

# Economic costs experienced by family carers of people with dementia in India: A qualitative study

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**Informal care is not free and not even cheap**  
**GOLTC Changing the Narrative on Long-Term Care**

28<sup>th</sup> November 2025

# Dementia in India

“Estimated dementia prevalence for adults **ages 60+ in India is 7.4%**, with significant age and education gradients, sex and urban/rural differences, and cross-state variation”

**Lee and colleagues (2023, p.2)**



Low awareness and stigma delaying diagnosis



Shortage of dementia specialized professionals



Limited formal long-term care services available



Family primarily provides long-term care at home



Psychosocial support offered to carers limited



Out-of-pocket payments (OOP) associated with accessing care services



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# 33 brain health clinics launched in Karnataka

These clinics have been set up at district hospitals under the Karnataka Brain Health Initiative (KaBHI), supported by Nimhans.



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▶ [J Family Med Prim Care. 2024 Sep 11;13\(9\):3719–3729. doi: 10.4103/jfmpc.jfmpc\\_1984\\_23](#)

## Effectiveness of a training program in improving knowledge and skills about selected common neurological disorders among primary healthcare doctors: The Karnataka Brain Health Initiative (KaBHI) in India

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## The Impact of Carer's Allowance in Karnataka, India and Beyond

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*UPDATE: In March 2025, the Government of Karnataka extended the Carers Allowance to include unpaid carers of those with autism, intellectual disabilities, and complex disabilities such as deaf-blindness, bringing the disability categories included in the allowance to seven. This is another huge milestone for unpaid carers in India.*

# Aims

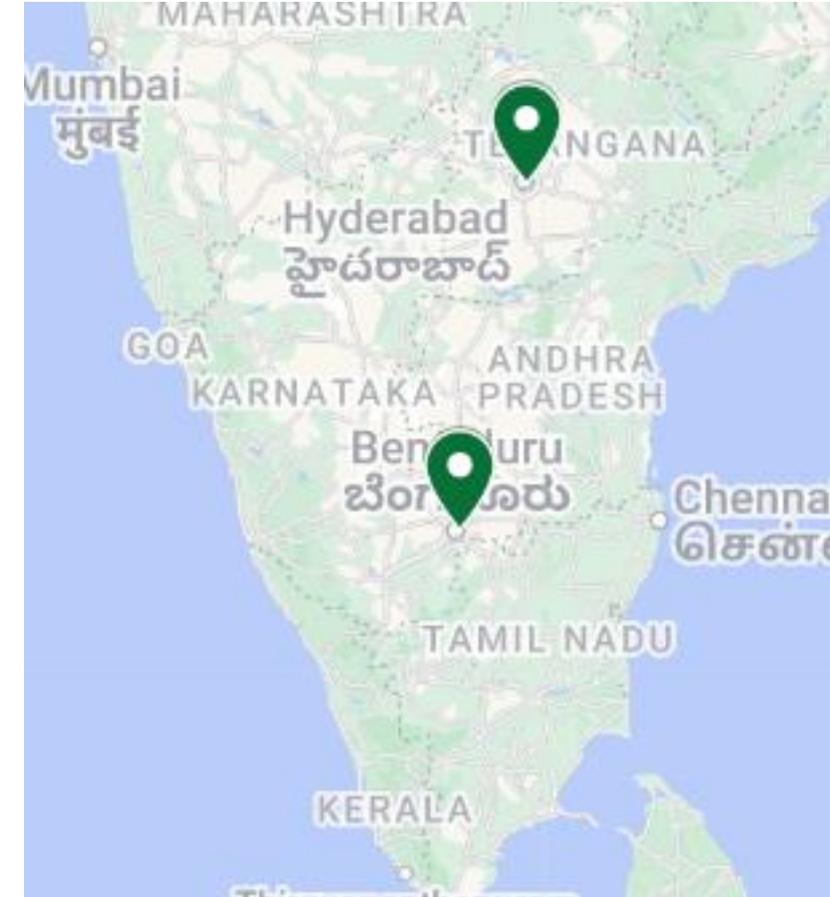
To understand the costs of providing care for persons with dementia in India:

- What are the range and nature of direct and indirect costs associated with caring for persons living with dementia?
- What is the impact of meeting them for persons with dementia and their families?

