physical illness, were also less likely to conceal their dementia.

- At the individual level females living with dementia reported experiencing greater impact of stigma, while those with university education reported less impact. At a country level those living in a country where the public felt it is important to remove family responsibilities from people living with dementia reported lower levels of stigma impact.

Quotations provided by people living with dementia

Respondents living with dementia were given the opportunity to write about their experiences of interacting with others in society. Many quotes illustrate discrimination and feelings of having been pushed out by friends or avoided. Several respondents refer to being discriminated against, or excluded, by their own family:

I call it the friendship divorce. I have lost a fair amount of people in my life that at one time considered friends.

Many have told me they are not at all interested in 'the dementia journey'

People avoid you because they're not sure what to say.

Shunned by hundreds in my home town. People would sooner have stage 4 breast cancer than my diagnosis. Couldn't look me in the eye

A limited number of long time friends have shied away since my diagnosis. They will send Birthday, Christmas cards but no phone calls or offers to get together.

Comments reveal perceived discomfort of others, or sweeping assumptions about capabilities:

Some friends don't like to talk to me because I repeat

I have a few people say don't talk to her she has no idea what she is talking about

A friend thought I could not cope with things and felt I should not be out of the house. We had words over it and we really haven't spoken much since. I think I have found my true friends and that's all I need.

People experience low levels of tolerance for some behaviours:

When I make statements that are out of character some friends and family have taken it personally and stopped talking to me.

Additional comments and quotations can be found in the extended, technical version of this report.

Methodology

Overall Methodology

These findings come from a survey of almost 70,000 individuals from 155 countries or territories. 66% of participants completed the survey in a non-English language.

The aim of the survey was to understand people's stigma-related knowledge, attitudes and experiences in relation to people living with dementia and questions were tailored to capture overarching knowledge, attitudes, behaviours and experiences. Respondents were asked to self-identify among four groups: people living with dementia, their family and/or carers, healthcare practitioners and the general public. Tailoring and dividing the survey into four target groups enabled us to compare findings across groups but also understand the specific experiences of certain groups.

In this report, we describe and discuss the results at a global and sometimes regional level, with some country level comparisons. More country level data and comparison can be found in the online technical report and appendix. We chose to group countries according to two methodologies: (1) by WHO Region (i.e., geographical locations) and (2) by World Bank income groups. By using these two categories, we aimed to capture cultural and economic differences. In addition, selected questions are presented by individual countries with at least 100 respondents.

How we developed the stigma survey questions

We selected several questions for each of the four target groups based on previous surveys and a review of the academic literature (research papers). We conceptualised stigma as covering three domains: (1) knowledge and causal attribution of dementia, (2) attitudes and beliefs about people living with dementia and (3) behaviour towards persons living with dementia and their carers.

Targeting these key domains, we developed tailored questionnaires for the four groups of respondents. We aimed for overlap in questions between these four groups where possible, but also included questions specific to each group.

The questionnaires were developed through a rapid review of previous work on stigma in dementia. Based on relevant studies, we first identified constructs which were reported as important for people living with dementia or their carers. For qualitative studies, these were themes that emerged as key aspects of stigma experiences or knowledge, attitudes or beliefs reported as important among study participants (e.g. patronising behaviour by family members of people living with dementia). For quantitative studies, these would typically represent any knowledge, attitudes or behaviour which were significantly associated with quality of life, functioning

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or well-being outcomes among people with dementia or their carers or key stigma outcomes (for example, proportion of people living with dementia experiencing stigma). In parallel, we reviewed the literature for stigma related dementia items, including all items from studies included in a recently published systematic review of the literature[3]. We also adapted items related to the stigma of mental illness from a recent global survey which incorporated a comprehensive review of stigma items and domains to people living with dementia [4]. All identified items were then mapped onto the identified constructs and further categorised into the three stigma domains (knowledge and attribution; attitudes and beliefs; behaviour). For each construct, we then reviewed all items and selected those deemed most appropriate and reliable.

We aimed to develop questionnaires for each of the four target groups with a completion time of approximately 10-15 minutes and were not able to include all items. The constructs were therefore reviewed by stigma experts and representatives from Alzheimer's associations in order to identify those that should be prioritised in our survey.

What other questions did we ask?

Participants were informed that this survey was looking to understand what they knew and thought about dementia; the survey was not described to participants as a survey on stigma.

To examine differences across regions and personal characteristics, we also collected information on: gender, age, highest level of education, country/territory of residence, area of residence (e.g. urban or rural), membership of a minority group and employment status.

Ensuring the survey was understandable

The survey questions were reviewed and tested by several stakeholders, including people living with dementia, NGO representatives and expert researchers, before being launched to the wider public in April 2019. This was to ensure that the questions captured relevant topics from the perspective of people living with dementia and that the questions were clear and comprehensible. We also contacted world experts in the field of stigma research to ensure that the questions were theoretically and conceptually relevant. All questions were optional and participants were told they did not have to answer anything they did not wish to.

We allowed for a proxy respondent, something used by 80 people living with dementia. We were also keen to enable survey respondents to write about their own experiences and provided opportunities to write longer answers in a text box.

How we translated the survey

One of our aims was to make the survey as accessible as possible. For this reason, the survey was translated into 32 different languages, and most of the translations were done by volunteers and staff of ADI member organisations. To ensure that translations were comparable across languages, we requested all sites to follow WHO guidelines [5]. Specifically, this comprised three stages: (1) forward-translation, (2) back-translation and (3) focus group 'concept checking'. The forward-translation required the translator to have his/her local language as their first language, with English as his/her second language. Any disputed items would be discussed with their study team. For the back-translation stage, when possible a different translator, whose first language was English and second language was the local language, would back-translate the document back into English. The study team was then asked to compare the new and original English versions, highlighting and resolving any differences in translation.

How we collected the data

The survey was 10-15 minutes in length, with questions tailored for each of the four groups: people living with dementia, their family and/or carers, healthcare practitioner and the general public. Most questions were multiple choice, with very few open-ended responses. The survey was delivered in a flexible format, either: (1) self-completed online or (2) in person via a mobile device with a volunteer. If needed, paper forms could be used and the survey data later entered into the app by volunteers.

The online survey

Most respondents completed the anonymous online survey using a web-based platform called Qualtrics. The online survey was an effective way to distribute the survey across the world, in the limited time frame which was available. For example, groups of people with dementia and their carers who are active on discussion boards, social media sites, and online in general helped to promote the survey. The survey was available to visitors of the ADI website and the survey link was emailed to contacts within the field of Alzheimer's and dementia, social care organisations, support groups, charities and faith-based organisations, all across the world.

Although online recruitment poses the risk of only including people with computers, the more highly educated and the most active members of the dementia community, the information from this survey provides valuable insights into the issues related to stigma and how this impacts the lives of people living with dementia, their families and society as a whole. We also tried to compensate for this risk by undertaking some data collection in more rural areas or with harder-to-reach populations using a mobile-based platform called Mobenzi, where data collection took place in-person.

The in-person survey

The survey was also distributed by health and community workers in some rural regions and places without internet access using Mobenzi, enabling people to complete the survey on a smartphone or tablet. A total of 29 responses were collected in-person. Mobenzi is a survey tool administered via mobile devices that can be used off-line, thus enabling data collection in areas without internet access. Once surveys are completed and an internet connection is available, the data are uploaded to an online survey management platform. The survey questions and response options used in-person (via Mobenzi) were identical to those used in the online survey (via Qualtrics).

Some of the ADI member organisations facilitated access to the online survey to people without access to internet at their own offices and events.

Recruitment strategy

Capturing the views of each target group required a different recruitment strategy. Generally, we aimed to achieve good representation across gender, age, socioeconomic group and urbanicity. We also wanted to make a considered effort in capturing the voices of individuals in rural areas.

We ran webinars for several of the ADI member organisations (in English and Spanish) and suggested two strategies to encourage diversity in our study population: (1) snowball sampling for the online survey and (2) targeted recruitment for the survey delivered by Mobenzi by volunteers in the community.

Using the snowball sampling technique, our contacts were encouraged to identify people with good social networks to complete the survey. Each person was asked to identify 3-4 additional individuals who could complete the survey. Contacts were then asked to further distribute the link to 3-4 further constituents and the social networks within their countries. Healthcare practitioners and members of the public who saw the survey link online could also raise awareness by sharing the link among their networks.

For the in-person survey, it was important to identify venues associated with the target characteristics (e.g., different types of shopping centres – some which attract young people, and some which attract persons of an older age). It was also important to explain to target groups why the survey was important and should be completed. For example, when asking healthcare practitioner to complete the survey, it was important to explain the reasons for the survey in a clear and concise manner, using key statistics to stress the importance and urgency of the topic matter.

Data security and consent

Participants were informed that their responses would be anonymous. They were also informed that survey data would be stored securely and did not include any personal identifiers. All data has been treated as confidential and kept on secure networks which are password protected. The Mobenzi app uses a secure format that complies with GDPR privacy legislation. Data storage, backup and recovery practices to eliminate data loss events are built into the app. All participants provided consent.

How we analysed the data

Because our sample was a convenience sample, we performed a series of adjustments to allow for comparisons across countries and country groups. First, we developed survey weights which account for sample selection. 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. Responses with weights greater than 20 were excluded (less than 0.2% of the sample) were excluded due to their non-representativeness [6]. For country comparisons, we also performed a pooled estimation technique (the meta-proportion command which is available in the statistical programme Stata) to compare across countries with at least 100 participants [7].

Description of survey respondents

Of the almost 70,000 people who engaged with the survey 60,889 answered at least one question on stigma related knowledge, attitudes and beliefs in relation to dementia. This included 1,446 people living with dementia (2.4%), 18,377 carers for a person living with dementia (30.2%), 14,124 healthcare practitioners (23.2%) and 26,913 members of the general public (44.2%).

Respondents came from 155 countries or semi-autonomous regions/territories and answered the survey in one of 32 different languages. Responses were aggregated by World Bank income category and World Health Organisation (WHO) geographical region. The majority of participants resided in high-income countries (74.7%). Individuals from low-income and lower-middle-income economies represented 0.4% and 7.2% of respondents, respectively. The remaining 17.7% 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 Region, most respondents were from the European Region (42.4%), Region of the Americas (25.7%) and the Western Pacific Region (19.1%). A lower proportion of respondents came from the African Region (1.7%), Eastern Mediterranean Region (2.4%) and South-East Asia Region (5.7%).

Our recruitment resulted in a large and diverse sample; however, respondents over-represented females and individuals with university education: more females (78.8%) than males (21.2%) completed the survey and

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68.8% of respondents had completed college/university or post-graduate studies. We developed survey weights to adjust for imbalances in relation to age, gender and education using nationally representative figures for each country.

Table 4. Characteristics of survey respondents by key group

	People living with dementia (n = 1,446)						**Carers (n = 18,377)**					
Gender	Female		Male		Unspecified		Female		Male		Unspecified	
	67.7%		30.8%		0.3%		82.4%		16.9%		0.1%	
Education	Secondary school or below		Vocational training		University degree or above		Secondary school or below		Vocational training		University degree or above	
	30.8%		11.5%		54.9%		24.1%		14%		60.1%	
Age	Aged 18-39	Aged 40-52		Aged 53-65	Aged 66-98		Aged 18-39	Aged 40-52		Aged 53-65	Aged 66-98	
	NA	17.5%		30%	39.1%		9%	24.7%		39.9%	23.6%	
World Bank Income Group	Low income	Lower middle income		Upper-middle income	High income		Low income	Lower middle income		Upper-middle income	High income	
	0.5%	8.9%		15.6%	70.3%		0.3%	3.1%		15.7%	78%	
WHO Region	A	EM	E	RA	SEA	WP	A	EM	E	RA	SEA	WP
	2.3%	1.9%	44.5%	28.2%	4.6%	14%	1.3%	1.2%	49.5%	26.9%	3.2%	15.1%

Note. **WHO** Regions: (A) African Region; (EM) Eastern Mediterranean Region; (E) European Region; (RA) Region of the Americas; (SEA) South-East Asia Region; (WP) Western Pacific Region.

Sample represent those who answered at least one stigma question (N = 60,860).
Not all participants shared their demographic information. Missing values are not reported on the table and explain why not all values total 100%.

	Healthcare Practitioners (n = 14,124)						General Public (n = 26,913)					
Gender	Female		Male		Unspecified		Female		Male		Unspecified	
	82%		17.4%		0.1%		74.1%		25%		0.2%	
Education	Secondary school or below		Vocational training		University degree or above		Secondary school or below		Vocational training		University degree or above	
	5.6%		12.2%		80.8%		21.3%		10.6%		66.5%	
Age	Aged 18-39	Aged 40-52		Aged 53-65	Aged 66-98		Aged 18-39	Aged 40-52		Aged 53-65	Aged 66-98	
	34%	27.7%		28.8%	6.6%		20.1%	18.4%		29.1%	28.8%	
World Bank Income Group	Low income	Lower middle income		Upper-middle income	High income		Low income	Lower middle income		Upper-middle income	High income	
	0.5%	10.3%		16.8%	69.8%		0.4%	8.3%		12.6%	75.1%	
WHO Region	A	EM	E	RA	SEA	WP	A	EM	E	RA	SEA	WP
	1.6%	4%	36.1%	22.4%	7.8%	25.8%	2%	2.4%	40.8%	26.5%	6.4%	18.7%

References

1 Thornicroft G, Rose D, Kassam A, Sartorius N. 2007. 'Stigma: ignorance, prejudice or discrimination?' Br J Psychiatry 190: 192–93.

2 Evans-Lacko S, Brohan E, Mojtabai, R*, Thornicroft G* 2012. 'Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. Psychological Medicine' 42(8):1741-1752.

3 Nguyen T, L. X. 2018. 'Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature.' Dementia 0, 1–34 (2018).

4 Pescosolido, Bernice A. Medina TR, Martin JK, L. S. 2013. 'The "Backbone" of Stigma: Identifying the Global Core of Public Prejudice Associated With Mental Illness.' Am. J. Public Health 103, 853–860 (2013.)

5 WHO (2014). Process of translation and adaptation of instruments. WHO. https://www.who.int/substance_abuse/research_tools/translation/en/ Last accessed 30 August 2019.

6 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.

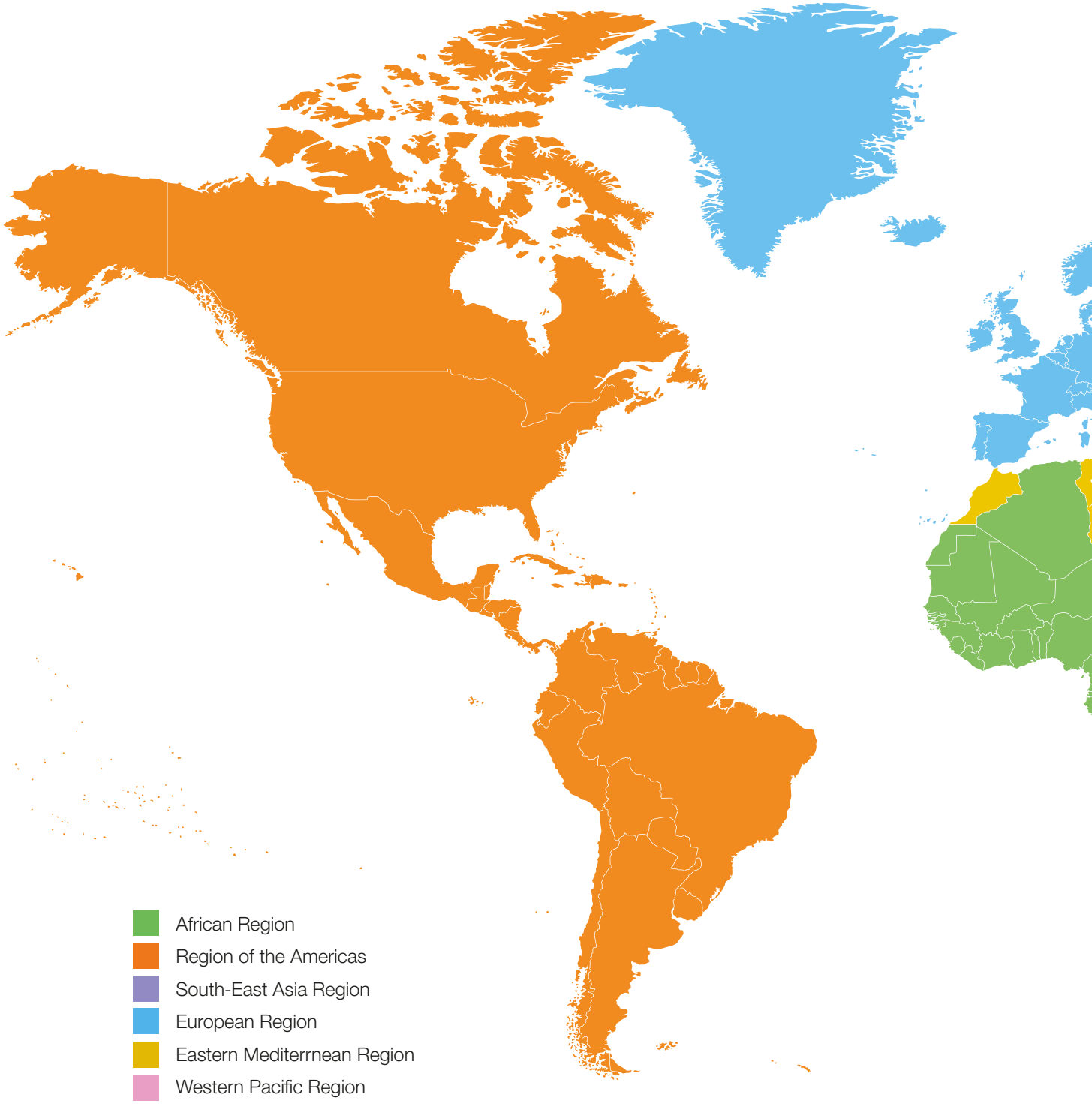
7 Nyaga VN, Arbyn M, Aerts M. 2014. 'Metaprop: a Stata command to perform meta-analysis of binomial data.' Archives of Public Health volume 72.

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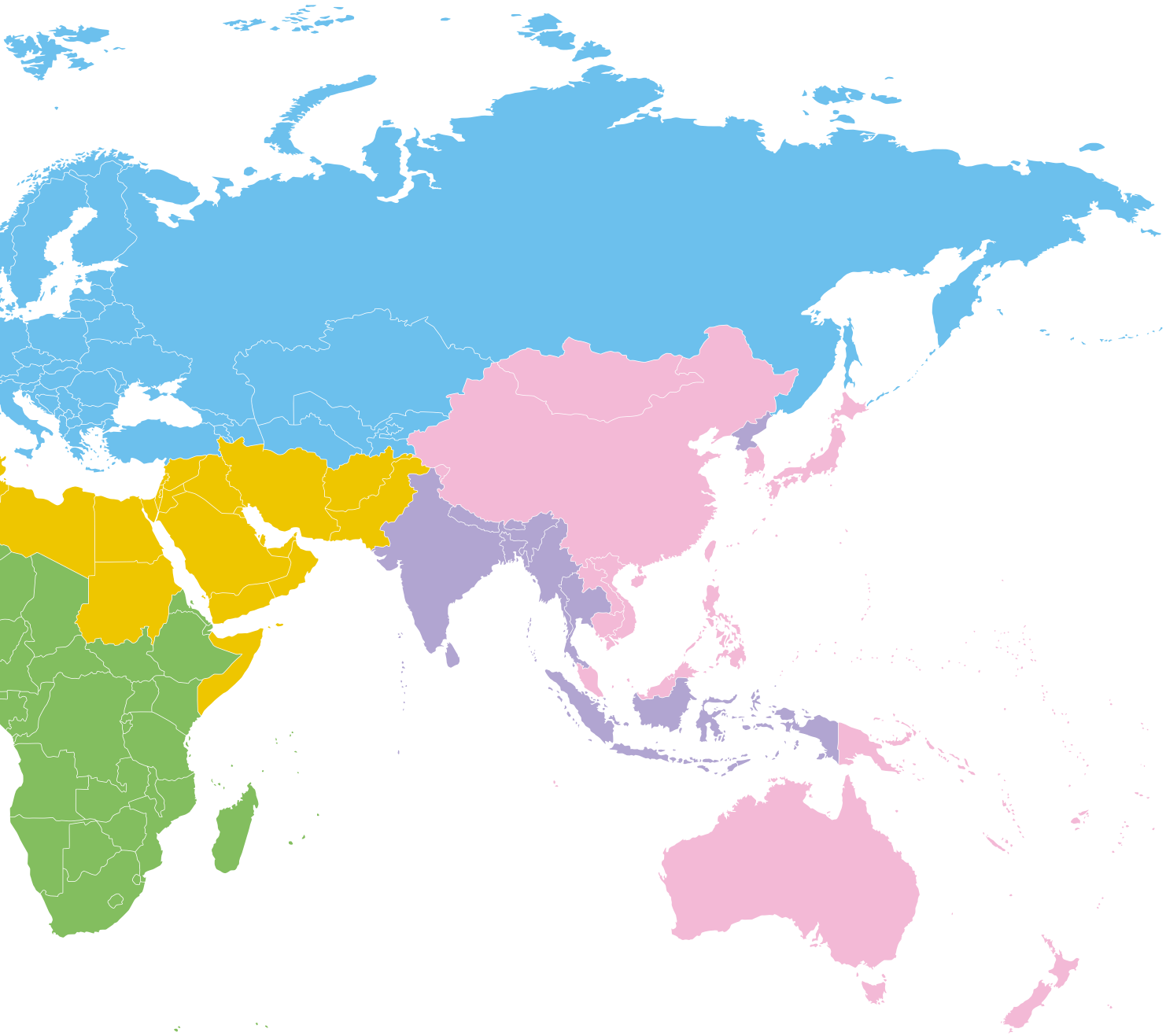
Appendix 1

Map 1. World Health Organisation (WHO) Regions



Reproduced with kind permission from the World Health Organisation

WHO Regional Offices - map
https://www.who.int/about/who-we-are/regional-offices



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Chart 1. World Bank Income Groups 2019-2020

Lower Income Countries	Lower Middle Income Countries	Upper Middle Income Countries	High Income Countries
Afghanistan	Angola	Albania	Andorra
Benin	Bangladesh	Algeria	Antigua and Barbuda
Burkina Faso	Bhutan	American Samoa	Aruba
Burundi	Bolivia	Argentina	Australia
Central African Republic	Cabo Verde	Armenia	Austria
Chad	Cambodia	Azerbaijan	Bahamas, The
Congo, Dem. Rep. of	Cameroon	Belarus	Bahrain
Eritrea	Comoros	Belize	Barbados
Ethiopia	Congo, Rep.	Bosnia and Herzegovina	Belgium
Gambia, The	Côte d'Ivoire	Botswana	Bermuda
Guinea	Djibouti	Brazil	British Virgin Islands
Guinea-Bissau	Egypt, Arab Rep.	Bulgaria	Brunei Darussalam
Haiti	El Salvador	China	Canada
Korea, Dem. People's Rep	Ghana	Colombia	Cayman Islands
Liberia	Honduras	Costa Rica	Channel Islands
Madagascar	India	Cuba	Chile
Malawi	Indonesia	Dominica	Croatia
Mali	Kenya	Dominican Republic	Curaçao
Mozambique	Kiribati	Equatorial Guinea	Cyprus
Nepal	Kyrgyz Republic	Ecuador	Czech Republic
Niger	Lao PDR	Fiji	Denmark
Rwanda	Lesotho	Gabon	Estonia
Sierra Leone	Mauritania	Georgia	Faroe Islands
Somalia	Micronesia, Fed. Sts	Grenada	Finland
South Sudan	Moldova	Guatemala	France
Syrian Arab Republic	Mongolia	Guyana	French Polynesia
Tajikistan	Morocco	Iran, Islamic Rep	Germany
Tanzania	Myanmar	Iraq	Gibraltar
Togo	Nicaragua	Jamaica	Greece
Uganda	Nigeria	Jordan	Greenland
Yemen, Rep.	Pakistan	Kazakhstan	Guam
	Papua New Guinea	Kosovo	Hong Kong SAR, China
	Philippines	Lebanon	Hungary
	Sao Tome and Principe	Libya	Iceland
	Senegal	Macedonia	Ireland
	Solomon Islands	Malaysia	Isle of Man
	Sudan	Maldives	Israel
	Swaziland	Marshall Islands	Italy
	Timor-Leste	Mauritius	Japan
	Tunisia	Mexico	Korea, Rep
	Ukraine	Montenegro	Kuwait
	Uzbekistan	Namibia	Latvia
	Vanuatu	Nauru	Liechtenstein
	Vietnam	Paraguay	Lithuania
	West Bank and Gaza	Peru	Luxembourg
	Zambia	Romania	Macao SAR, China
	Zimbabwe	Russia Federation	Malta

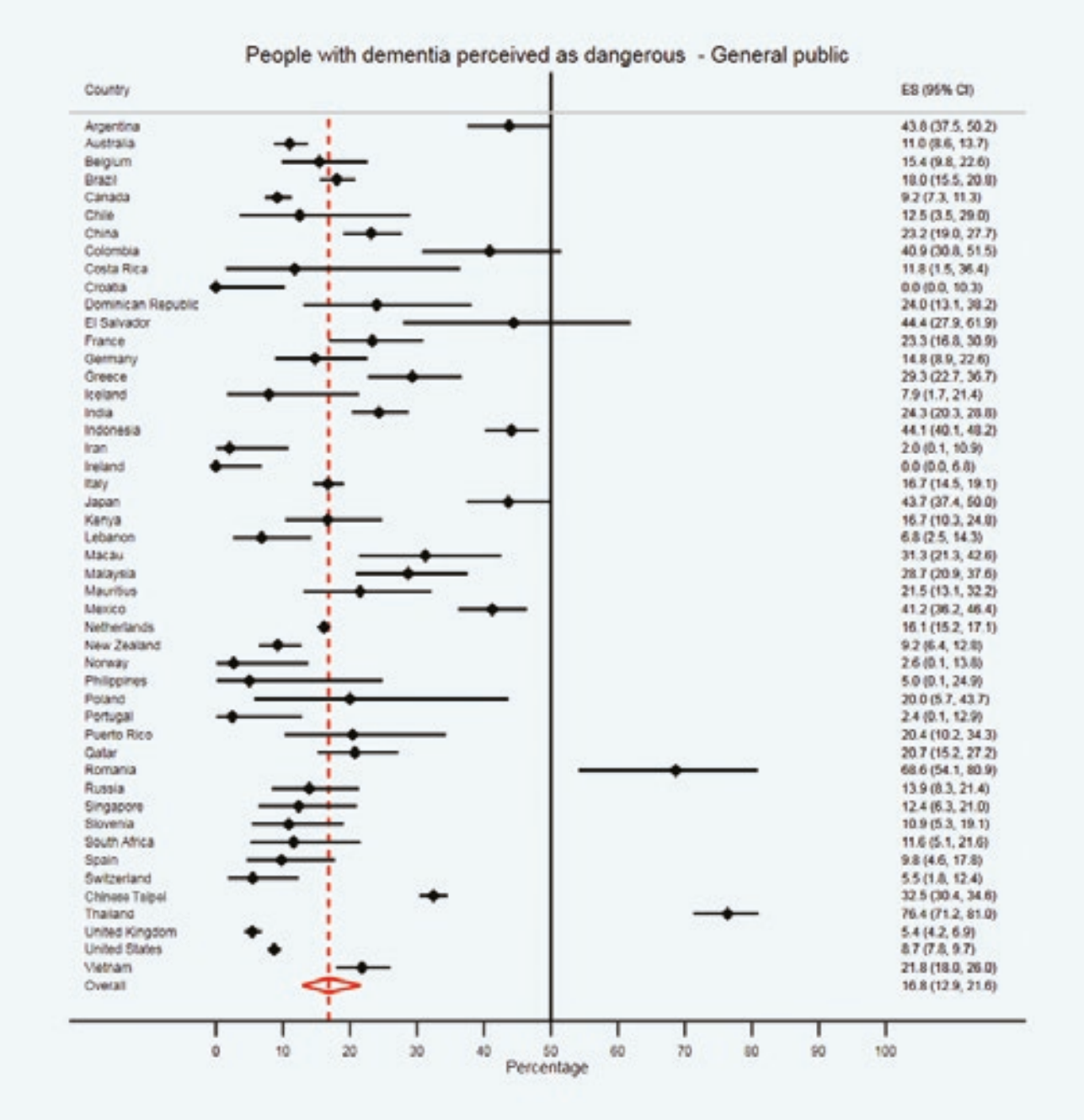
Lower Income Countries	Lower Middle Income Countries	Upper Middle Income Countries	High Income Countries
		Samoa	Monaco
		Serbia	Netherlands
		Sri Lanka	New Caledonia
		South Africa	New Zealand
		St Lucia	Northern Mariana Islands
		St Vincent and the Grenadines	Norway
		Suriname	Oman
		Thailand	Palau
		Tonga	Panama
		Turkey	Poland
		Turkmenistan	Portugal
		Tuvalu	Puerto Rico
		Venezuela, RB	Qatar
			San Marino
			Saudi Arabia
			Seychelles
			Singapore
			Sit Maarten (Dutch part)
			Slovak Republic
			Slovenia
			Spain
			St Kitts and Nevis
			St. Martin (French part)
			Sweden
			Switzerland
			Chinese Taipei
			Trinidad and Tobago
			Turks and Caicos Islands
			United Arab Emirates
			United Kingdom
			United States
			Uruguay
			Virgin Islands (US)

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Appendix 2(vi)

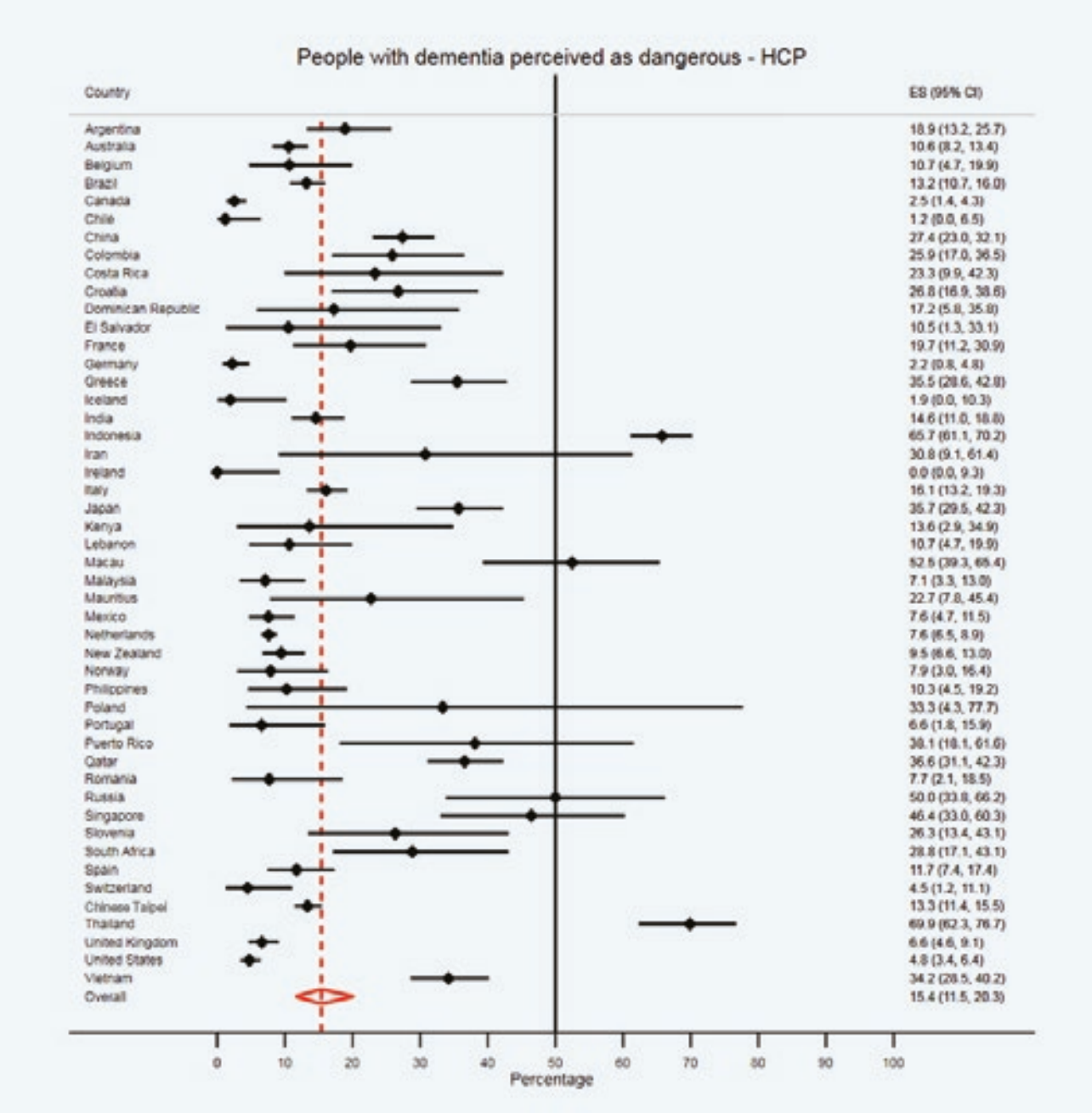
Forest plots(vii) for country comparisons(viii)



(vi) HCP refers to healthcare practitioners and PWD refers to people living with dementia.

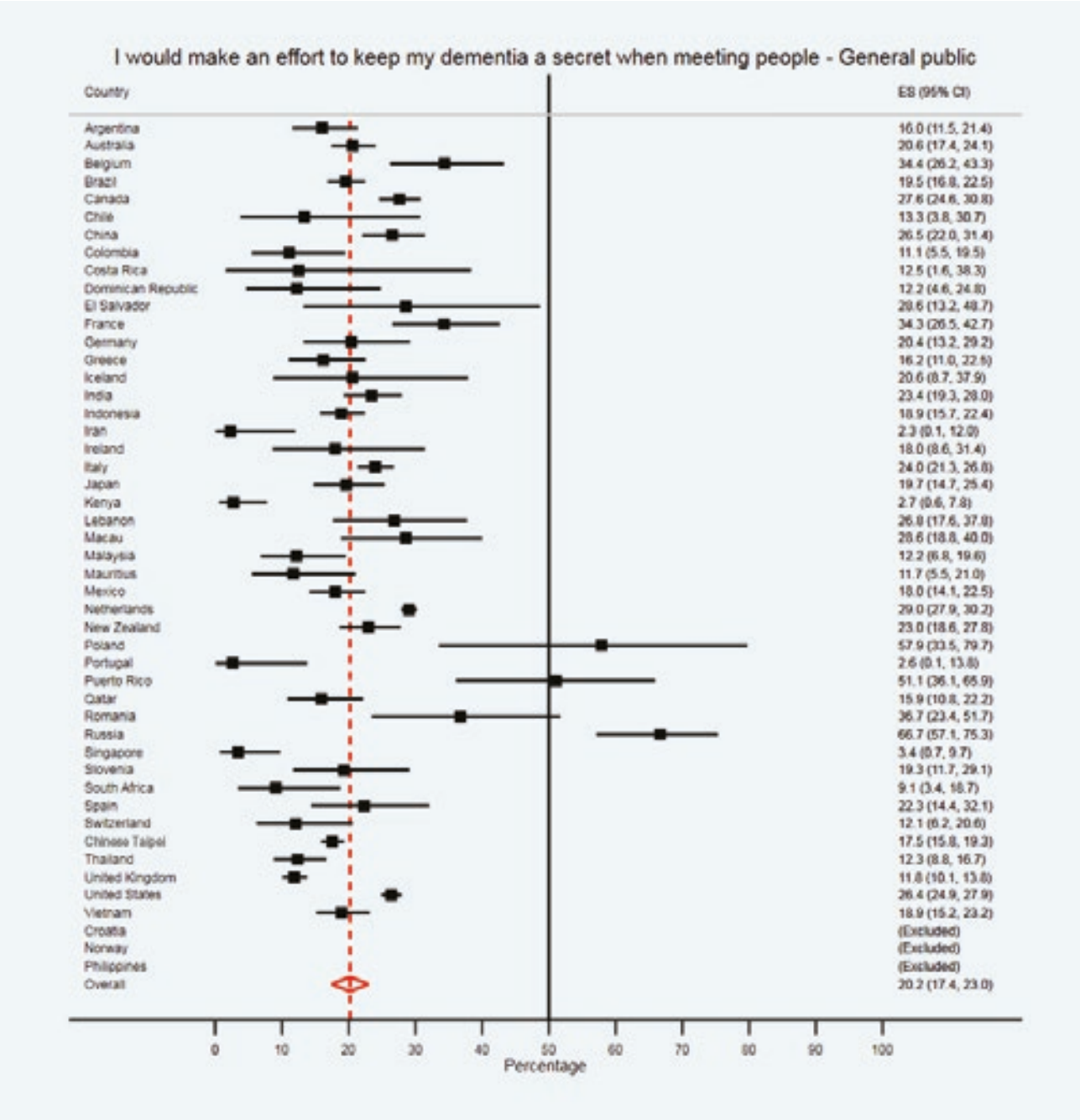
(vii) Note: The forest plots summarise the responses for each group. The best estimate of the response is represented by the box and the horizontal line represents the 95% confidence interval. Those groups with a greater number of participants / respondents have a narrower confidence interval and a smaller line.

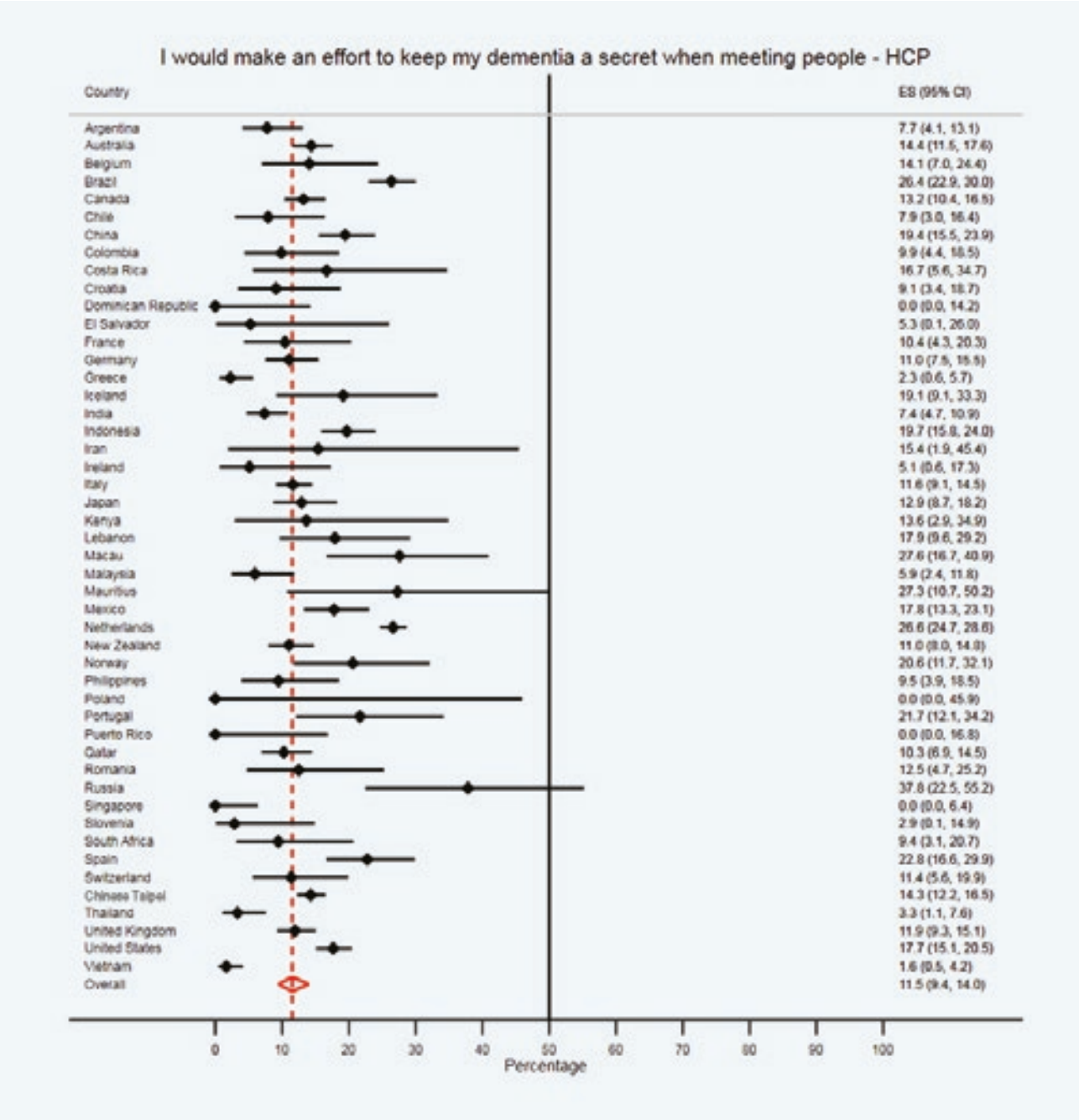
(viii) All analyses incorporated survey weights as described in the methodology section.



