

Abstract

India is the world's second-most populous country and there are about 5.3 million people with dementia in India. Only one out of ten people living with dementia in India ever gets a diagnosis, care or treatment. There are various obstacles to deliver dementia care and support to people living with dementia and their carers. Furthermore, there is inadequate understanding of dementia in the general public and within the health care professionals. Studies in India indicate that people with dementia experience stigmatisation in society as well as neglect from their families. Social prejudice associated with dementia makes it a challenging experience, in addition, it makes the persons with dementia and carers feel isolated and stigmatised. Focus groups and individual interviews were used to explore perceptions, beliefs and experiences of dementia across a number of stakeholders in India, with an effort to understand stigma towards people with dementia. Participants were recruited in two diverse cities of India (Chennai and Delhi), and were comprised of a range of key stakeholders, including persons with dementia (n = 8), caregivers (n = 19), health care professionals (n = 16) and the general public (n = 15). Following a thematic analysis, we identified three overarching themes; (1) Poor awareness, (2) Stigma and (3) Barriers to accessing care. These all occurred within the context of socio-cultural beliefs. Whilst each stakeholder group had different experiences of dementia, it was common for all participant groups to use stigmatising language associated with dementia. In many cases, stigmatising beliefs and poor understanding of dementia resulted in poor care. There is an apparent need to raise awareness of dementia in India across all stakeholder groups; the fact that participants were able to self-identify that they had a lacked awareness of the condition may indicate that these groups are receptive to learning more about dementia.

Keywords

dementia, stigma, awareness, India, culture, aging, qualitative study

Introduction:

India is the second-most populous country in the world, with a total population of 1.3 billion. Approximately 104 million (8.6% of the population), are aged 60 years and above (Borah et al., 2016), with numbers expected to continue to rise significantly with increases in life expectancy. Dementia is most common among older people, with the mean age of

presentation reported as 66.3 years in India (Alladi et al., 2011). Currently, it is estimated that there are 5.29 million people living with dementia (Alzheimer's & Related Disorders Society of India [ARDSI], 2010) in the country, and is projected to rise to 7.61 million by 2030 and 14.32 million by 2050. Despite the rising burden of dementia, only 10% of people with dementia receive any care, diagnosis or treatment in many lower-middle-income countries (LMICs) (Prince et al., 2015).

Stigma towards people with dementia is seen as universal problem, as it results in people not seeking diagnosis or support, and can leave people socially isolated (Alzheimer's Disease International [ADI], 2019). Erving Goffman (1963) defines stigma as "an attribute that is deeply discrediting" that diminishes an individual "from a whole and usual person to a tainted, discounted one" (p. 3). Further Goffman states that individuals who are stigmatized are perceived as having a "spoiled identity" (Goffman, 1963, p. 3). Dudley (2000) describes stigma as stereotypes or negative outlooks credited to a person or a group of people when their characteristics or behaviours are viewed as different from or inferior to societal norms. Defined as disgrace and discredit, stigma is considered to be an unwelcome characteristic by society (Byrne, 2000). Poor awareness, misinformation and misconceptions can also contribute to stigma (Stangl et al., 2019). For example in India a large proportion of nursing home staff hold misconceptions and stigmatising beliefs about dementia (Strøm et al., 2019). Caregivers of people with dementia also had limited knowledge of dementia, having not heard of the term dementia or Alzheimer's disease (AD), and were unable to differentiate it from normal ageing (Shaji et al., 2003). Cultural values related with different religions emphasise the significance of family values, duties and obligations contributing to complex characteristics of Indian society and culture. Although in the last few decades there has been a growth of geriatricians in India and growing awareness of dementia is still overlooked and the concept of aging is neglected. In India, stigma was related to psychological and behaviours challenges associated with dementia resulting in neglect and sometimes abuse of the person with dementia (Dias et al. 2009). Lawrence Cohen (1998) identified *Sathiyana* as 'gone sixtyish' term used predominantly in North India. *Chinnan* (childishness) in southern parts of India where people speak Malayalam (Iype, Ajitha, & Shaji, 2006) and *Nerva Frakese* (tired brain) in Konkani (Patel and Prince 2001) are also used to refer to dementia. These local idioms highlight how the understanding of dementia is

rooted socially rather than in medical pathology. These terms also reflect the healthcare gap in raising awareness and facilitating early diagnosis (Brijnath, 2014).

The overarching aim of this study was to understand attitudes and perceptions concerning people living with dementia residing in India from two diverse metropolitan cities, Delhi and Chennai. We explored views from three important, yet distinct, stakeholder groups: the general public, healthcare providers, people living with dementia and carers.

