

***Educational Approach of Leprosy in Primary School Students:
An Approach to Social Stigma Reduction***

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Abstract

The effort of eradicating leprosy in Indonesia has taken place for a long time, but new cases are detected up to now. The government has launched numerous efforts in light of eliminating leprosy. However, the results were not satisfactory. Medical and community approaches are equally important to be carried out simultaneously, in order to obtain comprehensive treatment. One of the aspects that needs to be emphasized is the stigma reduction, towards leprosy patients as well as the patients' self-stigma. KATAMATAKU Universitas Indonesia conducted an action research whose objective was increasing awareness, considering to complement the comprehensive leprosy management. The first collaboration was carried out with the Gemala Ananda School in Jakarta, Indonesia, specifically for fourth-grade students. The tiered educational model was chosen in order to produce impactful activities. After acquiring the education provided by the KATAMATAKU team, students were asked to re-explain the information to their closest social circle about leprosy. By this educational intervention trial, it is prospected that a better educational model could be applied to reduce the stigma of leprosy in Indonesia.

Keywords: Leprosy, Stigma Reduction, Education Approach

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INTRODUCTION

New cases of leprosy in Indonesia continue to emerge every year, even though the leprosy control program has been implemented comprehensively with the involvement of various disciplines. Based on WHO data for 2022, there were 10,976 new cases of leprosy in Indonesia, and 9.89% of them were new cases of leprosy at a young age. This fact places Indonesia in third place in the world after India (75,394 cases) and Brazil (18,318 cases). This situation shows that although leprosy has existed in Indonesia for a long time, the treatment carried out so far has not shown satisfactory results.

There are various reasons for not optimally suppressing the number of leprosy patients worldwide, including in Indonesia. Stigma is one of the factors in the dynamics of leprosy that causes patients to stay away from treatment (Luka, 2010). In India and other endemic countries, including Indonesia, it was found that the stigma from society and self-stigma in leprosy patients caused the actual number of leprosy sufferers to be far higher than what had been revealed. In many attempts, removing the stigma is difficult because the understanding of leprosy itself is still inaccurate and uneven in society. Even in some areas, regional leaders, religious leaders, or community leaders believe that leprosy is a form of the curse of the Creator still exists (Singh, Singh, & Mahato, 2019; Rai, Irwanto, & Peters, 2020). Stigma ultimately impacts individual, community, and public health programs and interventions (Luka, 2010).

Stigma can occur in various diseases, affecting public health programs and individuals suffering from it (Hatzenbuehler, 2013). Stigma can hit individuals with infectious diseases or not. Regarding infectious as the nature aspect of the disease, leprosy and HIV are two examples of easily stigmatized diseases (Van Brakel, Sihombing, Djarir, Beise, Kusumawardhani, Yulihane, 2012; Turan, Hatcher, Weiser, Johnson, Rice, Turan, 2017). Furthermore, the findings from the research of Rai, Irwanto, and Peters (2020) confirm the formulation of the experience of stigma by Scambler (2004), which existed beforehand and occurred at the structural, interpersonal, and individual levels. These three levels of stigma experience then impact four aspects, namely social, behavioral, psychological, and medical. On the social aspect, the impact that occurs is isolation or isolation (Van Brakel et al., 2012). On the behavioral aspect, there is a reluctance to come out (Peters, Hofker, Van Brakel, Marjolein, Seda, Irwanto, Bunders (2014). On the psychological aspect, there is stress, anxiety, and suicidal ideation (Browne, Ventura, Mosely, Speight, 2013); and on the medical aspect, namely delays in visiting health facilities or interruptions in the treatment process (Stangl, Earnshaw, Logie, Van Brakel, BarreI, Dovidio, 2019). Therefore, eliminating this stigma is a challenge in the management of leprosy.

According to Heijnders and Van der Meij (2006), various interventional approaches can be taken to reduce or eliminate the stigma on the issue of leprosy. Counseling, support groups, socio-economic development, and advocacy are alternatives that can be considered. Another formulation by Peters, Dadun, Zweekhorst, Bunders, Irwanto, & Van Brakel (2014) states that the intervention that needs to be done to reduce the stigma of leprosy patients is direct exposure by leprosy patients to the community or society. Singh, Singh, and Mahato (2019), from their research in Nepal, also previously emphasized that good public understanding is the main target for changing attitudes towards leprosy and, of course, patients suffering from leprosy.

