Improving Access to Health Services to Marginalized Population: A Case Study of Little Flower Leprosy Hospital, Bihar

Leprosy: The Indian Scenario

Leprosy, also known as Hansen's disease, is a chronic infectious disease caused by Mycobacterium leprae that majorly affects an individual's skin, peripheral nerves, eyes, lining of the nose, and respiratory tract.[1]

Symptoms can start showing within one year of being infected or sometimes even after 20 years or more. It can transmit through nose and mouth droplets during close and frequent contact with untreated individuals. Leprosy is curable with multidrug therapy.[2] Due to lack of knowledge and understanding about the disease, it carries the heavy burden of stigma. This stigma is present at multiple levels: self-perceived, familial, and community.[3]

In India, the National Leprosy Eradication Programme came into existence in 1954-55 with the vision of a leprosy-free India. As of 2005, the country had achieved the target of less than 1 case per 10000 population, eliminating it as a public health problem.[4] However, there seems to be a notion that this declaration was hurried which led to lowered efforts among professionals at working towards battling this disease, as new cases have continued to appear in the last decade.[5] Presently, the prevalence rate of the disease in the country is 0.4 per 10,000 population.[6] In Bihar, the prevalence rate of leprosy cases in the period of January-October 2021 was 0.63.[7]

In the context of COVID-19, the scenario of leprosy in the country underwent some turbulence. There was a 62.5% fall in the detection of active leprosy cases during the period of April-September 2020 (as compared to 2019) in the states of Bihar, Odisha, Andhra Pradesh, and Madhya Pradesh.[8] Moreover, patients were faced with new challenges and difficulties. For example, due to lockdown there was limited availability of key leprosy services. Moreover, leprosy patients co infected with COVID-19 faced stigma and discrimination, in addition to the leprosy induced stigma they faced earlier.[9]

The present document elaborates the case of Little Flower Hospital located in Bihar, the challenges faced by it, the support extended by PATH, and learnings for the future.

Little Flower Hospital

Little Flower Hospital, run by the Little Flower Leprosy Welfare Association, is in Sunderpur, a village in the Raxaul block of the East Champaran district of Bihar. The hospital was built in 1982 by Baba Kris Das for the service of leprosy patients following which, individuals have been treated free of cost at the facility. The hospital has 15 rooms, 140 beds, 15 critical beds, and 52 staff. Currently, 70 leprosy patients are being treated at the facility. Since this hospital is located on the border of Nepal, leprosy patients from Nepal also come here for treatment, thus overburdening the hospital with high numbers of patients. A leprosy colony is also situated near the hospital where around 258 leprosy families are currently residing.

Image 1. Little Flower Hospital

Challenges

- Poor infrastructure

The hospital had major infrastructural issues such as non-availability of biomedical equipment, inadequate hospital management system, and poor physical structure of the hospital, such as damaged walls with cracks and uneven surfaces that were poorly painted and damp, doors were extremely narrow, and improper electrical wiring such as a tangle of extension cords and power strips sprouting from a single outlet. These conditions became a cause of major inconvenience for patients as well as the hospital administration. Moreover, due to these issues, when the condition of leprosy patients within the facility worsened, they had to be taken to a nearby health facility and treated there.

Image 2. General ward of the Little Flower Hospital

- Lack of technically trained staff

Individuals working in the hospital were persons who had leprosy before. They did not have any technical training and only knew the basics of dressing and serving. The hospital does not have any permanent MBBS doctor. There are ten doctors associated with the hospital who come on on-call basis.

- Stigma

There existed, and still exists immense stigma around leprosy cases. Individuals in the community have multiple misconceptions about the disease such as that it is a punishment or curse from God for one's sins, it spreads by sitting next to an affected person, leprosy patients should be kept isolated, there is no hope for someone affected by leprosy and that it is untreatable. This stigma often leads to a lot of fear and aversion among individuals, which can lead to isolating leprosy affected persons.

- COVID-19

In the second wave of COVID, many hospitals were closed due to lack of oxygen and necessary treatment. Hospitals were giving more priority to non-leprosy patients rather than leprosy patients. In this backdrop, a need for respiratory care management (RCM) also emerged.

Moreover, COVID-19 called for the need for a high level of personal hygiene, something that leprosy patients were unable to manage due to their deformities.