Methods:

Between October 2019 to November 2019, we carried out a series of six focus group discussions across the stakeholder groups and two individual interviews with persons with dementia. To increase feasibility and comfort for participants, we also offered people with dementia an opportunity to participate via individual interviews to reduce any potential distress and improve their research experience. From both sites, one person with dementia was selected and was interviewed; their primary caregiver (spouse) was allowed to accompany them at the interviews with their consent to make them feel comfortable.

Alzheimer's and Related Disorders Society of India (ARDSI) is a national organisation which was the primary gatekeeper in recruiting participants for the focus group discussions. ARDSI has 22 chapters spread over 22 cities providing a network of volunteers and working closely with medical professionals, running dementia services to provide care and support to families and people with dementia. The chapters are better established in some cities like in Chennai and Delhi. These chapters have been well established since 1994. Both these chapters have working memory clinics, and the board members of these chapters are associated with renowned hospitals in the respective cities. These chapters also provide services to family (unpaid carers) of person with dementias including counselling, referrals and training. In addition, the Delhi chapter has a fulltime dementia day-care centre.

A total of 58 participants took part in six focus group discussions and two individual interviews were conducted with persons with dementia. The mean age of healthcare professionals in Delhi (N=5) was 35.4 years and in Chennai (N=11) was 32.72; general public in Delhi (N=6) was 47.66 years and in Chennai (N=9) was 50.4 years; Caregivers in Delhi (N=4) was 37.75 years and in Chennai (N=8) was 53.125 years; Person with dementia in Delhi (N=1) was 60 years and in Chennai (N= 7) was 67.71 years. The mean number of years the health care professionals worked was 11.5 years. The mean of number of years' family caregivers provided care for was

5.1 years. Sociodemographic details of participants, split by key stakeholder group, are provided in Table 1. Participants came from a range of socio-economic, cultural and religious groups.

TABLE 1 ABOUT HERE

Table 1. Socio-demographic characteristics of participants:

Participants:

Participants were recruited separately in two metropolitan cities— Chennai and Delhi. The sites were selected due to their diversity in demographic and cultural factors. Delhi is situated in North India, whereas Chennai is the southernmost metropolitan city of India. The availability of ARDSI chapters in these cities facilitated recruitment across different participant groups, using different strategies.

General Public: In Chennai, this category of general public was identified by ARDSI Chennai chapter with the aid of advertisements and word of mouth; some of the participants were recruited by local researchers as well. In Delhi, participants were recruited by the ARDSI Delhi chapter via word of mouth. All participants were required to be over the age of 18 and not formally identify themselves as having or caring for someone with dementia.

In Chennai, focus group discussions were advertised on the notice board of the Psychiatric Department at a renowned medical university associated with the ARDSI Chennai chapter. The gatekeepers at the university recruited health care professionals via word of mouth. In Delhi, participants were recruited and identified by Delhi ARDSI chapter. All the healthcare professionals recruited from this site were associated with dementia care in some way. The poster was posted in the psychiatric department of the medical hospital associated with ARDSI Chennai chapter for 10 days before the focus group discussions. This recruitment targeted mainly health care professionals working in the medical hospital. Out of the 11 healthcare professionals in Chennai, eight participants came after seeing the poster and the other three were approached via word of mouth. All people who showed interest were selected and included in the focus group discussions. The venue of the focus group discussions in Chennai was at this medical institute. In Delhi, the venue of the focus group

discussions was in a meeting hall of a pre-booked public social institute, which is generally used by social researchers and organisations for meeting purposes. This venue was far from the medical hospital where the poster was displayed. In Delhi, the poster was displayed in the psychiatric department of the hospital connected to the ARDSI Delhi. ARDSI members are connected to these respective hospitals where they were able to recruit the sample. Information on the participants' educational background was gathered.

In Chennai, persons with dementia and their caregivers were recruited by the local chapter of ARDSI Chennai and the associated medical university. The local researchers working with both these organisations recruited participants from the list of people with dementia and their caregivers who were frequent service users at these organisations. A total of 14 family carers were approached for the focus group discussion, of which eight were expected to come on the actual day of the interview, as it was anticipated that many of them might drop out due to situational reasons. In Chennai, we selected 14 caregivers and reached out to them to participate in the focus group discussions. Six caregivers responded 'not sure' to the focus group discussions innovation, and said they might not be able to make it on the particular day due to various reasons (e.g., the person with dementias may not cooperate, they may not have someone else to look after the person with dementia if they have to leave them back at home or some said they may have difficulty getting a transport to the venue as they have to bring the person with dementia along). However, on the day of FGD focus group discussions all 14 caregivers came and were involved in the focus group discussions. Most of the caregivers came specifically with the impression that they might learn more about dementia through these focus group discussions. This was expressed in the group discussions by participants from the caregivers' group.

