Accessibility of social entitlements by leprosy affected living in different localities: Leprosy Colonies and the general community in 4 states of India

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Summary
Objective: To study the level of access to general and specific entitlements for people affected by leprosy and to compare the level of access available to those living in leprosy colonies and general communities, among the four states Uttar Pradesh (UP), Chhattisgarh (CG), Andhra Pradesh (AP) and Tamil Nadu (TN) within India.

Methods: This is a cross-sectional descriptive study. A total sample size of 379 included 100 from UP, 100 from CG, 101 from AP and 78 from TN, of which 161 were from leprosy colonies and 218 from the general community. The study is the outcome of the baseline survey carried out from 2016 to 2017 for the CREATE Project.

Results: The study clearly shows that the largest difference in accessibility to general schemes between leprosy colonies and the general community was found in the state of UP (4 schemes) and is comparatively less in CG (3 schemes) with the lowest difference being found in the states of AP (2 schemes) and TN (1 scheme). With regards to specific schemes, UP once again had the greatest difference in accessibility (7 schemes) followed by AP (5 schemes) with the least difference being found in the states of CG (3 schemes) and TN (1 Scheme).

Conclusions: The study concludes that accessibility differences among the four states from maximum to minimum in order is UP, CG, AP and TN, indicating the influence of local demographic and cultural factors on the accessibility process required for state specific approaches. Overall the colony dwellers have better access to both the general and specific schemes when compared to those living in the general community.

Keywords: Person affected by leprosy, colony, community, entitlements, states

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Introduction

In India, the government provides many special schemes and entitlements for a number of physically and mentally challenged people, through acts such as Persons With Disabilities (PWD) Act 1995 and Rights of Persons with Disabilities (RPWD) Act 2016, which also cover those disabled through leprosy. The PWD Act 1995 constitutes an important step towards empowering the disabled in India. Based on the provisions of the Act those who are 40% disabled, as certified by a Governmental medical authority, are entitled to receive certain benefits from the Government of India.

In the new RPWD Act 2016, 21 different types of disability alongside those affected by leprosy are included and in order to gain access to governmental benefits a certificate is required noting the person as having a minimum disability of 40%.

Other special welfare schemes not covered by the above Acts, but provided by the state governments for those affected by leprosy with the 40% disability certification, include monthly disabled pension grants; for example, UP (Rs.2500/-), TN (Rs.1500/-), AP (Rs.1000/-) and CG (Rs.350/-). In all the states of India, Micro Cellular Rubber (MCR) footwear is provided twice a year free of cost, and an amount of Rs.8000/- is paid towards the indirect costs related to major reconstructive surgery for deformity correction.

It should be noted that the level of accessibility to these benefits by the potential beneficiaries is very low in general and especially in the case of those affected by leprosy. The possible reasons may be:

- The persons affected by leprosy are not aware of their rights and entitlements to access them.
- The authority which provides the entitlements is not well equipped with adequate knowledge to deliver their services.
- There may be various administrative and financial constraints.
- In some cases, the affected person is aware and the authority denies the entitlements due to incomplete documentation and follow up mechanisms.

A World Bank report emphasizes that there is limited awareness of the entitlements under the Act – a key constraint in implementation.

The three main challenges in receiving benefits and services include: (i) physical access problems; (ii) problems with procedures and officials; and (iii) communication difficulties for disabled people in approaching providers.

In addition, the institutions from which PWD most often reported receiving services and benefits were at the district level, though panchayats (local administration at village level) were growing in significance.

Before the advent of Multi Drug Treatment (MDT), many leprosy colonies developed across India. After effective cure for leprosy was ensured through MDT, the reduction in new cases helped to develop the concept of inclusion and reduce the stigma associated with leprosy.

The majority of Non-Governmental Organisations (NGOs) which worked very closely with the leprosy colonies for many years, advocated for their rights and entitlements, as groups were able to be located and trained easily. In contrast, those affected by leprosy living in the general community did not reveal their identity and were not willing to join any groups for fear of prejudice and discrimination. This meant that it was difficult for NGOS to form groups and locate these people for training and capacity building. There is therefore an
impression that the leprosy-affected living in the colonies have better access to social services and are more empowered than those living in the general community.

