

Zero Leprosy Best Practices

Best Practice: *Reduction of Stigma through Integrated Clinical Health Services that Include Leprosy at Anandaban Hospital*

Subthemes

- Reduction of stigma, discrimination, and exclusion

Target Audience(s)

- Policy leaders
- Program managers
- Trainers
- Health staff
- Donors

Contributors

S Kandel, C Sharma
The Leprosy Mission Nepal

Key Messages

- Vertical treatment of leprosy-affected individuals can trigger stigma
- Medical and surgical intervention is not sufficient to treat people affected by leprosy who have experienced stigma and discrimination from their family members and community
- Providing counseling as a focused intervention along with medical and surgical intervention helps people affected by leprosy recover from stigma and discrimination, hence speeding up the healing process
- Treating leprosy in the same system as other medical/health conditions normalizes the situation, promoting understanding and inclusion

Key Informant / Date Submitted

S Kandel, The Leprosy Mission Nepal
August 2019

Description of the Best Practice

Introduction

What triggered the introduction of this best practice?

Anandaban Hospital was established far from the city, when Nepal's leprosy case load was very high. At the time, people affected by leprosy were often segregated from their families and communities and stigma was very high. There was only one drug to treat leprosy. Anandaban Hospital was primarily involved in leprosy control—finding new cases, providing treatment, performing surgery, etc.

Zero Leprosy Best Practices

The availability of treatment at the hospital only for people affected by leprosy perpetuated stigma perceived by other community members. This also prevented a dialogue between people affected by leprosy and general patients (members of the community).

Which problem(s) needed to be addressed?

- Social stigma caused by vertical treatment of leprosy
- General health needs of the local community
- Medical and surgical conditions of leprosy-affected individuals
- Struggle of leprosy-affected individuals to access general treatment from general hospitals
- Stigmatization from health workers
- Catchment community's lack of awareness of leprosy-related conditions
- Labeling of Anandaban Hospital as leprosy-treatment only

How did the problem impact on the population?

The general public from the rural part of Lalitpur did not have access to general and affordable health care at Anandaban. The rural area of southern Lalitpur does not have quality health care.

Stigmatization and labeling of the hospital as leprosy-only would further prohibit community members from accessing general health services from Anandaban Hospital. Stigmatization was also furthered when the hospital's health staff treated people affected by leprosy separately or in isolation.

Family members often did not return to the hospital to bring a person affected by leprosy back home, thinking of leprosy as an abnormal health condition and different from other health conditions.

Marginalization of the leprosy-affected people caused them to be disenfranchised from family and recreational activities, formal and non-formal employment, and other opportunities for growth and wellbeing.

Treatment of leprosy-affected individuals only in isolated leprosy hospitals or treatment centres causes them to be unable to get general health treatment at general health centres. This places an extra burden on the cost of treatment in leprosy-only hospitals and continues to exaggerate stigma.

Health workers' stigma towards people affected by leprosy has led to superficial referral to leprosy treatment centres, including for treatment of general health conditions and otherwise basic health services that are available at any health centres.

Stigmatization of staff also results from health centres that treat leprosy only.

If not directly a leprosy practice, what is the relevance for leprosy control?

- Early detection of leprosy can prevent the development of leprosy complications, including disability, and can also prevent social exclusion and stigmatization
- Treatment compliance

Zero Leprosy Best Practices

Which objectives were achieved?

- Leprosy was detected and patients received appropriate leprosy treatment
- Disability of people affected by leprosy has been prevented and managed
- Stigma faced by the people affected by leprosy has decreased
- Leprosy-affected people and other community members can receive integrated health services
- Public awareness of leprosy has been raised as a result of integrated health services at Anandaban
- Applicable leprosy cases identified in the hospital are referred for social and economic rehabilitation
- People affected by leprosy with emotional and psychological problems have received mental health support

Objectives and Methodology

What were the main goal and objectives of implementing this practice?

The project sought to achieve integrated general health services for the local community, including persons with leprosy.

Other objectives in support of the above goal and specific to persons affected by leprosy include

- Leprosy detected and diagnosed at an early stage
- Government hospitals strengthened to provide advanced leprosy treatment
- Nerve impairment protected and prevented
- Complicated ulcers treated and managed
- Physical appearance and physical ability improved (cosmetically and functionally)
- Functional activity of the limbs improved and biomechanical needs of the patients met

What methodology did you use to reach your results?

