

1 **Title: Pathways to care for people with dementia in India: an exploratory study using case**
2 **vignettes**

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51

52 **Abstract**

53

54 **Background:** Limited evidence exists on how people living with dementia and their
55 family/unpaid carers navigate care and support in India.

56

57 **Aim:** This study used case vignettes to illustrate likely pathways to care for dementia, from
58 receiving a diagnosis to long-term support, in India and to highlight gaps and challenges
59 associated with current care provision for persons living with dementia.

60

61 **Methods:** As part of the Strengthening Responses to Dementia in Developing Countries
62 (STRiDE) project, and to contribute to an analysis of dementia care policies and systems in
63 India, case vignettes were used to illustrate the diverse situations that people with dementia
64 and their families may experience when seeking care in the Indian context. Eight hypothetical,
65 but realistic cases of people with dementia were created by a multi-disciplinary team with
66 experience in dementia care in India, to map out the likely care journeys of each case.

67

68 **Results:** Investigating eight diverse care trajectories of people living with dementia
69 highlighted important patterns relevant to the Indian context. We identified delays in
70 dementia diagnosis to be attributed to low awareness of dementia among the general public
71 and medical professionals in addition to a critical shortage of specialist services involved in
72 facilitating dementia diagnosis. Post-diagnosis, support was recognized as limited and
73 associated with considerable out-of-pocket (OOP) costs. Families primarily provide long-term
74 care for people with dementia till end of life.

75

76 **Conclusions and Recommendations:** Several steps need to be taken in order to improve
77 dementia care in India. Increasing dementia awareness among both medical professionals
78 and general public is essential. Shortages in dementia specialists can be addressed in part
79 through appropriate task shifting. Lastly, more research is needed to develop evidence-based

80 community interventions to support informal care provision for persons with dementia in
81 India.

82

83 **Keywords:** dementia, caregiving, case vignettes, health system, long-term care, India

84

85 **1. Introduction**

86

87 Globally, the numbers of persons living with dementia is projected to increase from 58 million
88 in 2020 to 152 million in 2050 (Alzheimer’s Disease International [ADI], 2017). Much of this
89 increase is expected to occur in low-and middle-income countries (LMIC) (ADI, 2017). In India,
90 approximately 3.8 million people were estimated to be living with dementia in 2019. (Nichols
91 et al., 2022). However, despite this relatively high burden, only 1 in 10 persons with dementia
92 receive any diagnosis, treatment or care in the country (Dias and Patel, 2009; Nulkar et al.,
93 2019). This considerable treatment gap can be attributed to low awareness of the condition,
94 poor accessibility to health care services, shortage of specialists to diagnose and manage
95 dementia, out-of-pocket [OOP] costs associated with care seeking, the absence of both a
96 strong referral system (Alladi and Rajagopalan, 2021) and a formal long term care system,
97 which are vital to the effective management of dementia.

98

99 The Indian healthcare system is complex , comprising a mixture of public, private and informal
100 providers that vary substantially across areas of the country (Chokshi et al., 2016; Gautham
101 et al., 2014). Partly as a result of this heterogeneity in service availability, health seeking
102 behaviors are also considerably diverse. In comparison to rural areas, urban areas have a large
103 concentration of private care providers (Chokshi et al., 2016), which allows for more choice
104 with respect to care services. Decisions regarding utilization of type of healthcare services are
105 influenced considerably by socioeconomic factors (Chatterjee et al., 2018). OOP expenditures
106 are a major contributor to total health expenditure in India (National Health Systems
107 Resource Centre [NHSRC], 2018b, 2021). However, the government is working towards
108 providing greater social protection for the socioeconomically disadvantaged in addition to
109 improved accessibility to essential services (e.g., maternal health, child health, elderly
110 services etc.) through the Ayushman Bharat [AB] programme (Ayushman Bharat-Pradhan
111 Mantri Jan Arogya Yojana (AB-PMJAY) and Ayushman Bharat- Health and Wellness Centres

112 (AB-HWCs) (National Health Authority [NHA], 2022; NHSRC, 2018a). While these are positive
113 steps, formal long-term care support services for dementia continue to remain minimal or
114 absent. A few day-care centres and residential care facilities exist only in metropolitan cities
115 and are associated with significant OOP costs (Alzheimer’s and Related Disorders Society of
116 India [ARDSI], 2010). As a result, care provided by families in their own homes remains the
117 cornerstone of dementia care in India.

