

Social stigma as an epidemiological determinant for leprosy elimination in Sitanala, Indonesia

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Abstract.

Leprosy has been eliminated as a public pathological state in most of development countries like Indonesia, however the social stigma to the sickness continues to be terribly high. This study was performed to research the role of social stigma as a determinant for infectious disease elimination in an exceedingly infectious disease endemic region of Indonesia. Focus cluster discussions, in-depth interviews and structured questionnaires were accustomed investigate infectious disease social stigma among lepers, their contacts and an effect cluster consisting of patients attending a hospital for reasons aside from infectious disease. consent was wanted and gained before beginning the study. Focus cluster discussions and in-depth interviews known 3 kindsof stigma; lack of vanity, social group stigma and complete rejection by society. From the 480 structured questionnaires administered, there have been over- all positive attitudes to lepers among the study population and inside the divisions ($P=0.0$). The proportion of participants that felt sympa- thetic with distorted lepers was 78.1% [95% confidence interval (CI): 74.4-81.8%] from a complete of 480. 300 and 99 (83.1%) respondents indicated that they may share a meal or drink at constant table with a distorted leper (95% CI: 79.7-86.5%). 103 (83.9%) participants indicated that they may have an acknowledgment and embrace a distorted leper (95% CI: 87- 87.3%). a complete of 85.2% (95.0% CI: 81.9-88.4%) participants thoroughbred that they may move with a distorted leper to the market or mosque. A high proportion of 71.5% (95.0% CI: 67.5%-75.5%) participants expressed that they may supply employment to a distorted leper. The results indicate that Sitanala 1 division had very cheap mean score of 3.3 on positive attitudes to infectious disease compared with Sitanala 2 (4.1) and Sitanala 3 (4.8) divisions. The high proportion of positive attitudes among the participants and in numerous divisions may be a positive indicator that the elimination of infectious disease social stigma is progressing within the right direction. Quantification of stigma to assess the elimination struggle may be a new analysis space publicly health.

Keywords: social stigma, leprosy, epidemiology, endemic

I. INTRODUCTION

Leprosy has been delineate as a neglected tropical sickness and social killer as a result of it causes incapacity, has economic implications and leads to social exclusion compared with alternative diseases like protozoal infection that square measure serial killers.¹ Goffman² has provided the fore most widely accepted definition and outline of stigma relating bodily signs designed to reveal one thing uncommon or dangerous concerning the ethical standing of the word. Stigma itself could be a advanced issue, with the capability to have an effect on all aspects of a leprosy affected person's life.³

several samples of social exclusion square measure within the literature.⁴⁻⁷ Today, infectious disease is clinically cured comparatively simply, yet, the results that it's on a patient's life will keep it up indefinitely.

³ The stigmatising condition will cause the person affected being rejected and excluded from society.⁸ Within the past 20 years effective treatment has reduced infectious disease prevalence within the world.^{9,10} However, the quantity of individuals living with its effects is counted in millions and prejudice still remains a burden to those have an effect oned that directly or indirectly affect its elimination. Leprosy social stigma has been delineate as worse than the malady itself by Hansen's disease patients.¹¹ Hansen's disease remains a public ill health in Indonesia despite the fact that the country has earned the elimination threshold set by the World Health Organization.¹² during this study we have a tendency to investigated the role of social stigma as a determinant for Hansen's disease elimination during this endemic focus in Indonesia.

II. METHODS

Study Area

The study space and strategies are delineate else where thoroughly.¹² Briefly, the participants were drawn from Sitanala 1, Sitanala 2 and Sitanala 3 divisions of Banten Region of Indonesia as a result of they'd the best prevalence of Hansen's disease (3.4/10,000 and four.5/10,000, respectively).¹³⁻¹⁵ These divisions still have the best Hansen's disease prevalence (1.7/10,000 for Sitanala 1 and 2/10,000 for Sitanala 2) within the Banten Region of Indonesia.¹⁶ This study was conducted from January 2020 to August 2021.

Design And Setting

The study was a descriptive data based case control study that was community based in one low (Sitanala 1 division) and 2 high (Sitanala 2 and Sitanala 3 divisions) areas. Hansen's disease patients brought about the cases and also the contacts were a unsound cluster for developing Hansen's disease. The management cluster consisted of patients attending a health center for reasons apart from Hansen's disease. Hansen's disease patients, their contacts and controls were matched for geographical location, age and sex.

Inclusion and exclusion criteria for Hansen's disease patients, contacts and controls All intrafamilial contacts (wife, youngsters and alternative relatives) and extra-familial contacts (friends, peers, colleagues and villagers) were concerned within the study. Controls were {those World Health Organization/those that/people who} attended the Sitanala Hospital for reasons apart from Hansen's disease who were hand-picked supported a well-structured, guidmale erectile dysfunction questionnaire; those that either live or lived with a leper within the same social unit or quarter were eliminated from the study.

