A Practicum Research Report
on
Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities

by

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Study Title

Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities.

Introduction

Leprosy, or Hansen's disease, is a neglected tropical disease (NTD) that persists in over 120 countries, with over 200,000 new cases reported annually (Leprosy, n.d.). It is a chronic infectious disease caused by Mycobacterium leprae a type of bacteria. The disease mainly affects the skin, peripheral nerves, mucosa of upper respiratory tract and eyes. If not treated, It could lead to disabilities in small proportion of patients (Leprosy (Hansen's Disease), n.d.). Despite significant progress in its control and management, leprosy remains a public health concern in many regions.

In 2019, there were 202,166 new cases of leprosy reported worldwide, with similar figures having been reported since 2006 (Leprosy, n.d.). Although figures reported in 2020 were 128,397 (Lower compared to 2019), this was due to reduced case finding activities as a result of the Covid-19 pandemic (Leprosy, n.d.). The number of cases disproportionately affects the WHO South-East Asia (SEARO) region, with 124,377 new cases reported in 2022 which accounts for approximately 70% of the total new cases worldwide (Leprosy (Hansen's Disease), n.d.). The lack of reduction in case numbers indicates that transmission of the infection is ongoing. One reason for this is nonadherence to prescribed treatment regimens (Meadows & Davey, 2022). Every effort must be taken to ensure that PB patients complete their treatment within 6 months and MB patients within 12 months. If this is not feasible, the treatment for PB leprosy must be finished within a maximum of 9 months, and for MB leprosy, within a maximum of 18 months (LEPROSY MANAGEMENT GUIDELINES FOR HEALTH WORKERS 1st Edition, 2014, n.d.). Failure to complete treatment within the maximum allowed time frame is considered defaulter.

Bhutan, a lower middle income South-East Asian nation was certified as a leprosy-eliminated country by World Health Organisation in 1997 but in recent years (between 2020 and 2022) an increasing number of cases have been detected (Wangdi, n.d.). However, managing leprosy treatment defaulters is challenging due to the necessity of prolonged treatment and extended follow-up periods (LEPROSY MANAGEMENT GUIDELINES FOR HEALTH WORKERS 1st Edition, 2014, n.d.). Improving treatment adherence is essential to reduce the incidence and prevalence of the disease. Non-adherence to treatment can lead to drug resistance, disease relapse, and continued transmission, posing a threat to both individual patients and the broader community. Several international studies have highlighted common barriers to treatment adherence in leprosy patients but there is limited local research on treatment adherence of leprosy patients in Bhutan, and this study will provide valuable insights specific to the country's context. It will contribute to the development of tailored interventions and evidence-based strategies to enhance treatment adherence and support for leprosy patients, ultimately, contribute to the control of leprosy in Bhutan.

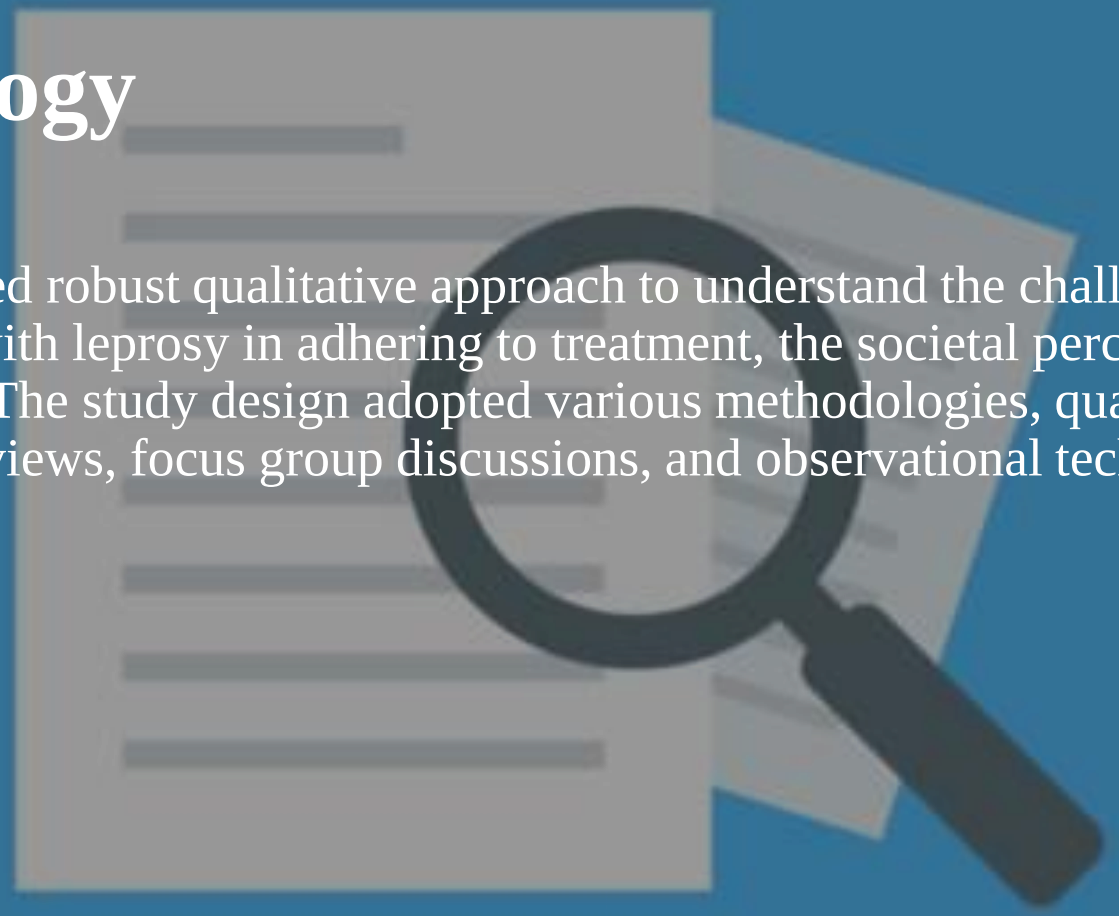
Objectives

1. To identify Barriers and Facilitators that leprosy patients encounter in adhering to the prescribed treatment regimens.