- Patient survey and feedback mechanism
- Support of assistive devices and physio and occupational therapy services
- Training of patients in self care
- Linking of different government line agencies and other agencies working in different sectors
- Regular monitoring of progress through baseline, midline, and end-line surveys
- As with other projects, there were four stages of management: situation analysis (stage 1), planning and design (stage 2), implementation and monitoring (stage 3), and evaluation (stage 4)
- Active involvement in Information, Education, and Communication (IEC) activities in the hospital as well as in the community
- Ensuring that all patients get adequate knowledge in self-care before they are discharged.
- Strengthening networking with government and international NGOs to establish a better working referral system
- Continuing to provide affordable medical services to poor villagers around the hospital, which will enable us to achieve full integration

Zero Leprosy Best Practices

- Facilitating orientation programmes for students of the allied health science institutes in Kathmandu
- Training of staff to enhance their skills to provide quality services. Organizing foot/disability and skin camps in highly endemic districts
- Working in partnership with beneficiaries to provide them with better services
- Referring patients to other institutions if they need further assistance that is not available
- Continuing relationships with patients and their family/community members to achieve a holistic understanding their situations
- Periodically reviewing our objectives, targets, and achievements. Working in unity and focusing on the needs of leprosy-affected individuals and the community
- Providing quality care for leprosy patients and affected individuals. Holding practical demonstrations for private practice nurses and medical professionals
- Ensuring effective treatment focused on holistic care and patient counselling

Was the design based on evidence? If yes, describe briefly.

Anandaban Hospital functioned as a general hospital from the very beginning, treating leprosy-affected individuals as well as people from the local communities who had different health conditions. However, the resources to scale up general hospital services were not enough. As the benefits of treating people with different conditions together in one setting (i.e., improved social interaction, reduced misunderstanding and stigma, etc.) have been demonstrated, the demand for integrated health service is increasing. Furthermore, such integration also enhances the capacity of the health institution to be self-sustainable by increasing its capacity for treatment provision.

Implementation of Practice

What were the main activities carried out?

- Activities specific to people affected by leprosy include
 - Outpatient and inpatient services for early diagnosis and management of problems requiring medical interventions
 - Diagnosis and management of problems requiring surgical interventions
 - Diagnosis and management of physical impairments, activity limitation, participation restriction, and mental health problems
 - Improved access to timely leprosy diagnosis, treatment, and referral through outreach clinics
- Provision of general services (dermatology, orthopaedic, paediatric, gynecology, emergency) at Anandaban and through outreach
- Diagnosis and management of physical impairments, activity limitation, participation restriction and mental health problems affecting people
- Building capacity of Anandaban staff and increasing solidarity
- Training for health care staff who can deal with complications of leprosy, neglected tropical diseases (NTDs), ulcers, and skin conditions

Zero Leprosy Best Practices

- Support for people affected by leprosy, NTDs, and disabilities to receive necessary interventions
- Increased awareness of leprosy, NTDs, and disabilities at local, national, and international levels

When and where were the activities carried out? Incl. training, logistics,
Anandaban Hospital, Lalitpur, Nepal (since 1957)

Were persons affected by leprosy participating in the design and practice itself?

Yes, people affected by leprosy were involved in the design of the projects. The hospital has established a mechanism to obtain feedback from clients before their discharge. This feedback provides information to improve the service of the hospital. Furthermore, persons affected by leprosy serve as board members of The Leprosy Mission (TLM) Nepal and their opinions are sought before, during, and after completion of the projects.

In addition, the International Association for Integration, Dignity and Economic Advancement (IDEA) Nepal, an association of people affected by leprosy, provides advice on an ad hoc basis. TLM Nepal also has a well-established project cycle management (PCM) monitoring tool to gather the views of people affected by leprosy on the projects. The information obtained through PCM is used to expand learning and ultimately to improve the design and implementation of the projects.

Who were the key implementers and collaborators?

- The Leprosy Mission Nepal
- Government institutions: Leprosy Control Division, District Health Offices, local health posts, local municipalities

What were the resource implications?

- The project is supported by TLM Global Fellowship
- Human resources included persons with knowledge and skills in leprosy and in health and disability management (e.g., dermatologists, consultant doctors, leprosy health and social experts, counselors, nurses, paramedics, project managers, administrators, etc.)

Results—Outputs and Outcomes

What were the concrete results achieved with regard to outputs and outcomes?