118

119 The study reported here was conducted as part of the wider Strengthening Responses to
120 Dementia in Developing Countries (STRiDE) international project led by the London School of
121 Economics and Political Science. STRiDE has been conducted across seven middle-income
122 countries (India, Brazil, Kenya, Indonesia, South Africa, Jamaica, and Mexico) with the aim of
123 building research capacity and bridging gaps in evidence with respect to dementia. In the first
124 phase of the project, we drafted an in-depth desk review of the dementia care landscape in
125 India (which is now published on the STRiDE website (Alladi et al., 2022)), which provided us
126 with an understanding of the diversity in support for people with dementia and their families
127 in the Indian context. Informed by this desk review, we attempted to take a systems wide
128 approach by compiling relevant aspects of the Indian system for dementia. We utilized
129 professional experiences of the multi-disciplinary team to highlight the complexity and
130 differences in care experiences of people with dementia and their families in India.

131

132 Very few studies have examined pathways to care for people with dementia (Hossien et al.,
133 2017) in India and none (to our knowledge) has specifically examined pathways to care from
134 receiving a diagnosis to long-term support. This paper aims to fill this gap. It contributes to
135 generating evidence on how people with dementia and families currently navigate care and
136 support services, understanding what factors shape care access and use, and investigating the
137 current treatment gap for dementia by highlighting existing challenges that need to be
138 addressed.

139

140 The paper uses a case vignette approach that gathers inputs from a multi-disciplinary group
141 of professionals with expertise in dementia and is informed by knowledge gathered through
142 the in-depth review of available evidence on the dementia care landscape in India (Alladi et
143 al., 2022).

144

145 **2. Methods**

146

147 We used a case vignette approach to illustrate pathways to care for people with dementia.

148 Case vignettes are short stories based on hypothetical persons or scenarios, often used to

149 support data collection in qualitative research (Mah et al., 2014; Gourlay et al., 2014; Lorenz-

150 Dant et al., 2021). In vignette-based studies, participants are asked to draw upon their own

151 experience to predict how the characters will behave or feel, or how the scenario will evolve

152 (Mah et al., 2014; Gourlay et al., 2014). As a result, vignettes represent a structured tool to

153 elicit participant's reasoning and to gather participant's experiential evidence and tacit

154 knowledge, which can then be utilized to complement formal evidence (Mah et al., 2014;

155 Gourlay et al., 2014). This approach has been used to determine pathways to care for people

156 with dementia (Bieber et al., 2017) and found to be particularly effective in facilitating

157 comparisons in care systems across countries (Bieber et al., 2015; Muir et al., 2017).

158

159 Prior to developing the India specific case vignettes, a comprehensive desk review of the

160 dementia care landscape (Alladi et al., 2022) was drafted involving answering series of

161 questions related to the health system, long-term care system, dementia policy context, social

162 protection schemes and diversity in services or support available for people with dementia

163 and their families in India. This in-depth desk review and expert inputs gathered from a

164 multidisciplinary group of professionals that comprised the STRiDE India team (i.e., a

165 neurologist, psychologist, psychiatric social worker, leads of an NGO focusing on supporting

166 people with dementia and their caregivers and a health and long-term care policy researcher)

167 contributed to the development of the case vignettes. It is important to highlight that as part

168 of the wider STRiDE project primary research interviews with various stakeholders on topic

169 areas such as stigma and awareness of dementia had also been conducted (Hurzuk et al.,

170 2022) and this further informed expert input in the vignette development. The case vignettes

171 were validated by six members of the project's national advisory group and analysed using an

172 approach that builds on framework analysis (Gale et al., 2013) to develop scenarios that 1)

173 identify how people living with dementia and their caregivers navigate care and support by

174 accounting for the diverse and heterogeneous factors that influence care; 2) highlight gaps

175 and challenges associated with existing models of dementia care services in the country; 3)
176 provide recommendations to overcome challenges identified.