Recruitment of persons with dementia was based on identification through ARDSI data, which included careful selection of person with dementia who fit the criteria of coherence, communication, and severity of dementia. Dementia severity was assessed through the medical professional assigned at the ARDSI Chapter. As part of recruitment at both sites, challenges were faced to identify a person with dementia in early stages who could understand and respond to the interview questions, as most of the persons with dementia

were in moderate to severe stages. This also reflects the delayed diagnosis or approach to seek healthcare support in the later stages of the condition.

Some ethical issues that were observed at the time of recruitment of persons with dementia was that capacity of consent from the person with dementia seemed to be uncertain.

Consent from the person with dementia was sought and in the case that the person with dementia was unable to provide informed consent (this was judged by the research team, which consisted of a dementia psychologist), proxy consent was taken from the family member that accompanied them. During the interviews with people with dementia, the caregiver was present (Chandra et al, 2021)

Ethical approval for this study was obtained from the London School of Economics and Political Science (LSE) Research Ethics Committee and National Institute of Mental Health and Neurosciences (NIMHANS) Ethics committee.

Procedure:

Eventually, all caregivers who were approached attended the focus group discussions. Along with their family members with dementia and other family carers, in total this resulted in 21 participants (please refer Table 1). SH, MP and RN conducted the focus group discussions who had experience working with persons with dementia. The team was very conscious of the possible needs of all participants. Prior to the discussion, basic instructions were given to the group such as only one person to talk at a time and other to wait for their turn, to keep phones on silent whereas they were allowed to take calls outside the hall, they were informed and cued for restrooms and were told that they are free to walk out of the hall in middle of the discussion if needed. One person from the team (SH) moderated the group, while MP and RN being more familiar with the local language and culture facilitated the discussions. The group was given a break after an hour for 15 minutes where they were served coffee and refreshments. The local gatekeeper sat outside the hall throughout the discussion in case there is any need for support, for example like a person with dementia getting restless.

In Delhi, participants were recruited through ARDSI Delhi chapter gatekeepers. For both the sites, the inclusion criteria were: 1) Persons with dementia with a confirmed diagnosis; 2) Persons with mild to moderate dementia, who were able to communicate and engage with

the research activities. There was no formal cognitive testing; 3) Primary caregiver of persons with dementia should be aged 18 and above. Paid carers were excluded from the study.

Information sheets were provided to potential participants and informed consent was obtained. Socio-demographic characteristics (e.g., gender, age, profession) and knowledge about the terms “Alzheimer’s Disease” and “dementia” were collected prior to interviews collected through a questionnaire. The facilitator introduced the focus group discussion (or interview) and set the ground rules. Topic guides were tailored for each of the stakeholder groups. The types of questions asked in the focus group discussions are reported in the topic guide in the Supplementary document. On average, the focus group discussions lasted between 40-60 minutes, whereas the large group of carers and people with dementia lasted for over 2 hours with a break in between. In Chennai, the focus group discussions were conducted primarily in Tamil, while in Delhi they were predominantly in Hindi. Across both sites, English was intermittently used based on the comfort and preference of participants. The study aimed to conduct one individual interview with the person with dementia in each site, with the set of questionnaires that was developed for this study and adapted for persons with dementia (please refer to Appendix for the questionnaires). At the ARDSI Delhi chapter only one person with dementia was recruited through purposive selection method for the requirement of person with dementia with mild to moderate stage, cognitive and communication abilities to be coherent for the interview. At Chennai chapter, the other persons with dementia were not selected, as they were either in severe stages or were unable to communicate for the individual interview.

Data analysis

We adopted an inductive thematic analysis approach (Braun and Clarke, 2006). After repeated reading of the transcripts to familiarize ourselves with the data, a member of the research team, SH, independently coded the transcripts. SH developed a coding framework,

which was presented and discussed among the wider research team. The research team met regularly to refine the coding framework iteratively 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. All focus group discussions and interviews were audio-recorded and transcribed verbatim. They were then entered into QSR NVivo 12 for Windows.

Reflexivity and rigour

The focus group discussions were carried out by the ARDSI team of MP, RN and SH. MP hailing from South India has a strong grasp of written and spoken Tamil. She has vast experience working with people living with dementia; she is currently serving as ARDSI chairperson. RN a former caregiver, works as Executive Director at ARDSI and is fluent in Tamil, Hindi and English. SH, has worked as a psychologist in the field of dementia for eight years, is fluent in English and Hindi. MP based in Chennai and RN in Delhi, made it easier as they are associated with the local chapters. This facilitated recruitment of the sample and enabled this recruitment to occur as per the pre-identified criteria of this study for the required target groups. As there are ARDSI chapters across the country affiliated with different medical organisations, it was more feasible to recruit from these chapters; once ethical approval was received from the affiliated organisations.