Anandaban Hospital has 110 beds: 80 for leprosy and 30 (15 in the medical ward, 15 in the surgical ward) for general health services. Currently, 18,000 registered leprosy patients receive care from Anandaban. In addition to providing treatment for both minor and complicated leprosy and leprosy-related disabilities, the hospital continues to provide general health services to the surrounding community and to receive referral cases from other mission hospitals in Nepal. The hospital offers specialist services for reaction management, wound care, reconstructive surgery, prostheses and orthoses, general orthopaedic surgery, dermatology, safe motherhood, paediatric, vaccinations, trauma, and other services. Anandaban employs 4 medical officers, 1 general surgeon, 3 orthopedic surgeons, 3 dermatologists, 25 nurses, 19 paramedics, and clinical staff). The hospital's experienced professional team provides quality health services for leprosy and general cases. Through on-the-job training,

Zero Leprosy Best Practices

incentives, and human resource planning, the hospital has retained qualified staff. As the number one hospital fostering integrated health care in the leprosy sector, social stigma and leprosy discrimination is being reduced.

Since 2010, Anandaban Hospital has over 17,000 medical and surgical visits each year. Around half of these cases are for orthopaedic, dermatology, COPD complications, and seasonal diseases. Despite its broad range of medical specialists to manage injury and trauma cases, patient treatment has faced challenges because of outdated buildings and wards. TLM Nepal has planned the construction of a 150-bed trauma center and complete revitalization of the hospital compound to make it more accessible, better equipped, and safer

Were data management processes of the best practice consistent and transparent to draw conclusions?

TLM Nepal has well-established data management tools and practices. The PCM's regular reporting system includes key performance indicators that reflect the quality of life experienced by people affected by leprosy. During the International Leprosy Congress (one of the major events for TLM Nepal), several research activities take place, increasing understanding in the area of leprosy including stigma and mental health.

Was an assessment of the practice carried out? If yes, what were the results?

Despite the declaration of leprosy elimination in the country, national data show that at least 3000 new leprosy cases are detected each year. The number is higher in Terai region where TLM Nepal has satellite clinics. The government does not have a leprosy-specialized hospital or human resources to carry out the training. It fully relies on Anandaban Hospital for leprosy training, research, and case validation. Therefore, it is clear that the ongoing projects are exceptionally relevant (see Mid-Term Evaluation).

The hospital currently offers services in dermatology, orthopedics, pediatrics, and gynecology in addition to leprosy through its outpatient and in-patient departments. It also offers the services through Patan clinic and two satellite clinics outside Kathmandu in Chapur and Butwal (see Mid-Term Evaluation).

All lab test records had been integrated in a computer-based software. Quality assurance of the lab has been obtained from the Nepal government and CMC Vellore. The *Mycobacterium* Research Laboratory (MRL) is one of six labs in the world accredited by WHO. Data showed an increasing trend of outpatient visits among both leprosy and general patients, with an average of 40-50 patient visits per day while the number of leprosy patients was up to 135 on leprosy clinic days. The out-patient clinics, dressing, and pharmacy are in the same complex and the space is congested (see Mid-Term Evaluation).

Considering the situation and the need of the people in the community, TLM Nepal has taken an inclusive and twin track approach to address the problem. Therefore, Anandaban Hospital not only provides specialized leprosy services but also other specialized services such as skin care and orthopaedic services which are in high demand. Furthermore, the hospital also provides other general services to the local community people and is currently planning to expand this with mother and child

Zero Leprosy Best Practices

health care and paediatrics services. It is also establishing a trauma center. Anandaban hospital has become a backbone of leprosy (see Final Evaluation).

Is the project completed or are some results still to be expected?

Anandaban Hospital is an ongoing project, which has completed several phases of its work in treating people affected by leprosy and other general patients.

Lessons Learned

Successes

Collaborative work during the projects inception period with other organizations working in the similar sector brings wider impact. Undertaking purposeful and deliberate partnering with community members and developing a collaborative approach in different areas of health and safety help in the integration of services and acceptance by the community members.

In addition to leprosy, identifying the health needs of the catchment area and providing accessible health services is an important aspect to bring about positive perception among the community members.

Participation of people affected by leprosy at different levels of project development and implementation worked well, and they were able to take ownership of the project.

The informal dialogues and discussions between the leprosy affected and non-affected clients in the hospital is important in developing empathy towards each other. This helps to dispel some of the myths and stereotypes existing in the communities.

The feedback mechanism from the clients upon discharge has helped the hospital improve its services.

