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# Stigma and its implications for dementia in South Africa: a multi-stakeholder exploratory study

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## Abstract

Stigma and discrimination in relation to dementia has a range of implications for people living with dementia and their families worldwide, including help-seeking, quality of life, social rejection and isolation. Few studies consider the perceptions and stigma towards dementia from multiple perspectives, such as people living with dementia, carers, general public and health-care workers. South Africa has limited evidence on the stigmatisation of people living with dementia, with responses to people living with dementia being driven by poor understanding of the condition, cultural beliefs about causes and social interaction problems associated with memory and cognitive impairment. This study explored the experiences of stigma among people living with dementia and their carers through understanding their own knowledge, attitudes and beliefs as well as those of the public and health-care workers. Qualitative data (N = 52) were collected across two provinces and in four languages (English, Afrikaans, Sesotho and isiZulu), with semi-structured interviews and focus groups with the following stakeholder groups: people living with dementia and their carers, the general public and health-care workers. Inductive thematic analysis generated themes across stakeholder groups. The study shows that people living with dementia and carers experienced high levels of internalised stigma, related to negative public attitudes, which were associated with high levels of isolation, health system unpreparedness and limited access to support. The study contributes to the evidence base needed in South Africa but also extends its relevance by contributing to a growing global evidence base on stigma and dementia in low- and middle-income contexts.

**Keywords:** dementia; stigma; South Africa; implications; qualitative; help-seeking; primary health care; STRiDE

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## Background

Stigma in relation to dementia has a range of implications including impeding help-seeking, quality of life, increased loneliness and isolation (Mukadam and Livingston, 2012), and together with the impact of the condition itself, significantly undermines the psychosocial wellbeing of people with dementia (Milne, 2010). Although there is considerable research on stigma in relation to HIV/AIDS (Visser *et al.*, 2009; Idemudia *et al.*, 2018) and mental illness (Pescosolido, 2013; Egbe *et al.*, 2014; Semrau *et al.*, 2014), dementia-related stigma in a low- and middle-income context like South Africa has received less attention.

Stigma is understood as possessing an ‘attribute that is deeply discrediting’ and where this attribute (or ‘undesired differentness’) (Goffman, 1963) signals a deviance from what is considered ‘normal’ and negatively impacts social interaction through rejection or isolation of the stigmatised person or identity (Major and O’Brien, 2005; Young *et al.*, 2019). There are several types of stigma discussed in the literature (Link and Phelan, 2001; Van Brakel, 2006). For the purposes of this paper, we focus on three broad types of stigma: *public stigma*, *internalised stigma* and *structural stigma*. *Public stigma* occurs when someone or a group possessing a stigmatising trait receives reactions from the public based on their ‘undesired differentness’. *Internalised stigma* refers to reactions directed to the self by the person possessing the stigmatising trait (Evans-Lacko *et al.*, 2016; Bachmann *et al.*, 2019; Young *et al.*, 2019). When internalised stigma affects family carers of people living with dementia, it is referred to as *affiliate stigma*, and includes cognitive (e.g. belief that this is a punishment), emotional (e.g. anger, fear, shame, resentment) and behavioural reactions (e.g. concealment, self-isolation, not seeking help) of internalising negative public views (see Su and Chang, 2020). Macro-social forms of stigma, termed *structural stigma*, are defined as ‘societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized’ (Hatzenbuehler and Link, 2014: 2). For the purpose of this study, stigma is deemed *enacted* when the stigmatised person is discriminated against by others as a result of the stigma, and is *experienced* when leading to the stigmatised individual’s behaviour changing, such as withdrawing from or restricting social movements (Gray, 2002).

## Dementia in South Africa

Dementia is a broad term used to describe a group of progressive, neurodegenerative conditions that symptomatically manifest as a decline in cognitive ability, memory loss and executive functioning that are severe enough to impede daily functioning (Alzheimer’s Association, 2019; World Health Organization, 2019). It is estimated that with global ageing, 50 million people are living with dementia in 2020 and that this number will increase to over 152 million people by the year 2050 (Alzheimer’s Disease International, 2020). Prevalence of dementia in sub-Saharan Africa and South Africa has not been established conclusively (Kalaria *et al.*, 2008; Kalula *et al.*, 2010). South Africa has a population of 60.14 million people of whom 9.1 per cent (5.5 million) are 60 years and over (StatsSA, 2021) but there is currently no nationally representative prevalence data, nor routine monitoring and surveillance of dementia. However, the *World*

*Alzheimer Report* estimated that in 2015 there were about 186,000 people living with dementia in South Africa, of whom 75 per cent are women, with an expected increase to 275,000 by 2030 (Prince *et al.*, 2016). A single, localised rural prevalence study suggests that the prevalence estimate may be higher at around 11 per cent for 65 year olds and above (De Jager *et al.*, 2017). This may change with national estimates and currently is considerably higher than the 2–4 per cent range previously estimated for the four sub-saharan regions (Prince *et al.*, 2013).

There are no dementia-specific services provided by the public health system in South Africa. Dementia-care services are currently provided by (a) a struggling non-governmental organisation (NGO) sector that typically offers psycho-educational support, training of care-givers and linking family social support groups; and (b) a private sector that provides specialised services to a minority of South Africans of higher socio-economic status, and includes a range of services from medical specialists to housing, support services, carer training, and residential and long-term care (Lombard and Kruger, 2009). Private care and support services are unaffordable and largely inaccessible to most South Africans as about 84 per cent of the population depend on free public state services (Mahlathi and Dlamini, 2015). People living with dementia are largely cared for at home, usually by an unpaid, female family member (Kalula *et al.*, 2010; Lloyd-Sherlock, 2019). Given the scarcity of health-care resources and training around dementia and how to reduce dementia-related stigma, myths, misconceptions and stigmatising behaviour are likely to be perpetuated. Moreover, most care-givers lack the support and resources formally and through the community to provide care and support in a non-stigmatising manner.

### **Dementia-related stigma and discrimination**

People with chronic conditions such as dementia are often stigmatised due to (a) poor understanding of this condition as a chronic, progressive health condition (Idemudia *et al.*, 2018); (b) cultural beliefs about its causes; and (c) social interaction problems associated with memory and cognitive impairment (Mukadam and Livingston, 2012). Discrimination is also largely an outcome of stigma (World Health Organization, 2021), and is defined as ‘the treatment of a person or particular group of people differently, in a way that is worse than the way people are usually treated’.<sup>1</sup> Examples of discrimination include avoidance, loss of self-determination and lack of opportunity (Vogel *et al.*, 2013), and where manifested, *ageism* legitimises or ignores poor services and marginalisation of older persons within society (Milne, 2010). Ageism often intersects with other forms of discrimination based on disability, sex and race (Milne, 2010). For example, the intersectionality of sexism, racism and ageism often renders older, black women as especially vulnerable to stigma and discrimination (even more so when they have dementia).

Symptoms of dementia are understood differently across the world (Alzheimer’s Disease International, 2012). Limited research in sub-Saharan Africa has shown that people hold different causal attributions for dementia, including biological, psychological and spiritual (Spitte *et al.*, 2019). Biological explanations are used less often, and most explanations for dementia and any mental health-related issue were considered to be psychosocial, including stress, alcohol use and the

effects of poverty (Spitte *et al.*, 2019). Supernatural or spiritual explanations (e.g. witchcraft, sorcery) were often used when knowledge about medical conditions were uncommon and strange behaviours associated with dementia were interpreted as dangerous and caused by evil spirits (Mavundla *et al.*, 2009; Brooke and Ojo, 2019; Spitte *et al.*, 2019).