Selection Techniques For Focus Cluster Discussions, In-Depth Interviews And Structured Form

Nine focus cluster discussions (FGDs) [5 with contacts and four with cases] and half dozen in depth interviews (IDIs) [3 with contacts and three with cases] were conducted employing a guide to gather data on Hansen's disease social stigma and to finetune the structured form. The participants within the FGDs were purposively chosen during which minigroups from the target population mentioned topics on leprosy social stigma. The groupings were supported the profession, literacy, and position of participants. Direct interviews were conducted male erectile dysfunction in artificial language, with the assistance of a trained interpreter. All told FGDs, the lead author acted because the moderator and trained spot students acted as note takers. All the FGDs and IDIs were recorded on cassette tapes. the aim of recording the interviews was explained to the participants and their consent obtained before this was done. The notes and replayed cassettes were transcribed once the interviews. The list of patients was obtained from health facilities.

The patients in numerous villages aided within the identification of alternative patients whose names weren't within the registers. within the leprosarium, all Hansen's disease patients on treatment, those discharged and living inside the neighbour villages, together with those restored, were concerned. Once distinguishing 138 Hansen's disease patients, 180 contacts and 162 controls were recruited for the study. A part open and closed pre-tested structured form was administered to any or all 480 respondents. {those World Health Organization|those that people who} may scan or write a people language crammed the form and people who couldn't were communicated to through associate degree interpreter in Indonesian dialects. The form contained socio-demographic variables on age, sex, legal status, religion, geographical location and profession. Attitudinal queries on social stigma of leprosy brought about the dependent variables.

Ethical Approval And Clearance

The authorization to hold out the work was obtained from the Faculty of Public Health of University of Indonesia. advised consent was obtained from all respondents before discussions/interviews were conducted, questionnaires administered and from the patient whose image is given.

Data Management And Analysis

The audiotapes from FGDs and IDIs were replayed and transcribed, and also the totally different responses to the queries on social stigma were analysed manually employing a code tree. Content and construct validity were checked to make sure the validity of transcribed FGDs by comparison the transcribed notes with written notes taken throughout FGDs. Relevant comments on social stigma were analysed. Similar views on every discussion item were sorted one by one from dissimilar ideas. Discussions on topics with several dissecting views were given within the style of graphic comments.

Each time the questionnaires were brought from the sphere, they were checked for nonreciprocal queries and emended for the employment of correct codes and completeness, together with vary and consistency errors. The structured form knowledge were analyzed exploitation Epidata once a double entry bookkeeping by 2 knowledge clerks. Knowledge outline like proportions and percentages and testing of the operating hypothesis were additionally administrated exploitation the chi-square and Fisher actual tests for tests of significance of association between categorical variables. The operating hypothesis was that attitudinal queries on social stigma weren't getting to vary among the study and also the management teams and inside the divisions.

III. RESULT

Focus Cluster Discussions Among Hansen's Disease Patients, Contacts And Controls

It was gathered from FGDs that there have been 3 sorts of social stigma, that vary from lack of vanity (self stigma) among the Hansen's disease patients, social group stigma, and complete rejection by society. Majority of contacts shunned interactions that might entail person- to-person contact particularly with illshapen patients. Most contacts aforesaid they might tolerate acknowledgment with a lepper. Solely few contacts accepted the thought of marrying a leper. The FGD views of the participants on the social stigma of Hansen's disease square measure given in Table one. Among the graphic comments created on the social stigma to Hansen's disease by contacts, the subsequent was pertinent and often mentioned. "There is rejection and other people contemn them as a result of they can't contribute to the development of the society; they lack correct lodging".

All community based rehabilitation staff (contacts of patients) commented that social stigma was a obstacle to Hansen's disease elimination as expressed within the following comments. "The Hansen's disease patient rejects his/herself initial by shying far from individuals and sitting at corners in gatherings, followed by the family and also the community". "There square measure thirteen villages in my space. These vilages have their ancient taboos. In some, the patients square measure rejected in "Manjong" homes (Manjong may be a social gathering), they don't drink from an equivalent pot with others. This happens to treated and untreated patients. they can't play the drum and dance well". All participants expressed the views that social stigma to Hansen's disease was high in their places of origin. Among the Hansen's disease patients concerned in FGDs, it had been nem con accepted that society had positive attitudes towards them compared with the past years of the 50s and 60s once social stigma was terribly high.

In-Depth Interviews Among Hansen's Disease Patients, Contacts And Controls Social Stigma Among Lepers

During IDIs, it emerged that social stigma was deeply stock-still within the study space among non-lepers. However, the lepers expressed the views that society was having positive attitudes towards them. Among the non-lepers the subsequent pertinent comments were often mentioned: "These patients square measure looked upon as second category voters. Discrimination forces some patients to try and do sure activities simply to seem like traditional individuals, which ends in any deformities. Some, World Health Organization came to the Hansen's disease colony for treatment, had their property taken. traditional individuals cannot marry them. However, social stigma is decreasing currently. If someone is treated of protozoal infection, there's no reason to continue vocation him/her a protozoal infection patient for all times.