The eradication of leprosy indeed prioritizes medical intervention or treatment. At the same time, strengthening the community and education regarding psychological dynamics also needs to occur because correcting the misunderstanding in the community from both sides is essential. In Indonesia, treating leprosy by administering Multidrug therapy (MDT) follows WHO guidelines (1982) accompanied by education about the disease, including medication adherence. The approach from the aspect of knowledge about leprosy sometimes still needs to touch and be comprehensive in various levels of society. This aspect is a side that is only sometimes a priority in education programs in the community due to various limitations.

We promote the strengthening of educational aspects as well as contact intervention as an intervention program that is carried out. In this action research, we jointly propose a tiered education model for elementary school students. The tiered education in question is a program that contains presentations on leprosy from a medical and psychological perspective to students, followed by giving assignments in the form of compiling campaign activities about leprosy. This education aims to make students understand leprosy, especially its psychosocial aspects so that they can empathize with people with it. At this age, they can properly and correctly receive education provided by experts because social stigma has yet to be formed within them. We offer a tiered education model as an alternative to regular education from limited government health resources. Gradually, the plan is that after the information is presented, it will be passed on to the surrounding community, starting with the closest family. Intervention models of strengthening education and contact intervention are believed to have the greater transformative power to correct the misunderstanding and stigma. This is because direct exposure can help improve the understanding of potential parties or certain groups that develop this stigma (Brown, Macintyre, Trujillo, 2003; Heijnders, 2004; Dalal, 2006). This model selection certainly requires full and ongoing support from the school. Thus, there is a hope that social stigma can be reduced gradually. In this report, we prioritize a review of the component of strengthening education for elementary school students as a particular population.

The KATAMATAKU University of Indonesia team designed the tiered educational model activity. Initially, the KATAMATAKU team designed activities through educational presentations from resource persons followed by sharing sessions from leprosy survivors with the audience. After discussing with Sekolah Gemala Ananda, the school aligned this activity with a program ready to be implemented at school, namely the end-of-semester project, since Sekolah Gemala Ananda also used a Project Based Learning approach. In general, the implementation of this activity is divided into three stages:

1) Preparation Stage

Preparation, participant and recruitment

In February 2022, the team agreed that a tiered education model would be the chosen activity. The material in this activity is related to the medical aspects of leprosy and the psychological dynamics of leprosy patients. The team chose this activity at the Sekolah Gemala Ananda (SGA) in South Jakarta because, since 2013, SGA has implemented a curriculum with an integrated model between subjects. This curriculum allows schools to incorporate particular material that aligns with the main learning objectives.

Agreement between the team and the school, the participant's criteria and activities were as follows:

1. This activity was given to the fourth-grade students who were undergoing learning on the theme of empathy and health.
2. This activity is carried out using the Zoom online virtual meeting media.
3. This activity was carried out in two days on May 30th, 2022, with 20 minutes for medical material, 20 minutes for psychological dynamics material, and 20 minutes for questions and answers, followed by a survivor's sharing session on June 3rd, 2022.
4. The accompanying teacher will act as a moderator of the activity.
5. The school will continue to assign students as their Grade Four Final Project to represent the material presented to families or people who live in the same house.

2) Activity Stage

The activity was carried out according to plan on May 30th, 2022. The day before, students were required to watch an animated video entitled "Knowing Leprosy", a duration of 10 minutes, specially designed by the KATAMATAKU team for elementary school students. An educational comic book also created by The KATAMATAKU team inspires this video with the same title.

The school opens the Zoom application at 12.30 PM and opens activities at 12.50 PM. A total of 43 Grade Four students attended the activity. The speaker on medical material started his session at 1 PM and immediately continued with the speaker on psychological dynamics at 1.20 PM. In medical-related material, the main content presented is about leprosy, its causes, ways of transmission, forms of abnormalities, treatment, and prevention that can be done. While on psychological-related material, the content presented includes how to behave towards persons with leprosy and the empathy that is developed. Each material is delivered in a simple and easy-to-understand manner for elementary school students with a presentation time of 40 minutes. The delivery structure is the presentation of the two parts of the material sequentially, followed by a question and answer session. The moderator opened the question and answer session at 1.40 PM, moderated several questions, and closed the session at 2.10 PM.