2. To assess the Knowledge, Attitude, and Practice (KAP) among individuals diagnosed with leprosy and community.

3. To recommend strategies to effectively address the issue.

Methodology



The study employed robust qualitative approach to understand the challenges faced by individual living with leprosy in adhering to treatment, the societal perceptions influencing their experiences. The study design adopted various methodologies, qualitative approaches like in-depth interviews, focus group discussions, and observational techniques to gather rich, contextual data.

Study Setting

The research was conducted at Gidakom General Hospital, located in Thimphu, Bhutan and four communities i.e. Jigmena and Sisina under Thimphu district and Changjukha and Wolakha under Punakha district . Gidakom General Hospital opened in the year 1966 is a 60 bedded hospital. Apart from being a general hospital, it is a national centre for leprosy and rehabilitation. It is a well-established healthcare facility and healthcare services for leprosy diagnosis, treatment, and follow-up. The hospital serves a diverse patient population from various regions of the country. This diversity offers a representative sample of Bhutanese society, making it an ideal location for addressing the objectives of the study.

The research started from January to June 2024. Recruitment of leprosy patients, health workers, key informants of the communities and community members occurred within the month of January. Data collection took place during the research period, with data transcription and analysis following the completion of data collection.

Study Instruments

Open-ended questionnaire is used to explore experiences, challenges, and supporting factors related to treatment adherence. Structured questionnaire is used to collect demographic information. Group discussions to elicit shared perspectives on barriers and facilitators. The tools are developed based on the research objectives and it has undergone iterative revisions to enhance it’s effectiveness in eliciting comprehensive responses from participants. Established rapport and trust throughout the study duration to maintain participant engagement and retention.

Sampling Strategy

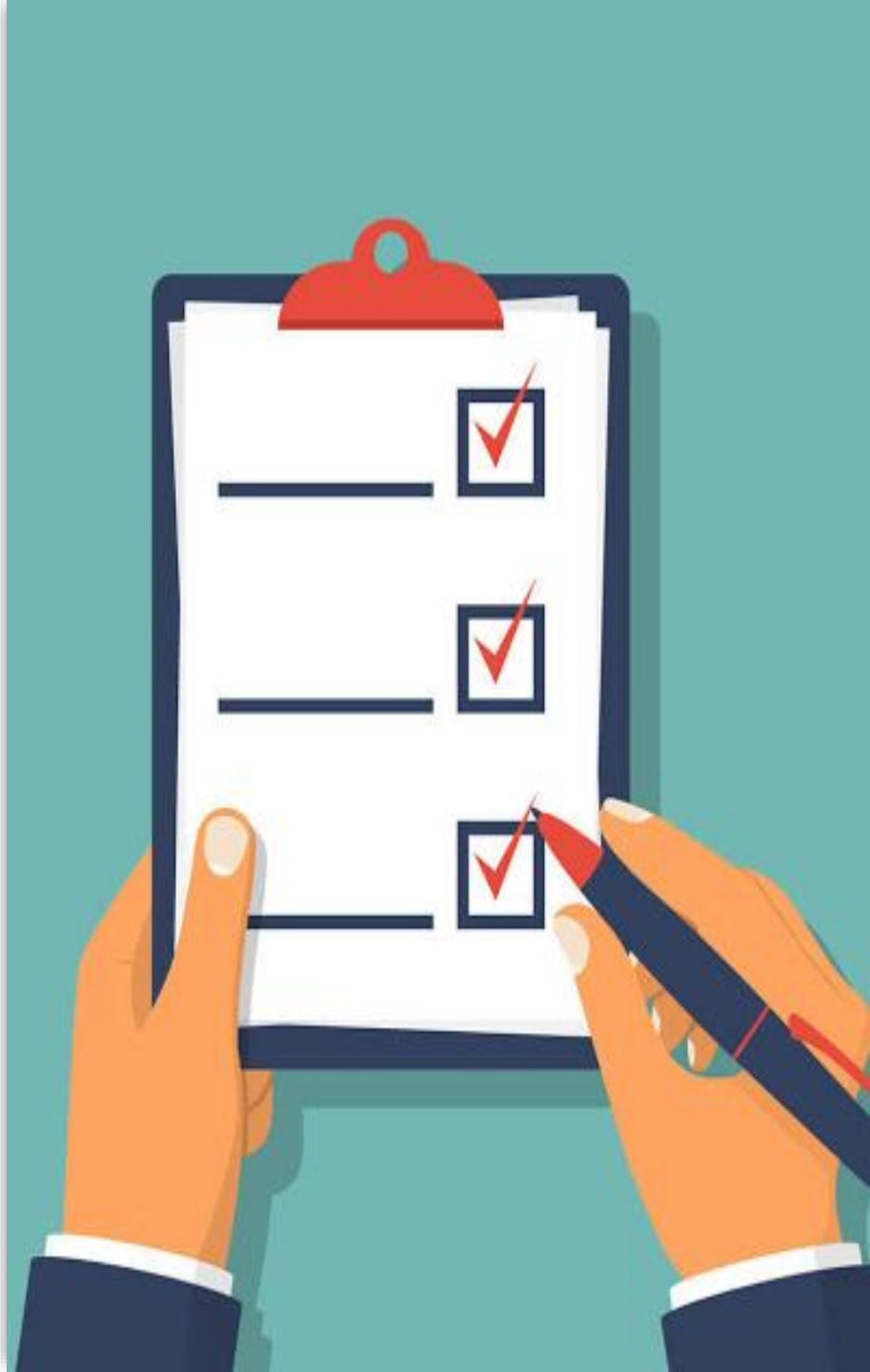
The study employed a purposive sampling technique to select leprosy patients and community, focusing on areas with number of diagnosed cases of leprosy. This approach aimed to meet specific study criteria, ensuring the inclusion of leprosy patients primarily from Jigmena, Khariphu Sisina in Thimphu district, and Changjukha, Wolakha in Punakha district. The sample included individuals at various stages of treatment, from diverse socioeconomic backgrounds, ages, genders, and geographical locations within these districts. Additionally, community members from different social strata were included to assess KAP regarding leprosy.

Data Collection

The data collection process in this qualitative study included in-depth interviews, focus group discussions and observation methods to gather comprehensive insights from the patients, health workers, key-informants and community members regarding leprosy treatment adherence.