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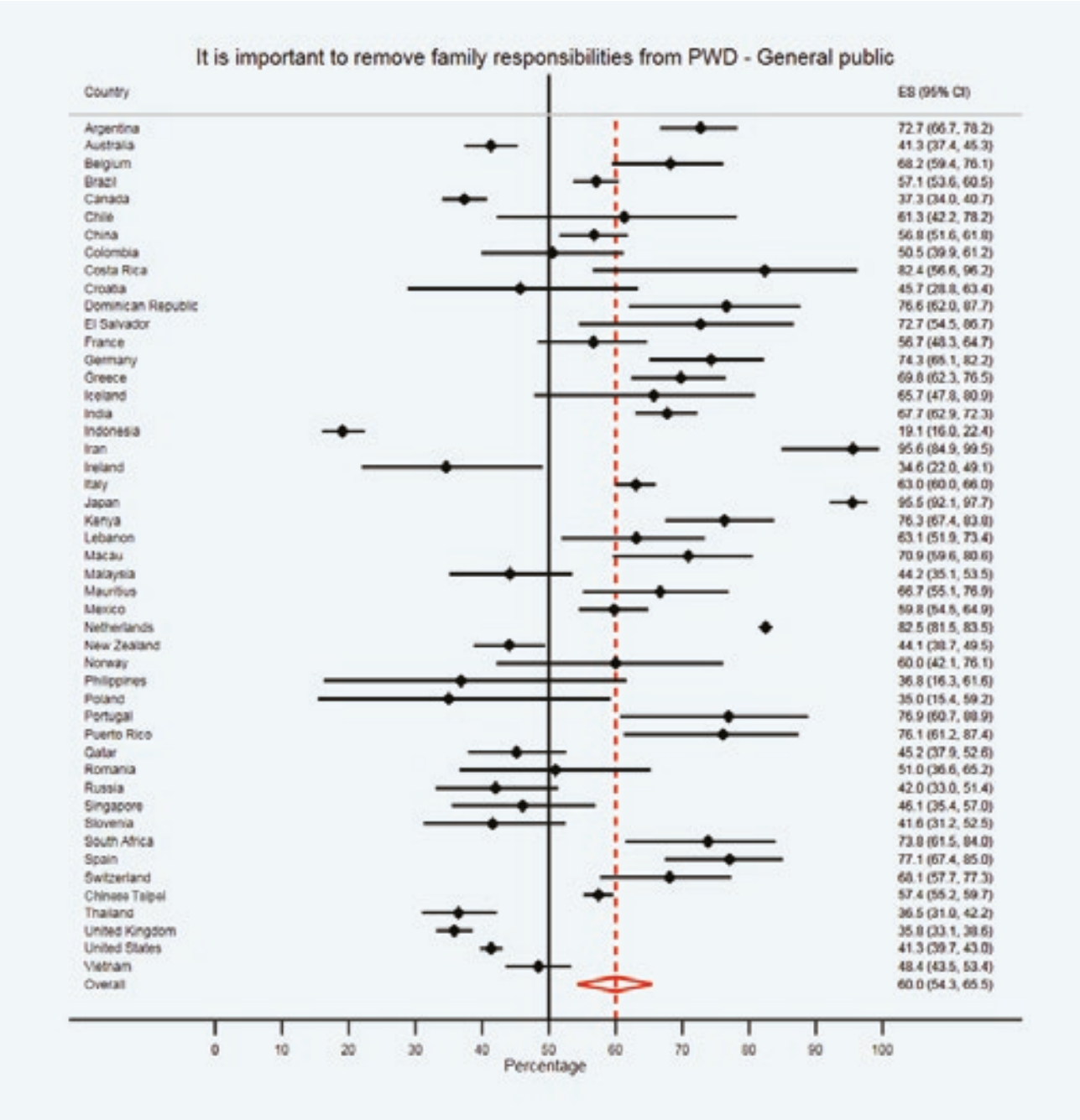
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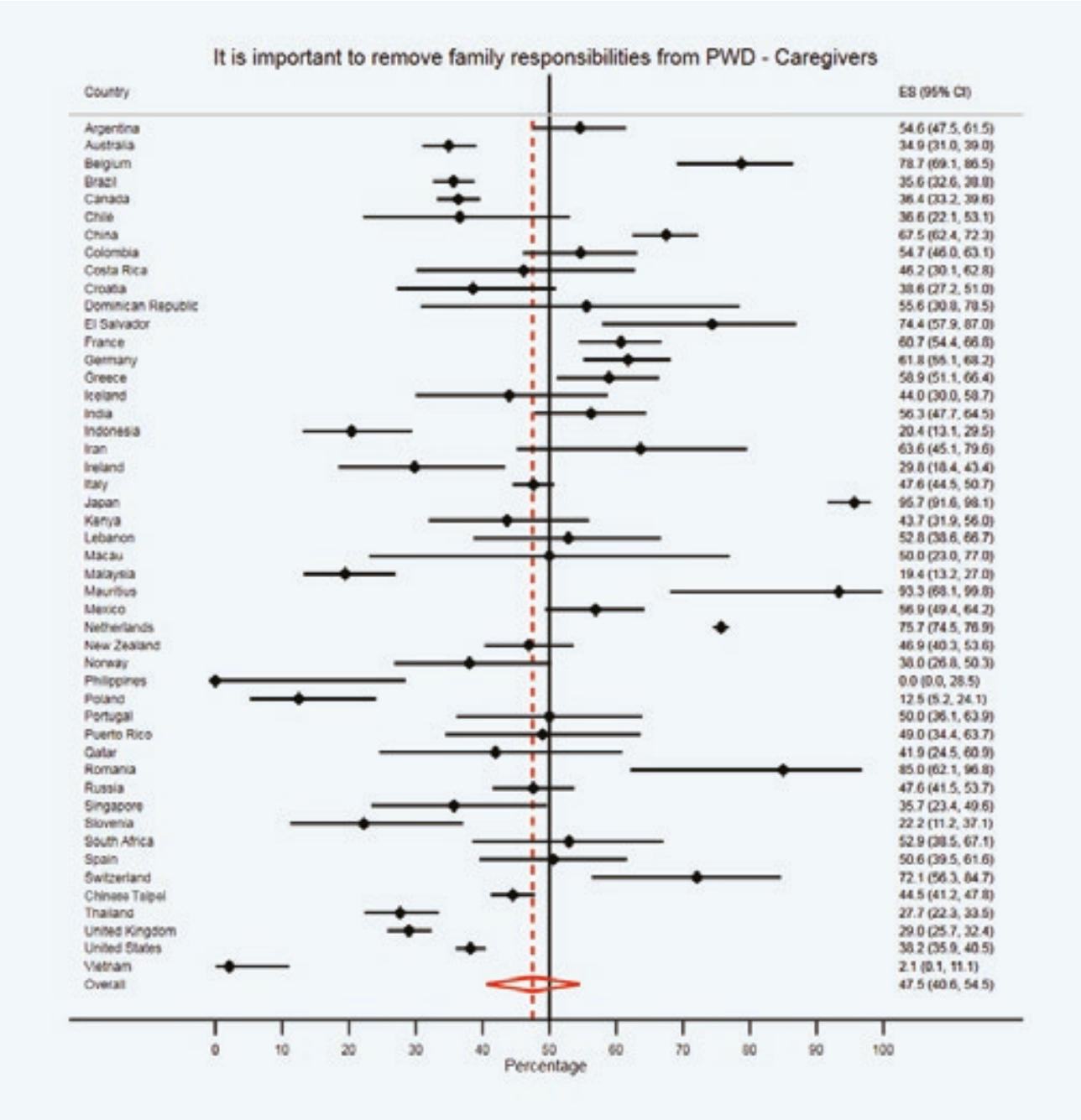




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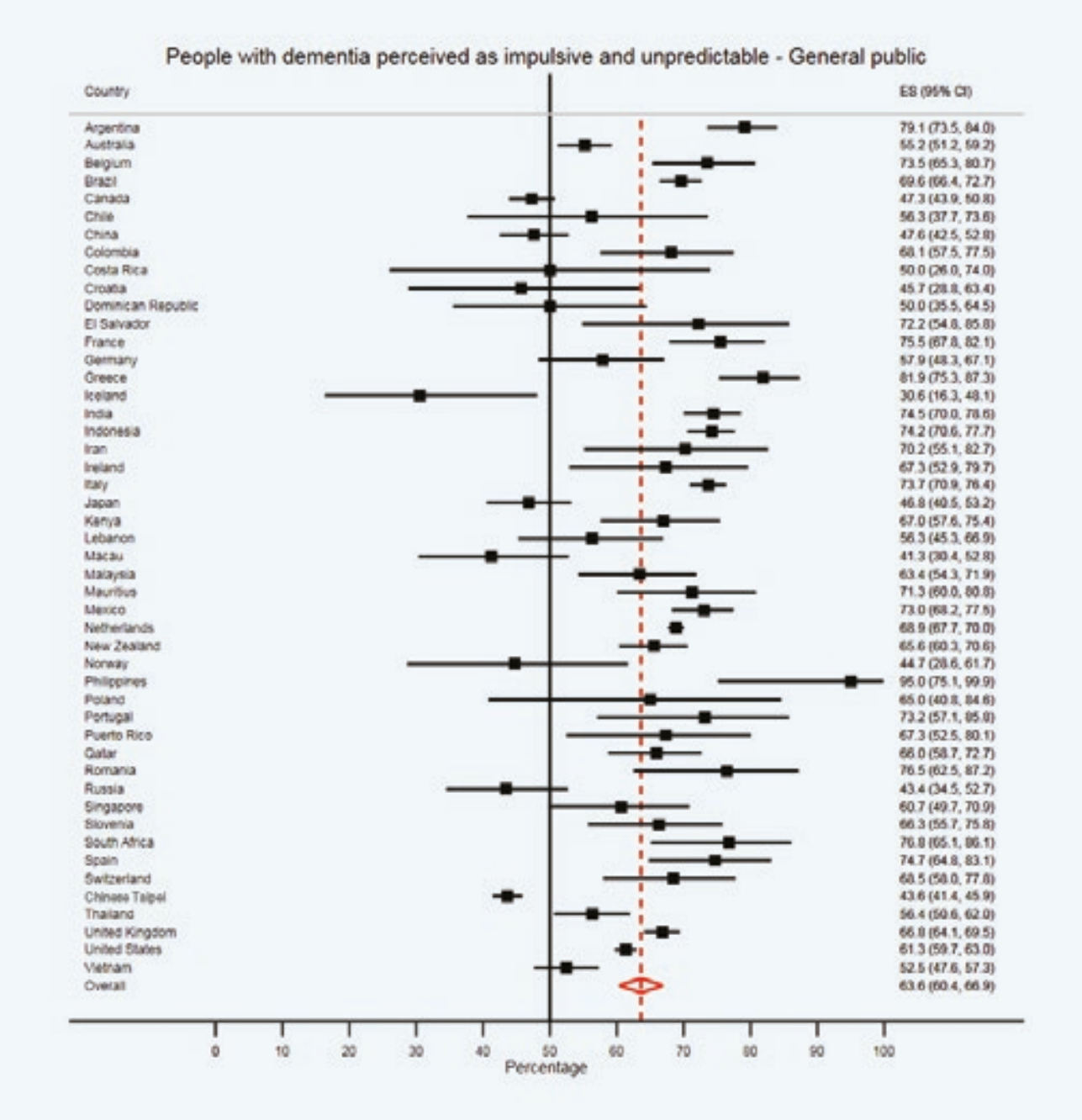
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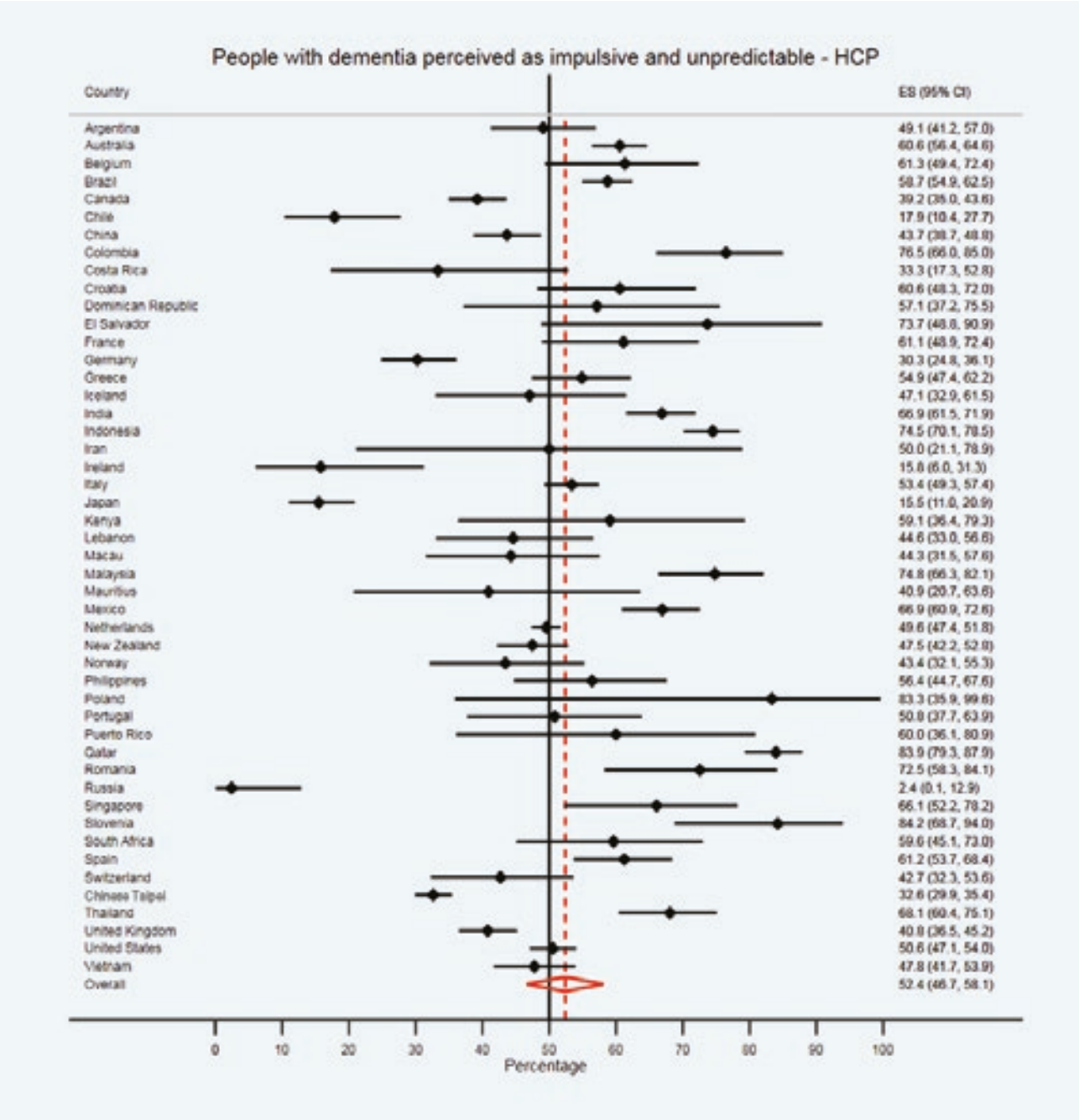




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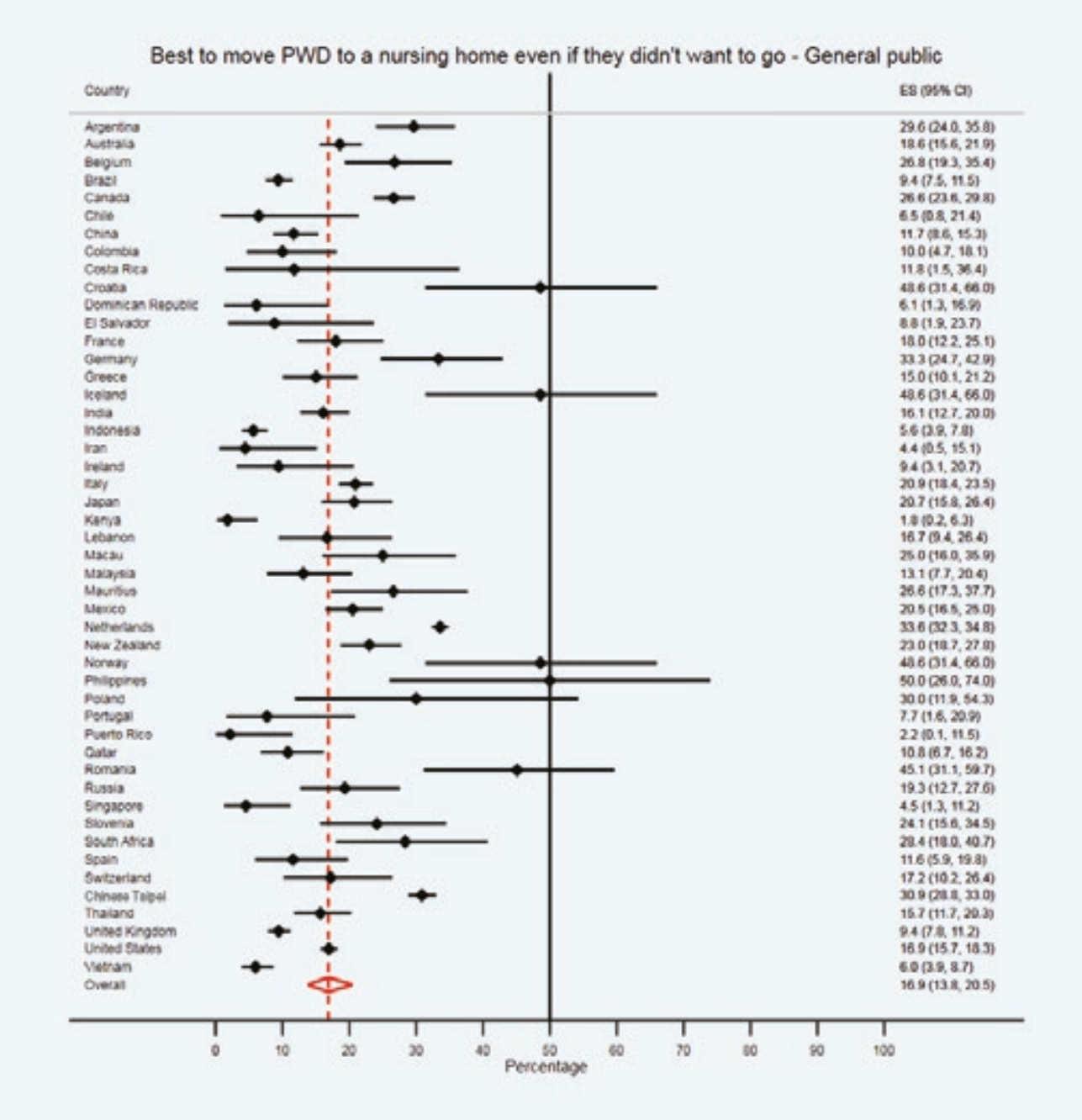
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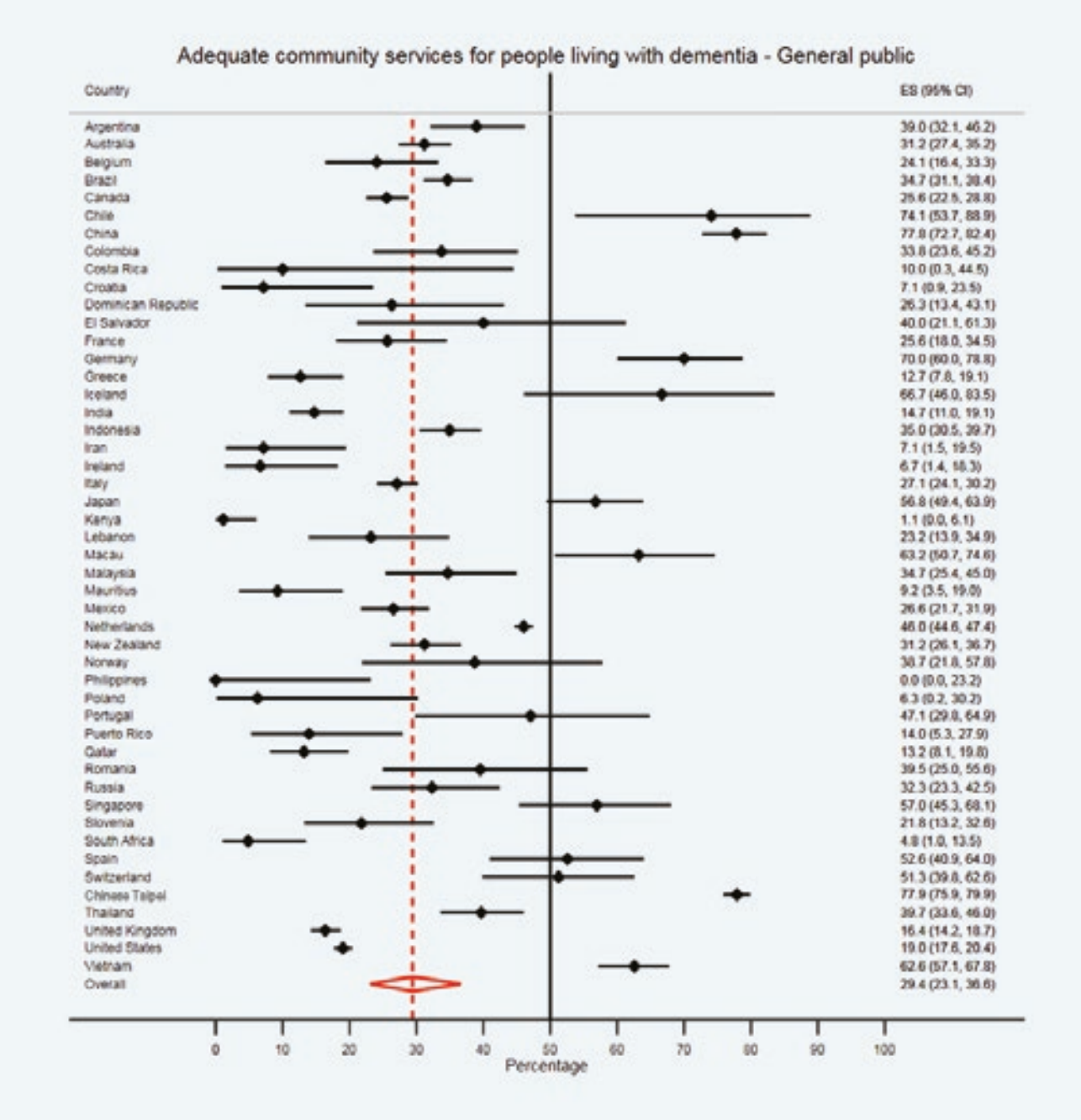




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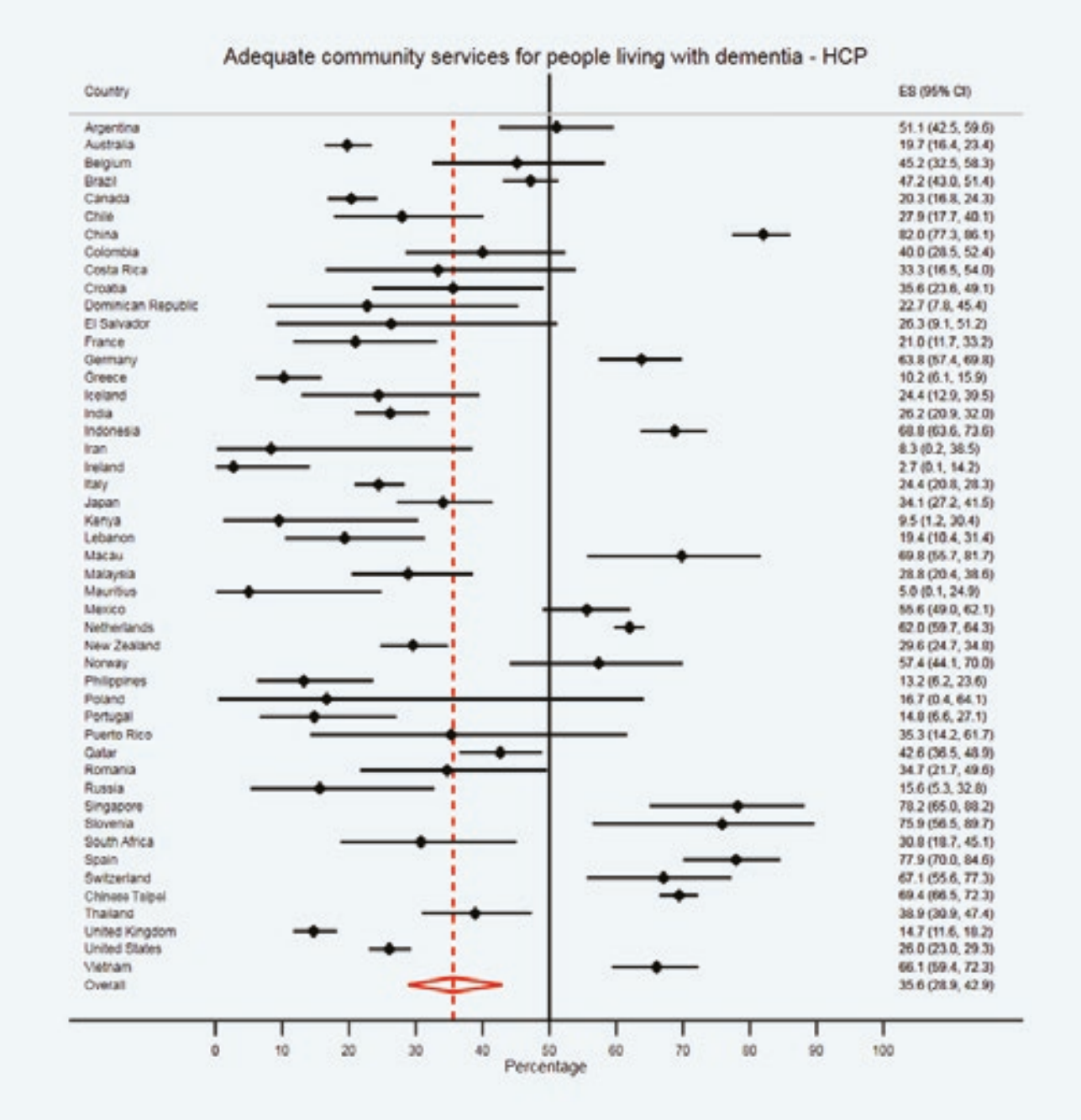
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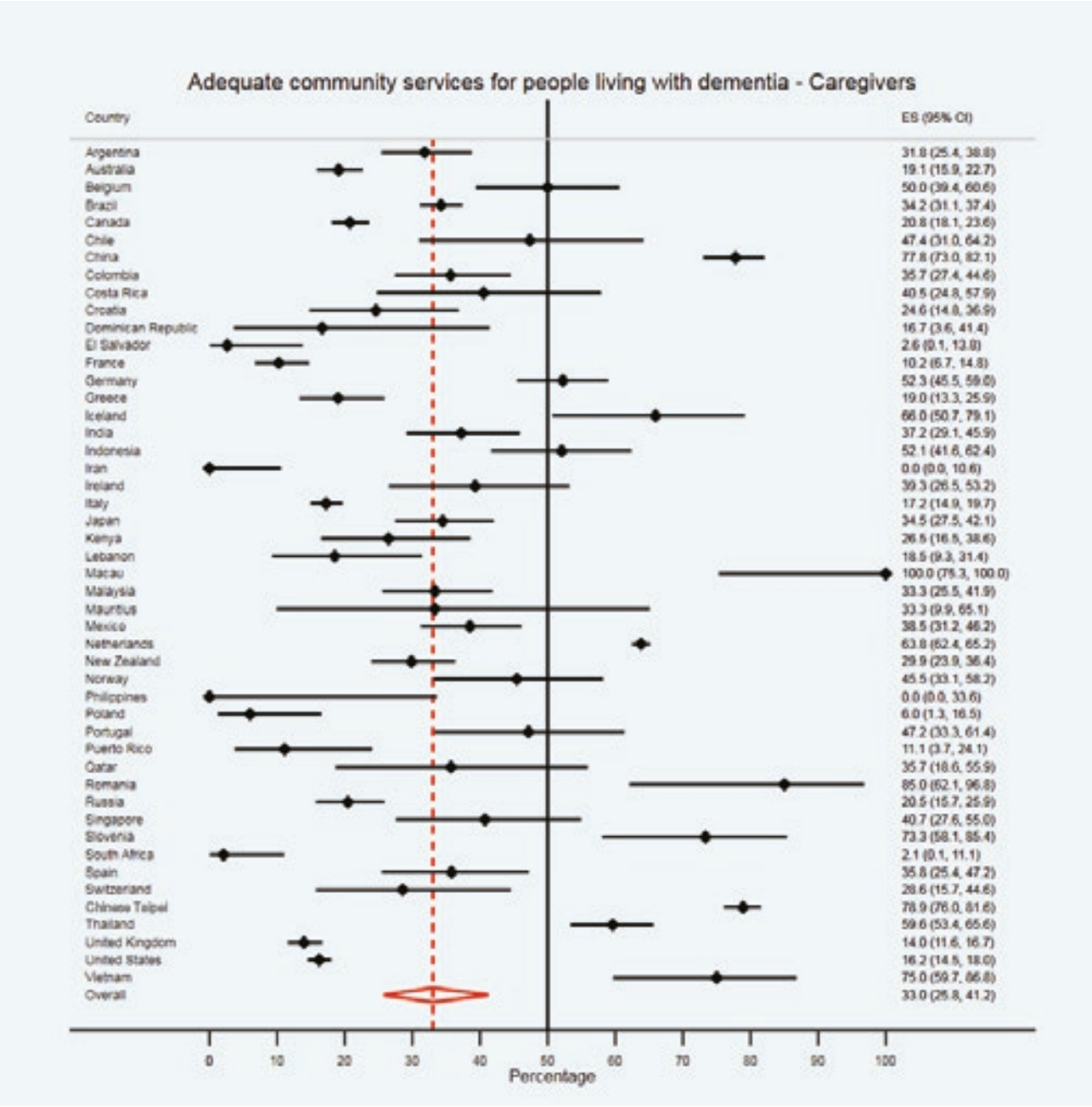




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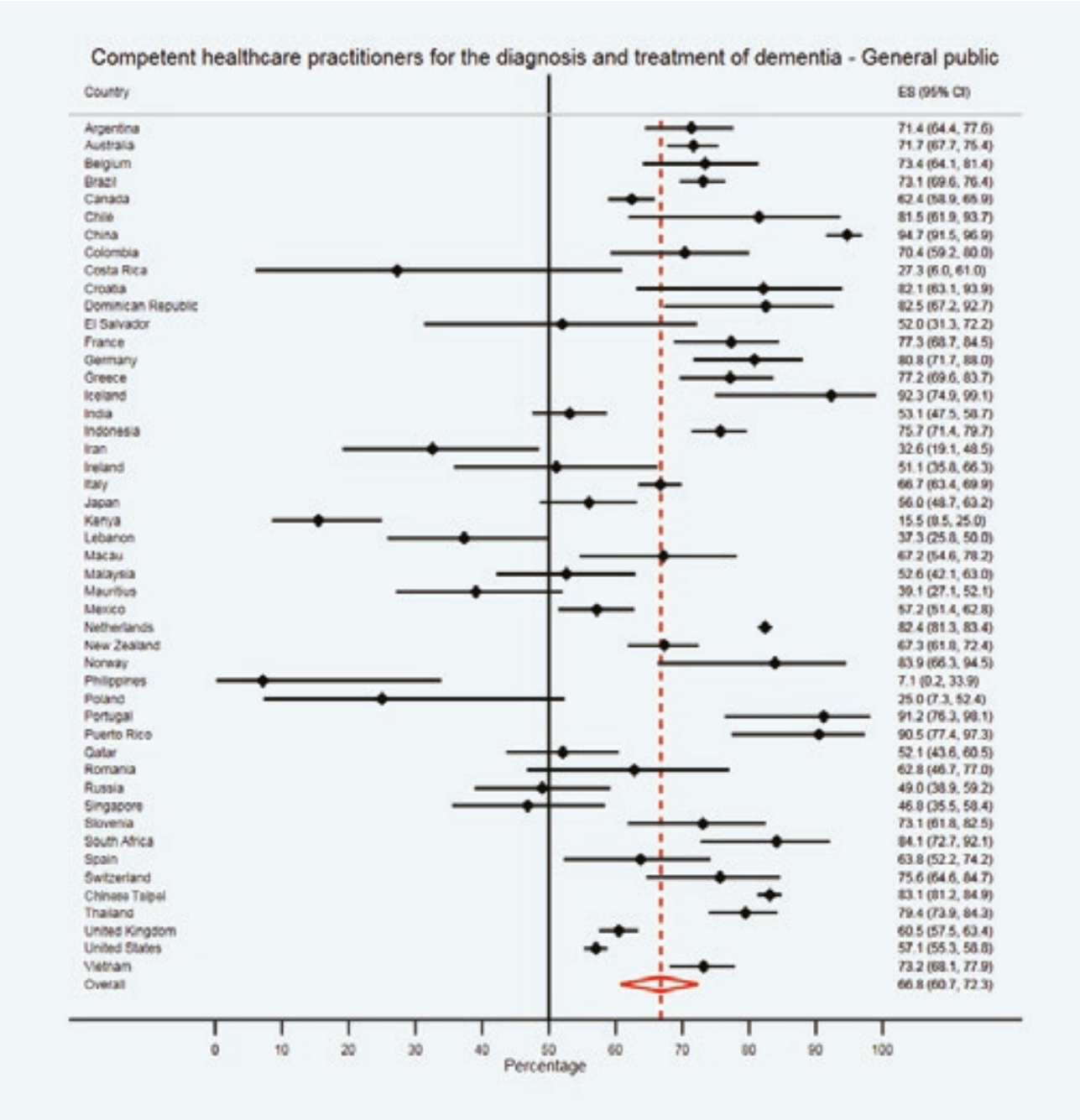
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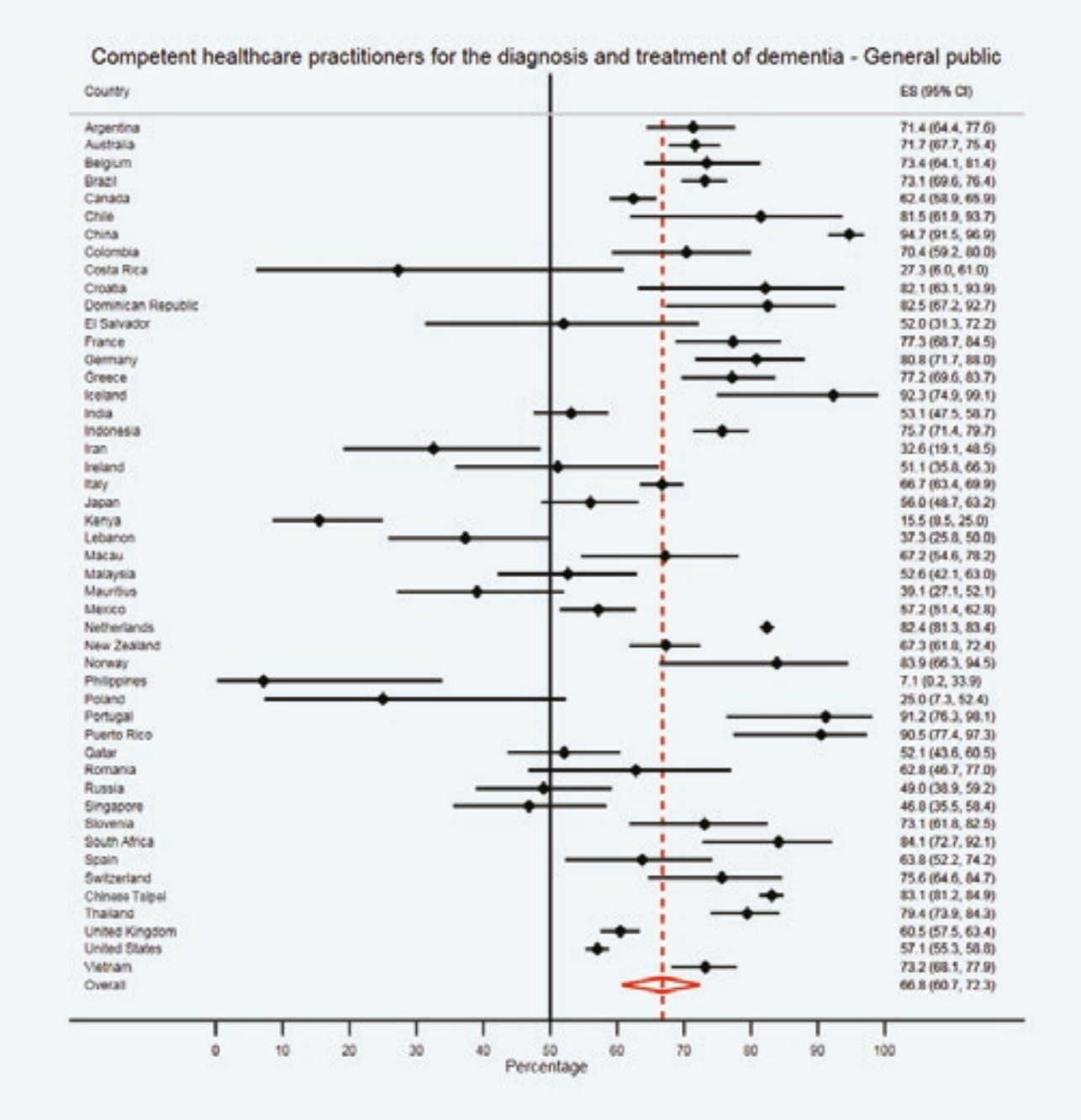




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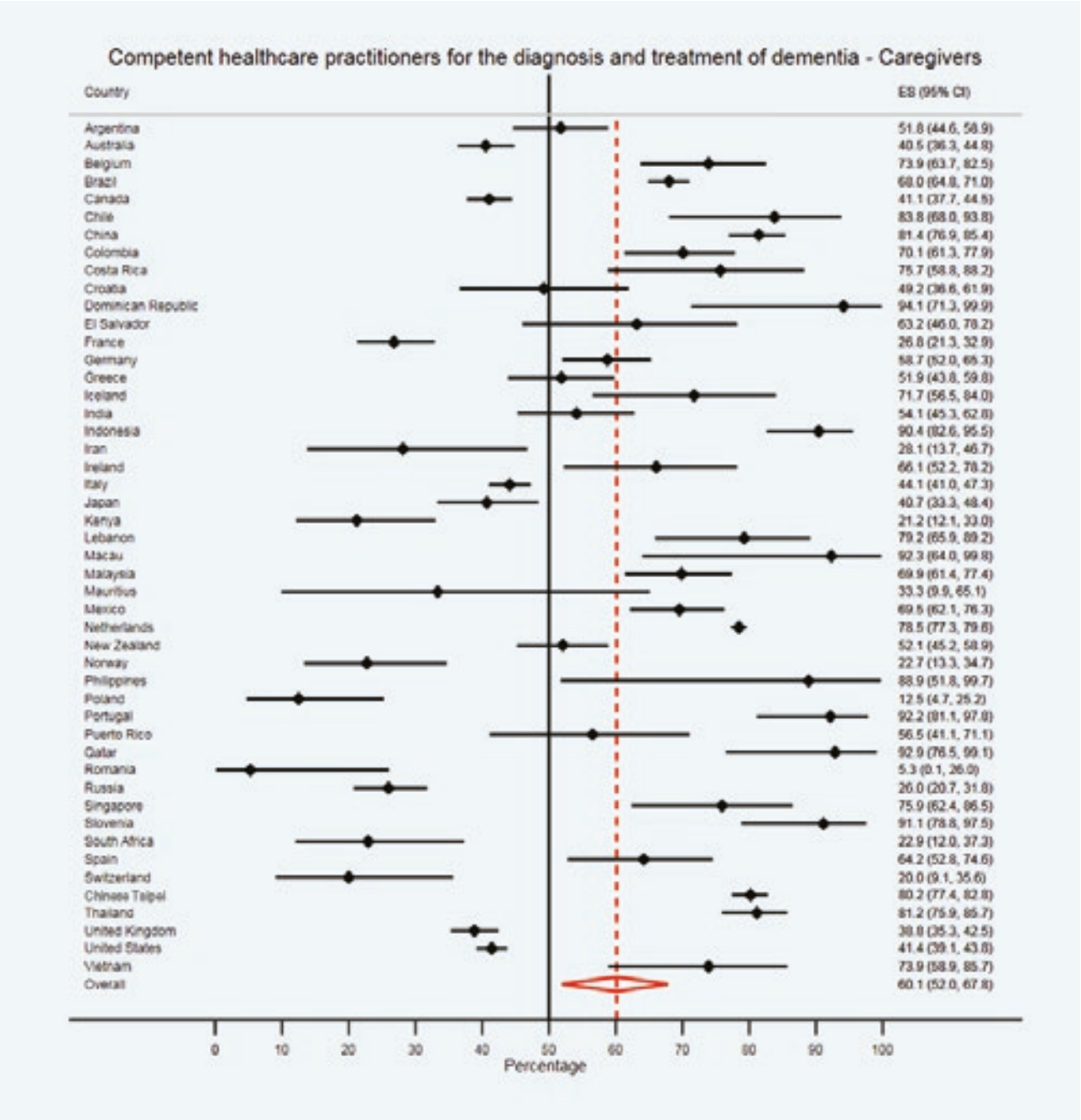
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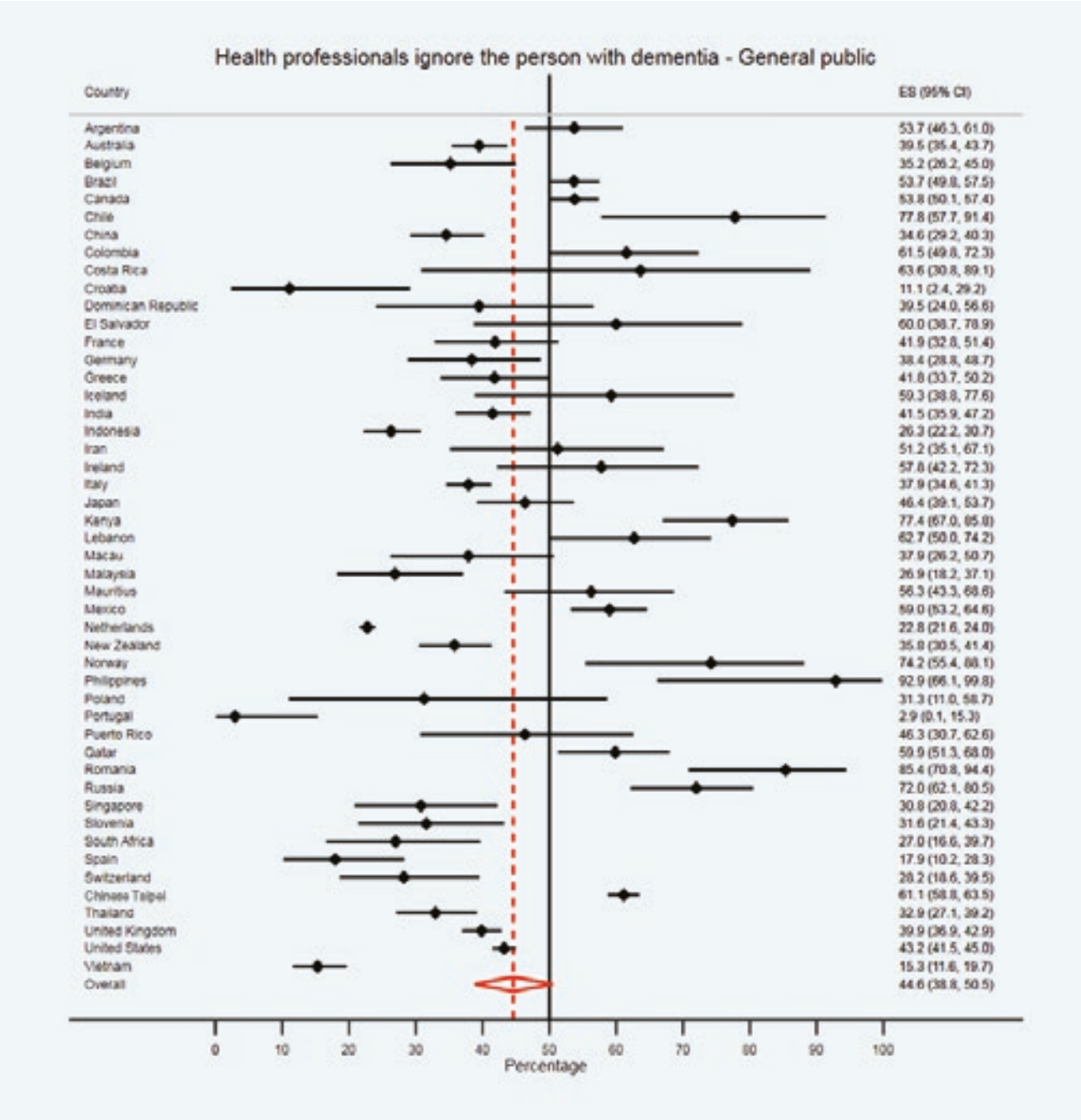




