

The COVID-19 Long-Term Care situation in India

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Corrections and comments are welcome at info@ltccovid.org. This document was last updated on 30th May 2020 and may be subject to revision.

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1. Key points

- While there are a large number of elderly people with comorbidities in India, there is a limited data available on the proportion with long-term care needs.
- There is no formal or organized long-term care system in the country. Long-term care is community based, with families primarily providing care.
- The numbers of positive cases of COVID 19 in India have risen significantly since the first case was reported on January 30th 2020. As of 30th May 2020, there are 86,422 active cases, 82,369 cured cases and 4,971 deaths. There is no data on the prevalence of COVID-19 among people with long-term care needs or number of deaths.
- The government has introduced several population level measures to contain the spread of COVID-19. These include: a nationwide lockdown to encourage physical distancing, establishing centres for COVID-19 testing, creating dedicated facilities for treatment, an app to facilitate contact tracing and guidelines/advisories for older people and people with disabilities.
- Care homes are largely unregulated and there is limited data available on their activities. As a result, it is difficult to determine the extent to which infection protocol measures have been adopted by all care homes in the country.
- There are no government guidelines directed specifically towards unpaid carers and people with dementia during the pandemic (as of May 30th 2020).

2. Introduction

India has a population of 1.3 billion, which makes it the second most populated country in the world. Approximately, 8.6% of the total population are aged 60 and over ¹ (Fig 1) and this is expected to rise to almost 19 % by 2050 ². There is high prevalence of non-communicable (60% of all deaths) ³ and communicable diseases (27.5% of all deaths) ⁴, which contribute towards the multiple co-morbidities in the older population ⁵. Long-term care is largely unorganised, informal and based in the community, with the families predominantly providing care.

100 Males Females
90
80
70
60
40
30
20
10

Figure 1: Population of India in 2020

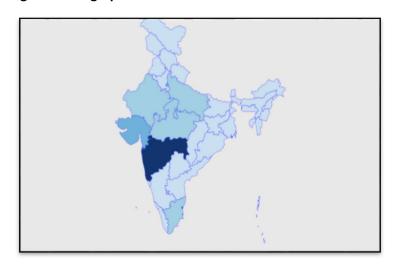
Source: United Nations 6

3. Impact of COVID19 so far

3.1. Number of positive cases in the population and deaths

The first case of COVD-19 was reported on 30th January in the southern state of Kerala in India. As of 30th May 2020, there are 86,422 active cases, 82,369 cured cases and 4,971 deaths reported by the Ministry of Health and Family Welfare (MoHFW) ⁷. The largest number of confirmed cases is in the state of Maharashtra—home to the financial capital Mumbai—; the dark blue region depicted in Figure 2

Figure 2: Geographical distribution of confirmed COVID-19 cases.



Source: MoHFW 7

An age-wise analysis conducted by the MoHFW (on April 4^{th}) has highlighted that from the total cases confirmed, 9% were between aged 0-20 years, 42% were between the ages of 21-40, 33% between 41-60 years of age and 17% were aged 60 years and over 8 . Over 50.5% of the total

deaths reported were in individuals 60 years and over and approximately 73% of all deaths have been among individuals with comorbidities ⁹. The case fatality rate (as of 26th May 2020) has been reported as 2.87% and has decreased from the 3.3% reported in mid-April ¹⁰. The mortality per population has been reported as 0.3 deaths per 100,000 (as reported on May 26th 2020) ¹⁰.

A total of 3,611,599 samples have been tested for COVID 19 infection, as of May 30th 2020 ¹¹. The Indian Council of Medical Research (ICMR) has published guidelines ¹² for COVID-19 testing in India. The guidelines recommend that asymptomatic individuals who have had "direct and high-risk contact" be tested within 5-10 days of coming in contact and that the following symptomatic (influenza like illness) individuals also be tested: those with international travel history, frontline/health care workers, contact with a confirmed case, living in containment areas, hospitalized patients and migrants/returnees within seven days of ailment. The rates of testing have increased 1000 fold over a period of 60 days ¹³. In January 2020, there was only one COVID-19 testing centre in the country ¹³. As of May 27th 2020, there are approximately 624 labs conducting testing ¹⁴. This is likely to further increase with time.