Dementia-related stigma has several potential consequences, such as deterring from or delaying help-seeking (Prince *et al.*, 2016). People living with dementia and their families often experience social rejection or isolation (Marais *et al.*, 2006; Gurayah, 2015; Mkhonto and Hanssen, 2018). This, together with a strong sense of familial responsibility among African cultures, results in families seeing the care of an older person living with dementia as a personal or family matter instead of seeking help from formal health structures (Mukadam *et al.*, 2011). Very few studies directly deal with the stigmatisation of dementia in South Africa, however, there is agreement that this condition is often misunderstood as a normal part of ageing (Kalula *et al.*, 2010; Gurayah, 2015; De Jager *et al.*, 2017), with a lack of awareness of dementia as a medical condition (Prince *et al.*, 2007; Kalula and Petros, 2011; Ramlall *et al.*, 2013; De Jager *et al.*, 2017; Mkhonto and Hanssen, 2018).

Limited research in South Africa suggest that perceptions of dementia (among some cultural groups) include a belief that it is a 'punishment from God/ancestors', a 'curse due to witchcraft' or being 'bewitched', and that dementia can be cured by traditional healers (Khonje *et al.*, 2015). This leads, as in other sub-Saharan countries, to behavioural and psychosocial symptoms associated with dementia being viewed with suspicion and fear, therefore preventing people living with dementia and their families from seeking social support, diagnosis, treatment and care. Reports on harmful reactions and extreme violence towards people living with dementia who are labelled a witch or bewitched are currently anecdotal, with no nationally representative data about these occurrences, except in media reports (e.g. Maseko, 2018; Seleka, 2020). Beliefs, knowledge and attitudes towards people living with dementia and their families are therefore important areas of investigation in understanding the manifestations of internalised, public and structural stigma. This study, therefore, aimed to explore the experiences of stigma by people living with dementia and their carers through understanding their own knowledge, attitudes, and beliefs as well as those of the public and of primary health-care workers.

## Methodology

This is a sub-study within the project 'Strengthening Responses to Dementia in Developing Countries' (STRiDE), funded by the UK Research and Innovation Global Challenges Research Fund, which broadly aims to improve the lives of people living with dementia and their families in seven low- and middle-income countries: South Africa, Indonesia, Brazil, Mexico, Kenya, India and Jamaica (see <https://stride-dementia.org/>). This is an in-depth, qualitative study with a cross-sectional design that explored the knowledge, attitudes and beliefs of stigma and dementia from the perspectives of four stakeholder groups: persons living with dementia, their carers, the general public and primary health-care providers in two provinces, the Free State (FS) and Kwazulu-Natal (KZN) in South Africa. Alzheimer's South

Africa (ASA) is one of two dementia-specific NGOs in the country (and partner on this project), with provincial offices in eight of South Africa's nine provinces. Based on their experience providing dementia support services across the country, ASA flagged KZN and FS as two provinces where stigma and dementia are most concerning for service users (*i.e.* people living with dementia and their families/carers). Specifically, we investigated existing knowledge, attitudes and behaviours towards people living with dementia and their carers; experiences of stigma and discrimination by people living with dementia and their carers; local culture-specific idioms of stigma and discrimination, current practices to promote social inclusion, and thoughts and preferences about how we can reduce stigma among these groups.

## Methods

In order to investigate both experienced and enacted stigma in relation to people living with dementia, we carried out (a) two focus groups (six to eight participants per group) with the general public (*i.e.* one group in each province); (b) one focus group in KZN and a series of individual interviews in FS with primary health-care workers (to take into account health facility operational requirements where it is difficult to take out more than one staff member to be interviewed at a time); and (c) six interviews in each location of people living with dementia and their carers interviewed together ( $N = 8$ ), or carers alone ( $N = 4$ ) where people living with dementia were unable to participate. Data collection was completed over two months (July and August) in 2019.

### Participant recruitment

Participants were recruited in collaboration with ASA (a partner on the STRiDE project) and local health services. The recruitment strategy varied according to the stakeholder group (*see* below). Researchers were not based in these two provinces and therefore collaborated with ASA offices to identify potential participants in their local areas for each of the stakeholder groups. Data were collected in four languages: English, Afrikaans, isiZulu and Sesotho.

### General public

For the general public, existing groups were identified by the local ASA social workers (one in each of the two provinces) where trust and rapport between members had already been established through their routine gatherings and social interactions. ASA social workers liaised with the organisers of the groups and shared the participant information sheet to help members of the group to make an informed decision about participation. People who were interested in participating informed the ASA member, who scheduled a face-to-face meeting with the research team. The researchers met individually with the groups (RJ in the FS province and MS in the KZN province) and obtained the written informed consent from individuals.

### Health-care practitioners

For health-care practitioners, a local primary health clinic was identified in each of the provinces within the catchment area where ASA social workers provide their

services. Researchers applied formally to the National Health Research Department to gain access to staff at these identified sites, and once institutional permission was obtained from the respective provincial health authorities, the local ASA social workers made initial contact with the facilities, provided information about the study and determined whether staff would be willing to meet with the researchers. ASA members then secured appointments during the scheduled data collection week for each province (focus group in KZN and individual interviews in the FS province to accommodate the operational demands of the facilities). Researchers (RJ and MS) met these commitments and commenced with obtaining written informed consent.

### **People living with dementia and carers**

For people living with dementia and carers, we recruited care-dyads via the local ASA offices' dementia support group networks and included carers of individuals with a reported diagnosis of dementia. We recruited adults that provided unpaid care for someone with dementia, with no restrictions on the age of the care recipient or severity of dementia. ASA social workers supported recruitment, translation (where necessary), information sharing and social support for all interviews with people living with dementia and their carers. ASA service users were approached with information letters describing the voluntary nature of the study, and appointments were made with those individuals who indicated they were interested in participating. Researchers (RJ and MS) visited the care-dyads at their homes (as participants' preferred meeting place) and completed recruitment by obtaining individual written informed consent.

### **Topic guide**

We developed different topic guides tailored for each of the stakeholder groups. All participants were asked about knowledge, attitudes and behaviour towards people living with dementia and their carers, local idioms, language and practices, and their thoughts on promoting social inclusion. People living with dementia and their carers were asked specific questions about their experiences in living with dementia, while health-care workers were asked more about their working practices involving people living with dementia and their family/carers at primary health-care settings.

### **Qualitative interview procedure**

All participants filled in a socio-demographic questionnaire (*e.g.* age, gender). Focus groups with the general public groups were carried out at (a) a quiet local coffee shop (led by MS) on a weekday morning; and (b) a church group member's home, which is the usual meeting place for this particular group (led by RJ). Group discussions lasted about 60 minutes. In KZN, the health-care workers' focus group discussion lasted for 53 minutes, whereas in the FS they were interviewed individually to ensure minimal disruption to the clinic. The individual interviews lasted between 15 and 25 minutes. All discussions were held in a private room with minimal disruption.

A series of dyadic or individual semi-structured interviews were completed with the participants. When interviewing people living with dementia, a pragmatic approach was taken, allowing participants to choose whether they participated in

separate or joint interviews (Eisikovits and Koren, 2010). The interviews were conducted in the comfort of participants' homes as a quiet, non-distracting environment to improve their interview experience (Quinn, 2017). On average, interviews lasted between 30 and 60 minutes. Interviews were led by two of the authors (RJ and MS – one in each province) together with relevant ASA staff members in that province. Interviews were completed in the language of the participant's choice (English, Afrikaans, isiZulu or Sepedi). ASA staff assisted with the translation of the topic guide questions into Sesotho and isiZulu and led these interviews. ASA staff were experienced interviewers by profession and were trained on the study's interviewing approach and the topic guide, and further supported by RJ and MS during the interview where queries arose. ASA staff facilitated rapport between the researchers and the participants with dementia and their carers as they provide ongoing counselling support services to these members as part of their ASA responsibilities. Where interviews were led by these ASA staff, researchers had a debriefing discussion after the interview to reflect on the process, content and interpretation of the completed session.

