



## Factors affecting treatment adherence among leprosy patients: Perceptions of healthcare providers

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### ABSTRACT

**Background:** Treatment adherence is a vital aspect in the management of chronic diseases like leprosy; however, most studies on treatment adherence focus on patients. This study aims to examine the perceptions of healthcare providers on factors that can promote or prevent patients from adhering to treatment.

**Methods:** We conducted three focus group discussions (FGDs) with healthcare providers who have at least one year experience in managing leprosy in three large leprosy case-holding hospitals in Metro Manila, Philippines. We audio-recorded, transcribed, translated the FGD proceedings, and analyzed the transcripts thematically to identify patient-intrinsic and patient-extrinsic enablers and barriers to treatment adherence of leprosy patients.

**Results:** Patient-intrinsic motivators to complete treatment include innate desire to be cured, fear of infecting family and friends, fear of disability, good knowledge about the disease, need for medical clearance to be considered fit to work, and experiencing leprosy reactions. Patient-extrinsic motivators to complete treatment include free treatment, immediate and sufficient counselling, flexibility in treatment, follow-up and motivation of healthcare workers, and presence of Hansen's Club and support groups. Patient-intrinsic barriers to good treatment adherence include distance between residence and hospital, financial and opportunity costs, adverse drug reactions, misconceptions about being cured, disabilities and presence of leprosy reactions, stubbornness and/or laziness, and undergoing clinical depression. Patient-extrinsic barriers to good treatment adherence include poor availability of MDT, transfer to other leprosy treatment facilities without informing current facility, and stigma.

**Conclusion:** Healthcare providers perceive that patient-intrinsic and patient-extrinsic factors influence the treatment adherence of leprosy patients through different mechanisms. We highlight the role of healthcare provider attitudes, stigma, and support groups in promoting treatment adherence.

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## 1. Introduction

Treatment adherence, which is the extent to which patients follow the recommendations for prescribed treatment, has significant impact on population health [1]. It is also an important facet in the management of chronic diseases such as leprosy [2]. In leprosy, poor treatment adherence is reported to be associated with relapse and antimicrobial resistance [3–7] and may also explain the continued plateauing in incidence and prevalence of leprosy in many endemic countries in Asia, Africa, and South America [8–10]. The Philippines, for example, continues to record the highest number of leprosy cases in the Western Pacific Region [11,12], and this could be partly explained by the poor treatment adherence of patients in the country [5,13,14]. Forty percent of new multibacillary leprosy cases in the country do not complete the prescribed World Health Organization Multiple Drug Therapy for the disease [15], providing a steady pool of infected people who can continue to spread the disease [14].

Many qualitative and quantitative studies on treatment adherence had previously been conducted on tuberculosis [16,17], HIV [18], hypertension [19–22], and even leprosy [5,14,23–25]. A systematic review of systematic reviews on treatment adherence has found that social determinants of health play an important role in promoting treatment adherence across different diseases [26]. Another systematic review of studies in leprosy has identified some demographic variables including socio-economic factors, education level of the patient, knowledge about the disease, inefficient health care delivery, adverse drug reactions, alcoholism, and other personal and medical factors that could affect treatment adherence for the disease [27]. However, most of the studies included in these systematic reviews are usually quantitative in nature, thus preempting a thorough and deep understanding of treatment adherence as a phenomenon and how the factors that affect treatment adherence interact with each other. Another common shortcoming is that many studies focus on patients, which fails to acknowledge the role of healthcare providers in treatment adherence. In recent years, the role of healthcare providers in treatment adherence is starting to be studied and documented. In Brazil, a study identified four main themes that affect treatment adherence of leprosy patients: personal factors, external factors, clinical factors, and the healthcare professional – patient – caregiver relationship [23]. To date, there are no studies in the Philippines that explore the perceptions of healthcare providers on the factors that could affect treatment adherence of leprosy patients.

This study aims to explore the perceptions of healthcare providers involved in the day-to-day care of leprosy patients on what they think are the factors that positively and negatively influence the treatment adherence of leprosy patients. In doing so, we enable a more nuanced understanding of treatment adherence of leprosy patients as perceived by healthcare providers.