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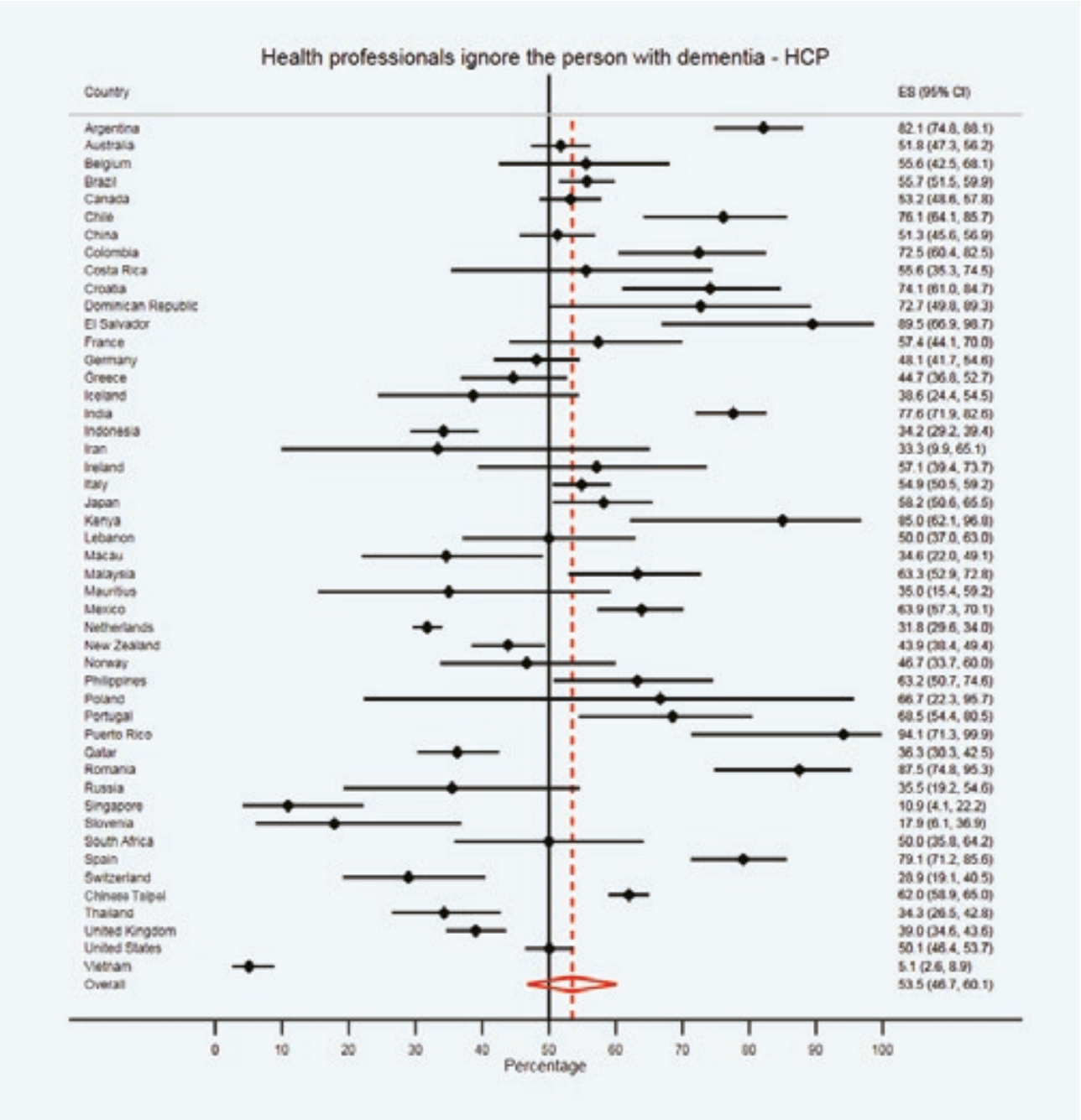
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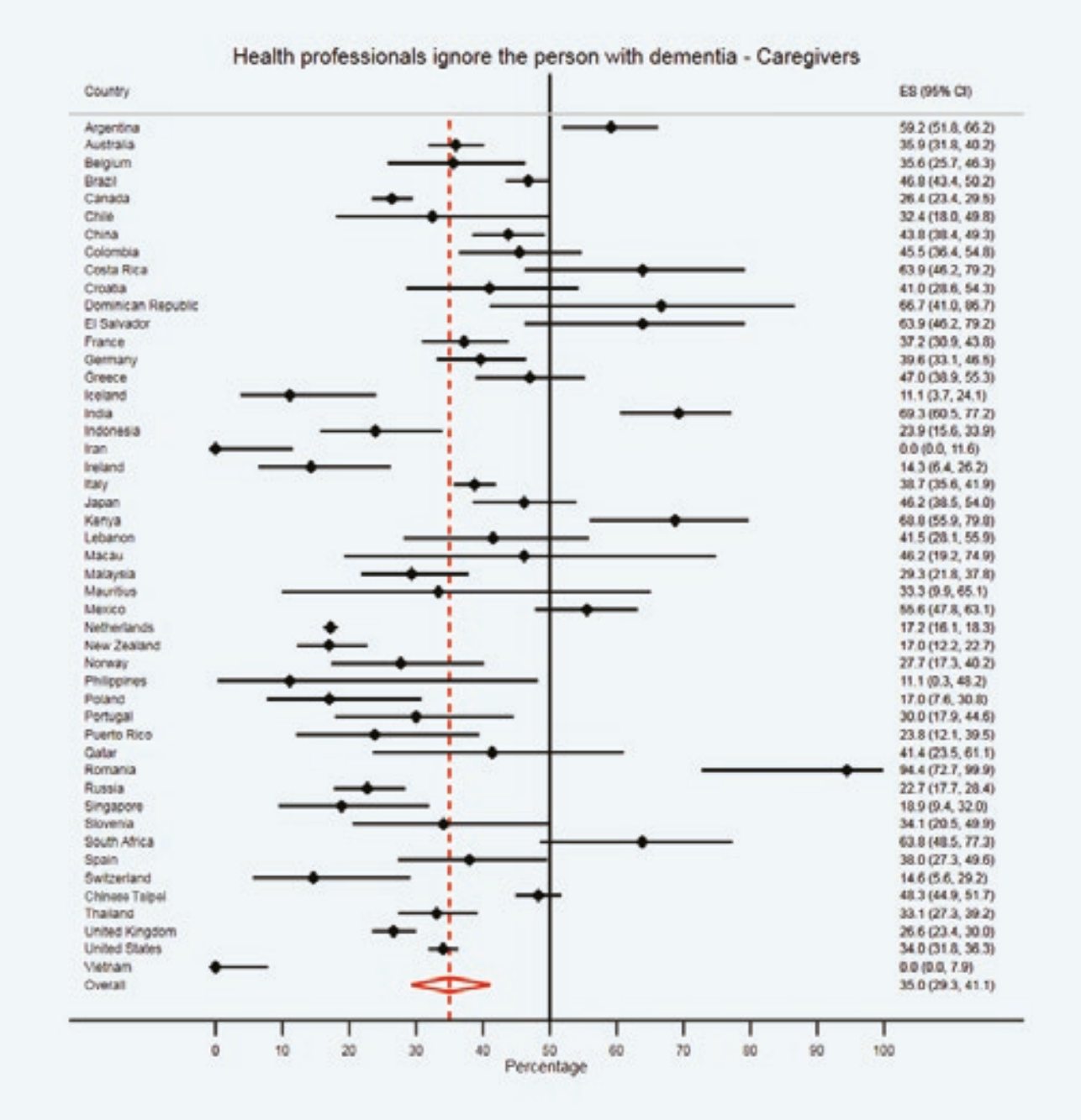




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CHAPTER 3

Expert essays

3.1 Stigma: a personal view 7 years on

Contributor: Dr Nori Graham. Honorary Vice President of ADI and a Vice President of the Alzheimer's Society (England), previous chair of each organisation; Honorary Fellow of the Royal College of Psychiatrists and Emeritus Consultant in the Psychiatry of Old Age at the Royal Free Hospital; honorary doctorate for public services to the Open University.

In 2012, I wrote a personal view on stigma that was included in the World Alzheimer Report that year.[1] In that article I wrote about how people with dementia and their carers suffered twice over from the shameful way they were regarded. The public turns away from old people and it prefers not to know about people with dementia. To be old and to have dementia is to be double stigmatised.

I described how my professional experience and my involvement with the voluntary sector had informed my view on stigma and how it might be overcome. I concluded with two suggestions for improvement. First there was a need to establish, to a much greater degree, high quality, effective services for the diagnosis and management of people with dementia and other mental illnesses, and their carers. Second, national Alzheimer associations were needed worldwide 'to raise awareness, put pressure on governments to achieve policy changes, provide quality information, bring people with dementia and their families together to talk and share problems, and encourage well-known people with dementia and their families to go public to show that they, at least, are not afraid or ashamed.'

You can talk about your glaucoma, deafness, arthritis, heart bypasses, cancers, even depression and Parkinson's disease, but admitting to dementia is a step too far

Since that time, there have been many significant improvements in our field. According to official numbers, certainly in the UK, the number of people receiving a diagnosis has increased so that over half living with symptoms receive a diagnosis. I have a concern that the drive for diagnosis has led to some people with non-progressive mild cognitive impairment rather than dementia being inappropriately diagnosed, but doubtless the overall impact has been positive. However, in low- and middle-income countries the numbers diagnosed remain very low. When I visited St. Petersburg, I was told that dementia was 'almost invisible' in Russia. In India I was told that only one in ten receives a diagnosis. In Africa it seems that, in many countries, dementia is regarded as due to witchcraft.

The Dementia Friends programme to raise awareness and reduce stigma started in Japan about 7 years ago. It is now well-established in the UK and in many other countries. It has started to impact on people's understanding of dementia and awareness and will reduce stigma perhaps on a very significant scale.

There have been other improvements on the international scene. In 2017 the World Health Organisation (WHO) adopted the Global action plan on the public health response to dementia.[2] There is now a target for 75% of Member States to have developed a dementia action plan by 2025. This is a very ambitious target, but ADI is encouraging and supporting its national members to work with governments and policy makers to achieve it. ADI now has 100 national member associations and federations which, in itself, is a huge step forward in raising awareness and reducing stigma amongst the general public, professionals and policy makers.

As far as improvement in services is concerned, there has been change for the better, but management after diagnosis remains a postcode lottery, at least in the UK. There are areas where the post diagnostic care is excellent with 'dementia wellbeing teams' liaising with GP (general practitioner) practices and offering ongoing support. But too often support after diagnosis is non-existent. One strongly positive development is that the 2018 National Institute for Health and Care Excellence (NICE) Guidelines recommend that every person with a diagnosis should have a named clinical person to contact.[3] Another positive development is the Alzheimer's Society (UK) pilot programme, Connect, which will link by telephone everyone with a diagnosis of dementia with a named person.

But it is still not widely acknowledged that a diagnosis of dementia is the start of usually many years of a slowly deteriorating mental and physical disorder with unpredictable challenges for all involved. Every country

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needs a skilled workforce properly paid for the job to help care for people in their own home and in care homes. We train teachers to teach our children. We need to train a workforce to take care of our older people with dementia. This is simply not happening in the UK or anywhere. The establishment of such a workforce would go some way to eliminate stigma.

Over the last seven years I've taken on several additional roles in the field. I have become a dementia specialist adviser to one of the largest care home companies in the UK, Care UK. In line with some other similar companies it has now fully acknowledged that the majority of its residents have some degree of dementia. Comprehensive training in dementia care is being carried out by staff from Worcester University together with lead staff in Care UK. As part of my role in the company, I deliver talks on 'understanding dementia' to people living in the community. These are free discussion events bringing me in close touch with the challenges people are facing.

For the last five years I have chaired the advisory group of a large research programme (IDEAL) looking at the meaning of living well with dementia by recording the experiences of people living with dementia and their carers after diagnosis.[i] On the advisory group, as well as professionals, there are people living with dementia and their carers.

In addition, on behalf of ADI, I have become a member of the advisory group for the research programme STRiDE (Strengthening responses to dementia in developing countries).[ii] This research aims to examine the way dementia is regarded, diagnosed and managed in a number of low- and middle-income countries. The group recently met in Cape Town where I was able to take an active part in our regional meeting of African National Associations.

Finally, and very sadly, my personal experience of dementia has vastly increased over the last seven years. Some of my closest friends are now living with a progressive dementia. My husband and I see them regularly, invite them to our home with or without their partners to give their partners a break. We have them to stay with us on holiday. I see them all at close quarters. I have to say I am often shocked, deeply taken aback by their attitudes to dementia and for the time it takes for them to accept the diagnosis. These are all people who are intelligent, well read and highly educated. Yet they simply cannot admit to significant memory problems either that they have themselves or that the person they are living with has. This is partly, but perhaps only partly, because they think dementia is a shameful condition. You can talk about your glaucoma, deafness, arthritis, heart bypasses, cancers, even depression and Parkinson's disease, but admitting to dementia is a step too far. Apart from stigma, this is partly because of accompanying radical physical and personality changes in the person with dementia. It is also partly because we do not have effective treatments but then this is also true for many of the conditions I have just mentioned.

One issue of which this personal experience with friends has taught me is what a difference it makes to carers if they can call on paid or voluntary help that is individually tailored to their needs. Of course, a national work force would help in providing a source of such help, but often it is not so much training as the right sort of personality and previous experience that seems most important.

Let me finish on an even more personal note. In 2012 I was a woman of (not to be too specific!) a certain age. My age is now even more certain. My chances of experiencing dementia have gone up. If I do develop dementia, I have numerous advantages over many others with that condition. I have professional knowledge about it and ready access to local excellent services. I have a family and many friends who would be supportive and helpful. I can afford good care. I would feel no shame at having the condition. And yet … and yet I still dread getting it. Of course, I know all about the fact that one can still lead a good life even if one has the condition. But the loss of all my lovely memories, the experience of confusion when I could not find my way about anymore, the humiliation of having to rely on others for my personal care, all these I dread. Let us not exaggerate the effect that overcoming the disadvantages that stigma brings with it. The complete removal of stigma which, of course I fervently desire, would result in a better life for those with dementia and their carers but it would remain an unutterably distressing condition. It has become even clearer over the past seven years that anything that can meaningfully be called a cure is still many years away. Roll on effective prevention!

(i) Find out more: http://www.idealproject.org.uk/

(ii) Find out more: https://www.stride-dementia.org/

References

1 Alzheimer's Disease International, 2012. World Alzheimer Report 2012: Overcoming the stigma of dementia online: < https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf> Last accessed 20 August 2019.

2 World Health Organization. Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0. online: <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1> Last accessed 19 August 2019.

3 National Institute for Health and Care Excellence. 2018. NICE guideline NG97 *Dementia: assessment, management and support for people living with dementia and their carers* online: <https://www.nice.org.uk/guidance/ng97/chapter/Recommendations> Last accessed 20 August 2019.

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3.2 Stigma, dementia and age



Contributor: Silvia Perel-Levin, International Longevity Centre Global Alliance (ILC GA) representative to the UN, Geneva; Chair, Geneva NGO Committee on Ageing

Dementia is not an inevitable result of ageing. However, as the risk of getting dementia greatly increases with age, people living with dementia are likely to experience a "double stigma". Because age is the major risk factor in developing dementia, those with the condition often experience the effects of dementia stigma in addition to the broader ageism older people encounter and the distinction between the two types of stigma often becomes blurred.[1]

We all age. That is a fact of life. More and more women and men live very long lives. However, everyone seems to want to live longer but only in good health and without getting older. Growing old does not mean that we cannot do the things we like doing. In fact, we can. There is evidence to support that many people over 60 are able to function in the same way as many people in their 20s or 30s. Therefore, the assumption that old age equals natural and inevitable decline is not totally accurate and has hidden preventable inequalities in the quality of life of older people.[2]

Despite the fact that older persons are able to function in multiple ways, we seem to require permission from society, our families or close ones in order to do the things we value, or indeed do them in hiding because we are either largely invisible, or would be looked at as a curious specimen, considered "demented" and too often be stripped of our rights. Prejudice and assumptions rule our lives. We are forced to retire, or to give up many of our routine activities simply because either we reached a certain age or because we were diagnosed with an "age-related" disease, regardless of what a person can or wants to do. No other disability acquired at younger "working age" would be treated in such a discriminatory fashion.

When a person has dementia, the condition takes over as the main descriptor of who they are. The stigma cancels the individual's personality or personal history. Care systems focus on the dementia rather than the needs of the individual. Inadequate medication management, and misinterpretation of symptoms mean that many people are receiving poorer services. This is in addition to the broader ageism in the healthcare system, which can also lead to reduced access to services. Old age is perceived as a synonym of frailty and cognitive decline and we are all put in the same bag, as if we were all the same.

Old age is perceived as a synonym of frailty and cognitive decline and we are all put in the same bag, as if we were all the same.

Ageist attitudes, combined with the stigma of the disease, will also have a detrimental impact on training and the development of practice amongst professionals and care staff. These attitudes contribute to the persistent and defeatist pessimism that characterize services for older people, especially those with dementia.[3]

People with dementia are likely to live with other medical conditions, many of which could be preventable and are often undiagnosed. People with dementia are not treated the same way as people without dementia.[4]

Ageism and the discrimination against individuals or groups, on the basis of their age, are the root cause of the multiple challenges that older persons face in all aspects of life. Ageist attitudes lead to lower quality of life, lack of access to preventive, adequate health care or rehabilitation services, and to abusive practices, such as refused or undignified treatment.

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Pension schemes are inadequate, as they are not conceived to cover care-related needs, but for the loss of work-related income. In fact, only one in four people over 65 in low and middle-income countries receives a pension at all (UN 2018). Abuse, including social isolation, neglect, physical restraints, disrespect for individual choices, being deprived of day-to-day decisions, of liberty, of privacy or of palliative care can be a reality for older persons both at home or in an institution. This abuse is mostly hidden and tolerated with lack of legislation or regular monitoring or adequate protection standards.

Older persons worldwide experience discrimination and the violation of their human rights at family, community, institutional and societal levels. Older persons with disabilities, their loved ones and caregivers, face numerous barriers. There are big inequalities between older persons who need support in their daily activities compared with younger persons with disabilities. Older persons are rarely consulted in decision-making processes meaning that their specific situation remains largely unknown and unaddressed.

Despite the fact that most international human rights treaties apply in principle to people of all ages, specific reference to older persons is rare, including in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Concerns are often expressed about possible conflicting messages and a perception of lack of cooperation between the movement for the rights of older persons and the disability movement, for example on issues of accessibility or legal capacity.

Often, older persons may not want to be identified as having a disability, despite having significant difficulties in functioning, because they may consider their level of functioning appropriate for their age. Should they be considered persons with disabilities because they encounter the same barriers even if they do not see themselves as having a disability? Persons with early onset dementia or another disability may not want to be identified as old. Should a person consider herself or himself old simply because society has put an arbitrary age or other characteristic to limit their activities and entitlements?

Human Rights are indivisible, interdependent and interrelated. Denying rights to one is like denying them to everybody. Denying one right is like denying them all. We all are human rights holders, whatever our gender, race, ability, health or any other status. The rights of persons with dementia need to be looked at with a perspective of disability, gender and age. After all, we are all ageing. It is crucial to ensure a human rights-based approach to dementia beyond the narrow medicalisation of the issue. People living with dementia have the right to participate in society and those who violate their human rights should be held accountable.

The United Nations Open-Ended Working Group on Ageing (OEWG), for the purpose of strengthening the protection of the human rights of older persons, was established by the UN General Assembly in 2010. An international convention on the rights of older persons will provide a definitive, universal position that age discrimination is morally and legally unacceptable.

References

1 Evans S. C, 2018 in Ayalon L, Tesch-Römer, C (eds.), 'Contemporary Perspectives on Ageism' International Perspectives on Aging 19.

2 Venkatapuram et al. 2017. Bulletin of the World Health Organization 95:791-792 online: < https://www.who.int/bulletin/volumes/95/11/16-187609/en/> Last accessed 20 August 2019.

3 Milne, A. 2010. 'The 'D' word: Reflections on the relationship between stigma, discrimination and dementia' Journal of Mental Health 19:3, 227-233.

4 Scrutton, J and Brancati, C. U. 2016. Dementia and comorbidities; Ensuring parity of care ILC UK online: <https://ilcuk.org.uk/wp-content/uploads/2018/10/Dementia-and-Comorbidities-Ensuring-Parity-of-Care.pdf> Last accessed 20 August 2019.

Further reading

Global Alliance for the Rights of Older People (GAROP): https://www.rightsofolderpeople.org

UN, 2018 Report on the World Social Situation: https://www.un.org/development/desa/dspd/report-on-the-world-social-situation-rwss-social-policy-and-development-division/2018-2.html

UN Open-ended Working Group on Ageing: https://social.un.org/ageing-working-group/

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3.3 Thinking more deeply about dementia friendliness

Contributors: Dr Linda Barclay, Philosopher at Monash University, Australia specialising in disability and justice. Glenn Rees, Chair, Alzheimer's Disease International

The priority of every Alzheimer's association this century has been to achieve a greater awareness and understanding of dementia - a natural response to the negativity and myths that have been associated with dementia for centuries. There has been an assumption that greater understanding and awareness are key to tackling stigma.

A more positive way of talking about dementia has been made possible by many new insights over the last two decades. The legacy of Tom Kitwood (author and founder of the Bradford Dementia Group), and knowing that good dementia care is person-centred and based on the needs of the individual rather than the task or the organisation are examples; along with the improved evidence base for dementia reduction; the knowledge that the pathology of dementia develops in the brain decades before symptoms appear, meaning that timely diagnosis and disease modifying treatments may delay onset; and that Alzheimer's medications have resulted in changed attitudes of doctors towards treating the symptoms of dementia.

There has also been recognition of providing guidance on the language used around dementia - avoiding terms like 'dementia sufferers' - and in some countries a new word for dementia has been introduced to remove previous contemptuous connotations.

The thinking has been broadened beyond awareness under the banner of dementia friendly.[1&2] It has taken multiple forms through:

- Social support: Memory cafes where people with dementia often meet, with informal carers and the wider community; volunteer programmes in community gardens, activity programmes to enable the person to continue their interests
- Greater public awareness: exemplified by the 'dementia friends' programmes in Japan, South Korea and the United Kingdom which provide basic dementia awareness training in the community
- Inclusive communities: setting up an alliance in the community involving local government, people with dementia and their families, and health services to identify ways in which the community could be made more dementia inclusive
- Better quality health and dementia services: increasing the capacity of the workforce to be dementia friendly by training staff in health services and identifying them as dementia friends
- Improving the physical environment: whether in private homes or residential facilities, public spaces or government buildings

These developments are recognised in action area 2 of the WHO Global dementia action plan on the public health response to dementia 2017-2025 in Dementia Awareness and friendliness.[3] The rationale for action in the Global action plan is that "Increasing public awareness, acceptance and understanding of dementia and making the societal environment dementia friendly will enable people with dementia to participate in the community and maximise their autonomy through improved social participation". The Global action plan goes onto state "A dementia friendly society possesses an accessible community environment that optimises opportunities for health, participation and security for all people, in order to ensure quality of life and dignity for people with dementia, their carers and families."

The question is how far can we rely on awareness and dementia friendliness alone to achieve a reduction in stigma and improve quality of life for people with dementia?

Quality of life

To reflect on the impact of dementia-friendly programmes it is necessary to think about what a good quality of life for a person with dementia might consist of. Some of the main elements that are widely recognised to contribute to quality of life are the following:[4]

Well-being. Being content, happy, feeling safe, experiencing pleasure and joy, having a sense of self-worth and purpose can all enhance a person's quality of life. Conversely, suffering pain, distress, fear, loneliness and humiliation can all detract from the quality of one's life.

We also rely on more objective measures in quality of life assessments. Health outcomes, income and quality housing, to name just a few, are often taken to be reliable indicators of some aspects of quality of life. Very poor health, poverty, insecure or poor-quality housing can all negatively impact quality of life.

Autonomy/Independence. It is hard to overstate the prominence of respect for individual autonomy or decision-making in health care contexts over the last 50 years. In cases where the necessity of substituted decision making or guardianship had been assumed, the emphasis has shifted to supported decision-making where possible, or a reliance on advance directives. Such options prioritise the values and preferences of the person affected as much as possible and assumes that doing so is at the heart of promoting a good life for each individual.

Equality. Along with autonomy, the value of equality has been equally prominent in discussions of quality of life and in medical ethics. Equality usually refers to our equal worth: despite all the differences between people – in their cognitive or physical capacities, in their ethnicity,

religion, gender or sexual orientation, in their age or level of wealth and so on – we are all of equal worth. It is widely recognised that people who are routinely treated with disrespect, as inferiors, have reduced quality of life.

The impact of awareness and dementia friendliness

How effectively are dementia-friendly programmes likely to promote well-being, autonomy and equality?

People on the receiving end of stigmatised attitudes and behaviour and the related social isolation are more likely to suffer a range of poor health outcomes and have reduced capacity to secure important needs, such a health, personal care and other support services. For people with dementia this starts with under diagnosis and failure to provide post diagnostic support which both stigmatises and increases the difficulty of accessing services that respond to their individual needs and builds on their capacities. It continues with frequent physical and medical abuse in institutional care.

Information and knowledge about dementia are needed because the ignorance around dementia results in discrimination, loss of rights and perpetuates negative beliefs towards those affected by the disease. But in all countries stigma and social exclusion is rarely just the result of ignorance. Social structures also play a part and need to be addressed by governments through legal protections and services.

Insofar as awareness and dementia friendliness can play a role in reducing stigma and facilitating inclusion, they can obviously promote well-being. It is likely that people who experience positive and warm relationships and are active in their communities are more likely to report feeling satisfied with their lives, to have a sense of self-esteem and purpose, and are less likely to suffer various forms of neglect. Training and education for informal carers and paid staff will also help. So, dementia friendly projects that focus on inclusion, social engagement that enables the person with dementia to continue their interests, and mentoring that enables voluntary and paid employment will have practical benefits.

Low income countries have generally not experienced the positive changes in the way dementia is talked about in high income countries. The stigma of dementia is great because of ignorance around dementia, other pressing health priorities, poor health infrastructure and cultural and spiritual factors. There is a need for information and knowledge about dementia among carers, care workers, healers and the community, in recognition of the fact that a lack of understanding of the condition fuels fear and discrimination and perpetuates negative beliefs towards those affected by the disease. In these countries stakeholder groups will require a better understanding of dementia and to adopt approaches that respond to the cultural understanding of dementia and beliefs about the causality of the condition.[5]

However, in all countries stigma and social exclusion is rarely just a result of ignorance. This concern is closely related to a deeper issue which can be provocatively presented as a question: how many of the difficulties confronting people with dementia are just “in the head”? In other words, to what extent does the stigma and exclusion experienced by people with dementia stem from ignorance and bad attitudes, as opposed to stemming from broader social *structures*?

The impact of social structures on stigma is arguably pervasive and insidious. For example, a diagnosis of dementia maybe used to exclude individuals from some forms of care e.g. rehabilitation and palliative care. Conversely, the absence of a diagnosis or post diagnostic support, for the majority of those with dementia, denies them access to health services. When people are excluded from the workforce, or do not receive the right resources to maintain their independence, then the effect can be that stigma around dementia is reinforced. When people do not receive adequate assistance to live in decent housing with high-quality support services, or when their own choices and decisions are not respected, then stigma is at play. And discrimination extends beyond services to research, where the priority for dementia research is clearly less than second best to what has been invested in cancer and HIV/AIDS.

In other words, we need to be modest in our expectations about how much awareness and dementia friendliness on their own can do to tackle stigma and social avoidance. In the light of serious under investment in medical research and treatment, housing and support services, and without legislative action to improve

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accessibility and address discrimination, stigma will persist, because it is reinforced daily.

The disability rights movement

We have much to learn here from the disability rights movement. The disability community prefers to talk about disability *rights*, rather than disability friendliness, an older and largely abandoned phrase. Resources, accessibility and protection from discrimination are fundamental entitlements, enshrined in the Convention on the Rights of Persons with Disabilities (CRPD), now ratified by the vast majority of the world's countries. Their delivery is not an act of friendliness (or kindness): it is a fundamental right owed to all members of the community. Failure to secure them is now described as a failure to respect the rights of people with disability, a failure to treat them as equals and respect their dignity. The blind philosopher Adam Cureton has dubbed it 'offensive beneficence' when a person's rights are offered as an act of charity, kindness or generosity.[6]

In addition, people with disability also remind us that however well intentioned, action that does not aim at supporting their capacities to make their own decisions and manage their own lives, can do more harm than good. We can seek to be welcoming, helpful and friendly to people with disabilities, yet they may experience it as paternalistic or even condescending. Most people with disability want their relationships with others to be directed by their own views about what their needs are, as much as is possible, and based on recognising them as capable. Anything less, however well-intentioned, it is often said, is to fail to treat them as equals.

While the CPRD includes dementia, and much has been made of the need to normalise dementia and refer to it as a disability, the language and emphasis of dementia-friendliness is quite different to what is widely preferred in the disability rights movement. In that movement, reference to 'special needs' and 'assistance' has been replaced with 'human rights', 'fairness' and 'opportunity'. When disability advocates talk about 'normalising' disability, part of what they mean to do is reject assumptions that disability is a 'deficiency' or even a 'disease', but instead a normal part of human variation.[7]

As advocates for people with dementia, do we want to also deny that dementia is a disease, or deny that it is often experienced as a very negative development in a person's life? Would borrowing this view from the disability rights movement do justice to the experience of people with dementia and their loved ones? There is a need for careful reflection on exactly how and why dementia advocacy can be part of the broader disability rights movement.

Conclusion

Awareness and dementia friendliness have a role to play in changing the way we think about dementia and achieve practical change to make societies more inclusive of people with dementia. But there is a risk that generalised notions of awareness and dementia friendliness may distract from the most important factors in ensuring a good quality of life for people with dementia and their loved ones – namely, resources and protections of various kinds: investment in diagnostic and health care resources and research, adequate income, housing, and high-quality support services, accessible environments and legal protection from discrimination, to name just a few. We should never underestimate the tendency of governments everywhere to support and prioritise solutions that shift focus away from their own responsibilities and demand less of them in terms of resources and legislative action.

Finally, we should be thinking more deeply about the relationship between dementia advocacy and the disability rights movement.

References

1 Alzheimer's Disease International. 2016. Dementia Friendly Communities: Key Principals (1st Edition) online: <https://www.alz.co.uk/dementia-friendly-communities/principles> Last accessed 19 August 2019.

2 Alzheimer's Disease International. 2017. Dementia Friendly Communities: Global developments (2nd Edition) online: <https://www.alz.co.uk/adi/pdf/dfc-developments.pdf> Last accessed 19 August 2019.

3 World Health Organization. Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0. online: <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1> Last accessed 19 August 2019.

4 Routledge Handbook of the Philosophy of Well-Being (First edition) London: Routledge; 2015.

5 Alzheimer's Disease International. 2017. Dementia in Sub-Saharan Africa online: <https://www.alz.co.uk/research/dementia-in-africa> Last accessed 19 August 2019.

6 Cureton, A. 2016. 'Offensive Beneficence' Journal of the American Philosophical Association 2(1) online: < https://www.cambridge.org/core/journals/journal-of-the-american-philosophical-association/article/offensive-beneficence/7CCBCE6ACE96D26CA4FF3ABB0C46E11C> Last accessed 19 August 2019.

7 Barclay, L. Disability with Dignity. Human Rights, Justice and Equal Respect. London: Routledge; 2019.

3.4 The role of the media: Help or hinderance?



Contributor: Pippa Kelly, UK. Journalist, dementia blogger, public speaker.

Since Julie Austen's husband David was diagnosed with Alzheimer's disease three years ago her younger brother hasn't talked to her. Her mother and sister-in-law keep asking when David, 66, will get better.

The 59-year-old East Sussex woman believes her relatives' response to David's condition stems from lack of understanding. *"I don't know if it's the result of ignorance or because they don't know what to say".* Either way, Julie and her husband have become very isolated.

Such an extreme example of stigma might seem rare in the 21st century but it isn't restricted to uninformed members of the public. Stephen Atkinson-Jones' 89-year-old mother Audrey has Alzheimer's and shares her flat in Bexhill-on-Sea with a live-in carer.

This January, Audrey was admitted to hospital with an impacted bowel and various infections. Stephen says the green leaf mounted above Audrey's bed to show she had dementia was ignored and when he asked why she wasn't being given a CT scan the consultant told him there was no point as *"something was going to get her anyway."* His mother would poison herself, Stephen was told, by vomiting her own faeces.

Stephen is convinced that this extraordinary lack of care was due, not to hospital failings, but the preconceived idea that Audrey wasn't worth treating because of her dementia.

It's not uncommon to hear stories such as Audrey's in the media. In the last five to ten years dementia campaigners have gained a voice – I say this with authority because (as well as being a journalist) I am one. Where injustice and stigma lurk, we speak out against it.

Stigma stems from fear. Fear breeds silence, which in turn perpetuates ignorance and misunderstanding. The key to killing off stigma lies in communication, of which we members of the media are, like it or not, the most skilled operators. So, how well are we professionals doing with this, what can we do better and what can organisations such as Alzheimer's Disease International do to help us?

The first thing to remember is that the media's role is not to combat stigma or disseminate messages from dementia organisations, it's to attract readers, viewers and listeners. But the media and dementia sectors can benefit each other. The media need powerful, newsworthy human-interest stories and it's up to those in the dementia community to understand what these are and provide them, quickly and accurately.

One of the biggest sellers of newspapers – for which read, "What the public really want to hear about and are prepared to part with their money for" – are celebrities. Which is why any dementia story with a famous name will make the news – in the UK think of Terry Pratchett (author), Prunella Scales (actor), David Baddiel (comedian and author). Celebrities make great news copy because the public relate to them – they think (bizarrely) that they know them.

Once a condition such as dementia is given a human face, your attitude towards it changes. Gone is the stigma and fear: mum may be behaving in an unusual way, she may be incontinent or unable to speak properly, but she's my mum. Barbara Windsor (UK actor) may have dementia but she's still "Babs" from countless Carry On films and latterly the Queen Vic (from the UK Soap

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EastEnders). These well-known, familiar faces bring home to us what dementia is. Use them. They show us that this frightening condition (it's the one that over 55s fear most) doesn't strike others, it strikes us.

Stigma stems from fear. Fear breeds silence, which in turn perpetuates ignorance and misunderstanding.

This sense of togetherness plays an important role in reducing stigma. Once dementia affected my mother I wanted to find out about it, in both human and practical terms, whereas before I'd turned away from it, metaphorically crossed the road away from it (a move guaranteed to breed stigma).

Which calls into question the merit of initiatives such as the Dementia Friends scheme and Dementia Friendly communities and shops. Is it helpful to compartmentalise those with dementia? I believe we're still in the early stages of informing people and changing perceptions, we're still raising awareness. To this end, public campaigns with clear and simple messages work.

The key is to build on these first steps, to ensure people understand that being dementia friendly means more than sticking a green leaf above a hospital bed, then ignoring it. It means appreciating that someone with dementia may not be able to identify the coins in their pocket, need more time at the till, have a problem with their balance or sight, may have a better memory in some respects than you or me – and it means respecting the brilliance with which those same people still sing, identify a little-known shrub or whittle a piece of wood.

In terms of the media, it means seeking out case studies that show – to the very best advantage – all of the above. When a Sainsbury's (a supermarket) in north London found different ways to keep employing a woman with dementia, it made it into all the national newspapers and onto national TV. It was a first-class human-interest story with which everyone connected. These stories are out there – find them, ensure you have the consent of everyone involved and feed them to the media.

An even more successful method of banishing stigma via the media is through the soft power of culture. Virtually every radio and TV soap opera contains a dementia storyline. When well executed, popular entertainment programmes such as the BBC's Our Dementia Choir (fronted by a celebrity with a personal interest in the subject) powerfully yet subtly convey to their several million viewers various stigma-busting messages.

UK dementia campaigners often tell journalists to use the phrase "people living with dementia" instead of "dementia sufferers" and avoid dramatic descriptions such as "a tsunami of dementia" in order to combat stigma. I understand the logic, but would you rather a national newspaper or TV station covered a story to raise awareness of young onset dementia using the phrase "dementia sufferers" or didn't cover it at all?

Compared to the relatively nuanced stigma encountered here in the UK, those living with dementia in other parts of the world face open hostility – in the black Caribbean they are sometimes viewed as possessing evil spirits. In recent years an elderly woman with dementia was found chained in a hut in the Kunene region of Namibia; she'd been kept there for twenty years for being a witch. On the other hand, unlike many minority ethnic communities, where elders are respected, British society tends to devalue old age, producing a double jeopardy of stigma.

I'm often told, "Dementia's where cancer was 30 to 40 years ago". Is it? A major breakthrough in reducing stigma around the Big C (as it was then referred to in hushed tones) occurred in 1965 when Richard Dimbleby, the "voice of the nation", announced on national television that he had testicular cancer. This wasn't 30 but 54 years ago.

In the first piece I wrote about my mother in 2006 I described her, in a national newspaper, as demented. She was my mum; I didn't do so to cause offence but out of ignorance. It could be argued a) my use of ill-chosen language fuelled stigma or b) my article in itself raised awareness.

Either way, I know better now and would never use the word. Like other people, we in the media are learning and adapting as the subject of dementia looms larger in everyone's lives. Our powerful role in changing public perceptions of dementia is, like stigma itself, complicated.

3.5 Stigma in 2019; you must be joking!

Contributor: Dale Goldhawk, Vice Chair, Alzheimer's Disease International & veteran advocacy journalist.

It's odd but I have always felt a warm place in my heart for Alzheimer's disease. It might seem strange that love could ever be found anywhere near dementia. Alzheimer's is a cruel disease. It gradually erases memory, personality and the ability to function. Then, after years of decline, Alzheimer's disease leads to death.

But the love is there. It's found in the attitudes and actions of the people in the Alzheimer family. The often unsinkable nature of those living with dementia; the courageous heroes who care for them; the tireless and devoted advocates, champions, doctors and scientists who fight for effective treatments and a cure.

Just spend a little time with the devoted staff and volunteers at Alzheimer's Disease International's associations and federations in 100 countries around the world. They care deeply. They're working hard to make a difference.

And yet, our own human nature often fights against progress and awareness when we encounter dementia. You probably know people who fear it, view it with distaste, avoid it whenever possible, are uneasy with unusual behaviour and uncertain about how to react themselves.

Stigma. The Oxford Dictionary has a stark definition, calling it "a mark of disgrace associated with a circumstance, quality or person."

Stigma is often accompanied by another, greater attack against our dignity, against our inherent humanity. And that's discrimination; the unjust or prejudicial treatment of different groups of people. Discrimination, in fact, violates the law in many countries; the United Nations Convention on the Rights of Persons with Disabilities has declared that people with disabilities (including those living with dementia) must enjoy all human rights and fundamental freedoms.

My father died of Alzheimer's disease after a seven-year-long, downward journey into dementia. My mother died after a sudden heart attack; her good health badly damaged by the stress of caregiving.

Stigma closed the door on Mom and Dad. Friends stopped dropping by to visit. There were hardly any calls inquiring about Dad's condition. It was as if he were already dead.

Back then, I often encountered the heartless insensitivity of Alzheimer related jokes. When I explained to friends and acquaintances that I was volunteering for the Alzheimer Society of Canada, the reaction was often an Alzheimer's related joke. I don't think there was any malice in it. They just forgot how deeply words can hurt. They really didn't know what to say.

In the beginning I got angry. *"Not funny,"* I would say. *"There's nothing funny about cancer and not much humour in heart disease."* In later years, I offered a more reasoned reaction hoping for a teachable moment. I seldom got one. None of the people who ever tried to crack an Alzheimer's related joke with me knew anything about dementia. Perhaps that lack of knowledge produced the feeble attempt at humour.

I still remember vividly the day Mom and I took Dad to the long-term care home where he would live, since Mom could no longer care for him at home. It was a heart-breaking decision that always kept Mom (and me and my brother and sisters) close to tears. Dad was distressed. He didn't want to go.

As we pushed his wheelchair up the front walk into the home, Dad turned and looked up at Mom and said: *"you did this to me, didn't you."*

No. Nothing funny there.

So-called Alzheimer's humour does much more than annoy and hurt those who work hard to make life better for the 50 million plus people in the world living with dementia. It trivialises the disease. Worse, humour is often used as a weapon today. If you can laugh at somebody, they lose credibility. They can't be taken seriously. So, what if every 3 seconds in the world somebody develops dementia. If dementia is somehow funny, stigma has a place to grow. The sense of urgency about dementia starts to fade.

The good news is that Alzheimer's jokes are not nearly as prevalent as they once were. The attempted humour is disappearing as awareness of dementia in its most common form, Alzheimer's disease, is growing. I have seen it in my years in broadcasting, where I have often raised dementia issues in my radio and television open line programmes. In earlier years, people had trouble even pronouncing the word 'Alzheimer' but gradually people learned from listening. They started telling their own stories on television and radio, stories of how their families and loved ones cared for, and still loved those living with dementia. There were stories about how those with dementia were still able to find a little peace and quality of life. After a while, the stories about dementia families just became stories about families.

But stigma remains a tough customer. Even today when I tell people I'm involved with Alzheimer's Disease International I usually get a polite but strained reaction, occasionally a raised eyebrow and few, if any, questions about the work my colleagues and I do. It was never like that when I worked as a volunteer to help children with physical disabilities. Everybody felt comfortable asking questions. It was familiar territory. Someday soon I hope the Alzheimer's family will move securely into that neighbourhood.