In-depth Interviews

In-depth interviews (Semi-structured/Open ended questionnaire) using IDI guide was conducted. The interviews explored barriers and facilitators related to treatment adherence from the patients, healthcare providers and key-informant’s perspective and also assessed KAP regarding leprosy from the patients and key-informants. The interviews were audio-recorded with the participant’s consent and transcribed for analysis.



Focus Group Discussions (FGDs)

Focus group discussions were conducted with 8 participants from the Jigmena, Changjukha, and Wolakha communities, and 9 participants from the Sisina community, ensuring diverse representation across socioeconomic backgrounds, ages, genders, and education levels. Prior to the discussions, the research objectives, methodology, and potential benefits and risks were explained, and informed consent was obtained. The discussions, lasting 45 minutes to 1 hour, focused on factors influencing treatment adherence, community knowledge, attitudes, perceptions, support for leprosy patients, and potential strategies for improving treatment compliance. Held in convenient, accessible locations, participants sat in a relaxed circular format during leisure hours to avoid disrupting their routines. With consent, discussions were audio-recorded and transcribed for analysis, and participant identities were coded.

FGD in Jigmena

FGD in Khariphu Sisina

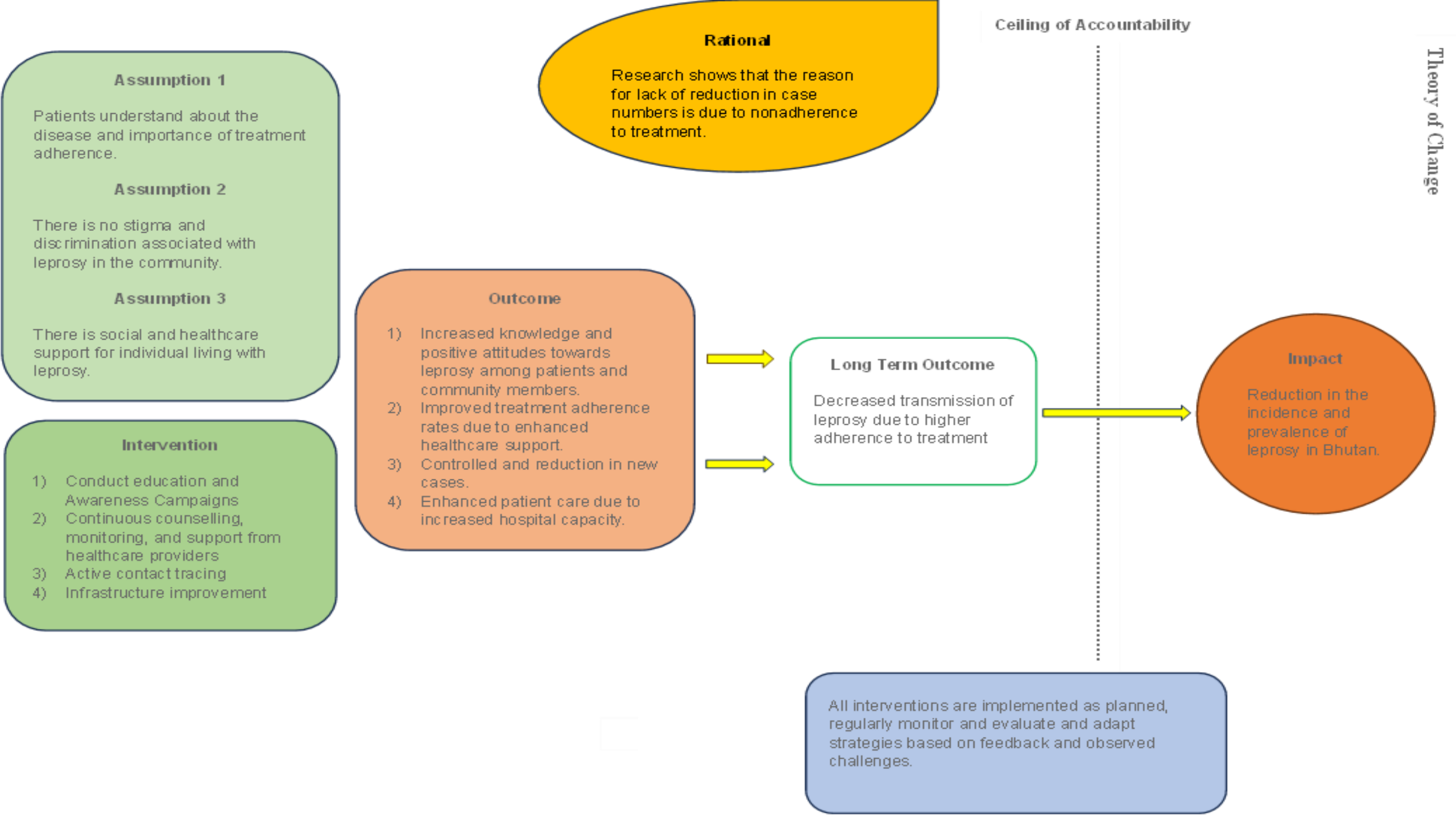
FGD in Changjukha

FGD in Wolakha

Observation

The observational technique was employed using observation guide and noted in observation form which included Observation of the physical environment, community dynamics and infrastructure available for patient's support and treatment. The study noted the accessibility of treatment facilities, availability of medication, and resources for patients in the community. Documented community member's attitudes, beliefs, and support towards individuals affected by leprosy. Also observed any stigma or social barriers affecting patient's integration and adherence to treatment. Observed patient interactions with healthcare providers, noting communication styles, patient engagement, and rapport.

Then analyzed observational data for recurring themes, patterns, and significant observations related to treatment adherence and community perceptions. Compared observation findings with other qualitative data sources (interviews, FGDs) to validate and enrich insights. Interpreted observations within the context of the study objectives, forming conclusions about treatment adherence factors. We ensured confidentiality and ethical handling of observed information and behaviors.