A recent study conducted on access of leprosy colony dwellers to entitlements, points out that the least accessible entitlement was the labour card, followed by the railway concession certificate, bus pass, disability pension and low caste certificate – accessed by 29%, 31%, 34%, 49% and 49% of eligible individuals, respectively. Access to such essential benefits by less than 50% of those eligible colony dwellers leaves us in a dilemma – whether it is better to emphasize the colony approach or the community approach to promote maximum access to these benefits and entitlements. Furthermore, it is essential to assess the influence of increased services on the colony dwellers by comparing the access of those living within the leprosy colony as homogenous groups in a closed association, with those living in the general community in scattered heterogeneous groups in an open environment. In the present study we attempted to answer the above questions.

Objectives: specific objectives of the present study are:

1. To study the level of access to general and specific entitlements for the persons affected by leprosy among four endemic states of India.
2. To compare the profiles of access to general and specific entitlements among the leprosy affected living in colonies or the general community.

Materials and methods

Study design, sample and setting:
This is a cross-sectional descriptive study carried out within four states, designed to compare the level of accessibility between the leprosy colony dwellers and those living in the general community with regard to all the schemes and entitlements applicable for the leprosy affected, specifically in each state and on aggregate of the four states of AP, TN, CG and UP.

The total sample size of 379 includes from Uttar Pradesh (UP) 100, Chhattisgarh (CG) 100, Andhra Pradesh (AP) 101 and Tamil Nadu (TN) 78, out of which 161 are from leprosy colonies and 218 are from the general community. This study used baseline data collected during 2016 to 2017 for the CREATE Project, which was approved by TLM Research ethical committee and received financial support from European Union and TLM England and Wales.

Study tools:
Interview Schedule: An interview schedule was used to gather the information about the demographic details and data about the schemes and entitlements accessed by those affected by leprosy living in colonies and the general community. This information comprises of eight general schemes including the AADHAR Card, Ration Card, Voter ID Card, MNERGA scheme, BPL Card, AAY, unemployment allowance and housing grant. It also includes 11 specific schemes such as the disability certificate, disability pension, old age pension, bus pass, train pass, MCR (Micro Cellular Rubber) footwear, tricycle, aids and appliances, RCS (Reconstructive Surgery) economic assistance, SHG (Self Help Group) loans and any other benefits of the various entitlements available for those affected by leprosy in India. (Appendix 1)

The data were collected by trained research workers in scheduled interviews through asking simple questions about the possession of the entitlements from all the respondents of four states. Verbal consent was obtained from each respondent beforehand and anonymity was ensured. The data collected were analyzed in SPSS using appropriate statistical tests.
Results

Access to general and specific schemes and entitlements by leprosy affected persons living in leprosy colonies, referred to below as ‘Colony’, was compared with those living in the general community, referred to below as ‘Community’.

Access to general schemes:

1. Access to AADHAR Card in Colony and Community (Table 1): All (100%) the leprosy affected persons living in colonies of TN, AP, CG and UP and almost all those living in Communities of TN, AP, CG and UP (98.1%), possess the AADHAR card. The difference between Colonies and Community is not significant in all four states. Since this entitlement is mandatory to access all essential services for every Indian citizen, little variance was expected.

2. Access to the Ration Card in Colony and Community (Table 2): The majority of leprosy affected persons living in colonies of TN (100%), UP (97.7%), CG (95.7%) and AP (95%) as well as those living in Communities of AP (100%), CG (94.3%), TN (93.1%) and UP (92.3%) have a Ration Card. The difference between Colony and Community is not significant in all the 4 states. Since this entitlement is mandatory for providing rations and for proof of address, little variance was expected.

3. Access to the Voter ID Card in Colony and Community (Table 3): The majority of leprosy affected persons living in colonies of TN (100%), CG (97.9%), AP (96.9%) and UP (75%) and those living in the Communities of CG (98.1%), AP (97.6%), TN (97.2%) and UP (94.2%) have a Voter ID Card. The difference between Colony and Community is not significant in TN, AP and CG but is significant in UP and for the total sample (P < 0.05). Since this entitlement is mandatory for every Indian citizen to be able to vote there was not much difference in most states, except for UP. Here the differences may be due to various socio-demographic and cultural factors.