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3.6 Alzheimer's disease, stigma and disclosure



Contributor: Prof Nicolas Rüsch, Ulm University and BKH Günzburg, Germany

People with mental illness as well as individuals with Alzheimer's disease struggle with two kinds of problems. On the one hand, they have to cope with the symptoms and disabilities of their disorder such as anxiety or memory problems. On the other hand, they struggle with the stigma associated with these disorders. Stigma can be a heavier burden than the disease itself. One reason that stigma has such a big impact is that it comes in three forms: public, self and structural. Public stigma occurs when members of the general public endorse negative stereotypes ('This person with dementia is contagious, I'll stay away from her'), often leading to social exclusion or discrimination in work or private settings. If people with dementia agree with negative stereotypes and turn them against themselves, this is referred to as self-stigma ('Because I have dementia, I cannot decide anything'). Self-stigma is often associated with shame, social withdrawal and secrecy. Structural stigma refers to rules and regulations, for example in health or social care settings, that disadvantage people with the disorder. Here I briefly summarise a few themes from recent research on stigma and disclosure. Colleagues such as Perla Werner, from the University of Haifa in Israel, and many others have done ground breaking research on stigma and dementia, and their work offers more thorough orientation than this brief outline[1].

Attitudes to dementia and to ageing in general have varied a lot throughout history and across cultures. The Roman philosopher and politician Cicero provides an early example in his 44 BC book 'Cato the Elder on Old Age' in which he refutes various negative views of old age and ageing. Modern approaches to dementia have been very diverse too: Alois Alzheimer thought of it as a brain disorder, while others emphasised psychosocial factors that contribute to dementia because a lack of social support for people with dementia increases their disability[2]. Recent research has produced solid evidence of widespread stigma and discrimination currently associated with Alzheimer's disease and dementia in general[1].

The media also play a role. In terms of social media, a study found that dementia is an object of ridicule on Twitter[3]. News media often use catastrophic metaphors of dementia as a wave, flood, monster, enemy or the plague of our century[4]. It is not hard to imagine how this leads to reactions such as fear and avoidance. Probably the most malicious of these metaphors is the one of people with Alzheimer's disease as zombies because it dehumanises individuals[5]. We should respond by stating the obvious: people with Alzheimer's disease are first and foremost human beings with feelings and dignity.

Given these popular images, general population surveys unsurprisingly reveal ambivalent attitudes towards people with Alzheimer's disease: On the one hand members of the general public report empathy and willingness to help, on the other hand they show anxiety and avoidance[6]. Negative attitudes shape help-seeking behaviours because they are associated with more scepticism about screening for dementia, making early intervention more difficult[7].

How do people with Alzheimer's disease react to stigma? Many, along with their carers and relatives, struggle with shame and self-stigma. Many people with Alzheimer's disease are also aware of public stigma and therefore hesitate to disclose their condition. *"It's a strange life when you 'come out' – people get embarrassed, lower their voices and get lost for words"*, wrote the novelist Terry Pratchett after he was diagnosed[1]. As for people with other mental disorders, disclosure decisions are often complex and personal and depend on the person and the environment. Both disclosure and non-disclosure have pros and cons. Disclosure carries the risk of being labelled and discriminated against; but it also facilitates help-seeking, social support and authentic exchange with others. On the other hand, non-disclosure can protect against discrimination, but may lead to social isolation, the stress and fear to be 'found out' and can be a barrier to seeking care and support.

Disclosure is not an all-or-nothing decision, but people can learn to reveal certain things to certain people. They will likely want to tell more to a close friend than to a neighbour, and more to a trusted healthcare professional than to a person in the supermarket. Navigating the continuum between varying degrees of disclosure for different addressees, people with Alzheimer's disease can learn to make strategic choices of what to disclose to whom. The decision is not whether to disclose or not to disclose, but to find the right choice and level of disclosure, if any, for each context, after weighing pros and cons. This is a continuing process as people can and will learn from previous experiences of (non-) disclosure. It is helpful if people with Alzheimer's disease and their carers discuss disclosure decisions together. Patrick W. Corrigan and his colleagues in Chicago developed "Honest, Open, Proud" (HOP; www.hopprogram.org) as a peer-run group programme that supports people with mental illness in such disclosure decisions. It is HOP's aim to empower people to make their own decisions and to enable them to tell their stories safely, if they decide to do so. As disclosure and non-disclosure are one way to cope with public and self-stigma, HOP has the potential to reduce self-stigma. A couple of evaluations of the HOP programme have shown reductions in self-stigma and other positive effects among participants[8]. HOP has been adapted for a range of target groups, and Jem Bhatt, University College London (UCL), and her colleagues in London are currently working on a version for people with dementia.

Based on self-confident disclosure decisions, people will gain confidence whether, how, and when to tell their story. This can be an important part of their recovery – or, in other words, of their living as well as possible with dementia. First-person narratives of people with Alzheimer's disease, available online or in books, about their lives with the disease are also one of the best ways to reduce public stigma. Through these stories, members of the general public can learn about the perspectives of people with Alzheimer's disease and reflect on their views and stereotypes. For people with Alzheimer's disease, telling their story can be an act of self-affirmation and resistance against the disease and the associated stigma. Such stories may describe disability and loss, but also coping, as an opportunity for growth and for refocusing on important things in life[9]. Many stories show acceptance and gratitude for one's life. Telling one's story can evolve into art: there are moving poetry collections of people with Alzheimer's disease and other dementias online (e.g., www.alzpoetry.com/read-me). Participation in and experience of art for people with Alzheimer's disease can be found in museums, theatres and other cultural institutions. Along with media education and other targeted anti-stigma efforts, these kinds of grass-roots programmes may be the best way to counter stigma and empower people with Alzheimer's disease[10]. As stigma contributes to the burden of Alzheimer's disease and other types of dementia, programmes of this kind should be evaluated and, if successful, more widely implemented.

References

1 Werner P 2014. Stigma and Alzheimer's disease: A systematic review of evidence, theory, and methods. In: Corrigan PW (Ed.) The stigma of disease and disability: Understanding causes and overcoming injustices. American Psychological Association, Washington, 223–244.

2 Ballenger JF 2017. ‚Framing confusion: Dementia, society, and history.' *AMA J Ethics* 19(7):713–719.

3 Oscar N, Fox PA, Croucher R et al. 2017. ‚Machine learning, sentiment analysis, and tweets: An examination of Alzheimer's disease stigma on Twitter.' *J Gerontol B Psychol Sci Soc Sci* 72(5):742–751.

4 Zeilig H 2014. ‚Dementia as a cultural metaphor.' *Gerontologist* 54(2):258–267.

5 Behuniak SM 2011 ‚The living dead? The construction of people with Alzheimer's disease as zombies.' *Ageing & Society* 31(1):70–92.

6 von dem Knesebeck O, Angermeyer MC, Ludecke D et al. 2014. ‚Emotional reactions toward people with dementia: Results of a population survey from Germany.' *Int. Psychogeriatr.* 26(3):435–441.

7 Martin S, Kelly S, Khan A et al. 2015. ‚Attitudes and preferences towards screening for dementia: a systematic review of the literature.' *BMC Geriatr* 15:66.

8 Mulfinger N, Müller S, Böge I et al. 2018. ‚Honest, Open, Proud for adolescents with mental illness: Pilot randomized controlled trial.' *Journal of Child Psychology & Psychiatry* 59(6):684–691.

9 O'Connor D, Mann J, Wiersma E 2018. ‚Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship.' *J Aging Stud.* 44:45–51.

10 Bienvenu B, Hanna G 2017. ‚Arts participation: Counterbalancing forces to the social stigma of a dementia diagnosis.' *AMA J Ethics* 19(7):704–712.

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3.7 The costs of dementia: advocacy, media and stigma



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The costs of dementia to society are very large and have been estimated to have reached 1 trillion dollars globally in 2019[1]. The scale of these costs is widely used for advocacy, in order to argue for a public health policy response, and also to make the case for increased public and private funding on research to find a disease-modifying treatment.

In some cases, to create a sense urgency, campaigners present dementia as an "economic catastrophe", suggesting that the costs of dementia are unsustainable. However, it is important to clarify that stating that because the costs of dementia care are high, they are not sustainable, involves an intellectual short cut. It takes a leap from the research finding that the costs are large and will be even larger in the future, to the conclusion that this will be unsustainable. The assessment of the sustainability of costs is different than their simple calculation: it requires consideration of a wider range of economic, fiscal, political and public factors. In fact, it may be that the current levels of public funding for the care, treatment and support of people living with dementia in many countries is unsustainably low (as compared to the size of the economy, the fiscal capacity of the country and the values of its citizens).

And how is this relevant to stigma? Campaigns that emphasize dementia as an "economic catastrophe" may be contributing to public, private and structural stigma (see Prof Nicolas Rüsch's essay in this volume). With regards to public stigma, most academic studies that have looked at how dementia is represented in the media and popular culture report on the frequent use of metaphors that invoke natural disasters (such as "rising tides", "silent tsunami"), the language of war or weaponry ("time-bomb"), comparisons to infectious diseases ("silent epidemic")[2,3,4]. This is often coupled by language emphasizing "financial imperatives": "burden, weight, crisis", suggesting that the societal and economic costs of dementia cannot be managed[2,4].

The language of burden and crisis is often coupled with one of blame, in a "panic-blame" framework (as identified by Peel[3]), which may contribute to private stigma. The "blame" part of the messaging comes from presenting findings around risk reduction in ways that over-emphasize individual responsibility, implying that those who go on to develop dementia are to blame for not

having "behaved well". In fact, the evidence suggests, that at most, only a quarter of the risk of developing dementia can be attributable to modifiable factors[5].

While the argument that "the costs of dementia are so large that unless we find a cure, dementia will bankrupt us" may work well in terms of persuading donors and policymakers to support biomedical research, there is a danger that it may also contribute to structural stigma, by suggesting that our health and social care systems cannot do anything about addressing the challenges posed by dementia. There have long been concerns that advocacy campaigns that use cost of dementia studies to promote the idea that dementia is an economic catastrophe could be hampering the development of policies to address the care, treatment and support of people who are currently living with dementia and their carers[6,7,8].

In fact, other than highlighting the economic importance of dementia, the real value of cost of dementia studies (that are based on individual level data) lies in what they tell us about what the main cost components are (e.g. inpatient health care, primary care, medicines, social care, unpaid care), who bears the costs (health or social care system, families), who has access to services and what the reasons are for cost variability[9,10]. A more nuanced understanding of how we are currently spending on dementia can help us better prepare for a future when more of us will be living with dementia.

We know, for example, that the models of dementia health care predominant in high-income countries are very reliant on the role of specialist care, but in most countries there are already shortages of dementia specialists, usually neurologists, old-age psychiatrists and geriatricians[11]. The World Alzheimer Report 2016 explored evidence-based alternative models of dementia health care based on primary care and specially trained health workers that could potentially be expanded to deliver similar quality of care to larger numbers of people and a lower cost per person covered[12]. We also know that there are cost-effective dementia care, treatment and support interventions that could be more widely adopted.

Addressing public, private and structural stigma surrounding dementia requires a concerted effort. Dementia advocacy organisations face a difficult balance between communicating the importance and urgency of policy action on dementia while at the same time ensuring that the language and messaging they are using is not hampering their own efforts to reduce the stigma associated with dementia.

References

1 Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., Prina, A. M., Winblad, B., … Prince, M. 2017. 'The worldwide costs of dementia 2015 and comparisons with 2010.' Alzheimer's & Dementia : The Journal of the Alzheimer's Association, 13(1), 1–7. https://doi.org/10.1016/j.jalz.2016.07.150 Last accessed 30 August 2019.

2 Burke, L. 2017. 'Imagining a future without dementia: fictions of regeneration and the crises of work and sustainability.' *Palgrave Communications*, 3(52), 1–9. https://doi.org/10.1057/s41599-017-0051-y Last accessed 30 August 2019.

3 Peel, E. 2014. "The living death of Alzheimer's" versus "Take a walk to keep dementia at bay": representations of dementia in print media and carer discourse. *Sociology of Health & Illness, 36*(6), 885–901. https://doi.org/10.1111/1467-9566.12122 Last accessed 30 August 2019.

4 Zeilig, H. 2014. Dementia As a Cultural Metaphor. *The Gerontologist, 54*(2), 258–267. https://doi.org/10.1093/geront/gns203 Last accessed 30 August 2019.

5 Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K., & Brayne, C. 2014. Potential for primary prevention of Alzheimer's disease: An analysis of population-based data. *The Lancet Neurology*, 13(8), 788–794.

6 Binstock, R. H., Post, S. G., & Whitehouse, P. J. 1992. *Dementia and aging : ethics, values, and policy choices*. Johns Hopkins University Press.

7 Blank, R. H. 2019. *Social & Public Policy of Alzheimer's Disease in the United States*. Singapore: Springer Singapore. https://doi.org/10.1007/978-981-13-0656-3. Last accessed 30 August 2019.

8 Manthorpe, J., & Iliffe, S. 2016. *The dialectics of dementia*. London. Retrieved from https://www.kcl.ac.uk/sspp/policy-institute/publications/The-dialectics-of-dementia.pdf

9 Byford, S., Togerson, D. J., & Raftery, J. 2000. Economic Note: Cost of illness studies. BMJ, 320(7245), 1335. https://doi.org/doi: 10.1136/bmj.320.7245.1335.

10 Tarricone, R. 2006. Cost-of-illness analysis: What room in health economics? *Health Policy*, 77(1), 51–63. https://doi.org/10.1016/J.HEALTHPOL.2005.07.016 Last accessed 30 August 2019.

11 Hlávka, J. P., Mattke, S., & Liu, J. L. 2018. *Assessing the Preparedness of the Health Care System Infrastructure in Six European Countries for an Alzheimer's Treatment*. Retrieved from https://www.rand.org/content/dam/rand/pubs/research_reports/RR2500/RR2503/RAND_RR2503.pdf Last accessed 30 August 2019.

12 Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). *World Alzheimer Report 2016: Improving healthcare for people living with dementia. Coverage, quality and costs now and in the future*. London. Retrieved from https://www.alz.co.uk/research/world-report-2016 Last accessed 30 August 2019.

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3.8 Women as carers: gender considerations and stigma in dementia care



Contributor: Dr Nicolas Farina, PhD, MSc, BSc, Research Fellow in Dementia, Centre for Dementia Studies, Brighton & Sussex Medical School.

Dementia has a profound impact on those close to the person with dementia, particularly the family and family carers. Whilst some family members may find meaning in their new caring role, family carers often experience worsening physical and mental health, poorer quality of life and increased financial burden as a result of providing dementia care[1]. Gender is an area of importance in relation to dementia care, and whilst a report by Alzheimer's Disease International has previously reviewed in depth the experiences and impact of women as carers[2], it is still commonly overlooked. Female carers are likely to experience greater social restriction, and experience higher levels of burden and depression when compared to male carers[3–5]. Whilst there are many potential explanations for these gender differences (e.g. different coping strategies between men and women)[6], the route to which women specifically become carers for someone with dementia is an important determinant of negative outcomes.

Between 60% and 70% of all family carers of people with dementia are women[7]. Female spouses, daughters and daughters-in-law are more likely to take on the caring role compared to their male counterparts. The extent to which this occurs by choice is unclear, though the preference for women to take on the role as a family carer appears to stem from deep rooted gender norms. There is the common myth that women are better carers[8], and whilst there are certain personality traits that may support such notions (i.e. nurturance)[9], there is no conclusive evidence that women make better carers than men. Societal messages often dictate that caring behaviours are linked to being female, and therefore can create the expectation that women should fulfil this role when such as situation arises. These societal messages can also lead to external pressure, making women feel guilty if they choose not to adopt the carer role. Importantly, women are expected to become carers even if they do not have sufficient knowledge, or without sufficient preparation to become a carer[6]. Conversely, there is little societal pressure for men to become carers, in fact, there may be more societal and cultural pressures acting on men not to become carers. Globally there are many examples of the view that men should be masculine (e.g. machismo in Latin America), which nurturing and caring behaviours do not conform to.

Gender norms and societal pressures can also lead to men and women adopting different caring responsibilities[10]. Personal care (e.g. dressing, bathing)

is seen as difficult irrespective of gender, though male carers report greater difficultly or discomfort in completing these tasks; it is therefore it unsurprising that women are more likely to take on these roles. Men on the other hand are more likely to focus necessary tasks, separating their emotions from the caring role. As such, men may adopt a more pragmatic approach to caring, and be more willing to access external resources to support the person with dementia. Whilst it is difficult to quantify the exact value of different care provision by family members, care should be holistic and should meet all the needs of the person with dementia.

Irrespective of whether it is illness or childcare related, societal messages ultimately lead women to become the de facto carer in many situations. For some women this means adopting multiple carer roles, typically of their parent and a child. This "sandwich generation" are at greater risk of poorer physical and mental health, with also having a significant impact on free-time and finances.

The influence of societal and gender norms in women adopting the caring role are even more difficult once we consider the complexities of family dynamics and other cultural pressures. For example, within Pakistan there is the view that it is the children's responsibility or privilege to provide care for their parents if they develop an illness such as dementia[11]. Whilst this responsibility may traditionally fall to the son, gender and cultural norms can lead to the daughter-in-law becoming the primary carer. In such scenarios this can lead to additional stress and resentment, as the daughter-in-law may not want to provide, or be capable of providing adequate care. Not providing individuals a choice to be a carer leads to reluctance, which results in a deterioration in the relationship between the person with dementia and the carer, and reduced quality of care. Importantly, the hierarchy in the household may mean that the head of the house (typically male), may prevent women from speaking out, which might lead to familial strain.

Irrespective of whether it is illness or childcare related, societal messages ultimately lead women to become the de facto carer in many situations. For some women this means adopting multiple carer roles, typically of their parent and a child. This "sandwich generation" are at greater risk of poorer physical and mental health, with also having a significant impact on free-time and finances[12]. A better understanding is needed of the routes by which women become dementia carers and how these pathways impact their health and wellbeing. Due to variation of cultural and societal norms and access to paid care, this is likely to differ between countries. However, the best quality of care comes from choice, both from the perspective of the person receiving care but also from the person providing it. There is no "one size fits all" approach, and women cannot (and should not) shoulder the responsibility for providing care for family members with dementia.

References

1 Pinquart, M., Sörensen, S. 2003. 'Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis' *Psychol Aging* 18(2):250.

2 Erol R, Brooker D, Peel E 2015. *Women and Dementia: A global research revie*w, London: Alzheimer's Disease International.

3 Sharma, N., Chakrabarti, S., Grover, S. 2016. 'Gender differences in caregiving among family - caregivers of people with mental illnesses' *World J Psychiatry* 6(1):7–17.

4 Akpınar, B., Küçükgüçlü, Ö., Yener, G. 2011. 'Effects of Gender on Burden Among Caregivers of Alzheimer's Patients' *J Nurs Scholarsh* 43(3):248–54.

5 Pillemer, S., Davis, J., Tremont G. 2018. 'Gender effects on components of burden and depression among dementia caregivers' *Aging Ment Health* 22(9):1156–61.

6 Papastavrou, E., Kalokerinou, A., Papacostas, SS., Tsangari, H., Sourtzi, P. 2007. 'Caring for a relative with dementia: family caregiver burden' *J Adv Nurs* 58(5):446–57.

7 Alzheimer's Research UK. Women and Dementia: A Marginalised Majority. London, England: Alzheimer's Research UK online: < https://www.alzheimersresearchuk.org/wp-content/uploads/2015/03/Women-and-Dementia-A-Marginalised-Majority1.pdf> Last accessed 20 August 2019.

8 Pruchno, RA., Smyer, MA, Smyer, PMA. 2007. Challenges of an Aging Society: Ethical Dilemmas, Political Issues *JHU Press*, p. 474.

9 Hyde, JS. 2014. 'Gender similarities and differences' *Annu Rev Psychol* 65:373–398.

10 Friedemann, M-L., Buckwalter, KC. 2014. 'Family Caregiver Role and Burden Related to Gender and Family Relationships' *J Fam Nurs* 20(3):313–36.

11 Zaidi, A., Willis, R., Farina, N., Balouch S, Jafri H, Ahmed I, et al. 2019. 'Understanding, Beliefs and Treatment of Dementia in Pakistan: Final Report'. London: Age International.

12 DeRigne, L., Ferrante, S. 2012. 'The sandwich generation: A review of the literature' *Fla Public Health Rev* 9(1):12.

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3.9 "What Matters Most"; Conceptualizing cultural aspects of stigma of Alzheimer's disease and other dementias.



Contributor: Lawrence H Yang, Department of Social and Behavioral Sciences, New York University; Department of Epidemiology, Columbia University

Stigma is likely to be experienced differently across distinct sociocultural contexts, as stigma may be shaped by culturally patterned responses to dementia-related changes in cognition, behavioural symptoms, and/or disability. In its severe stages, Alzheimer's disease leads to diminished memory and behavioural impairments that signify loss of autonomy and sense of self, which violates fundamental Western European-American cultural values of self-control, productivity, and independence.[1-3] Yet stigma elicited by loss of these individual capacities may be further shaped in both positive and negative ways by culturally-salient factors, including normative expectations regarding the ageing process, labelling of illness, etiological beliefs, and the sociocultural experience and responses to the person and family.[4] To identify cultural features of stigma related to various illness conditions, including Alzheimer's disease, a theory has been articulated which emphasises how culture specific mechanisms shape stigma.[5,6] This theory, which conceptualises stigma in relation to "what matters most" for a cultural group, holds great promise for stigma related to Alzheimer's disease. To engage in activities that "matter most", or the interactions that define "full status" within a cultural setting, is to recognise an individual as having "full personhood" within a cultural group. Culture may thus act in varying ways to protect against, or to exacerbate stigma due to Alzheimer's disease, as this condition takes place within the context of actors (including the affected elder, family carers, and community members) striving to enact the activities that determine "what matters most" (or "personhood") within a cultural context.

The Chinese example is instructive to illustrate how the "what matters most" framework might be applied to a specific cultural group. As noted above, Alzheimer's disease leads to compromised memory, behavioural impairments, loss of productivity and ultimately loss of independence, which threatens one's claim as an "autonomous being" across settings.[1] On the one hand, traditional Chinese beliefs of normalized and expected changes accompanying ageing, i.e. that elders are like a "machine with worn-down parts", signal the inevitability of decline and may help to mitigate any stigma due to dementia-related deterioration[4,7]. Yet occurring in tandem with these normative cultural beliefs, Confucian influences, which are common in South and East Asia (e.g. China, Vietnam), dictate that parents and children are duty-bound to provide for one another. Parents first raise children; children in turn are obligated to producing offspring to perpetuate the lineage, supplying financial support throughout the lifetime, and performing rituals to ensure that support is continued into the next life.[8] The immersion into "an eternal chain of filial children" and enacting these obligations within a system of total economic, social, and spiritual support reflects "what matters most" for many traditional Chinese or Vietnamese groups; when

the onset of Alzheimer's disease is seen to violate these core cultural engagements, stigma's effects may be compounded beyond the individual's core loss of autonomy.[9] Due to unpredictable and bizarre seeming behaviours, community members may first misattribute etiological beliefs of Alzheimer's disease to a condition of severe mental health, thus implicating moral failure on the family's part. Such misattributions to severe mental illness may provide a partial explanation for why respondents to the ADI survey in the South-East Asian region endorsed that people with dementia were dangerous (45-48% - the highest among world regions) as well as impulsive and unpredictable (70% - second highest among world regions). Further, having an elder family member who is seen as severe mental illness may be viewed by community members as a sign that either current or past family members neglected to honour filial obligations (i.e., violated "what matters most").

Of further consequence, due to the elder's loss of autonomy and inability to fulfil their demands of social reciprocity within the family, compounding any stigma of Alzheimer's disease is the experience of severe loss of status as the former head of the household's social structure to someone who is incapable of living independently (e.g., being seen to require care like a child[4]). As Alzheimer's disease symptoms progress in severity, diminished participation in (and acceptance from) the affected elder's social exchange network of close social others (i.e. exclusion from "guanxi") further signals a loss of personhood. With growing perceptions of incompetence in myriad life domains, family members may decrease efforts to communicate with the affected elder, and the elder may be excluded from highly valued social activities, including family visits or events.[4] This loss of moral standing from the community's perspective may be manifested as "loss of face" among family members, in that public exhibitions of abnormal behaviours (e.g. "confused speech elicit shame among family carers"). The "diminished personhood" associated with stigma, in addition to augmenting exclusion of the elder with dementia, leads to efforts to conceal the condition by family to preserve "face"[8]; e.g. carer respondents from the South-East Asian region were the most likely (33%) among world regions to hide the person with dementia when they were out of the home or in the home. This concealment in turn has substantial effects on family carers' attempts to obtain much-needed social support from others.

Yet despite this near-complete loss of social status (or "di wei"; i.e. respect or political power) within the home due to the symptoms of dementia, the adult children's obligation to enact "what matters most" (i.e. providing material and social support throughout, and oftentimes beyond, the lifetime) remains intact. The existence of these core lived values may thus limit the extent to which the family may ultimately reject or relegate care of affected elders to professional services provided by non-kin; e.g. carer respondents from the South-East Asian region were the least likely (11%) among world regions to endorse moving a family member with dementia into a nursing home even if they were unwilling, and were also least likely (4%) among regions to be "not at all willing" to have a family member with dementia move in with them. That is, while stigma may unfold to diminish the affected elder's standing from both the family and community members' perspectives, the obligations of family members to fulfil these core lived engagements consequently shields many elders from being rejected or abandoned. Consequently, when considering stigma of Alzheimer's disease in cross-cultural settings, stigma may be experienced not just at the level of the affected individual or family, but may also be strongly shaped by the broader cultural directives that the individual, family, and community members at large are seeking to fulfil. We direct attention to the possibility that in many contexts, understanding stigma of the affected elder and bolstering support for family carers could be facilitated by considering the core, culturally-defined activities that are most prized by actors within a cultural setting. Following prior findings, ascertaining "what matters most" may not only elucidate how the most harmful effects of stigma affect life domains in affected elders, but what cultural engagements might offer protection against local forms of stigma[10]. We intend for this analysis to spur future research regarding how cultural processes shape experiences of stigma of Alzheimer's disease and other dementias and the capacity of family members to provide effective caregiving in this[11] and other cross-cultural groups.

References:

1 Behuniak, SM. 2011. 'The living dead? The construction of people with Alzheimer's disease as zombies' *Ageing & Society* 31(1): 70-92.

2 *Kontos, PC. 2003.* '"The painterly hand": embodied consciousness and Alzheimer's disease' *Journal of Aging Studies 17(2): 151-170.*

3 Luborsky, M. R. 1994. 'The cultural adversity of physical disability: Erosion of the full adult personhood' *Journal of Aging Studies, 8: 239–253.*

4 Liu, D., Hinton, L., Tran, C., Hinton, D., Barker, J.C. 2008. 'Reexamining the Relationships Among Dementia, Stigma, and Aging in Immigrant Chinese and Vietnamese Family Caregivers *Journal of Cross Cultural Gerontology* 23: 283–299.

5 Yang, L.H., Kleinman, A., Link, B.G., Phelan, J.C., Lee, S., Good, B. 2007. 'Culture and Stigma: Adding Moral Experience to Stigma Theory' *Social Science and Medicine* 64(7): 1524-1535.

6 Yang, L.H., Purdie-Vaughns, V., Kotabe, H., Link, B., Saw, A., Wong, G.. Phelan, J. 2013. 'Culture, Threat, and Mental Illness Stigma: Identifying Culture-Specific Threat among Chinese American groups' *Social Science and Medicine* 88: 56-67.

7 Hinton, L., Fox, F., & Levkoff, S. 1999. 'Exploring the relationships among aging, ethnicity, and family dementia caregiving' *Culture, Medicine and Psychiatry 23:* 403–413.

8 Yang, L.H., Kleinman, A. 2008. ''Face' and the Embodiment of Stigma: Schizophrenia and AIDS in China' *Social Science and Medicine 67(3):* 398-408.

9 Stafford, C. 1995. *The roads of Chinese childhood: Learning and identification* in Angang Cambridge, UK: Cambridge University Press, p. 86.

10 Yang, L.H., Chen, F., Sia, KJ, Lam, J.J., Lam, K, Ngo, H., Lee, S., Kleinman, A., Good, B. 2014. '"What matters most:" a cultural mechanism moderating structural vulnerability and moral experience of mental illness stigma' *Social Science and Medicine* (special issue on Structural Stigma) 103: 84-93.

11 Chen, Z., Yang, X., Song, Y., Song, B., Zhang, Y., Liu, J., Wang, Q., Yu, J. 2017. 'Challenges of Dementia Care in China' *Geriatrics* 2(7).

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3.10 Alzheimer's disease in the lived experience of Lesbian, Gay, Bisexual, Trans and Gender Diverse (LGBT) persons



Contributor: Victor Madrigal-Borloz. Senior Visiting Researcher at the Harvard Law School Human Rights Program and United Nations Independent Expert on protection from violence and discrimination based on sexual orientation and gender identity.

As United Nations Independent Expert on protection from Violence and Discrimination based on Sexual Orientation and Gender Identity, the international community has asked me to raise awareness about the multiple, intersecting and aggravated forms of violence and discrimination that are perpetrated against persons every day, around the world, on the basis of their sexual orientation or gender identity, and to work to identify their root causes. In that connection, I am deeply intrigued by temporal intersectionality. All aspects of life are impacted by the passage of time, and just as a person's needs in relation to health, education, housing, employment and family relations mutate as she ages, the particular concerns of lesbian, gay, bisexual, trans and other gender diverse persons also evolve and change.

Intersectionality of LGTB concerns and the challenges raised by Alzheimer disease creates a space of great vulnerability and potential disempowerment owing to stigma and discrimination, but also to the disproportionate impact of certain predictors, in relation to which the little information that exists in a handful of countries of the global north paints a deeply worrisome picture: a survey carried out in Britain in 2010 reported that LGB older persons are less likely to see their biological family frequently; they are also more likely to drink alcohol, take drugs, and have a history of poor mental health, and to have been diagnosed with depression. All of these have been identified as risk factors for cognitive decline and dementia. The same can be said of HIV/AIDS –which, as is well documented, impacts disproportionately the key populations of men who have sex with men and trans women.

In their 2018 study, Frederiksen-Golden et al identify barriers to care and health such as those as particularly significant in that space, and added factors placing LGBT population at higher risk of developing Alzheimer's disease and of suffering disproportionate impact when living with it: the historical context (i.e. the pathologizing environments under which the LGBT older persons of today lived their whole lives) and unique family structures determining that older LGBT persons are more likely to be childless and live alone[1]. J.D. Flatt et al refer to studies that document 50% of LGBT older persons reporting subjective cognitive decline, with higher rates among ethnic or national minorities[2]. Members of the community describe additional challenges in bereavement, including a lack of acknowledgement of loss, legal complications and the exclusion of non-legally recognized family as part of the unit of care. LGBT couples who live in secrecy because of stigma, discrimination or even criminalization may be forcibly outed when they are in need of care, with care givers invading their privacy – either at home or in care or assisted living settings.

This problematic could be qualified as an exacerbated space in the larger context of the human rights concerns of older persons who self-identify as LGTB, the segment of the population which is rapidly growing: some researchers estimate that by 2060 it will reach 20 million in the United States of America alone. This makes my findings as to the prospects for their quality of life all the more disturbing. This year I reported to the UN General Assembly[3] that while I have received consistent information suggesting that LGTB older persons are under extreme risk, created by social isolation and

discrimination, research and data on the root causes of these lived realities, and, most importantly, the dynamics to reverse them, is extremely scarce.

For older LGTB persons, unsurmountable barriers to access to health care are created by limited availability of and support for caregivers and higher rates of certain chronic illnesses which are compounded with stigma and discrimination. As a result, it is a general finding that LGBT persons do not perceive housing and support services for older persons as offering safe or welcoming accommodation and support; for example, it is reported that sometimes family and care staff refuse to affirm the gender identity of older trans and gender diverse persons and force them to live in denial of their orientation or according to the gender assigned at birth. This scenario is further complexed by the very nature, or characteristics of Alzheimer's disease and other dementias, involving memory loss and the potential implications and fears this could entail for LGBT persons.

In certain contexts, discrimination in employment will mean that LGBT individuals contribute less to pension schemes and therefore have less income later in life, on top of which individuals might not be (and in most of the world are not) eligible to pension entitlements of same-sex partners. This leaves them unable to pay their rent or mortgage and leads to evictions and homelessness. LGBT persons might not be able to legally leave property to a surviving partner and surviving partners might not be able to remain in public housing following a partner's death. While end-of-life considerations, affect all persons, I have received information about particular expressions of discrimination that include partners not being consulted and not being given decision-making power and affectation of survivor benefits including pensions and social security payments.

A particular feature of the lives of older LGBT persons is characterised as a disproportionate caregiving burden, as they are more likely to be acting as caregivers for loved ones and friends, with an estimated 27% providing caregiving assistance[1]. This factor bears particular significance: in most of the world, LGBT persons providing care for a loved one will not be recognised any decision-making rights when their loved ones live with declining cognitive abilities. Even when they do, historical discrimination and trauma play a significant role in underlying fears and anguish: in a 2019 submission to my Mandate, Ireland noted that older LGBT individuals are often fearful that their end-of-life and after-death wishes will not be respected by other family members, a situation that is exacerbated when States limit the legal recognition of certain family configurations.

To this situation, already critical, must be added the reality that in vast parts of the world, diversity in sexual orientation and gender identity remain deeply affected by stigma, violence, and criminalisation. As of mid-2019, 69 countries still criminalise homosexuality with punishments that oftentimes include imprisonment for years or decades and, in some cases, effective implementation of the death penalty. Dozens of countries criminalise lesbianism and/or gender diversity or maintain legislation with disproportionate criminalising impact on that basis. Even where criminalisation has been wiped off the books or never existed, social stigma remains the source for extreme violence that has been extensively documented by my Mandate. While research and data on the lived realities of older LGBT persons living with Alzheimer's disease is simply non-existent in most of these contexts, the logical presumption is that the risk factors identified before are exacerbated, and my working theory is that many of these older persons live for years under the violence and discrimination that comes with losing their ability to ascertain their sexual orientation and gender identity(i) [4]. From a human rights perspective, this is directly contrary to the full enjoyment of autonomy. As my colleague, the United Nations Independent Expert on the enjoyment of all human rights by older persons has identified, this right includes "not only the right to equal recognition before the law, legal capacity, dignity, self-determination, empowerment and decision-making, but also the right to choose where to live, the right to work, the right to vote and to the right to participate actively in all spheres of society"[5]. Among many other reasons, this is why I have called for a world free of criminalisation of sexual orientation and gender identity by 2030, and for the adoption of effective anti-discrimination legislation and public policies.

Awareness of lived realities of communities and populations of aging LGBT persons who live with Alzheimer's disease, as well as their needs in relation to care and support is, within this context, a task that cannot be postponed.

References

1 Frederiksen-Goldsen K I, Jen S, Bryan A E B, and Goldsen, J 2018. 'Cognitive Impairment, Alzheimer's Disease and Other Dementias in the lives of Lesbian, Gay, Bisexual and Transgender (LGBT) Older Adults and their Caregivers: Needs and Competencies'. *Journal of Applied Gerontology*, Vol. 37(5) doi 10.1177/0733464816672047.

2 Flatt J D, Johnson J K, Karpiak S E, Seidel L., Larson B, Brennan-Ing M. 2018. 'Correlates of Subjective Cognitive Decline in Lesbian, Gay, Bisexual and Transgender Older Adults'. *Journal of Alzheimer Disease* 64 doi 10.3233/JAD-171061.

3 Madrigal-Borloz V, 2019. 'Protection against violence and discrimination based on sexual orientation and gender identity'. Report to the UN General Assembly, Seventy-fourth session Item 72 (b) of the preliminary list, A/74/181. Retrieved from https://undocs.org/en/A/74/181

4 Yarns B, Abrams J, Meeks T, Sewell D. 2016. The Mental Health of Older LGBT Adults. Current Psychiatry Reports 18:60 doi 10.1007/s11920-016-0697-y.

5 United Nations Human Rights Council, 30th Session of the Human Rights Council: Reports. A/HRC/30/43, par. 45 Retrieved from https://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session30/Pages/ListReports.aspx Last accessed 3 September 2019.

(i) Even in environments in which legal protection is solid it is reported that "research with LGBT caregivers of individuals living with dementia identifies loss of an LGBT identity in response to the lack of cultural competence of health care service providers as a current unfortunate occurrence.

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CHAPTER 4

Case studies

4.1 Stigma and negative attitudes towards people with dementia still pervade: the importance of working together

Contributor: Kate Swaffer, Chair, CEO & Co-founder Dementia Alliance International

Dementia Alliance International (DAI), was launched in 2014 by eight people all diagnosed with dementia, from the USA, Canada and Australia, due to the need for international collaboration between people with dementia. The goal was to increase equal inclusion, change attitudes, and reduce stigma. DAI still seeks to represent members, now in 49 countries, and is an organisation whose goals are to provide advocacy and support of, and for people diagnosed with any type of dementia, and global campaigning for human rights and access to the Convention on the Rights of People with Disabilities (CRPD) at organisations including the United Nations and the World Health Organisation. All services for DAI members, including membership, are free.

Many members still report they receive few if any services or support elsewhere, as most support is for care partners.

There has been an increasing emergence of self-advocacy and Dementia Working (or Advisory) Groups (DWGs) globally. In spite of this, DAI founders felt when it was launched, and still believe that by collaborating globally we will eventually have a stronger impact on policy and services.

In 2000, Christine Bryden and a group of international self-advocates founded the first online self-advocacy group, Dementia Advocacy and Support Network International (DASNI), although membership was not limited to people with dementia. Then, in 2002, James McKillop and others founded the Scottish Dementia Working Group (SDWG), the first national group dedicated to the voices of people with dementia, funded by the Scottish Government and supported by Alzheimer Scotland. It took many years for more groups like this to materialise, and there are now a growing number of DWGs that are local, regional or national in demographic. The late Peter Ashley and a group of UK self-advocates were part of the first DWG in the UK, which existed for only a few years, and were instrumental in the development and implementation of the English National Dementia Strategy and the Prime Minister's Challenge on Dementia. The Alzheimer's Society again funds a Dementia Working Group, which came about after a meeting of DAI members and their CEO Jeremy Hughes, planned to initially discuss setting up a DAI Chapter in the UK. Subsequently the 3 Nations Dementia Working Group (3NDWG) covering England, Wales and Northern Ireland was established in May 2017.

It is also important to note there is a continuing emergence of self-advocates in countries primarily due to the work of DAI and some of the DWGs, as well as ADI members who are now determined to empower and enable the inclusion of people with dementia in their own countries.

The current known National, Regional or Local Dementia Working Groups include:

2000: Dementia Advocacy Support Network International (DASNI)

2002: Scottish Dementia Working Group (SDWG)

2006: Alzheimer's America Early-Stage Advisory Group (EAG)

2012: Highlands Dementia Working Group, Scotland (HDWG)

2012: European People with Dementia Working Group (EUPDWG)

2013: Dementia Australia Dementia Advisory Committee (DADAC)

2013: Irish Dementia Working Group (IDWG)

2014: Japan Dementia Working Group (JDWG)

2014: Southern (Kiama) Dementia Advisory Group, Australia (DAG's)

2014: New Zealand Dementia Advisory Committee (NZDAC)

2015: Ontario Dementia Advisory Group, Canada (ODAG)

2016: Dementia Advocacy Awareness Team, Australia (DAAT)

2017: 3 Nations Dementia Working Group (3NDWG)

2019: Finnish Memory Working Group

2019: Flemish Working Group for People with Dementia

2019: Icelandic Working Group of People with Dementia (IWGPWD)

2019: Dementia Working Group in Chinese Taipei

As an invited keynote speaker to the World Health Organisation (WHO) First Ministerial Conference on Dementia in March 2015, representing DAI, I made the following three demands:

1 That we have human rights to a more ethical pathway of care

2 Being treated with the same human rights as everyone else, under the Disability Discrimination Acts and CRPD

3 That research does not only focus on a cure, but also on care

These three demands were included in the Final Call to Action, and since then, there has been a snowball effect, and people with dementia are demanding human rights all around the world. These three demands also inspired a long-time disability expert and advocate, and DAI member, Professor Peter Mittler to become actively involved in supporting DAI. Peter is an Emeritus Professor of Special Needs Education, University of Manchester, UK. He is a former President of Inclusion International, and was a UN Consultant on disability and education, although has since retired.

The CRPD is relevant to persons with dementia because it defines persons with disabilities by saying *'persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'*

Regardless of dementia falling within the definition of 'disability' within domestic and international law, people with dementia continue to face a number of challenges to have their rights respected. Often, many of the stakeholders and policy makers do not even see the need for those of us advocating for our rights to be included and the stigma and misperceptions about our potential to continue to contribute abound. This is partly due to the fact that symptoms of dementia are often 'hidden' or 'invisible' disabilities, until progression into old age.

Yet, in spite of the increasing numbers of DWGs and individuals with dementia speaking out, the misperceptions of people with dementia continue.

A persistent view is that we go straight to late stage dementia upon diagnosis, and should be unable to function well, if at all. It is certainly not yet seen as the norm for people with dementia to be living positively, which is likely due to ignorance, negative attitudes about people with dementia, as well as stigma, and the pervasive 20th Century views of dementia.

The task of speaking out against people causing us harm is complicated (and sometimes precluded) by the fact that many of them are well-intentioned, medical staff, service providers, advocacy organisation and close friends or family who are also often our care partners, but who may be ignorant, unwilling or unable to take the time to find out about our wishes and needs. Although we are grateful for the support of family and friends, we have sometimes been demonized for needing them.

We have also been demonized for not needing them, and for daring to live positively with dementia, and the misguided under-estimations of our potential continues to create oppressive and humiliating barriers to our full engagement in society.

That younger people are more likely to be self-advocates does not mean they should not have a voice, nor does it mean they represent older persons in the later stages of dementia. It simply means they are less likely to accept the stigma, are often diagnosed much earlier in the disease process, and are therefore more functional for a longer period of time than was once expected for people with dementia.

Now that the WHO Global action plan on the public health response to dementia 2017-2025 [1] has been adopted, human rights must be included in all dementia services, as well as national dementia plans and strategies. This not only means receiving a timely diagnosis, it means receiving rehabilitation and disability support at the time of diagnosis.

Borrowed from the disability community, one of our mottos is also Nothing about us without us, and we are asking governments and civil society for human rights in dementia care which includes us at every level, and includes proactive cognitive and physical rehabilitation, access to a timely diagnosis, and risk reduction and prevention strategies, and equal access to proactive disAbility support immediately following a diagnosis.

Many people with dementia are now advocating for the phasing out all institutional care, the cessation of segregation in locked dementia units, and for all health care staff to be fully competent in dementia as well as disability. We want 'Inclusive Communities' that provide us with the same access as all others with disabilities, aligned to the CRPD. Hence, many people with dementia are also now questioning whether Dementia Friendly Communities and Dementia Villages are in fact, further segregating us, and unintentionally increasing the stigma and sense of 'otherness', rather than supporting us to be included in our community on an equal basis.

