Item generation in the development of a questionnaire for predicting multidrug therapy compliance in leprosy

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Item generation in the development of a questionnaire for predicting multidrug therapy compliance in leprosy

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Abstract

Background: Lengthy therapeutic regimens in leprosy are prone to defaults, contributing to more antibiotic-resistant Mycobacterium. Intervening patients’ medical habits midway would be more complicated than understanding their perception of undergoing such regimens in advance. We study the factors considered relevant to leprosy patients’ compliance to construct a novel self-reporting questionnaire that can predict the patients’ adherence before initiating multidrug therapy.

Methods: According to the Delphi methods, we conducted three rounds of interviews with twenty-three respondents from various backgrounds, including dermatologists, government officials, healthcare workers, and patients with leprosy, to infer the associated factors of the included items. Each item was scored using the Likert scale, and accepted items (scores above 75%) were classified into six-dimensional categories based on the health belief model theory.

Results: The initial 236 items were simplified to 72 items. Then, a panel discussion was conducted to score each item. Finally, 48 items were accepted and categorized into 12 indicators from 6 dimensions. The 12 indicators encompass knowledge about leprosy, its severity, therapeutical options, stigma, challenges in the treatment maintenance, availability of medical facilities and workers, therapeutic impact, drug regulation, health personnel, personal beliefs, attitude, and motivation.

Conclusion: The study identified 12 critical factors influencing adherence to leprosy treatment, contributing to the prevention of antibiotic-resistant mycobacterium and providing valuable insights through the predictive self-reporting questionnaire.

Keywords: compliance, leprosy, multidrug therapy, predictors

Background

Indonesia has one of the highest leprosy rates globally alongside India, Brazil, Nepal, and Bangladesh, which summed up to 82.70% of all cases worldwide. The data in 2015 showed that more cases were found in India, Brazil, and Indonesia. Another data from the World Health Organization (WHO) Global leprosy update in 2018 showed that amongst 208,641 new cases globally, 8% were found in Indonesia (17,017 cases) with a prevalence of 0.2 per 10,000 population. The societal burdens of the disease yield tremendous desperation. Aside from its external signs, such as skin lesions and type 1 and 2 reactions, disabilities seen in patients, such as sensory and motoric nerve problems, blindness, and facial deformities, have always formed a stigma that would relegate the patients from their communities. In addition, historical documentation found in several countries indicates that leprosy patients have always been the subjects of prejudice and abuse. One of the proposed causal arguments regarding this event is the low compliance in patients already receiving...
treatments, thereby prolonging the duration of the WHO multidrug therapy (MDT) and impeding the means of eradicating the disease.\textsuperscript{5} In 2017, a cross-sectional study in Jember, East Java, reported that 11.1\% of paucibacillary and 11.5\% of multidrug leprosy patients have a history of defaulting from the regimen.\textsuperscript{6} Aside from potential adverse effects, there have been many concerns regarding Mycobacterial resistance towards rifampicin and dapsone, which pose a significant global threat.

Siskawati, et al.\textsuperscript{7} (2018) revealed that the risk of \textit{Mycobacterium leprae} resistance to rifampicin with poor drug compliance was eleven times higher than those with good drug compliance (p=0.012). Moreover, the length of therapy, which is around six to nine months for the paucibacillary (PB) type and twelve to eighteen months for the multibacillary (MB) type, may cause the patients to become non-compliant.\textsuperscript{8} Furthermore, though the leprosy treatment regimens are available in specific packaging that facilitates daily medication, the primary health facilities in remote areas do not always have sufficient supplies. This situation applies particularly in Eastern Indonesia, such as Sulawesi, Maluku, North Maluku, Papua, and West Papua.\textsuperscript{9}

