

## 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<sup>1</sup>

For persons living with dementia, full and equitable engagement in everyday life activities often is compromised by the stigma associated with dementia<sup>2&3</sup>. 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<sup>4</sup> 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<sup>5-7</sup>. One model<sup>8</sup>, which has proven particularly useful in understanding dementia-related stigma<sup>9-11</sup>, 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*<sup>3</sup>. The type and severity of stigma can differ depending on who holds relative power over another<sup>7</sup>. 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<sup>13-18</sup>

### 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

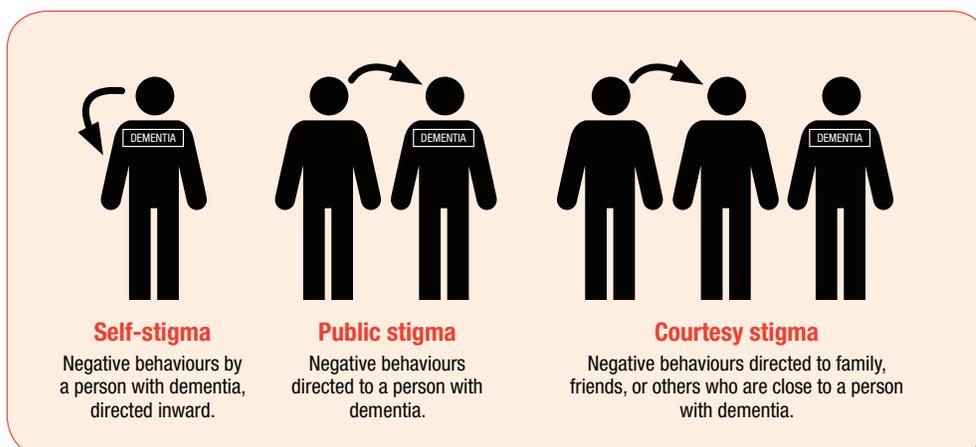


Figure 2. Three types of stigma <sup>2,23</sup>

1). Stereotypes are powerful because they are created and perpetuated in many different ways<sup>11</sup>. 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’<sup>12</sup>);
- 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*<sup>19-21</sup>. The severity of prejudice is shaped by age, gender, profession, ethnicity, culture and understandings of dementia prognosis, among other factors<sup>22</sup>.

### Component 4: Discrimination

*Discrimination* refers to negative behavioural responses to prejudice<sup>9</sup>. 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<sup>2,24,16</sup>.

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<sup>25,26</sup>; and limited or delayed referral to dementia-appropriate services or treatment<sup>27,28</sup>.

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<sup>29</sup>. Courtesy stigma is expressed in the form of social isolation or exclusion of family members or friends of persons living with dementia<sup>13,30</sup>, or by staring at or by talking about formal caregivers and friends behind their backs<sup>31</sup>, 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<sup>22,23</sup>. To date, the most promising approaches to reducing stigma include:



- 1 Specialised education about dementia-related stigma<sup>32,33</sup>.
- 2 Social contact with persons living with dementia<sup>34,35,36</sup>.
- 3 Targetted public health awareness / messaging / education<sup>37</sup>, through:
  - public advocacy by persons living with dementia<sup>38</sup>;
  - arts-based approaches, such as musical performance by persons living with dementia<sup>39</sup>; and
  - short film<sup>40,41</sup>, for example.
- 4 Changes to public policy (e.g., relating to employment, health insurance)<sup>42</sup>.

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.

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## 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<sup>(i)</sup>, 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<sup>(ii)</sup> 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.

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)<sup>1</sup>. 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<sup>2</sup>. 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.