All focus groups and interviews were digitally recorded and transcribed verbatim and translated into English (where required).

### **Data analysis**

Inductive thematic analysis was undertaken to derive frequent or dominant themes from interpretations made by the researchers (authors) (Thomas, 2006), and to allow for complexity and richness of the data collected (Nowell *et al.*, 2017). The six phases of thematic analysis originally developed by Braun and Clarke (2006) followed: (a) familiarisation with the data; (b) generating initial codes; (c) searching for themes; (d) reviewing themes; (e) defining and naming themes; and (f) producing the report (Braun and Clarke, 2006). Data were analysed to categorise themes into three types of stigma: public stigma, internalised stigma and structural stigma. After repeated reading of the transcripts to become familiar with the data, a member of the research team (RJ) did an initial coding of the transcripts. Two strategies were used to verify sampled codes from the full codebook by two independent research members (NF, MS). At the first level of verification, RJ and NF independently coded two transcripts and compared coding, and through discussion reached consensus on the approach to continue coding. The second level of verification involved the third reviewer (MS) where the completed codebook was reviewed, discussed and corroborated. The South African research team developed a coding framework, which was presented and discussed among the wider STRiDE research team. The research team met regularly to refine the coding framework iteratively and to reach consensus on the definition and content of the themes. The framework was further refined by merging similar themes, removing extraneous themes and exploring the interrelationships between themes. Transcripts were entered into QSR NVivo 12 for Windows (<https://qsrinternational.com/nvivo/nvivo-products/>). The main author (RJ) led on the coding of the transcripts, supported by MS and NF in verifying codes and emerging analytic maps. In addition, the coding framework was presented to the wider STRiDE group (led by SEL), to stimulate discussion and reflection, and the finalisation of the analysis.

### Ethical considerations

Special precautions were taken by the researchers (RJ and MS) to explain information sheets and consent forms verbally (Cridland *et al.*, 2016) to all participants, including people living with dementia. Lead interviewers screened to assess whether the participant was able to understand the purpose of the study and what is involved (Lee, 2010), retain and weigh up information to make a decision, and communicate that decision (Gilbert *et al.*, 2017). Participants with severe dementia and whom researchers felt did not have capacity to consent were not interviewed. In these cases, informed consent was obtained to interview the carer only. The carer was consulted about whether the care recipient would have objected to the research if they had capacity. Therefore, despite capacity to consent and not being interviewed themselves, the person living with severe dementia's wishes were considered via proxy. All people living with dementia and their carers were regular service users of the ASA at the time of this study. An ASA social worker assisted each person living with dementia and their carer throughout the interviewing process with follow-up services where required.

## Results

### Demographics

Participants were predominantly female (86.5%) with a relatively equal distribution of participants between provinces (*see Table 1*).

Despite having the choice to be interviewed in their mother tongue (*e.g.* Sesotho and isiZulu), most participants preferred to be interviewed in English (57.7%), followed by Afrikaans (26.9%), isiZulu (11.5%) and Sesotho (3.8%). Participants were aged between 25 and 90 years old, as shown in *Table 2*.

**Table 1.** Recruitment of participants, split by key stakeholder group and recruitment site

Target group	Free State province	Kwazulu-Natal province	Languages in which interviews were conducted	Total
<i>Frequencies</i>				
General public	6	8	English (14)	14
Persons with dementia	6	6 (only 4 participated in the actual interview)	English (5) Afrikaans (4) Sesotho (0) isiZulu (3)	12
Carers	6	6	English (5) Afrikaans (4) Sesotho (0) isiZulu (3)	12
Health-care workers	7	7	English (12) Sesotho (2)	14
Total	25	27	–	52



**Table 2.** Basic demographic characteristics of participants, split by key stakeholder group and language of the interview

Target group	English	Afrikaans	Sesotho	isiZulu	Total
<b>General public:</b>					
N	8	6	0	0	14
Mean age (range)	38.6 (27–45)	71.2 (65–75)	0	0	52.3 (27–75)
Gender	8 female, 0 male	6 female, 0 male	0	0	14 female, 0 male
<b>Persons with dementia:</b>					
N	5	4	0 <sup>1</sup>	3 <sup>2</sup>	12
Mean age (range)	63.8 (40–75)	81.8 (76–89)	0	71.0 (62–81)	71.6 (40–89)
Gender	4 female, 1 male	2 female, 2 male	0	2 female, 1 male	8 female, 4 male
<b>Carers:</b>					
N	5	4	0 <sup>3</sup>	3	12
Mean age (range)	61.6 (39–81)	73.3 (54–90)	0	48.7 (31–61)	62.3 (31–90)
Gender	3 female, 2 male	3 female, 1 male	0	3 female, 0 male	9 female, 3 male
<b>Health-care workers:</b>					
N	12	0	2 <sup>4</sup>	0 <sup>5</sup>	14
Mean (age range)	34.2 (26–42)	0	27.0 (25–29)	0	33.1 (25–42)
Gender	12 female, 0 male	0	2 female, 0 male	0	14 female, 0 male

Notes: 1. Two participants spoke Sesotho but were comfortable to be interviewed in English. 2. One participant spoke isiZulu but was comfortable to be interviewed in English. 2. Two participants spoke Sesotho but were comfortable to be interviewed in English. 4. Seven spoke Sesotho but were comfortable to be interviewed in English. 5. Seven spoke isiZulu but were comfortable to be interviewed in English.

*Carers* (N = 12) reported caring mostly for a spouse (N = 7), parent (N = 4) or a child (N = 1), with care experience ranging between a period of five months and 10 years (mean = 3.8). Most *people living with dementia* were reported to have a dementia severity of either mild (N = 5) or moderate (N = 5). Two participants who were identified as severe were excluded. The sample included 12 carers aged 31–90, of whom three were male. People living with dementia were predominantly female (eight out of 12 participants) and ranged from 40 to 89 years of age (see Table 2). The care-dyad participants were diverse in that they included native Afrikaans-, Sesotho- and isiZulu-speaking participants, from middle-class and lower socio-economic contexts. Most participants in this group had high school (five carers and four people living with dementia) and less than high school

education (two carers and five people living with dementia). Four carers and three people living with dementia completed tertiary education.

Although participation was open by gender, for the *general public* group only female participants volunteered to participate. One group was recruited from a local tennis club and were younger (27–45 years old) than the second group recruited from a local church group (65–75 years old). A total of 14 participants were recruited across the two sites. Attempts were made to recruit a culturally diverse group of participants, though we struggled to identify groups that were willing to participate. This is recognised as a significant limitation of the study methods. Participants in both groups were native English- or Afrikaans-speakers, middle class and relatively well educated (six high school and seven completed tertiary level).

A total of 14 health-care workers were recruited (seven in FS and seven in KZN) including five nurses with a mean of 6.8 years of experience (five months to 11 years) and nine community health workers, with a mean of 5.7 years of experience (<1 year to 14 years of experience). No specialist training in dementia was reported for both nurses and community health workers although most of the KZN participants had received some sessions on awareness of dementia, including from ASA. The health-care workers were all female and were aged between 25 and 42 years. All health-care workers were from the public sector and were predominantly native Sesotho- and isiZulu-speakers, with eight having completed high school, one less than high school and five with tertiary-level qualifications.

**Thematic map**

Figure 1 provides an overview of themes identified from participants’ expressed knowledge, beliefs and attitudes towards dementia, and how these narratives represent internalised, public and structural stigmatisation of this condition.