All individuals involved in the focus group discussions and coding received the same standardised training on the process, irrespective of prior experiences. All transcripts were transcribed in the language in which the interviews occurred (Tamil or Hindi), and then translated into English. The wording was kept as close to the original phrasing whenever possible. SH was involved in the initial focus group discussions and transcription and was also responsible for coding; this provided familiarity with the topic and content. Due to the education and qualification backgrounds of the researchers, there is the possibility that participants were less likely to speak freely on certain issues. To reflect the process of coding, frequent discussions were held with an independent researcher not involved in the data collection or transcription (SEL or NF). The reflection on the coding by senior researchers (SEL and NF) may have been biased by their experiences of dementia within a western context. In addition, the coding framework was presented to the wider STRiDE group, to stimulate discussion and reflection. STRiDE (Strengthening responses to dementia in developing

countries www.stride-dementia.org) is a multi-national project led by a wide team of researchers from and related field of dementias, which aims to understand the impact of dementia in social, economic and cultural contexts in order to strength planning, implementations and evaluations on dementia plan in India. This study was conducted as part of the wider STRiDE project. The aim of these discussions was not to achieve a unified theme across India to understand the attitudes and perceptions of the various focus group discussions and persons with dementia, but to capture different themes that emerged.

Findings

Data from the focus group discussions and interviews revealed three overarching themes; 1) Poor awareness, 2) Stigma, and 3) Barriers to accessing care. All themes occurred within the context of socio-cultural aspects which typically framed discussions. The main themes and subthemes identified from the data are shown below in Figure 1.

FIGURE 1 ABOUT HERE

Figure 1 : Key themes and subthemes identified across participant groups

259

260 **Theme 1: Poor Awareness**

261 The most common theme that emerged across participant groups was poor dementia
262 awareness. This could be broadly split into lack of knowledge and misconceptions; the
263 former represented a self-described absence of knowledge, the latter represented an
264 incorrect understanding of dementia.

265 Participants, irrespective of site or stakeholder group had poor understanding and
266 awareness of dementia; they also expressed being conscious of the fact that they have low
267 dementia awareness. Most caregivers said they came to the focus group discussions in
268 order to learn more about dementia. Caregivers brought their loved ones with dementia to
269 the focus group discussion as they thought that it would benefit them.

270

271 *“Why I came here because, in India [we have] no awareness, we do not know*
272 *where to go, we are totally confused” – PMS07, Male, Carers group, Chennai*

273

274 *“...this group discussion happening here is also very helpful. When lot of*
275 *people discuss this, I thought I would get some tips from this” – PM03, Male,*
276 *Carers group, Chennai*

277

278 Caregivers shared their experience of their confusion with receiving a dementia diagnosis
279 and attributed it to failings of medical professional’s knowledge. In a one-on-one interview,
280 a caregiver reported the impression from their physician after seeing the dementia
281 diagnosis:

282 *'I know her because something happened to her suddenly, it will affect her, it*
283 *is nothing to do with all these things (dementia). This is a joke and words (the*
284 *diagnosis), kindly throw it out,' – PMSHCG, Male, Carer, Chennai*

285

286 Healthcare professionals trained in dementia and who theoretically had access to dementia
287 resources also seemed to have a limited knowledge of the nature of the disease, cause and
288 overall understanding of dementia.

289 *“(what causes dementia) is due to deficiency of vitamins, exactly I don't*
290 *know what is the reason of it, some problem with nervous system also...” -*
291 *PMCG003, Male, Healthcare professional, Delhi*

292

293 Notably, there appeared to be a divergence in the dementia knowledge of healthcare
294 professionals. Those who had experience working abroad tended to have greater expertise
295 on the topic.

296

297 It also emerged from the discussion that dementia gets mislabelled. Across family carers and
298 healthcare professionals focus group discussions, many participants referred to a gap within
299 the healthcare system and poor training of medical practitioners in dementia care.

300 Misdiagnosis was one concern that participants had spoken about.

301 *“They are misdiagnosed and treated for something else, they are treated for*
302 *mental disorders, they are treated for OCD, obsessive-compulsive disorder for*
303 *that they are given medicines.” – PMPt002, Male, healthcare professional,*
304 *Delhi*

305

306 Irrespective of different types of challenges faced such as misconception, stigma,
307 mistreatment, or lack of accessibility to treatment, most participants attributed these
308 challenges towards a lack of dementia awareness. Throughout discussions among all the
309 groups, a dire need to raise dementia awareness across all levels [HCP, GP, CG] was
310 identified.

311

312 *"The most important thing is to educate the caregivers, spread awareness as*
313 *there is not much treatment for dementia" - PMCG003, healthcare*
314 *professional, Male, Delhi*

315

316 Some participants believed that dementia awareness in urban areas is better, as there is
317 some amount of awareness and access to services that provide dementia treatment.