3.2. Population level measures to contain spread of COVID-19

The Indian government has taken a number of measures to contain the spread of COVID-19:

- A travel advisory recommending that all travel to China be avoided was issued on the 17th of January and the very next day thermal screening of passengers travelling from China and Hong Kong was started at airports ¹⁵. Once the first case of COVID-19 was confirmed in the country on 30th January, a number of travel restrictions were brought into place. On 3rd of March, the government suspended visas for countries such as Iran, Italy, Japan, China and South Korea and mandatory health screening was initiated for those travelling from Singapore, South Korea, Japan, Italy, Nepal, Taiwan, Indonesia, Thailand, Iran, Hong Kong, Vietnam and China ¹⁵. By the end of March, railway services, domestic and international flights were completely suspended ¹⁵. Since May, some railway services (currently only to transport migrants) and domestic flights have resumed.
- On March 22nd, the Prime Minister proposed a 'Janta curfew' (public curfew), during which people were requested to stay home from 7 am to 9pm in order to facilitate social distancing and reduce the spread of COVID-19 ¹⁶. Soon after, the government announced a nationwide lockdown from March 25th to April 14^{th 17}. There has been a phased relaxation of lockdown measures since the initial announcement. During **PHASE** 1 [March 25th to April 14th], facilities such as public transport, schools, shopping malls, offices, and restaurants (delivery services were permitted) were closed. People were only allowed to leave their homes for essential services (groceries, pharmacies, emergency services at hospitals), which remained open throughout this time. While the government's rapid response has slowed down the spread of infection, the pandemic has proven to be a double-edged sword in the sense that controlling its spread has impacted a vulnerable group of population: migrant workers who lost their jobs and were left stranded, resulting in a large-scale exodus. While authorities have made

efforts to help this vulnerable population, this has exposed the vulnerabilities in society and raised concerns regarding the existing inequalities. As cases continued to rise, the government initiated **PHASE 2**[15th April to 3rd May] of lockdown, which involved a two-week extension of lockdown measures, along with significant restrictions in hotspots/containment zones ¹⁸. **PHASE 3** [4th May to 17th May] of lockdown involved a further two-week extension of lockdown measures, although with considerable relaxations in certain areas ¹⁹. The Ministry of Home Affairs (MHA) conducted risk profiling of districts by dividing them into red, orange and green zones and substantial easing of restrictions were permitted in green and orange zones ¹⁹. **PHASE 4** [18th May to ongoing] of lockdown is ongoing at the time of writing this report. Educational institutes, malls, restaurants, cinema halls, religious sites continue to remain closed, but businesses and public transport vehicles such as taxis, buses and auto-rickshaws have been allowed to resume services in non containment zones ²⁰. All permitted non-essential activities are allowed only between 7am and 7pm, with night curfew still in force ²⁰.

- The government has communicated with the public throughout the pandemic. Regular conferences with members of the health ministry are carried out via multiple media outlets. The MoHFW website regularly updates the number of active cases and deaths across various states in the country ⁷. The MoHFW has also published a health advisory ²¹ for the elderly population and provided guidelines to maintain mental and physical wellbeing on their website ⁷. Moreover, in order to make the public more aware of their risks of contracting COVID-19, the Ministry of Electronic and Information Technology launched a contact-tracing app known as 'Aarogya Setu' (bridge to health) on April 2nd ²². This app uses Bluetooth technology to inform an app user if they are/have been in the vicinity of someone who has tested positive and also has a self-assessment questionnaire ²³. Those who are identified to be in contact with positive cases or require guidance after a self-assessment are approached by the National Health Authority ²³.
- The government has published guidelines and advisories for at risk/vulnerable populations such as older people ²¹ and people living with disabilities ²⁴. Certain states have developed specific measures to identify and support at risk/vulnerable populations. Kerala, for example, has launched a senior citizen cell with the aim of reaching out to vulnerable older people and providing them with essential items such as food and medications during the pandemic ²⁵. Meanwhile, the southern state of Karnataka has been conducting a statewide survey to identify at risk/vulnerable households (50 lakh identified as of May 28th 2020) in order to monitor their health and provide medical support when required ²⁶. The survey has revealed that 1 in 3 homes in the state are vulnerable to COVID-19 ²⁶.

3.3. Rates of infection and mortality among long-term care users and staff

As of May 30th 2020, there is no data available on the rates of infection and mortality among long-term care centres (old age homes, residential facilities, day care centres etc.) in India.

4. Brief background to the long-term care system

There is currently limited data available on the proportion of population with long-term care needs in the country. The 10/66-dementia research group conducted a population-based survey ²⁷ examining the impact of chronic diseases on the prevalence of dependence among those aged 65 and over in China, Latin America and India. The study reported the prevalence of dependence (after standardizing for demographic and health related factors) as 1.0% in urban India (sample size: 1005) and 2.2% in rural India (sample size: 999).