Until today, no consensus has been reached in elucidating 'adequate treatment compliance.' It is mainly understood as a multifactorial circumstance of the patients' attitudes towards their treatments.\textsuperscript{10,11} Many experts tried to develop self-reporting questionnaires (SRQs) to identify factors and challenges experienced by leprosy patients while undergoing treatments. These SRQs include the medication adherence questionnaire (MAQ), The Hill-Bone compliance scale, adherence to refills and medications scale (ARMS), and the multibacillary leprosy patients MDT compliance. Unfortunately, these questionnaires measure compliance retrospectively.\textsuperscript{11-14} Patients who have not complied with the therapy would show more restraints towards medical encouragement. Therefore, we would like to propose a novel instrument to be utilized before starting the therapy. This questionnaire is meant to predict patients' tendencies during the treatment period. Its purpose is to encourage clinicians to conduct early interventions for patients with a tendency of non-compliance behavior and to gather several points of view from various backgrounds with experiences facing Leprosy cases. This article reports the initial phase of developing a novel instrument, focused on generating items to identify predisposing factors for multidrug leprosy treatment compliance before the initiation of the treatment from the perspectives of patients, healthcare providers, and experts.

**Methods**

As part of constructing an SRQ and understanding factors affecting patients' compliance towards multidrug therapy, we conducted a three-round study adapted from the Delphi survey method.\textsuperscript{15} The first round was to collect semi-structured responses to the question: "In your opinion, what are the factors that can predict MDT regimen compliance in leprosy patients?". The second round then scored the relevance of each item yielded from the answers collected from the first round. The final round determines whether each item is accepted or rejected from the study.

**Data collection and study participants**

This preliminary study was conducted for one month, between November 2019 to December 2019. Ethical approval was obtained from the Faculty of Medicine, Universitas Indonesia, Ethical Committee Number 88/UN2.F1/ETIK/2019. We determine the number of samples based on a study by De Villers, et al.\textsuperscript{15} that applies to respondents from various backgrounds. The method of choosing the respondents in this deductive and quasi-qualitative study was purposive sampling.

We included participants from various backgrounds, such as dermatologists specialized in leprosy, primary health care workers including general practitioners and nurses assigned to treat leprosy cases in their facilities, a government official from Jakarta Public Health Department with experience in constructing health policies on leprosy cases, and lastly, former leprosy patients with the history of confirmed multibacillary leprosy case who had undergone WHO MDT for minimum six months and by the time the study took place had already been released from treatment. The dermatologists in this study came from various institutions across Indonesia (Jakarta, Bali, Aceh, South Sulawesi, and East Java province), while the primary care personnel and the former leprosy patients came from five sub-district primary health care facilities in Jakarta, Indonesia.

The inclusion criteria for the dermatologists were as follows: Possessing the knowledge and experience about the pertinent subject and practical communication skills and participating voluntarily in the study. The latter includes devoting him-/herself as long as the course of the study takes place. All the participants were aged > 17 years old, could communicate, read, and write in
Indonesian, with existing medication history recorded in the health facilities, brought their supplies of drug packages from WHO, and agreed to participate as research subjects by signing the informed consent form. Patients who also underwent MDT for tuberculosis and patients with certain conditions that would limit their ability to fill the self-reporting questionnaires, such as patients with disabilities in sight, hearing, motoring, patients with neurological disturbance, psychiatric patients, and patients with cognitive impairment, are taken out of the study.

Steps to define factors affecting compliance to multidrug therapy

The ideas yielded from the first round of the study will be termed items of presumed factors affecting patients’ compliance and grouped according to the dimensional categories adapted from the health belief model (HBM) theory by two respondents from different backgrounds. The six components of HBM are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. Perceived susceptibility measures one’s opinion of one’s chance of contracting the disease depending on the risk subjectively felt by the patient. Perceived severity is defined as one’s perception of the seriousness of the pathological condition or the residual symptom after the disease has subsided. An individual feels perceived benefits after attempting to change their health-related behaviors with the sole purpose of lowering the risk of contracting the disease, while perceived barriers are the challenges felt during those dramatic changes. Cues to action are events that inspire the patient to change their behavior. Self-efficacy is interpreted as an individual’s self-assurance before taking action.16,17 These items will then be compiled and assessed for redundancy and similarity.