Changing attitudes towards dementia is a key element in reducing stigma, but even changing the attitudes of people in developed countries continues to be a challenge, and we believe will take a novel approach; the time is now for people with dementia to work together, rather than under the influence of their national associations.

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.

References

1 World Health Organization. 2017. *Global action plan on the public health response to dementia 2017–2025*. Geneva: World Health Organization.

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4.2 A young person makes a difference – but have things changed?



Contributor: Walter Dawson DPhil, Atlantic Fellow for Equity in Brain Health at Global Brain Health Institute, University of California, San Francisco

My father received a diagnosis of Alzheimer's disease when I was eight years old. At this young age, I was confronted with the need to be a care partner for my father – an unusual role for a child. I was also confronted with the many challenges of the dementia care system in the United States, particularly for families like mine living in rural communities of low socio-economic status. At the time (in the early 1990s), my family lived in a very rural part of the State of Oregon, where very limited services and supports were available for someone like my father.

Watching my father slowly lose his ability to be a parent was incredibly difficult. His behavior was often hard for me, as a child, to understand. Why did he wander and become lost in familiar places? Why was he so anxious, especially at night when his anxiety made it impossible to sleep? Ultimately, my father, whose love of words and language were his defining characteristics, lost his ability to speak.

My mother and I made the difficult choice to place my father in a memory care community when we no longer felt we could safely care for him ourselves. The day I realized my father would never return home remains one of the hardest in my life.

While my father began to receive the care he needed, his care was prohibitively expensive. Within just a few months, we spent all of our savings, including anything that had been set aside for my future college education. Thankfully, my father became eligible for Medicaid, the public program that provides health care and long-term services and supports to low-income individuals and families in the United States.

Even though I was only a child, I knew the loss of our financial stability so that my father could be safe and properly cared for was not right. I knew my father and other people like him deserved better. I also knew I wanted to do something to help.

One day, I noticed my mother writing a letter and I asked her what she was doing. She responded that she was writing to our local Member of Congress about how impossibly expensive my father's care was. I thought that I could write a letter, too. I thought that if only people with power and influence heard our story then change would happen.

People did listen to our story. The unusualness of a child advocating for his father was a powerful image. Camera crews from the major news networks soon arrived at our door (in the middle of rural Oregon). It was not long before I found myself traveling to Washington, DC to testify before the United States Senate about my family's experiences caring for my father and the need to create a better system of care. I remain one of the

youngest persons in US history to ever testify before the Congress on any issue, let alone Alzheimer's disease and dementia.

People did listen to our story. The unusualness of a child advocating for his father was a powerful image. Camera crews from the major news networks soon arrived at our door (in the middle of rural Oregon). It was not long before I found myself traveling to Washington, DC to testify before the United States Senate about my family's experiences caring for my father and the need to create a better system of care

I learned an important lesson from my early advocacy efforts: that one person can have an impact. I also learned that when we join forces and work together we become more powerful advocates for change. These experiences continue to guide and inform my professional work in public policy and dementia today. My research and policy work focus on improving the way dementia care is financed, by expanding access to publicly funded long-term services and supports. My research also seeks to demonstrate the role that wider screening for cognitive impairment can play in getting people living with dementia (and their family care partners) the support they need. This is particularly important for people who lack access to formal medical care due to cost or other systemic barriers as well as those living in rural areas where medical care is simply too far away.

Stigma as a barrier to accessing care

In reflecting on those early days and the work I do today, the impact of the stigma that surrounds dementia continues to stand out as an obstacle that must be overcome. Stigma is one of the biggest barriers to better public policy, access to care, and ultimately a treatment for dementia. The stigma of dementia takes many forms and looks different across cultures, communities, and countries. We have made great progress in building awareness and in overcoming some of the stigma that surrounds dementia. Yet, we still have a long way to go.

Alzheimer's disease and other related dementias were not well understood in the early 1990s when my father lived with dementia. As an immigrant, my father was already treated differently by people within our community, but that difference became truly pronounced after his diagnosis of Alzheimer's. Family and friends often did not understand and withdrew. Physicians told us nothing could be done and it did not really matter if he had Alzheimer's or some other form of dementia – the trajectory and outcome would largely be the same. Often, people living with dementia and their families never receive a formal diagnosis. I consider my family lucky that we at least received that.

Stigma in the US plays a role in impeding a more robust and equitable financing system for care of people living with dementia. The stigma surrounding dementia serves as a barrier to getting dementia care onto the political and policy agenda in many societies and communities – a necessary, yet insufficient component of better policies and public programs. Disrupting the wider societal stigma will help policymakers and advocates advance better public polices for people living with dementia.

Access to care is for far too many people the biggest issue they face in their journey with dementia. As the prevalence of dementia increases around the world, how to finance long-term services and supports and provide social care must be a priority of all governments. Without a more coordinated system in place, individuals and families will continue to slip through the cracks.

Stigma, cognitive screening and detection

A more robust dementia care system would include earlier and wider screening for cognitive impairment. Earlier and wider screening for cognitive impairment is needed in order to provide better dementia care. In countries like the United States and in Western Europe, it is estimated that as much as 50 percent of all people living with dementia never receive a formal diagnosis[1-2] In other countries, such as China and India, this lack of diagnosis is much higher, perhaps as high as 70-90 percent.[3-4] Stigma along with economic factors are significant barriers to wider screening for cognitive impairment and detection of dementia.

Some may say that in the absence of a cure or disease-modifying treatment there is little point in wider cognitive

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screening to detect dementia. Further, some say that without a cure or disease-modifying treatment, wider screening may actually be harmful. In other words, wider screening and detection can amplify the negative effects of stigma without offering anything to improve the lived experience of a person living with dementia.

"Let us be clear: cognitive screening can help promote better disease management and provides an opportunity for care planning to take place, including legal and financial planning. This does not replace the need for a treatment, but it is the best way to reduce the burden of dementia for individuals, families and ultimately the public and private systems that provide and finance care."

This viewpoint overlooks the vital role that better disease management and care planning can play in the experiences of people living with dementia and their care partners. Let us be clear: cognitive screening can help promote better disease management and provides an opportunity for care planning to take place, including legal and financial planning. This does not replace the need for a treatment, but it is the best way to reduce the burden of dementia for individuals, families and ultimately the public and private systems that provide and finance care.

Treatment and stigma

As we move closer to the day when we have a disease-modifying treatment for Alzheimer's disease and other related dementias, the need to overcome the barriers of stigma and the financial costs associated with the condition become more urgent. Once a treatment is available, stigma will remain a barrier to people seeking out treatment. The costs of the treatment may also prevent people from accessing it. We must ensure that any new treatment is widely accessible, that people know it is available, and that they are not afraid to seek it out.

Again, wider screening and detection will help both in identifying people who would benefit from a treatment as well as by further de-stigmatizing dementia care. But we must continue to raise awareness that dementia is not a normal part of aging, that dementia care management and care planning can help improve the lived experiences of people, and that wider access to treatment is needed to create more equitable dementia care systems.

References

1 Amjad, H., Roth, D., Sheehan, O., Lyketsos, C., Wolff, J., & Samus, Q. 2018. 'Underdiagnosis of Dementia: An Observational Study of Patterns in Diagnosis and Awareness in US Older Adults' *Journal of General Internal Medicine 33(7): 1131–1138.*

2 Connolly, A., Gaehl, E., Martin, H., Morris, J., & Purandare, N. 2011. 'Underdiagnosis of dementia in primary care: variations in the observed prevalence and comparisons to the expected prevalence' *Aging Mental Health* 15(8):978-984.

3 Chen, R., Hu, Z., Chen, R., Ma, Y., Zhang, D., & Wilson, K. 2013. 'Determinants for undetected dementia and late-life depression' *British Journal of Psychiatry* 203(3):203-208.

4 Dias, A., & Patel, V. 2009. 'Closing the Treatment Gap for Dementia in India' *Indian Journal of Psychiatry* 51 Suppl 1: S93–S97.

4.3 The circle of life; Indigenous knowledge about dementia in Canada

Contributors: Prof Kristen Jacklin, Ph.D, Professor, Medical Anthropology, University of Minnesota Medical School Duluth and Karen Pitawanakwat, a member of the Wikwemikong Unceded Reserve, Onatario, Canada, Registered Nurse and Community Researcher for NAANDWECHIGE-GAMIG Wikwemikong Health Centre

We have been involved in dementia research with Indigenous communities for over 10 years. Our work on this topic began in 2007 when Indigenous community leadership from health centres across Ontario, Canada, began noticing more cases of dementia in their communities. Through discussions with key stakeholders, it was quickly realised that the dementia care needs of Indigenous people were distinct and required deep understanding of Indigenous culture, language and experience to be met effectively. Importantly, it was clear, very early on, that Indigenous knowledge concerning dementia was at odds with biomedical understandings and this was leading to culturally unsafe dementia care. The experience of dementia in Indigenous communities was gentler and showed a greater acceptance of the illness and its symptoms. These early discussions with communities sparked for us a long-term commitment to community-based research aimed at understanding experiences of dementia in Indigenous populations with the aim of translating these research findings into information that can help communities and providers plan and respond to Indigenous dementia care needs in culturally appropriate ways.

Our research on this topic in Canada has revealed many commonalities concerning experiences with dementia across diverse Indigenous peoples. We have been gifted with stories from Elders, Knowledge Keepers, people with dementia, their caregivers and formal care providers. This research, coupled with a handful of other such studies in Canada, allows us to cautiously put forward a collective narrative of the dementia experience for Indigenous peoples in Canada. Cautiously, because we must recognise that although we have uncovered common experiences and beliefs, the cultures, languages and experiences of Indigenous peoples in North America are diverse. We also must recognise that the well-being of Indigenous people in Canada has been severely undermined by colonialism, contemporary structural violence, and the resulting intergenerational trauma. Varying impacts of colonialism also contribute to diversity in experiences.

What has been shared with us suggests that Indigenous people understand dementia as something that some people get when they get old. It is thought to be normal, natural and part of the 'circle of life' or 'coming full circle'. This understanding is rooted in Indigenous knowledge frameworks and cultural teachings; that is to say, this is not a simplified understanding of a complex disease; to the contrary, the perspective is formed on the basis of Indigenous science, spirituality and culture. The cultural framework that leads to an understanding of dementia as part of the circle of life also leads to a greater acceptance of the illness. In this regard the behaviours associated with Alzheimer's and dementia, especially in the later stages, are understood in relation to Indigenous teachings. Some brief examples follow*:*

'Memory loss' is a concept at odds with Indigenous teachings. When memories cannot be accessed they are described as 'buried' or 'covered' and are inaccessible to the person at that time. This understanding allows the person's identity, roles, and knowledge to remain with them, never lost, but covered for the time being. Memories that are covered might be brought to the surface again by sounds, smells, or other stimuli. This is particularly the case with important, cherished childhood memories.

…it was clear, very early on, that Indigenous knowledge concerning dementia was at odds with biomedical understandings and this was leading to culturally unsafe dementia care

A person experiencing a vision is thought to be in a moment where they are closer to the Creator and to the 'other side'. During this experience they may be in discussion with relations who have passed and may be receiving important teachings. It is important to have these experiences and for the teachings to be transferred. *"Elders with dementiaare in a time of preparation to leave this physical earth. When the Elder with dementia is not making sense in conversation or talking about another place or time, that is not being experienced by all those listening, their spirit is actually travelling and amongst their next life (after life experiences/on the other side). These experiences are verbally passed on in stories and not considered hallucinations but a real part of what we know as the circle of life."* – Anishinaabe Expert Language Group Manitoulin Island, Ontario Canada.

Experiences of 'child like' behaviours are also expected and described as such. Cultural

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understandings of the life cycle accept that in older age one may return to a child stage where they will behave like children and need more care like children. *"The older people, they always refer to that term of going back into their childhood, but they use the Anishnawbe word for that, and that term is 'keewayabinoocheeaway'. That's returning back to childhood."* (Indigenous Older Adult, Thunder Bay, ON). There is no concern around 'infantilising' individuals or compromising 'personhood', rather there is an acceptance that helps all involved understand what is happening and what is needed.

Cultural values and teachings also underlie Indigenous care giving practices. We have found that although there are usually one or two primary family carers, there can be many carers for a person with dementia in the community: friends, neighbours, family, and formal providers. The Indigenous teaching concerning the value of 'Love' is paramount to care. We have received many teachings from Elder Jerry Otowadjiwan, Wikwemikong Unceded Territory, who reminds us that the person with dementia, who is being cared for, is in need of a lot of love. He urges the use of 'loved one' to refer to the person with dementia so that we remember that they are loved. He shared that using the words 'loved one' serves as a reminder of how care providers should be treating and respecting the person with dementia.

Dementia is thought to be normal, natural and part of the 'circle of life' or 'coming full circle

We also want to emphasise that the collective narrative includes an understanding that more people are experiencing dementia now than in the past and that some people are getting dementia at an early age. This experience has led to a complementary narrative that understands that dementia is sometimes brought on by injury, trauma, and/or other diseases and medications that cause you to be out of balance. Colonialism, and the resulting changes in lifeways and disconnection from land, is considered the cause of this phenomenon. A small number of studies have been conducted that confirm the original community concern that rates of dementia are increasing in Indigenous populations. While more evidence is needed what has been published suggests rates of dementia are higher in First Nations in Canada when compared to non-First Nation populations, rising more quickly and occurring at younger ages.[1]. Yet despite this intersection with western perspectives, core Indigenous values prevail and for the most part in our experience, dementia is not stigmatised.

Our ethnographic research on dementia in Indigenous contexts has resulted in a series of tools and guides describing dementia and the dementia journey from Indigenous perspectives, as well as guidelines for appropriate services and care. More details on what we have summarised are available from www.i-caare.ca/factsheets and www.i-caare.ca/practicetools. As we have shared the work of our team over the years it has been clear to us that non-Indigenous care providers, both formal and informal, have a deep appreciation for Indigenous views on dementia. Many have commented on how much mainstream (biomedical) services have to learn from Indigenous teachings. We hope that what we have shared provokes thoughtful discussion on what we can learn and what we can do better.

References

1 Jacklin, K., Walker, J., Shawande, M. 2013. 'The emergence of dementia as a health concern among First Nations populations in Alberta, Canada' *The Canadian Journal of Public Health* 104(1) online: https://pdfs.semanticscholar.org/8fcf/2edb97bb733aa0b1bb4abc39eed98e5feda3.pdf Last accessed 19 August 2019.

4.4 Dementia discrimination, even by the language we use, a view from Québec, Canada

Contributor: Nouha Ben Gaied, PhD, director research and development quality of services Federation of Quebec Alzheimer Societies

Wherever you live around the globe, you are likely to have heard of the word "dementia" in English. Dementia being the umbrella term that embraces several neurodegenerative diseases such as Alzheimer's disease, fronto-temporal dementia or Lewy body dementia and define the final stage of cognitive decline. The word dementia is also widely used by people with lived experience, carers, healthcare professionals as well as the media. The broad usage of the word dementia has even led one the biggest Alzheimer association, Alzheimer's Australia to take the move in 2017 and change their brand to become Dementia Australia, to be more inclusive of all people living with a neurodegenerative illness who face different symptoms but who share a universal journey. A dozen other organizations have also included the word dementia in their name, leaving aside the word "Alzheimer".

Can we think of a similar change in Canada? A country that is officially bilingual and where the French is predominately used in the Province of Quebec? The situation is indeed rather different and complex when we look at the meaning of the word 'démence' in French. Even though the word démence refers to a medical term, it has been very much associated, since the end of the 19th century, with craziness, losing one's mind and mental health issue such as schizophrenia. A definition of the word démence, in the Petit Robert dictionary, mentions alienation, delirium, wandering, madness and unconsciousness and refers to a progressive and irreversible decline of mental and psychical activities. All these definitions refer rather to psychiatric disorder rather than a neurodegeneration decline and contribute therefore into the stigmatisation of people with Alzheimer's disease and related illnesses as well as their carers.

In 2013 a major change happened in the DSM-V (Diagnostic and Statistical Manual of Mental Disorders) with the replacement of the word "démence" by "troubles neurodégénératifs" as well as the introduction of diagnostic criteria for both mild and major neurodegenerative decline.[1] But did this major change impact those who live with the disease and their carers? Did it change the way we see dementia among French speaking societies and finally, did healthcare professionals actually replace the word démence in their practice?

To answer some of these questions, the Alzheimer Society of Canada shared the results of a large survey during the Alzheimer's awareness month in January 2018.[2] The results showed that 8 out of 10 Canadian anglophones were familiar with the word "dementia" as a medical term that refers to Alzheimer's disease or a related illness. A similar result was also observed among francophone Canadians (7 out of 10) indicating that dementia is rather a neutral word that can widely be used. It was very striking, however, to see that 54% of francophones Canadians consider the word "démence" as offensive and disparaging compared to only 16% anglophone Canadians. A large number of francophone Canadians still relate to démence with a negative connotation and a pejorative word to be used. Finally, when francophone Canadians were asked whether they prefer to use the word "maladie neurodégénérative" rather than "démence", a large majority (between 76% and 87%) responded yes. This final answer should raise awareness among healthcare professionals for the need to change the medical terms they use when providing a diagnosis.

When a person receives a diagnosis of démence, it's their whole world that seems to fall apart. That's what Murielle, a person living with dementia, experienced 3 years ago when her family doctor announced the word "démence" during a long-awaited appointment. *"I'm not demented! When I received the diagnosis, people around me had the impression that I'm not 'normal' anymore, I can't take decisions or have a normal conversation with my loved one, I lost my self-esteem and I was hiding. I didn't speak about it for a long time because I was afraid of how others will look at me or talk to me. I felt isolated and couldn't seek help".*

Démence is not just a word with a negative connotation, it can have broader consequences. Fifty percent of people who receive a diagnosis are already at a mild or moderate stage of the disease making pharmacological intervention ineffective and thus preventing any significant improvement. The fear of the stigma they know they will face, once referred to as a person with dementia, contributes to enhancing the feeling of denial and fear as well as the stress and isolation, instead of them looking and asking for much needed help.

A lot of hard work has been put forward to provide support, counselling, education and activities to dissipate stigma, based on a better understanding of the disease, but mainly to allow people with lived experience to consider a life that is worth living. Let's not allow a single word to jeopardise all these efforts.

References

1 American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders* (5th Edition: DSM-5) ISBN 978-0-89042-554-1.

2 Survey Léger, Alzheimer Society of Canada, 2018 online: https://alzheimer.ca/sites/default/files/2018-01/Awareness2018-en.pdf Last accessed 20 August 2019.

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4.5 Stigma in Brazil: The narrative of a person with young-onset dementia

Contributors: Prof Cleusa Ferri, Federal University of Sao Paolo (UNIFESP), Prof Elaine Mateus, Brazilian Federation of Alzheimer´s Associations (FEBRAZ), Dr Deborah Oliveira, UNIFESP, Dr Fabiana da Mata, UNIFESP

My name is Andrea, I am 56 years old and married, with four children, and I was diagnosed with Alzheimer´s disease eight months ago. My mother has Alzheimer's and so do her two sisters, but I had never imagined that this would happen to me. And then suddenly, I started to forget things, to forget my friends´ names, and the things I had to do. I also misplaced objects that I would find days later. I felt frustrated, got mad at myself many times, and wondered what was going wrong with me. At first, my husband Eduardo was angry too. He also could not understand what was going on. After the diagnosis and the beginning of the treatment, I felt less stressed. Now I go out by myself and drive in the neighbourhood. I am going to start swimming classes and I want to go back to my English lessons. I am slowly getting back on my feet. It is never going to be the same again, but I want to get involved with different things.

Shortly after the diagnosis, I realised things would change. Eduardo would not allow me to go to places I am not familiar with anymore. I used to walk by myself all over the city. Now, whenever I need to go to a distant place, he drives me. My routine is kept to a minimum. I do not use my cell phone as often, but my closest friends still remember me and invite me to parties. The last time I went to their party, I noticed them whispering in groups and I felt it was about me and my illness. I also quit my job as a dentist because I felt embarrassed many times for not doing the reports I was supposed to do. Despite having supportive colleagues, it was overwhelming.

Andrea was interviewed in her own house by a member of the Brazilian Federation of Alzheimer's Disease (FEBRAZ) and she was happy to maintain her real identity in this report. Andrea's brief narrative shows how much anger and frustration the symptoms were for her and her family before they knew she had dementia. Soon after the diagnosis, however, she started to relax and was slowly able to cope. At first, the dementia symptoms made Andrea become self-judgmental – and felt judged by others. However, when the diagnosis was revealed, she began to be able to cope better with the symptoms and to be more self-accepting.

Andrea was fortunate to have an early diagnosis. This is rare in Brazil as the majority of people with dementia are either not diagnosed (around 77% of the older population) or have their diagnosis only in the late stages of the condition. The fact that Andrea had good access to healthcare and that she is a health professional herself might have helped her get diagnosed sooner and to plan a strategy for a smoother transition into her new reality. Often, most people living in poverty in Brazil would not have such rapid access to a diagnosis. It is also common for people in Brazil to believe that dementia only affects older people, which may explain why the diagnosis of dementia came as a shock to Andrea at the age of 56, even though she has several family members with dementia. It is common for such stereotypes to hinder middle-aged and older adults in Brazil from seeking help when their first dementia symptoms appear. This also reflects a common belief in Brazil that dementia is inevitable in later life, which may hinder the prevention of modifiable risk factors for some dementias.

The diagnosis brought some stigmatising experiences to Andrea, who was kept from going outside on her own as her family feared for her safety. Not only were there small changes in her routine, but also in her social circle. Andrea knows that dementia will change her and anticipates that her friends might leave her in the future due to her illness. Despite her good socioeconomic position, Andrea is very likely to experience the feeling of isolation most people living with dementia and their carers experience as the disease progresses. Social stigmatisation is commonly reported by people with dementia. Very often, it is difficult to know whether the relationship with friends and relatives wane over time because most of them lack knowledge to cope with the challenges of the disease or whether people with dementia are slowly drawn from social interactions due to the fear of possible negative reactions to their symptoms. Hopelessness, anxiety, uneasiness and a sense of awkwardness are all embedded in discriminatory practices.

In many ways, the early stages of the condition allow individuals to keep up with their daily lives. Dementia became a disabling and isolating experience for Andrea at first, but a few months after the diagnosis, she is starting to enjoy her life again through new hobbies and experiences. However, not all people with dementia in Brazil are included in everyday life. The most common barriers are stigma and financial issues, both preventing access to services and resources. The more advanced the stage of the dementia, the harder to engage the individual.

Negative associations about people who have dementia in Brazil is pervasive. Even among more educated people, the lack of understanding about what dementia is permeates personal and professional relationships. Andrea realises that she has been exposed to shame and discriminatory experiences in her workplace since diagnosis, which has led her to quit her job, but she is slowly becoming more empowered and is feeling able to cope.

4.6 Stigma and response to dementia in Guatemala's indigenous populations

Contributor: María Cecilia López Murga, Executive, Association Grupo Ermita, Alzheimer de Guatemala

Our mission in the Association Grupo Ermita is to offer support, counselling, education, information and care to people living with dementia, family members, careers, health professionals and the general public about the care of patients with Alzheimer's and of the elderly, for a better and healthy quality of life in that segment of the population.

The indigenous population of Guatemala constitutes 41% of the total population of the country.

The largest indigenous population group in the country is the Maya, as it represents 39.3% of the total population and is made up of 22 linguistic communities: achi, akateko, awakateko, chalchiteko, ch'orti', chuj, itza', ixil, jakalteco or popti', kaqchikel, k'iche', mam, mopan, poqomam, poqomchi', q'anjob'al, q'eqchi', sakapulteko, sipakapense, tektiteko, tz'utujil and uspanteko. 28% of the Mayan population belong to the Mayan K'iche linguistic community, 19.3% to Maya Q'eqchi', 18.9% to Maya Kaqchikel and 14% to Maya Mam. Garifuna and Xinca represent only 1.7% of the population.[1].

In Guatemala, indigenous people have a conception of health and disease that is different from that of the non-indigenous population groups. Disease is not based solely on pathologies or biological aspects that denote some imbalance, but also considers social, environmental and spiritual factors.

Indigenous people have their traditions and customs, which are very deep rooted.

When Alzheimer's disease or some other type of dementia occurs in an indigenous family, it is taken with a lot of fear and superstition.

Any consultation at our Association normally only occurs when the disease is already very advanced and cognitive, neurological and physical deterioration is already severe.

We attended the case of a person of Kaqchikel descent, a 78-year-old married woman, mother of 13 children. When she was around 65, according to the family, she began experiencing very "strange" changes. At one time they thought it was witchcraft and visited the sorcerer of the region who was treating her for about five years, yet the problem continued to get worse. It reached such a point that on four occasions she was lost in the community for more than three days at a time. The last time she was lost, they found her 225 kilometres from the village of her origin.

At the time they visited our medical consultation, the husband told us about the extreme changes that his wife went through, and how in order to cure her and to prevent her from getting angry with everyone and getting violent, or from leaving the house, they locked her in the last room of the house and kept her there until she fell asleep and calmed down.

We were also visited by the 13 children who were very worried about their mother's situation, since she was the one in charge of controlling everything in the house, but when this strange situation started, she had disregarded everything that had to be done at home and everything turned into chaos. They even thought that because of witchcraft she had gone crazy and that there was nothing left to do

We were also visited by the 13 children who were very worried about their mother's situation since she was the one in charge of controlling everything in the house, but when this strange situation started, she had disregarded everything that had to be done at home and everything turned into chaos. They even thought that because of witchcraft she had gone crazy and that there was nothing left to do.

We could not communicate at all with the lady herself because she only spoke the Kaqchikel language. Although she had spoken some Spanish, with the advance of the disease she had already totally forgotten it.

The biggest challenge we had in the Association was to explain to the husband and children about Alzheimer's

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disease and its process. Thankfully the information was very well received and with the help of the doctor a pharmacological treatment could be given, and the family could be taught how best to treat the lady to give her quality of life.

This is the most significant case we have had. There are others, but now people from several communities in Guatemala are taking part in our diploma course, which is increasing knowledge and awareness.

For the Association it is a great challenge because we have reached very few people from the indigenous population. We hope soon to be able to have more presence in our indigenous communities.

Our National Alzheimer's Congress in 2019 will be held in the south-western region of the Country, in Quetzaltenango, to be able to provide training to professionals, family members and caregivers.

References

1 Verdugo, L. (n.d.). *Atlas sociolingüístico de pueblos indígenas en América Latina*. Bollivia: Unicef y FUNPROEIB Andes, p. 855. online:_ https://www.unicef.org/honduras/tomo_1_atlas.pdf Last accessed 19 August 2019.

4.7 From despair to the courage to cope; a carer's story, Guerruro, Mexico.

Contributor: Guadalupe Ponce Ozuna, Psychologist and President of the Guerrero Alzheimer Foundation and Rosa Ma Farrés, G.S. Federación Mexicana de Alzheimer y Enfermedades Similares A.C.

The State of Guerrero has 3,533,251 living in poverty and 825,214 in extreme poverty.[1] Poverty is extremely painful when talking about indigenous peoples and communities, because it is a key indicator of less development, including food insufficiency, lack of public services and education, as well as health issues. The poorest municipality in Mexico is located in the high mountain of the State of Guerrero where levels of poverty are comparable to some African countries, such as Mali and Malawi.[2]

The basis of social organisation lies in the nuclear family and the extended family. In these communities, spontaneous groups of solidary support or "hands-in-return" emerge between relatives and friends, to support issues and activities such as marriages, christenings, crop cultivation or housing construction.

Men marry at an average age of 17 and women of 15. In some cases, it is the parents who choose the partner for their child.

The following testimony was written by Psychologist Guadalupe Ponce Ozuna in 2008, who has a support group in the city of Acapulco, Guerrero, about a 52-year-old woman (her age at the time Guadalupe met her) whose 55-year-old husband had dementia. In her village there is only a small health centre, attended from time to time by a General Practitioner (GP) and there is a nurse who sometimes attends, which is why the woman had to go first to Acapulco and then to Mexico City looking for someone to explain why her husband was behaving so strangely.

"When my husband began to get lost in our town, with people returning him home, because we all know each other, I realised that something was happening with him. I talked with his family, they told me that I had bewitched him with something that I gave him to drink. I was sure I had not done such a barbarity and I just told them that God and I knew that I would not do something like that. He started shouting and asking me who I was and then telling me I must be his mother; he would call me many names except for my own, which he had completely forgotten. I started taking him to the health centre, to the hospital in my town and they told me that it had to be a very rare disease, since he was 55 years old and they did not understand why he behaved that way. They told me that I should take him to Mexico City to the Fray Bernardino Hospital, where they would relieve him and so I sold my little house, since it was all I had, to have money to travel with him, as there was no treatment for my husband locally.

"I went to different hospitals and nobody told me anything. I was recommended to see a psychiatrist in Acapulco who was good, and he told me your husband has Alzheimer's and he is not going to be cured, don´t spend any more money, go back to your home, and he gave me a description of what was waiting for me with my husband. I returned, very sad, to live with my daughter and that night I did not sleep, thinking about what the doctor had told me; that he was not going to know anything anymore about his life. And how I was going to manage, if I had no home to live with him in, and had to live with my daughter, who was married and so I felt sorry for her husband.

After about ten days I made the decision that I was going to take him to the federal highway and I was going to throw myself under the wheels of a trailer – the biggest one I saw pass by – together with my husband, because I was not going to be able to bear everything that was coming. I woke up that day very early with my decision taken, to clean the house and leave everything ready, so they could hold vigil over us afterwards that day.

"After about ten days I made the decision that I was going to take him to the federal highway and I was going to throw myself under the wheels of a trailer – the biggest one I saw pass by – together with my husband, because I was not going to be able to bear everything that was coming. I woke up that day very early with my decision taken, to clean the house and leave everything

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ready, so they could hold vigil over us afterwards that day.

"When I was cleaning the house the TV was on and a journalist asked a woman in the street what she would want from the people who were watching her, and the woman told him to just ask them to buy the tamales and atole (maize cakes and maize drink) she was selling, to have money to feed her sick husband and her disabled son. He told her again, many people are seeing you on TV, ask them for what you need - and she answered 'nothing for me, I only want them to buy my tamales and my atole so I can feed my sick husband and my disabled son'. At that moment I thought, 'What a coward am I? That woman is 65 years old, I am 52 and how it is possible that I do not have the courage to fight for my husband?' I kneeled down in the middle of the house and I asked God for forgiveness for what I was thinking to do, and I swore that I would take care of him as long as necessary. And here I am! Now he goes to the toilet by himself. I have diabetes and hypertension. I do not sleep. I worry a lot because I have to work to feed him - and he eats a lot because he keeps on being hungry."

Psychologist Guadalupe Ponce Ozuna

The diagnosis was given to the wife in the year 2000, two years after her husband began to have the symptoms. The husband with Alzheimer's lived about ten more years, dying in 2010, by which point the wife was left in poor health; her toe about to be amputated but they managed to save it. She was hospitalized for 15 days. Today she has a hearing disability because of a traffic accident but continues fighting. A woman of solidarity; philanthropic, kind, a beautiful woman in all aspects.

We share this story in the training courses that we give in the different regions and municipalities of Guerrero, to doctors, nurses, social workers, psychologists, to create awareness and sensitivity towards people who have this type of disease. It's a real story that has a lot of impact.

References

1 National Institute of Statistics and Geography (INEGI) (Mexico). 2015. online: http://www.inegi.org.mx Last accessed 20 August 2019.

2 United Nations Development Programme. 2011. 'Equipo del Informe sobre Desarrollo Humano México 2011' online: http://hdr.undp.org/sites/default/files/nhdr_mexico_2011.pdf Last accessed 20 August 2019.

4.8 Stigma and dementia care in Kenya; Strengthening Responses to Dementia in Developing Countries (STRiDE) Project



Members of the STRiDE - Kenya National Advisory Group

Contributors: Christine Musyimi, Africa Mental Health Research and Training Foundation (AMHRTF), Elizabeth Mutunga, Alzheimer's and Dementia Organization Kenya, Dr David Ndetei, Senior Researcher AMHRTF

Dementia knowledge in Kenya is still at the nascent stages and many people associate the condition with normal ageing, witchcraft, or that one has done something wrong to the gods and is thus being punished. Creating awareness of the condition through media, churches, home visits and support groups has been one way of opening up the conversations as dementia is close to a taboo topic in Kenya.

These conversations have been instrumental in empowering carers and enabling others to understand what carers are dealing with. Most carers have stated that a lot of people do not visit their homes anymore as they are scared of contracting the disease that their loved ones have. Others have offered to bring prayers to the family to exorcise demons. Due to this, most carers suffer from self-stigma. They will not speak out publicly of what their loved ones are going though. Others will go to great lengths to hide their loved ones from the public as they do not know how best to handle them and they feel by hiding them it is the best for their loved ones.

Most carers have confessed to having gone through the five stages of grief developed by Elizabeth Kuber Ross namely: Denial, Anger, Bargaining, Depression and Acceptance[1]. In a support group run by Alzheimer's and Dementia Organization Kenya (ADOK), one month carers share they are at a point of acceptance, and the next month they are back to being angry. We allow them the space to be themselves as they are in a safe place at the support group, where they are not judged, nor are they stigmatised. But out "in the real world" they may not have the same luxury and often opt to hide their feelings and put on a brave face so that they are not judged.

Self-stigma is an issue that ADOK continues to address during the support group meetings to constantly empower the carers and to ensure they speak out without fear and without worrying about what the people around them think. The joy of seeing them take steps to overcome their stigma is exhilarating. They are becoming the mouthpieces to fight for the rights of their loved ones - be it on family issues, care by doctors or any other issues that touch on the welfare of their loved ones. This is key as it ensures that the people living with dementia are getting quality care from all angles and they are living a life of dignity each day.

Dementia detection and management is still not a priority in most primary care settings in Kenya. It is

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often considered a secondary condition with detection in inpatients rather than the point of contact at the outpatient clinic. In one of the rural counties in Kenya – and perhaps in most counties – health care workers do not routinely screen for dementia. Different cadres of mental health professionals approach management in different ways. For instance, psychologists, social workers and psychiatric nurses rely on diagnosis made by a medical doctor. Oftentimes, psychologists speak to the carers because they only receive the person with dementia at an advanced stage, making it difficult for the practitioner to have a conversation directly.

…carers have stated that a lot of people do not visit their homes anymore as they are scared of contracting the disease… Others have offered to bring prayers to the family to exorcise demons.

In the communities, dementia is viewed from the following perspectives;

1 It does not require medical attention since it is a waste of time unless there is evidence of a physical condition i.e. it is less treatable than physical conditions with poor prognosis.

2 It is associated with "something that one's ancestors did not do or a curse". For example a clinician in a rural hospital explained *"There was a patient who developed dementia at an old age (around 65 years) and this person was rich, so the community will start saying that this person was engaged in devil worshiping and that is the reason he is developing dementia symptoms."*

3 It is considered as a consequence of not associating with other community members at a time when one was employed i.e. before retirement. In one of the ethnic groups (Kamba), this is referred to as previously *"thinking high"*, an origin of the local idiom of dementia *(Thing'ai)* which is popular among the Kamba people. However, this local term *(Thing'ai)* is considered derogatory but is often understood by the community members. Some of the members take offense if the word is used for them after revealing some early signs of dementia such as forgetfulness and poor judgement.

4 Persons with dementia cannot be left alone or live independently.

Despite these beliefs, there is little or no literature around dementia specific stigma in Kenya. The misconceptions by the community members linked to stigma and lack of detection of dementia at the early stage are already barriers to accessing care and a hindrance to creating awareness of dementia. A hospital health care worker states *"Most of our health workers are not really well equipped with information on diagnosis and management of dementia."*

It is also important to note that stigma does not only affect persons with dementia but also family members or carers. With these community perceptions, carers resort to self-exclusion from communities to avoid;

1 Questions like "what happened to your relative?"

2 Blank stares at the person with dementia or carer

3 Intentional exclusion from social interaction for the person with dementia and carer by community members

4 Mockery statements from community members

The Strengthening Responses to Dementia in Developing Countries (STRiDE) Project, run in collaboration with ADI and London School of Economics and Political Science (LSE), funded by UK Research and Innovation's Global Challenges Research Fund, is attempting to address these barriers, by;

1 Reducing stigma by increasing understanding and awareness of dementia among healthcare professionals and community members and reduce delays in seeking help via healthcare professionals' increased capacity to identify and treat people. This will be feasible with the help of an anti-stigma toolkit for implementation in Kenya by the Africa Mental Health Research and Training Foundation (AMHRTF) and ADOK.

2 Providing recommendations for development of a national dementia Plan that incorporates the rights of people with dementia.

Dementia care in Kenya is clearly undergoing great change. Although stigma remains a key issue, programs such as ADOK and STRiDE are breaking down barriers and creating greater awareness – not only within the health sector, but more importantly, for people living with dementia and their families. This is clearly a country to watch – and one that is making great strides.

References

1 E. Kübler-Ross and D. Kessler. 2009. "The Five Stages of Grief," in Library of CongressCatalogin in Publication Data (Ed.), On grief and grieving, 7–30.

4.9 The stigma of dementia - a personal story from South Africa



Andre and Maryna

Contributors: Maryna Lehmann and Andre Mauritz, as told to Sarah-Jane Meyer, freelance journalist

Maryna's story

Like most people, if I thought of it at all, I considered dementia to be an ailment experienced by elderly people and I vaguely knew that it caused a loss of memory. I certainly never dreamt it would be my destiny – after all, no one in my family had ever had dementia.

What a shock it was when I was diagnosed with Alzheimer's disease. I was just 56 – far too young, I believed – and it felt as if I had been stripped of my identity. As an academic in agriculture, my passion was mentoring a new generation of farmers that would feed the nation, and my mind was my identity. I know there was so much more I could have contributed.

In 2017, when I was diagnosed, I experienced the reality that dementia – especially young onset dementia – can be grossly unrecognised and underdiagnosed. For some time, I had experienced numerous problems carrying out the daily tasks that I had previously taken in my stride. Multiplication sums, marking test papers and explaining formulas in class were often beyond me. I frequently forgot to attend meetings and on occasion had difficulty completing sentences when presenting lectures. I became extremely anxious, which led to more difficulties and I made an appointment to see my family doctor.

He told me I was too young to have dementia and put my difficulties down to work stress. This made sense at the time, as I had been under enormous pressure at work for the past few years. This was the result of the number of students more than doubling – from 25 to 60 – while the number of lecturers was halved. Instead of four lecturers overseeing 25 students, there were two of us managing 60 students. We were doing our best to cope under extremely difficult conditions.

I tried advocating to have more lecturers appointed to lessen the workload, but the University authorities were unsympathetic and, only after pressure from the trade union, the best they could do was to allocate funds for appointing an additional lecturer for a few months.

This step didn't do much to alleviate the extreme workload, and after another two years I had a complete breakdown. In that time my difficulties included:

- Losing my way while driving in the town I had lived in for more than ten years.
- Being stuck at a green traffic light, quite incapable of moving on.
- Being unable to perform calculations – formerly a regular part of my daily work.
- Inability to complete sentences while lecturing.
- Inability to recall students' names, even those I had worked with for several years.
- Inability to follow discussions in meetings.

Seriously worried, I went to a second doctor who referred me to a neurologist for further investigation. This is when I experienced the first instance of stigma. At the first consultation and throughout the various tests, the neurologist spoke to me quite normally. But, after the CT scan that showed my frontal lobe had started shrinking, she spoke only to my husband, Andre, who had been with me throughout the consultations. I had suddenly become a non-person, no longer to be considered when discussing matters of importance that affected me personally.

I also found that many of my former colleagues started avoiding me once they heard that I had Alzheimer's. This is possibly because they weren't quite sure how to treat me, and didn't know what to say to me. Many people are uncomfortable around those who are 'different' from themselves, so they find it easier to stay away.

Our children have been enormously supportive, though. We discussed the situation with them once we had the diagnosis and explained that they should treat me just as they always have. We still laugh and joke in the same way as before, and this is heartening.

Our friends and neighbours, too, have been encouraging and continue to visit just as they did previously.

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After the diagnosis, Andre and I started the lengthy process of arranging my early retirement due to Alzheimer's disease. Without him I would have been completely lost. The intricacies of financial issues and dealing with the authorities, completing the necessary forms and all the formalities were quite beyond me.

Fortunately, that is all behind us now, and after his recent retirement we are looking forward to a life that still has much to offer. We are extremely fortunate in being financially secure, not wealthy, but we have enough for our present and future needs.

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So much is lost when Alzheimer's strikes, and it is crucial that effective treatments and preventative measures are found to combat this condition – for the present age group and for the generations to come.

Andre's story

My first thought when Maryna was diagnosed with Alzheimer's disease was that I had to try and protect her from everything.

Of course, this was an over-reaction, but to be expected under the circumstances. After all, this is the woman I love, my soul mate.

She also happens to be a strong-minded person and has always been very independent. She was hurting, but over the past few years she has let me know that she is still in control of her faculties and doesn't want me to do everything for her. She can, and does, do most things for herself, including driving to the shops on her own on occasion.

We have found that one of the most important factors in dealing with Alzheimer's is communication. Because the person with Alzheimer's isn't always able to communicate their needs and wishes as clearly as they would like, those living with and caring for them need to hone their own listening skills.

I have deliberately developed the habit of never interrupting Maryna when she is talking, because I know she might forget what she started saying. Losing your train of thought happens to most of us at some time, but when you have dementia it leads to anxiety. You can't help wondering if you are deteriorating, and this only makes you more anxious.

There is a general lack of knowledge and understanding of Alzheimer's disease and it would be enormously satisfying and rewarding to be able to help change this. This is especially the case in countries like South Africa, our home country, where many poor people are affected by the condition and don't have adequate resources for dealing with it.

One of the startling facts uncovered during our dementia journey was that unlike cancer or heart disease, Alzheimer's disease is not considered to be a 'dreaded disease' so it is not covered under insurance policies. Anyone who has been affected by any form of dementia will testify to the devastating consequences of the condition, and this sorely needs to be addressed.

4.10 Stigma and dementia in sub-Saharan Africa: a Namibian experience

Contributor: Berrie Holtzhausen, CEO Alzheimer's Dementia Namibia

Introduction

In sub-Saharan Africa there is not enough data about dementia, which has a direct impact in the quality of information available. Whereas it's clear that raising awareness and increasing education will help break down the walls of stigma in Africa, it's also important to understand the cultural context and beliefs that can influence this stigma.

Belief in witchcraft, HIV-AIDS, perceptions about western medicine and un-enforced laws, are key causes of stigma towards people living with dementia in Africa. This stigma leads to the perception in communities that it is okay to discriminate against people living with dementia. Many are perceived to be witches and are ostracised, isolated, chained-up with very little food and water and sometimes killed.

