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RESEARCH ARTICLE

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Attitudes to long-term care in India: A secondary, mixed methods analysis

Sweedal Alberts[1] | Abinaya Nadarajah[1] | Claudia Cooper[1] | Bianca Brijnath[2] | Santosh Loganathan[3] | Matthew Varghese[4] | Josefine Antoniades[2] | Upasana Baruah[2] | Briony Dow[2] | Mike Kent[5] | Rachita Rao[3] | Jessica Budgett[1] | Amaani Ahmed[1]

[1]Centre for Psychiatry and Mental Health, Wolfson Institute of Population Health, Queen Mary University of London, London, UK

[2]National Ageing Research Institute (NARI), Parkville, Victoria, Australia

[3]National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru, India

[4]St. John's Medical College, Bengaluru, India

[5]Curtin University, Perth, Western Australia, Australia

Correspondence
Claudia Cooper, Yvonne Carter, Queen Mary University of London, 58 Turner St, London E1 2AB, UK.
Email: claudia.cooper@qmul.ac.uk

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Abstract

Objectives: In India, globalisation is purported to have contributed to shifting family structures and changing attitudes to long-term care (LTC) facility use. We investigated the attitudes to and usage frequency of LTC in India.

Methods: We conducted secondary analyses of: (a) The Moving Pictures India Project qualitative interviews with 19 carers for people with dementia and 25 professionals, collected in 2022, exploring attitudes to LTC; and (b) The Longitudinal Ageing Study in India (LASI) 2017–2018, cross-sectional survey of a randomised probability sample of Indian adults aged 45+ living in private households.

Results: We identified three themes from qualitative data: (1) *LTC as a last resort*, describes how LTC could be acceptable if care at home was "impossible" due to the person's medical condition or unavailability of the family carer, for example, if family members lived overseas or interstate. (2) *Social expectations* of care at home from family members and paid carers and; (3) *Limited availability of LTC* facilities in India, especially in rural localities, and the financial barriers to their use. Of 73,396 LASI participants, 40 were considering moving to LTC; 18,281 had a parent alive, of whom 9 reported that their father, and 16 that their mother, lived in LTC. LTC use was rare. While a third of participants with a living parent lived in urban areas, 14/24 of those with a parent in LTC lived in an urban area, supporting our qualitative findings that LTC is mainly accessed in urban areas.

Conclusions: Preference for intergenerational community care combined with limited availability and societal stigma contribute to low rates of LTC use among Indian families. Future social policies should consider how to plan for greater equity in strengthening care at home and in the community, and bolstering respite and LTC services as a last resort.

KEYWORDS
ageing, India, institutionalised care, long-term care, older adults

Key points

- In India, the demand for long-term care (LTC) facilities is low, with only a small number of people residing or considering residing in one. Most people prefer intergenerational community care at home.
- Contrary to the population as a while, more people who had a parent living in LTC were residing in urban versus rural areas; in qualitative interviews, family carers and healthcare professionals of people with dementia reported having less access to LTC in rural areas, which may be linked to increased financial challenges and limited resources for more specialised care.
- Given the strong preference for care at home over LTC, initiatives are needed to increase community resources for family carers of older adults with unrecognised and undiagnosed conditions such as dementia. Additionally, there should be improved access to LTC for those with fewer financial resources.

1 | INTRODUCTION

Due to declining birth rates and increasing life expectancies, one in five Indians will be aged 60 years and above by 2050.[1,2] Similar to other low- and middle-income countries, there are limited resources in India to address the rise in prevalence of chronic conditions and disabilities associated with an ageing population.[2–5] In 2020, nearly 9 million Indian people were estimated to have dementia, and this is expected to treble by 2040.[6]

Multigenerational cohabitation or joint family structures are the traditional, primary support network for providing care to older adults in India.[3] With modernisation and globalisation, more nuclear family structures are emerging.[7] Family carers, usually women, are increasingly balancing caregiving responsibilities with employment, or providing care at a distance due to emigration.[8] Carers receiving less help from extended families may be more likely to turn to LTC facilities.[9] Hereafter, we will use the term LTC in this paper, to refer to residential care facilities for older adults, as internationally accepted terminology, though in the survey participants were asked about "old age homes" as this descriptor is more commonly used in India.