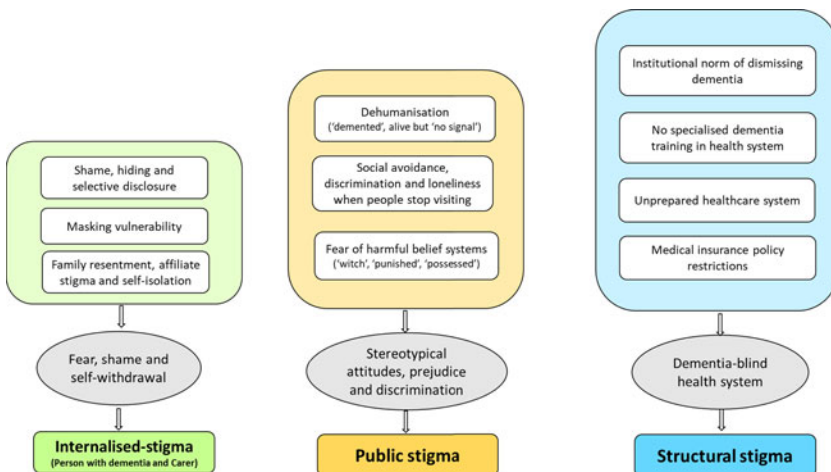


Figure 1. Dementia-related stigma in South Africa.

**Internalised stigma***Shame, hiding and selective disclosure*

The experiences of participants living with dementia and their carers varied. Some spoke about hiding their diagnosis:

I have been trying to hide ... It's fine ... keeping this to myself, I didn't want to involve other people into it. (Person living with dementia (PWD) 15, joint interview)

Another example came from a carer who spoke about her mother initially hiding her symptoms from her family because she feared that she would be stripped of her rights and lose access to her money:

...she saw the signs a long time ago. But she kept them secret thinking: 'oh they are going to think I am crazy or mad or they are going to take away all my rights, they are going to take my money, they are going to take away the bank cards' and all these things ... long ago those kinds of things used to happen. (Carer 15, joint interview)

Another person living with dementia spoke of wanting to hide herself since symptoms started to become more noticeable because she felt that she could not let others see that things were not 'right':

...now that it is getting worse, [I] hide myself (starts crying). One tends to be that way. You know ... it is maybe just how I am. Everything should be right ... my sisters ... I have not yet said anything to them ... Because I just feel it is not necessary. (PWD 7, joint interview)

Her husband, who is also her carer, shared how they eventually told the family and that although they do not consider the diagnosis a secret, they decided to only disclose to close family:

...we have finally told them. So our small family unit here, everyone here is aware that she has a problem, so it is not necessarily a secret. We, in the beginning kept it under wraps, you know because she felt [she] is just not herself. (PWD and Carer 7, joint interview)

Hiding symptoms, feelings of shame and disclosing a diagnosis only to a select few were common experiences shared by participants in response to their diagnosis. Delaying disclosure of diagnosis was common and if disclosure did occur, only close family were told. Beliefs about vulnerability and a need to protect themselves or their family member living with dementia also varied, where some participants felt that it was imperative to maintain a public image that hides dementia and masks vulnerability.

### *Masking vulnerability*

One care-dyad talked about keeping up appearances in the community by presenting an image of being active, as a way of masking dementia:

...other grannies are sitting down. This dementia is with someone who is sitting down ... But this grandmother is active, she walks and talks and walks. So, no one will believe you that this one has dementia ... Because she is busy. (Carer 15, joint interview)

It was important for this particular care-dyad to hide the diagnosis because they feared a range of reactions from the community, including being taken advantage of or 'tricked' for money:

Carer: ...some people will distance themselves. There are those who do want to help ... But others will take advantage ... Borrow money...

PWD: And pretend ... Taking advantage of a situation ... they say that ... 'I heard of a certain medication. I will bring it to you', he comes back ... bringing water with salt ... And [I must] pay for it. (PWD and Carer 15, joint interview)

Masking symptoms and projecting an image of being active was this family's way of managing the social impact of the diagnosis and protecting themselves from their community and people who would potentially exploit the situation.

### *Family resentment, affiliate stigma and self-isolation*

Carers often spoke about how they had become socially isolated from their families and friends since caring for a family member with dementia due to internalised or affiliate stigma. One carer described how family denial of the diagnosis resulted in strained relationships between herself and her children:

...they say 'Oh you are talking nonsense', or 'you are imagining it'. Then they act as if you are lying. Or 'Mom is not understanding'. But if you have to care 22–24 hours you will see ... I don't sleep. I don't know where he's walking to ... I don't even mention it to them [children] ... because you end up being resentful. (Carer 17, joint interview)

Caring for someone with dementia has therefore been described as a lonely undertaking, where in some instances the isolation is self-inflicted to distance themselves as carers from seemingly unsupportive family and friends:

...I think with the care-givers, it's a lonely road. People don't want you to complain ... That is why I say you withdraw yourself completely. You present yourself in a way that is not true ... 'Yes, it is always going well' ... You are standing on an island. (Carer 17, joint interview)

One carer described a self-isolating situation where there are currently no family relationships beyond members of the immediate household:

I don't really concentrate on my family. I know nothing of them, I just split away, I just stay away. The only family I know is my elder sister and my mum, my uncle, which we also live with, and then our kids. So I can tell you of those ... The rest, null and void. (Carer 29, joint interview)

Another carer described a combination of feeling socially excluded and avoiding social engagements due to a lack of understanding and acceptance of the dementia diagnosis from family:

Having family over for an afternoon, for me is very tiring ... I don't think I should have to explain myself for my wife's actions ... she's got a condition, accept it, don't question it, don't try and analyse it ... don't try and make it seem like it's something that it's actually not ... but to try and explain to other people what they can do to make it easier, it's like too much of an effort you know, just avoid it ... any conflict, any situation that we can see is going to become a complex situation, we remove ourselves from them. (Carer 25, joint interview)

Carers in this study were equally affected by negative views and reactions of others towards dementia. These participants demonstrated how internalised stigma, or more specifically affiliate stigma, leads to concealment, loneliness and self-isolation when internalising negative public views and reactions. Carers spoke about family denial of the diagnosis, unsupportive and strained relationships with family members, and as result the self-initiated removal of themselves from social situations to avoid the social impact of dementia.

### **Public stigma**

#### *Dehumanisation*

For the general public groups, the terminology used to describe dementia and Alzheimer's disease reflected negative public views of the condition. Alzheimer's disease was understood as being separate from dementia. 'Dementia' was understood as the behavioural manifestations of the condition (*i.e.* being 'demented' or 'out of one's mind'), whereas the term 'Alzheimer's disease' is viewed as a medical condition or a formal diagnosis. The latter terminology was seen as having fewer negative connotations:

Dementia ... it's a word that's got a ... negative connotation to it, like saying someone is like actually 'demented'. So there's a very negative connotation to that word whilst Alzheimer's sounds more of a diagnosis. That's how I say it is that Alzheimer's is the disease, Dementia is the spin-off of what happens to a person with Alzheimer's. (General public 2, focus group discussion (FGD) 2)

The negative connotation of dementia can be highlighted in part through the general public groups conceptualising dementia as being alive but without a 'signal':

Like someone said once her mother is still alive but gone because she is not there anymore. She has got no signal. (General public, FGD 2)

Another explained that people living with dementia are often neglected by their friends and families because it is believed that someone with this condition does not seem to possess human emotions and do not remember their family members, and therefore there is just no point in visiting them:

And what you said ... about they still have the same feelings and emotions ... To us, it doesn't seem like they do and I think that's why they often get neglected like friends and family because you go there [repeatedly], and they don't remember who you are, so is it going to make a difference if I actually go there? (General public, FGD 2)

These views reflect the dehumanisation of people living with dementia, whereby individuals with the condition are seen as less than human and believed to be deprived of human qualities and emotion. In other words, they are viewed as 'demented' or 'not there anymore'. These public beliefs may also lead to discriminatory behaviours, such as social avoidance towards people living with dementia and their carers.