Although there is a commonality about dementia all over the globe, the situation in sub-Saharan Africa is unique; dementia needs to be demystified in order to reduce stigma against people living with dementia.

The belief in witchcraft and stigma

In sub-Saharan Africa, many people use traditional means (witchcraft) to seek explanations for misfortune, illness or death. The fact is that the belief in witchcraft is common and is thus one of the main reasons why stigma against people living with dementia is so prevalent in the region.

In the Journal of Clinical Nursing, Professor Ingrid Hanssen, Registered Nurse and Doctor in Political Science, and Flora Mkhonto, Registered Nurse, introduce the reader to the consequences of perceiving people with dementia as witches, a common belief in sub-Saharan Africa.[1] They also demonstrate how lack of understanding about dementia being a disease, creates psychological distress and lack of care for people living with dementia.

An American University study by Boris Gershman, notes that *"…witchcraft beliefs can have a direct adverse effect on interpersonal relations via two main channels: by fostering the fear of bewitchment and by spreading the fear of witchcraft accusations, potentially entailing severe sanctions, from destruction of property to ostracism and even ritual killing."*[2]

In the 2016 documentary film, the African Witchfinder, the reality of believing in witchcraft and the stigma regarding people living with dementia in rural Namibia, is depicted very clearly.[3]

Witchcraft beliefs breed anxiety, uncertainty, suspicion and mistrust. They are fuelled by fear, jealousy and dreams.

This creates the perfect storm for stigma in a society that still accepts the belief in witchcraft as a part of its culture. Many sub-Saharan African countries have a law called: Witchcraft Suppression Law, however, there has been a reluctance to enforce it as it is often regarded as a discriminatory law.

Namibia

According to the Chairperson of The Law Reform and Development Committee (LRDC), the Law is outdated, discriminatory and accusatory: *"A consolidated and contemporary law must be developed, that balances individual rights of freedom of persons, with the harm associated with witchcraft, thus, it became a criminal offence for African people to use their traditional conventional means to seek explanations for misfortune, illness or death."*[4]

Alzheimer's Dementia Namibia responded as follows: *"The weapons in the fight against stigma and discrimination of dementia are: awareness, education, the Constitution of Namibia and the Witchcraft Suppression Law. Laws never will, and can't change culture but laws do change behaviour and changed behaviour can change the stigma and discrimination in cultures."*

If LRDC believes that it is necessary to redesign the Witchcraft Suppression Law in order to be more in line with the Constitution of Namibia, and to be a more contemporary law, Alzheimer's Dementia Namibia will be the first to help - for the sake of many people in Namibia who are living with dementia and are not free; not because of a disease but because of the stigma and discrimination surrounding them.

South Africa

On 23 March 2010, the Minister of Justice and Constitutional Development approved a South African Law Reform Commission project to review Witchcraft Legislation.[5]

One of the Commission's projects, the review of Witchcraft Legislation, supported the constitutional guarantee of freedom of religion and protected vulnerable groups. It was mostly women advanced in age that were persecuted as witches by communities holding traditional beliefs. These innocent victims were vulnerable to a double degree: as women and as older persons.[6]

This project was put on hold because the Traditional Healers council and New Paganists opposed it.

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Witchcraft related stigma will never be stopped if the gross human rights violations against people living with dementia, perceived to be witches and wizards, are not exposed as unacceptable.

Witchcraft beliefs breed anxiety, uncertainty, suspicion and mistrust and witchcraft beliefs are fuelled by fear, jealousy and dreams. This is the perfect storm for stigma in a society

HIV-AIDS

Out of the 34 million HIV-positive people worldwide, with roughly 23.8 million living in the continent of Africa. Sixty-nine percent live in sub-Saharan Africa. Ninety-one percent of the world's HIV-positive children live in Africa.[7]

HIV dementia is a common cause of dementia in African nations. AIDS Dementia Complex (ADC) is more common than Alzheimer's disease in Namibia, South Africa, Uganda, Kenya, Tanzania, Nigeria, Gabon, and Togo. So, an underestimation of dementia numbers in many African nations could be due to the Alzheimer-centric view of dementia (Professor William Hu).

Some of the side effects of treatments also exacerbate beliefs and issues around witchcraft. One medication called EFV 600mg (Efavirenz) describes side effects as: *"Changes in the shape or location of body fat, especially in your arms, legs, face, neck, breasts and waist" and "…serious mental health problems, unusual dreams and seizures..."*. These side-effects, especially for men developing breasts, are often interpreted as a person either being a witch or being bewitched.

Access to medication and person-centred care

The fight against stigma in sub-Saharan Africa can't be won without access to correct medication and properly trained physicians and medical professionals, focusing on some important facts, namely:

- The belief in witchcraft is real
- Firmly establishing that dementia is not part of normal ageing but a terminal disease
- The very specific link between HIV-AIDS and dementia in Africa
- Discussing the cause of the disease and the diagnosis in detail with patients and their carers is vital
- Explaining what the physician wants to achieve with the medication (e.g. suppression of the viral load, managing high blood pressure, high blood sugar etc.)
- Explaining and being transparent about possible side effects: establishing the benefit of the medication over the side effects or the danger of side effects and that these need to be reported and discussed immediately with the physician. Plus giving people clear examples of how side effects have been misunderstood as signs of witchcraft

In order to better support members, Alzheimer's Dementia Namibia is in the process of employing a Registered Nurse with 11 years of experience in screening, awareness and education of people living with HIV-AIDS.

According to him, *"Combination HIV medication can cause a lot of side effects, most of them are psychotic in nature and psychosis is seen as one of the key signs of being a witch. Identified side effects include hallucinations, violence, removal of clothes, talking to yourself, slurred speech, being withdrawn, drowsiness, irritability, constant headaches, loss of memory. This has misled a lot of health professionals because they did not, and still do not recognise these symptoms as side effects of the medication. We admit these people living with dementia and put them on anti-psychotic medication".*

This was brought to the attention of the Ministry of Health, and from 2019 new guidelines were implemented so that anyone developing psychosis, as a side effect of Efavirenz, is switched to another anti-retroviral drug. This is now happening in Namibia and also in Zimbabwe. The previous dosage of Efavirenz has now also been reviewed, reducing it from 600 to 400 milligrams.

Conclusion

The stigma and misunderstanding surrounding dementia in sub-Saharan Africa are a devastating reality for individuals living with the condition.

No nation can be free before everyone is free. People living with dementia are not free, not because of a disease such as Alzheimer's or HIV-AIDS related dementia, but because of the stigma and discrimination against people living with dementia.

The challenges of stigma in sub-Saharan Africa regarding dementia diseases ask for a holistic approach of the origin, role and place in the belief of witchcraft, western medicine, the way western medicine is being practiced, the relationship between western and traditional medicine, judiciary (common law and the traditional

law, and human rights balance with every country's constitution.

References

1 Mkhonto, F. and Hanssen, I. 2017. 'When people with dementia are perceived as witches. Consequences for patients and nurse education in South Africa' *Journal of Clinical Nursing* 27(1-2) online: https://onlinelibrary.wiley.com/doi/abs/10.1111/jocn.13909 Last accessed 19 August 2019.

2 Gershman, B. 2015. 'Witchcraft Beliefs and the Erosion of Social Capital: Evidence from Sub-Saharan Africa and Beyond' *Journal of Development Economics* 120 online: https://pdfs.semanticscholar.org/6ef4/41f0162e5e2e60b899d580cc3822725918ac.pdf Last accessed 19 August 2019.

3 African Witchfinder. ©2016 Heehaw Ltd. online: http://www.africanwitchfinder.com/ Last accessed 19 August 2019.

4 The Namibian. 2019. 'Call to revise witchcraft suppression law' online: https://www.namibian.com.na/185323/archive-read/Call-to-revise-witchcraft-suppression-law Last accessed 19 August 2019.

5 KLRC Blog. 2017. 'Justification For Review Of Witchcraft Act, Cap 67' *Kenya Law Reform Commission (KLRC)* online: http://www.klrc.go.ke/index.php/klrc-blog/518-justification-for-review-of-witchcraft-act-cap-67 Last accessed 19 August 2019.

6 South African Law Reform Commission. 2011. 'Thirty Eighth Annual Report 2010/2011' online: http://www.justice.gov.za/salrc/anr/2010-2011-anr.pdf Last accessed 19 August 2019.

7 DoSomething.org. 2019. '11 facts about HIV in Africa' online: https://www.dosomething.org/us/facts/11-facts-about-hiv-africa Last accessed 19 August 2019.

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4.11 A carer's perspective: My life with my father Joel Mbithuka Kasimu

Contributor: Elizabeth Mutunga, CEO & Founder Alzheimer's & Dementia Organisation Kenya

My father's name was Joel Mbithuka Kasimu. He was a senior police officer with the rank of Officer Commanding Station (OCS) and a very well-dressed individual who loved his family immensely. Although he was a busy man, he took time each evening to read to me and these story books helped develop my language and imagination. Being the first born, in sharing these powerful stories, he made me believe I could be anything I wanted to be.

In 1984, when I was only 9 years old, my Dad went into a diabetic coma. It was frightening to see my hero unable to do much for himself. In 1985, he had to retire early due to medical reasons. This made him really sad, as he loved wearing his uniform and he also missed not being able to serve the community. In 1989, we lost a sister, and this added to my Dad's sadness. The reason I am giving this background is to illustrate how far back the issues started. In 1992, my Dad moved the family from a four-bedroom house to a five roomed house. He then started selling the car in parts; the tyres separately from the rest of the vehicle. This was shocking to us. He then became violent which was totally out of character. This created a rift in the family as he was always looking for an opportunity to fight with us. I soon had to go and look for work to provide for the family.

It wasn't until 2007 that I heard the word dementia. I was shocked when we were informed that there was no cure. This was almost 15 years after fighting with Dad and not understanding what the issue was. A lot of people in Africa in the 1990's believed that dementia was a disease of the West and thus Africans could not get it. My father came from a community where people believed if there were issues happening to you and they could not be explained it was because you had been bewitched; you must have done something bad to the gods and thus you were being punished. As he was elderly, others believed it was a normal part of ageing. Due to the stigma of the disease, a lot of people would not visit our homestead for fear of the same disease affecting them.

This prompted me to look for a support group to plug into so I could understand more about the condition - but there was none. This pushed me to start a group, which ran till 2009, when my Dad rested. The journey with dementia was gruesome and I did not want anything to do with it anymore and so packed away that part of life and moved on.

In 2013, I received five phone calls from different individuals who had been referred to me, or who had read my story, as I used writing as a way of dealing with the pain I went through with my Dad's illness. I was initially quite angry when I received all these calls as I had made a pact with God and myself that I would never do anything or come close to this condition again. The people calling were so persistent that I decided to have one meeting where we could decide way forward. We never turned back since then and the support group still runs today. We have invited experts to come to speak to caregivers during the monthly meetings and educate them on the condition. This has changed their perceptions on dementia.

As caregivers one of the things we have worked on is creating awareness about dementia. We have used both print and digital media and awareness in the church to combat stigma and the misbeliefs surrounding the condition. Initially, when we started creating awareness, we would have to make many calls for even one radio or television station to interview us but now it is them calling us, and that is a great shift.

Referrals from neurologists have also helped Alzheimer's and Dementia Organisation Kenya (ADOK) in that we are now able to support more people. Involvement by the Ministry of Health in all their Technical Working Groups has helped in pushing forward the agenda of ensuring that we are moving towards having a national dementia plan in Kenya and policies to cater for people living with dementia and their carers.

There are a lot of studies now being carried out in Kenya as there is very little data on dementia and even the Government needs to recognise it is a huge burden to the carers; financially, emotionally and spiritually. Kenya is also part of STRiDE (Strengthening responses to dementia in developing countries) and this has been beneficial as we have more interactions with the Ministry of Health and so, for anything on dementia, ADOK is the go-to organisation. In 2017 Kenya also held our first conference in partnership with ADI and this was an eye opener to how big the problem of stigma really is. I remember most people were shocked to know that there was an Alzheimer's association in Kenya.

The issue of stigma is still rife especially in some areas in Kenya, but this is changing as more people are calling ADOK to ask where to start. If they have seen a doctor, then they are directed to attend our support group. By meeting other people going through the same thing, it helps with acceptance. People are then more confident to speak out and this reduces self-stigma. Self-stigma is the greatest hinderance to dealing with dementia and once this is dealt with, it will have a ripple effect on the issue of stigma in general.

4.12 Fighting stigma in the Middle East. Who speaks on behalf of people with Alzheimer's and dementia?



Contributor: Princess Nouf bint Muhammad, acting CEO of the King Khalid Foundation

My first encounter with Alzheimer's, that then curious disease with a strange sounding name, came many years ago when most of what we knew of such mental health issues was "senile dementia", which seemed inevitable, yet you prayed and hoped your elderly relatives, and eventually yourself, would escape its ravages.

What was it, what did it mean, how did it differ from other forms of dementia; all questions still unknown to many of us at the time; talked about quietly, and only between family members. Visits were limited to a smaller and smaller number of people, not as result of the anxiety it might cause, but to preserve the dignity of the person living with dementia. Sons and daughters wanted to protect their loved one as they lost their ability to communicate, to judge situations, and conduct themselves in the manner that suited their age and social standing, as family patriarch or matriarch.

As family awareness of the disease increases, and we know more about how it starts, how it affects the mind, and that it could start much earlier on in life, the stigma is reducing. Understanding the different stages, and that it is a medical condition and not a natural progression of old age, has helped family members cope better, and has reduced the embarrassment that they felt for themselves, as well as their diagnosed family member.

Unfortunately, that is only one source of stigma reduced and others remain.

Stigma associated with diseases and mental disorders manifest through a series of interconnected factors such as the spread of misinformation, lack of awareness, and prejudice that leads to discrimination. The fear of tackling cultural taboos and the systemic lag in public provision of education, health and social services are among the culprits as well. As I have been privileged with chairing the board of the Saudi ADHD (Attention Deficit Hyperactivity Disorder) Society (Ishraq), I have also seen the dangerous side effects of stigma, against what are considered mental health disorders. Many of the families were often resistant to accepting diagnosis and seeking assistance out of fear of the stigma they and their children might face. I believe this also happens to people living with Alzheimer's disease and other dementias, their carers and families. Moreover, unfortunately, limiting their options to seek care and support, accept diagnosis, and take advantage of the coping mechanisms that can be available to them.

Arab societies assign larger roles to extended families and greater social connections. We consider values of respect and dignity for the elderly as a duty and source of pride. This leads some families to avoid reaching out to healthcare professionals, carers or professional social services to help relieve the burden of their ill loved ones or the responsibilities associated with taking care of them. Families are intimidated by the stigma of care

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homes, which might be perceived as abandonment. Another disincentive to families seeking care is the damaged reputation of public social care institutions for the elderly and the perceived poor quality of the services they provide. Due to those factors, the stereotype about older age and dementia pushed people living with it to stay in the shadows. For that, the role of raising awareness of the disease and advocating for the rights of people living with it and their families serves as important solutions to those problems.

Many of the families were often resistant to accepting diagnosis and seeking assistance out of fear of the stigma they and their children might face

In addition to awareness, one of the important ways we can fight stigma is by making affordable, high quality governmental and non-governmental health and social services available to people with dementia. They should also be mindful of the needs and support that cannot be provided at home. These services should not be considered as luxuries available only to those who could afford home care. Subpar standards of these services leave many individuals, rich or poor, vulnerable.

Who should carry the burden of tackling this disease? I believe that governments cannot deliver inclusive healthcare and work toward eradicating the stigma against dementia alone. It is a collective effort that we all can be a part of, as governments, private sector, non-profit organisations and societies. Investing in the number of non-profits and building the capacity, in particular, can drastically improve the lives of people living with dementia, their loved ones and carers. As too would increasing training and expertise, especially around diagnosis and coping post diagnosis. Non-profit organisations serve an important role in raising awareness of Alzheimer's disease and dementia, advocating for the rights of patients and their carers. Those types of contributions would hopefully lead to correcting the negative connotations associated with the disease, improving the way people are treated; with dignity, respect and free from prejudice.

Our strength at The King Khalid Foundation is in our ability to bring the voices of our beneficiaries forward. For the longest time, the non-profit sector in the Middle East and North Africa has focused on delivering the basic needed services on the ground, and responding to basic demands of their beneficiaries. When it comes to tackling stigma, it is essential for NGOs (Non Governmental Organisations) to spread awareness about stigmatised communities, most importantly to push forward the voices of those who are being stigmatised; not as victims but to validate the challenges that they are going through. NGOs need also provide solutions and road maps to build the awareness of and help direct policy in their developmental, health, and education, and financial plans too.

At the Foundation, we work closely with various non-profits by providing them with funding and investing in social awareness campaigns that promote social inclusion, acceptance, and celebration of the added value and benefits, those who are vulnerable provide to society and the economy once they are enabled. Through our capacity building workshops, we were fortunate to serve our local Saudi Alzheimer's Disease Association since 2011. We worked with the Association on training their team on project planning, monitoring, and measuring impact. We are proud to commend the Saudi Alzheimer Association for their advocacy efforts to normalise Alzheimer's as a legitimate disease that needs proper services in the Saudi healthcare. In 2019, the Association succeeded in making diagnosis and treatment of Alzheimer's disease available without out-of-pocket costs at the minimum mandatory health insurance coverage in Saudi Arabia, unlocking needed funding and allowing greater access for millions of people to those services. Such efforts, encompassing the consistent engagement of the public and dedicated direct advocacy with policymakers are a great example of how non-profits serve their beneficiaries directly and indirectly.

Whether it is through research, pursuing policy change, or through spreading awareness publicly, we truly believe that NGOs in the region need to spend more time and effort to bring the voices of the vulnerable forward, including the voice of people living with Alzheimer's disease. The best way to help people with Alzheimer's is not only to provide them with the needed services but to give them a voice. As NGOs, the best that we can offer them and their families is the gift of understanding and advocating, and for society to remember that the burden of disease needs to be shared publicly.

Note*: The King Khalid Foundation is an independent Saudi non-profit that works on creating prosperity in the Kingdom by mobilizing stakeholders through social investment, capacity building and advocacy. The Foundation, established in 2001, has championed the cause of expanding the non-profit sector and spreading sustainability practices in the private sector. The Foundation has a long-standing history for pioneering socioeconomic research relating to poverty, financial inclusion, and quality of life, with a special attention to put forth evidence on the characteristics of vulnerable groups in the country. For more information, kindly visit the Foundation's website: www.kkf.org.sa*

4.13 A view from a memory clinic in Oman



Contributor: Dr Hamed AL Sinawi, Senior Consultant Psychiatrist, SQUH, Chairman, Oman Alzheimer›s Society & Oman Psychiatry Society

Stigma and negative attitudes toward people with mental health problems are a global phenomenon, which is often extended to include patients, their caregivers, and also mental health professionals. In Oman, mental health services used to be provided at separate hospitals, which meant mental health workers didn't get to work with other health professions. This lack of contact with others led to them being perceived as "working with crazy people" or "acting like their patients". More recently, mental health services have been integrated with other health services. This means both patients and mental health professionals have a chance to mix with others and challenge negative stereotypes. Dementia services are relatively new in Oman with the first memory clinic being introduced in 2011. People with cognitive impairment who were admitted to medical or surgical wards often got discharged from hospital without referral to the memory service as some health workers believe that not much can be done for such patients, since there is no cure for dementia.

Unfortunately, stigma still exists and this means people are sometimes denied access to services or denied their right to make choices about their health care. At times, during the medical interview, health care professionals only talk to the caregivers without involving the person with dementia even when they are at the early stages of the disease. Some caregivers ask that the person with dementia is not told about the diagnosis, which in my opinion is also stigmatizing to the person, as it denies them the right to know about their condition.

Self-stigma is quite common in people with dementia who attend our clinic, especially those in the early stages where denial is exhibited. They may seek a second opinion abroad and refuse to accept the diagnosis. This eventually makes them endure unnecessary expenses and delays the start of treatment.

But things are slowly changing. Many people, including health care professionals, are becoming more receptive to learning about dementia and to referring patients to the memory clinic for assessment. This can be partly attributed to the dementia awareness campaign that was introduced few years back and included workshops, social media posts and lectures to non mental health workers in other department about dementia. We often come across colleagues from other hospital departments who contact us for a consultation as one of their family members is exhibiting symptoms of dementia and this personal experience makes them realize how we can support patients and their caregivers, even if there is no cure for dementia.

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4.14 Creating an Alzheimer association; the story of the Alzheimer Indonesia Foundation

Contributor: DY Suharya Regional Director, Asia Pacific Alzheimer's Disease International

When my Dad informed me that my Mom (75 years old) was diagnosed with vascular dementia back in August 2009, I was shocked and confused. I was in the first year of my PhD scholarship after earning my Master of Public Health at Curtin University in Perth, Western Australia. When I had left Indonesia back in 2007, I was actually planning to move and live in Australia for good. However, my destiny seemed to bring me back home and I realised that God (and the universe) had better plans laid out for me.

Learning about my Mom's vascular dementia diagnosis in 2009 helped me reconcile almost two decades of struggling with my relationship with her. Mom had actually showed symptoms of dementia in her mid 50s. I felt real guilt.

The circumstances literally led me to a big decision, to simply 'let go' of my PhD and return to Jakarta in May 2012 and to commit to taking care of my Mom and to supporting my 80-year-old Dad. As he was the main carer, I tried my best to protect his physical and mental health in the "unknown" caring journey facing us.

The journey started when I accompanied Mom to a psychogeriatrician and was definitely not satisfied with all the answers to the questions we had. How to deal with challenging behaviour – sundowning? Refusing to eat? Agitation? Delirium? Suspicion? Hallucinations?

The doctor suggested I attend the Alzheimer's Disease International (ADI) conference in Taipei in April 2013 which led me to cross paths with the ADI "family" – at that stage, more than 80 member associations (now 100). I was inspired by members around the world who had done many things related to awareness raising, risk reduction, research, training, education, person-centered care methods, and advocacy. I learned so much from the conference and felt so lucky to have crossed paths with everyone including one of the people I admired from TADA – Secretary General Li Yu Tang. I pledged then to establish an association back home – what was to become The Alzheimer Indonesia Foundation.

On 3 August 2013, Alzheimer's Indonesia Foundation (ALZI) was officially established in Indonesia by multi-disciplinary founders, from a carer to a lawyer, a psychogeriatrician, a neurologist, a communication specialist and sports medicine doctor.

In truth, the new ALZI was actually a follow up, a transformation, from The Association of Alzheimer Indonesia which was created in 2000 and became a member of ADI in 2009. ALZI's vision was, and is, to improve quality life of people with dementia and carers and empower them with knowledge, skills and a network to support each other in the journey of caring.

I started off the new ALZI in 2013 supported by the Board of Trustees, only 5 volunteers and no funding. We were committed to conduct activities to end stigma around people with dementia and carers in Indonesia, a country with a 250 million population; where 8% of the population are over 60 and the estimated number of people with dementia is 1.2 million; with US$2 billion economic cost. We believe in our vision and mission immensely. If there's a will there is a way.

I had been inspired by Steve Jobs, who talked about why we should "connect the dots" in everyone's life, which was something that I did in my early days in kickstarting the first ever Alzheimer's awareness raising program, in September 2013. With only 500 participants, we managed to convince the Indonesian Minister of Health to support our cause.

One of my biggest goals was to influence policy makers and the Government about the importance of having a national dementia plan with sufficient budget. The Government of Indonesia subsequently launched its first ever Dementia National Plan with a modest budget in March 2016, one of the first countries in ASEAN (Association of Southeast Asian Nations) to do so.

I had a vision that nothing would be impossible if we could work together to create an inclusive society, following the principles of human rights and involving all partners – including people with living with dementia, carers, institutions, national and local government, private sector, non-profit organisations, health and care professionals and many others.

I was motivated to make things happen and to spread awareness that memory loss is not a normal part of ageing; that it's important to identify the 10 warning signs of dementia early so you can make comprehensive plans for a good quality life in the long- run. I had experienced it myself, in caring for my Mom. She was actually showing symptoms of cognitive impairment for two decades before she was diagnosed, and the entry points that affected her were hypertension, malnutrition and depression. The fact is; one person is diagnosed with dementia – but the entire family is affected and knowledge is definitely power.

My Dad is in his 90s now. He was the primary carer for my late Mom, who passed away in April 2017 - but her legacy continues. Now my Dad has been helping other husbands navigating the dementia carer path.

My sister won a traditional nationwide Poco Poco dance competition involving people in their 50s and she's now the official Poco Poco dance instructor, a dance that's designed as part of risk reduction activity around

dementia - if done consistently, for example for 30 mins a day, 5 times a week, there can be 37.5% improved neuroplasticity[1].

ALZI started its movement in 2013 and 6 years on, in 2019, we have more than 50 partners, 21 chapters (18 chapters in Indonesia and 3 chapters in USA, Netherlands and Switzerland) that have committed to increasing awareness in their own communities. For the past six years our movement of "Do Not Underestimate Memory Loss", #EndStigma and "RespectYourElderly" has changed the landscape of dementia and elderly awareness in Indonesia through the production of an information materials, including the 10 warning signs, introduced carer meetings and hosted the country's first Alzheimer's walks, with over 10,000 people attending in Jakarta alone over 5 consecutive years. Twenty other cities throughout Indonesia have hosted walks, picnics, inter-generational initiatives, virtual runs and many other activities.

Through ALZI's strategy in building partnerships with all sectors, the organisation has garnered support from government departments and local and national businesses.

After three years running the organisation on a voluntary basis, the ADI Twinning Programme helped link up Alzheimer Netherlands and Alzheimer's Indonesia. In 2017 Alzheimer Netherlands and the Ministry of Health, Sports and Welfare also supported ALZI to host the first ever Asia Pacific Conference in Indonesia. A very strong partner – Atma Jaya University has been part of the journey since 2015 and as a respectable academic institution under the leadership of Dr Yuda Turana, ALZI has strengthened its programmes to deliver impact to the society involving youth and technology and innovative interventions including film, webinar, and many others.

ALZI now leads a network of dedicated volunteers who plan events, conduct advocacy, and lead carer meetings. Purple Troops in Jakarta was established to help the elderly and link them up to receive screening in the nearest clinic in Jakarta. Capacity building is indeed the key as well as conducting programs that are impactful.

Indonesia has the fourth largest population in the world at 250 million. It's made up of over 17,000 islands, and 600 cultures call these islands home. Asia, specifically Asia Pacific, has the fastest growing population of people with dementia in the world, out of 50 million people with dementia, almost half live in the region.

Often, in low- and middle- income countries health and care priorities focus on tackling and reducing the number of communicable diseases, improving access to clean water and poverty eradication. However, with the growing population of people with dementia expected to rise to 4 million by 2050, every sector of society will be impacted. How dementia is perceived in these sectors may be very different within each culture and geographic region - which is a challenging task. In the villages, outside the major cities, many families believe dementia is a normal part of aging and keep their loved one at home, isolated from society, out of shame or embarrassment.

The path forward? To continue to support and strengthen Indonesia and other members in the Asia Pacific Region to be able to maximise their resources and assets, empower and improve quality life of people with dementia and carers. For me, this is a lifetime commitment.

References:

1 Ria, M T et al. 2019. 'The Effects Of Poco-Poco Dance On The Executive Functions Of Type 2 Diabetes Mellitus Patients With Mild Cognitive Impairment Achieved Through Improvements In Neuronal Functions And Plasticity,' *International Journal of Pharmaceutical Research,* 11(2): https://doi.org/10.31838/ijpr/2019.11.02.097 Last accessed 1 Sept 2019.

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4.15 145 Indigenous languages and no word for dementia: use of innovation and technology to help overcome stigma

Contributor: Dementia Australia

In Australia today there are 145 Indigenous languages in use and within these the word dementia, cannot be found.[1] This directly results in stigma and misunderstanding associated with the condition.

Recent studies have shown Indigenous Australians are 3-5 times more likely to develop dementia and at an earlier age of onset than non-Indigenous Australians.

Generating meaningful communication pathways between dementia researchers, health service providers and Indigenous communities is critical to providing better prevention, diagnosis, treatment, and care options for Indigenous Australians living with dementia. Recent hearings at the Australian Royal Commission into Aged Care Quality and Safety highlighted the need for culturally-safe practices to be embedded into care as well as stressing the need for more research to support the development of good models of care for Indigenous Australians. Witnesses to the Commission reported a lack of respect of culture and customs in the delivery of care, including racism, lack of understanding of the Indigenous attachment to country and a lack of Indigenous carers within the aged care system.

While timely diagnosis can be problematic for anyone living with dementia, within Indigenous communities this can be heightened by a lack of culturally appropriate diagnostic tools. Poor recognition of dementia within Indigenous communities and among health care workers and service providers compounds the issue. The use of culturally appropriate validated cognitive assessment tools is critical, especially when we note that, within the 145 Indigenous languages used across Australia today the word dementia cannot be found, which in turn results in stigma and misunderstanding associated with the condition. [1]

The preferred tool is the Kimberly Indigenous Cognitive Assessment tool (KICA)(i). This is a tool designed for Aboriginal and Torres Strait Islander people in the Kimberley region and has been modified for Aboriginal and Torres Strait Islander people in urban areas.

Innovative approaches to engaging Indigenous populations are being developed, tested and deployed in Australia programmes including Dementia Yarn Up(ii), a collaboration between Dementia Australia, the Gunditjmara community, Nathan Lovett-Murray, Winda Mara Aboriginal Corporation and Indigenous Hip Hop Projects that has resulted in the production of a hip hop music resource on dementia, wellbeing, culture and respect, going some way to reducing the stigma within Indigenous communities.

Dementia Australia's innovation and leadership in the application of virtual reality (VR), interactive video games and apps (applications) is also being adapted to assist engagement with Indigenous populations. Dementia Australia's Centre for Dementia Learning (CDL) has developed a wide range of applications in consultation with carers, people living dementia and educators. The application of VR, interactive video games, and apps continues to transform dementia care and practice for people living with dementia, families and carers across residential and community care settings. Some of the programmes have also now been introduced to Canada, Singapore and Czech Republic.

The CDL's exploration of emerging technologies such as VR and computer games has been an exciting focus for more than six years and a wide range of applications have been developed in consultation with carers, people living with dementia and educators. The drivers have been to create immersive and impactful experiences that aim to build empathy and meaningfully resonate with users to inspire positive change. The different applications are powerful tools and offer an experiential way for all who work in the industry to increase their understanding thereby improving their practice.

The impact of these technologies has been measured through ongoing and independent evaluation as well as consumer consultation that demonstrates how the use of these tools in education and information sessions is influencing change in residential and community care and improving the lives of those living with dementia.

Key products that have been developed are two apps, The Dementia-Friendly Home™ and recently, A Better Visit™, which are examples of the way technology can be accessible via everyday devices. One empowers carers to understand how they can better support a person living with dementia to maintain their independence and dignity and continue living at home, while the other has fun, engaging games to enhance communication and facilitate positive social interactions with visitors.

A third application is The Virtual Forest™, an interactive computer game which creates a beautiful, calming, natural setting, and provides people living with dementia the opportunity to reclaim a sense of control over a part of their lives by interacting with ducks, fish, a dragonfly, a butterfly and forest trees with just the wave of their hands.

(i) https://www.perkins.org.au/wacha/our-research/indigenous/kica/

(ii) https://www.dementia.org.au/resources/indigenous-hip-hop-project-yarn-up-about-dementia

For those who do not live with dementia, it can be difficult to understand what it might be like for someone experiencing changes in their brain, or to comprehend the way in which communication and the environment around them impacts on their cognitive function. The Virtual Dementia Experience™ provides an immersive, experience-based workshop which allows carers to develop a strong sense of empathy by 'virtually' being in the shoes of someone living with dementia. An evaluation by Australian-based Swinburne University found that dementia care workers who undertook the Virtual Dementia Experience training gained threefold more empathy for the person living with dementia and they were able to identify more dementia-friendly elements and care practices.

The workshop has been adapted as technology has evolved, with an updated version now available on lightweight, mobile VR googles, called EDIE (Educational Dementia Immersive Experience)™. The virtual reality experience enables participants to see, feel and hear through the eyes of a person living with dementia as he navigates his house late at night trying to find the bathroom. Participants are fully immersed and can even hear the heart beat faster as the situation becomes more and more confusing and challenging.

This portable experience has resulted in the ability to rollout EDIE workshops all over Australia, enabling aged care workers in regional and remote areas to experience the insights the technology elicits. It also offers a more economical option for providers since it minimises or removes the need for staff travel and time away from their workplaces.

An evaluation of EDIE has found it significantly improves knowledge, changes attitudes towards dementia, and stimulates greater empathy and understanding of care needs. While not all challenges are that simple to address, it shows how valuable Information Technology and applications can be for the health industry.

EDIE is also being used to break down the barriers and educate Aboriginal and Torres Strait Islander communities, with an educational programme being delivered to remote Indigenous communities in far north Queensland's Cape York region, including Wujal Wujal, Hope Vale, Lockhart River, Bamaga, Pormpuraaw, Kowanyama, Weipa. Funded by the State's Northern Queensland Primary Health Network, the programme is aimed at health, community, hospital and other staff and community members who are working with adults, older people and those living with dementia.

Dementia Australia is committed to creating unique, accessible, learning experiences for participants that touch, move and inspire them to transform their dementia practice through a change in attitudes and behaviours. A whole of society focus on educating the wider community and not just people living with dementia and their carers is key to reducing stigma, discrimination and increasing understanding of dementia in communities.

For more information on all the products and programmes above visit https://dementialearning.org.au/technology.

References

1 Korff, J. 2019. 'Aboriginal languages' *Creative Spirits* online: https://www.creativespirits.info/aboriginalculture/language Last accessed 19 August 2019.

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4.16 Māori, Mana and Mate Wareware: Rauawaawa Kaumātua Charitable Trust and its experience in supporting Kaumātua with Dementia

Contributors: Rangimahora Reddy & Pare Meha Rauawaawa, Kaumātua Charitable Trust, Etuini Ma'u, Waikato District Health Board, John Oetzel, University of Waikato

When asked to contribute to the World Alzheimer Report, we set out to identify the challenges of stigma, awareness raising, and diagnosis for Māori along with a unique cultural programme to address these challenges at a kaumātua (elder) serving organisation in Aotearoa (New Zealand)

With a vision of *"Hei manaaki ngā Kaumātua*" – "To enhance the quality of life and wellbeing of Kaumātua" – Rauawaawa Kaumātua Charitable Trust was established in 1997 by a group of Kaumātua (elders) concerned about loneliness and other key challenges facing Kaumātua. Based in Hamilton, New Zealand, Rauawaawa is an organisation firmly rooted in Kaupapa Māori principles (a philosophy of Māori for Māori). Central to these principles is the concept of mana (status, prestige), promoting practices that protect and uphold the dignity of Kaumātua, supporting their independence, and ensuring Kaumātua voices resonate through what we do, how we do it and when and where it is best done.

Rauawaawa is based out of Te Puna o Te Ora, a facility set up in 1941 as a residential facility for Māori moving from the rural areas into the city for work. It offers a rich history in its service to Māori and is unique in serving those that are the same age or younger. Many Kaumātua that engage with Rauawaawa today fondly recall the role the facility played in their earlier lives.

As in Maoridom, Kaumātua at Rauawaawa are revered for the mātauranga (knowledge/wisdom) gained from their lived experiences and for the central role they play in their whānau (extended family) and wider iwi (tribe). Many are also known for their experience as practitioners and custodians of tikanga (cultural customs). Kaumātua are often the first point of call in whānau crises; the cultural equivalent to the health emergency number. They are also greatly relied on by organisations to provide tikanga for events (e.g., opening a new building) and cultural training. In short, the reliance on Kaumātua has grown significantly over time.

But what happens when Kaumātua who have been the rangatira (leader) in the whānau end up needing manaaki (caring) themselves because of mate wareware (dementia)? Holding mana as a result of their rangatira role in a whānau can make it extremely challenging for both themselves and their whānau to acknowledge the symptoms, become informed, seek out a proper diagnosis, and access the support they need to enhance the quality of life and wellbeing of their Kaumātua. In a nutshell, the stigma of mate wareware may be enough for Kaumātua to resist sharing what they experience in the early stages, to disagree to having a proper assessment and to decline the opportunity to learn about the illness.

The stigma may also be enough for whānau members to try and hide what is happening with their beloved Kaumātua in an attempt to protect the mana of their Kaumātua and ensure they are not categorised or treated in a way that is not befitting of them, their whānau or their past. Other efforts to protect a kaumātua's mana may include wrapping them in "cotton wool" or surreptitiously curtailing their independence by assuming more of the decision making for them. Another challenge with this stigma is it can induce assumptions of independence no longer being possible for the Kaumātua concerned; e.g., a vehicle, bicycle or scooter maybe confiscated by whānau as they try to protect their Kaumātua and others from physical harm and yet it still may be possible for the Kaumātua to have independence.

The realities of caring for Kaumātua with mate wareware are as diverse as they are challenging, as a balance is sought between promoting independence whilst maintaining safety. Rauawaawa as a provider of culturally focussed day programmes have been tested a number of times with providing adequate care for those with mate wareware. The outcomes have not always been up to our own expectations. The realisation that, as an organisation, you are no longer able to provide the level of oversight needed for a Kaumātua can bring on a rapid and horrendous sense of panic for their safety when they go missing. The possibilities of harm that run through your mind are endless as is the hole in your stomach from worry and the ache in your heart from failing to be the safe pair of hands that Kaumātua need you to be and that Whānau rightly expect you to be.

These experiences made us realise at Rauawaawa that safely integrating Kaumātua with mate wareware into our usual programmes, whilst still maintaining their mana, would be difficult for those with a more advanced mate wareware and that a more robust programme focussed solely on kaumātua with mate wareware was needed. In 2018, Rauawaawa were supported by Alzheimer's New Zealand (NZ) to develop and implement a culturally responsive programme to promote understanding of mate wareware and the services available to support both the individual and whānau. The programme is called Hiki te Wairua (Lift the Spirit) and includes four key components:

1 A weekly group-based programme incorporating opportunities to engage and participate in activities such as te reo (Māori language), waiata (Māori

songs), poi (Māori action songs) and rakau (Māori stick games).

2 Individualized visits that incorporate opportunities to educate and share information on mate wareware with whānau and Kaumātua, as well as provide information on the services available for them to access for support.

3 The incorporation of mate wareware service providers in quarterly health expos to promote awareness, and include opportunities for providers and potential clients to develop relationships.

4 To profile mate wareware in our annual Kaumātua Olympics which hosts Kaumātua service providers and their Kaumātua from across the North Island of NZ. This programme will be launched in Alzheimer's month with Alzheimer's NZ at Rauawaawa.

Kaumātua are a cultural taonga (treasure). Symptoms that change them from what they have been in the past to who they are with mate wareware are challenging. Their significant contribution to the wellbeing of a whānau, iwi and community is a small reminder of why they deserve the best of care available to ensure *"Hei manaaki ngā Kaumātua."*

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4.17 Federazione Alzheimer Italia – developing a model for Dementia Friendly Communities.



Contributor: Mario Possenti, Segretario generale, Federazione Alzheimer Italia

The Italian Dementia Friendly Community program was started in 2016 by Federazione Alzheimer Italia, the largest national non-profit organization dedicated to the promotion of medical and scientific research on the causes, care and assistance for Alzheimer's disease and dementia.

For the pilot project Abbiategrasso was chosen, a 30,000 inhabitant town in northern Italy, on the basis of a protocol developed in the United Kingdom by Alzheimer's Society. The basic idea was to evaluate the feasibility of a large-scale dissemination of these communities while always keeping in mind the peculiarities of Italian society. For this reason, the project was designed, integrating best practices from various experiences of European and non-European countries.

We used the Dementia Friends logo created by the Alzheimer's Society, however, we considered that, in Italian, the best translation for the project was "Friendly communities of people with dementia" to pay more attention to the person as the center around which the whole community revolves: listening to their voice and being guided by their indications adds meaning and great value to the whole project.

Federazione Alzheimer Italia considers every reality in creating a path towards a community that knows how to listen and support people with dementia. Through practical examples and suggestions on the main actions to be taken, the communities can then decide which activities and initiatives to use in order to make their territory welcoming for people with dementia.

From the beginning we felt the need to frame the project in the most precise way so that it was not only replicable and sustainable, but also really effective in achieving the aim of placing the person at the center and fighting the stigma of dementia. For this reason, each community starts with an active participation of people with dementia, including through an investigation of their needs.

Already in 2017 we had welcomed the review by Imogen Blood and Associates (a social research agency) in partnership with Innovations in Dementia (a UK based Community Interest Company, established to help people with dementia to keep control of their lives), which collected experiences, voices and opinions of experts, people involved and people living with dementia with the intent of providing a definition of Dementia Friendly Community and outline examples and best practices of action.

This work is part and result of Act on Dementia[1], which involves 13 States with the aim of developing consensus on the evidence of diagnosis, post diagnostic support and quality of care, and understands how these changes can be put into practice and evaluated.

When the Italian Ministry of Health asked the Abbiategrasso's community to participate in this transnational initiative, we felt it was important to give our contribution with a view to assessing whether the impact of the Dementia Friendly Community (DFC) was objectively relevant and what were the best ways to approach this project.

Federazione Alzheimer Italia, with the pilot site in Abbiategrasso, is involved together with Greece and

Bulgaria in the Work Package 7 of the Joint Action, namely the one dedicated to Dementia Friendly Communities. The aim of the pilot is to validate a series of indicators and to provide indications for the creation of a shared model.

Measuring progress during the journey to become a more welcoming Community is useful in order to demonstrate the effectiveness and impact of DFCs on the lives of people with dementia and their families. It also better clarifies the scope, responsibilities, resources and path that each initiative must have within the Community and make the long process of supporting and maintaining a DFC, traceable and repeatable.

Today in Italy there are 24 Communities: towns and portions of cities, from north to south and from east to west, which have accepted the challenge of Federazione Alzheimer Italia with conviction and commitment to launch a path on their territory where citizens have the opportunity to become a network, able to welcome and involve people with dementia. This path is made up of informative meetings, recreational, cultural and sports events aimed at the participation of citizens, never forgetting the active involvement of people with dementia at every stage of the project.

From the beginning we felt the need to frame the project in the most precise way so that it was not only replicable and sustainable, but also really effective in achieving the aim of placing the person at the center and fighting the stigma of dementia. For this reason, each community starts with an active participation of people with dementia

This experience is also bearing fruit at the institutional level. Together with the Ministry of Health, some representatives of the Italian regions and other dementia friendly experiences, we have written a document of recommendations for DFCs that will be approved, hopefully by the end of 2019, from all the Italian regions and will constitute the operational base for the constitution of a larger involvement. This document will allow the regions, which are public bodies, to become promoters of this initiative without, however, obscuring the fundamental role of the municipalities, associations and local communities that are the real engine of this project.