In the second stage, the respondents must score the relevance of each idea or item, which was collected from the first round. The scoring method uses the Likert scale: 1=Strongly disagree, 2=disagree, 3=slightly disagree, 4=slightly agree, 5=agree, and 6=strongly agree.18 Finally, each item will be brought up individually during the panel discussion with all the respondents to determine whether it will be omitted or accepted for future studies.

In the final step, the average score of each item will be determined and used to calculate the final score by dividing the number with the highest Likert scale point, which is 6, multiplied by 100 to create a percentage score. We purposefully determined that the items with final scores below 75% will be rejected from this study and will not be included in the next part of the study in the future. The remaining items will be reviewed individually during the panel discussion with all the respondents on whether they will be omitted or accepted for future studies. Furthermore, the final results will include new items that may arise during the panel discussion as deemed necessary.

Results

The initial study was conducted with twenty-three respondents. The first round of the study yielded 236 items. These items were gathered, and redundant ones were omitted; hence, the number was reduced to 72. Afterward, a panel discussion was held, and each item was reviewed and scored using the Likert Scale by all respondents. The final results further reduced the items to 48, grouped into 12 indicators distributed in six dimensions (Figure 1).

Demographic characteristics of the study respondents

Out of the twenty-three respondents who participated in the study, nine were dermatologists from various institutions with an extensive background related to leprosy, six were healthcare providers at the primary facilities, one was a policymaker official from the Leprosy Division of the Health Department in Jakarta, and six were multibacillary leprosy patients who had just finished their multidrug therapeutic regimen in Dr. Cipto Mangunkusumo Hospital, Jakarta (Table 1).

Most respondents are female (68.2%) due to the higher number of female health personnel in the Leprosy Division in almost all hospitals and primary care. The mean age of the respondent is 45.27 years old (±10.4). Most participants possess a high level of education (beyond high school).

Listing and ranking the items from unstructured interviews (first and second round)

There were 236 items yielded from the first round of interviews (Supplementary Table 1). After omitting duplicates and similar meaning items, two respondents (one from the dermatologists and one from leprosy patients) were then chosen to rank which items were to be discussed further. In the second round, all 72 items were ranked individually by all participants subjectively using the Likert scale based on relevance. The accepted items had
been classified into specific indicators and dimensions adapted from the HBM concept. All 48 accepted items were grouped into 12 indicators and six dimensions based on the HBM.

The indicators are knowledge about leprosy (4 items), knowledge of the disease severity (8 items), knowledge of therapy (2 items), stigma (6 items), challenges in treatment maintenance (3 items), medical facilities and workers (2 items), treatment impact (5 items), drug regulation (1 item), health personnel (2 items), personal belief (5 items), attitude (5 items), and motivation (5 items) (Table 2).

Accepted items categories

Each item was thoroughly considered in the final round. Appropriate items were accepted, and unfit or redundant items were discarded. Here, we present the final items bought for the next part of the study (Table 2).

![Flowchart Depicting the Research Process](image)

**Figure 1.** Flowchart Depicting the Research Process.

**Table 1.** Sociodemographic Characteristics of the Respondents (N=23)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7 (31.8%)</td>
</tr>
<tr>
<td>Female</td>
<td>15 (68.2%)</td>
</tr>
<tr>
<td><strong>Age, years (mean ± SD)</strong></td>
<td>45.27 ± 10.4</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td>Diploma 3</td>
<td>4 (18.2%)</td>
</tr>
<tr>
<td>Strata 1</td>
<td>5 (22.7%)</td>
</tr>
<tr>
<td>Strata 2</td>
<td>5 (22.7%)</td>
</tr>
<tr>
<td>Strata 3</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td><strong>Expert</strong></td>
<td></td>
</tr>
<tr>
<td>Dermatologist</td>
<td>9 (40.9%)</td>
</tr>
<tr>
<td>Primary healthcare provider</td>
<td>6 (27.3%)</td>
</tr>
<tr>
<td>Policymaker</td>
<td>1 (4.5%)</td>
</tr>
<tr>
<td>Leprosy patients</td>
<td>6 (27.3%)</td>
</tr>
</tbody>
</table>