177

178 Ethical approval was not required as only the research team was involved in this study. The
179 overall project received ethical clearance from the institutes involved in the study.

180

181 **2.1 Approach**

182

183 As part of the STRiDE project, base case vignette scenarios were developed collaboratively by
184 researchers and NGO partners from the seven STRiDE country teams and facilitated by the UK
185 based LSE team during a workshop in March 2019. As part of the workshop, the STRiDE team
186 worked in small groups and identified and ranked a set of variables likely affecting care and
187 support people with dementia and their caregivers receive (Lorenz-Dant et al., 2021).
188 Focusing on these variables, five core scenarios were developed, that briefly introduce people
189 with dementia and their families across different socio-economic groups and living
190 environments (Lorenz-Dant et al., 2021). Each STRiDE country team then provided feedback
191 as to whether these scenarios were applicable in their country and suggestions about how
192 the vignettes could be improved (Lorenz-Dant et al., 2021). The base vignettes were finalised
193 once no further feedback was received. A detailed description of the different steps involved
194 in completing and validating the base vignettes can be found in the STRiDE vignette guidance
195 document (Lorenz-Dant et al., 2021).

196

197 **2.2 Development of India specific vignettes**

198

199 The five base case vignettes were initially reviewed by the STRiDE India country team. The
200 majority of the team had been working in service provision for people with dementia and
201 their families for over 10+ years in India. Based on individual expertise of the team and the
202 STRiDE India desk review of the dementia care landscape (Alladi et al., 2022) the country team
203 identified gaps in these five vignettes that were pertinent to the Indian context. Group
204 consensus on modifications and addition of new vignettes were achieved over multiple
205 meetings through which team members shared their insights and comments until a collective
206 decision was reached. Taking into consideration the heterogenous situations that people with

207 dementia and their families find themselves in India, the country team modified one base
208 case vignette and further developed three additional case vignette scenarios. One base case
209 vignette was revised to include a case of vascular dementia, as stroke has been identified to
210 be a leading cause of non-communicable neurological disease burden in India (Singh et al,
211 2021) and a major cause of dementia in LMICs including India (Kalara et al., 2008; Shaji et al.,
212 2018). Three additional vignettes were subsequently developed to capture specific features
213 of the Indian context. Firstly, approximately 90% of families receive no diagnosis, treatment
214 or care (Dias and Patel, 2009) and a case vignette representing undiagnosed dementia was
215 included. Secondly, the proportion of young-onset dementia has been found to be higher in
216 India than in developed countries, which may be due to the younger age of the Indian
217 population (Das et al., 2012). Young onset dementia is accompanied with significant economic
218 burden and is often associated with delays in diagnosis or even misdiagnosis (Mukku et al.,
219 2019). To reflect this, a case vignette on young-onset dementia was developed. Lastly, there
220 was a need for the vignettes to highlight health insurance in the Indian context. About 41% of
221 households have “any usual member” covered by a health insurance scheme (primarily
222 hospitalization related) (Ministry of Health and Family Welfare (MoHFW), 2021, pp.3). We
223 however attempted to reflect the substantially smaller proportion of households covered by
224 health insurance schemes that cover some outpatient expenses, a case vignette representing
225 a government health insurance scheme was included and a private health insurance scheme
226 was added to the young onset dementia vignette. Therefore, a total of eight case vignettes
227 were created to represent the dementia care context in India.

228

229 For each vignette, the team then articulated how the socio-demographic characteristics and
230 personal and family circumstances of each character were likely to shape aspects such as
231 health-seeking behaviors, time to diagnosis, stigma experienced, and costs associated with
232 care. These aspects were identified in the STRiDE guidance document (Lorenz-Dant et al.,
233 2021) and also by expert inputs from country team. Comments shared by the team members
234 about individual case vignette scenarios were consolidated and subsequent discussions
235 involved listing of ideas and seeking clarifications on how each vignette scenario would evolve
236 until consensus was achieved. Hypothetical names were added to the vignettes to make them
237 more personable; they do not refer to any existing people with dementia or caregivers. These
238 vignettes are published and freely available for viewing on the STRiDE website (STRiDE India,