Agarwal and Bloom[3] estimated that, by 2036, there will be a 34% increase in demand for LTC across India and argue that national policy needs to identify the structural and financial resources to meet this demand. There is currently limited research to guide policy-makers in their decision-making.[10] The Indian LTC system is fragmented, unregulated, and usually run with untrained staff or unreliable funding.[1,3,7] LTC facilities in India include private facilities for middle-class and elite populations, government- and charity-funded facilities for destitute peoples (very poor), and religious facilities (ashrams and temples), usually also for poor people.[11] One survey estimated that there were 1176 privately-owned LTC facilities in India, with the highest number in Kerala.[7,12,13] Though the frequency of LTC use and characteristics of their residents in India is unknown, it appears that the prevalence in India is less than in Western countries, such as the United Kingdom, where 2.5% of people aged 65 and older lived in care homes in 2021.[14,15]

As the number of LTC facilities in India grows, we must understand how attitudes towards their use might be shifting.[16] We carried out secondary analyses of two data sources to investigate how commonly the Indian population consider and use LTC facilities: (1) The Moving Pictures India project, which aimed to co-produce with key stakeholders simple, culturally appropriate, and easily accessible video resources to provide family carers with the information and skills to better manage dementia at home[17] and (2) Nationally representative survey data from the Longitudinal Ageing Study in India (LASI).

2 | MATERIALS & METHODS

We describe below the methods for study 1 (qualitative) and study 2 (quantitative), reporting results of each analysis separately and integrating findings in the discussion.

2.1 | Study 1: Qualitative analysis

2.1.1 | Sample and data collection

A secondary analysis was carried out of the qualitative interviews undertaken in the Moving Pictures India project.[17] In the original study, face-to-face video interviews were conducted with 19 family carers of people living with dementia and 25 healthcare professionals, using purposive and snowball sampling (Tables 1 and 2) in Bengaluru, India. As guided by Staller, K,[18] sample size was planned to ensure sufficient diversity of information-rich cases. Interviews lasted 30- to 90-min and were conducted in English, Hindi, or Kannada, then translated and transcribed into English. All participants gave informed consent to take part. The study was approved by the National Institute of Mental Health and Neurosciences (NIMHANS) Ethics Committee, Health Ministry's Screening Committee, India (HMSC), Curtin University Human Research Ethics Committee (HREC), and the National Ageing Research Institute (NARI) Research Governance Office.

TABLE 1 Demographic information for healthcare professionals.

	Included in analysis?	Gender	Religion	Age	Role
Professional 1	Y	Female	Christian	29	Medical staff
Professional 2	Y	Female	Christian	29	Allied health
Professional 3	Y	Female	Hindu	56	Administrator
Professional 4	Y	Female	Hindu	34	Allied health
Professional 5	Y	Female	Hindu	30	Allied health
Professional 6	Y	Male	Hindu	41	Medical staff
Professional 7	Y	Male	Christian	36	Medical staff
Professional 8	Y	Female	Hindu	55	Medical staff
Professional 9	Y	Male	-	53	Medical staff
Professional 10	Y	Female	Christian	43	Medical staff
Professional 11	Y	Female	Hindu	39	Allied health
Professional 12	Y	Female	Hindu	41	Medical staff
Professional 13	N	Female	Hindu	34	Allied health
Professional 14	Y	Female	Hindu	24	Allied health
Professional 15	Y	Female	Hindu	42	Medical staff
Professional 16	Y	Male	Hindu	44	Medical staff
Professional 17	Y	Male	Hindu	48	Allied health
Professional 18	N	Female	Christian	45	Nursing staff
Professional 19	Y	Female	Christian	35	Nursing staff
Professional 20	N	Female	-	32	Allied health
Professional 21	N	Male	Christian	27	Nursing staff
Professional 22	N	Female	-	36	Nursing staff
Professional 23	Y	Female	-	48	Medical staff
Professional 24	Y	Female	Hindu	42	Medical staff
Professional 25	Y	Female	-	52	Medical staff

RR, a female psychiatric social worker recruited as a research associate, conducted the interviews in presence of a videographer. There were no direct questions in topic guides regarding attitudes to LTC, as the primary objective of the interview focused on exploring the detailed care journey, available resources and care plans. Participants were asked about sources of help they had accessed, any discussions with health professionals about future care needs for the person they care for with dementia, and any plans for palliative care/end of life care they had made. Health professionals were asked how they navigated discussions about care, including end of life care with families of people with dementia, how families and carers responded, and the interventions and services available in their organisation for people with dementia and their families. They were also asked about stigma. Detailed Interview schedule are in the Supporting Information S1: Appendix.