#### *Social avoidance, discrimination and loneliness when people stop visiting*

One care-dyad spoke about how relationships have changed and feelings of loneliness have increased since diagnosis. A carer reflected on how her mother's behavioural changes have negatively impacted her mother's relationships with friends, who now avoid social contact and are no longer visiting:

She mistrusts anyone and everyone. And so they all, her friends from church, there in the neighbourhood, they are all afraid to come because if she can't even greet you, how are you going to be able to visit her? They can see there is something wrong with her. (Carer 15, joint interview)

The mother confirmed this form of discrimination and shared how she experienced a problem in connecting with others as friends tend to avoid her. She talked about spending more time at home alone, and finding ways to be around people to allow for some human contact:

The problem is connection with the people. Sometimes when I am all by myself I feel, ahh let me just go and buy something ... [in order to] meet people and talk to them so that I have somebody to talk to, otherwise I will be sitting like this here [alone] ... Meeting these girls from the school [along the road], asking them what time is it ... just to talk to them. (PWD 15, joint interview)

Another person living with dementia spoke about how others would avoid her since she started talking about her symptoms:

I start sharing my symptoms, people started to shun away from me. So people will rather keep those symptoms to themselves rather than sharing because once you start sharing, people will start to side-line you. They will start to label you.

So rather keep it, your small problem, and then you suffer alone. (PWD 29, joint interview)

Social avoidance and isolation are not limited to people living with dementia and their families. A participant from the general public group reflected on how discrimination against older people in general is embedded in our society, where families distance themselves from older members once they reach a certain age:

...it appears to be very much like we don't look after people once they get to a certain level. I mean as a society we definitely become more insular ... And so when your parents get to a certain age they go into a home and then they're forgotten ... They're just put away. And the only time they ever come to visit again is when they're almost on the death bed and they need to check on the will. And that's actually a reality though, in terms of we don't have appreciation for people over a certain age. We've kind of written them off. (General public, FGD 2)

Participants shared how their lives have changed since being diagnosed with dementia, including social avoidance, and feeling labelled and socially distanced by others. These discriminatory responses are not isolated to dementia itself but reflect a social norm where older persons in general are treated differently and often isolated, when they reach a certain age.

In some instances, social norms and harmful belief systems were also linked to fear and the restriction of freedom and movement amongst people living with dementia and their families.

### *Fear of harmful belief systems*

Many carers, people living with dementia and primary health-care workers recognised that the wider community did not understand dementia and its symptoms, leading to concern about how others would react. One carer admitted that she keeps her mother with dementia indoors and only goes out when necessary, for example when going to the clinic:

...she no longer goes out, I keep her indoors with me. She only goes [out] when we go to the clinic. (Carer 30, individual interview)

A community health worker spoke about how important it is for families to know there is a problem and to provide support to protect the person with dementia from community reactions. For example, to check their attire before going out to avoid being stigmatised by the community:

Not knowing that there is a problem, look I mean that they have this [dementia] and they have to do this to avoid being stigmatised in the community ... people who have support ... you can remind them no you're not wearing this, no you're not doing this, your dress is not okay and all that but those who don't have any support, it's devastating. (Community health worker (CHW) 9, individual interview)

When asked about attitudes and behaviours towards people living with dementia and their carers, care-dyads and health-care sector participants reported concerns about harmful belief systems in some communities. For example, fear of being labelled a 'witch' or being accused of 'witchcraft' emerged as a recurring theme that was introduced by participants. Although there were no participants with first-hand experience of being labelled a 'witch', primary health-care workers were reflecting on their community health experience and what they have learnt about belief systems in other areas. They explained the risk of strange behaviours that are symptomatic of dementia, leading to older adults (and their families) being accused of being a 'witch' or practising 'witchcraft':

... We don't have much cases but from what I've heard from other locations, they will just say it's witchcraft and all that ... Like a person ... wet[ting] themselves when they go out, [would be said to] 'become wicked' and ... they will just call everybody in the area to just see what the person's doing and they will say 'it's witchcraft, you deserve to be burnt' or something ... it's devastating because [it] can be ... your granny or grandfather being called [a] witch ... Because it derails you as a person, then you are even afraid to go out because you will be called a daughter of a witch or something. (CHW 9(4), individual interview)

Health-care workers also believed that fear and stigma influence help-seeking behaviour. When asked if they thought families would refrain from coming to the clinic for help as result of this cultural belief, one community health worker summarised how the fear of being labelled a 'witch' influences carers' healthcare-seeking decision-making:

Some will do, very committed ones will do, but others they'll just hold back. (CHW 9(4), individual interview)

Health-care staff interviewed understood the spiritual significance of their community's belief systems as staff share a cultural background with the service users described. These staff members spoke about the important role of education about dementia as a medical condition in their community to combat stigmatisation of people living with dementia and labelling as 'witches':

And then educate the family members also, we need to tell them. Because for example ... within our area most of the time they believe people living with dementia mostly will be the people that [do] witchcraft and they believe that they are *Umthakathi* [witch] and all that stuff. And then we need to educate the community. We also do the [talks] ... in the morning ... give the education in ... our waiting areas ... so that the community can understand the people living with dementia better, not to treat them [as] insane, call them names and understand them. (Nurse 21.1, health-care worker FGD 1)

Some carers feared that public reactions to someone with dementia showing wandering and strange behaviours in the community could be dangerous, and



that this form of public stigma is inherently gendered as ‘witchcraft’ is believed to be a female practice, especially amongst older women:

Carer: It is very dangerous because a person can start wandering around not knowing where he or she is going and people are murdered being accused of witchcraft whereas the older person is just old ... Going naked, going to people’s homes naked and wandering. This is all dangerous. People are always suspicious about witchcraft and they might kill you.

PWD: As I am a male, if I take my clothes off it would be just loss of memory.  
(Carer and PWD 26, joint interview)

People living with dementia and carers struggled with the widespread lack of knowledge and understanding of dementia amongst the general public and within their communities. Participants also shared how their fear of harmful beliefs about common dementia symptoms restrict their freedom of movement in order to avoid negative reactions from the public.

Health-care workers shared these concerns about harmful beliefs and provided further insight into the structural stigmatisation of dementia in the South African health system.

### **Structural stigma**

#### *Institutional norm of dismissing dementia*

One community health worker shared her views about staff not seeing dementia as a priority for primary health care and that they tend to ignore the condition:

...we’re not doing anything, even if we see the problem ... we[re] not taking it very seriously and that’s how it is ... but ... we don’t have information of the disease, even though they usually talk about it, we tend to turn a blind eye on it too.  
(CHW 9(4), individual interview)

Some community health workers spoke about a lack of information about dementia and that they explain symptoms to patients and community members as a normal part of ageing:

...we don’t have information on what is what, we just say it’s old age ... They [older persons] are meant to act that way. (CHW 9(4), individual interview)

From a service user perspective, carers’ experiences with the health-care system also reflect this institutional norm (of dismissing dementia) where health-care professionals specify that not much can be done in terms of providing treatment for people living with dementia:

We ... even spoke to [hospital name] Neurology Department and they said ‘well there’s not much you can really do about a patient with Alzheimer’s/dementia problems’ and that kind of stuff. ‘Parkinson’s you can give medication but the Alzheimer’s and the dementia there’s not much you can really do for them, so

we don't really treat them that much', so you know. 'We assess them and we see how they go'. (Carer 25, joint interview)

These institutional norms therefore constrain opportunities for people living with dementia to access appropriate treatment, and therefore contributes to community and societal beliefs that 'nothing can be done'. It is important to remember that this interpretation excludes the perspective of doctors and specialists (not interviewed in this study), and that communicating to a patient that 'nothing can be done' could in fact reflect a lack of services available for doctors to refer patients to, and not a lack of knowledge of medical and social interventions that could delay the condition's progression. Both these possibilities highlight structural challenges people with dementia and their families face with the health-care care system.