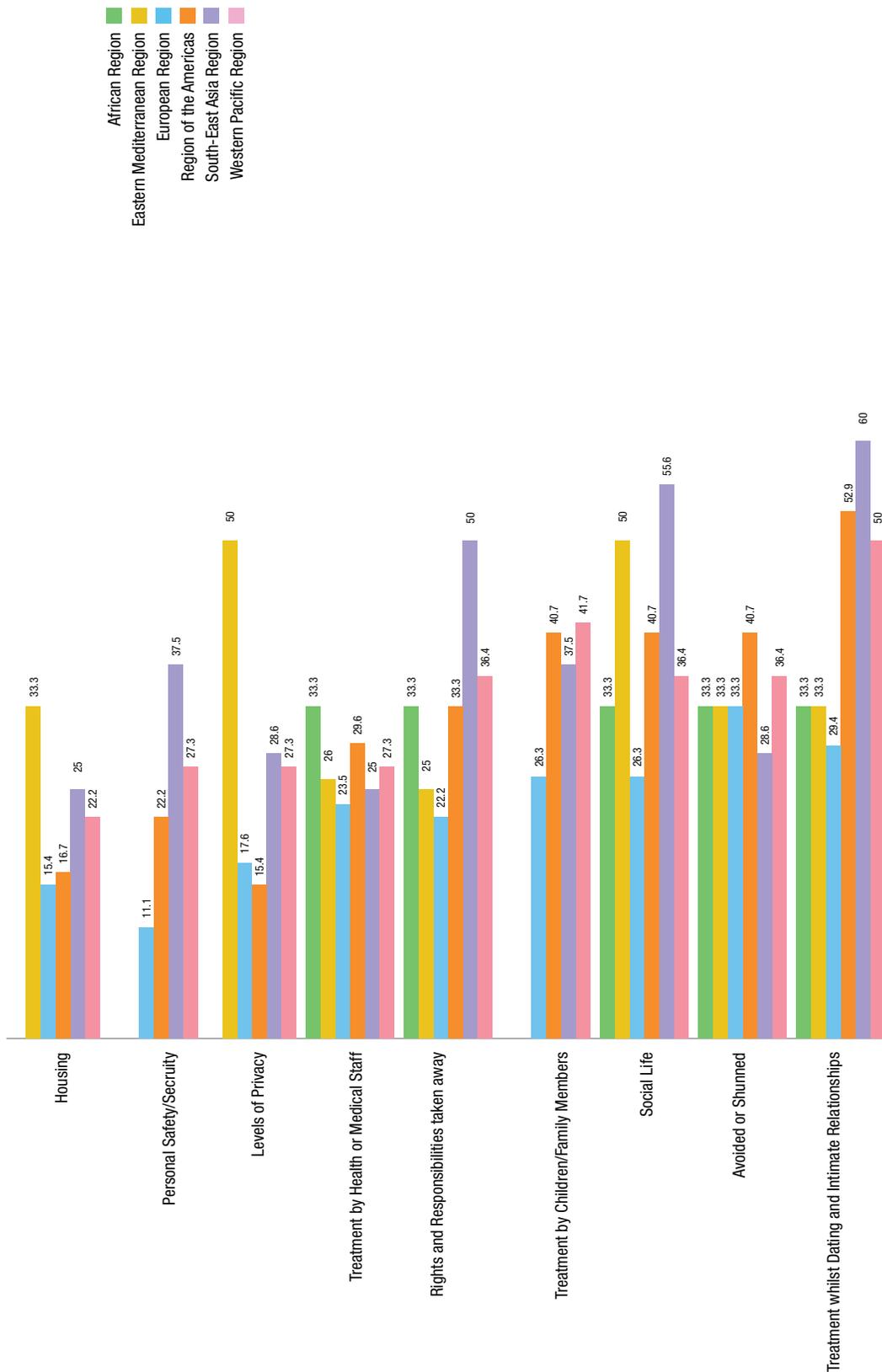
**Unfair treatment experienced by people living with dementia**

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

(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.