## 2. Methods

### 2.1. Study design and population

This qualitative study reports the results of three focus group discussions (FGDs) conducted between February and June 2015 with healthcare providers (physicians, nurses, nursing assistants) with at least one year of experience in the day-to-day diagnosis and management of multibacillary leprosy patients in three large leprosy case-holding urban hospitals in Metro Manila, Philippines. This study is a part of a larger project which aimed to study the factors affecting treatment adherence of multibacillary leprosy patients, of which manuscripts have been published [14,28].

### 2.2. Data collection

The topic guide for the FGDs covered usual procedures for managing leprosy patients, reasons for treatment completion and default, and recommendations to improve treatment adherence. The results on treatment completion and default and recommendations to improve treatment adherence were published in another manuscript [28]. The FGDs were conducted by trained moderators and lasted for 1–2 h. Depending on the preference of the participants, English and Filipino were used in the FGDs. The FGDs were audio recorded. One FGD was conducted in each hospital after a brief introduction and signing of informed consent forms.

### 2.3. Data management and analysis

The audio-recorded proceedings of the three FGDs were transcribed verbatim and translated to English when necessary. These transcripts were then analyzed thematically by the researchers (VCFP, AML, REDS, SJAA, DNLF) who determined patient-intrinsic and patient-extrinsic factors that affected treatment adherence positively or negatively. The basis for these classifications are previous studies, one of which classified factors into patient factors and medical factors [27,29]. However, a more recent study has found this classification scheme deficient [23]. For our study, we designated as ‘patient-intrinsic’ the factors that act on the level of the patient to influence to complete MDT, while ‘patient-extrinsic’ factors act external to the patient that influence them to finish MDT. This classification was used so that interventions can be targeted at the appropriate levels.

We individually coded the transcripts via NVivo 10 [30], and when differences in coding occur, we elevated the issue to our senior author (OPS) who facilitated to arrive at a consensus on the final themes to use.

### 2.4. Reflexivity

VCFP and AML are junior researchers in epidemiology and health systems and have done quantitative and qualitative studies on

leprosy, hypertension, infant and young child feeding, and self-care. REDS is an emergency medicine resident physician, DNLF is a neurosciences resident physician while, SJAA is an internal medicine physician. The study was conducted while they were all undergraduate students at the University of the Philippines Manila. OPS is a professor emeritus of epidemiology at the University of the Philippines Manila and has served as principal investigator for mixed-methods and qualitative studies on infant and young child feeding, maternal mortality, and sexual and reproductive health. All researchers are fluent in the languages used in the focus group discussions and are based in the Philippines.

## 2.5. Ethics

Ethical approval to conduct the study was obtained from the University of the Philippines Manila Research Ethics Board (Reference No.: UPMREB 2015-092-UND, dated January 30, 2015). Ethical approval to conduct the study was also obtained from each of the participating hospitals prior to the conduct of the study; however, the identities of these hospitals are withheld to maintain their anonymity.

## 3. Results

### 3.1. Description of study participants

We conducted one FGD each with three nurses in Hospital A, five resident physicians training on dermatology in Hospital B, and 14 resident physicians and one nursing assistant in Hospital C. All three hospitals are public hospitals, but only Hospitals A and C are managed by the Philippine Department of Health. Hospitals B and C are training hospitals for physicians intending to specialize in dermatology, with affiliations to the Philippine Dermatological Society. Most of the participants are female. Resident physicians have one to three years of experience in managing multi-bacillary leprosy patients, while nurses and nursing aides have managed leprosy patients from one year to more than twenty years.