239 2022). After exploring the individual care pathways via the case vignette approach, we then
240 used a framework approach to identify patterns as well as differences

241

242 **2.3 Validation of vignettes**

243

244 Our study is reflective of the professional experiences and expertise of team members. We
245 attempted to ensure that we are not portraying just our professional views by having our
246 vignettes critically reviewed by experts from the STRiDE India National Advisory Group (INAG).
247 The INAG was formulated at the beginning of the STRiDE project and comprises of 21
248 members whose role was developed to hold the research team accountable for the activities
249 of the project and included professionals with diverse experience in health and/or long-term
250 care in India in addition to members of the general public such as former carers. The INAG
251 was invited via email to validate the vignettes considering whether the vignettes represented
252 the diverse situations that people with dementia and their families find themselves in and
253 accurately described health seeking behaviors and care trajectories. They were also asked to
254 suggest any other scenarios for inclusion. Six INAG members (including healthcare
255 professionals, non-governmental organization representatives, a former caregiver, and a
256 health economist) provided feedback on the vignettes via email. This was consolidated and
257 discussed by the core team.

258

259 **2.4 Analysis of vignettes**

260

261 An approach based on the framework method (Gale et al., 2013) was used for to look across
262 the individual vignette scenarios for common elements, differences, and barriers to dementia
263 care services across the country. Utilizing a framework template provided by STRiDE (Lorenz-
264 Dant et al., 2021), the country team charted data manually for each vignette on the Excel
265 spreadsheet based on questions prevalent in the guidance document for each of the columns
266 (main carers, support available to carers/people with dementia, where would a family go for
267 memory concerns/behavioral symptoms, ongoing health and medical support.) (Lorenz-Dant
268 et al., 2021). The India team also added a section on pre-diagnosis and awareness to a column
269 as this was an important topic in the Indian context. Subsequently, we charted data on gaps
270 and challenges to be overcome for each vignette scenario by reflecting on the data captured

271 for each of the previously highlighted questions. Using these pre-determined categories, the
272 country team grouped them together to form three major topic areas. Pre-diagnosis and
273 awareness were grouped together to form **topic 1: pre-diagnosis**; where a family would go
274 for memory concerns/behavioral disturbances formed **topic 2: diagnosis**; and support
275 available to carers/people with dementia were grouped to form **topic 3: post-diagnostic**
276 **support and long-term care**. Gaps and challenges to access care were reflected upon and
277 included in each of the three topic areas above.

278

279

280 **3. Results**

281 **Table 1** provides a brief overview of key characteristics from each of the 8 vignette scenarios
282 developed. We set out to explicitly explore the diverse situations that people with dementia
283 and their families find themselves in India and highlight patterns we identified. The vignettes
284 characterize the potential pathways to care for people with dementia that reside in rural,
285 semi-urban or urban areas, from different socioeconomic groups and relying on different
286 levels of support from the family. Across all the scenarios, socioeconomic and demographic
287 related factors typically play a critical role in influencing utilization and access to services.
288 Other factors [cultural and/or societal beliefs; knowledge of dementia; severity of dementia;
289 age of dementia onset; availability of resources; social protection; living arrangements;
290 support and relationship with family members] were also illustrated as determining help-
291 seeking behaviors and care services sought by people with dementia. Utilizing key topic areas,
292 we highlight how such factors shape specific phases of the dementia care journey.

293 *[Insert Table 1 here]*

294 **3.1. Pre-diagnosis**

295 Irrespective of socioeconomic status or geographical area (rural versus urban), awareness of
296 dementia was typically low among the general public and medical professionals. People with
297 dementia and their families do not recognize symptoms of dementia, associating signs such
298 as memory disturbances to be a result of old age. It is only when significant behavioral
299 symptoms emerge that families may seek professional help. When behavioral symptoms

300 occur families isolate themselves or the person with dementia from the community; often
301 arising due to misunderstandings or incorrect beliefs regarding cause (e.g., Mrs Hari vignette
302 [STRiDE India, 2022]). Such beliefs have been demonstrated in the vignettes to influence type
303 of support sought, if any (e.g., Mrs Hari vignette [STRiDE India, 2022]). However, even if
304 support is sought from non-specialist medical professionals such as general physicians (GPs),
305 they have been described in the vignettes to have limited understanding or awareness of
306 dementia often attributing symptoms to natural signs of ageing in older people (e.g., Mrs
307 Bhatt vignette [STRiDE India, 2022]) or stress in younger persons displaying early symptoms
308 of young-onset dementia (e.g., Mr Gautam vignette scenario [STRiDE India, 2022]). The phase
309 before reaching a diagnosis is highlighted as turbulent in several of the vignettes suggesting
310 that receiving a diagnosis is an issue that people with a range of characteristics share.