The interview guide was pilot tested. Participants knew their interviews would be used for film resources and scientific publications, but no interview guide was provided. The researcher set aside their preconceived notions and biases to explore culturally relevant care practices such as role of gender, cost effective care solution and attitude of people about care institutions. Data collection was stopped when data saturation was reached.

2.1.2 | Analysis procedures

AA and AN read all 44 original transcripts to identify sections that were potentially relevant to the research question, which they imported into NVivo, and thematically analysed.[19] After initial familiarisation, they inductively coded the data, then met to compare coding frameworks. Following this initial discussion, the team met to discuss emerging themes, having read pre-selected excerpts from the transcripts. The themes and coding frameworks were further refined during these discussions.

TABLE 2 Demographic information for family carers.

	Included in analysis?	Gender	Age	Religion	Level of education	Work status	Job	Relationship of person with dementia to carer	Number of years as a carer
Carer 1	N	Female	65	Christian	University	Retired	Ex-banker	Husband	10
Carer 2	N	Female	72	Hindu	University	Retired	School teacher	Husband	7
Carer 3	N	Male	35	Hindu	University	Full time	Software engineer	Father	12
Carer 4	Y	Male	47	-	University	Full time	Manager	Mother	11
Carer 5	Y	Male	32	Muslim	University	Full time	Software engineer	Grandmother	1.5
Carer 6	Y	Male	45	Hindu	University	Full time	Manager	Mother	3
Carer 7	Y	Female	49	Muslim	University	Homemaker	Homemaker	Father in law	6
Carer 8	Y	Female	71	Hindu	University	Retired	Banker	Husband	2
Carer 9	Y	Male	37	Muslim	High school	Full time	Senior system engineer	Father	4
Carer 10	Y	Male	79	Hindu	University	Retired	Government job in defence	Wife	14
Carer 11	Y	Female	44	Hindu	High school	Casual	Coolie	Father	2
Carer 12	Y	Female	39	Hindu	University	Homemaker	Homemaker	Mother	1
Carer 13	Y	Female	63	Hindu	University	Part time	Self Employed	Mother	10
Carer 14	Y	Male	67	Hindu	University	Retired	Banker	Wife	4
Carer 15	Y	Female	35	Hindu	University	Homemaker	Homemaker	Father	2
Carer 16	Y	Male	34	Hindu	University	Full time	Business man	Mother	6
Carer 17	Y	Male	49	Hindu	University	Full time	Salesman	Father	9
Carer 18	Y	Male	63	-	University	Full time	Professor	Wife	7
Carer 19	Y	Female	31	Hindu	University	Full time	Associate manager	Father	3

2.2 | Study 2: Quantitative analysis

2.2.1 | Sample and data collection

We undertook a secondary analysis of data from the LASI Wave 1 Survey, a cross-sectional household survey administered between April 2017 and December 2018 (Sikkim state data collection in 2020-21) in all Indian states and Union Territories.

The survey, described in detail elsewhere,[20] used multistage stratified systematic sampling. A total of 8077 villages and 6181 urban blocks were randomly selected, from which households were selected. 73,396 older adults living across all Indian states and union territories were included in the survey, which was primarily intended to measure socio-economic factors and pre-retirement behaviours. A household member aged 45 and above was identified but, as spouses were also invited to take part irrespective of age, a small number of participants were aged below 45.