### 3.2. Patient-intrinsic factors that encourage treatment completion

These factors are perceived by health professionals as motivators that encourage patients to complete their treatment that directly act at the patient level. These factors include:

- Innate desire to be cured. Patients inherently want to be cured of the disease, so they take their medicines and attend scheduled consultations religiously.
- Fear of infecting family and friends. Another frequently cited reason by healthcare providers as a reason why patients religiously complete treatment is that they are afraid that they will infect their family and friends, most especially their children.
- Fear of disability. Another reason mentioned by health professionals as to why patients complete MDT is their fear of disability. This reason is emphasized by health professionals to motivate patients to complete their treatment:

*“We do health education. We show them pictures (of leprosy patients with disabilities). And we emphasize to them ‘if you do not complete the treatment, you will go blind, or your feet will just fall off’”. - Nurse from Hospital A*

- Good knowledge about the disease. Health professionals always emphasize to their patients that leprosy is not caused by "God's wrath and punishment for sinners" and the disease is curable as long as they complete MDT. They also emphasize to patients that taking the first few doses of MDT greatly reduce the patients' chance of infecting their family and friends. They note that patients are more adherent to treatment if patients know more about the disease.
- Need for medical clearance to prove that they are fit to work. Despite the outpatient nature of MDT treatment and the high prevalence of people with immunity to leprosy [31], some employers still require patients to finish treatment before they are allowed to come back to work:

*“I had one patient whose main reason for finishing treatment was job-related because no matter what kind of clearance I give to him to certify that he can still work despite his condition, the company wants him to finish treatment first. He is the sole breadwinner of his family. He really had no choice but to complete the treatment.” - Resident dermatologist from Hospital B*

- Experiencing leprosy reactions. Experiencing reactions was considered by health professionals as a major factor that may enhance treatment adherence among patients because patients with reactions return more frequently for consults:

*“When patients with reactions see me, I usually tell the patients that ‘When you have reactions, it doesn't mean that the medicines are not working. We will also treat the reactions’. Usually they're compliant, because if there is a reaction, follow-up becomes every two weeks, so they become more compliant with the treatment.” - Resident dermatologist from Hospital C*

### 3.3. Patient-extrinsic factors that encourage treatment completion

These factors are perceived by health professionals as motivators that encourage patients to complete their treatment. These factors are outside the level of the patient and oftentimes they operate at the level of the healthcare provider or the health system. These factors include:

- **Free treatment.** MDT is provided for free in public hospitals in the Philippines. Considering that many leprosy patients in the country are indigent, providing free treatment ensures that even the poorest patients have access to essential medicines.
- **Immediate and sufficient counselling.** Once a patient is diagnosed with leprosy, he/she is immediately counselled by health professionals about the disease, emphasizing its curability and the benefits of getting treatment.
- **Flexibility in treatment.** Ideally, MDT packs are given to the patients monthly to provide health professionals the opportunity to monitor how their patients respond to treatment. However, considering that some patients find these hospital visits too expensive or time-consuming, health professionals often give some leeway to patients. Many health professionals give at most three MDT packs if the patient asks for it. In this case, it is emphasized to the patients that they should return to the hospital once their MDT supply is depleted, or if they experience leprosy reactions.

*“The maximum is three months but there are exceptions like those who work overseas. We did not have a choice. He is working in Saudi (Arabia) and we had to give him one year worth of medication. But there are conditions where we told him to return, like if the condition got worse. But I think his condition did not worsen because if it did, he would have returned. When he returned after a year, he is already doing fine.” - Nurse from Hospital A*

- **Follow-up and motivation of health workers.** Nurses from Hospital A go as far as reminding their patients via Short Messaging Service (SMS) to have their monthly check-up and complete their treatment. For some cases, this is seen to contribute to treatment adherence.
- **Hansen’s Clubs and support groups.** Each hospital maintains an active support group for their leprosy patients. Often called Hansen’s Club, this is a way for healthcare providers to conduct group counselling and health education, and for patients to share experiences, provide moral support, and socialize with each other:

*“Regarding ways to improve treatment compliance, we have Hansen’s Club. The Hansen’s Club ... we’re fortunate enough that we are being funded by the Philippine Leprosy Mission and so after three months of consecutive attendance, the patients are entitled to Php 50 (~US\$ 1) transportation fee. So they come back on Wednesdays. They get seen by their doctors and they get to attend the Hansen’s Club. They see a lot of other patients, they are going through the same thing and at the same time, snacks are served. There is food. It is a way of fellowship with one another.” - Resident dermatologist from Hospital B*