The activity continued with assignments from accompanying teachers to students who took part in this activity. Students presented back to family members at home and recorded using each student's cell phone or their parents'. The results of the recording are given to the school teacher to be used for evaluation and giving feedback.

3) Evaluation Stage

Activity evaluation

Activity evaluation was completed by filling out a questionnaire with parents and interviewing the schools involved. Activity evaluation is carried out to obtain an overview of 1) the overall implementation; 2) the assessment of the material; 3) the assessment of the sources; 4) the accuracy of the activity method; 5) the possibility of repeated implementation in the future. We compiled a questionnaire instrument with ten items covering the aspects of the assessment that have been mentioned. At the same time, in-depth interviews were conducted to the school's staff from questions derived from the items in the questionnaire. Interviews were chosen as an evaluation method by the school to be able to obtain more comprehensive data.

a. Participants

Eight participants from parents completed the questionnaire, and we interviewed the school principals and education coordinators for grades four, five, and six who were directly involved in designing activities.

b. Result

i. Parent's aspect

In Table 1, we can see that all of the responder already had prior information about leprosy; belief that the activity can reduce stigma; belief that students empowerment are one of the effective way; and also says that the activity can be replicated to other educational institutions. While 87.5% of the responder claimed gain more information about leprosy after the activity and also perceived that the students are capable to reproduce the information to others. From Table 2, we can obtain that added information after the activity is started from a basic information, such as source of leprosy and the fact that leprosy is curable. We also can see that responders perceived a mass education about leprosy through various media is needed to increase community's awareness.

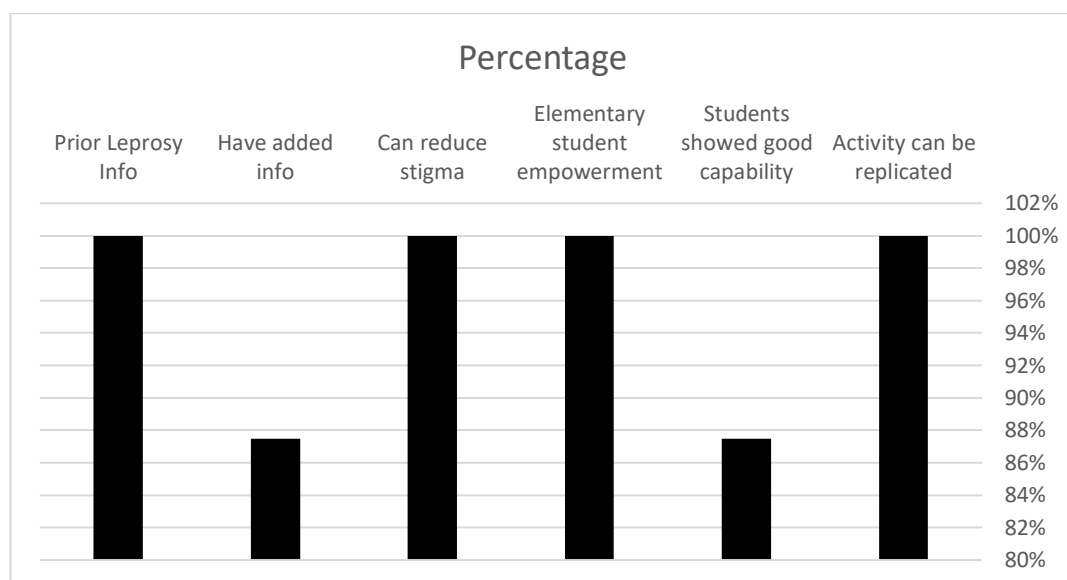


Table 1: *Parents' questionnaire result*

Inquiry of question number 6 about additional information after the activity	
1.	How to prevent
2.	That leprosy is curable
3.	That leprosy is not as contagious as perceived before
4.	That leprosy caused by bacteria
Inquiry of question number 13 about how to increase community's awareness about leprosy	
1.	Socialization through social media
2.	Increase the frequency of leprosy education through all media probable (social media, talkshow, schools/educational institution)

Table 2: *Inquiry on question number 6 and 13*

ii. School administrator's aspect

The following are the results of the interviews, which have been summarized in Table 3 according to the five aspects explored:

Aspects \ Person	School's Principal (JJ)	Fourth to Sixth Academic Coordinator (EN)
1. Overall evaluation	<ul style="list-style-type: none"> It is excellent because it follows how the school implements project-based learning. Thus, the KATAMATAKU program can run in harmony with school principles. 	<ul style="list-style-type: none"> The teachers and children were very enthusiastic and happy with this program. The teachers only need to consider how technical it would be delivered to the children and who suits the activity better. It has been perfect because it aligns with SGA's vision and mission: solutions and benefits. This program can also be carried out by children so that it runs smoothly and benefits the community.
2. Material evaluation	<ul style="list-style-type: none"> Information conveyed with pictorial illustrations: provides an excellent initial understanding for children. It is felt that it will be right on target if this program is meant to eliminate the stigma on sufferers/survivors because children meet people directly. Make it easier for children to carry out campaigns because they understand clearly and have traces of experience received → increasing understanding of the case. 	<ul style="list-style-type: none"> The books provided can be used to prepare students to understand what leprosy is, how to treat it, and its distribution in Indonesia. Through an actual campaign program, children can directly take a small role in reducing the stigma of leprosy in their immediate environment (family).
3. Speaker's evaluation	Competent. Providing a platform for children to have discussions, triggering curiosity, and increasing empathy for survivors → This is evidenced by the many questions that keep popping up despite the duration of the event.	Competent. The presence of resource persons can make children understand how leprosy affects the resource persons so that it fosters compassion for children.
4. Activity choice	Precise, following the learning objectives to be achieved.	It is proper because it includes three taxonomic domains (cognitive, affective, and psychomotor).

<div>Person</div> <div>Aspects</div>	School's Principal (JJ)	Fourth to Sixth Academic Coordinator (EN)
5. Future feasibility	<p>Very feasible, with more attention to:</p> <ul style="list-style-type: none"> • Need for a comprehensive assessment of school readiness. • Ensuring that KATAMATAKU assists (runs simultaneously) with the teacher. • Need to understand more deeply the extent of information exposed to children. For example, are there any children familiar with leprosy around the house because their neighbors are sufferers/survivors? • The output for this activity can be adapted. For example, if it is not possible to use a campaign, a reflection session can serve as an alternative. It is essential to understand each school's readiness with various characteristics of teachers and students. • Understand the technical implementation of the Permendikbudristek No. Program. 56/M/2022, P5 (Project for Strengthening Pancasila Student Profiles) can be a gateway for KATAMATAKU to carry out similar activities in other schools. The P5 program has a composition of 20% in each school's teaching and learning process. 	<p>Very feasible, with more attention to:</p> <ul style="list-style-type: none"> • There needs to be a program framework to run smoothly and have an impact. • Other school may need examples/templates/models provided so the program can be implemented in a more structured manner • Search for resource persons for survivors or persons with disabilities that are appropriate for the age of the children (participants) so that children are more "in touch" with the story.

Table 3: School administrator's interview result

CONCLUSION

From the result, the program trials carried out are considered successful in several aspects. The program designed supports the main objective of the activity, namely reducing stigma. In general, some of the points that can be concluded are:

1. In terms of implementation, the activities have gone very well. Material aspects, presenters, and the arrangement of activities are considered to have all the necessary elements. This activity can also be replicated in various other educational institutions.
2. Regarding activities, the tiered model applied and strengthened by exposure to survivors is considered to have a reasonably substantial impact. The impact was sufficient to fill the need for exposure to leprosy materials in society, which was not comprehensive enough in reality by far.
3. In terms of material, it was found that medical and psychological materials and direct discussions with survivors could make students learn in total, covering the cognitive, affective, and psychomotor domains.

SUGGESTION FOR FURTHER STUDY

This activity needs to be developed again at various levels of society. Some points of note if this program wants to be replicated in other educational institutions are:

1. A thorough assessment of the destination school is needed so that good coordination can be achieved because not all schools are ready with a student-centered and project-based learning approach.
2. Submission of video and book material before the presenter's session will help to facilitate the discussion process.
3. We can consider various survivors with varying conditions of leprosy to present a better discussion because students will see for themselves the condition of the leprosy patient.

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3. Parents of the Fourth Grade Student in 2022. We express our appreciation to the parents that are very cooperative in the activity.

GLOSSARY

KATAMATAKU: Identifikasi tanda mata, ekstremitas dan kulit pada kusta. Is an organization with a concentration of activities on education and intervention for people with leprosy. This action research group was formed in 2019, with members from various lecturers and researchers from all faculties at the University of Indonesia.

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