311 **3.2. Diagnosis**

312 The diagnosis seeking phase is likely to vary substantially based on availability of services
313 within a given area and individual socioeconomic status. Accessing a specialist is often key in
314 receiving a diagnosis for dementia across the case vignettes. In rural areas, families from a
315 lower-socioeconomic group have been shown to have heterogenous pathways to care (e.g.,
316 Mrs Anand vignette, Mrs Hari vignette [STRiDE India, 2022]). People with dementia or their
317 families may seek a traditional medical practitioner, or directly communicate concerns to a
318 community health worker who may direct them to a primary health centre (PHC), or the
319 family may not seek any formal care services at all. Even if a person with dementia or their
320 family sought a GP at a PHC, it was established in the vignettes that the GP would be unlikely
321 to recognize symptoms of dementia; possibly recommending a visit to a specialist in the city.
322 In both rural and semi-urban areas (e.g. Mrs Anand vignette, Mrs Bhatt vignette, Mr D'Souza
323 vignette [STRiDE India, 2022]), families are likely to have to travel significant distances to seek
324 a specialist, as such services are concentrated in urban areas. As a result, the person with
325 dementia or their family may or may not choose to seek a specialist due to direct [e.g.,
326 travelling costs] and indirect costs [e.g., opportunity costs due to travel] incurred. Whereas,
327 in urban areas, people with dementia and/or their families typically directly seek a specialist
328 (e.g., Mrs Chatterjee vignette, Mr Ebrahim vignette [STRiDE India, 2022]).

329 The type of specialist sought (psychiatrist or a neurologist) is likely to be influenced by certain
330 beliefs, for example, societal stigma associated with the term ‘psychiatrist’ has been
331 illustrated as a possible deterrent to initial help-seeking (e.g. Mrs Chatterjee vignette [STRiDE
332 India, 2022]). In addition, time to receive a diagnosis and associated costs was further
333 determined to be dependent on whether the specialist is sought in a public or private
334 healthcare service setting. In public hospital settings, the vignettes highlight that OOP costs
335 associated with tests and consultations are subsidized (based on socioeconomic status
336 assessment), however the waiting times are recognized to be long (e.g., Mrs Chatterjee
337 vignette, Mr D’Souza vignette [STRiDE India, 2022]). In contrast, vignettes illustrate private
338 health services to have shorter waiting times, but more considerable OOP costs (e.g., Mr
339 Ebrahim vignette, Mr D’Souza vignette [STRiDE India, 2022]). In a very small proportion of the
340 population, the costs of seeking medical care may fully or partially be covered by a public
341 (e.g., scheme for government/retired employees) or private (very few schemes have recently
342 began offering some coverage for outpatient expenses at an additional premium [Gambhir et
343 al., 2019]) health insurance scheme (e.g., Mr Fawaz vignette, Mr Gautam vignette; [STRiDE
344 India, 2022]).

345 **3.3. Post-diagnostic support services and long-term care**

346 After receiving a diagnosis from a specialist, the vignettes highlight the absence of a system
347 to provide coordinated care and support services for people with dementia or their families.
348 Day care centres, residential care centres, paid attender agencies (often employing staff who
349 are not familiar with dementia) and psychosocial support services for caregiving are discerned
350 to be few in the entire country; primarily concentrated in metropolitan cities (e.g. Mrs
351 Chatterjee vignette, Mr Gautam vignette [STRiDE India, 2022]). These services were depicted
352 to be associated with substantial OOP costs thereby more affordable to those from a higher
353 socioeconomic group. Although even among higher socioeconomic groups, stigma associated
354 with the utilization of institutional services such as residential care may possibly influence
355 service uptake or sustained use.