*“We have leprosy clubs. Almost every month, we have activities for the patients, such as spiritual discussions, meetings, and livelihood programs. This is one factor why patients persevere with the treatment because they feel that they are not alone. Older members emphasize to the newer members ‘That happened to me before, but the doctors were able to manage it.’ That motivates them to continue with treatment or go back (to taking treatment) because they have an assurance that whatever happens to them, it can be managed.” - Resident dermatologist from Hospital C*

### 3.4. Patient-intrinsic factors that discourage treatment completion

These factors are perceived by health professionals as factors that discourage patients from completing their treatment that act at the level of the patient. These factors include:

- **Distance between patient’s residence and hospital.** Some patients live far from hospitals or health facilities where MDT is available. Other patients go to relatively distant treatment facilities even if there is one near them, to ensure that they cannot be recognized. According to the health professionals, the latter phenomenon can be attributed to stigma. Regardless, travel costs and time spent travelling act as a disincentive to getting treatment:

*“I remembered a patient from Baguio (City; 261 km away from Manila) who actually insists on coming all the way here because he does not want to see anyone that he knows. It is possible to get medicines from a treatment facility closer to home, and that would probably improve compliance, but because he is embarrassed, he only wants to come here.” - Resident dermatologist from Hospital B*

- **Financial and opportunity costs.** Some patients are either students or employees and may not be in a position to miss even a single day at school or work. Employees will miss a day’s salary if they will be absent at work for their checkup or to get drugs. Even if the medicines are given for free, visits to the hospital to get their medicines will entail costs.
- **Adverse drug reactions.** Another frequently cited reason for poor treatment adherence is adverse drug reactions, most especially skin discoloration due to clofazimine. Often found by patients to be cosmetically unacceptable, some patients stop taking MDT

altogether. To address this problem, health professionals explain that these negative side effects are relatively rare and that there are alternative drugs (e.g., Rifampicin-Ofloxacin-Minocycline (ROM) regimen) that will not cause skin discoloration. Unfortunately, these alternative drugs are not available for free. Resident dermatologists from Hospital C report that most patients who initially opt to take ROM revert to taking MDT after a while because the former is expensive.

- Misconceptions about being cured. Few months after taking MDT, leprosy patients experience an improved feeling of well-being, causing them to think that they are already cured. Because of this, they stop taking MDT prematurely and they only come back to the hospital once they experience the symptoms again or when they experience leprosy reactions.
- Disabilities and/or presence of leprosy reactions. In some cases, the presence of leprosy reactions acts to improve treatment adherence; however, some patients sometimes feel too sick or weak to get the drugs themselves. Patients with disabilities may also find it unacceptable and inconvenient to go to the hospital to get MDT.
- Perceived stubbornness and/or laziness. A few health professionals perceive that some patients are stubborn (or lazy) to continue treatment despite repeated reminders, education, and counselling efforts of health workers:

*“Some patients are stubborn. They get lazy in getting treatment, especially if they feel well already. We always emphasize, explain that even if they feel well, as long as they don’t finish 12 months of treatment, they are still not considered cured. The bacteria are still in your body. Very stubborn. If they feel well, they will no longer return.” - Nurse from Hospital A*

- Undergoing clinical depression. One health professional recounted her experience with a patient who had depression and how it affected the latter’s treatment adherence:

*“He was undergoing treatment for quite a long time. His treatment was extended for another six months. He came here regularly but I noticed he was losing weight. He was no longer eating meals regularly. He got diagnosed with clinical depression. Even if he was getting the drugs from us, he is not drinking it. I really took the time to talk to him. I had him referred to another institution that can handle his psychiatric needs but emphasized that he can still get his (leprosy) medicines here and he should start taking it again.” - Resident dermatologist from Hospital C*

### 3.5. Patient-extrinsic factors that discourage treatment completion

There are factors that are perceived by healthcare providers to work beyond the patient’s control that discourage treatment completion. Two factors act at the level of the health facility (poor availability of MDT drugs and transfer to other leprosy treatment facilities), while one factor acts at the societal level (stigma):