### *No specialised dementia training in health system*

Health-care workers' views that dementia is 'not a priority', a 'normal part of ageing' and that 'nothing can be done' can be explained by the lack of specialised dementia training available to health-care staff within the health sector. The level of dementia training differed depending on the participants' role, with community health workers reporting that they had received none. When asked about whether they think there is a need for them to be trained, all participants expressed a desire for training on dementia, for example:

Yes, definitely ... Because we deal with mostly older people who come to the clinic and we as community health workers, we focus much on older people ... unlike us [that] can take [our]selves to the clinic and [although] older people sometimes come, so we go to them instead of them coming here, so we will hear about their problems, then we will refer them here [to the clinic], so, it's a need. (CHW 9(4), individual interview)

Another believed that there is a need for increasing knowledge about the condition at primary health-care level, and in doing this it would lead to the detection and diagnosis of dementia:

I think we need more knowledge about it and how to go about it. I think maybe that is why it hasn't been diagnosed. (CHW 10, individual interview)

Nurses, on the other hand, indicated that they had some training on dementia as part of their basic training when they were student nurses, and that despite this training not being specialised, it is sufficient for them to recognise symptoms:

Researcher: Okay. So, as part of your basic training ... You get trained on dementia?

Nurse 2: Yes ... But it's not a specialised course or anything.

Researcher: Do you think that training was sufficient for what you need to do in your job?

Nurse 2: I think so 'cause we're able to recognise the symptoms. (Nurse 2, health-care worker (21) FGD 1)

All nurses reported that they received no specialised dementia training while working at the primary health-care level. This lack of specialised knowledge about dementia is also reflected in carers' experiences with the health-care system, describing it as unprepared in meeting the needs of people living with dementia and their families.

### *Unprepared health-care system*

One carer was distressed about the manner in which hospital staff were not able to manage her husband's care while he was hospitalised for a brief period:

In hospital he packed all his stuff. When I got there, he was leaving. They phoned me before and they said he's very agitated, he wants to leave, he's going to leave now. So, I said, well 'can't you do something?' I mean, every time my husband's in hospital ... the nurses always phone me for advice, [to ask me] what must they do. Every single time. A little while ago he was also in intensive ... He was smoking in the bathroom ... in ICU [intensive care unit]. So, I said, but why are you phoning me in the middle of the night? Why are you phoning me? I was already in a [emotional] state... (Carer 28, individual interview)

This carer also spoke of a perceived apathy, lack of knowledge and inhumane care received from health-care staff in hospital:

They [nurses] don't know, and they don't care ... I said to them, please, my husband can't eat by himself. When I got there it nearly broke my heart. I can even just break into tears now. He was sitting with a bowl, (starts to cry) and he was licking it like a dog ... And I went to the nurses and I said, why isn't somebody helping my husband? ... They just left him to eat like a dog, to lick out of the bowl, that upset me so much. You see, these things do upset me. I don't want them to ... Because they don't know ... I'm sorry, the hospitals don't know what to do. (Carer 28, individual interview)

Another carer reported that from his experience, health-care professionals held discriminatory beliefs about people living with dementia and in one instance advised a carer to desert his wife and forget about her as soon as she is unable to remember who he is:

You know what happened ... there's one thing that actually hurt me a lot ... I was told by a health-care professional that as soon as [wife's name] forgets who I am, put her in a home and forget about her. Sorry, I'm not going to do that. I will not do that, that's just ... not in my DNA, I can never do that, really and that's what people basically say you know, just put them in a home and just throw away the key you know. I don't know, I don't understand how people do that. (Carer 25, joint interview)

People living with dementia reported that doctors' tests offer inconclusive diagnoses of dementia and are based on the person's age and, in some instances, misinformation about the causes of dementia:

I used to go to the clinic because I had severe headaches, and I was starting to lose memory. I would forget even like simple things in the house. I would put a thing here, and the next ten minutes, I can't recall where I put it. Then they start doing like blood tests, electives, HBs [hemoglobin tests] and all that stuff, but they could not come to any conclusive diagnosis. But they kept on saying that maybe due to your age, you might be suffering from dementia ... I haven't got the final diagnosis because like the doctors kept on moving from this test to another one, but they kept on saying that I'm more on the dementia side and because of my age and my involvement in trainings and over-usage of computers and all that. That is what they said. (PWD 29, joint interview)

Misdiagnosis was also common amongst these participants, with depression and anaemia identified by doctors as common causes for symptoms observed:

We realised that there were strange incidents and things happening. And then I took her for tests and things. Then they first thought it was depression and then we saw it getting worse. (Carer 13, individual interview)

And we went to our house doctor and I asked him, 'Doctor, his mother had Alzheimer's and his sister stopped talking at the age of 70', now they had not diagnosed him at that time but one was always cautious. So he told me it is anaemia. He has an iron deficiency and he wrote out a script for three months. (Carer 14, joint interview)

Some carers reported that they were given medication immediately after diagnosis specifically to manage behavioural-psychological symptoms. However, there was great variation in reported experiences with the health system, *e.g.* one carer expressed his frustration in accessing treatment for his wife. He described a difficult three-year journey moving between the private and public health system from the point of his wife being diagnosed, to finding a doctor that had the capacity to prescribe treatment to manage his wife's behavioural symptoms:

Researcher: ...how long has it been since the point of diagnosis to when you actually received treatment...?

Carer: ...approximately 3 years....

Researcher: It is a long time.

Carer: Yes ...You know it makes one very hopeless, just I do not know how to explain it ... It makes you hate the people. It makes you think very bad about the people, you know ... I was very much stressed ... So that doctor gave us treatment. And of which we are taking and she explained because I explained that one or other problem that I am experiencing with her is, how do you call this, fighting ... Aggressive ... Very, very much aggressive. She said no, she will deal with that [with] the treatment. (Carer 12, individual)

Service users described health-care staff as unequipped to manage patients with dementia within hospital settings, holding discriminatory views, and lacking diagnostic and treatment capacity. These structural challenges deny access to adequate health-care responses, and increase the care demands on family carers.

Another structural issue relates to the restrictions posed by medical insurance companies in covering the cost of dementia-related treatment in South Africa.

### *Medical insurance restrictions*

People living with dementia and carers reported great difficulty with medical insurance schemes to pay for tests when accessing a diagnosis for dementia. One participant shared that health-care providers had to find ways to by-pass the restrictions imposed by medical aid schemes in order to authorise tests under the patient's other health conditions to support diagnostic testing for dementia:

...now the doctor just when he sees me because ... I do get seizures ... And he just puts me down as epilepsy so then they [medical aid] cover. (PWD 25, joint interview)

Participants also spoke out about their battle with medical insurance companies to pay for medication to manage symptoms of dementia. For example, a person living with dementia voiced her frustration with her medical insurance scheme that simply does not cover these costs:

But medication [name of medical aid company] doesn't pay for any of it [dementia]. It's not even on the PMB [prescribed minimum benefits] list, so it's expensive to get. It's over R700 a month. I mean you're paying your premium for the month and they can't even approve the medication. (PWD 25, joint interview)

Another carer shared her frustrations and noted that the chronic nature of these medications means that they are not supported by medical insurance, and that monthly out-of-pocket costs for these are expensive to maintain:

...the medical aid isn't paying that chronic medication. We had to pay that in each month ... of course it is expensive. (Carer 17, joint interview)

Engaging with medical insurance companies to include dementia-related treatment in insurance options available, and cover the costs associated with specialist visits, are described as the fight they are not winning:

...we fight with the medical scheme on a daily or virtually daily basis and to continue fighting with everything it's just getting a bit much so yes ... it should be a part of a PMB [prescribed minimum benefits] condition. They should have it ... and because [dementia] it's something that a lot of people have ... they could possibly put a new 'basket' [category] to see your neurologist three or four times a year and that kind of thing but to get them to do that, I don't know, we've tried. (PWD 25, joint interview)

A minority of South Africans can afford medical insurance, of which dementia-related treatments are not covered as a prescribed benefit. Service users in this study

share their frustrations with out-of-pocket payments for dementia-related tests and treatments in addition to costly medical insurance rates. Medical treatment for dementia in South Africa is therefore financially motivated and reserved for those few who can afford it.