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



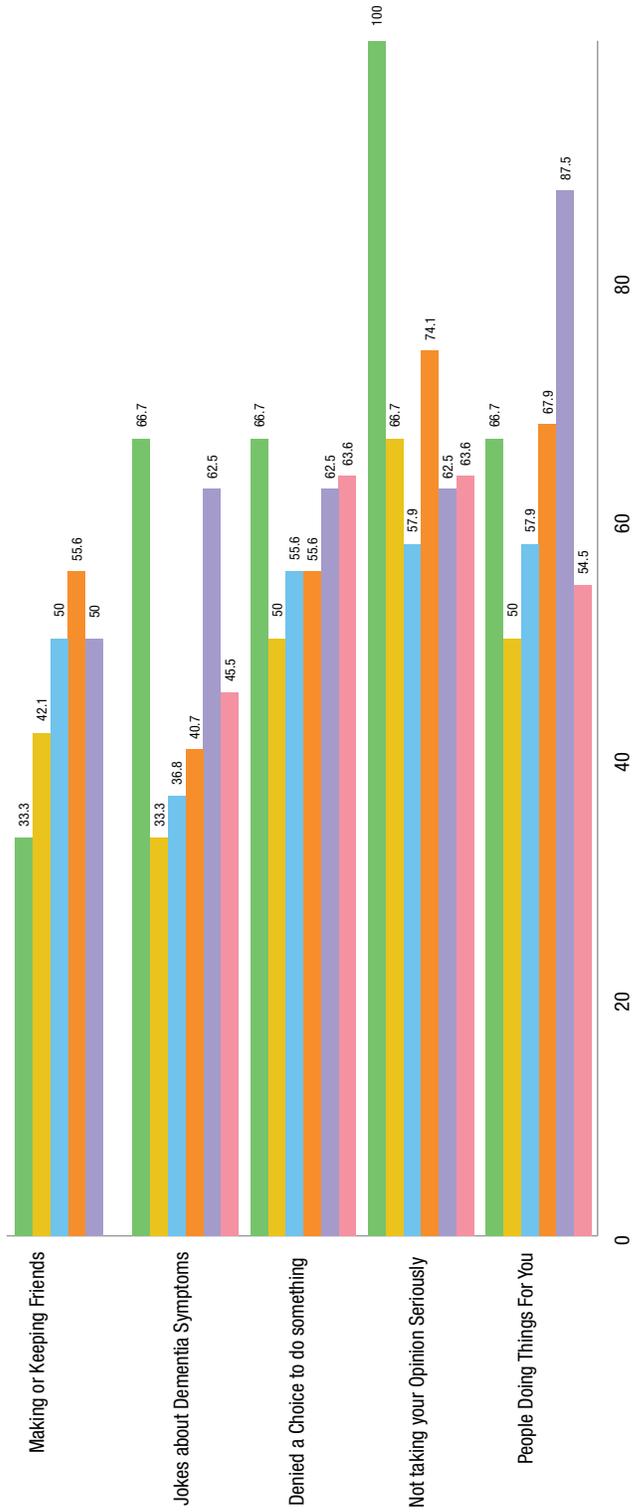
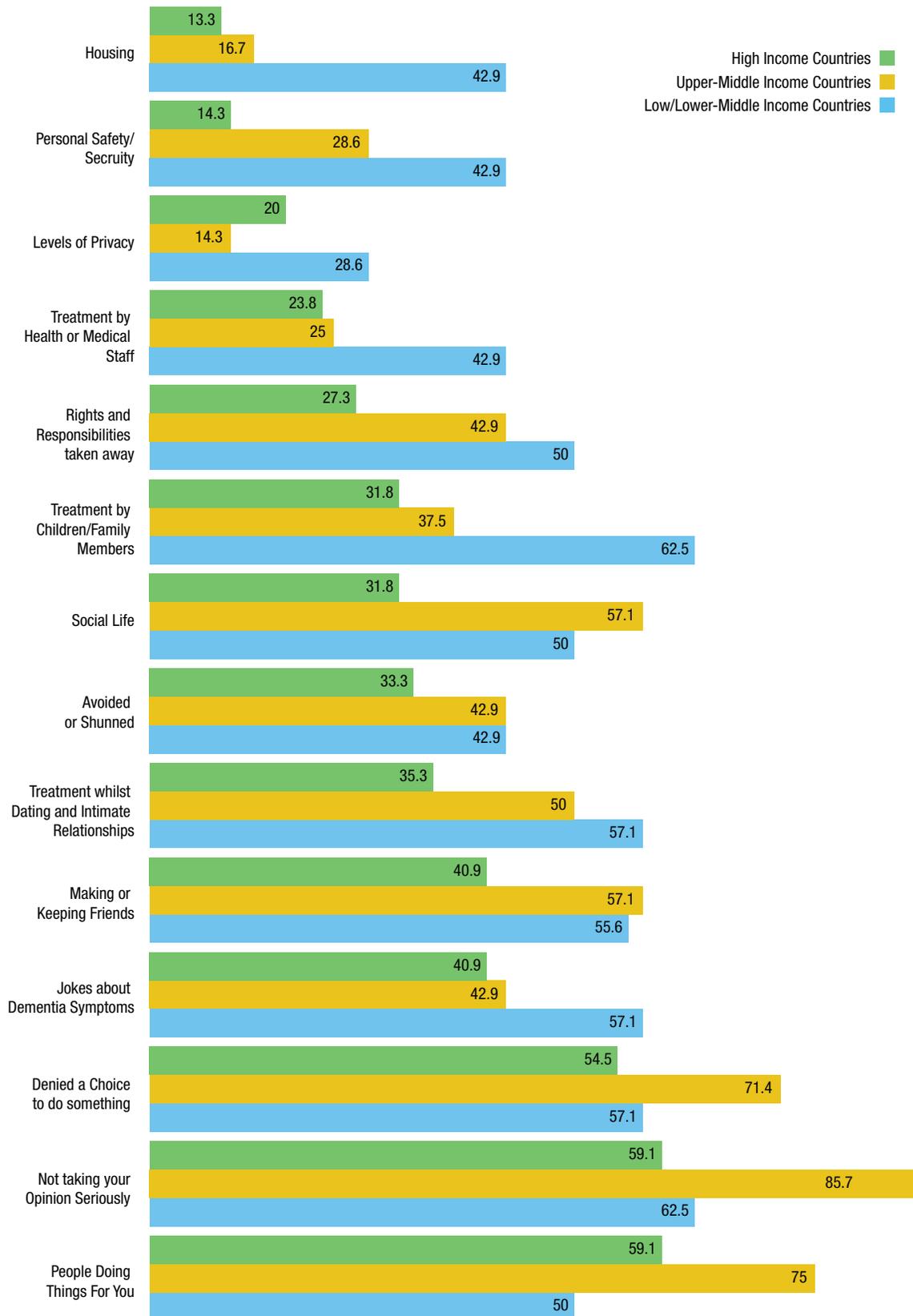