4. Access to Mahatma Gandhi National Rural Employment Guarantee Act (MNERGA) in Colony and Community (Table 4): The majority of leprosy affected people living in colonies of TN (66.7%) and in the community of TN (70.8%) possess MNERGA. whereas, the majority of those in colonies in CG (97.9%), UP (93.8%) and AP (86.7%) and in the communities of UP (84.6%), CG (77.4%) and AP (65.9%) do not have MNERGA. The difference between Colony and Community is not significant in TN and UP, but is significant in AP and CG and for the total sample (P < 0.05). Since this entitlement was not mandatory, and the person has to apply for it, the difference between the states is due to various socio-demographic and cultural factors.

5. Access to BPL Card (Below Poverty Line) in Colony and Community (Table 5): The majority of leprosy affected persons living in colonies of UP (89.6%), AP (81.7%), CG (68.1%) and TN (50%) and those living in the communities of CG (86.8%), AP (85.4%), UP (65.4%) and TN (22.2%) possess a BPL Card. The difference between Colony and Community is not significant in TN and AP but is significant in CG and UP and for the total sample (P < 0.05). Since this entitlement is not mandatory and the person has to apply for it, the difference among the states is due to various socio-demographic and cultural factors.

6. Access to the AAY scheme (Antodaya Anna Yojna) in Colony and Community (Table 6): The majority of leprosy affected persons living in the colonies of CG (72.3%), AP...
(65%), UP (62.5%) and TN (50%) are part of the AAY Scheme. Whereas the majority of those living in the communities of TN (83.3%), UP (59.6%), CG (56.6%) and AP (53.7%) are not a part of the AAY Scheme. The difference between Colony and Community is not significant in TN, but is significant in AP, CG and UP and for the total sample ($P < 0.05$). Since this entitlement is not mandatory and the person has to apply for it, the difference between the states is due to various socio-demographic and cultural factors.

7. Access to the unemployment allowance in Colony and Community (Table 7): A majority of leprosy affected persons living in colonies of TN, AP, CG & UP (100 % each), as well as those living in Communities of AP, CG & UP (100% each), TN (98.6%) do not have the unemployment allowance. The difference between Colony and Community is not significant in all the 4 states. Since this entitlement is not mandatory and the person has to apply for it, the difference between the states is due to various socio-demographic and cultural factors.

8. Access to the housing grant in Colony and Community (Table 8): The majority of leprosy affected persons living in colonies of UP (64.6%) and AP (55%) possess a Housing Grant. Whereas the majority of those living in the Colonies of CG (89.4%) and TN (50%) and in the Communities of UP (90.4%), CG (83%), AP (78%) and TN (66.7%) do not have a Housing Grant. The difference between Colony and Community is not significant in AP and CG, but is significant in TN and UP and for the total sample ($P < 0.05$). Since this entitlement is not mandatory and the person has to apply for it, the difference among the states is due to various socio-demographic and cultural factors.

9. Access to the Disability Certificate in Colony and Community (Table 9): The majority of leprosy affected persons living in the colonies of TN (100%), UP (93.8%), AP (93.3%) and CG (63.8%) and those living in communities of AP (100%), TN (94.4%), UP (69.2%) and CG (39.6%) have a disability certificate. The difference between Colony and Community is not significant in TN and AP but is significant in CG and UP and for the total sample ($P < 0.05$). Since this entitlement is applicable for person with disabilities and they have to apply for it, the difference between the states is due to various socio-demographic and cultural factors.

10. Access to the disability pension in Colony and Community (Table 10): The majority of leprosy affected persons living in colonies of TN (100%), UP (89.6%), AP (78.3%) and CG (44.7%) as well as those living in communities of AP (92.7%), TN (77.8%), UP (42.3%) and CG (26.4%) have a disability pension. The difference between Colony and Community is not significant in TN, but is significant in AP, CG and UP and for the total sample ($P < 0.05$). Since this entitlement is applicable to persons with disabilities and they have to apply for it, the variance between the states is due to various socio-demographic and cultural factors.

11. Access to old age pension in Colony and Community (Table 11): The majority of leprosy affected persons living in colonies of TN (100%), UP (100%), AP (95%) and CG (88.9%) as well as those living in the communities of TN (100%), AP (100%), UP (100%) and CG (98.1%) do not have an old age pension. The variance between Colony and Community is not significant in all the four states, but is significant for a total sample ($P = <0.05$).