356 Notably, while the vignettes indicate that domestic helpers may aid in caregiving among more
357 middle and higher socioeconomic groups (e.g. Mrs Chatterjee vignette [STRiDE India, 2022]),
358 their role was highlighted as particularly relevant in situations where there is no family

359 support available (e.g. Mr Ebrahim vignette [STRiDE India, 2022]). Overall, within families the
360 vignettes have emphasized that it is the women who primarily provide care with respect to
361 instrumental activities of daily living for people with dementia with limited or no psychosocial
362 support and while managing multiple households and/or professional responsibilities in
363 addition to their caregiving responsibilities (e.g. Mrs Anand vignette, Mrs Bhatt vignette
364 [STRiDE India, 2022]). As a result, they have been shown to experience emotional distress and
365 negative consequences for their physical health (e.g. Mrs Chatterjee vignette [STRiDE India,
366 2022]). Certain exceptions (e.g. Mr Gautam vignette [STRiDE India, 2022]) have also been
367 highlighted in the vignettes with respect to access to post-diagnostic support, such as paid
368 attenders/residential care centres, among high socioeconomic groups residing in
369 metropolitan areas.

370 **4. Discussion**

371 To our knowledge this is the first attempt to comprehensively illustrate the care pathways of
372 people living with dementia in India using input from a multi-disciplinary group of experts
373 using a case vignette approach. We organized the care pathways in three topic areas (pre-
374 diagnosis, diagnosis, post-diagnostic support and long-term care) and identified the
375 challenges across each phase. Low awareness of dementia among the general public and
376 medical professionals is depicted to contribute to delays in dementia diagnosis across case
377 vignette scenarios. Specialists are highlighted to be key to providing a dementia diagnosis,
378 but large urban-rural disparities in distribution of specialist services were recognized. After
379 receiving a diagnosis, post-diagnostic support is emphasized to be limited, and it is the
380 families that are described to primarily provide long-term care until the persons with
381 dementia die. Overall, these findings highlight challenges that lie within the current provision
382 of dementia care services in India. A summary of the challenges identified are provided in
383 **Table 2.**

384 *[Insert Table 2 here]*

385 Prior to dementia diagnosis, awareness of dementia among the general population and
386 medical professionals are illustrated as a crucial factor influencing whether, when and how a
387 family receives a formal diagnosis, if at all. Awareness of dementia as a medical condition is

388 low in the Indian context. Studies have found that memory problems are often thought of as
389 part of natural ageing and that the behavioral symptoms associated with the condition are
390 stigmatized, perceived in certain communities to be deliberate (Shaji et al., 2003). However,
391 this lack of awareness is not limited to general public. A study conducted in a medical college
392 in the state of Gujarat reported that only 49% of undergraduate medical students were aware
393 of dementia symptoms (Patel et al., 2021). This is more concerning as the mean age at
394 presentation of dementia is also lower in the Indian context (Das et al., 2012) and young-
395 onset dementia in particular is more likely to be associated with delays in diagnosis (Mukku
396 et al., 2019) as also demonstrated in one vignette scenario (e.g. Mr Gautam vignette (STRiDE
397 India, 2022)). Therefore, poor awareness among GPs further contributes to diagnostic delays
398 as highlighted in several case vignettes; this can be attributed to the significant lack of
399 emphasis of dementia in the undergraduate medical curriculum (Patel et al., 2021).

400 Outside of seeking a GP, in the diagnosis phase people with dementia and their families may
401 access several other services as well. Differing beliefs and variability in availability of services
402 are likely to influence care services sought; studies have found utilization of services from
403 non-registered practitioner (Narapureddy et al., 2012), unlicensed medical practitioners
404 (Qadri et al., 2013) to be prevalent among elderly residing in rural India. Seeking such services
405 can contribute to further diagnostic delays. It is important to recognize that India has a strong
406 traditional system of medicine (e.g., Mrs Anand's vignette illustrates how traditional medical
407 practitioners may be commonly approached in rural areas) and efforts have been made by
408 the government through the Ministry of AYUSH (Ayurveda, Yoga and Naturopathy, Unani,
409 Siddha and Homeopathy) to support and promote traditional medicine systems (Sen and
410 Chakraborty, 2016). There are opportunities to integrate traditional medical practitioners into
411 models of dementia care service delivery possibly through collaboration with trained general
412 practitioners or dementia specialized professionals.