318

319 There was a prevailing view that dementia was a normal part of ageing and thus not a major
320 health concern.

321 *"Whenever there is a cognitive deficiency in a cluster of family, what they*
322 *think is, he is aged, it is common in this age." PdR01, male, healthcare*
323 *professional, Chennai*

324 Across all groups, participants identified a range of potential causes of dementia;
325 attributing dementia to depression, stress, older people living alone, poor nutrition or
326 according to some, due to demons, spells or due to the person's Karma.

327 *"I see a lot of reasons why it happens; it is correct that one main reason is*
328 *because of stress, along with stress, in Indian culture we don't have a proper*
329 *diet in the first place" - CPF03HCp, Female, healthcare professional, Chennai,*

330

331 One of the misconceptions that emerged from some participants was that in general,
332 people thought that the disease will be passed on to the next generation through the family
333 genes.

334 *“(If) There is someone in my house with this similar issue, and a girl is getting*
335 *marriage proposal in my house, so they might think if you make the alliance*
336 *here will this person get this disease due to heredity, in future if there is a kid*
337 *the kid might have to you suffer all this” - PGp01, Female, general Public,*
338 *Delhi,*

339 As per socio-cultural norms, children are expected to care for their parents as they age. As a
340 result of such norms, some participants perceived one cause of dementia to be older people
341 living alone by themselves.

342 *“I feel because of this reason a lot of people get dementia issues other than*
343 *this another major reason is the neglecting of parents (by their children)*
344 *which leads them to depression they are not able to share the daily things*
345 *with others.” – S003, Female, Delhi*

346
347

348 People with dementia and their caregivers had some idea about existence of dementia
349 memory clinics or other care services, as they were either associated with the hospital
350 memory clinic or the dementia support services provided in these two cities. However, the
351 general public participants perceived that there is no treatment, care or support available
352 for dementia.

353 *"I don't feel that till now there is any treatment for this, or there is any place*
354 *where they provide counselling for this, or people get any information about*
355 *this."* - PM2, Male, General public group, Delhi

356
357

358 **Theme 2: Stigma**

359 Most of the time participants felt that stigma occurred as a result of poor awareness of
360 dementia in society. Participants were more comfortable discussing stigma in the third
361 person plausibly creating distance in relation to the person with dementia. Most of the
362 participants discussed that dementia is most commonly related to mental illness and this
363 contributes to stigmatisation. Participants were hesitant to say the local idioms for
364 dementia on their own, but when one initiated the conversation, the rest of the group
365 followed breaking the ice, after which participants spoke at length.

366 For instance, in Hindi language some common terms used for dementia was expressed:

367 *"(Who toh sathya gaye hai, who mandhuddhi hai, pagal hai) He has gone senile, has*
368 *gone cuckoo, mad. If there is an old man in a house who has gone senile, the whole family*
369 *faces the stigma of it, people don't want to marry off their daughters in such family' –*
370 *P03gP, Female, General public group, Delhi*

371

372 Also, from the Tamil language it was observed that common idioms were used instead of
373 the term dementia:

374 *'Dementia I don't think (any one uses the term dementia), for all the conditions they*
375 *are using the word, '(Paittiyam)' Lunatic or 'Mana noyali' mentally ill.'* –P04H,
376 *Female, Health care professional, Chennai*

377

378 It was very common for participants to refer to people with dementia in the same way that
379 they would to small children, due to the poor cognitive and functional abilities associated
380 with the condition. Even experts in dementia who attended the focus group discussions
381 referred to persons with dementia as being childlike, without realising it diminishes the
382 person. As the person with dementia experiences more cognitive challenges, they were
383 described as 'childlike' which was considered to be reflective of their lower cognitive
384 abilities, dependency on others or just acting 'foolish or difficult'.

385 *“They (persons with dementia) are almost like child, you have to take care as (they*
386 *are) a child, even a child doesn't know anything, dementia person also doesn't know*
387 *anything.” – PM1, Healthcare professional, Chennai*

388 *“(in villages people refer to persons with dementia and) decide that elderly has*
389 *started behaving childlike” - PMPt002, Healthcare professional, Delhi*

390 Participants described families' and friends' stigmatising behaviour towards the person with
391 dementia. Many families perceived dementia as mental illness and behaved in a negative
392 way towards the person with dementia. It was highlighted in most of the groups that the
393 person with dementia was generally isolated by the family, as they feared how others would
394 react to the condition.