Figure 2. Domains of unfair treatment experienced by people living with dementia by World Bank income category (% of respondents)



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.

### 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).

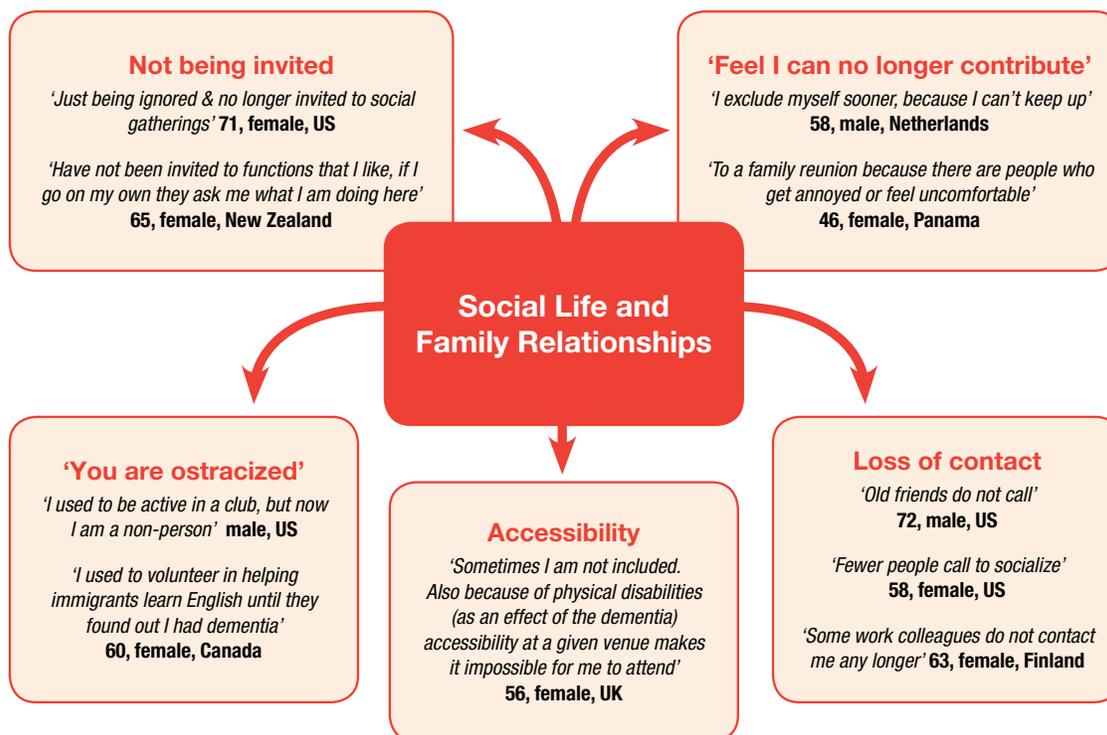
### Key themes

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
<b>Accessibility</b>	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
<b>'Feel I can no longer contribute'</b>	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
<b>Loss of contact</b>	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
<b>Not being invited</b>	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
<b>'You are ostracized'</b>	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