12. Access to Bus passes in Colony and Community (Table 12): The majority of leprosy affected persons living in the colonies of TN (100%), UP (85.4%) and AP (73.3%) as well as living in communities of AP (61%) possess a bus pass. Whereas, in CG (100%)
majority in Colony and in Community CG (100%), TN (72.2%) and UP (63.5%) do not have a bus pass. The variance between Colony and Community is not significant in AP and CG, but is significant in TN and UP and for the total sample (P = <0.05).

13. Access to Train passes in Colony and community (Table 13): Majority of leprosy affected persons living in the colonies of UP (58.3%) and AP (55%) possess a train pass. Whereas, the majority of those living in the colony in CG (95.7%) and TN (66.7%) and in community in CG (100%), TN (90.3%), UP (88.5%) and AP (70.7%) do not have a train pass. The variance between Colony and Community is not significant in TN and AP, but is significant in CG and UP and for the total sample (P = <0.05). Since this entitlement was applicable for those affected by leprosy and they have to apply for this the variance among the states are due to various socio demographic and cultural factors.

14. Access to MCR (Micro Cellular Rubber) footwear in Colony and Community (Table 14): The majority of leprosy affected persons living in the colonies of CG (83.3%), AP (77.1%), UP (70%) and TN (48.9%) and in the Communities of TN (59.7%) and AP (53.7%) possess MCR Footwear. Whereas the majority of Communities in CG (83%) and UP (78.8%) do not have MCR Footwear. The variance between Colony and Community is not significant in TN and AP, but is significant in CG and UP and for the total sample (P = <0.05). Since this entitlement was applicable for those affected by leprosy and they have to apply for this the variance among the states are due to various socio demographic and cultural factors.

15. Access to tricycle in Colony and Community (Table 15): Majority of leprosy affected persons living in colonies of UP (58.3%) possess a tricycle. Whereas, the majority of Colonies in TN (100%), CG (93.6%) and AP (80%) and in the communities of AP (100%), CG (98.1%), TN (94.4%) and UP (94.2%) do not have a tricycle. The variance between Colony and Community is not significant in TN and AP, but significant in CG and UP and for the total sample (P = <0.05).

16. Access to aids and appliances in Colony and Community (Table 16): The majority of leprosy affected persons living in the colonies of TN (100%), AP (90%), CG (89.4%) and UP (50%) and in the Communities of AP (100%), CG (94.3%), UP (92.3%) and TN (90.3%) do not have aids and appliances. The variance between Colony and Community is not significant in TN and CG, but is significant in AP and UP and for the total sample (P = <0.05).

17. Access to Self-help Group (SHG) Loans in Colony and Community (Table 17): The majority of leprosy affected persons living in the colonies of AP (55%) possess SHG loans. Whereas the majority from the Colonies of UP (100%), CG (95.7%) and TN (66.7%) and in the Communities of AP (100%), CG (98.1%), UP (98.1%), TN (76.4%) and AP (61%) do not have SHG Loans. The variance between Colony and Community is not significant in all the 4 states, but is significant for the total sample (P = <0.05).

18. Access to Reconstructive Surgery (RCS) economic assistance in Colony and Community (Table 18): The majority of leprosy affected persons living in the colonies of TN (100%), CG (87.2%), AP (85%) and UP (72.9%) and in the communities of CG (94.3%), UP (80.8%), TN (77.8%) and AP (73-2%) do not have RCS economic assistance. The variance between Colony and Community is not significant in all four states. Since this entitlement is applicable for those affected by leprosy and they have to apply for this, the variance among the states are due to various socio demographic and cultural factors.

19. Access to any other benefits in Colony and Community (Table 19): The majority of leprosy affected persons living in colonies of TN (100%), UP (100%), CG (66.7%) and AP (66.7%) and in the communities of AP (100%), CG (94.3%), UP (97.2%), TN (90.6%) and AP (87.8%) do not have any other benefits. The variance between Colony and Community is
not significant in TN, CG and UP, but is significant in AP and for the total sample (P = < 0.05).