395 *“I feel that it is the major issue, where you need to deal with the person as a normal*
396 *person, give them the same position in the family, make them sit in the gathering,*
397 *where the visitor is should I understand that this person is unwell and they should*
398 *also deal well, not that this person is mad and we should avoid them.” – PF0o1 ,*
399 *Female, general public, Delhi*

Healthcare workers who had experience dealing with families with persons with dementia reported that it is generally perceived that in rural areas there is limited awareness of dementia resulting in increased stigma and greater negative consequences like neglect and abuse. The Delhi healthcare professionals who visit rural areas as part of dementia campaigns for awareness and screenings had experienced and observed the attitudes of people towards people with dementia and shared similar experiences towards mental health conditions. A lot of people related to rural experiences from their own hometowns.

“Villagers do not know what it is, in villages they throw stones (on persons with dementia), try to shoo them off, meaning (if) that helpless person (disabled/ demented) is walking people will shoo or tease, the small kids, group of 4-5 kids, say teenagers (beat them) that is with stone or stick.” – PMPt002, Male, Healthcare professional, Delhi

Theme 3: Barriers in accessing care

Certainly, while misconceptions and poor awareness (above) were likely to act as a barrier to care, other physical barriers were also identified, including accessibility, affordability, family neglect and dependency of older people on their family for mobility.

“When it comes to cost, there is both direct cost and indirect cost. Direct cost could be less compelling to indirect cost, so if there is a person is taking care of them he has to lose his one-day job and come and bring him here and transportation cost full and everything. That becomes again a second cost factor for the person” - CPm01h, Male, Healthcare professional group, Chennai.

424
425 Irrespective of experience with dementia, participants held the general view that there is a
426 lack of specialized hospitals, especially in rural areas, which also applies to dementia care.

427 *'This care is available only in big hospitals. Small hospitals, Primary Health*
428 *Care Centres don't have this, and I think we need to make awareness in*
429 *Primary Health centres about dementia. We need to talk about this to doctors*
430 *in Health Care Centres too, they themselves don't know this. ' - Pf005N,*
431 *Female, General Public group, Chennai*

432 Even amongst healthcare professionals, there was a common impression that dementia care
433 is specialised and only experts can provide such care, which may be lacking in rural areas.

434 *"Even the doctors there [rural areas] they also don't have information*
435 *because they are only MBBS (Bachelor of Medicine and Bachelor of Surgery),*
436 *simple MBBS in rural areas, he does not know the neurology and they don't*
437 *even diagnose Alzheimer's" – PPh02, Male, Healthcare professional group,*
438 *Delhi*

439
440 It was a common perception among all the participants that there is poor or no treatment
441 available for dementia, even if a person gets a diagnosis. Generally, people did not trust
442 private healthcare services as they think it is more of a commercial venture; with them
443 trying to make money out of them. With respect to public health sector services, however,
444 people were generally not happy with the services provided (free of cost).

445 *"...another factor is that since we are government institution, we do not*
446 *charge for anything for consultation, most treatment is free, most (medical)*

447 *investigations are also free, so the commercial motives cannot be imposed*
448 *on.” - P001, Female, Healthcare Professional, Delhi*

449 Families who received the diagnosis mentioned that it was not always possible to follow the
450 recommended course of treatment as advised, due to accessibility and affordability of
451 suggested therapies.

452 *“but we were not able to apply and follow occupation therapy in full-fledged*
453 *manner, so it slowly it progressed... now 9- 10 years his family is taking care*
454 *and is managed by daughter” – MCG, Male, Caregivers group, Chennai*

455

456 **Cross-cutting themes: Societal norms, culture and religion**

457 Throughout the focus group discussions and interviews, it was apparent that societal norms,
458 culture and religion played an important role in framing conversations and thought
459 processes surrounding dementia and its care.

460 Participants highlighted cultural norms wherein older people tend to lose their family
461 position, independence and increasingly needed support and assistance from others in their
462 older age, especially after their retirement.

463 *“They are dependent on son or the daughter, they are taking care of them,*
464 *they (elderly) are not independent in our culture” - PF002, Female, General*
465 *Public, Chennai*

466 Even for minor errands like visiting banks, grocery stores or hospitals, they needed
467 assistance and could not perform simple tasks on their own. The dependency on others and
468 the migration of younger population made them feel further helpless. All the groups
469 conveyed that having older people living alone is not seen as a good practice in Indian
470 society.

471 *“another major reason is the neglecting of parents (by their children) which*
472 *leads them to depression they are not able to share the daily things with*
473 *others.” – PF003, Female, General Public group, Delhi*

474 It was observed that caring for older people is traditionally viewed as a family responsibility
475 in the Indian context.

476

477 Most of the participants seem to have the belief that dementia is caused because of one's
478 bad Karma, yet they avoided speaking about this in the group. It was observed that they
479 were afraid that others would judge them for their beliefs.