# Methodology

This research is part of a wider study that aims to understand the costs and consequences of providing unpaid carers for persons with dementia in India:

- Carers of people with dementia were identified among those accessing services at the National Institute of Mental Health and Neurosciences (NIMHANS), **Bangalore** and the Alzheimer's and Related Disorders Society of India Hyderabad Deccan Chapter, **Hyderabad**, or through existing participants
- Overall, **56 in-depth, semi-structured and repeat interviews** were conducted with **24 economically diverse participants** via telephone between March to September 2021
- In-depth, highly iterative **thematic analysis**



Type of Direct Cost	Summary
<p data-bbox="127 121 382 171"><b>Healthcare</b></p> <p data-bbox="12 235 509 514">Medical consultations, assessments and tests, hospitalizations, alternative medicine consultations.</p>	<p data-bbox="535 178 2535 349">For some even with subsidizations, costs were hard to manage: <i>“I don’t have the money to afford the MRI scan, since I have the BPL card, it is 1,900 for the scan....even to pay that much I don’t have”</i> [P18, 40-49, spouse of person living with early dementia, <b>38% of MI</b>].</p> <p data-bbox="535 406 2535 578">Health insurance not common: <i>“Those procedure are all big headaches. There won’t be enough funds in the government, it will get delayed, there won’t be people who will pursue it.”</i> [P21, 60-69 spouse of person living with early dementia]</p>
<p data-bbox="114 806 394 856"><b>Medications</b></p> <p data-bbox="38 921 471 1142">Dementia related medications, medications for co-morbid conditions</p>	<p data-bbox="535 863 2509 1035"><i>“But we are poor, so we did not take all the medicines we were able to take only six months....we didn’t have money to buy more medicines, so the medicines are stopped”</i> [P6, 30-39, son of person with moderate dementia, <b>cost 6x higher than MI</b>]</p>

Type of Direct Cost	Summary
<p data-bbox="71 111 428 211"><b>Travel and accommodation</b></p> <p data-bbox="25 282 504 668">Travel from one state to another for specialist services (train, bus, auto), accommodation in city, auto/taxi to health facility.</p>	<p data-bbox="540 111 2344 157">This was significant for participants from semi-urban, rural areas and/or other states:</p> <p data-bbox="540 282 2458 442"><i>“to go from here and then to come back it took almost about nine to ten thousand only on travelling, so we stayed there for ten days, so one thousand rupees per day we had pay”</i> [P16, 18-29, daughter of person living with moderate dementia, <b>costs 40% of MI</b>]</p>
<p data-bbox="25 699 484 799"><b>Care support services ('social care')</b></p> <p data-bbox="25 871 504 1085">Attender, domestic helper that supports care provision, day care services.</p>	<p data-bbox="540 699 2509 742">Incurred only by participants residing in urban areas and who were middle income and above.</p> <p data-bbox="540 813 2484 913"><i>P1 mentions they are only able to afford to use day care services on alternate days.</i> [P01, 18-29 years, son of person living with early dementia.</p> <p data-bbox="540 1042 2458 1142"><i>P4 sold land he owned to meet costs of attenders.</i> [P04, 80-89 years, spouse of person living with severe dementia]</p>

Type of Indirect Cost	Summary
Reduction in person with dementia's income	<p><i>"When uncle was earning, I didn't have problem [with finances] and all. He used to maintain all the household expenses."</i> [P18, 40-49, spouse of person living with early dementia].</p>
Reduction in carer's income	<p><i>"We were there for 17 days , (then) 15 days, we didn't work, we lost that money (daily wage), then it cost so much"</i> [P6, 30-39, son of person living with moderate dementia]</p>
Impact on education/career opportunities	<p><i>"Unfortunately, I did not get to complete my degree in the US. So, when I came back, I was finishing my graduation in the US, okay? Now, effectively my credits never transferred over. had other things to take care, so I finally decided to start college all over again."</i> [P10, 30-39, daughter of person living with severe dementia"]</p> <p><i>"I will sometimes take half a day off or some time off and re-join again. I have told them [employer] the reason. I also mentioned that because of that only I have a job requirement"</i> [P24, 18-29, daughter of person living with dementia]</p>

Type of Indirect Cost	Summary
<p><b>Impact on financial security</b></p>	<p><i>“The rest of the tablets, everything it was from my savings. I had my savings for my marriage” [P22, 18-29 years, daughter of person living with moderate dementia]</i></p>
<p><b>Impact on carer health</b></p>	<p><i>“I don’t know how many days it takes [ for knee surgery] who is there to look after Mamu, a least it will take 3 months for me to come back to the normal routine...For money...the older son was ready to help a little bit” [P8, 60-69, spouse of person living with severe dementia]</i></p>

**We identified indirect costs that had not been noted before because of the inductive approach and use of repeat interviews.**

# Conclusions

- As found in previous studies on costs of dementia in LMICs, families experience several costs (direct and indirect) associated with care provision.
- Direct and indirect costs are not proportionate to income.
- Costs considerably affected the lowest income groups.
- This research has the potential to aid in the development of the measures currently used in costing studies - both on dementia and other long-term conditions.

# Thank you

For more information please contact: [j.rajagopalan@lse.ac.uk](mailto:j.rajagopalan@lse.ac.uk)

STRiDE India Country Page: <https://stride-dementia.org/country-page/india/>

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