413 Currently, diagnosis of dementia is primarily provided by specialists (neurologists or
414 psychiatrists [Alladi and Rajagopalan, 2021]). This is problematic because the number of
415 neurologists and psychiatrists available in the country to meet population needs is grossly
416 inadequate (Singh, Khadilkar and Jayalakshmi, 2020; Garg et al., 2019); with a particularly high
417 shortage experienced in rural areas where about 70% of the population resides

418 (Chandramouli, 2011). This was also highlighted in the case vignettes, which further
419 emphasized the challenges experienced by persons living in rural or semi-urban areas, who
420 have limited access to specialists and have to travel significant distances to seek care often
421 incurring multiple direct and indirect costs (Rao and Bharat,2013).

422 Household OOP expenditure was identified as the main way to access services during the
423 diagnosis phase and for ongoing post-diagnostic support. OOP expenditure by households has
424 been identified as a major contributor towards total health expenditure in India (NHSRC,
425 2018b; 2021). As a result, socioeconomic status plays a crucial role in determining access to
426 care in the Indian context. Studies have demonstrated that persons from higher income
427 groups are more likely to choose private hospitals associated with more costly care
428 (Chatterjee et al.,2018) compared to persons below poverty line who are likely to choose
429 government services (Bhojani et al., 2013). However, this varies, and public health
430 infrastructure of individual states greatly influences choices in care services (Chatterjee et al.,
431 2018). Coverage by a health insurance scheme in association with other factors (e.g., caste,
432 distance from facility, number of empaneled hospitals in an area (Prinja et al., 2017)) also
433 influences healthcare utilization. The vignettes depict a very small proportion of the
434 population (e.g., government employees under scheme that cover outpatient expenses, high
435 income groups that can afford or are aware of the very few private insurance schemes with
436 additional outpatient coverage) covered by health insurance schemes with some outpatient
437 coverage, but importantly highlight that predominantly these schemes do not provide
438 coverage for long-term care services such as day care, residential care and paid attender
439 services for dementia.

440 Long term care irrespective of a diagnosis is primarily provided by families in their own homes
441 with limited psychosocial support as emphasized by the vignettes. A gender disparity with
442 respect to this family-based care provision however exists, with women predominantly
443 providing care, as highlighted in the vignettes. This has been consistently reported by studies
444 on unpaid care for elderly in India, with women experiencing worsening mental health as a
445 result of their caring role (Brinda et al., 2014; Prince et al., 2012). While families have had to
446 take on this caregiving role with limited support as a result of societal norms (Gupta, 2009)
447 and the absence of a system or services to provide continuity in care (Dias and Patel, 2009),

448 there are a few long-term care services that are available in the country to select groups
449 (ARDSI, 2010). These services are predominantly in large metropolitan cities and associated
450 with high OOP costs that make such services inaccessible to the majority of the population
451 (Dias and Patel, 2009) (ARDSI, 2010). In addition, there is inadequate regulation or monitoring
452 of services such as paid attender agencies, residential care centres (Harbishettar et al., 2021)
453 or day care centres, so the quality and costs of these care services are highly variable
454 (ARDSI,2010). However, well-developed states such as Kerala have a larger number of old age
455 homes as well as a palliative care facilities to support those with terminal illnesses, the latter,
456 however, primarily for persons with cancer (Kumar, 2007).

457 The strengths of this study are that we relied on the considerable direct professional
458 experiences of the research team. The majority of the team members were providing actual
459 care services to people with dementia and their caregivers in India. Our methodological
460 approach can further be considered as an innovative way to illustrate pathways to care for
461 people living with dementia in the Indian context and doing so in a cost-effective way. The
462 developed vignettes help to provide information about the support available to people with
463 dementia and their families in the light of limited published evidence in this area. In addition,
464 we also ensured that our results were checked for face validity with key stakeholders in the
465 field of dementia in the country.