480

481 *“See that Karma theory is a different thing”- PM1, Male, General Public,*
482 *Delhi.*

483

484 *“(Yes, Karma is a cause of dementia) Its some stigma, as they have aged they*
485 *have gone mad. People say like this generally.”- PF3, General Public, Delhi.*

486

487 *“They also say (‘Upar ka prakop ho gaya’) it is a doing of Ghost or demons.”-*
488 *PMCG003, Male, General Public group, Delhi*

489

490 The role of faith and spirituality also formed beliefs about prognosis. In one circumstance a
491 participant with dementia believed that she would be cured if it was God's will.

492

493 *“Yes, I do think, at the mercy of the one above (God) and I will be cured” -*
494 *PF01SH, Female, Person with dementia, Chennai.*

495

496 However, it was observed that participants were hesitant to talk about their beliefs openly
497 such as dementia is caused by Karma or magic. When prompted, they shared that others
498 had such beliefs.

499 *"So people call these kinds of patients with a lot of names like he has gone*
500 *mad, there is no proper diagnosis, everyone is calling the patient mad or is*
501 *under the cast of Ghost, or someone has cast a magic spell."* - PMPt002,
502 *Male, Healthcare professional, Delhi*

503 Social isolation of persons with dementia and their family caregivers were reported. The
504 family avoided taking the person with dementia to social gatherings. This is because as the
505 disease progresses, dependency on the caregiver increases and they eventually drop out
506 from attending social functions and gatherings. In addition, when caregivers were not able
507 to get the person with dementia outside the house for a social gathering and did not have
508 anyone else to look after them at home, they also dropped out from socialising.

509 *"A person who was very involved (earlier) in meetings and family functions*
510 *gets isolated, if you take this person to marriage what if the person starts*
511 *misbehaving? I also feel impression that is made (by others) in my family is*
512 *behaving like a mad person."* PF1, Female, General Public, Delhi

513

514 *"Though it is tough we don't have a choice. Don't take him to family*
515 *functions. all people come and ask why it has happened. we should take them*
516 *somewhere different, mixed along with public like beach."* PM05, Male,
517 *Caregiver, Chennai*

518

Discussion

The principal aim of this study was to understand the perceptions, attitudes and beliefs of dementia in India from two diverse metropolitan cities, Delhi and Chennai. The study explored dementia-related insights and experiences in relation to people living with dementia among four stakeholder groups: the general public, healthcare providers, people living with dementia and carers. Explicitly, this study investigated existing knowledge, attitudes and behaviours towards people with dementia and carers; experiences of stigma and discrimination; local culture-specific idioms of stigma and discrimination, current practices to promote social inclusion and preferences about how to reduce stigma among the population.

Across all key stakeholder groups, there appeared to be a gap in knowledge surrounding dementia. Healthcare professionals shared that they did not have sufficient understanding of dementia, but this was due to not being taught about it in the medical curriculum, whilst also believing that they did not come across such patients on a regular basis. This supports previous quantitative research from India, in which gaps in knowledge were present amongst a group of doctors and nurses (Biswas et al., 2017) and nursing staff within nursing homes (Strøm et al., 2019), albeit to varying degrees. Caregivers supported the view that doctors had insufficient knowledge and training of dementia, as exemplified by an experience of a doctor denying diagnosis even in the presence of a brain scan. Raising awareness is seen as one of the key pathway to tackle stigma (Mukadam & Livingston, 2012), and as such, it is unsurprising that raising awareness of dementia is recommended in India (Dias & Patel, 2009; Emmatty et al., 2016).

542 There seems to be no standard word for dementia in the regional languages, and the focus
543 group discussions highlighted multiple words used in different languages for dementia, out
544 of which some words highlighted a stigmatising approach of addressing the person with
545 dementia or the disease. In Tamil '**Nyabaga maradhi**' which means memory loss; '**Paittiyam**'
546 meaning lunatic, '**Mana noyali**' meaning mentally affected similarly in Hindi language
547 '**Sathyajana**' which means going cuckoo or senile or growing old '**pagalpan**' which means
548 madness, insanity, lunacy; '**bhulakad**' which means forgetfulness, '**Bawla**' meaning
549 dementia, mad, pippy; '**Man Buddi**' meaning half-witted. Due to the lack of terminology for
550 dementia in other languages outside of English, dementia is perceived as a Western disease.
551 All the stakeholder groups who participated in the focus group interview commonly referred
552 to people with dementia as childlike, including the healthcare professionals. Concurrently,
553 healthcare professionals reported that family members would accompany their relatives
554 and complain that they were behaving in a childlike manner. In Indian societies, it seems to
555 be a common saying in general that (Hindi) '**Buda aur bacha ek saman hota hai – PF3,**
556 General public, Delhi', which means an older person and the child are the same. Language
557 is a crucial instrument (Cayton, 2006) at the same time language can be pernicious (Parker,
558 2001). Language reflects one's opinions and sentiments, at the same time in their own way
559 languages can show respect or disrespect. The various words used in different languages not
560 only have strong influence on how others perceive dementia and how others behave
561 towards people with dementia, also it impacts how the person with dementia views self and
562 relate to others, which contributes to negative emotions towards self. The way dementia is
563 addressed has the potential to promote, empower, enable a person's ability to self-help,
564 develop self-esteem or it can demean, disrespect, devalue and offend. It is reported that
565 there is a need to have better language and terminology to address dementia, which is