In alignment with the challenges highlighted by the World Health Organization ²⁸ with regard to long-term care needs, those unique to the long-term care system in India have been identified:

- There is no formal or organized public service delivery system for long-term care in the country ²⁹. However, programmes such as the Integrated Programme for Older Persons, National Programme for Healthcare of Elderly, National Mental Health Programme and National Programme for Palliative Care all include components of long-term care ²⁹.
- Long-term care in India is largely community based. Family remains the cornerstone of care in India and as a result the long-term care system is largely informal (unpaid carers), with significant diversity in care provision across various regions and socioeconomic groups.
- The institutional model of care may be unpopular in the country due to sociocultural factors ³⁰.
- Few long-term care services such as old age homes, day care centres, residential
 facilities and domiciliary care services are available ³¹. These are predominantly
 provided by private and not-for-profit organizations, although a few public facilities also
 exist.
- Public funding towards long-term care is limited. An extremely small proportion (0.1%) of the country's GDP is reported to be spent on long-term care ³².
- There are a few public benefit schemes such as disability benefits and pension schemes, but the amount provided is very small and variable across states ²⁹. Out-of-pocket payments (OOP) are predominantly how people with long-term care needs access services ³².
- Paid care workers such as home care attenders are often untrained and provide support mainly with activities of daily living. Unpaid carers such as family caregivers are predominantly women; it is the wives, daughters or daughters-in-law who primarily provide care ³³.
- Many Indians live in multigenerational households (joint family system), which allows
 for the rotation of caregivers in order to provide the primary caregiver with some much
 needed respite time. However, this model of care is slowly breaking down due to
 demographic and economic transitions (rise in nuclear families).

5. Long-term care policy and practice measures

5.1. Whole sector measures

As of May 30th 2020, there are no specific measures taken by the government addressing long-term care during the pandemic.

5.2. Care coordination issues

5.2.1. Hospital discharges to the community

General guidelines ³⁴ for hospital discharge of COVID-19 patients has been issued and later revised on May 9th 2020 by the MoHFW. The guidelines categorize discharge policy by clinical severity. For mild cases, the guidelines recommend that patients can be discharged 10 days after the development of symptoms, as long as there is no fever for 3 consecutive days. For moderate cases, the guidelines suggest that if a patient has no fever after three days and their oxygen saturation remains over 95% over the following four days, then the patient can be discharged 10 days after the development of symptoms, but only if they have no fever, if breathlessness has resolved and they do not require oxygen support. In both moderate and mild cases, it is recommended that patients isolate themselves at home for seven days after discharge ³⁴. For severe cases, the guidelines recommend that discharge is dependent on clinical improvement and if the patient tests negative (RT-PCR test) after symptoms have resolved.

5.2.2 Hospital discharges to residential and nursing homes

As of May 30th 2020, there is no data available on hospital discharges to residential and nursing homes in India.

5.3. Care homes (including supported living, residential and nursing homes, skilled nursing facilities)

While there are no government issued guidelines directed specifically towards care homes in India during the COVID-19 pandemic (as of May 30th 2020), a few of the care homes (provided by NGOs and private organizations) are adopting the COVID-19 infection prevention guidelines ³⁵ published by the government. Whether such measures have been adopted by all care homes in the country is difficult to ascertain, as care homes are largely unregulated and limited data is available on the total number of such homes and their activities (as of May 30th 2020).

5.3.1. Prevention of COVID19 infections

Few care homes have introduced strict infection protocol measures at their facilities. This includes stringent sanitization of facilities (e.g. disinfecting floors) and training of staff to implement hygiene practices among residents (e.g. encouraging hand washing and use of hand sanitizers). They have stopped new admissions, reduced entry of staff members that are not inhouse, restricted all visitors (including family members) and sent back a few residents whose families preferred to provide care for them at home. However, many care homes are likely to be under-resourced and may be unable to implement such measures in an optimal manner.

5.3.2. Controlling spread once infection is suspected or has entered a facility

No cases of COVID-19 have been reported to the best of our knowledge at the few care homes that were contacted (as of May 30th 2020). Care homes have plans in place for when or if they have a positive case/s. Separate rooms have been allocated for quarantining residents that develop influenza like symptoms. If symptoms continue to persist despite medications, residents will be transferred to the designated hospitals in line with government directives. However, there may be cases where people are asymptomatic, but are still likely to transmit infection. This can be a significant challenge for care homes to address.