Data were collected in face-to-face interviews. Ethical approvals were obtained from Indian Council of Medical Research (ICMR), Delhi; IRB, International Institute for Population Sciences (IIPS), Mumbai; IRB, Harvard T.H. Chan School of Public Health (HSPH), Boston; IRB, University of Southern California (USC), Los Angeles; IRB, ICMR-National AIDS Research Institute (NARI), Pune; IRB, Regional Geriatric Centres (RGCs); and Ministry of Health and Family Welfare (MoHFW). Written consent was acquired before data collection. Access was granted to analyse the data set, which was stripped of identifiers before being shared with our study team.

2.2.2 | Main outcomes

We included variables describing current use of LTC facilities by the parents of respondents. Study participants were firstly asked, *"Is your father/mother alive?"* followed by the question, *"Does he/she live alone or with others"* with the following possible response options: lives alone, lives with your father/mother or his/her partner, lives with other children, lives in old age home, lives with others.

We also described whether participants indicated that they wished to move into an old age home via responses to the question: *"Do you have any intention of changing your living arrangement in the future?"*, reporting the frequency with which the option "*prefer to move into old age home*" was endorsed. As discussed above, though the survey question describes 'old age homes', we refer to this as LTC throughout to maintain consistency across the two data sources.

2.2.3 | Exposures and covariates

We reported the sociodemographic characteristics of all respondents —including gender; age category; whether their hometown was classified as urban or rural; MPCE (Monthly per Capita Expenditure, a measure of household consumer expenditure to describe the economic well-being of households in the absence of income data, categorised into five quintiles poorest, poorer, middle, richer and richest); ability to read or write; and highest level of education. We also included measures (all self-reported) of respondents' health scores ranging from excellent to poor and the presence of diagnosed Alzheimer's disease.

2.2.4 | Data analysis

All analyses were conducted using SPSS (Statistical Packages for Social Sciences) version 29. India-level weighting was applied to account for selection probability. We reported actual numbers and weighted percentages to describe the sociodemographic and health characteristics studied for the whole sample and for participants who report having a parent who is alive. We also reported actual numbers to describe (a) the proportion of respondents reporting that their mother or father was living in LTC; and (b) the proportion who reported an intention to move to LTC themselves. As numbers were so small, we omitted weighted percentages for these samples (Table 1).

3 | RESULTS

3.1 | Study 1: Qualitative findings

3.1.1 | Sample description (Tables 1 and 2)

The transcripts of 16 family carers and 20 professionals were deemed relevant to the current research question and included in the final analysis. 7/16 (44%) family carers were women and their mean age was 49.1. 15/20 (75%) professionals were women and their mean age was 41.1. For demographic characteristics of interviewees quoted, please see Tables 2 and 3.

3.1.2 | Themes identified

We identified three themes. The first theme, *LTC as a last resort*, describes how care at home was considered an expression of familial love and the norm for Indian families, with LTC seemingly acceptable only if care at home was deemed "impossible". The second theme, *social expectations*, describes social stigma around LTC usage. Our third theme, *limited availability of LTC*, notes the unavailability of facilities in many, especially rural, localities and the financial barriers to use.

3.1.3 | Theme 1: LTC as a last resort

Most participants expressed a strong commitment to providing care at home:

> Many people ask us to keep a maid or nurse for him, but we tell him that we find happiness in serving him. We don't let anyone else do things for him. We love to take care of him.
>
> [Carer 7: woman, caring for father-in-law]

> I wasn't comfortable, you know, because I know how she is, you know, and I couldn't just go and leave her in some strange place and go to office because I would not have the peace of mind
>
> [Carer 5: man, caring for grandmother]

Care decisions were made by the entire family. Findings suggested intergenerational differences in views on LTC however, and even among families with the financial means to support formal LTC, traditional views and attitudes on elder care often prevailed.

> So I would have preferred she accepted for a caretaker. She would have had more time to take care of herself. She didn't do it that one of my regret. Despite being a very good salesman in my profession I am unable to sell this idea to my mother. Maybe her sense of old values… This thing or she was very uncomfortable with an outsider coming and staying with them. I couldn't decide. Also, I didn't want to broach the subject because she's very uncomfortable talking about it. Extremely uncomfortable.
>
> [Carer 17: man, caring for father]

Several participants viewed LTC as a potential solution to overwhelming challenges, highlighting that it could be acceptable where more specialised medical care was needed:

> [I]nstitution based care there will be very systematic, it will be to definitely improve or prolong the lifespan of a person [to] be taken care because every problem will be observed and then appropriate treatment will be initiated so they are always under the care of a doctor and the team is always available.
>
> [Professional 17: man, Senior Physiotherapist]

LTC facilities were generally seen as a last resort for when family carers could no longer manage, for example, due to exhaustion or because they had moved abroad:

> For the residential care facilities, it comes at the later stage. Residential care is there for the support for the family carers when they have distance, when they're not able to manage their loved ones at home.
>
> [Professional 19: woman, Care Manager/Centre In-charge]

Since residential care is expensive, health professionals often advice it as a last resort. Even during the COVID-19 pandemic when many services were unavailable.

> If you cannot handle it, see if you can admit her there. So, we contacted [LTC agency] Nightingales at that time. But they had stopped everything by then. They had nothing. Daycare was completely stopped. The Residential was there for 15–20 days. But they said it is not necessary to leave her in the residential. Because she has feelings and she will recognize them. And then, she, even now also, wears her dress by herself. She brushes by herself. So residential care was not necessary.
>
> [Carer 14: man, caring for wife]

The decision to go to LTC also depended on whether the person with dementia could comprehend their surroundings. Till the carer feels they are being recognised and the person with dementia might feel connected to the family, they would want to continue care at home, to make them feel comfortable and cared.

> If I go home, she will understand that I came. But, where did I go, she does not know. But she understands that I came in. The happiness she feels at that time, I would like to take care till that feeling remains. Tomorrow if she forgets that also, she could not understand what she is eating, if it is chicken, kesaribath [local sweet], that is a different case. Till then, what they enjoy doing, how much they feel, what gives them happiness, to that moment, that is their life. That we must give. Nothing else can be done. Before which, if put in residential care or appoint anybody, it becomes mechanical, and they will not get happiness. Here they get happiness, and we can give the happiness to them that's it.
>
> [Carer 14: man, caring for wife]

> Slowly the family members start losing their patience … And the person who looks after them, becomes frustrated that it [dementia] will not be cured. … After that level, they may need day care and residential care.
>
> [Carer 14: man, caring for wife]

Only one respondent cared for a relative who lived in a LTC facility. Their narrative also highlighted that LTC was only considered because care at home was found to be "impossible":

> That decision was tough, but we still took it. We took the decision that it is only the best thing for her. They are looking after her very nicely which I cannot do because in this condition it is almost impossible to take care at home. She needs medical attention daily twice or thrice. They are giving physiotherapy, this and that, and then they have training also.
>
> [Carer 18: man, caring for wife]

3.1.4 | Theme 2: Societal expectations

Societal stigma surrounding LTC facilities was evident in most transcripts. To care for one's family was seen as a moral responsibility and expectation for the younger generation, and using LTC facilities as a shirking of their familial duties:

> Taking care of the person, of their elderly is I think very, what you say, imbibed in our culture and if you are not doing that it stigmatizing, right, you are not taking care of your parents… What will, if I have to leave this person in a long term, you know, care facility what will my relatives, you know, talk about it?
>
> [Professional 11: woman, Rehabilitation Professional]

> And if the children are not in favor of looking after their parents, [we] need to counsel and make him understand that it is their duty to look after the old parents. There are cases where such patients are neglected, are admitted to some hospital or somewhere. It is unfortunate.
>
> [Carer 15: woman, Consultant (Clinical Neuropsychology)]

Several participants noted that these views overlapped with expectations that women should be the primary carers in families:

> There is this stereotype in our society that it is the wife's job to take care of her husband, it is the mother's job to take care of her son, or it is the daughter-in-law's responsibility to take care of her mother-in-law.
>
> [Professional 6: man, Consultant (Psychiatry)]

However, there was a suggestion that, with shifts to nuclear families, social stigma surrounding LTC was reducing where in such instances, providing direct care was not a viable option for adult children:

> Another thing, that has happened in our setup is, parents will be somewhere, and children will be somewhere else. Or any one parent will be there, children will be away. Children will have their own responsibilities. They will also have children. And in this nuclear society, they cannot stay together. I don't say that is wrong. That is not wrong at all. Because they have their own responsibilities, they cannot look after these responsibilities also.
>
> [Carer 14: man, caring for wife]

3.1.5 | Theme 3: Limited availability of LTC

Several interviewees reported that no LTC facilities were available in their area.