- Reduced Funding

Since India declared leprosy as eliminated in the country, leprosy care is receiving less attention from donors and the Government. This is leading to reduction in much needed funds for managing existing and new cases. This leads to a major challenge for charitable hospitals in the sense of provision of services without funds.

Support by PATH

- Provision of bio-medical equipment

To address infrastructural issues, PATH provided the hospital with necessary equipment such as multi para monitor, syringe pump, c-pap/bi-pap machine, ambu bag adult, and among others. To help with RCM, PATH provided equipment for oxygen-related needs of the patients. This helped the hospital provide better quality services to leprosy patients. For the complete list of equipment provided, please refer to Annexure 1.

- Capacity strengthening

Online and offline training and capacity strengthening sessions were conducted for the hospital staff (n=5). The sessions focused primarily on the use and operation of biomedical equipment provided to the facility by PATH. Since most of the equipment was new to the staff, they needed to be trained on their usage.

Image 3. Capacity strengthening session on use of biomedical equipment

- Improving physical structure of the hospital

PATH extended support in improving the physical structure of the facility such as painting the hospital, broadening the doors for easier trolley movement, etc. PATH supported the replacement of electrical wiring with high-quality, heavy-duty wiring, a much-needed resource for improving quality health services and patient safety, as well as for oxygen systems, especially during COVID-19. Moreover, support was also extended to make ramps in the facility, enabling easy movement for wheeled objects and devices.

- Awareness building for de-stigmatization

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In efforts to destigmatize leprosy, PATH onboarded and trained various community volunteers. The training focused on raising awareness and destigmatizing leprosy. These volunteers then went into the community and spread information and awareness about leprosy, dispelled myths, and misconceptions about the disease, and are still in the process of doing so. PATH also organized a workshop on the role of charitable hospitals in strengthening health and wellness.

Learnings

- Stakeholder coordination

Little Flower Hospital was one of the many facilities where this intervention was intended. Some facilities viewed PATH's support as an encroachment on their religious (Christian) land and were reluctant to accept the intervention. However, after seeing the success with Little Flower Hospital, they were more open and accepting of the intervention in their respective facilities. Building trust and long-lasting relationships with stakeholders is important and can help facilitate interventions in a better manner. Furthermore, adopting a community-centric approach towards leprosy can be a helpful way of dealing with such issues.

- Vendor allocation

While working with vendors on improving the physical structure of the hospital, there were instances wherein the work would take a very long time and would not be completed as the vendors moved to the next facility, leaving work half done in one. It is crucial to only allocate two facilities per vendor to ensure on-time completion of work.

Conclusion

Charitable hospitals are an important pillar of the Indian health system. They are often unnoticed despite their provision of quality health services to a large volume of patients at a very low cost, or in some cases no cost. Such hospitals need to be supported and require more investment/funding to continue their services.

PATH's intervention at Little Flower Hospital was successful and intentions to carry out the same in other facilities remain strong. Though the process of de-stigmatizing leprosy has been initiated, it will still take time to completely overcome the prejudice and bias that shackles this disease. The way forward is to strengthen the charitable hospital to an extent that it can provide immediate care for patients. Furthermore, rehabilitating leprosy-affected families and connecting them to the central and state welfare schemes of the state government is also required.

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Annexure 1

List of equipment provided by PATH to Little Flower Hospital:

S. No.	Equipment type
1	Multi para monitor
2	Syringe pump
3	Infusion pump
4	ECG machine12 channel
5	Portable x-ray machine
6	C-pap/bi-pap machine
7	Thermometer - infrared type
8	Ambu bag adult
9	Electrical suction apparatus
10	Stethoscope
11	ICU bed - motorized with mattress
12	Patient stretcher
13	Wheelchair (foldable)
14	Bedside stool
15	Crash cart
16	Dressing trolley
17	ECG machine trolley
18	Instrument trolley
19	Oxygen cylinder trolley
20	Biomedical waste bin - small - set of 3
21	Overbed table
22	Paint materials
23	Paint materials
24	Ventilator
25	ABG machine
26	D-type cylinder
27	DG set
28	Radiant warmer
29	Phototherapy unit
30	Resuscitator neonate

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