5.3.3. Managing staff availability and wellbeing

Care homes have taken multiple measures to manage staff availability and wellbeing. Staff have been minimized to reduce risks of infection, but partial or full salaries are continued to be given to staff that are not coming into the centre. This has increased financial strain among administrations, but they see no alternative options, as they do not want to lose trained caregiving staff. With respect to in-house staff, care homes are providing them with incentives (e.g. free food) and also taking measures to motivate and de-stress staff through regular checks-in/counselling.

5.3.4. Provision of health care and palliative care in care homes during COVID-19

Care homes are continuing to address medical needs and provide palliative care at their facilities. Residential facilities specific to dementia (such as those provided by Nightingales Medical Trust (NMT)) have professionals such as trained caregivers, family physicians, psychologist, therapists and psychiatrists, who are well equipped to manage medical issues and provide palliative care.

While there are no specific government guidelines for health care or palliative care provision during COVID-19 in care homes (as of May 30th 2020), the government has published a guidance note ³⁶ on enabling delivery of essential health services during the pandemic, which is directed towards states/UTs and briefly mentions elder care and palliative care. Pallium India—a national registered charitable trust and knowledge partner to the Kerala government— has published an e-book ³⁷ developed by a task force of palliative care experts containing guidelines for palliative care during COVID-19 targeted towards health professionals. This may be useful to professionals working in care homes.

5.4. Community-based care

5.4.1. Home-based care

Members of the family generally provide home-based care. In some cases, families may hire paid care attenders to help support the person they are providing care for with activities of daily living. However, due to measures in place to reduce risks of infection (such as the lockdown), these paid care attenders have been unable to come in. Families have had to fill this gap in care provision themselves.

The government has published a guidance note ³⁶ on enabling delivery of essential healthcare services during the pandemic directed towards states/UTs. The guidelines briefly remark on

care for elderly/disabled and palliative care patients. For these population groups, the guidelines emphasize that sub health centres (first point of contact to the primary healthcare system) must maintain a list of individuals that require support during the pandemic to enable frequent follow-ups. The guidelines state that Auxiliary Nurse Midwives (ANMs—community health workers) must visit these households twice a month to monitor development of complications/ treatment adherence and that Accredited Social Health Activists (ASHAs—community health workers) should keep in contact with these individuals and their families via telephone. It is also recommended that communication of risks and screening for onset of symptoms (such as cough/breathlessness etc.) must be conducted in these population groups.

5.4.2. Day care

There is data available on the measures adopted by dementia specific day care centres. This is elaborated in 5.7.

5.5. Impact on unpaid carers and measures to support them

There is limited published information on the impact of the pandemic on family caregivers (unpaid carers) in India as of end of May. Primary caregivers (family members) are likely to be spending a greater proportion of their time on providing care during the pandemic than prior to. This can significantly increase caregiver stress, as families may struggle to adapt to changes in routines. With the temporary closure of facilities such as day care centres and the inability of paid home carers to come in, many family caregivers may have limited respite time. Other than ensuring that the person they are providing care for remains engaged; carers also have to take additional preventative measures to reduce risks of infection, which can lead to further increase in stress experienced by caregivers. In addition, the pay cuts and job losses associated with the pandemic may exacerbate the financial burden experienced by family caregivers.

Currently (as of May 30th 2020), there are no measures issued by the government that are specifically targeted towards addressing the needs of unpaid carers during the pandemic. However, a few initiatives may indirectly provide support to unpaid carers at this time. The Ministry of Health and Family Welfare (MoHFW) has issued an advisory ²¹ directed to elderly population, which may provide guidance to caregivers of older people. The MoHFW has also established a psychosocial behavioural helpline, released videos on meditation and yoga for stress management and provided tips to take care of one's own mental health and mental health of elderly during this period on their website ⁷.

5.6. Impact on people with intellectual disabilities and measures to support them

According to Census (2011) data ³⁸, 2.2% of the total population (1.3 billion) are living with a disability in India. On March 27th 2020, two days after a nationwide lockdown was introduced, the Ministry of Social Justice and Empowerment (MSJE) published comprehensive guidelines ²⁴ to states/UTs for the protection of persons with disabilities during the COVID-19 pandemic. These guidelines emphasize the importance of caregivers being able to reach the person they are providing care to and recommend for passes be issued for caregivers to travel during the lockdown. The guidelines also recommend that essential services (such as food, medications)

be delivered to people with disabilities at their place of residence and stresses that all information available on COVID-19 should be in formats (braille, audio tapes, videos with subtitles etc.) accessible to persons with disabilities.