- Poor availability of MDT. Many government health facilities no longer report leprosy cases in their communities. As a result, they no longer receive supplies of MDT packs. When a patient from that community is diagnosed with leprosy, he/she may need to go to distant treatment facilities just to get their drugs and this situation negatively affects treatment adherence.
- Transfer to other leprosy treatment facilities without informing current treatment facility. This phenomenon artificially creates poor adherence from the perspective of the current facility as it increases the number of patients defaulting from treatment, even if the patient may have actually completed treatment elsewhere. Furthermore, it affects leprosy statistics in the country:

*“Many patients transfer to other facilities without giving us prior notice. Of course, here, we count it as default. What’s wrong is that they are counted twice. If there is a census of leprosy patients in the Philippines, that patient is counted here and in the facility he/she transfers to.” - Nurse from Hospital A*

- Stigma. Health professionals have always emphasized that the stigma of leprosy has been present since biblical times and this contributes to poor treatment adherence:

*“What the patients usually do is that they go see us, they tell us their supposed addresses, but it’s not really true. This is due to stigma. They don’t want us to know where they live. That’s what the DOH (i.e., Department of Health) would like to avoid because patient monitoring and contact tracing can’t be performed. Sometimes, it is really difficult; many patients do not provide us with the right information. Some do not give addresses or contact numbers at all.” - Resident dermatologist from Hospital C*

## 4. Discussion

We identified patient-intrinsic and extrinsic factors that, in the healthcare providers’ opinion, affect treatment adherence. Patient intrinsic motivators to complete treatment include innate desire to be cured, fear of infecting family and friends, fear of disability, good knowledge about the disease, need for medical clearance to be considered fit to work, and experiencing leprosy reactions. Patient extrinsic motivators to complete treatment include free treatment, immediate and sufficient counselling, flexibility in treatment, follow-up and motivation of healthcare workers, and Hansen’s Club and support groups. On the other hand, patient intrinsic barriers to good treatment adherence include distance, financial and opportunity costs, adverse drug reactions, misconceptions about treatment

duration and cure, disabilities and presence of leprosy reactions, stubbornness and/or laziness, and experiencing clinical depression. Lastly, patient-extrinsic barriers to good treatment adherence include poor availability of MDT, transfer to other leprosy treatment facilities without informing current facility, and stigma. Most of these factors corroborate previous research in Brazil [23,27], however, some differences remain. For example, misdiagnosis and lack of symptomatic relief were identified as barriers to treatment adherence in Brazil but were not mentioned in this study [23]. However, some of the perceived factors have to be discussed in greater detail considering the importance of healthcare providers in treatment adherence [32–34].

One of the factors, which is perceived by the healthcare providers that can adversely affect treatment adherence, is patients' stubbornness and laziness. While it is certain that some patients have poor health-seeking behavior, the way the respondents phrased it highlights the negative attitudes of some healthcare providers towards some patients. Such reported negative attitudes of healthcare providers in Philippine government healthcare facilities have also been documented even in studies on maternal care, highlighting a systemic problem [35]. While the vignette highlights the common frustration of healthcare providers on the failure of patients to adhere to treatment despite persistent information, education and communication efforts, healthcare providers should become more tolerant and understanding with their patients. They should get to the level of the patient and understand the patient's motivations, belief systems, and values, and leverage these information to improve health-seeking behavior and medication adherence [1]. This implies that health education, while there are common key messages, should be individually tailored to each patient, considering that each patient has different motivations, beliefs, and values. However, this would entail additional investments in training, specifically in providing counselling services and health education, which the respondents have recognized [28]. This is also important as some leprosy patients may also be suffering from clinical depression and this condition has been recognized as a major deterrent towards patients' treatment adherence [23,36]. It is also vital to ensure that there are adequate health human resources, equipment, and medicines to provide an optimum care to patients [35]. The importance of these investments cannot be overemphasized especially for leprosy, whose stigmatizing nature and being a 'neglected' tropical disease, could mean that healthcare providers at first contact might be the only link patients have to the continuum of care [37].