idiom-free, non-elitist, uncomplicated and non-judgmental. This will highlight on the person and not the language trends, social care system or the disease (Swaffer, 2014). The Japanese government is one such country that has changed the terminology used for dementia, to avoid negative connotations associated with the existing word (*'Chiho'*) (Takeda et al., 2010).

Dementia, as reported by the participants, was associated with many different beliefs depending on an individual's educational background, religious beliefs, societal and traditional norms. It was observed in the focus group discussion's that dementia is one's destiny, Gods will, Karma or evil doings. Caregivers reflected that dementia is a natural course of life and one's destiny that cannot be altered. Whilst culturally distinct, we can observe some parallels with findings in Pakistan. Religion appears to be central in shaping attitudes amongst the general public (Farina et al., 2019), and family members perceived duty of care (Balouch et al., 2020). Whilst the heterogeneous religious population within India makes the importance of religion less clear, it is evident that filial piety still features heavily in the culture. The introduction of the Maintenance and Welfare of Parents and Senior Citizens Act of 2007, in which there is a statutory duty for adult children to support their parents who are unable to provide for themselves (Serrano et al., 2017), could be a symptom (and cause) of such attitudes of care provision of people with dementia. The Maintenance and Welfare of Parents and Senior Citizens Act was not explicitly asked in the focus group discussion, which limits these conclusions whereas this aspect can be explored in further studies. When combined with a perceived lack of adequate infrastructure and skilled workforce, it is likely that these barriers bolster attitudes of "keeping it in family" and reluctance to place family members into long-term care facilities (Brijnath, 2012; Sharma &

590 Marwah, 2017). Furthermore, awareness about institutional care, and subsequently, the
591 demand for services like care homes or dementia assistive livings are much lower. Studies
592 reported that older people prefer to live in their own home with family even if they lack
593 emotional support or are subjected to verbal or physical abuse, neglect, and disrespect from
594 their children (Kumar et al., 2012) (Khurana, 2013). With the influence of multiple religions,
595 cultures and traditions, the Indian society values family as the most important institution
596 and like most of the eastern societies, is a collectivist society which emphasises on family
597 integrity, loyalty and unity.

598 A key limitation of this study is that it is derived from a modest sample of key stakeholders
599 in Delhi and Chennai. As such, it is important to not assume this is a representative sample
600 of general public, healthcare professionals, caregivers or people with dementia. As
601 dementia diagnosis rates are low and tend to happen late in India, this acted as a barrier to
602 recruiting people with dementia that were cognitively able to engage with this research. In
603 addition, those that did enrol in the research were likely to have some interest in the topic,
604 therefore the views presented here might reflect those who in fact are more aware of
605 dementia. Similarly, we should recognise that other regions of India, most notably more
606 rural areas, are likely to have different attitudes of dementia, not least because of different
607 education levels, service availability and cultural norms. Whilst lessons can be learnt from
608 this study and applied to Indian communities living abroad, it should be done so cautiously
609 due to structural and societal differences. The findings may, however, be more pertinent to
610 first generation immigrants. Another key limitation of the study was that healthcare workers
611 were identified from the hospitals associated with the respective chapters. In Chennai the
612 healthcare professionals were a multi-disciplinary group, including nutritionist, pharmacists,
613 researcher, physiotherapist but with no experience of working with dementia. In Delhi they

were from different backgrounds like paid carer, physiotherapist, researcher but has had experience working with dementia. Due to the limitation of study design and resources it was more purposive and limited data collection.

Conclusions:

The study provides further evidence of a lack of awareness and potentially stigmatising attitudes towards dementia in India. The study builds upon past literature by incorporating perspectives of different stakeholders who will interact with dementia within different capacities. In addition, recruitment of these stakeholders from different settings and languages, provides different perspectives from this multi-cultural country. It highlights the societal and cultural influence on dementia related stigma, which contributes towards delay in accessing care. The study demonstrates the need for proper recognised terminology in various Indian languages, which may help to reduce stigma towards dementia. However, it is important to note that the use of stigmatising language is also reflective of culturally embedded aspects, which cannot be resolved with only simple changes in terminology. With the given demographics of dementia in India, it is essential to address these issues with anti-stigma campaigns at higher levels like in dementia national policy and/or strategy, which can help to educate and reach out to larger populations across different regions of India.

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