**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)'

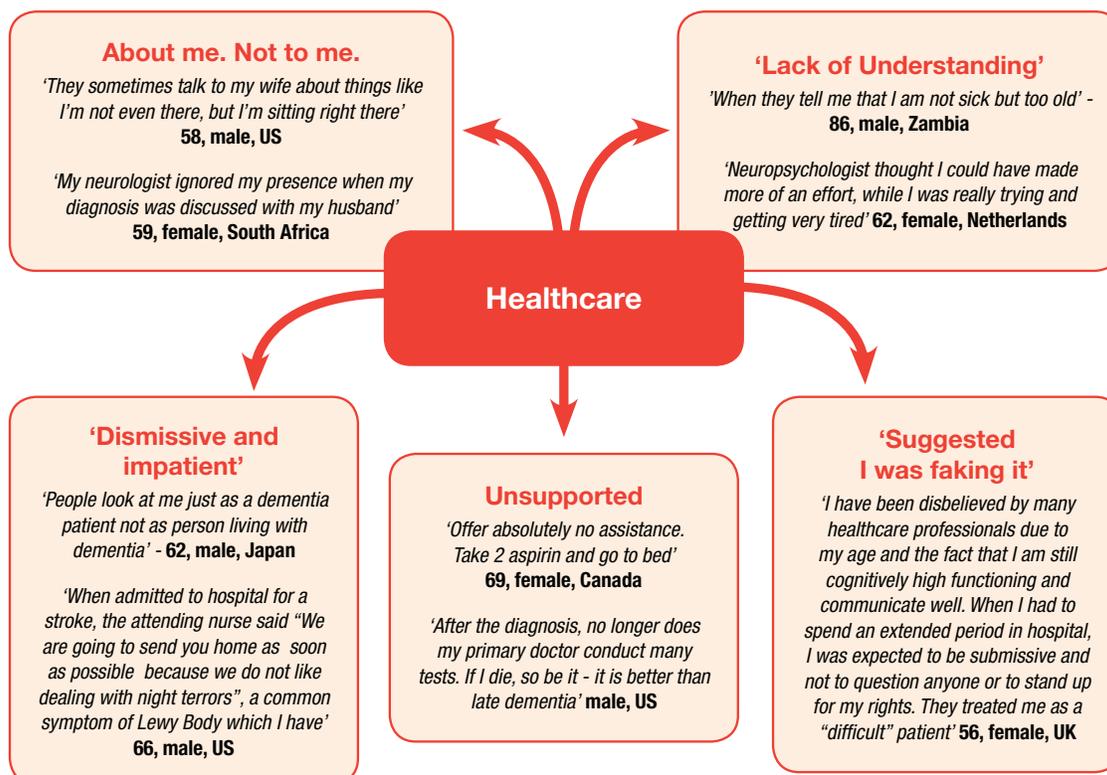


Table 2. Respondent examples of being treated unfairly in healthcare because of dementia, categorised by theme

Themes	Respondent examples
<b>About me. Not to me.</b>	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
<b>Dismissive and impatient</b>	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
<b>Lack of Understanding</b>	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
<b>'Suggested I was faking it'</b>	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
<b>Unsupported</b>	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

**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
<b>People doing things for you that you could do yourself because they know you have dementia</b>	<p>My partner has taken over all our finances - I think I could manage some of the – 63, female, South Africa</p> <p>Sometime people try to speak for me, but I insist I am still able to do this – 56, female, United Kingdom</p> <p>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</p> <p>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</p> <p>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</p> <p>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</p> <p>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</p> <p>Always volunteering to do stuff not wanted by me. Tiresome – 60, female, Malaysia</p> <p>I was excluded from the rotating duty of the neighbourhood association – 87, female, Japan</p>
<b>Not taking your opinion seriously because of your dementia</b>	<p>Sometimes in open conversations in groups of friends, I feel my opinion is “sidelined” – 63, female, South Africa</p> <p>They simply think I am dumb. Especially since I look 10+ years younger than my age – 48, female, Uganda</p> <p>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</p> <p>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</p> <p>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</p> <p>People just don’t listen when I talk – 69, female, United States</p> <p>I have even been told, “but you have dementia, so what would you know!” – 60, female, Australia</p>
<b>Denied a choice to do something that you still thought you could because of your dementia</b>	<p>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</p> <p>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</p> <p>Taking away carrying credit cards, cash – 81, male, United States</p> <p>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</p> <p>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</p> <p>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</p>