The project born from Federazione Alzheimer Italia continues to spread and grow because more and more communities have perceived the importance of initiatives like these to make dementia known but above all to fight the stigma towards people who live with dementia. However, it is necessary to monitor and evaluate these initiatives over time as it is essential to have data to be able to know, in the long term, the impact on the population and to be able to overcome those difficulties that may arise, for example, from different social contexts.

In Italy, of the 24 DFCs, 19 are located in the north and only 5 are located in southern Italy. What most characterizes the realities of the south is that the activities of the Community revolve around already consolidated experiences such as day centers or listening centers. What is lacking in the territory and in the institutions is reinforced by the presence of local associations and the richness of their initiatives.

The differences and peculiarities of the various Italian communities certainly represent a challenge for the project. For this reason it is important that local stakeholders contribute to creating a network capable of understanding the needs of people with dementia, and together with them, put in place a series of well-planned initiatives.

It should be noted that, where the networks are stronger, there is an intense collaboration between the various stakeholders, and the Community carries out more significant initiatives. However, when a real network is missing, or the fundamental contribution of an Alzheimer association, and the direct engagement of people with dementia is missing, and the initiative is left in the hands of local institutions only, the Community tends not to express its full potential.

In Italy the DFCs project is just at the beginning, however, from 2016 to date we have been able to see an increase in media coverage of the initiatives and this is undoubtedly a result that traces a path towards greater knowledge of dementia and, in perspective, towards a victory against stigma.

References

1 European Joint Action DEM-2, 2016-2019. https://www.actondementia.eu/about Last accessed 3 September 2019.

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4.18 Dementia in prisons; How to address the double stigma of people with dementia or memory issues in prisons and forensic institutions.

Contributors: Sophie N. Gaber, MSc OT, PhD Candidate at Karolinska Institutet, Sweden & Birgit Heuchemer, MSc. registered. OT at HELIX Forensic Psychiatric Clinic of Stockholm; Research Assistant at Karolinska Institutet, Sweden.

Interviews with older ex-prisoners, as well as professionals working with prison and forensic populations in the UK and Sweden, shed insight into the "double stigma" of living with dementia, or memory issues, in prisons or forensic institutions. International policies such as the United Nations' Sustainable Development Goals, strive to "leave no one behind", however, in this case study we ask whether the marginalised population of older people with dementia or memory issues, in prisons or forensic institutions, are at risk of being left behind.

Ageing stigma: The growing population of older prisoners

Older prisoners are one of the fastest growing populations among all prisoners, in many countries (e.g. UK, US, Australia).[1] The growing population of older prisoners is attributable to several factors, including governmental policy changes. This has resulted in longer prison sentences where people age in prison, in addition to the imprisonment of older people without consideration of their specific needs.[2] The lack of consideration of the specific needs of older prisoners is compounded by insufficient research or policy on the topic.[3] Lack of information about the prevalence, incidence or experiences of older prisoners living with dementia has contributed to what prisoners have described as a "double stigma". They face not only the typical ageist assumptions that dementia is a natural part of ageing (e.g. forgetfulness, reduced ability or capacity, slowness, etc.) but also the prejudices associated with being a prisoner including views on criminals by society. One ex-prisoner described the stigma she faced, which was intensified by not only her age and memory issues but also her gender;

"There's a stigma when you're in prison, because you're older people, especially if you're a woman, they think you should know better. There was a stigma from guards and other people. They would say 'well we can understand a young kid doing this because they don't know what they're doing or they're on drugs or something' but you're looked down upon."

Older prisoners cost approximately two to three times more than younger prisoners.[4] Prisoners age at an escalated pace; it is estimated that the physiological age of prisoners is 10-years greater than their chronological age.[5] Consequently, the care needs of older prisoners with and without dementia tend to be higher due to the number of chronic health conditions they are living with (e.g. diabetes, high blood pressure, arthritis and mobility impairments).[3] However reports show that prison staff lack training or education about caring for older people with dementia or memory issues.[2] An older prisoner reflected that

"I think society probably doesn't expect older people to be in prison so much. And anyone that has aged in prison has been put to prison for a very long time, which must mean that their crime is something very, very serious if they've been there for many years. And the thing about being an older person in prison is that on the whole prison is a very young place. People are very busy and they run everywhere and they fight a lot. And I found it dangerous even walking down the corridors".

Due to the large amount of resources that are required to care for the complex needs of older people living with dementia in prisons, it is essential to develop knowledge about this population and consider whether prison is the appropriate place for older people with dementia convicted of a crime.

Everyday stigma: Risk factors for dementia and cognitive decline among older prisoners

The harsh living conditions of prisons are well reported internationally, however, the potential risk that such conditions pose for dementia and their direct opposition to dementia prevention guidelines, has not been widely acknowledged.[6] Research indicates that we are able to influence between 30 to 50% of the risk factors for Alzheimer's disease, including high blood pressure (hypertension), depression, education, and limited physical inactivity.[7] Yet, this is not the case for prisoners.

- **High blood pressure:** In the case of blood pressure, prisoners described a poor diet of meals and commissary snacks rich in salts, sugars and fatty foods. Smoking is widespread with limited opportunities to visit a health professional to monitor blood pressure or one's general health and wellbeing.
- **Depression**: A high rate of depression has been reported in this population.[6] Depression has been associated with the increased sense of isolation and a lack of privacy or safety experienced by prisoners.
- **Education**: Whilst some prisons offer education programmes this is inconsistent and prisoners, as well as professionals working in prisons, described limited opportunities for cognitive stimulation.
- **Limited physical activity:** The highly-structured prison routine limited opportunities for physical activity, particularly in outdoor spaces for older

people. Additionally, the rate of alcohol and substance use, blood-borne viruses and non-communicable diseases is higher than the general population.5

The absence of cognitive stimulation or education as a risk factor for dementia or cognitive decline was highlighted by both ex-prisoners and prison staff as a key issue. One prison staff member noted that possibilities for making decisions, even minor ones such as when to make a cup of tea, are reduced.

One ex-prisoner elaborated,

"I lost a lot of my memory. You know before I went in I used to think that I could remember numbers. I could remember my PIN code. I could remember phone numbers and things. And I found once I got in there for a while, with the strange life you live, a lot of that I couldn't remember. In fact it hasn't returned. I don't think I'm as sharp because of that experience as I was before. That's not just about old age, it's about being in a place where you're left to deteriorate, quite badly. Without the necessary stimulation that a human being needs every day."

Another older ex-prisoner compared the stigmatising effects of the everyday living environment to the disorientating monotony of the film "Groundhog Day".

"The film Groundhog Day - that's what it makes me think of. You wake up, you have your toast, you go back in, you have your lunch, you go back in, you have your dinner, you go back in… The only way I knew one day a week that was a point of reference for me was that on a Thursday I did my laundry."

Diagnostic and support stigma: Managing dementia or memory issues in prison or forensic institutions

Diagnosing dementia in prisons and forensic institutions is problematic for a variety of reasons, such as a lack of cognitive screening when a person enters prison or during their stay in prison, inadequate training of staff to identify the signs and symptoms of dementia, and a reluctance of prisoners to report memory issues or dementia due to a fear of repercussions.[4] Dementia is not a diagnosis that automatically determines whether a person convicted of a crime is sent to prison or an alternative place, such as a forensic institution. Recognising signs of a problem is based on a person's presentation of symptoms and level of functioning, which is in turn reliant on the ability of staff to identify symptoms and make the necessary actions to support the person.

Guidance for staff is inconsistent. For instance, in the United Kingdom there is no national plan for managing older prisoners.[8] One prison staff member admitted that, *"dementia is not a common part of the vocabulary"* and that the entire system is not adapted for people with dementia or cognitive impairment, with even meetings with social services being challenging. Furthermore, the staff member observed that prison services are frequently preoccupied with other mental health conditions which may even "cloak" the dementia. There is a risk for dementia to be hidden because symptoms may be dismissed as challenging behaviour. Cognitive impairment is included in many other diagnoses that are prevalent in prisons and forensic institutions (e.g. depression or psychoses) and can be attributed to the many side-effects of medications. Ageist assumptions may further cloak dementia if people do not realise that dementia affects many different people and not only the frail, very old population.[4]

A prisoner described the lack of support or activities for older people in prison;

"There's sometimes a pastoral chaplain that could come and talk to you but it's very difficult because the medical staff are all so busy and they're only really there for serious injuries or doing things like giving out pills."

A lack of support by fellow prisoners or opportunities for social engagement was also reported;

"So, in there it is very difficult to find someone you can talk to and staff are constantly changing. When you talk about memory issues you are told that it is just due to the new, unfamiliar environment. You feel very isolated."

A staff member explained the lack of support for older prisoners is due to staff members not having experience working in geriatric care and called for greater cooperation with care home or nursing home professionals, as prison may not be the most suitable place for an older person with dementia. There may also be a bias of lowered expectations for older prisoners, especially those with chronic health issues such as dementia, compared to rehabilitating young prisoners who have "their whole lives to live".

"So, something like memory loss, would be considered I know, as something not important. Not life threatening as far as they're concerned. You'd be waiting a very long time to see anybody. It would probably be only if you requested an outside agency like Mind (a mental health charity), or something like that, if you could actually get any of them to come in. But whether you would be able to do that or not - I don't know. So, it would be very, very difficult to get help."

One lawyer explained that, *"there is some hesitancy in addressing the issue of an ageing prison population. There is a fear that with dementia we are just uncovering the tip of the iceberg, there are serious financial, social and legal implications if we are going to address health and cognitive issues to make life fairer and better for prisoners."*

In summary, this case study is intended to be used as a launchpad for advocacy towards increased awareness and meaningful changes to support the lives of older people living with memory issues or (un)diagnosed dementia in prisons or forensic institutions internationally.

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Three recommendations for change:

1 Introduction of a mental health assessment including screening for dementia/cognitive impairment at the probation stage (prior to imprisonment).

1 An annual health and wellbeing check-up that includes a cognitive assessment for all prisoners aged 50 years and over (by mental health/dementia charities).

2 Dementia-awareness training for all professionals and volunteers working with prison populations (by dementia charities and organisations).

References

1 Peacock, S., Hodson, A., MacRae, R., Peternelj-Taylor, C. 2018. 'Living with Dementia in Correctional Settings: A Case Report' *Journal of Forensic Nursing*. 2018; 14(3): 180-184.

2 Newcomen, N. *Dementia. Prisons and Probation Ombudsman Independent Investigations. Learning lessons bulletin* 11, 2016. online: http://www.ppo.gov.uk/app/uploads/2016/07/PPO-Learning-Lessons-Bulletins_fatal-incident-investigations_issue-11_Dementia_WEB_Final.pdf Last accessed 20 August 2019.

3 Brooke, J., Diaz-Gil, A., Jackson, D. 2018. 'The impact of dementia in the prison setting: A systematic review' *Dementia* 0(0): 1-23.

4 Cipriani, G., Danti, S., Carlesi, C., Di Fiorino, M. 2017. 'Old and dangerous: Prison and dementia' *Journal of Forensic and Legal Medicine* 51: 40-44.

5 Sindano, N. 2016. The Prison Project: Raising awareness of dementia in prisons. online: https://www.alzheimers.org.uk/blog/prison-project-raising-awareness-dementia-prisons Last accessed 20 August 2019.

6 Christodoulou, M. 2012. 'Locked up and at risk of dementia' *Lancet Neurology* 11(9): 750-751.

7 Norton, S., Matthews, FE., Barnes, DE, Yaffe, K, Brayne, C. 2014. 'Potential for primary prevention of Alzheimer's disease: an analysis of population-based data' *Lancet Neurology* 13(8): 788-794.

8 National Dementia Action Alliance. 2019. *Meeting the challenges of dementia in prisons: Roundtable discussion briefing paper* online: https://www.dementiaaction.org.uk/assets/0004/2263/Prisons_and_Dementia_-_NDAA_briefing_paper_Update.pdf Last accessed 20 August 2019.

4.19 Challenging stigma in mental health: What we've learnt over 10 years



Contributor: Sue Baker, Director, Time to Change Global.

This is a case study on challenging stigma in mental health as inspiration and a call for collaboration.

Ending mental health stigma is the work of a generation. I think that's the most important thing we've learnt since starting Time to Change more than 10 years ago.

Stigma is deeply ingrained, through cultural norms, families, workplace culture, the media and even the words we speak. It is present at almost every level of society, which means our work takes time, perseverance, and a broad, flexible approach.

Time to Change is one of the most evidence-based social movement campaigns in the world. We have robust, independent evaluation in place to track progress and show the difference we are making.

I am very proud to say attitudes are changing. Between 2007 and 2016, there was a 9.6% improvement in attitudes - that's around 4.1 million adults in England with better attitudes towards mental health problems. Eleven percent more people say they would be willing to live with, work with or continue a relationship with someone with mental health problems. This research carried out by the Institute of Psychiatry, Psychology and Neuroscience (IoPPN) at King's College London shows levels of discrimination have also fallen. People report experiencing 7% less discrimination from family, 15% less discrimination from friends and 10% less discrimination in dating.

We cannot be sure the precise amount of social change due to our campaign. The work of many organisations and individuals has combined to drive positive change. But we are extremely proud to have been at the forefront of social change around mental health stigma and discrimination.

More than 1,000 organisations have signed the Time to Change Employer Pledge. We've worked with more than 2,000 schools and there are over 7,000 Time to Change Champions speaking out to end stigma in their communities.

While it is important to celebrate these huge steps, there is still a long way to go.

Going global

Mental health problems know no boundaries; neither does stigma. They affect people of all ages, all income groups, and all cultures. That's why in 2018, we launched Time to Change Global.

One in four people around the world will experience a 'mental or neurological disorder' in their lifetime. Yet nearly two-thirds of these people never seek help from a health professional.

Stigma and discrimination are a big part of this. Stereotypes, misconceptions and fear are so deep-rooted, mental health is treated as a 'poor relation' to physical heath. People with mental health problems are mistreated and misunderstood all over the world. We can be excluded by families, friends, neighbours, employers and schools.

"I had a relapse at the prayer camp, and I was tied like a sheep. They tied my legs together, like a pig or an animal at a butcher to be carried home." (Champion, Ghana)

Despite being a global issue, much of the evidence on how to tackle mental health stigma is concentrated to a few countries - mostly in the Global North.

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The Time to Change Global programme seeks to address this balance and help build a broader evidence base for stigma reduction.

We are working with international disability and development organisation, CBM, and with local partners to pilot anti stigma campaigns in Ghana, India, Kenya, Nigeria and Uganda.

"People say it is a waste of time to give you food – or they say you should stay outside." Champion, India

The five pilots will look very different, depending on the needs and capacity of our local partners. Each campaign is being developed, tested and adapted with the local partner and a group of Champions. All Champions have their own experience of mental health problems.

While language, context and approach might look different, the pilots share three core elements:

- **Lived experience leadership:** People with mental health problems shape and lead all that we do.
- **Social contact**: Conversations can change lives. We know that sharing personal stories within communities is vital for ending stigma.
- **Social marketing**: Public campaigns allow us to reach more people, increase knowledge and change perceptions.

Lived experience leadership

To effectively tackle stigma, whether you're in Accra or Accrington, we know that people with lived experience must shape, lead and deliver social change campaigns.

Those of us with personal experience of mental health problems are best placed to drive the change we want to see. It is so important that our voices are heard. It means so much to me to see Champions planning and running events and sharing their stories how they want to share them.

"When I had my crisis, I felt I was a disappoi*ntment to everybody that looked up to me. Now though, I can see people are still being inspired by my experience. I'm sort of giving back in my own small way."* Project Coordinator, Ghana

Social contact

Conversations really do change lives. When those of us with experience of mental health problems start talking more openly, we can reduce stigma and discrimination in our communities. By sharing our stories and telling you how it really feels to live with a mental health problem, we can change opinions and shift attitudes.

"We should not stay back because of our mental illness. We can all help to create awareness." Champion, India

In the five pilot countries, Champions are planning and running social contact events to engage the public and share their stories. In Accra, Ghana, events have taken place at malls and shopping centres to reach wide sections of the public. Social contact events in Doddaballapur, near Bengaluru in India, look very different. Champions here are from rural communities. They have been sharing their stories alongside travelling actors and singers at schools and in outdoor spaces.

Social marketing

One of the reasons our work in the UK has been so successful, is our ability to reach wide audiences through social marketing. These campaigns are effective because we take time to understand public perceptions and then we develop creative approaches which challenge and address public fears, misunderstandings and stereotypes.

Time to Change Global is replicating this approach, to help change public perceptions and behaviour in the five pilot countries. In Ghana, the work began with a set of focus groups to understand how members of the public feel about people with mental health problems.

This research has highlighted pervasive beliefs linking mental health problems to violence. One focus group member explained, *"They are not predictable. You don't know when they will strike*". Others described how people are shunned and rejected, *"mad people are not supposed to appear in public… we don't see them as humans".*

We asked the focus groups to think about how we could challenge these negative perceptions. Building empathy was a core recommendation. As one participant explained:

"I wouldn't like to be in that situation and people rejecting me, if I see a person in that situation, I would like offer a helping hand because it might happen to me as well".

These insights will allow us to develop a campaign in Accra that is truly audience-led.

Stigma and discrimination ruin lives. We won't stop until no one has to face this injustice. No one should be made to feel alone, ashamed or worthless because of their mental health problem. Together with our local partners, we will keep fighting to remove the barriers that stop people living their lives to the full.

We want to inspire other campaigners, other organisations and anyone facing stigma in the Global South, and around the world. We want to learn from other campaigns and in turn, share our learning, our tools and our approaches.

To anyone working to end stigma – whether that's related to mental health, disability or any other issue – I want to say that we are in this together. By sharing inspiration, ideas and celebrating our successes, we can make change happen.

Find out more on our website: https://www.time-to-change.org.uk/global.

4.20 Case study: Advertising and dementia; the power of a cup of tea

Contributor: Chris Lynch, Deputy CEO & Director of Policy, Communications & Publications, Alzheimer's Disease International



Following the launch of a TV advert in India with a strong dementia theme I interviewed Shiva Krishnamurthy, Vice President, Tea & Foods at Hindustan Unilever Ltd. about why their tea brand, Brooke Bond Red Label, decided to commission, film and distribute the advert and how they went about it.

It is really interesting, and timely, to see how the media is evolving in its depiction of dementia but also how brands are starting to engage; understanding that there is a market around dementia, for advertising their products or services, and in Brooke Bond Red Label's case, for positioning of their brand. It is a tricky area. Undoubtedly there is an economic decision by brands to engage, to sell products and services, but decisions about aligning a brand to a certain cause, challenge or disease means that a brand is making a conscious decision, perhaps based on its nature, its culture, its aspiration and the market's perception it.

The Brooke Bond Red Label advert tells the story of a lady living with dementia sharing tea with a neighbour who she mistakes for her son. It is a very well-crafted and thoughtful short film that raises lots of questions about society, dementia awareness, neighbourliness, loneliness, caring and possibly the geographically dispersed nature of families today.

Brooke Bond Red Label has an identified brand strategy to "make India more inclusive". In recent years they have explored some of the social tensions in society and produced adverts and short films in response; these have included pieces on live-in relationships, religion and eunuchs. For this advert they felt that they wanted to explore why the elderly can feel excluded and left behind, and to find an "honest" way to talk about it.

Shiva Krishnamurthy explained that they were looking for a deep story about the loneliness that can accompany old age. Dementia/Alzheimer's disease, positioned at an intersection of two big societal challenges – exclusion of the elderly and lack of awareness about mental health issues – felt like an area they wanted to tackle. The story they developed is not just about a woman who forgets; it is as much about a woman who is forgotten. A key goal of the advert is thus about bringing people together, over something as simple, but as powerful, as a cup of tea.

Brooke Bond Red Label work with the media agency Ogilvy and Mather in India and they developed this advert from the client brief. One of the writer's grandfathers had lived with Alzheimer's disease, giving the agency added insight, alongside their own research. Brooke Bond Red Label then commissioned India's top advert filmmaker, Prasoon Pandey, who showed great interest in the story. He immersed himself in research on the subject - from watching documentaries to speaking with carers. Krishnamurthy confirmed that only after thorough research and developing a deeper understanding, Prasoon took the story to the shooting floor. The aim was not to have a single moment look constructed but to convey an everyday scenario and interaction, conveyed through the natural feel of the advert.

Shiva Krishnamurthy explained that dementia, like other mental health issues, can be an awkward subject in India and in producing and airing this advert Brooke Bond Red Label has taken the subject of dementia into millions of households. It was initially screened in cinemas and then transferred to TV, guaranteeing a large audience. They feel that this advert has undoubtedly resulted in people talking about dementia, taking what was a conversation from those that are already engaged, professionals, advocates, carers, and extending the reach exponentially, by putting it on people's TV in their own homes, in a domestic setting they could relate to. "Getting a conversation started is a big job" Krishnamurthy commented.

In this report, journalist Pippa Kelly also highlights that many TV companies and film makers have developed dementia related storylines. Dementia in an advertising space, however, is still very much in its early stages and, like with Brooke Bond Red Label, often a brand statement aligned to positioning goals and societal change. Undoubtedly it raises awareness, starts a conversation and should help challenge stigma. Going forward, however, it will be interesting to see how brands, marketeers, creative agencies, etc. develop adverts around dementia. Products and services designed specifically for dementia should follow established creative routes, for example, the often emotive marketing of a drug or medical treatment, but it is the positioning of brands attracted to the market that remains to be seen. For example, Swedish furniture giant IKEA has partnered with Swedish construction company Skanska to make available 'flat-pack' dementia homes, through the BoKlok joint venture. If and how they advertise this venture will be monitored by others interested in the sector. Certainly news coverage to date has come from the design and construction press, along with some interested general press titles.

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4.21 Young onset dementia, a personal story; time for change



Contributor: Christine Maddocks

Following a stroke in 2015 I became concerned about my memory and went to see my GP (General Practitioner) who told me that she was there for my physical health and not my mental health. My GP said that, in her opinion, there was nothing wrong with my memory, even though she didn't test it, and that she would not refer me to a memory service.

This situation went on for a while until I was suddenly admitted to hospital with a suspected stroke in 2016. Despite only being 60 years old, I ended up on an elderly care unit. This led to a subsequent appointment for a memory assessment, however I was not advised that this might lead to a possible diagnosis of dementia, so I attended the appointment on my own. I was told at the end of the assessment that I had dementia. I couldn't remember anything else and just felt as though I had been given a death sentence.

I went home and cried for three months, and during this time I received no follow-up from the diagnosis appointment. I received no information about dementia and did not fully understand what it would mean for me. I became depressed and anxious and couldn't leave the house, I was referred to Mind (a mental health charity) for a therapy group, but my difficulties were very different to

the other people in the group, so I didn't really find it to be helpful.

I saw some information by the Alzheimer's Society and it really made sense to me. I rang the Society and they came to see me at home and I started a 'Living Well with Dementia' group, and this felt like a life line to me.

During this time, I lost my job, and I felt that this was managed very badly. Following my stroke in 2015, I had been off work on sickness absence. During this time I had been recovering from my stroke, struggling with my memory and my mood, due to receiving my dementia diagnosis. I decided that I wanted to go back to work, but my employers said that they were not ready for me to return. They suggested a phased return, but I was not given any support, even when I struggled to remember how to log onto my computer on my first day. They were unable to find me another position and started disciplinary procedures as I was struggling to do my work, even though there was no support and no reasonable adjustment on their part. Ultimately, I had to go off sick and had to involve my union but was given ill-health retirement against my wishes. I felt that people couldn't see or understand my dementia, that I wasn't believed and that I was almost having to prove that I had the condition.

I was put in touch with an Early Onset Dementia service in the local hospital which was a specialist team, which was very good, with lots of activities tailored to younger people. I also began helping out with the Alzheimer's Society, and felt valued for contributing and being involved.

I began to struggle living alone, and I decided that I would relocate to live with my partner. I didn't feel that my family were very understanding. I felt that they were scared of dementia, because my father had the condition and had been in a very bad way towards the end of his life, and therefore they held a very negative outlook about it. I felt also that as well as my family, many of friends didn't understand the condition, and I felt that they avoided me, and stopped keeping in touch.

Since I moved to live with my partner, I have struggled to receive specialist help or advice, for example obtaining a doctor's opinion annually on whether I can continue driving. Whilst my GP is pleasant, she doesn't not seem to have much understanding about the condition and the things which help me, such as contact with other people with the condition. She has described me as a 'difficult' case, as I don't neatly fit into the 10 minutes appointment slot.

However, living with my partner has made a great difference and she is able to support me, as has doing voluntary work at a local hospice, where having a diagnosis of dementia is not held again me. I have also been very involved in working with the Alzheimer's Society, more recently becoming a Dementia Ambassador, as well as the Time for Dementia programme. I feel that lots of negative assumptions are made about the diagnosis of dementia, and therefore involvement in these activities has helped me stop feeling useless,

I decided to get involved in the programme Time for Dementia because of my own, not very good, experiences with health care professionals. I felt that it was a good opportunity to raise awareness about dementia, by telling people how it is for people living with dementia, both the positives and negatives. I thought that if I can raise awareness and help even one person to avoid what I have been through then it would be worthwhile.

My partner and I have been seeing Occupational Therapy and Physiotherapy students as part of Time for Dementia. I have been really keen that students get this exposure to dementia because it can be a hidden disability - you cannot see that people have dementia by just looking at them. I have really enjoyed doing the programme, the students are lovely. They come to our house, to our environment and this feels so much better. They are able to hear how my partner and I have been affected by dementia, and this information comes from the mouth of person with dementia, and their carer and this feels like a much better way for them to be learning. This kind of direct experience must be invaluable.

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CHAPTER 5

Programmes to reduce stigma

5.1 Time for Dementia; preparing the future workforce to understand and meet the challenges faced by those with dementia and their families

Contributors: Dr Stephanie Daley, Dr Wendy Grosvenor, Christine Maddocks, Dr Zoe Cashin, Dr Jaewon Phee, Jayme Hill, Prof Sube Banerjee

There is a need to improve how we prepare future generations of healthcare professionals to understand and support people affected by dementia to live well from diagnosis to end of life. This means enhancing the education they receive in training. Typically, healthcare education tends to focus on block clinical placements with an emphasis on crisis, or acute illness; this does not provide student learners with a true understanding of what it like to live with dementia, or other long-term conditions. This current way of learning rarely enables students to understand and challenge stigma, or to experience and create a person-centred approach to their care, or to build the compassion and understanding needed to help those affected by dementia. Seeing people with dementia only as patients and in acute settings can also build in attitudes towards and beliefs about dementia that are negative and that are not appropriately optimistic about the possibility of living well with dementia.

The ADI World Alzheimer Report 2016 advocates the development of experiential methods of teaching that involve experiences of patients; arguing that they engage staff at an emotional level to help address some of the negative perceptions about working with older people with dementia.[1] Time for Dementia is one such programme.

What is Time for Dementia?

Time for Dementia is an innovative undergraduate educational programme, set up to address these challenges, and funded by Health Education England. It has been developed with people with dementia and the Alzheimer's Society in the United Kingdom (UK), to help create an age-friendly curriculum and lead to students building confidence in working with people with dementia that will lead to enabling improved outcomes for people with dementia when they enter clinical practice[2].
The purpose of Time for Dementia is to enhance undergraduate learning about dementia specifically, and more generally about older people's health, long-term conditions, and the role of families in care.

Along with supporting workshops and reflective assignments, students visit a person with dementia and their family in pairs for two hours every three months for two years. The programme was first established as a core component of the curricula for medical, nursing[3] and paramedic students at Brighton and Sussex Medical School (BSMS) and the University of Surrey.[4] The programme is unique in a number of ways including: the inclusion of multiple professional groups; the compulsory nature of the programme; the active involvement of people with dementia along with their carers; and the collaboration between universities, the voluntary sector (Alzheimer's Society) and local NHS trusts.

Where are we now?

Due to the initial success of Time for Dementia as indicated by preliminary data from its integral mixed methods evaluation, in 2017, the programme was widened to include a broader range of undergraduate healthcare training programmes including Allied Health Professional (e.g. Occupational Therapy, Speech and Language Therapy, Physiotherapy and Radiography) courses at the University of Brighton, University of Greenwich, and Canterbury Christ Church University. To date the programme has involved 2,600 students and 1,200 families. This network of families is recruited and supported by staff paid for by the programme, employed by the Alzheimer's Society, which is a full partner in Time for Dementia with the universities.

What have we found?

Emerging data from the evaluation have shown improvements in dementia knowledge and attitudes in students receiving the programme compared to those who are not. These include the development of empathy and compassion.[5] Participating in the programme as a person with dementia or as a family member was also seen as a benefit by those taking part including the understanding that they are making a positive contribution to education of the future workforce[6].

Student accounts

Feedback from students who participated in the programme has identified four key themes: (a) Insight and understanding, (b) Challenging attitudes and stigma, (c) Relational learning, and (d) Enhanced dementia practice. Students have identified that their original perceptions of dementia had changed throughout the visits. Students felt able to see beyond negative stereotypes about dementia, and instead recognise

that a person with dementia could remain intelligent, humorous, and continue to make decisions and accomplish challenges and tasks.

"…he is still quite switched on, and he makes jokes and stuff, which is, I wasn't expecting that at all. Because you know, in, like, films and stuff, dementia is, like, so stereotyped, like, it's not really like that at all…" Paramedic student

Students also reported that the programme has helped them to recognise that people can live well with dementia; that people can be well supported by family or services and cope well with the condition, that not everyone with dementia is isolated and struggling, and that many people with dementia still find joy in everyday life.

"They're still enjoying life, still going out…I didn't expect that…seeing hope in their lives...I thought that they will not enjoy a good quality of life." Nursing student

Significantly many of the students reported an increased interest in wanting to find out more about dementia, decreased apprehension and an increase in the desire to work with people with dementia in the future.

"It's definitely made me more interested in working with people that have dementia rather than not. I think I was a little bit scared by elderly medicine and people that have dementia and cognitive deficits before this and now it's definitely changed, for sure." Medical student

In-depth follow up of adult nursing students found that there was a broadening of views of dementia to encompass the person's life and relationships, which led to a person-centred shift in students' practice. Notably, students were able to develop an understanding of the importance of *'being'* (engaging with the person) rather than just *'doing'* (performing tasks) in practice which contributed to how they saw themselves as future nurses. Adult nursing students reported that that they could be active in their contribution to care and serve as change agents in transforming dementia care.

"We often disable people with dementia in practice, assumption is they cannot perform their own care tasks. Visits have helped me to reframe dementia… focus on the person more and what is important to them. Staff in practice often don't know how to care for dementia, many just try and ignore it. Programmes such as this illuminate the experience of dementia… talking about it helps to reduce stigma…gives an opportunity to slowly face our misconceptions and gives the next generation of healthcare professionals a better understanding of dementia." Adult nursing student

Person with dementia account

I decided to get involved in Time for Dementia because of my own not very good experiences with health care professionals. I felt that it was a good opportunity to raise awareness about dementia, by telling people how it is for people living with dementia, both the positives and negatives. I thought that if I can raise awareness and help even one person to avoid what I have been through then it would be worthwhile.

My partner and I have been seeing Occupational Therapy and Physiotherapy students as part of Time for Dementia. I have been really keen that students get this exposure to dementia, because it can be a hidden disability and therefore unseen, as you cannot see that people have dementia by just looking at them. I have really enjoyed doing the programme, the students are lovely. They come to our house, to our environment and this feels so much better. They are able to hear how my partner and I have been affected by dementia, and this information comes from the mouth of person with dementia and their carer and this feel a much better way for them to be learning. Christine Maddocks.

Newly qualified nurse and doctors accounts

The Time for Dementia programme was extremely valuable and I continue to use my knowledge and experience gained in practice now and going forward in my career. My experience of the Time for Dementia programme has informed my practice as a junior doctor, when I meet patients with a diagnosis of dementia and their families I have a much greater insight and understanding of the potential struggles that the individual and their loved ones are going through. The treatment and management I provide patients with dementia is more individualized to their needs and their families' because I now have the insight into the journey they are on and attempt to understand what their specific needs are. I am in a position to educate and challenge misconceptions held by other members of the multidisciplinary team towards their understanding of dementia, sometimes often bleak and stereotypical perceptions of what living with dementia really means. I also feel more competent in supporting families through pre diagnosis, diagnosis and advanced care planning in dementia. Time for Dementia has also instilled in me transferable skills and understandings that ensures I treat the person behind the diagnosis in clinical practice. Remembering that people aren't their diagnosis of dementia and have other health conditions inclusive and exclusive of the disease. Dr Zoe Cashin, junior doctor

It is nearly four am and I have been bleeped to see a patient in the ward who has been struggling to breathe. I drag my tired body to see the patient in the dark. The patient is a 69 years old lady with a background of dementia and Huntington's disease. She is being treated for sepsis secondary to urinary tract infection. I asked her how she is and she does not say much but keeps repeating 'help'. I do a quick assessment head to toe and I am not clinically worried about her, but I can sense that she is scared. I hold her hand tightly to reassure her that she is safe here. Since I started my foundation year, I have not felt hesitant to approach patients with dementia. I try my best to be considerate and sensible. I

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often reflect on our patient visits of the Time for Dementia studies during the medical school and remind myself that there is always more that could be done for patients with dementia and that value of love and of family bonds never goes away and needs to be promoted and supported at all stages of the dementia journey.

Unfortunately, there is still stigma around dementia and we clinicians cannot help but to find ourselves focusing on presenting complaints but not the person inside. I am planning to start my GP training next year and I am grateful that I will always have something to look back into and remind myself why I am doing this. Dr Jaewon Phee, junior doctor

Having little experience with dementia prior to starting my degree, the Time for Dementia programme gave me an insight of how families and patients with dementia live. Working in the community I visit a lot of people who are on their own, and many of these have dementia. Previously, I visited a patient who had dementia, but unfortunately was not able to communicate verbally. Through my discussions with the patients' family, I was able to communicate with the patient through non-verbal communication. Luckily this particular patient did have family present. This isn't always the case. Time for Dementia highlighted not only how important holistic assessments are, but also how important it is that families get the support they require. I firmly believe the programme has improved my confidence and reiterated the importance of treating everyone with the dignity and respect they deserve. It has also taught me to be more patient and understanding, which I now use in my daily practice. Jayme Hill, newly qualified nurse

Conclusions

The definitive evaluation of the programme is not yet completed. Any impressions at this point must therefore be made with caution, however all the initial information we have suggests that Time for Dementia develops students in ways that more traditional healthcare education does not. The testimony of student participants is that it helps students to develop appropriately positive attitudes, understanding and optimism at how well people can live with dementia. The special ingredient in Time for Dementia is that it places the people with dementia and their families as the mentors and teachers of our students. They teach what is possible in dementia by sharing their experiences of life and of health care systems both positive and negative. Our students start to see the world though the experiences of their Time for Dementia families, they see what is done badly, and they resolve to act differently when they are in practice. The accounts above from the first tranche of students to transition into clinical practice following qualification give grounds for hope that this will happen.

Currently Time for Dementia is provided in the health schools in one region (Kent, Surrey and Sussex) in the UK, this is a proof of the concept. It is a complement to more traditional education and is provided at relatively low cost (administration in the universities, Alzheimer's Society support of the person with dementia and family network and travel). If the data continue to be positive, the next phase should be to roll it out in other health schools nationally and internationally. There is certainly no lack of people with dementia or family members who are willing to participate. It appears that this is one small, relatively simple thing that can be done that is likely will make modest positive changes to practice. The real challenge to healthcare in the 21st century is how to provide good quality care for older people with multimorbidity as exemplified by people with dementia.[7] Time for Dementia helps us provide a workforce willing and able to meet and beat this challenge.

References

1 Alzheimer's Disease International. 2016. *World Alzheimer Report 2016: Improving healthcare for people living with dementia: Coverage, quality and costs now and in the future* online: https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf Last accessed 21 August 2019.

2 Banerjee, S., Farina, N., Daley, S., Grosvenor, W., Hughes, L., et al. 2017. 'How do we enhance undergraduate healthcare education in dementia? A review of the role of innovative approaches and development of the Time for Dementia programme' International *Journal of Geriatric Psychiatry* 32: 68-75.

3 Daley, S. and Grosvenor, W. 2016. Integrating dementia care into undergraduate nurse curricula London: Nursing Times Online: www.nursingtimes.net/careengland/integrating-dementia- care-into-undergraduate-nurse-curricula/7009643 Last accessed 21 August 2019.

4 Grosvenor, W., Hebditch, M., Daley, S., Vyvyan, E., Banerjee, S. 2017. 'Time for Dementia: an innovation in education' *Journal of Paramedic Practice* 9(11).

5 Bickford, B., Daley, S., Sleater, G., Hebditch, M., Banerjee, S. 2019. 'Understanding compassion for people with dementia in medical and nursing students' *BMC Education* 19:35.

6 Cashin, Z., Daley, S., Hebditch, M., Hughes, L., Banerjee, S. 2018. 'Involving people with dementia and their carers in dementia education for undergraduate healthcare professionals: a qualitative study of motivation to participate and experience' *International Psychogeriatrics* (6):869-876.

7 Banerjee, S. 2014. 'Multimorbidity—older adults need health care that can count past one' *The Lancet*. S0140-6736(14)61596-8.

5.2 Dementia research participation; challenging stigma



Contributor: Howard Gordon. Dementia Alliance International, 3 Nations Working Group

As a person living with dementia, it was important to be able to include the voice and experience of someone living with this condition in Alzheimer's Disease International's world report 2019. I am grateful for the opportunity to comment on the role of research and research participation, attitudes and stigma.

On 10th May 2019, I took part in the Alzheimer's Disease International webinar "Let's Talk Dementia Research: Maintaining hope when trials end" where we discussed the importance of researchers seeing people living with dementia as partners in research rather than participants.

People living with dementia no longer want research done for them or for others to decide what research should be undertaken.

A new Project in the UK called "Dementia Enquirers", facilitated by DEEP (Dementia Engagement and Empowerment Project) aims to put people living with dementia in the driving seat of research, showing that we can design, develop, run, report and publish research, with academics and professionals as advisors not participants.

In the last 18 months, I have taken part in over 20 research studies, one a clinical trial lasting 12 months, some as simple as a questionnaire.

On the positive side, research engages people living with dementia, giving them a purpose and whilst we understand that research may not benefit us, we do it for others, for our children, grandchildren and those that follow.

On the negative side, once research is completed, we rarely hear anymore, we may feel discarded like an old shoe or worse, we may find out that a particular study has finished early, devaluing our self-worth.

One of the greatest challenges people face following a diagnosis of dementia is stigma, which manifests itself in many ways.

The broad use of terms such as "suffering" perpetuate the misconceptions and stigma of living with a diagnosis of dementia.

Language is hugely important and changing words is important. We all suffer at times, but with increasing numbers of people being diagnosed, as young as 2 years old, it is important to differentiate the experiences of people living with dementia at different stages and abilities, while acknowledging that some, especially in the palliative stage, may feel they are suffering.

Use of the term "palliative stage" instead of "end stage", may reinforce the view that we are entitled to palliative care, not to be written off, and in a recent document there was a question asking about our "opinions" which is now going to be changed to the word "choices". A simple but powerful change.

We may still be working and driving, often we are told we have to stop at diagnosis, but may be able to continue to do so, depending on our abilities at that time.

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Stigma can strip us of our personhood, belief in our own ability, to continue as we were the day before the diagnosis, leaving us with a feeling of failure, of disablement, leading us to take on the role that stigma lays out for us.

I was relieved to get the diagnosis as it put a label on what had been happening to me but the perceptions and stigma, based on working in healthcare for nearly 20 years, and on those often portrayed in media, that I carried into my neurologist's office, would have a negative, disabling effect on me during the next 12 months.

I was relieved to get the diagnosis as it put a label on what had been happening to me but the perceptions and stigma, based on working in healthcare for nearly 20 years, and on those often portrayed in media, that I carried into my neurologist's office, would have a negative, disabling effect on me during the next 12 months.

I was diagnosed with early onset Alzheimer's and Frontotemporal Dementia (FTD) and "Dr Google" told me my prognosis was 18 months to 20 years and told me how negative and horrendous my life would be. It didn't tell me that Christine Bryden (24 years post diagnosis), James McKillop (20 years), Kate Swaffer (12 years) et al, were still active in their communities, campaigning and changing the lives of people living with dementia. All it seemed to tell me was how bad it would be, how these diseases would strip me of who I am, leading to feelings of guilt. How I was going to put my family through such terrible torment?

With people being diagnosed at a younger age, experiences have changed, and the negative stigma and perceptions are being challenged but with the understanding that experiences change over time.

As with any chronic, terminal disease, there are differing experiences and abilities at each stage of a disease. The language and words used to describe these stages and changes need to evolve and adapt alongside with those experiences and abilities.

Often stigma informs the decision making processes of local authorities where dementia services are often one of the first to be cut, yet in 2017, according to official UK figures, dementia was the leading cause of death in the UK, which you would have thought would have led to an increase in funding for dementia services.

The United Nations has redefined dementia as a "Cognitive Disability" and since 2006 the United Nations Convention on the Rights of Persons with Disabilities (CRPD) has set out the universal rights of people living with dementia and other disabilities; rights which you cannot lose when you lose mental capacity.[1] Although these rights are part of international law, they are not yet being fully integrated and reported on at national level.

Were these fully integrated into national laws they would then go some way to challenge the stigma and often ill informed perceptions of society and professionals, removing the need for people living with dementia to fight for those rights individually, or collectively, through organisations such as ADI and Dementia Alliance International (DAI).

International law, via the CRPD, sets out the rights we have, regardless of capacity, additionally giving us the right to make mistakes, even if they have negative consequences, and in doing so it moves the power of decision making from the professional to empower people living with a disability.

In saying that, as with any chronic terminal disease, we may develop mental health problems as the disease progresses but by changing its definition, the United Nations recognises that there is not one set list of experiences of life with dementia and that we all have our own individual experiences.

In terms of research participation, I would advocate not just for more dementia research but for greater inclusion on people living with dementia in every step of the process, from design to analysis, whether a success or failure. There is a potential risk of introducing stigma by participating in research, for example if someone is identified as high risk, but my belief is that research and participation can help us tackle stigma around dementia, by introducing hope, by normalising the language and simply by helping people understand the nature of this condition.

References

1 Mittler, P. 2018. 'Dementia is a cognitive disability' online: https://www.dementiaallianceinternational.org/dementia-as-a-cognitive-disability/ Last accessed 19 August 2019.