Limitations

Some patients attending Anandaban Hospital are not aware of leprosy, and noticing leprosy patients with high disability has triggered fear and abandonment of their treatment. Therefore, there should be enough IEC materials for the general patients to help them understand leprosy.

Having an on-site counselor and paramedics ready to educate uninformed patients on leprosy can prevent the backlash of stigma.

The name “Anadaban Leprosy Hospital” misidentified the hospital as catering only to leprosy-affected individuals. Therefore, the name was changed to “Anandaban Hospital.”

Zero Leprosy Best Practices

Replicability and Scalability

Has the practice be implemented in more than one setting?

Yes, the practice has been implemented in other hospitals as well.

The government of Nepal was carrying out leprosy control as a vertical programme but has now adopted a horizontal approach where people affected by leprosy are treated through all government health institutions in the communities, although though there is a lack of resources in the rural settings for complete integration of the services.

The vertical programme created unnecessary confusion and stigma towards people affected by leprosy. Affected people even had to face stigma from the government health workers, however recent efforts of integration have minimized the stigma. Basic leprosy drugs and treatments are now available free of cost in the communities.

Several other hospitals in Nepal and elsewhere have integrated other general health services in their regular leprosy work. The basic principle is that with more interaction between different groups of patients comes more understanding of each other; with additional information on a particular disease or condition, there is an opportunity for increased social empathy.

Although well-developed counseling and mental health services are very useful in addressing fears associated with leprosy and stigma, these services are lacking for patients.

What long term effects can be achieved if practice is sustained over time?

People affected by leprosy and those with disability could be mainstreamed and can contribute to the development of the nation.

People in the community will be aware of leprosy and its complications. There will be reduction of disability as people suspect leprosy and access leprosy services. As people have confidence to access services before or soon after a diagnosis of leprosy, there will be improved physical and mental health and improved socioeconomic status.

What are the requirements to sustain the practice over time considering contextual factors, institutional support, human resources?

- Having people affected by leprosy serve as advocates for the hospital. Even other people from the communities can be advocates who lobby on behalf of the institution.
- Leadership of people affected by leprosy in the project activities
- Having mental health counselors in the hospitals to provide counseling and guidance
- Ownership taken by people affected by leprosy and other community members
- Linkage and coordination with the government and other agencies
- Frequent interaction between the governments and other institutions that implement this practice

Zero Leprosy Best Practices

Conclusions

How have the results benefited the population?

The number of people receiving treatment from integrated health services has increased.

The health professionals working in leprosy tend to be more empathetic as a result of working several years with people affected by leprosy; this also benefits other general patients.

Integrated services bring more harmony and understanding between groups of patients and their caretakers.

With a reduction in stigma, people are willing to bring their issues forward earlier which can prevent complications.

As a result of surgical intervention and treatment at Anandaban Hospital, several individuals have been able to find employment, a continued education partner for their lives, and acceptance in their families and communities.

People affected by leprosy who have received treatment, support, and counseling provide feedback in different platforms and will become resilient individuals who can tackle issues that they face.

The health care staff at Anandaban Hospital changed their perceptions towards leprosy stigma and discrimination once they began working with both leprosy-affected and general patients. This hospital is sending the message across the country and abroad that an integrated health system is one of the best practices to reduce stigma associated with leprosy or any other disease.

Why may that intervention be considered a “best practice”?

- Providing treatment for other health conditions allows community members to interact, observe, and hence change their attitude towards people affected by leprosy
- Not all patients affected by leprosy develop the kind of disability perceived by the general community. Having integrated health services helps to dispel the myth of disability caused by leprosy
- Self-help groups/cooperatives operating in business models can provide opportunities for people affected by leprosy to access easy microcredit services.

What recommendations can be made for those intending to adopt the documented “best practice” or how can it help people working on the same issue(s)?

Proper community assessment should take place before implementation of the project. Assessment of the knowledge, attitude, and practices of the community members towards leprosy could be helpful in understanding the community perspective. The Social Distance Scale could also be a good tool to administer at different times to understand the perception of the community members towards people affected by leprosy.

Zero Leprosy Best Practices

The project discussed here is large. Therefore, an organization considering implementing a similar project should have adequate human and financial resources and also be prepared to carry out the project for a number of years.

Further Readings

The following secondary materials are available along with the Best Practice at <http://zeroleprosy.org/toolkit/>.

- Mid-Term Evaluation of Anandaban Hospital 2014-2018
- Final Evaluation of Anandaban Hospital 2014-2018