In summary, the structural challenges experienced by people living with dementia and their carers reflect a health-care system that is unprepared to diagnose, treat, and provide care and support for most people living with dementia. Available treatments are restricted to those who can afford it, without the support of medical insurance. These structural norms and lack of available dementia training in the health-care system further constrain opportunities, resources and wellbeing of service users, and influence how dementia is perceived and responded to by health-care workers, service users themselves and their broader communities.

## Discussion

This study provides an important contribution to the available literature about stigmatising experiences, attitudes and beliefs about people living with dementia worldwide. In particular, few studies consider the voices of people living with dementia and their carers, and how this may be reflected in perceptions of others including the general public or health-care practitioners, and we know of no studies which consider this in South Africa. It is important to generate evidence from different cultures and health systems as it is likely to influence the stigma. We found that people living with dementia and carers experienced high levels of internalised stigma, related to negative public attitudes, which were associated with high levels of secrecy and loneliness, and inhibited access to support. These findings highlight the potential impact that reducing stigma against people living with dementia could have on individuals and families, including promoting help-seeking behaviour, access to social care, and health-system preparedness and support. Within this study we adopted a framework of splitting stigma into internalised, public and structural stigma, and set out to explore the experiences of stigma associated with dementia in South Africa from the perspective of people living with dementia, their carers, primary health-care workers and the general public. The findings highlight that these three broad types of stigma (internalised, public, structural) exist within FS and KZN, leading to people living with dementia being isolated, and lacking care and support. Examples from this study for each of these broad stigma types are discussed below.

The experiences with stigma varied across people living with dementia and their carers. *Internalised stigma* were evident in the selective disclosure of diagnosis, and self-withdrawal as result of feelings of shame, or self-isolation from strained relationships as a direct result from unsupported caring responsibilities and ensuing loneliness. This finding therefore supports previous research where the internalisation of negative stereotypes is linked to a decrease in self-esteem (Karakaş *et al.*, 2016), feelings of alienation (Szcześniak *et al.*, 2018) and social unacceptability (Vogel *et al.*, 2013), as well as social-avoidance behaviours and depression (Manos *et al.*, 2009).

Others actively hid their family member with dementia, for fear of behavioural-psychological symptoms being treated with suspicion and fear by

their community, as a way of protecting them from *public stigma* and a perceived threat of being labelled a 'witch'. There is not enough research in South Africa to understand the extent of this phenomenon, but where present, it is said to position families living with dementia as being especially vulnerable to social rejection and isolation (Mkhonto and Hanssen, 2018). The few existing studies suggest that older women in particular are targets for victimisation, violent attacks and death through public acts of violence targeting 'witches' (Benade, 2012; Khonje *et al.*, 2015), sending family members along with people living with dementia into hiding, and negatively influencing their care (Mkhonto and Hanssen, 2018). This form of affiliate stigma is known to increase anxiety amongst carers and is of great concern for its impact on their ability to ward off negative views, seek help and provide quality care (Su and Chang, 2020). These public beliefs are, however, not limited to South Africa and are found in other countries such as Nigeria (Adewuya and Oguntade, 2007), Uganda (Quinn and Knifton, 2014), Ghana (Ofori-Atta *et al.*, 2010), Tanzania (Mushi *et al.*, 2014) and many more (*see* Spittle *et al.*, 2019). Various religions also underpin beliefs of 'evil spirits', 'satanism', 'possession', 'punishment' or 'social jealousies' in understanding the origins of mental health issues, including dementia (Ally and Laher, 2008; Spittle *et al.*, 2019). Unlike Western belief systems that understand illness in biological terms, some African belief systems accept illness or misfortune to have a spiritual or social component. These belief systems support public stigmatisation of people living with dementia and have been identified as significant barriers to help-seeking behaviour (Mavundla *et al.*, 2009; Egbe *et al.*, 2014; Mkhonto and Hanssen, 2018; Spittle *et al.*, 2019). Public stigma is also linked to the development of internalised (self) stigma, with devastating effects on the person's sense of self. Longitudinal research on the temporal effect of public stigma and internalised (self) stigma found that public stigma is not only a barrier to help-seeking, it also directly influences people's ability to develop healthy, constructive attitudes about themselves (Vogel *et al.*, 2013). In fact, evidence suggests that public stigma can be especially problematic as it also increases symptoms, the likelihood of relapse, and adds to the person's distress and sense of hopelessness (Vogel *et al.*, 2013).

A form of public stigma was also found amongst participants from the general public groups. Most participants were familiar with the condition but used stigmatising language to describe someone with dementia. In line with dementia stigma literature, participants characterised dementia as 'identity-consuming' (Young *et al.*, 2019) and showed how *public stigma* dehumanises the individual with dementia as 'empty/an empty shell' and subject to neglect and abandonment.

People living with dementia and their carers in this study highlighted a range of structural issues that underlie their experiences of unequal access to diagnosis and treatment both within the public and private health-care sectors. Inconsistent knowledge amongst health-care staff fuelled beliefs that nothing can be done for someone with dementia, with age often proposed as the defining characteristic (and cited as the 'cause') of dementia (Kalula and Petros, 2011; Alzheimer's Disease International, 2019). Health-care workers provided insight into the *structural stigmatisation* of dementia in South Africa by sharing their experiences that reflect the institutional norms of dismissing dementia. They described current primary health-care practices as not taking dementia seriously, while attributing

noticeable changes in older persons' behaviour and memory as an expected and normal part of ageing. Limited research on dementia in South Africa supports this finding (Kalula *et al.*, 2010; Gurayah, 2015; De Jager *et al.*, 2017), and suggests that awareness and understanding of dementia as a medical condition, even among health-care workers, is poor (Prince *et al.*, 2007; Kalula and Petros, 2011; Ramlall *et al.*, 2013; Mkhonto and Hanssen, 2018). While lack of understanding of dementia is one explanation, specialists who generally know more about neurocognitive conditions may also not be responding to treatment needs because there is simply no treatment pathway available to refer to. Lack of resources and budget allocations within a health system that does not include dementia as a priority condition are structural constraints that practitioners have to navigate on a daily basis. These structural realities combined with poor awareness of dementia at various levels (including policy and health and social care sectors) therefore constrain opportunities, resources, and the wellbeing of people living with dementia and their families.

A carer's perceived discriminatory practices amongst health-care workers included staff apathy and lack of training to care for someone with dementia. Routine nursing care tends to focus on physical care as work demands, poor knowledge and resources often do not allow for person-centred approaches in dementia care (Houghton *et al.*, 2016). The pursuit of safety through physical care often outweighs dignity in care, where sitting down and providing individual attention (*i.e.* spending time with a person living with dementia) is considered a luxury nurses cannot afford (Jones *et al.*, 2006; Houghton *et al.*, 2016). These structural realities undermine person-centred care approaches at the expense of the patient's safety and dignity.

Furthermore, the lack of formalised training on how to understand and respond to dementia care needs at the primary health-care level suggests an institutionalised form of discrimination against dementia service users and the presence of *structural stigma* preventing access to basic health-care and support. Training of health staff is critical to promoting adequate care responses for service users. Research on the management of patients with dementia comparing doctors (general practitioners) with and without special training suggest that medical professionals with some dementia care training are more confident in managing patients with dementia and have less-negative attitudes towards care (Liu *et al.*, 2013). Increasing information and training on dementia among primary health-care workers in South Africa should be seen as a priority and span all those who have contact with patients with dementia. Community health workers, in particular, are optimally located to detect potential cases at grassroots level (*i.e.* via routine home visitations), and refer older persons for consultation, diagnosis, and health and social care responses via the local primary health clinic. Therefore, training of community health workers to detect, refer and support service users is critical in strengthening the current primary health-care response to dementia. The absence of adequate and appropriate dementia health and social care provisions available in the public health-care system may therefore contribute to the lack of prioritisation of dementia detection at the primary health-care level, supporting negative attitudes of hopelessness and beliefs that 'nothing can be done' for someone with dementia.