5.3 Hope through dementia research participation.

Contributor: Serge Gauthier MD, C.M., C.Q., MD, FRCPC, Director, AD Research Unit, McGill Center for Studies in Aging, Montreal, Canada, Member and Past Chair of ADI Medical and Scientific Advisory Panel

A 65-year-old woman came to our Research Center asking "to be tested for her risk of developing Alzheimer's disease", which had affected her mother from age 78 to 85. She was offered the opportunity to join a cohort observational study where cognitive test results are correlated with biomarkers associated with brain ageing and are measured in the brain, spinal fluid and blood, every two years. Over one thousand people have volunteered in the past three years for such a study, some of them have heard about it by word of mouth; others tell family members. This is a notable cultural shift in attitudes where people want to know more about themselves and contribute to the greater good. The motivation for many is that what is learned from their participation in observational research will help their children and grand-children in delaying age-associated cognitive decline and dementia.

We need to find a cure but in the interim we need to encourage and facilitate research participation. Research and participation lead to hope; hope increases awareness; awareness tackles stigma.

That being said, how do you tell a healthy 65-year-old woman that she has a significant build-up of amyloid and tau proteins in their brain? We do not yet know what the natural history is of such a finding, in terms of progression to dementia in subsequent years. There is a risk of a depressive reaction if the results of the biomarker testing are not disclosed properly. A step-by-step counselling approach akin to genetic disclosure for genetic conditions such as Huntington's disease is used.

Another concern is the proposed research classification of the National Institute of Aging that equates amyloid and tau protein build-up with some evidence of neurodegeneration (ATN positivity) to having "Alzheimer's disease", even without any cognitive symptom or measurable decline. This may lead to stigmatisation of research participants who would be labelled as having this condition even if they may never have symptoms. This is now a significant social and ethical issue that needs further discussion; discussion which must involve the research participants themselves.

The other issue is that amyloid and tau build-up alone do not explain fully the emergence of symptoms in very old persons: other proteins are at play.

Finally, neuroinflammation may be an accelerating factor whichever protein build up there is.

One hope for many research participants is that the early identification of biological risk factors towards Alzheimer's disease will accelerate the recruitment in various types of interventional studies, ranging from a ketogenic drink to a structured physical exercise program or to anti-amyloid and/or anti-tau drugs. These interventions will be done in more homogeneous groups than in the past, with better hope of therapeutic success. For instance, the lack of positive results of anti-inflammatory drugs despite the weight of evidence suggesting that they reduce significantly the risk of Alzheimer's disease, may be due to treating people without knowing if they indeed have active inflammation in their brain. New ligands for positron emission tomography are being tested in this regard in our cohort.

The other positive outcome of these observational studies is the personalisation of the risk assessment, which will eventually incorporate genetic data and biomarkers from blood tests, rather than the current multiple brain scans and lumbar puncture.

We need to find a cure but in the interim we need to encourage and facilitate research participation. Research and participation lead to hope; hope increases awareness; awareness tackles stigma.

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5.4 Scottish working groups: advisors, advocates, influencers



Members of the Scottish Dementia Working Group

Contributor: Jim Pearson, Director of Policy & Research, Alzheimer Scotland

For Alzheimer Scotland, the active voice of people with dementia and carers of people with dementia is central to informing everything we do. People with dementia, and carers, participate in all aspects of our work; including our governance, development of campaigning priorities, public policy reports, research priorities and our practice. Providing a platform to ensure that people with dementia and carers have meaningful opportunity to influence national and local decisions about the things that matter to them has been a key part of our work for many years. We support and fund, along with the Scottish Government, two national groups; the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Group (NDACN). For the past several years we have worked with both groups to fund and establish local active voice networks to ensure that people with dementia and carers are able to influence the decisions of their local Health and Social Care Partnerships and elected representatives.

The SDWG is a national campaigning and awareness-raising group whose members all have a diagnosis of dementia. The group has its origin in 2001 when James McKillop, the group's founding member, began discussions with a social researcher from Edinburgh University about why there were no groups for people with dementia. They worked together to organise a conference in city of Dundee the following year for professionals and people with dementia, and it was at that conference that the idea for the SDWG took shape and a small steering group was established. Rather than set up as an independent entity the group accepted Alzheimer Scotland's invitation to join the Organisation. The group considered that Alzheimer Scotland's position as Scotland's leading dementia charity, its history campaigning for the rights of people with dementia and their families, and its ability to provide support for the group, made it the ideal partner. The group was formally established in 2002 as the independent voice of people with dementia within Alzheimer Scotland.

Over the past 17 years the SDWG has made a substantial contribution as a campaigning group working to raise awareness of dementia, challenge stigma, and crucially to shape and influence dementia policy and practice in Scotland. The group have been key partners in developing and monitoring the implementation of the commitments of Scotland three national dementia strategies and participate fully in all of dementia strategy workstreams. Members meet twice per year with Scottish Government Ministers to discuss issues that matter to them and to ask questions of the Minister relating to the gaps they experience in policy commitments and the lived experience of people with dementia in Scotland.

In addition, the members have led work in many areas to improve awareness of and educate others about dementia through the collective experience of those living with dementia. The group has been a major contributor to "Promoting Excellence" and education framework which sets out the knowledge, skills and behaviours expected of all health and social care staff who work with people with dementia. They have worked with other professionals and agencies to improve their

knowledge and understanding of dementia to ensure that the services they provide are accessible to people with dementia. There are too many to list here, but these include working with transport providers across Scotland to ensure that all forms of public transport are accessible and appropriate for people with dementia. It also includes the development of "Core Principles for Research" setting out how people with dementia can be meaningfully involved in research.

Both SDWG and NDCAN have established themselves as key partners in in all aspects of dementia policy and practice within Scotland and to ensure that, alongside Alzheimer Scotland, the active collective voice of people with dementia and carers of people with dementia shape how Scotland responds to dementia now and the decades to come.

The SDWG members participate in Alzheimer Scotland's governance as members of Alzheimer Scotland's standing committees and every chair of the group has been involved as a member of the Board of Trustees. More recently the current Chair, Archie Noone, was elected as the vice convenor of the Board of Trustees. In 2018 Archie represented Alzheimer Scotland at the Alzheimer's Disease International Council Meeting in Chicago.

Members of the SDWG speak at conferences, including national and international conferences and have participated in many ways to Alzheimer's Disease International and Alzheimer Europe Conferences over many years. The group has been recognised as world leading and has been the inspiration for national member led groups for people with dementia in countries across the world.

In 2011, Alzheimer Scotland founded the group's sister network, the NDCAN. The need for this became apparent from the work of campaigner and carer, Tommy Whitelaw, who had gathered letters from carers across Scotland sharing their experiences of caring for someone with dementia. In an event hosted by Alzheimer Scotland, Tommy delivered the letters to the then Cabinet Secretary Nicola Sturgeon (now First Minister of Scotland). The experiences shared by carers highlighted to Alzheimer Scotland the need to ensure that carers of people with dementia had a national platform to raise awareness and campaign for the things that mattered to carers. Henry Simmons, Alzheimer Scotland's Chief Executive, committed to establishing the NDCAN.

The NDCAN is a national campaigning and awareness raising group whose members all have experience of caring for someone with dementia. It is based on a core belief similar to that of SDWG, that carers should be an integral part of the planning and implementation of health and social care policy and practice, and that all professionals and organisations should acknowledge carers' experience, the issues they face as carers, and the value of their knowledge of the person they are caring for, which is valid and equal to that of health, social care and other professionals who work with people with dementia.

Though it's a decade younger than SDWG, the NDCAN has a similarly long list of achievements as a national campaigning group. It participated in the development and implementation of Scotland's National Dementia Strategies, meets regularly with Scotland's Minister for Mental Health, it trains health and social care professionals and sits on the implementation group for Scotland's Carers Act. Like SDWG, members of NDCAN speak at and participate in national and international dementia and related conferences.

The future for SDWG and NDCAN

In the past 5 years Scotland's health and social care system has being going through the most significant change since the establishment of the welfare state in the 1940's. The development of integrated adult health and social care has meant that decisions about spending and priorities are taken locally by Integrated Health and Social Care Partnerships. For both SDWG and NDCAN this has resulted in a shift of focus to work with and support Alzheimer Scotland's local active voice networks across Scotland to influence local decision making and ensure that dementia is a priority for every Health and Social Partnership. Both groups have benefited from this local focus, seeing not only a growth in membership but a more broadly representative membership, not only geographically, but of a wider range of experiences of dementia and caring. Both have established themselves as key partners in all aspects of dementia policy and practice within Scotland; ensuring that, alongside Alzheimer Scotland, the active collective voice of people with dementia and carers of people with dementia shape how Scotland responds to dementia now and in the decades to come.

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5.5 Dementia Advisory Group Brings Chinese Taipei to a New Era of Human Rights



Members of the Dementia Advisory Group

Contributor: LiYu Tang Secretary General, TADA Chinese Taipei, Su-Yuan Chan, Policy Researcher, TADA Chinese Taipei

Human rights becoming a priority in Chinese Taipei

Following the announcement of the WHO Global action plan on the public health response to dementia 2017-2025, TADA Chinese Taipei (TADA) considered the human rights of people with dementia a priority[1]. In 2017, TADA invited Glenn Rees, Chair of Alzheimer's Disease International (ADI) and Kate Swaffer, Chair and CEO of Dementia Alliance International (DAI), to advocate to the government of Chinese Taipei for human rights of people with dementia. The Ministry of Health and Welfare referenced the Convention on the Rights of Persons with Disabilities (CRPD) when developing "Dementia Policy 2.0" and budgeted TWD 90 billion, which was equivalent to 2 billion US dollars and 60 million euros[2]. In addition, the Control Yuan of Chinese Taipei made two investigation reports, examining all policies related to dementia, whether they were considered human rights or not. The national policy and the investigation reports provided actual situations and clear recommendations for the government departments to go onto the next step for people with dementia. Hence, human rights have become more and more important in the hearts of the people of Chinese Taipei and the government.

Involving people with dementia in societies

TADA has involved people with dementia in many activities. In 2017, 22 persons with dementia were invited to be tour guides or to make coffee and cookies in the World Alzheimer's Month Event. In 2018, TADA expanded the activities and encouraged people with dementia to teach their unique skills to the participants. The lessons included drawing traditional Chinese paintings and making paper flowers, and about 40 people with dementia played important roles in the World Alzheimer's Month activities. It was a huge success, and more and more people with dementia got involved in various activities. These brought to the attention of the general public a new image of people with dementia and the appreciation for their contribution. It was also a great achievement for people with dementia and their families to get the confidence to join activities in the community and try to dedicate themselves into societies.

Afterwards, people with dementia started to tell the public their own stories. In 2018, Amy Su, a 70-year-old woman diagnosed with mild dementia, made the first

self-advocate video in Chinese Taipei, talking about how dementia influenced her life. The video started a trend, and 3 other people living with dementia also expressed their voices through touching and inspiring videos. Amy Su also delivered a speech at the annual dementia conference.

Chinese Taipei Dementia Advisory Group

A dementia advisory group is a good model for expressing voices, needs, and rights of people with dementia. TADA has tried hard to develop a dementia advisory group since 2017. However, it was difficult to find suitable participants in the beginning and the group did not form successfully. In 2018, with the cooperation with Integrated Dementia Care Centers (IDCC), TADA held 4 meetings to collect opinions from people with dementia. About 22 people with dementia joined the events, and 13 of them came without carers' accompanying. Most of them were able to express their feelings and thoughts; some of them even made concrete and useful suggestions for policies. The topics covered the accessibility of long-term care services, disease labelling, prevention, financial safety, the process of services application, resources to prevent people from getting lost, etc.

This year TADA formally established a self-funded dementia advisory group. Thanks to the referrals from doctors, case managers, and other resources, there are 9 participants in the advisory group, including 6 people with dementia and 3 family carers. The group meets once a month. Since April of 2019, they have focused on the topics of dementia friendly facilities, transportations, problems associated with getting lost, and financial security.

Members in the group share their experiences, thoughts, and needs at their ease. For example, when discussing driving experiences, the members sincerely shared the meaning and value of driving to them. At the same time, carers were also able to talk about their worries and the methods of convincing people with dementia to stop driving. Furthermore, people with dementia also sometimes recommended one another to stand in their carers' or passengers' shoes to consider retiring from driving. Members of the Dementia Advisory Group have established the trust between themselves.

Keys to starting a Dementia Advisory Group

Based on the past two years of experience, TADA has found 3 keys to creating a dementia advisory group. First, participants should clearly understand their situation and be able to express their own opinions related to dementia. Not every person with dementia is ready to join the group. Second, the support of family carers, doctors, and case managers will enable the process. If doctors and case managers promote the advisory group, people with dementia and their carers will be encouraged to join the group. Last, but not least, "advisory" is a good word to use, and attitude to have, when discussing issues with people with dementia. Professionals, policymakers, and carers all need to consult people with dementia to respect their rights.

Advocating with people with dementia in the new era of human rights

TADA would like to invite more participants through the connection with doctors and case managers. Moreover, TADA has encouraged many local city governments to invite people with dementia to participate in the policymaking process. Nowadays, people with dementia have become hosts at press conferences. People with dementia are also invited to give speeches. We truly believe that people with dementia can be empowered and advocate policies by themselves.

Not only is it important to support people living with dementia in working groups to advocate for change and for improved support and services but through visibility and communication, with and about working groups, it also helps to change perceptions, increase awareness and tackle stigma. TADA's dream is not only to advocate policies for people with dementia, but also to advocate with them. We believe that people with dementia will bring Chinese Taipei to a new era which promotes and ensures the human rights of people with dementia and all people.

References

1 World Health Organization 2017. Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization. Licence: CC BY-NC-SA 3.0. online: https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/ Last accessed 19 August 2019.

2 UN General Assembly 2007. Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106. online: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html Last accessed 19 August 2019.

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5.6 Forget dementia, remember the person! Breaking down stigma to move forward towards an inclusive society in Flanders (Belgium)



Flemish working group of people with dementia

Contributor: Olivier Constant, Flanders Centre of Expertise on Dementia

If we focus on the possibilities of people with dementia instead of their limitations, their dementia will disappear behind their talents and not the other way around; that is the starting point of the Flemish awareness raising campaign 'Vergeet dementie, onthou mens' ('Forget dementia, remember the person'). The emancipatory story of this campaign forms one of the foundations of the Dementia Strategy of Flanders (Belgium) and is written together with people with dementia and their caregivers. Their vision is the beating heart of 'Forget dementia remember the person'; respectful communication is the basis for person-centered care and an inclusive society.

Listen to us. Give us a voice. Give us the opportunity to meet peers. Use respectful language. Include us in setting policy guidelines. Give us the opportunity to learn and experience new things.

The best medicines for someone with an incurable condition do not come from a pillbox, we have them in our own hands; attention, empathy, a listening ear and time. People with dementia and their loved ones want to be valued, understood and included. That is exactly what we want to do in Flanders with 'Forget dementia, remember the person'. Not starting from a well-intended kind of pity for people with dementia, but from sincere compassion and a firm belief in their everlasting capacities, not only right after their diagnosis but in all stages of the condition.

As the Flanders Centre of Expertise on Dementia and official partner organization of the Flemish Authority in Belgium, we coordinate the campaign together with our partners in the field. With 'Forget dementia, remember the person' we have a clear ambition: to give more power to the people. Personal experiences are the heart and soul of this movement. Through this grassroots strategy we want to break down the walls between (in)formal care and the rest of society, bridge gaps between generations, urge more respectful communication, smash stereotypes and sustain existing dementia-friendly efforts.

The power of visual communication

On the dynamic web platform and social media for the campaign, people can find a wide range of dementia friendly communication tools, as a starting point to break down the stigma on dementia and to give a voice to the person behind the condition. The mission statement of our campaign was translated in a short animation movie, written together with people with dementia and their caregivers. Moreover, there are series of cartoons that stress the importance of respectful language when we talk about dementia and want to invite others to stay close to people with dementia instead of avoiding them. Dementia is already difficult enough to cope with, so we pose the question, "Why don't we start to find more joy in things that people with dementia still love to do?"

Together with a professional photographer and people with young-onset dementia at a day care center in the city of Antwerp in Belgium, we also made brand new posters that explain in short poems and quotes the feelings of people with dementia and invite you to enter their world. Additionally, we designed four short graphic novel-stories about communication in the last stages of dementia, with a clear message that was written down on one of the visuals by a person with dementia, *"Learn to read the language of people with dementia. Try. Listen. Search. Feel. Find. Look. Listen to me, also when words disappear."* To distribute the campaign message, people can also order free photographs from a rich picture database that translates the baseline 'Forget dementia, remember the person' visually.

Personal stories are the key to change

The beating heart of the campaign is the personal stories of the experts, namely people living with dementia, their carers and the people who experience dementia day-to-day. The more than 50 audiovisual testimonies that were released in Dutch during the first half of 2019 have one thing in common; the massive impact of the taboo on the challenges in the daily care and support for people with dementia, like timely diagnosis, care acceptance, advance care planning and the sustainability of their social network. This is also the reason why reducing the stigma of dementia was, and is, the foundation of the previous and current dementia strategy in Flanders. The video statements are centralised around three basic questions, which form the core of our taboo breaking initiatives of the campaign 'Forget dementia, remember the person':

- What can we learn from people with dementia?
- How can we guide them and their loved ones towards tailored care and help them to accept help?
- How can we include people with dementia and informal carers as long as possible in society?

During the second half of 2019, the personal stories will also be made available for the international audience with English translation through the YouTube channel of the Flanders Centre of Expertise on Dementia. In this way, we also want to contribute to the international movement towards advocacy and involvement of people with dementia – not only through the different communication tools described, but also through a pioneering initiative in the field: the start of the first-ever 'Working group of people with dementia' in Flanders.

Valuing the experts by experience

The start of this working group is not a symbolic initiative, but a crucial step towards empowerment and validation of people with dementia and their caregivers. Not only to include their voice more proactively in the media, but to also include them fully in new projects, research and policy work. The Flanders Centre of Expertise on Dementia started brainstorming about the idea at the beginning of 2018, together with the other plans for the new chapter of 'Forget dementia, remember the person'. The centre joined forces with the Alzheimer's Association of Flanders to translate the ambitions for this new working group into practice.

At the moment we have six people with dementia involved, together with their family carers. It is our ambition to involve people with dementia in all stages of the condition, not only in the first phase of dementia and not only people who are younger than 65 years. Since the group held its first meeting in October 2018, we initially focused on creating an open, strong partnership between the members, as a foundation to move forward with tangible actions in 2019. After five intensive meetings we shot an introduction movie with the members of the working group as our call to action for a dementia friendly society. In May of 2019 we released the movie for the media and public in Flanders and on World Alzheimer's Day 2019 the English version of the movie will be released for the international audience.

Together with the introduction video we released the first 'Charter for a Dementia Friendly Society' written by people with dementia; another unseen initiative in our country. We want to empower people with dementia and reach out to society to respond to their needs and respect their rights. The goals were defined crystal clear by the working group: *"Listen to us. Give us a voice. Give us the opportunity to meet peers. Use respectful language. Include us in setting policy guidelines. Give us the opportunity to learn and experience new things."* These ambitions are not optional. They will form the compass for an eventual new dementia strategy in Flanders of which the realisation could start, following the elections of May 2019 and the formation of the new government later that year.

These first steps we have taken are the start of an intensive and inspiring journey that will lead to more results and an integrated vision for the coming years. We sincerely hope that the message of the 'Flemish working group of people with dementia' in Belgium gives people in other countries an extra dose of inspiration and motivation to continue building on an inclusive society that gives people with dementia and their loved ones the place they deserve; not in the margin, but at the centre of a kind and understanding society. And we also hope that our campaign baseline 'Forget dementia, remember the person' may inspire people across the globe, because in the end people with dementia should always be the reference point and quality check of a dementia friendly society. That is true inclusion and empowerment and the only way forward.

For more information on 'Forget dementia, remember the person':

- YouTube: https://www.youtube.com/channel/UCmKn3gOZLLdzneir-HlQE5g
- Website: www.onthoumens.be

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5.7 From Seldom Heard to Seen and Heard: why communities should not be viewed as hard to reach



Contributor: Sarah Tilsed, Campaigns & Partnerships Manager, National Dementia Action Alliance

Think about the imagery that you see around dementia. Certainly, in the UK it tends to portray healthy, white, heterosexual couples, supported by a family in a comfortable environment. But as we know, dementia is not just confined to this homogenous group. People from any race or sexuality can develop dementia, as can people with no family or home. Consider people in prisons, with learning disabilities, in remote areas - no situation is the same and each has very different complexities.

It goes without saying that these groups and communities need to be researched further, to have awareness raised about them, and to be supported appropriately. Work is taking place, but as always, more can be done to ensure that the needs of people affected by dementia are being met.

The National Dementia Action Alliance (NDAA) has been working in the UK in this area since 2017 on the campaign 'From Seldom Heard to Seen and Heard'. The NDAA is a national alliance for dementia care and research organisations across England to connect, share best practice and take action on dementia. We have over 110 health and social care members, all committed to supporting people affected by dementia, with an action plan setting out what they hope to achieve.

We bring these members together through campaigns, social media, and newsletters. We run webinars, roundtables, conferences, and thematic events; and meet up with all of our members to find out what they are working on. Focussing on campaigns is a large element of our work and campaigns have included decreasing the use of antipsychotic drugs, considering the language around dementia that is used, supporting carers, and creating dementia friendly hospitals by implementing a charter that we created.

Dementia statements, created by the NDAA, are designed to represent people living with any type of dementia regardless of age, stage etc. and highlight the rights of everyone living with dementia. These rights are enshrined in the Equality Act, mental capacity legislation, health and care legislation and international human rights law, and therefore can be used as a tool to highlight the support for every person with dementia, regardless of background or community.

Dementia can be challenging enough for people who access mainstream services. For individuals with more specific needs, the challenges are even greater. Through its campaign, NDAA choses to challenge this unfair disadvantage by running three roundtables looking at learning disabilities, prisons and the LGBT+ (Lesbian, Gay, Bisexual, Transgender) community. We wanted to shine a light on these groups and look at the inequalities they face. We brought together people living with dementia, carers and people working within these groups and communities to discuss key issues. We have produced recommendations from these roundtables, which demonstrates the need for system wide change.

The campaign *'From Seldom Heard to Seen and Heard'* focusses on dementia and learning disabilities, within the LGBT+ community, and in prisons.

Prisoners over the age of 60 are the fastest growing age group in prisons and many prison staff lack the training required to spot the signs of dementia and to make the relevant referrals, meaning that prisoners' dementia can go undiagnosed. The NDAA's campaign aims to address the inequality that currently exists, where many people with dementia and carers who come from seldom heard groups face a number of additional barriers when trying to access care and support. In the first instance many are not even aware that there are services out there for them. Other times, people attend services only to find out that they are unsuitable for their needs. There are a number of reasons for this, ranging from a lack of training and awareness, insufficient funds to adapt services or in some cases, simply people's bigotry.

Many of you will have heard the term 'hard to reach' communities. When we started thinking about this

campaign, this is how we referred to the different communities we wanted to support. It was then brought to our attention that people from these communities are actually not hard to reach at all. They are very much in plain sight, living where and how they have always lived. But instead they have different needs that can sometimes be overlooked. As one person put it, not so much 'hard to reach' but more 'easy to ignore'.

Through our campaign, we have tried to highlight some of the unique challenges faced by people with dementia who come from seldom heard groups. Many of these people struggle to access good quality care and support, they face a system that doesn't truly recognise their needs and cannot respond to them. It would be short-sighted not to acknowledge some of the financial strains being placed upon the health and social care sector in the UK at the moment, however this shouldn't be used as an excuse. In fact, NDAA members are demonstrating how they can, and do, provide excellent care, not just for a small group of people in England – but for all people. MacIntyre, a learning disability charity stated that "I'm extremely proud to have worked alongside NDAA for their campaign, they really have ensured that Seldom Heard Groups are 'Seen and Heard'. Thanks to the NDAA, many of their members came together, united, to pledge their support to improving outcomes for people living with dementia and their carers - many Seldom Heard Groups were represented, such as LGBT+, BAME (Black, Asian and minority ethnic), prison population as well as people living with a learning disability".

Many of the effective interventions we see do not require money, rather careful consideration, planning, and most importantly taking the time to engage with people from seldom heard groups. To engage in dialogue with them, to understand not only the challenges but what they want to receive in order to live the best possible lives.

We found there were common inequalities across the groups, such as the lack of services with joined-up working, lack of person-centred care and recognised the importance of an early diagnosis. These findings aren't surprising, and they can relate to any number of seldom heard groups. You can find the full recommendations on the NDAA website.(i) A BAME, LGBT+ person with young onset dementia said that "without my involvement with the NDAA...I would not have been able to set up the LGBT Dementia Network and show that dementia can affect anyone"

As well as holding an event on this campaign, presenting on it at an Alzheimer's Society Conference, Health Education England steering group and at Alzheimer's Disease International, it has led us to the following:

LGBT+ communities

- held webinars on LGBT+ communities
- had an article in Diva, the largest international Lesbian magazine
- written for a London borough's LGBT+ forum
- had the CEO of Stonewall (UK LGBT+ advocacy organisation) write a blog for us
- Stonewall recommending us to speak to DHSC (Department of Health and Social Care) about the LGBT+ community and how they can adapt their internal policies
- collaborated with Alzheimer's Society, people affected by dementia from the LGBT+ community, and LGBT+ organisations to create a booklet, poster and webpage, called Bring Dementia Out
- co-presented to medical students with a person with dementia from the LGBT+ community
- an LGBT+ person with dementia forming an LGBT+ and dementia network as a result of being involved in our campaign

BAME communities

- held webinars on BAME communities
- were consulted as a partner in a Race Equality Foundation report 'Dementia and Black, Asian and Minority Ethnic Communities'[1]

Prisons

- sat on a national prisons steering group
- ran an event on dementia in prisons in partnership with Alzheimer's Society

Learning Disabilities

- worked with MacIntyre (a learning, support and care charity) on an easy-read version of the Dementia Statements for people with learning disabilities
- sitting on a national learning disabilities steering group
- collaborated with The Foundation for People with a Learning Disability on its report Hidden in Plain Sight(ii)
- held webinars on learning disabilities and dementia

It is evident, through our work so far, that much more needs to be done in these areas to make sure that no one is left behind. The next immediate steps are to pull together all of this information, along with case studies, pledges and our recommendations, and this should be available within the next six months.

References

1 Samir Jeraj, S. and Jabeer Butt, J. 2018. *Dementia and Black, Asian and Minority Ethnic Communities Report of a Health and Wellbeing Alliance project* VCSE Health & wellbeing alliance.

(i) Find out more at: https://nationaldementiaaction.org.uk/

(ii) Read the report here: https://nationaldementiaaction.org. uk/campaigns/hidden-in-plain-sight-dementia-and-learning-disability/

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5.8 The role of technology around stigma: Marie's journey



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This story is about Marie's journey; the problems she encounters whilst using Everyday Technology in places and activities in public space; the stigma these problems create; and how she manages the situations. The story is based on research about the experiences of people living with dementia in the UK and Sweden[1-5].

Marie begins the daily routine of picking up the various items she will need for going out. *Keys…check, purse... check, coat…check, phone…check, shopping list… check*! With her mental checklist ticked off, Marie steps outside her house and makes her way to the bus. Marie waits for her regular bus but there is a waiting line and the driver overshoots the stop, so Marie rushes to catch up with it. Marie breathes a sigh of relief - she has made it onto the bus. It takes a moment for Marie to steady herself and to search for her travel card in the bundle of cards wedged inside her purse. Marie can sense the people behind her are getting impatient so she asks the bus driver for help and hurriedly searches for the travel card.

Once seated, Marie sees that the electronic bus announcer is not showing the correct next stop. The bus is being diverted. Marie looks around to ask for help but notices everyone is looking down. She realises they are all looking at their phones. Marie reaches for her phone, she stares at the screen trying to recall where to find the maps. She swipes backwards and forwards through her phone but she cannot find it and so she puts the phone back in her pocket. The surroundings are not as familiar as they once were, but Marie looks out the window to try and use the local buildings as a landmark to guide herself.

Marie sees the supermarket through the bus window. She is anxious that she might miss her stop so she repeatedly presses the stop-button and makes her way as quickly as she can off the bus. Marie waits at the crossing for the green light to come up and then tries to hurry over the road as the green light flashes with a tick, tick, tick sound. Marie glances up from her shopping list and feels a little overwhelmed at the supermarket. Her senses are overloaded with so many impressions. She sees endless aisles of products, displayed in a messy and unfamiliar way. She hears many different sounds, background music, announcements, the cashier ringing, and children crying.

Marie starts to shop for the items on her shopping list. In the fruit and vegetable department, she wants to buy a couple of apples. She reaches out to collect them before realising she is touching the reflection of the apples in the mirror. Marie reaches down and collects the apples. After quite some time, Marie has located most of the items on the shopping list but she cannot find the coffee she usually buys. Eventually, she finds a shop assistant to ask for help. The shop assistant quickly mumbles the directions to the coffee then shuffles off before Marie could ask again. Marie goes up and down every aisle looking for the coffee, walking much further than she needed because the placement of the coffee is different today.

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Marie pushes her heavy trolley to the checkout queue. This is the moment she dreads the most. Marie feels her anxiety building as she discovers it is the line for the self-service check-outs which she often experiences problems using. She glances behind at the long line and tries to follow the instructions on the self-service check-out screen. Marie manages to scan some items but one item was on sale and would not scan. Marie feels very anxious indeed. A shop assistant comes over and helps her before leaving Marie to cope alone.

By this time Marie is feeling stressed and she cannot remember the PIN number for her card. She tries two different numbers but she still cannot recall the correct number. So Marie decides to pay with cash but she cannot find which slot to put the cash in. The shop assistant comes over again and helps Marie put all her shopping back in the trolley and takes her to another till with a cashier where she can pay with cash. Marie collects her bags and takes a deep breath before she sets off on her journey back home.

The pace of everyday technological change

In an age where technology is being adopted more and more frequently to everyday situations, often replacing a human interaction, there should be a consideration of the potential impact on people living with dementia, in the same way there could or should be for someone with a more visible disability (for example, the height of a cash machine). The speed of technological change is itself a challenge, with operators updating and adapting at a pace not previously seen. For example, self-check-in desks at airports are improving through user feedback but airports are notoriously stressful environments to begin with and introducing multiple, touch screen, scanning, printing and self-tagging requirements can be overwhelming. Some banks have been embracing dementia awareness training, especially in the UK and in Hong Kong, but as with supermarkets, the drive to reduce human costs, means not only a reduction in the number of branches, but also the introduction of more automation of tasks like transfers, cheque deposit and bill paying.

It is evident that people living with dementia can and do adapt to technology and it can be a real assistance. For example, using tablets and mobile devices enables people to keep in touch with video calling, even when distance is a challenge. Software and applications (apps) on devices are also being adapted for therapeutic use and simple touch screen and swipe technology can be a huge benefit. However, to ensure that people with dementia are engaged and benefitting from Everyday Technology advances it is vital to include them in the design and development processes. Just think how complicated choosing and watching a TV programme has become over the last few years, across multiple devices, apps and streaming services.

Recommendations

Dementia-friendly and usable places and services:

More service providers (e.g. retail and public transport) should consider some simple measures that could improve the experience of people with dementia when accessing their products or services, including design and layout adjustments. In addition, consider engaging people with dementia and their caregivers about what works well and not so well. Assess the implications of moving products and facilities from familiar and accessible locations and sign-posting any changes. Explain more about the vision, hearing and perception challenges and consider providing ongoing and regular dementia-friendly training to staff to enable them to recognise if a person has dementia and to provide optimal customer support, patience and consideration.

Dementia-friendly and usable Everyday Technology:

Technology developers should engage people living with dementia and their carers in the design and testing stages, to help identify and alleviate potential issues and challenges - often simple things that are not perceived as challenges at the outset, primarily as the question is often not being asked. In retail environments, where the use of self-check-out technology is rapidly increasing, consider testing and adapting the technology from the perspective of someone with dementia. Usability testing and technology development in collaboration with people living with dementia and caregivers also conveys a thoughtful and caring approach from the business operator.

When technology is not always the answer, consider other options. In Scotland a supermarket introduced a “slow lane” for people with dementia, where check out assistants received basic awareness training and were able to assist people and simultaneously help reduce anxiety and stress. Evidently, the benefits of such a choice by the retailer also helps other people who need more time or who become anxious around technology.

References

1 Brorsson, A., Öhman, A., Lundberg, S., & Nygård, L. 2011. ’Accessibility in public space as perceived by people with Alzheimer´s disease’. *Dementia, 10*(4), 587-602.

2 Brorsson, A., Öhman, A., Cutchin, M., & Nygård, L. 2013. ‘Managing critical incidents in grocery shopping by community-living people with Alzheimer’s disease’. *Scandinavian Journal of Occupational Therapy*, 20(4), 292-301.

3 Brorsson, A., Öhman, A., Lundberg, S., & Nygård, L. 2016. ‘Being a pedestrian with dementia: A qualitative study using photo documentation and focus groups interviews’. *Dementia, 15*(5), 1124-40.

4 Brorsson, A., Öhman, A., Lundberg, S., Cutchin, M., & Nygård, L. 2018. ’How accessible are grocery shops for people with dementia? A qualitative study using photo documentation and focus group interviews’. *Dementia,* 0(0)1-17.

5 Gaber, S., Nygård, L., Brorsson, A., Kottorp, A., and Malinowsky, C. 2019. ‘Everyday Technologies and Public Space Participation among People with and without Dementia’. *Canadian Journal of Occupational Therapy.* 1-12. DOI: 10.1177/0008417419837764

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5.9 Can design play a role in increasing awareness and challenging stigma around dementia?

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Dementia is often perceived as a hidden disability but much can be learned from the progress that has been made in response to the needs, and importantly the rights, of people living with more visible disabilities; for example, access ramps into public buildings, pavement level access for public transport, accessible height cash machines. Strategic design underpins this progress, which is equally important in public spaces, care environments and in the home. Product design, as well as built environment design, is also important and by increasing awareness of the need for design solutions for dementia, it can be argued, this goes some way to increasing overall awareness, acceptance and even helping reduce stigma, by legitimising the need for innovation in this space.

Twenty-one years ago, 'Design for Dementia' was published. It was one of the first publications to comprehensively describe the importance of design in supporting people with dementia.

It set out 8 principals that were needed to inform thinking:

- Reinforce personal identity
- Maximise independence
- Enhance self-esteem and confidence
- Compensate for disability
- Allow control of stimuli
- Be orientating and understandable
- Demonstrate care for staff
- Be welcoming to others

And the features that an environment should have:

- Be small (in scale and in numbers)
- Be domestic and familiar
- Provide good visual access
- Reduce unwanted stimulation
- Highlight important features (for residents)
- Be unobtrusively safe and secure
- Provide for planned walking (access to safe outside space)
- Provide links to the community
- Provide opportunities for privacy and social interaction
- Promote autonomy and choice

Understanding the experience of a person living with dementia is essential to providing an enabling environment and to support the person to live at home or in a care setting. To be able to 'see and sense' is critical because unfamiliar environments and situations may cause increased stress and confusion.

The majority of people with dementia live in their own home and want to be part of their communities for as long as possible. It makes good economic sense to invest in the design of cities and communities that are able to support people with dementia. Without this, premature admission to care has not only a personal but a financial cost.

When it comes to design, while familiarity is key, most people's homes and communities weren't built with dementia or ageing in mind. Companies like IKEA have only recently recognised the need for key features and adaptations in their flatpack housing options, but it's the range of positive changes that can be made to enhance the home or care environment for a person with dementia that remain a priority.

Some design changes may help support the person physically while others may assist the person in understanding their environment and overcoming specific perceptual challenges, these include:

- In the kitchen reducing clutter by clearing benches and workspaces of occasionally used items and leaving out things that are needed every day such as tea and coffee making items
- Reducing distracting noises such as both a radio and television
- Creating a special, calming space where the person has favourite and familiar items and to which they can retreat if feeling tired or overwhelmed
- Adjusting light levels is a critical issue, remembering that people with dementia and older people generally benefit from more light
- Thinking about what signs and cues would reduce confusion or uncertainty such as in the kitchen (pictures work well as the ability to read words may be lost)

Case study

When supporting her dad David's bathroom independence, Rosemary noticed he had been having some toileting difficulties recently and often seemed quite distressed afterwards. Rosemary thought David may have been unwell, but then noticed when assisting him to the newly renovated, all white bathroom, he was unsure about locating the toilet. Later, he fumbled with the new modern tap fitting at the basin and left without washing his hands - unusual for David as he

was fastidious about hygiene. When discussing this with a support person, Rosemary learned that greater contrast benefits older eyes and people with dementia, and that the shiny mixer tap would be unfamiliar to her dad. A new black toilet seat and easy to understand tap seem to have addressed most of David's difficulties and distress. Familiar handles and tap fittings often support independence especially if they clearly identify hot and cold.

In addition to changes with the ageing eye, for people with dementia, sensory changes mean that colour contrast is very important. The simple step of introducing, in some situations, contrasting colours, helps people understand the room and situation to find their way. At other times, keeping colour uniform avoids drawing attention to things that are confusing or to be avoided. For example, having contrasting bed linen so the bed is more obvious and a different colour top and bottom sheet that contrast to the floor makes finding and getting into bed easier and can be the difference between needing assistance and getting into bed independently. The recognition that the wrong flooring can slow or stop a person is now well evidenced. Pick a smooth, matte surface and ensure the same flooring is across as many rooms as possible. These surfaces are safer and easier for people with dementia. In kitchens and other wet areas, opt for a surface that is not shiny and reflective as this may look like water on the floor and a person with dementia may wisely refuse to enter! Between rooms, make the carpet bar or strip the same colour as the flooring. This can also reduce the risk of falls and prevent perceptual confusion[1]

Most design innovations and solutions around dementia have been for domestic spaces and in care settings, but is the case to translate this to public environments gathering the momentum needed and can we use disability rights to be the platform to do this? Cost is always a barrier but increasing awareness, providing advice and often introducing low-cost solutions is a route to change. It does not always have to be advocacy either, education works, for example, including design in dementia friendly community programmes; and we can decide where we spend our money, making a decision on a conference venue, a choice of hotel or restaurant and who we travel with should increasingly be based on their embracing of dementia considerate design and their investment in staff awareness.

It can be daunting for businesses such as shops, banks, cafes, theatres, transport providers, etc. to learn more about dementia and to start to look at dementia related design, but in doing so they are not only fulfilling their role from a disability rights perspective but they are also sending out a strong positive message about their nature and their brand and in doing so helping to increase awareness, which in itself can help reduce stigma.

The importance of design cannot be over-stated and much more research is required for what is needed from diagnosis through to when symptoms are advanced.

New technologies, including virtual and augmented reality, are proving to be enablers of people and designers. A key design challenge for innovators will be to span the varied and individual needs of people with dementia while creating spaces that are both aesthetically pleasing and that satisfy the functional and at times complex care requirements of the people who live there.

'Talking Sense' and 'My Home My life' are just two examples of publications on design that are 21 years later and are informed by research and the experience of people with dementia. They are free at https://www.dementiacentre.com/resources

References

1 Judd S, Marshall M, Phippen P 1998. 'Design Dementia', Journal of Dementia Care, London: Hawker Publications.

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Conclusion & recommendations

When ADI decided to undertake a new survey on attitudes toward dementia, we had no idea that we would receive a 28-fold increase in responses from our last survey in 2012. The public has spoken – and almost 70,000 voices have told us that we still have a long way to go to 'normalise' the language, attitudes and behaviours around dementia and integrate people living with the condition fully into society in a supported way.

Almost all respondents feel they will one day develop dementia themselves, with the majority concerned by this, adding to the fear that surrounds the condition. Most of us agree that we shouldn't hide it – but with the majority of people living with dementia stating that at one time or another their opinions have not been taken seriously or they have been treated unfairly in medical, social or domestic situations, and some reporting their symptoms have even been joked about - does this encourage openness and disclosure?

In the absence of a disease-modifying treatment, we need to find ways of dealing with the condition in the 'here and now' – to ensure that people with dementia live the best quality of life they can and that those who care for them are supported. We need to tackle stigma head-on. Increased awareness leads to better understanding and empathy. Better knowledge reduces fear and changes behaviour.

A seismic shift needs to occur at all levels in society to break down the barriers of stigma; in particular in the governmental, health and care sectors, community services, and global research. Change can start with just one conversation, hence the focus of the campaign that goes with this report "Let's talk about dementia".

Now more than ever before, it's time to talk about dementia.

Recommendations

1 Targeted public health awareness campaigns

2 Promotion of timely diagnosis and better post diagnostic support

3 Global evolution of dementia friends' programmes and dementia friendly/inclusive communities - with people living with dementia and carers at the heart of their design, implementation and evaluation

4 Increased public advocacy of people living with dementia – amplifying the voice of lived experience

5 Increase advocacy focused on carers experiences – whilst improving the understanding of first-hand experience

6 Specialised education about dementia-related stigma and person-centred care practice for healthcare practitioners

7 Call for local governments to increase the funding, range and quality of community services for people living with dementia

8 Changes to public policy relating to employment, health and insurance for both people living with dementia and their carers

9 Full adoption of a rights-based approach to dementia including full compliance with the Convention of Rights of Persons with Disabilities (CRPD)

10 Increase funded research – for both a disease-modifying drug as well as further understanding of stigma. We know from other high stigma illnesses, including cancer and HIV-AIDS, that medical treatment breakthroughs can be a catalyst to stigma reduction – and we also need to better understand the complex role stigma plays throughout society in order to tackle it and change hearts and minds.

Alzheimer's Disease International

About ADI

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 100 members is a non-profit Alzheimer association supporting people with dementia and their families. ADI's mission is to strengthen and support Alzheimer associations, to raise awareness about dementia worldwide, to make dementia a global health priority, to empower people with dementia and their care partners, and to increase investment in dementia research.

What we do

- Support the development and activities of our member associations around the world.
- Encourage the creation of new Alzheimer associations in countries where there is no organisation.
- Bring Alzheimer organisations together to share and learn from each other.
- Raise public and political awareness of dementia.
- Stimulate research into the prevalence and impact of Alzheimer's disease and dementia around the world.
- Represent people with dementia and families on international platforms at the UN and WHO.

Key activities

- Raising global awareness through World Alzheimer's Month™ (September every year).
- Providing Alzheimer associations with training in running a non-profit organisation through our Alzheimer University programme.
- Hosting an international conference where staff and volunteers from Alzheimer associations meet each other as well as medical and care professionals, researchers, people with dementia and their carers.
- Disseminating reliable and accurate information through our website and publications.
- Supporting the 10/66 Dementia Research Group's work on the prevalence and impact of dementia in developing countries.
- Supporting global advocacy by providing facts and figures about dementia, and monitoring as well as influencing dementia policies.

ADI is based in London and is registered as a non-profit organisation in the USA. ADI was founded in 1984, has been in official relations with the World Health Organization since 1996. ADI is partnered with Dementia Alliance International (DAI), a collaboration of individuals diagnosed with dementia providing a unified voice of strength, advocacy and support in the fight for individual autonomy for people with dementia.

You can find out more about ADI at www.alz.co.uk/adi

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