Rational
Research shows that the reason for lack of reduction in case numbers is due to nonadherence to treatment.
Ceiling of Accountability
Theory of Change
Assumption 1
Patients understand about the disease and importance of treatment adherence.
Assumption 2
There is no stigma and discrimination associated with leprosy in the community.
Assumption 3
There is social and healthcare support for individual living with leprosy.
Intervention
1) Conduct education and Awareness Campaigns
2) Continuous counselling, monitoring, and support from healthcare providers
3) Active contact tracing
4) Infrastructure improvement
Outcome
1) Increased knowledge and positive attitudes towards leprosy among patients and community members.
2) Improved treatment adherence rates due to enhanced healthcare support.
3) Controlled and reduction in new cases.
4) Enhanced patient care due to increased hospital capacity.
Long Term Outcome
Decreased transmission of leprosy due to higher adherence to treatment
Impact
Reduction in the incidence and prevalence of leprosy in Bhutan.
All interventions are implemented as planned, regularly monitor and evaluate and adapt strategies based on feedback and observed challenges.

PESTEL/Context Analysis

Political	• Healthcare policy and regulation affecting service delivery and infrastructure development. • Government prioritization of other healthcare program and funding allocation.
Economic	• Socioeconomic disparities impacting access to healthcare services affecting regular follow-ups and medication adherence.
Socio-cultural	• Leprosy is often associated with social stigma and discrimination, leading to isolation and reluctance to seek treatment. • Cultural beliefs and practices about illness and healing can influence adherence to treatments.
Technological	• Lack of Integration of electronic health records to track patient progress. • Insufficient utilization of healthcare technologies, such as telehealth services to reach remote areas and digital platforms for patient education and follow-up.
Environmental	• Terrain land and its impact on accessibility to healthcare services. • Weather conditions affecting transportation and access to healthcare facilities.
Legal	• No specific laws protecting leprosy patients from discrimination and ensuring their integration into society.

Stakeholder Analysis

Interest \ Influence	High	Low
High	• National Leprosy Control Programme, MoH	• Healthcare providers • Community leaders • Individual living with leprosy • Family members
Low		• Community members

Results

Description of study participants

In-depth interview was conducted with 11 individual living with leprosy, 3 healthcare providers (Doctor, Nurse, and Sr. health assistant) of Gidakom general hospital and 4 key-informants (Tshogpa-Assistant community leader) of Jigmena and Sisina under Thimphu district and Changjukha and Wolakha under Punakha district. Focus group discussions conducted among community members of Jigmena, Changjukha, Wolakha which consist of 8 participants each and 9 participants in Sisina community. A total number of 51 participants including patients, health workers, key-informants and community members participated in the study.

Factors associated with leprosy patient’s treatment adherence

Patient-intrinsic factors that encourage treatment adherence

1. **Knowledge about the disease**: Patients are more adherent to their treatment regimen when they have a better understanding of the disease and the importance of treatment adherence.

2. **Fear of disability**: Patients adhere to Multi-Drug Therapy (MDT) because of concerns about disability. Health professionals highlight this reason to encourage patients to complete their treatment.

3. **Fear of infecting others**: Patients adhere to treatment because they are afraid that they will infect their family members, most especially their children/grandchildren.

Patient-extrinsic factors that encourage treatment adherence

1. **Social support**: Community support is found to be very important during the treatment journey of individuals living with leprosy.

2. **Counselling**: Upon diagnosis of leprosy, immediate counseling by health professionals is crucial. This counseling should emphasize the disease's curability and stress the importance of adhering to treatment.

3. **Health worker’s follow-up**: Monthly follow-up visits and home visits by health workers for check-up and reminding their patients to complete their treatment. This is seen to contribute to treatment adherence.

4. **Adequate infrastructure and facilities**: If healthcare facilities has adequate infrastructure, it will benefit individual living with leprosy and improve treatment adherence.

5. **Free healthcare services**: Multi-Drug Therapy (MDT) is available at no cost in hospitals. Given that many people affected by leprosy in the country are economically disadvantaged, providing free treatment ensures they have access to essential medications.

6. **Flexibility in treatment**: Normally, patients receive monthly MDT packs to allow health professionals to monitor their response to treatment. However, some patients find these hospital visits costly or time-consuming, health professionals send the medicine through post to other district hospitals where patients can get their medicine. Sometimes health professionals may provide up to three MDT packs upon request by the patient, with an emphasis on the importance of returning to the hospital when their supply runs out or if they experience reactions related to leprosy.

Factors associated with leprosy patient's treatment adherence

Patient-intrinsic factors that discourage treatment adherence

1. **Financial**: Even though the medicines are provided at no cost, patients will still incur expenses for hospital visits to collect their medications. Some patients are students and they don't want to miss even a single day at school. Some are sole breadwinner of the family and don't want to miss their daily wage.

2. **Distance between patient's residence and hospital**: Gidakom general hospital being the only national centre for leprosy diagnosis, treatment, and follow-up, patients from different district come to Gidakom general hospital to avail services. So, the costs and time involved in traveling serve as barriers to accessing treatment.

3. **Leprosy reactions**: Experiencing reactions was considered one of the factor that affect treatment adherence among patients because they feel that the medicines are not working or it doesn't suit them.

4. **Shyness**: Gidakom general hospital is known by people as leprosy hospital and also leprosy being highly stigmatized disease and considered worst disease, that's why they do not come forward to seek treatment because they feel shy to go to hospital due to name and shame and hide at home.

5. **Attitude**: Some leprosy patients feel there is no use of taking MDT as leprosy already affected their skin, nerves and limbs. Some patients after taking MDT for few months they think that they are already cured. Because of this, they stop taking MDT prematurely.

6. **Sad/depression**: Some leprosy patients feel depressed or sad thinking they are worthless and do not take MDT or stop MDT prematurely.

Patient-extrinsic factors that discourage treatment adherence

1. **Lack of Information**: Patients do not have adequate information about the disease, its treatment, and the importance of adherence. Lack of information can lead to non-compliance to MDT.

2. **Stigma**: Leprosy is often associated with stigma, leading to discrimination and social ostracism. And it still persist. So, patients avoid seeking or continuing treatment to escape this negative social perception.

3. **Lack of support systems**: Most of the patients do not receive support from the community, especially from their family members. This can negatively impact a patient's motivation and ability to adhere to treatment.

Patients and Community member's knowledge regarding leprosy

42 out of 48 (almost 88%) study participants (excluding healthcare workers) heard about leprosy and out of 48 study participants only 4 study participants (leprosy patients- 8%) know that its bacterial cause.

10 out of 48 (nearly 21%) study participants mentioned that it's a hereditary cause and also due to serpent/Naga.