> In [area], there are no such institutions where we can admit her, or maybe we don't know about them.
>
> [Carer 16: man, caring for mother]

> It's very expensive managing things. So I think if there was an NGO, or somewhere or, rehabilitation home where I can take my mom, because right now, if I am admitting in any rehabilitation it would cost me around 25 to 30k minimum which is very expensive, actually. I mean, yeah, it could be reasonable for them. But for a single earning member that's very expensive. So probably some kind of NGO could initiate, you know, probably help us, that would have been really helpful.
>
> [Carer 6: man, caring for mother]

One professional, commenting that existing LTC facilities were unaffordable to many, proposed financial government aid for families from a low socio-economic background:

> Many of these support services are quite expensive and not affordable for persons with limited social economic kind of support. So, they need to be kind of, we need to have programs, government fundings and support systems which will take care of support for this initiative. Something like a social care insurance or a social care grant can be very helpful in this regard.
>
> [Professional 16: man, Professor and Head Geriatric Psychiatry Unit]

A second professional suggested that day care may be a more affordable option:

> If there's a day care service centre actually affordable, and is it accessible in the first place, and can they come for thrice a week, or can they come for a month and then not for the next month.
>
> [Professional 1: woman, Psychiatric Social Worker]

Professionals also expressed their concerns that there were very few specialised dementia facilities. They further highlighted that there is a limited workforce in the country who are specifically trained in providing dementia care:

> There is not enough centres which particularly cater to patients with dementias. There are not enough specialized centres which are equipped to understand the kind of cognitive changes that occur which are equipped to also treat the cognitive changes that occur.
>
> [Professional 5: woman, Clinical Psychologist]

3.2 | Study 2: Quantitative findings

3.2.1 | Sample description

Of 73,396 total respondents, most aged between 45 and 54 years, two-thirds came from rural areas. The sample was evenly distributed across income quintiles. Around half were unable to read or write with only one in 10 having received education beyond secondary provision. The most common self-rated health score for all respondents was 'Good' with only 404 respondents reported having a diagnosis of Alzheimer's disease. There were significant levels of non-response for three variables of interest: ability to read or write, highest level of education and self-rated health (Table 3).

Of the 73,396 respondents, 18,281 had a parent alive. Over half of these respondents were aged between 45 and 54 years, came from rural areas, despite an even distribution across all income quintiles. Over two thirds were unable to read or write, with primary level being the most common level of education provision. Of the respondents who had a parent alive, 150 reported that their mother, and 72 that their father, had a diagnosis of Alzheimer's disease.

3.2.2 | Current use of LTC

7798 people reported that their father was alive; in nine cases, their father lived in a LTC facility also known as an old age home in India. 15,819 people reported that their mother was alive; only 16 reported

TABLE 3 Sociodemographic and illness characteristics of LASI sample, for whole population and those who (a) reported having a parent in LTC (b) expressed an interest in moving to LTC.