Health-care workers in this study recognised the need for professional dementia training and highlighted the importance of community education in combating harmful belief systems that stigmatise dementia and undermine help-seeking behaviour. Educating the public has been recommended as an essential step in overcoming the stigma of dementia by Alzheimer's Disease International's *World Alzheimer Report* (Alzheimer's Disease International, 2012); and has been proposed as an important area of intervention to reduce anxiety amongst people living with dementia associated with negative societal perceptions of this condition (Riley *et al.*, 2014).

In summary, these structural challenges are inherently inequitable and unjust, and reflect a health system that is restricting services to people living with dementia and their families. Structural stigma usually provides the context for interpersonal discrimination and is widely recognised as a significant barrier to accessing services (Pugh *et al.*, 2015). Structural stigma against service users is often characterised by low-quality service delivery, fragmented care pathways accessing treatment, care and support, and inadequate funding and prioritisation (Pugh *et al.*, 2015). Understanding how structural stigma manifests and sustains interpersonal imbalances of power is critical in combating stigmatisation of people living with dementia and their families.

Therefore, the findings of this study have shown that fear, shame and self-withdrawal (internalised stigma), together with stereotypical attitudes, prejudice and discrimination (public stigma) and a *dementia-blind* health system (structural stigma), negatively impact dementia help-seeking behaviour as well as treatment, care and support of people living with dementia and their families at the individual, public and structural levels.

## Limitations

The findings of this study are based on a small sample, across two areas in South Africa, and are not representative of experiences of people living with dementia and their carers, health-care staff or the general population in South Africa. For example, all fears reported of being labelled a 'witch' or accused of 'witchcraft' were not supported by first-hand accounts of being victimised as result of these beliefs, *e.g.* name-calling, chastising or violence (except where carers and people living with dementia avoided going out for fear of stigmatising community reactions). It is important to note that the fear of being labelled a 'witch' does not represent all belief systems and experiences of people living with dementia and their families in South Africa, as there is currently no research available on the prevalence of this phenomenon and the extent to which this results in stigmatised and discriminatory reactions. These concerns were, however, a recurring theme across interviews that emerged spontaneously during discussions about the attitudes and beliefs that participants viewed relevant to the dementia experience in their communities. This study did not set out to explore traditional conceptualisations of dementia from an indigenous cultural perspective, and therefore does not provide an analysis of indigenous belief systems (that include aspects such as witchcraft) in South Africa. Instead, this study reports on participants' understanding of events as a way of validating their knowledge of what they believe is true for themselves, and persons living with dementia in South Africa. It is important to

note that these views were voluntarily shared by participants who were accustomed to the belief systems described, and that their views were informed by their personal understanding of the culture, tradition and languages relevant to its practice. The researchers, on the other hand, are situated outside the belief system described and their understanding is limited to the explanations provided by participants themselves.

Sampling of carers and people living with dementia were skewed to those persons currently receiving psychosocial support from a dementia-specific NGO, the majority of whom have had access to psycho-education on dementia, diagnosis and care support. Their experiences therefore do not represent (a) the experiences of individuals and families that are cared for at home without having accessed mainstream (medical) health or social care services; and (b) those families who prefer consulting alternative and more traditional pathways of care and support (e.g. traditional and/or spiritual healers, and faith-based organisations). These traditional avenues in seeking treatment, care and support were unexplored by this study and need attention in future investigations.

There is also a bias in the sampling of health-care workers as there were no doctors or other health-care professionals (other than nurses and community health workers) interviewed in this study. Staff at public primary health-care facilities in South Africa generally do not include permanent medical doctors or psychiatrists. Medical doctors are often allocated to a health service catchment area, rotating between primary health-care facilities within that area with nurses being the backbone of primary health care. The views of doctors and other relevant professionals are missing from this study. As such, caution should be taken in our interpretation of why doctors communicate fatalistic views (*i.e.* 'nothing can be done'). Health-care staff interviewed were all from the public health sector, with no views and experiences included from staff working in the private sector as this was beyond the scope of this study and will need attention in future research.

Another limitation is the sampling bias in the general public focus groups, where existing groups were targeted for recruitment to facilitate rapport and group homogeneity and fit within the small time and budgetary constraints of the project. Efforts to recruit culturally diverse and gender-representative groups within the specified time-frame of the data collection period were unsuccessful. For example, local community centres were approached to recruit participants who attend community programmes (such as computer skills training, community gardens). As with all research, there is a tendency for participants to comprise those who are already interested and engaged in the topic. Having to rely on convenience sampling for this group therefore biases the findings for the 'general public' to white women of middle to higher economic status. Although the groups differed in ages and language, they did not include the voices of the myriad of cultures, economic and educational backgrounds, and languages characteristic of South Africa. As such, future research should seek to explore these attitudes across a larger sample, better representing the cultural heterogeneity of South Africa. Given the small and exploratory scope of the study, we did not specify population groups of the participants but only their language, to avoid making generalisations for any population groups based on such a small sample.

## Conclusion

This study explored the knowledge, beliefs and attitudes towards dementia across three groups including the general public, people living with dementia and their family carers, and primary health-care workers. The findings provide insight and understanding of stigma and discrimination towards people living with dementia and their families in South Africa and help us understand where we need to focus efforts to reduce stigma and provide more accessible support. The study contributes to the evidence base needed in South Africa but also extends its relevance by contributing to a growing global evidence base on stigma and dementia in low- and middle-income contexts.

Although participants had some knowledge of dementia, the presence of stigma led service users to self-isolate and actively protect family members with dementia from negative reactions from social networks beyond the immediate family. Pathways to diagnosis and care in the public sector is confounded by a lack of formal training to detect and manage dementia. This was apparent amongst community health workers who, in performing their routine home visitations, perpetuate beliefs that dementia is a natural part of ageing, possibly as a way of combating more harmful beliefs such as symptoms being due to 'witchcraft'. These realities have implications for the training of community health workers to provide knowledge and support to services users that destigmatises community responses to dementia. With limited specialist services available in the private sector to those few who can afford it, diagnosis and care pathways in South Africa are fragmented, with no dementia-specific services available to the vast majority of service users in the public sector. Building capacity among primary health-care staff has the potential to strengthen the South African public health system to diagnose, treat, and provide care and support for service users. Adequately addressing internalised, public and structural stigma not only strengthens existing health and social care systems, but also has the potential to promote help-seeking behaviour, support early diagnosis and intervention, and improve the quality of life of people living with dementia and their families.

Lastly, the role of traditional and indigenous belief systems in the diagnosis and management of dementia needs attention. Exclusively explaining the psychosocial needs and experiences of people living with dementia in African contexts from a medical, predominantly biological, framework overlooks the importance of spirituality in cultures that embrace a broader understanding of illness. This is especially relevant if we want to combat the stigmatisation of dementia in South Africa and similar global contexts, and activate locally acceptable sources of support as potential allies in dementia detection, referral, care and support.

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**Conflict of interest.** The authors declare no conflicts of interest.

**Ethical standards.** Ethical approval for this study was received from the University of Cape Town's Human Research Ethics Committee (HREC reference 021/2019) and the London School of Economic and Political Science's Research Ethics Committee (REC reference 000834b).

## Note

1 See <https://dictionary.cambridge.org/dictionary/english/discrimination>.

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