Concerning the symptoms of leprosy, 45 out of 48 (almost 94%) study participants mentioned skin lesions, loss of eyebrows and deformity as a symptoms of leprosy. Sharing items (i.e., cloths, plates and mugs) with leprosy patients was stated as main means of leprosy transmission by 39 out of 48 (81%) study participants.

5 out of 48 (10%) study participants do not know how leprosy is transmitted from person to person. Among the 42 study participants who were aware of leprosy, 40 (95%) study participants stated that it can be spread through aerosol droplets from those infected.

45 out of 48 (nearly 94%) respondents believed that leprosy is a curable disease and mentioned that it can be treated with MDT drugs.

Patients and Community member's attitude toward leprosy

All 48 (100%) study participants believed that early diagnosis of leprosy can lead to better treatment outcome and poor treatment compliance can affect recovery from disease. Out of 48 study participants, 46 (almost 96%) study participants reported that improving treatment adherence among leprosy patients and eliminating leprosy is a team effort not the sole responsibility of the healthcare providers and Ministry of Health. Inorder to dispel myths and misconceptions that contribute to stigma and for improving the lives of patients living with leprosy, 47 out of 48 (nearly 98%) study participants suggested raising awareness about leprosy.

Patient's Practices

In the daily life of individual living with leprosy, 8 out of 11 (almost 73%) of them apply medications and maintain cleanliness to care for their skin and nerves affected by leprosy. Additionally, 3 out of 11 (27%) patients rarely discuss with their healthcare provider about their treatment and care plan, remaining 8 (73%) patients occasionally discuss with their healthcare provider. Out of 11 patients, 5 (45%) of them mentioned that they engage in activities they enjoy (e.g. watching television, gardening, taking a walk) as a coping strategies to deal with emotional and psychological challenges associated with leprosy. Also 5 leprosy patients among 11 (45%) of them mentioned that emotional support from family is very much important. Among 11 leprosy patients, only 1 (9%) patient's future aspirations or goals is to raise awareness about leprosy while 10 (nearly 91%) of them do not have any aspirations and goals for the future while living with leprosy.

Community member's Perceptions regarding leprosy

In the perception of the key-informants and community members of Jigmena, Sisina, Changjukha and Wolakha; all 37 (100%) study participants stated the reason for not adhering to leprosy treatment is that some individuals after taking medicine for few months, they feel now they have recovered and stop their medication, it's due to lack of awareness. When asked about any community-driven initiatives or practices in the community; all 37 (100%) participants mentioned that there are no such initiatives or practices as they are not aware about the leprosy cases in the community because usually individuals who are diagnosed with leprosy do not inform or tell them, they hide it. Even if they ask, they become angry. So, it's difficult for them to understand their needs and support them.

In their understanding, 36 out of 37 (97%) study participants stated that leprosy significantly affect the daily lives of those affected as leprosy affects the nerves and limbs, they are not able to walk properly. In village working in the field is a challenge for them due to that they are not able to earn. Additionally, stigma and discrimination associated with leprosy still persist in the community due to that leprosy patients feel shy or hesitant to go to Gidakom general hospital and also there is lack of support from their family members.

Regarding support from the community side, 27 out of 37 (almost 73%) participants mentioned; by not differentiating them, not feeling disgusted, Social inclusion and most importantly emotional support. 24 out of 37 (nearly 65%) participants had direct interactions or experiences with leprosy patients, when asked about how did it impact their attitudes or beliefs, they mentioned that they didn't see any wounds and there is no foul smell, though their limbs are affected they should be treated equally. They eat together and mentioned that it's not contagious due to treatment. Inorder to improve community understanding and encourage better adherence to leprosy treatment, all 37 (100%) study participants stated; conduct awareness and advice from the healthcare system regarding leprosy, its sign and symptoms and its treatment adherence.

Discussion

The study's primary importance lies in uncovering the persistent misconceptions and stigma surrounding leprosy. It reveals critical gaps in knowledge about leprosy's causes, symptoms, and transmission, which directly impact treatment adherence. One of the main findings was the widespread misconception about leprosy's causes. In one of the blog written by editorial team and medically reviewed by Continental Hospitals (6) highlighted similar misconceptions, indicating that leprosy is highly contagious, leprosy is a curse or punishment for sin and leprosy causes body parts to fall off. However present study found two additional misconceptions that is many participants mistakenly believed it to be hereditary and transmitted by serpents/Naga. The potential reasons in specific beliefs could be attributed to local cultural narratives and historical misinformation that persist within different countries. This poor knowledge can significantly affect treatment adherence, as individuals may not recognize the importance of medical intervention, relying instead on incorrect beliefs about the disease's nature. The findings underscore the necessity of enhancing community education and support to improve treatment outcomes, reduce stigma and also addressing misconceptions about leprosy.

We identified patient-intrinsic and extrinsic factors that affect treatment adherence. Patient intrinsic motivators to complete treatment include fear of disability, fear of infecting others and knowledge about the disease. Patient extrinsic motivators to complete treatment include social support, counselling, health worker’s follow-up, adequate infrastructure and facilities, free healthcare services and flexibility in treatment. On the other hand, patient intrinsic barriers to treatment adherence include financial, distance, leprosy reaction, shyness, attitude and psychological. Lastly, patient-extrinsic barriers to treatment adherence include lack of information, stigma and lack of support system. Most of these factors support findings from earlier research in Philippines (7), however, there are some slight differences. For example, experiencing leprosy reactions is identified as one of the factors that encourage treatment adherence (7), however in this study, experiencing leprosy reactions is identified as one of the barrier to treatment adherence and similar findings have been highlighted in a systematic review conducted by Meadows and Davey (3) This difference could stem from context, knowledge and how patient perceive and respond to adverse reactions.

Another critical result was, misconceptions about transmission, like sharing personal items, persisted. Participants acknowledged the importance of early diagnosis and consistent treatment adherence, emphasizing that managing leprosy requires collective effort beyond healthcare providers. Community members noted that some patients discontinued treatment prematurely due to a perceived recovery, largely due to a lack of awareness. Stigma and discrimination remain significant barriers and this aligns with previous study conducted in India (8) that have shown social stigma as a commonest cause of dropout. Stigma causes patients to hide their condition and avoid seeking treatment. Improved community understanding and support, alongside raising awareness about leprosy, were recommended to enhance treatment adherence and reduce stigma.