Characteristics	Total *N* (weighted %)	Respondents with parent alive *N* (weighted %)	Respondents with parent in LTC[a] (*n*)	Plans move to LTC (*n*)
Total	73,396	18,281	24	40
Gender				
Male	31,135 (42.0)	5481 (28.0)	4	12
Female	42,261 (58.0)	12,800 (72.0)	20	28
Age (years)				
≤34	474 (0.6)	387 (2.1)	0	0
35–44	6316 (8.1)	4270 (23.5)	5	3
45–54	24,537 (31.9)	9369 (50.3)	12	5
55–64	20,434 (27.2)	3499 (19.4)	5	7
65–74	14,755 (21.7)	702 (4.5)	2	14
75–84	5412 (8.2)	51 (0.2)	0	7
85+	1468 (2.2)	3 (0.0)	0	4
Area				
Urban	25,970 (31.8)	6889 (33.6)	14	14
Rural	47,426 (68.2)	11,392 (66.4)	10	26
MPCE quintile				
Poorest	14,422 (20.7)	2992 (17.5)	3	11
Poorer	14,757 (21.2)	3481 (20.0)	4	6
Middle	14,764 (20.5)	3658 (20.2)	9	5
Richer	14,908 (19.6)	4010 (21.8)	3	11
Richest	14,545 (18.0)	4140 (20.6)	5	7
Ability to read or write				
Read only	787 (1.2)	167 (1.7)	0	1
Write only	1595 (2.0)	442 (4.4)	0	1
Read and write	10,017 (12.7)	2349 21.2)	4	5
Neither read nor write	34,626 (51.0)	6921 (72.8)	7	26
No answer	26,371 (33.2)		0	0
Highest level of education completed				
Less than primary	8188 (10.8)	1815 (17.5)	2	5
Primary	9849 (12.4)	2774 (24.3)	3	3
Middle (standard 8–9)	7345 (8.8)	2398 (19.4)	5	4
Secondary	6800 (8.2)	2157 (16.3)	1	0
Higher secondary & above	7452 (10.4)	2462 (22.5)	7	2
No answer	33,762 (49.5)		0	0
Self-rated health score				
Excellent	3035 (4.5)	1085 (6.3)	0	0
Very good	14,504 (18.2)	4380 (22.9)	9	4
Good	28,526 (36.8)	7536 (39.1)	11	9
Fair	19,434 (28.6)	4104 (24.9)	2	12

TABLE 3 (Continued)

Characteristics	Total *N* (weighted %)	Respondents with parent alive *N* (weighted %)	Respondents with parent in LTC[a] (*n*)	Plans move to LTC (*n*)
Poor	6950 (10.4)	1136 (6.8)	2	15
No answer	947 (1.6)		0	0

[a]One respondent reported that both their mother and father were living in LTC (Long Term Care).

that their mother lived in a LTC facility. In total, out of 18,281 participants reporting that at least one parent was alive, only 24 (0.1%) reported that their mother or father was living in LTC; both parents of one participant were residing in LTC. Due to these small numbers, we have not analysed further, but in Table 3, shows the number of people who had a parent in LTC, relative to the whole sample who had at least one living parent. The only characteristic explored in which there appeared to be a marked difference between these samples is in urbanicity, with one third of people with a living parent, but over half of those whose parent was in LTC, living in an urban area. Out of the 25 parents in LTC, none had a dementia diagnosis.

Of the nine fathers who are currently reported to reside in LTC, the majority were aged 65+ and lived in rural areas. Four were from the lowest or lower income quintiles and one was able to read or write. Of the 16 mothers who are currently reported to reside in LTC, the majority were aged 65+ and lived in urban areas, from middle-income households. All but four were unable to read or write.

3.2.3 | Intention to move to LTC

Forty participants expressed a wish to move to LTC themselves; none had a parent living in LTC.

4 | DISCUSSION

To our knowledge, no previous research has captured the frequency of LTC use in India and linked it to the attitudes of professionals and family carers. Despite globalisation, demand for LTC in India remains low, with few people currently residing in, or wanting to move to, LTC facilities. Whilst some qualitative interview participants acknowledged benefits of LTC in reducing caregiver burden and providing specialised medical support, they viewed caring at home as preferable and LTC as a last resort. As reported a decade ago, LTC facilities are highly stigmatised spaces in the Indian legislative policy and social discourse, often interpreted as the abandonment of relatives due to family conflict or psychological distress and a symbol of social degeneration.[11,21] Our findings indicate that these attitudes and stigmatisation remain. Intergenerational living and community-based care are preferred; these usually deliver better, more cost-effective outcomes for older people living with frailties, including dementia, and are preferred by older people.[22,23] Interestingly, in Western countries, where care home residency is more common, experimental programmes of intergenerational living are re-emerging.[24]

Most LASI participants whose parents lived in LTC facilities were from urban areas. None had an Alzheimer's disease diagnosis. LTCs in India include private facilities for those with more socioeconomic resources, and religious, government- and charity-funded facilities for people living in deprivation. As many have admission criteria that exclude those experiencing behavioural symptoms and mental illness, the low proportion of older people with dementia in LTC may be a function of admission criteria as well as social stigma.[11]

The extremely low rates of dementia diagnoses in LASI indicate that most dementia cases remain undiagnosed, suggesting that the unmet needs of family carers for people with dementia in India is vast. Future policies in India must thus consider how to best support care at home and in the community, including greater support for family carers, and day care and respite facilities. Whilst much of the evidence base is from high-income countries, there is evidence to show that family carers benefit from structured support.[25] Such investments will support higher quality, cost-effective care for the ageing Indian population.