SD: standard deviation
### Table 2. Categorizing of the Items

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Indicators</th>
<th>Items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Perceived susceptibility</strong></td>
<td>(1) Knowledge about leprosy</td>
<td>Before initiating the treatment regimen, I have already understood the cause of this disease</td>
</tr>
<tr>
<td></td>
<td>Cause of the disease</td>
<td>I understand that MDT takes quite a long time</td>
</tr>
<tr>
<td></td>
<td>Treatment of the disease</td>
<td>I understand that MDT takes quite a long time</td>
</tr>
<tr>
<td></td>
<td>Disease transmission</td>
<td>I know how leprosy can spread to other people</td>
</tr>
<tr>
<td></td>
<td>Reactions that may come up during treatment</td>
<td>Changes on the skin as leprosy reactions may occur before, during, or after the treatment</td>
</tr>
<tr>
<td><strong>Perceived severity</strong></td>
<td>(2) Knowledge of the disease severity</td>
<td>According to my knowledge, leprosy will not cause any other health problems</td>
</tr>
<tr>
<td></td>
<td>Patient’s understanding of the disease severity</td>
<td>I understand that leprosy can lead to death</td>
</tr>
<tr>
<td></td>
<td>Patient’s understanding that leprosy may cause permanent disability</td>
<td>I understand that leprosy may cause permanent disability</td>
</tr>
<tr>
<td></td>
<td>The impacts of discontinuing MDT and treatment completion</td>
<td>I understand that irregularity in consuming the drugs may increase the risk of disability</td>
</tr>
<tr>
<td></td>
<td>* Reactions that may come up during treatment</td>
<td>The disease that I am contracting will cost some fortune, albeit insurance coverage</td>
</tr>
<tr>
<td></td>
<td>Types of disability in leprosy</td>
<td>Leprosy reactions may aggravate the disease itself</td>
</tr>
<tr>
<td></td>
<td>* Disabilty due to leprosy will interrupt my ability to work</td>
<td>Disability due to leprosy will interrupt my ability to work</td>
</tr>
<tr>
<td></td>
<td>(3) Knowledge of therapy</td>
<td>Failure to maintain regular drug consumption will yield an adverse effect on the length of therapy</td>
</tr>
<tr>
<td></td>
<td>The impacts of discontinuing MDT and treatment completion</td>
<td>Failure to maintain regular drug consumption may cause drug resistance</td>
</tr>
<tr>
<td><strong>Perceived barrier</strong></td>
<td>(4) Stigma</td>
<td>My relatives may stay away from me due to my disease</td>
</tr>
<tr>
<td></td>
<td>Social stigma</td>
<td>Disabilities due to leprosy will create distance between my relatives and me</td>
</tr>
<tr>
<td></td>
<td>Self-stigma</td>
<td>Leprosy symptoms may disturb my daily activities</td>
</tr>
<tr>
<td></td>
<td>I will not have difficulties in forming a relationship with others due to</td>
<td>I am concerned that other people will know my condition if I get treated</td>
</tr>
<tr>
<td></td>
<td>the disease</td>
<td>I am embarrassed to get treated due to my condition</td>
</tr>
<tr>
<td></td>
<td>(5) Challenges in treatment maintenance</td>
<td>My job may impede me from maintaining regular treatment</td>
</tr>
<tr>
<td></td>
<td>Moving jobs</td>
<td>The length of therapy may generate more difficulties for me to maintain regular treatment</td>
</tr>
<tr>
<td></td>
<td>Length of therapy (6-9 months for the Paucibacillary (PB) type and 12-18</td>
<td>The length of therapy may generate more difficulties for me to maintain regular treatment</td>
</tr>
<tr>
<td></td>
<td>months for the Multibacillary (MB) type)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>History of adverse events during MDT consumption</td>
<td>I am worried that I may not be able to withstand the side effects of MDT</td>
</tr>
<tr>
<td></td>
<td>(6) Medical facilities &amp; healthcare workers</td>
<td>I had a pleasant encounter with the healthcare worker</td>
</tr>
<tr>
<td></td>
<td>The medical personnel are nice</td>
<td>I can reach the medical facility where I get treated</td>
</tr>
<tr>
<td></td>
<td>A precise location for leprosy outpatient clinics</td>
<td></td>
</tr>
<tr>
<td>Dimension</td>
<td>Indicators</td>
<td>Items</td>
</tr>
<tr>
<td>-----------</td>
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</tr>
</tbody>
</table>
| **Perceived benefits** | **(7) Therapeutic Impact** | Patient’s understanding that MDT can break the chain of transmission  
The patient understands that consuming the drugs routinely can help in eradicating the disease  
Promptly evading stigma | I took medicine regularly so I would not spread the disease to other people  
If I forget to take the drugs, it will not affect my recovery  
Taking the medication regularly will hinder me from disability  
Finishing the regimen early according to the recommended length of therapy will help me to revert to my daily activities  
The cost of the therapy will be higher if I fail to maintain regularity in getting the treatment |
| | **Cues to action** | **(8) Drug regulation** | Leprosy drugs are free of charge | No cost of the drugs will facilitate the course of my treatment |
| | | **(9) Health Personnel** | Form an agreement declaring that the patient will devote participation in the treatment until treatment completion  
Build rapport with the patient | I will have difficulties in coming regularly every month  
I understand the health personnel’s explanation |
| | **Self-efficacy** | **(10) Personal beliefs** | Patient’s belief that routine medication can yield recovery | I believe that this treatment will facilitate my recovery from the disease  
I am not confident that I can take medicine regularly for the next months  
I have been able to solve my problems  
It is generally easy for me to solve my problems  
It is difficult for me to think when I encounter problems |
| | **(11) Attitude** | **Self-discipline** | According to many people, I am a disciplined person in doing my work  
Living in a regular and routine rhythm makes me calm  
I am not apprehensive when delaying an appointment | I am not confident that I can take medicine regularly for the next months  
I have been able to solve my problems  
It is generally easy for me to solve my problems  
It is difficult for me to think when I encounter problems |
| | | **Confident with the leprosy skin condition** | My skin condition does not reduce my motivation to continue the medication  
My skin condition does not thwart my meeting with friends and relatives |  |
| | **(12) Motivation** | **Motivation to prevent disabilities, which may develop in the future** | I will regularly get treated to avoid future disabilities |
| | | **Desire to increase the quality of life** | After remission, I will have a more pleasant life |
| | | **Motivation from within** | I can motivate myself when I encounter life challenges |
| | | **Patients are motivated not to spread the disease to other people** | I do not want to transmit the disease to other people |
| | | **Family support** | My closest relatives support me to get treated |