Discussion

Furthermore, one of the factors that can affect treatment adherence is patient's shyness. While it is certain that stigma and misconception regarding leprosy still persist in the community, due to that some leprosy patients may also experience depression. Previous study conducted in Philippines highlighted, patients undergoing clinical depression as one of factors that discourage treatment completion (7). Similar findings have also been highlighted in this study that patients feeling sad or depressed as one of the factors that discourage treatment adherence. In this study, the way the respondents phrased it highlights that most of the people in the community feel scared and uncomfortable towards individual living with leprosy. Such attitudes of people in the communities have also been observed during the focus group discussion with community members highlighting historical misconceptions. So, the programme needs to be strengthened as there is no one to oversee and lack accountability. More focus is on other programme and less in leprosy because they think the prevalence and incidence rate is less and it is almost eliminated and through that there should be plans, especially advocacy plan and health education. There should be active contact tracing and counselling needs to be strengthened inorder to gain insights into patient's motivations, beliefs, and values, and use this information to enhance their healthcare-seeking behaviors and adherence to medication. It is also vital to ensure that there are adequate infrastructure and facilities to accommodate leprosy patients and provide an optimum care. This will benefit leprosy patients and improve treatment adherence.

Lastly, the study conducted in Philippines shows each hospital maintains an active support group i.e. Hansen's Club or leprosy club for their leprosy patients (7). This approach allows healthcare providers to facilitate group counseling and health education, enabling patients to share experiences, offer moral support, and socialize. These support groups play a crucial role in improving treatment adherence. Similar support group can also be formed within the community by involving community members, family members and peers of leprosy patients in these support groups. This can help reduce stigma, correct misconceptions, psychosocial support, and improve the well-being of leprosy patients. Such support group can focus on providing vocational training and rehabilitation programs for individual affected by leprosy to help them reintegrate into society and achieve economic independence.

Recommendations

1. In order to enhance treatment adherence and improve community understanding and support to reduce stigma and discrimination associated with leprosy, it's important to conduct comprehensive awareness campaigns using health information, education, and communication (IEC) materials to dispel misconceptions about leprosy and the effectiveness of MDT. Utilize media platforms like television, radio, and social media to reach a wider audience. Emphasize the importance of early diagnosis and continuous treatment adherence through regular counselling by healthcare professionals. Implement monthly follow-up visits and home visits to monitor patient's progress and address any challenges they may face.

2. Ensure healthcare facilities have adequate infrastructure to accommodate leprosy patients, including dedicated rooms or wards and provide an optimum care. This will benefit leprosy patients and improve treatment adherence.

3. Forming support group within the community, including community members, family members and peers of leprosy patients, to provide moral support, share experiences, and offer psychosocial support. This will encourage social inclusion and reduce stigma by promoting positive interactions among them. These support groups play a crucial role in improving adherence to treatment.

4. Improve the effectiveness of contact tracing by updating and maintaining accurate patient records, ensuring all leprosy cases are tracked and monitored closely. Strengthened contact tracing efforts will help identify and support new cases promptly, preventing the spread of the disease.

5. Offer vocational training and rehabilitation programs for individuals affected by leprosy to help them reintegrate into society and achieve economic independence. This can also improve their overall well-being and self-esteem.

6. Enforce laws that protect the rights of people affected by leprosy. Ensure that discrimination in employment, education, and public services is illegal and punishable, such measures are vital to address the stigma and discrimination associated with leprosy in the country.

Conclusion

This study identified key factors influencing treatment adherence among leprosy patients, categorized into patient-intrinsic and extrinsic motivators and barriers, assessed knowledge, attitudes, and practices (KAP) among leprosy patients, key-informant of the communities and the community members. Study revealed that many participants lacked accurate knowledge about leprosy, with misconceptions about its causes and transmission. Stigma and discrimination were significant barriers, causing patients to hide their condition and avoid seeking treatment. Knowledge about the disease emerged as strong intrinsic motivators for treatment adherence. External support, including social and healthcare system support, was crucial in facilitating adherence. Conversely, lack of information, stigma, lack of support systems, financial constraints, distance to healthcare facilities and leprosy reaction were significant barriers. To enhance treatment adherence, tailored interventions are essential. These should include strengthening health information, education and counselling, ensuring better infrastructure to reduce stigma and correct misconceptions about leprosy. Establishing support groups could further aid in improving treatment adherence and the overall well-being of leprosy patients. By addressing these multifaceted challenges, Bhutan can make significant strides towards better leprosy management.

Study limitations

This study has limitations. First, study may not be representative of the whole country as eastern site was not included, we couldn’t travel to eastern side of Bhutan i.e. Lhuntse and Trashigang where there are highest number of leprosy cases recorded due to budget and geographical constraints. So, the study may not be representative of the whole country, particularly to the eastern regions where the disease burden is highest. Second, leprosy patient register is not up to date as contact number of some patients are missing, hindering the ability to include a comprehensive sample of current leprosy patients. As a result, the study might underrepresent those who are more isolated, marginalized, or facing significant barriers to care. Lastly, we couldn’t interview the focal of national leprosy control programme due to some circumstances. This could limit the study’s understanding of challenges faced in implementing national strategies, and the overall effectiveness of the national leprosy control efforts. Therefore, these limitations suggest the necessity for further research to address the gaps in this study. Despite its limitations, the study offers valuable insights into the knowledge, attitudes, and practices related to leprosy in Bhutan, highlighting the importance of social support, community involvement, and awareness campaigns. It identifies key intrinsic and extrinsic factors affecting treatment adherence, providing a foundation for targeted interventions and future research to improve leprosy management.

Ethics approval and consent to participate

We received administrative clearance from MOH and obtained ethical clearance from the Research Ethics Board of Health (REBH) before proceeding to the study site. Prior to the commencement of the study, all participants, or their parents/legal guardians for minors or those unable to consent, provided informed consent. They received clear and comprehensive information about the study's objectives, procedures, potential risks, and benefits. Participants were informed of their right to refuse participation or withdraw their consent at any time without any consequences. The confidentiality of all participant’s personal information was strictly maintained throughout the study.