466 While this work provides an important first step towards a more systematic illustration of
467 dementia care pathways in India, we nevertheless acknowledge several limitations . The case
468 vignette approach while useful in describing a general overview of pathways to care for
469 people with dementia in India, could not account for the substantial state-wide differences
470 that are likely to influence these care pathways. Also, we are aware that the vignettes may be
471 shaped by the experiences of the team. We aimed to mitigate this risk of providing a biased
472 or partial account of dementia care in India by working as an interprofessional and multi-
473 disciplinary team, constantly discussing and challenging the results of our own work among
474 us. We also sought feedback from stakeholders as well as anchored the vignettes in the
475 existing literature about dementia in India. In addition, we acknowledge that people living
476 with dementia and their caregivers did not contribute to the development of the vignettes.
477 While the professional inputs of majority of team members are informed from their day-to-

478 day work with people with dementia and/or their families as well as other aspects of the
479 STRiDE project including some empirical work (Hurzuk et al., 2022), we recognize the urgent
480 need for primary research on pathways to care for dementia care in India.

481 **5. Conclusion and Recommendations**

482 This paper has highlighted that low awareness, stigma, heterogeneity in health seeking
483 behaviors, poor infrastructure and human resource availability, costs associated with seeking
484 care and an absence of a formal long term care system considerably influence care journeys
485 of people with dementia and their families in the Indian context. A number of
486 recommendations have been recognized as crucial to address these challenges and have been
487 identified in part through the in-depth desk review (Alladi et al., 2022):

- 488 • Raising awareness among the general public in order to reduce stigma and so that
489 people with dementia are able to recognize symptoms early on and seek the
490 appropriate help is critical. Development and implementation of awareness
491 programmes that take into consideration context specific factors influencing
492 perceptions of dementia, with a strong focus as well on prevention through behavioral
493 change communication strategies is essential (Kalkonde et al., 2020).
- 494 • Placing greater emphasis on dementia in the undergraduate medical curriculum in
495 order to raise awareness among primary care physicians to recognize, diagnose and
496 appropriately refer people with the condition. Community health workers such as
497 Accredited Social Health Activists (ASHA) workers should also be trained to identify
498 dementia. Such task shifting interventions are vital in settings wherein specialist
499 shortages exist. Such interventions have been trialed and found to be effective for
500 mental health conditions in rural areas of India (Nimgaonkar and Menon, 2015).
- 501 • Improving financial protection, with programmes such as Ayushman Bharat having
502 considerable scope of reducing OOP expenditure. It is critical that dementia
503 stakeholders actively engage in continued operationalization of the programme to
504 ensure services for people with dementia are well integrated with efficient delivery.
505 In addition, development of schemes that cover costs associated with informal care
506 provision is critical. For example, the state of Kerala provides a nominal remuneration

507 per month to female unpaid carers of persons with mental or physical illness (D’Cruz
508 and Banerjee, 2020).

509 • Developing evidence-based community interventions to support informal care
510 provision. For example, a randomized controlled trial in Goa utilized home care
511 advisors, recruited locally and trained for a week on dementia, to support caregivers
512 at their homes through fortnightly visits for a period of 6 months, supervised by
513 specialists (Dias et al., 2008). The authors found that this intervention led to
514 improvements in caregiver mental health. There is a need for larger studies that trial
515 such community-based interventions in different parts of the country using locally
516 available resources.

517

518 **6. Next Steps**

519 To our knowledge this is the first study in India to systematically illustrate care scenarios for
520 people with dementia and their families from pre-diagnosis to post-diagnostic and long-term
521 care support utilizing a case vignette approach. It has highlighted situations that people with
522 dementia and their families may experience and provided possible recommendations to
523 address challenges informed by an in-depth desk review of the dementia care landscape
524 (Alladi et al., 2022). By describing potential care situations of people with dementia and their
525 families, this paper provides a base for future larger empirical work with persons with
526 dementia and their families that examine care pathways for dementia in the Indian context.
527 This could include primary qualitative research with people with dementia and/or carers
528 wherein the vignettes may be used to elicit their responses on pathways to care for dementia
529 in the Indian context.

530

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534

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538

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540 The Authors declare that there is no conflict of interest

541

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