The word 'stigma' has always been associated with leprosy [24,37–39], but as shown, it can act both as a motivator and a deterrent towards treatment adherence. Utilizing stigma to promote treatment adherence (i.e., through health information, education, and communication (IEC) materials depicting discrimination, disability, or disfigurement due to leprosy) should be considered carefully as it may have unintended consequences. Many anecdotes show that stigma due to leprosy persists across different sectors of Philippine society – with one vignette showing discrimination that prevented the patient from having gainful employment. The Philippine Constitution explicitly states that while Filipinos have equal protection under the law and that the state guarantees full respect of human rights [40], the absence of an enabling law means that those who discriminate according to leprosy status, especially in the private sector, cannot be prosecuted. Measures to criminalize discrimination according to medical status, among others, have been filed in the Philippine Congress [41]; such measures are vital to address the stigma of leprosy in the country. On a smaller scale, medical societies and health advocates should take the lead in correcting misconceptions of people regarding leprosy; specifically, misconceptions that leprosy is highly contagious, that leprosy is due to bad luck or an act of God, and that leprosy is not curable. Such misconceptions remain common, as shown in recent studies conducted in India, Ethiopia, Nepal, and the Philippines [42–45].

Hansen's Clubs and similar support groups provide a relatively stigma-free environment where people with leprosy can empathize and socialize with each other. As demonstrated, these support groups are vital in improving treatment adherence, and can be improved further by also involving the family members of leprosy patients in these support groups. Involving family members, friends, and peers of leprosy patients in these support groups will help reduce stigma, correct misconceptions, facilitate management of the condition, and improve the well-being of leprosy patients [46,47]. Such support groups can benefit from collaborations with government, other non-government agencies such as medical societies, and the private sector through corporate social responsibility initiatives. Such collaborations can focus on correcting misconceptions of the public on leprosy as well as providing measures to provide livelihood and re-integrate leprosy patients to mainstream society.

It should be kept in mind that perceptions of different individuals or groups on the same phenomenon could vary significantly [48]. This study documents the factors that were *perceived* by healthcare providers to affect treatment adherence. Had the FGDs been conducted with patients, only the factors that could affect their own adherence to treatment may be brought to light. Nevertheless, it examined one perspective often overlooked when studying factors that influence treatment adherence of patients, that is, the perspective of health professionals.

This study has limitations. First, the responses have not yet considered the effect of the COVID-19 pandemic, which have adversely affected treatment adherence as lockdowns have limited patients' access to health facilities for follow-up and to obtain medication [49]. Second, we were unable to inquire about the monitoring of drug resistance and the follow-up of other regimens such as ROM as this was beyond the scope of our study. Lastly, due to varying cultural contexts in leprosy, caution should be exercised in generalizing the findings of the study to other contexts [27].

## 5. Conclusions

Patient-intrinsic and patient-extrinsic factors influence treatment adherence in different but interconnected ways. Patient intrinsic factors, such as the intrinsic motivation to get cured, and their desire to prevent their friends and family from being infected and preventing disability could be used as key messages to improve treatment adherence. Healthcare providers should individualize health education approaches to get to the level of the patient and leverage the latter's motivations, belief systems and values to promote treatment adherence. Support groups have a vital role in promoting treatment adherence but can be expanded to include family and friends of leprosy patients and should be scaled-up through collaborations with government, medical societies, and corporate social

responsibility arms of the private sector. Lastly, further research is needed to follow-up treatment outcomes and adherence in other leprosy treatment regimens, and to establish how other stakeholders like primary care providers, disease control program officers, non-government organizations, and the private sector could play a role in strengthening prevention and control and treatment adherence interventions to mitigate the burden of leprosy as the Philippines transitions to Universal Healthcare [50].

### Other information

The results of this study have been presented via a poster presentation in the 20th International Leprosy Congress held at Manila, Philippines on September 10–13, 2019.

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### Author contribution statement

Veincent Christian Pepito: Ofelia Pardo Saniel: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper. Arianna Maever Loreche: Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper. Rae Erica D. Samontina: Sarah Jane A. Abdon: David Norman L. Fuentes: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data.

### Data availability statement

Data will be made available on request.

### Declaration of competing interest

VCFP and AML received funding from Sanofi Consumer Healthcare to conduct research on self-care. They have also received funding from the International Initiative for Impact Evaluation, Inc. (3ie) to propose a study on programs designed by the Philippine Health Insurance Corporation. VCFP is an advisory board member of *Heliyon*. Other authors have no conflicts of interest to disclose.

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### Appendix A

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