Summary of findings with regard to variation between Colony and community: All the above findings with regard to the significance of the differences between leprosy colony and general community towards accessibility have been summarized in the following table.

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<th>Variation on aggregate</th>
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<td>Any other Benefits</td>
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NS: Statistically not significant; SIG: Statistically significant.

**Discussion**

Significant differences between Colony and Community in accessibility of general schemes:

- A significant difference is found in three states with regard to Antayodaya Anna Yojna (AAY) schemes which occurs in AP, CG and UP but is not found in TN
- A significant difference is found in two states with regards to three schemes:
- For the MNERGA scheme there was a significant difference in AP and CG but not in TN and UP. For the BPL card scheme there was a significant difference in CG and UP but not in TN and AP. In regards to the housing grant scheme there was a significant difference in TN, UP, AP and CG
- A significant difference is found in one state with regards to Voter ID card in UP and not in TN, AP and CG
- There were no significant difference found in any of the four states with regards to the AADHAR Card, ration card and unemployment allowance
Significant differences between Colony and Community in accessibility of specific schemes:

- A significant difference is found in three states with regard to disability pension and is found in AP, CG and UP but not in TN.
- There is a significant difference in two states for a total of four schemes:
  - The disability certificate was significantly different in CG and UP but not in TN and AP
  - The bus pass was significantly different in TN and UP but not in AP and CG
  - The train pass was significantly different in AP and UP but not in TN and CG
  - Aids and appliances were significantly different in AP and UP but not in TN and CG
- A significant difference is found in one state with regards to all other benefits in AP but not in TN, CG and UP
- There was no significant difference found in any states with regards to old age pension, SHG loans and RCS economic assistance

Access to general schemes:
Persons affected by leprosy living in colonies have more access to general schemes than those living in communities, for the following schemes: BPL card (78.9% and 60.1%), AAY scheme (65.8% and 34.4%). On the other hand, persons living in community have more access than those in colonies for schemes such as the Voter ID Card (96.8% and 90.7%), MNERGA scheme (39% and 9.9%) and housing grant (78.4% and 55.3%). It is important to note that only one (1.2%) person out of a total sample of 122 accessed the unemployment allowance.

Access to specific schemes:
Persons affected by leprosy living in colonies have more access to specific schemes than those living in communities for the following schemes: disability certificate (85.1% and 76.1%), disability pension (72.7% and 59.6%), old age pension (5% and 0.5%), bus pass (56.5% and 29.4%), train pass (40.4% and 11.5%), MCR footwear (66.5% and 39%), tricycle (26.7% and 3.7%), aids and appliances (21.7% and 6.4%), SHG loans (23% and 16.1%) as well as any other benefits (17.4% and 5.5%). The data show clearly that access to specific entitlements in both groups is limited and is reduced for the those living in the community.

Our findings are similar to an earlier study done in Gujarat,8 where 71% of the disabled people had certificates, but 19% did not know about the certificate at all.9 Even with a disability certificate, benefit entitlements vary enormously across the country. Only 40% of the participants in the focus group held in Kolor district, Karnataka, were receiving the state disability allowance, despite being active members of disability self-help groups and Karnataka being one of the most proactive states on disability issues. In Gujarat, most disabled people with a certificate had used it only to access certain benefits, such as a bus pass and educational scholarships. Only 3% had received monetary support from the government on a regular basis.9 One of the reasons for the low level of access, as also stated in earlier studies, may be that the procedures to obtain the benefits are often byzantine and costly. Even when official records indicated that a large number of medical camps had been organised, many people remained unaware of them and were unable to get themselves assessed by a doctor for a disability certificate.10

Lack of awareness influenced by illiteracy also may be other reasons, as stated in earlier studies - many disabled people are not aware of their rights under the act. In a country with 15
Major languages, and low levels of literacy, dissemination of information is a problem\textsuperscript{11} and people affected by leprosy are still illiterate and not aware of their rights and entitlements.\textsuperscript{12}

Access to services is time-consuming and cumbersome government procedures and corruption both act as additional barriers that prevent disabled people from accessing services. Most informants noted the difficulty in obtaining disability certificates, required in order to access state subsidized disability services and entitlements.\textsuperscript{9}