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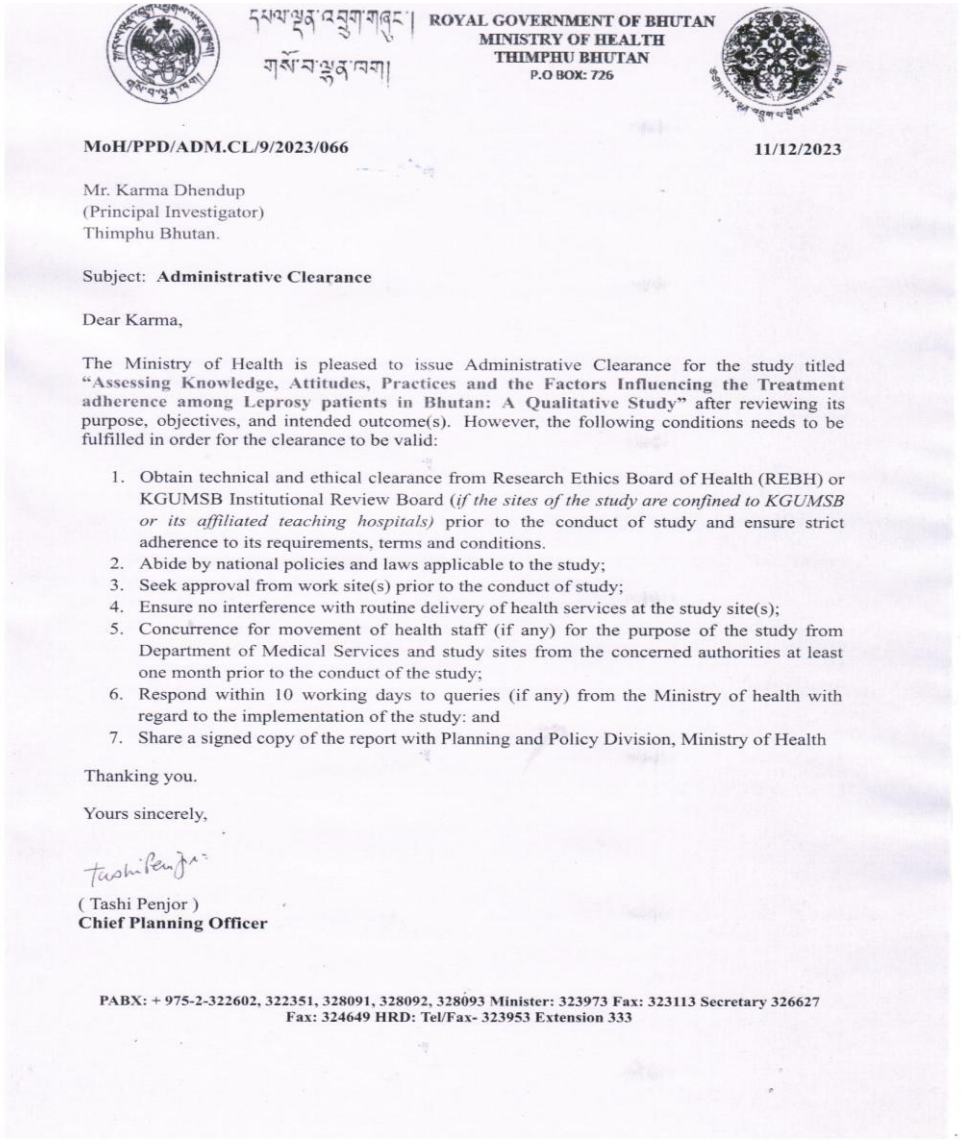
Annexures

Research Ethics Board of Health, MoH Approval



ROYAL GOVERNMENT OF BHUTAN
MINISTRY OF HEALTH
THIMPHU BHUTAN
P.O BOX: 726

MoH/PPD/ADM.CL/9/2023/066 **11/12/2023**

Mr. Karma Dhendup
(Principal Investigator)
Thimphu Bhutan.

Subject: **Administrative Clearance**

Dear Karma,

The Ministry of Health is pleased to issue Administrative Clearance for the study titled **"Assessing Knowledge, Attitudes, Practices and the Factors Influencing the Treatment adherence among Leprosy patients in Bhutan: A Qualitative Study"** after reviewing its purpose, objectives, and intended outcome(s). However, the following conditions needs to be fulfilled in order for the clearance to be valid:

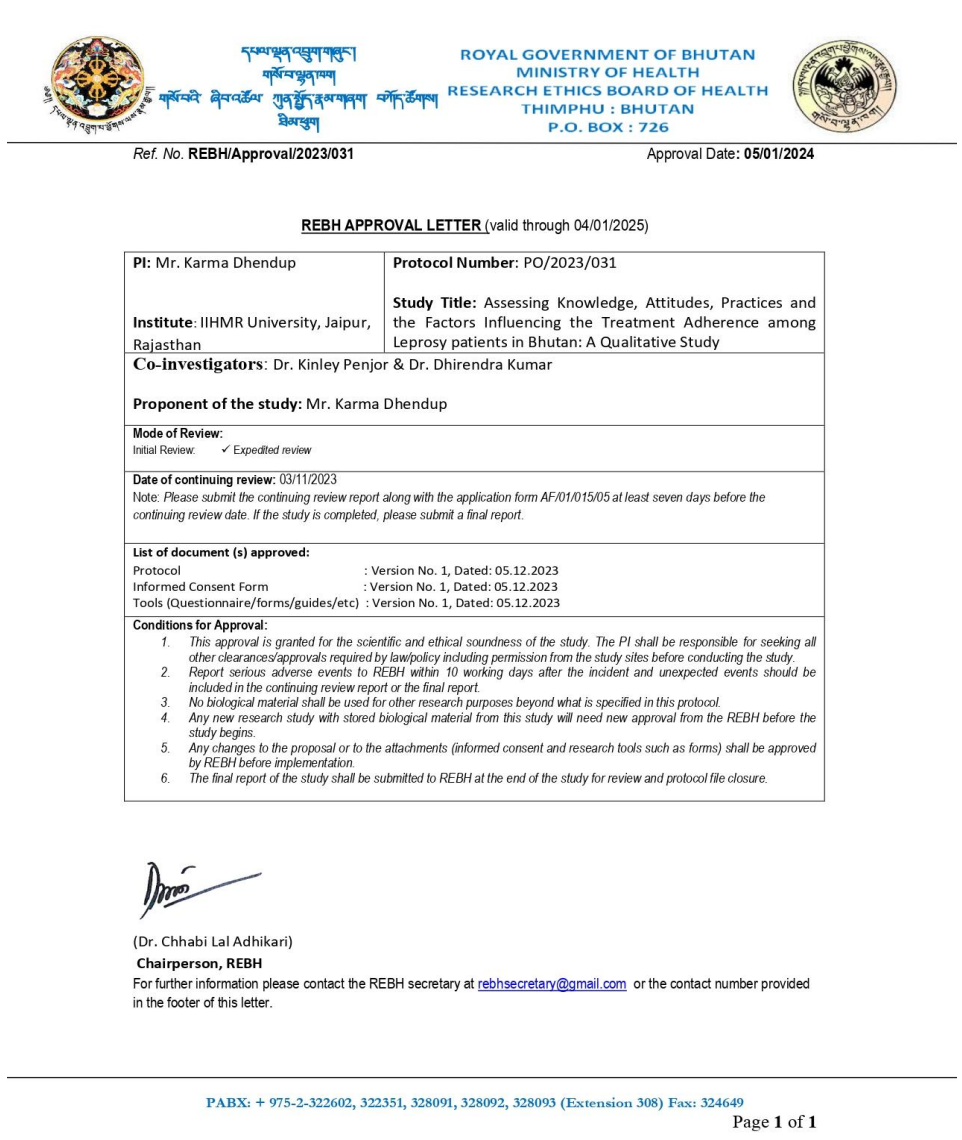
1. Obtain technical and ethical clearance from Research Ethics Board of Health (REBH) or KGUMSB Institutional Review Board (*if the sites of the study are confined to KGUMSB or its affiliated teaching hospitals)* prior to the conduct of study and ensure strict adherence to its requirements, terms and conditions.
2. Abide by national policies and laws applicable to the study;
3. Seek approval from work site(s) prior to the conduct of study;
4. Ensure no interference with routine delivery of health services at the study site(s);
5. Concurrence for movement of health staff (if any) for the purpose of the study from Department of Medical Services and study sites from the concerned authorities at least one month prior to the conduct of the study;
6. Respond within 10 working days to queries (if any) from the Ministry of health with regard to the implementation of the study: and
7. Share a signed copy of the report with Planning and Policy Division, Ministry of Health

Thanking you.

Yours sincerely,

(Tashi Penjor)
Chief Planning Officer

PABX: + 975-2-322602, 322351, 328091, 328092, 328093 Minister: 323973 Fax: 323113 Secretary 326627
Fax: 324649 HRD: Tel/Fax- 323953 Extension 333



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MINISTRY OF HEALTH
RESEARCH ETHICS BOARD OF HEALTH
THIMPHU : BHUTAN
P.O. BOX : 726

Ref. No. **REBH/Approval/2023/031** Approval Date: **05/01/2024**

REBH APPROVAL LETTER (valid through 04/01/2025)

PI: Mr. Karma Dhendup **Institute**: IIHMR University, Jaipur, Rajasthan	**Protocol Number**: PO/2023/031 **Study Title:** Assessing Knowledge, Attitudes, Practices and the Factors Influencing the Treatment Adherence among Leprosy patients in Bhutan: A Qualitative Study
Co-investigators: Dr. Kinley Penjor & Dr. Dhirendra Kumar **Proponent of the study:** Mr. Karma Dhendup	
Mode of Review: Initial Review: ✓ *Expedited review*	
Date of continuing review: 03/11/2023 Note: *Please submit the continuing review report along with the application form AF/01/015/05 at least seven days before the continuing review date. If the study is completed, please submit a final report.*	
List of document (s) approved: Protocol : Version No. 1, Dated: 05.12.2023 Informed Consent Form : Version No. 1, Dated: 05.12.2023 Tools (Questionnaire/forms/guides/etc) : Version No. 1, Dated: 05.12.2023	
Conditions for Approval: 1. *This approval is granted for the scientific and ethical soundness of the study. The PI shall be responsible for seeking all other clearances/approvals required by law/policy including permission from the study sites before conducting the study.* 2. *Report serious adverse events to REBH within 10 working days after the incident and unexpected events should be included in the continuing review report or the final report.* 3. *No biological material shall be used for other research purposes beyond what is specified in this protocol.* 4. *Any new research study with stored biological material from this study will need new approval from the REBH before the study begins.* 5. *Any changes to the proposal or to the attachments (informed consent and research tools such as forms) shall be approved by REBH before implementation.* 6. *The final report of the study shall be submitted to REBH at the end of the study for review and protocol file closure.*	

(Dr. Chhabi Lal Adhikari)
Chairperson, REBH
For further information please contact the REBH secretary at rebhsecretary@gmail.com or the contact number provided in the footer of this letter.

PABX: + 975-2-322602, 322351, 328091, 328092, 328093 (Extension 308) Fax: 324649
Page **1** of **1**

Annexures

Organization Certificate

སྨན་གཡོག་དང་མི་མང་གསོ་བའི་སློབ་ཚོགས།
གེ་སར་རྒྱལ་པོ་གསོག་རིག་གཙུག་ལག་སློབ་སྡེ།
FACULTY OF NURSING AND PUBLIC HEALTH
Khesar Gyalpo University of Medical Sciences of Bhutan
Thimphu: Bhutan

TO WHOMSOEVER IT MAY CONCERN

This is to certify that **Mr. Karma Dhendup,** student of Master of Public Health (MPH - Implementation Science) Program offered by IIHMR University, Jaipur, India has undergone Practicum Attachment at **Faculty of Nursing and Public Health, Khesar Gyalpo University of Medical Sciences of Bhutan (KGUMSB)** from **30th October 2023 to 29th February 2024.**

The candidate has successfully carried out the research study planned as part of his master level training. His approach to the project planning and implementation has been sincere, scientific and analytical.

The Practicum training is in fulfillment of the course requirements.

I wish him success in all his future endeavors.

Dr. Kinley Penjor,
Khesar Gyalpo University of Medical Sciences of Bhutan (KGUMSB)
Practicum Advisor

Thank you