A number of guidelines and advisories specific to COVID-19 have also been published by The National Institute for Empowerment of Persons with Intellectual Disabilities (under the MSJE) on their official website ³⁹. These include handouts/ guidelines for: informing people with disabilities about COVID-19, parents of children with special needs and addressing challenging behaviours in a young person at home ³⁹.

In addition, certain states (e.g. Telangana) also launched toll free helplines to support people with disabilities and senior citizens during the lockdown ⁴⁰.

5.7. Impact on people living with dementia and measures to support them

There are currently 5.29 million people living with dementia in India ³¹, though only 1 in 10 people with dementia are likely to receive a diagnosis and hence the numbers may be substantially higher ⁴¹. People living with dementia have an increased risk of infection — due to difficulties in understanding or remembering preventive measures such as social distancing and frequent hand washing— and are more susceptible to complications associated with COVID-19 due to various co-morbidities ⁴². The efforts taken to contain the spread of COVID-19 infection and protect at risk populations have significantly impacted the routines of people with dementia. People with dementia are restricted to their houses, unable to carry out daily activities like visiting day care centres for cognitive stimulation exercises or engaging in outdoor physical activities. Their paid care attenders are also unable to come in due to travel restrictions. Such changes in routine can result in the development of distressed behaviours such as confusion, restlessness and wandering among people with dementia. This can create substantial stress among caregivers, who are unable to visit their physicians for guidance due to the suspension of routine healthcare services and also fears of exposing themselves and the person with dementia to COVID-19.

While there have been no government measures specific to people with dementia, the government has issued a health advisory for elderly population ²¹ and guidelines for people with disabilities ²⁴, which are applicable to people with dementia. Some public hospitals (e.g. National Institute of Mental Health and Neurosciences) have also initiated telemedicine consultations ⁴² and issued guidelines for caregivers of older people with dementia ⁴³.

Efforts are also being carried out by private and non-governmental organizations to support people with dementia and their families. With day care facilities being temporarily suspended in line with government directives, NGOs (e.g. Alzheimer's Related Disorder's Society of India (ARDSI), Nightingales Medical Trust (NMT) and Silver Inning's) have published guidelines for family caregivers for people with dementia ⁴⁴, are reaching out to families via social media platforms, providing one-on-one counselling via telephone and holding caregiver support meetings via Zoom ⁴². The Nightingales Medical Trust (NMT), for example, is using an app known as DemKonnect to offer expert advice to family members during the pandemic and engage persons with dementia through activities such as brain games and guided reminiscence therapy.

For people with dementia residing in long-term care facilities —predominantly provided by NGOs and private organizations— steps have been taken to reduce risks of infection and protect residents. NGOs have adopted sanitization and disinfection measures and are providing regular training to staff to facilitate implementation of such preventive measures. They have restricted visitors (e.g. stopped new admissions, restricted staff that do not reside at the facility and restricted family members) and created separate rooms/wards to isolate residents that have influenza like symptoms. Staff members are also being motivated through de-stressing activities, regular counselling and preparation of duty rosters in such a way that no staff member is overly burdened with responsibilities. It is uncertain to what extent such measures have been adopted by all residential facilities and care homes in the country, as there is limited data available on this as of May 30th 2020.

6. Lessons learnt so far

- The COVID 19 pandemic has highlighted the significant vulnerabilities in public health and social care systems and demonstrated the urgent need to recognize and address these issues in order to reduce the impact of the current pandemic and improve responses to future public health emergencies.
- There has been a successful coming together of experts from medical, social and policy domains. Sustained collaboration between these groups is critical to reframe and adapt existing models of service in the country.
- The COVID 19 crisis has revealed the critical role played by traditional systems of caregiving (family-based care) in long term care, while underscoring the need to develop formal ways of providing long-term care and support to carers.

6.1. Short-term calls for action

- There is a crucial need for people with long-term care needs and their carers to be identified and acknowledged as vulnerable groups so that immediate efforts can be directed towards supporting these populations.
- There is an urgent need for information on the prevalence of COVID-19 in individuals with long-term care needs and their carers, as there is a clear gap in evidence with respect to this.
- Guidelines on reducing and managing risks of infection in long-term care centres need to be developed as soon as possible.
- It is critical to ensure that vulnerable people with long-term care needs and their carers have access to medical and psychological support services during this period of emergency.

6.2. Longer term policy implications

• The COVID 19 pandemic has demonstrated the major gaps in the long-term care system and the resulting consequences this has had on people with long-term care needs and

their families. It is imperative to establish an organized system that is able to effectively also support informal care provision. The first step towards achieving this would be to develop a national long-term care policy or plan.

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