People with disabilities can only organize themselves to claim their rights when their additional practical needs, such as for mobility aids, have been met. People with disabilities also face numerous barriers in realizing equal opportunities; environmental and access barriers, legal and institutional barriers, and attitudinal barriers which cause social exclusion. Social exclusion is often the hardest barrier to overcome, and is usually associated with feelings of shame, fear and rejection. Negative stereotypes are commonly attached to disability. People with disabilities are often assigned a low social status and in some cases are considered worthless.\textsuperscript{13}

Attitudes are a major barrier to equalization of opportunities: While lack of services and lack of knowledge and technology are serious constraints, perhaps the greatest obstacle to full participation and equality is the prevalence of negative attitudes on the part of non-disabled persons in the family and the community.\textsuperscript{14}

Limited access to social protection and security are a major barrier to economic and social development. Only 27\% of the world’s population enjoys access to full social protection. Persistent low coverage of these benefits, especially among persons with disabilities, results in restricting their engagement as productive/contributing members of society.\textsuperscript{15}

James Staples, a social anthropologist carried out a study in South India which explores some of the contexts in which leprosy patients actively manage their own situations in colonies, often in defiance of prevailing development orthodoxies. He concludes that closer observation and analysis of the strategies patients use to manage their disease status would have important policy implications.\textsuperscript{16} Similarly in Brazil, new approaches to providing benefits to people affected by leprosy are being pursued, including for those in long-term care.\textsuperscript{17}

Many studies have shown the significant impact of those living in colonies which have both better resources combined with social exclusion. In our study those people living in leprosy colonies have better access to entitlements and resources due to their homogenous groups, with and sharing of information being better facilitated by the group leaders. The NGOs working for the people affected by leprosy are able to involve the leprosy colonies in capacity building training on rights and empowerment. The people living in colonies feel empowered and more capable of organizing themselves to achieve their rights than those living in mixed communities who have fewer opportunities and suffer more discrimination, resulting in limited access to entitlements.

Inter-state variance in the profile of accessibility:
Our study clearly shows that the maximum difference between the colony and community as regards accessibility to general entitlement schemes was found in the state of UP (four schemes) and is comparatively less in CG (three schemes) and is the lowest in the states of AP (two schemes) and TN (one scheme). Whereas, with regards to specific entitlement schemes, the largest differences were present in the state of UP (seven schemes) followed by AP (five schemes) and the least in the states of CG (three schemes) and TN (one scheme).
This may suggest that awareness about the schemes and entitlements needs to be raised in all the states, but is more essential in UP with regards to both general and specific schemes in comparison with CG, AP and TN.

Access to general schemes is better among colony dwellers with regards to the AADHAR card, ration card, BPL card and AAY scheme. Whereas, those living in the general community have better access to certain schemes like the Voter ID Card, MNERGA scheme and housing grant.

With regards to specific entitlement schemes, colony dwellers have better access to the disability certificate, disability pension, old age pension, bus pass, train pass, MCR footwear, tricycle, aids and appliances, SHG loans and any other benefits, whereas persons living in the community have better access only to RCS economic assistance. While most of the entitlements have been accessed by colony dwellers, it is important to advocate that government authorities should give priority for those affected in mixed communities to access their rights and entitlements, in order to enhance their quality of life.

**Conclusion**

The study concludes that:

- Significant differences between colony and community as regards the accessibility of general and specific entitlement schemes in all four states suggests the need for different approaches in different states.
- The differences between the four states rank in order from maximum to minimum: UP, CG, AP and TN. Overall, the differences demonstrate the influence of local demographic and cultural factors on the accessibility processes, which clearly require state specific approaches.
- On average, the colony dwellers have better access to both the general as well as specific entitlement schemes and benefit from their group approach.
- The few entitlements better accessed by general community members require high individual motivation, but sustainable change in relation to other schemes will be possible only through a collective approach. Government authorities and NGOs working to improve the welfare of those affected by leprosy should aim to make all the necessary schemes and entitlements available at community level so that those affected don’t have to live in colonies.

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Contributions of each author

Mr MD Monickaraj, was involved in the study conceptualization and design, obtaining permission for the study, as well as monitoring and manuscript writing.

Dr MS Raju, was involved in data analysis and interpretation, writing the first draft of manuscript and finalizing it for submission.

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