MDT= multidrug therapy; *Additional statements brought up during the panel discussion
Discussion

The accepted items were generally ranked higher than others by all participants. Some of the items with the highest ranks are “motivation to recover,” “the impacts of discontinuing MDT and incomplete treatment,” “events of MDT drop-outs,” “Patient’s belief that recovery would be achieved by routine drug consumption,” and “Motivation from within.” The latter two are either grouped into the self-efficacy dimension or were associated with the patient’s mental health state.

Most of the rejected items have a similar meaning to their accepted counterparts. For example, ‘reminded to attend MDT regimen by significant others’ has the same meaning as ‘family support’. This also applies to ‘patient can accept leprosy condition’ with a similar intention to ‘confident with leprosy skin condition.’ Other items like ‘unreadiness to receive leprosy diagnosis’ are considered ambiguous since the criteria to measure the patients’ readiness have not been established, and ‘unwillingness to give up’ is a broad term with similar meaning to the indicator ‘motivation’ itself.

An interesting trend was seen where dermatologists seemed to think that the unavailability of health personnel and the idea that patients are uncomfortable coming to health facilities may cause compliance issues. In contrast, the patient group did not seem to think so (see Supplementary Table 1). Likewise, the item ‘MDT drugs are available in primary care facilities’ had lower Likert scores among patients than the health and governmental personnel. Similar trends were also observed in items such as ‘patients’ understanding of the disease severity;’ ‘counseling to acquire patients’ needs during MDT;’ and ‘self-stigma.’ In contrast, ‘patient’s will to bring happiness to loved ones’ and ‘patient’s will to achieve future goals’ showed the opposite.