Despite the strong preference for community care, LTC facilities are likely to rise with ageing populations and a growing Indian middle class.[26,27] Under the Indian "Maintenance and Welfare of Parents and Senior Citizens Act, 2007, adult children and relatives (legal heirs) are legally obligated to provide financial assistance to family members aged 60 and over, if they are unable to maintain themselves. Future Indian policies should also consider steps to reduce stigmatisation of LTC facilities through governmental schemes that increase both awareness and equity of access for people seeking outsourced support. A future survey on LTC facility residents and their families would be informative to explore their perspectives and inform the development of effective policies and interventions. While none of the interviews discussed concern about the quality of care in LTC, as use increases this will also be an area for policymakers to consider.

4.1 | Limitations

Secondary analyses are limited by the inability to influence data collection. Qualitative interviews were only conducted in Bengaluru, a megacity, more economically prosperous than other areas of India and with a largely middle-class sample, so findings are unlikely to be representative of the Indian population, the majority of whom live in rural areas.[28] In the quantitative analysis, we did not measure actual care home use, instead estimating it from household respondents' descriptions of their parents' living situation. Further,

the living situations of the older people are reported for a population that have children and therefore may not be representative for a population without children. With the stigmas associated with LTC across India, particularly the idea of placing parents in LTC, it could be possible that many respondents inaccurately represented the living arrangements of their parents in the self-report. Lastly, the timing of COVID, occurring between the collection of the quantitative data (LASI) and the qualitative study in 2022, may have influenced individual's views of care homes which were substantially affected by COVID across the world. However, to our knowledge, limited data is available on care homes activities across India, including the potential impact of COVID for us to comment further on this.[29] Moreover, as cultural resistance towards LTC homes in India has been well established for over 10 years (see[11]); it is likely that the pandemic amplified this resistance but did not initiate it.

5 | CONCLUSIONS

Very few Indian families use or consider LTC due to societal stigma and preference for intergenerational and community care, lack of availability, and financial factors. Our qualitative findings suggest that LTC use may be acceptable in circumstances where families move away or experience high burden, but community care was the prevailing model described. Future social policies should consider how to plan for greater equity in strengthening care at home, supporting care in the community, and bolstering respite and LTC services by making them more accessible, affordable, and within the reach of all Indian families.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the LASI team in receipt of a reasonable request via https://www.iipsindia.ac.in/content/LASI-data. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

The LASI Study ethical approvals were obtained from Indian Council of Medical Research (ICMR), Delhi; IRB, International Institute for Population Sciences (IIPS), Mumbai; IRB, Harvard T.H. Chan School of Public Health (HSPH), Boston; IRB, University of Southern California (USC), Los Angeles; IRB, ICMR-National AIDS Research Institute (NARI), Pune; IRB, Regional Geriatric Centres (RGCs); and Ministry of Health and Family Welfare (MoHFW). The Moving Pictures India project was approved by the National Institute of Mental Health and Neurosciences (NIMHANS) Ethics Committee, Health Ministry's Screening Committee, India (HMSC), Curtin University Human Research Ethics Committee (HREC), and the National Ageing Research Institute (NARI) Research Governance Office.

PERMISSION TO REPRODUCE MATERIAL FROM OTHER SOURCES

N/A.

ORCID

Sweedal Alberts https://orcid.org/0009-0005-9466-4215
Abinaya Nadarajah https://orcid.org/0009-0002-5048-0877
Claudia Cooper https://orcid.org/0000-0002-2777-7616
Bianca Brijnath https://orcid.org/0000-0002-0536-6859
Matthew Varghese https://orcid.org/0000-0001-5670-5710
Jessica Budgett https://orcid.org/0000-0003-1095-5065
Amaani Ahmed https://orcid.org/0009-0003-2017-5537

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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