Domain of unfair treatment	Quote from respondents living with dementia
<p><b>People joke about your dementia symptoms</b></p>	<p>They call me names – 55, female, Zambia</p> <p>I put humour in my own situation to let other people feel comfortable – 56, female, South Africa</p> <p>My grandchildren mock me that my decisions are not sound – 86, male, Zambia</p> <p>Becoming a joke / joked about – 69, male, Indonesia</p> <p>Bullying, speaking about dementia as a funny joke – 40, female, Thailand</p> <p>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</p> <p>You can’t remember anything! – 70, female, United States</p> <p>How long before you become fully demented – 60, female, Canada</p> <p>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</p> <p>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</p> <p>My child said that I looked like an alpaca when I dribbled saliva – 53, female, Japan</p> <p>People said that I did not look like someone with dementia – 58, male, Japan</p>
<p><b>Treated unfairly in making or keeping friends because of your dementia</b></p>	<p>They tend to visit less often avoid visits – 74, female, South Africa</p> <p>Forgetting their names or when to meet...makes them think I do it intentionally – 48, female, Uganda</p> <p>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</p> <p>My siblings don’t talk to me or ask how I am anymore – 62, male, United Kingdom</p> <p>Barred from my Sister’s house because they said I have used abusive and obscene language – 70, male, Canada</p> <p>People tend to run when they learn you have dementia – 60, male, United States</p> <p>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</p> <p>I feel isolated – 65, female, Argentina</p> <p>Many have told me they are not at all interested in “the dementia journey” – 60, female, Australia</p> <p>Some friends don’t like to talk to me because I repeat – 87, female, Singapore</p> <p>I have a few people say don’t talk to her she has no idea what she is talking about – 65, female, New Zealand</p> <p>Some people cannot cope with the different me – 69, male, Australia</p>
<p><b>Avoided or shunned by people who know that you have dementia</b></p>	<p>Because they think that they cannot cope up to their standard of thinking – 55, female, Zambia</p> <p>They avoid socialize – 74, female, South Africa</p> <p>Close friend doesn’t call at all anymore – 60, male, United states</p> <p>In my faith community, avoiding me – 66, male, United States</p> <p>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</p>

Domain of unfair treatment	Quote from respondents living with dementia
<p><b>Treated unfairly by your children or other family members</b></p>	<p>My children are more distant and are not acknowledging my condition, refusing to talk about it – 56, female, United Kingdom</p> <p>I have a daughter who has distanced her and her family since I was diagnosed – 55, female, United Kingdom</p> <p>Not being included in conversations. I stopped attending family gatherings for the last 9 years since diagnosis – 70, male, Canada</p> <p>Too much expected of me sometimes. Irritation that I don't remember things – 70, female, United States</p> <p>Family frustrated, angry, and in denial themselves – 69, female, Canada</p> <p>Children sometimes seem to dismiss my decisions regarding my future – 79 female, United States</p> <p>[being told] “You’re a crazy mother” – 52, female, Brazil</p> <p>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</p> <p>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</p> <p>I am blamed for my mistakes due to my disease as if it were laziness - Japan</p> <p>People don't expect anything from me because I have dementia – 53, female, Japan</p> <p>My child dislikes me because I am slow and cannot clearly articulate my question – 65, male, China</p> <p>Since they cannot tolerate my behaviours, they do not want to contact me – 58, male, Chinese Taipei</p>
<p><b>Rights and Responsibilities unfairly taken away from you because of your dementia</b></p>	<p>The right to work and at times to think for myself – 63, male, UK</p> <p>My wife handles all finances even though I think I am capable – 79, male, Canada</p> <p>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</p> <p>Forced to apologize for my behavior – 67, female, United States</p> <p>Mother brother and sister cheated me out of large share of inheritance – 69, female, United States</p> <p>Rating at work was decreased – 59, female, United States</p>
<p><b>Treated unfairly in your levels of privacy because of your dementia</b></p>	<p>In hospital, psychiatric doctor did not give me my medical records – 60, female, Czech Republic</p> <p>Hospital lack of dementia protocols – 67, male, United States</p> <p>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</p> <p>Financial info, asking neighbours about me without telling me – 69, female, United States</p> <p>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</p> <p>Hospital moving from bed to bed. Manager does not understand dementia – total lack of training – 68, female, Europe</p>