Another thing is that the item ‘level of education’ was not accepted because it was unrelated to the HBM concept. Other indicators such as age, gender, and personality based on clinical questionnaires or scores, the emotional factor that can be measured through the perceived stress scale, and social factors such as economy, social support, and cultural norms and beliefs have not been explored yet. The items were transformed into statements to create a more relatable format for our respondents.

Although both healthcare professionals and patients voted on some accepted items, whether any of these factors contribute to leprosy patients’ compliance with their regimens is still debatable. A study in Sumenep District, East Java, found that factors including knowledge of leprosy disease, family support, social stigma, health care workers encouragement, and accessibility to the drugs have significant associations with treatment compliance (p<0.01). Knowledge-based medical-seeking behavior was theorized to have a long-lasting impact. Holmes, et al. also noted that components of the HBM theory, such as perceived barrier, perceived susceptibility, perceived adverse effects, and perceived benefits, might be linked to treatment compliance. Self-efficacy (belief) is the most prominent and meaningful component of treatment compliance. In addition, personal factors, such as personality patterns and emotional factors, can also contribute to the individual’s treatment compliance. However, Susanti, et al. in Jember reported that social stigma and motivation for healing did not significantly affect medication adherence.

Non-compliance was defined as either a defaulter or a treatment interruption. It is further elucidated that a defaulter is interpreted as an individual who is unable to complete the MDT and does not attend the healthcare center for at least 12 months, while a treatment interruption is defined as a prolonged duration of Leprosy treatment to ≥ 7 months for PB type and ≥ 13 months for the MB type. One medication-related factor that was identified pertained to the occurrence of adverse drug reactions (ADRs) with MDT. According to the quantitative data, discontinuation due to ADRs was observed in 9.6% of patients. Kumar, et al. reported that hyperpigmentation resulting from clofazimine was the cause of discontinuation for 7.5% of MB type leprosy patients. It significantly affected adherence due to the associated stigma and perception of beauty. Also, improving positive attitudes toward leprosy-affected persons can reduce the community stigma and increase their early health-seeking behavior and quality of life.

Future studies upon finding the relationship between dimensions or indicators for predicting drug compliance shall be attempted so that the health care professionals and the patients will understand their disease and its management course well, hoping that they tend to be more motivated to undergo the treatment suitably.

We admit that this study still needs improvement. Firstly, we did not objectively determine the number of participants and data saturation, yielding an unequal distribution of the backgrounds, such
as most participants graduated from secondary school; thus, there were few ideas from lower educational backgrounds. In addition, subjective responses in this study were high considering the qualitative form of the study. Moreover, our initial data collection used open-ended questions, yielding diverted participant responses. Some of the unaccepted items had a dramatic variety of scores given by the different groups of participants.

Furthermore, the number of participants from each group was distributed unevenly, which might affect the scoring results. For example, the individual responses obtained from merely one public health office may add to the subjectivities of the study. Then, while a Likert scale yields nominal categories, we counted the means to conclude. Along with only including variables with scores ≥75%, this may cause the exclusion of important indicators. Lastly, we did not include ‘defaulters’ in this study because most refused to participate or were untraceable due to a change of address and contact number.

The accepted items will contribute significantly to other remaining studies as factors contributing to treatment compliance in patients undergoing leprosy treatment. These factors will be further validated in our future studies. It is important to note that no similar studies in Indonesia have found the predictive factors for multidrug treatment compliance in leprosy patients. Future studies are required to analyze whether one of these factors is more significant than others.

Conclusion

Forty-eight final items were accepted according to the Delphi method to develop factors relevant to leprosy patients’ compliance. These final items are then processed for further research in developing a novel self-reporting questionnaire that can predict patient compliance before initiating long-term medication of multidrug therapy.

Acknowledgments

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Author Contributions

Conception and design, funding, investigation, analysis and interpretation of data, drafting and revising the article.

Conflict of Interests

No conflict of interest.

References