Why then with leprosy? once a significant wind blows down a plantation stem, once the wind the stem cannot rise up. we have a tendency to cannot say that the wind remains processing. Why ought to we have a tendency to continue vocation these individuals Hansen's disease patients? "Deformities square measure like scars of any wound". "Social stigma accustomed be terribly high however currently many patients World Health Organization square measure discharged live, play and dance well in society". The lepers nem con united that the attitude of society towards them was rising as expressed within the following comment: "All children born in Sitanala village square measure married to organization and none of them has leprosy; we have a tendency to move with individuals freely".

Social Stigma Among Non-Lepers

It emerged from the study that social stigma to {leprosy|Hansen's malady|infectious disease} was high within the study space among nonlepers which may hinder the effective elimination of the disease. 3 sorts of stigma were identified first, the patient rejecting himself attributable to lack of vanity, and second, the repulsive perspective of the society to the patient.

Leprosy Determinants From Structured Form Among Hansen's Disease Patients, Contacts And Controls

The significant findings on attitudes to leprosy among lepers, contacts, and controls square measure shown. The proportion of participants that indicated that they felt sympathetic with ill shapen lepers was 78.1% (95% CI: 74.4- 81.8%). There was no statistically important relationship between the sentiments of intra-familial and extra-familial contacts towards ill shapen lepers ($P=0.8$). 300 and 99 (83.1%) respondents accepted that they might share a meal or drink at an equivalent table with a ill shapen leper (95% CI: 79.7- 86.5%). There was no statistically important association within the perspective of sharing a meal or a drink at an equivalent table with a treated however deformed-leper among intra-familial and extra-familial contacts ($P=0.4$). 403 (83.9%) participants accepted that they might have a acknowledgment and embrace a ill shapen leper (95% CI: 80.7-87.3%).

409, such as 85.2% of total participants [95.0% CI: 81.9-88.4%], accepted that they might move regarding with a treated however ill-shapen leper to a public place (market or mosque). Additional intra-familial than extrafamilial contacts (85.9% s. 52.8% respectively) accepted that they might move with a treated however ill shapen leper to a public place ($P=0.3$). 343 (71.5%) participants accepted that they might supply employment to a ill shapen leper [95.0% CI: 67.5-75.5%]. The outline statistics on attitudinal queries on feelings, sharing a meal or drink, movement to public places, acknowledgment and job supply to treatmale erecticle dysfunction however ill shapen lepers is shown. Lepers and controls had higher mean scores than contacts for these determinants.

IV. DISCUSSION

This study has important implications for the management and elimination of infectious disease in Indonesia as a result of social stigma may be a major determinant for the rehabilitation of infectious disease patients. infectious disease has been eliminated in Indonesia¹² in line with the United Nations agency common place, however there ar still endemic foci like that in Sitanala. infectious disease has been integrated into primary health care in Sitanala however throughout FGDs and IDIs, infectious disease social stigma among health personnel was terribly high which may lead infectious disease patients doubt the effectiveness of treatment, that has negative effects on elimination. By drawing attention to stigma, this study will facilitate fine tune public health messages and sharpen awareness campaigns as a result of stigma has proved to be staggeringly helpful in neglected tropical illness management.²⁰ Stigma is a very important deterrence to treatment²¹ and this has been proved for infectious disease.

²² The damage of stigma is that it inhibits treatment of the stigmatising illness, and therefore each unhealthiness and stigma persist,²⁰ which can have an effect on infectious disease elimination in Indonesia. Social stigma is manifested in many ways that verbal abuse, ostracism from social functions, implemented isolation and separation from the family. If stigma is carried through to its conclusion, the person could also be forced into destitution. In several cases, going forward for treatment is left too late to avoid deformity. this is often due fairly often to lack of information of the symptoms of infectious disease.²³ Stigma is expounded to the very fact that infectious disease is one in all the diseases with physical imperfections that ends up in disabilities however rarely kills that the patient lives and continues to suffer. These deformities worsen with age²⁴ and since malformed lepers ar poor due to physical disabilities, there's no can power, they can't feed and accommodate their families nor educate their youngsters. This ends up in despair and lack of self esteem.²³ Every society considers illness in numerous ways and this influences the perspective of the community to infectious disease patients.

²³ Within the study scope, the utilization of ancient medication to clarify life activities is often practiced which inspires belief. this could justify why the respondents associated infectious disease to sorcery, unhealthy behaviour or sin. These cultural taboos will hinder infectious disease management within the study scope.²³ Social contact with infectious disease patients was generally shunned by majority of participants. A community based rehabilitation employee commented that “sleeping with eyelids open, create youngsters to run off from lepers that they're not traditional individuals. individuals don't need to take a seat with them on constant bench within the church, or eat with them.” These findings are in agreement with the work of Touko et al.²³ in Yaounde, Cameroon United Nations agency found that social relationships with lepers were shunned due to physical imperfections. Most non infectious disease participants believed that patients with clawed hands and feet and different deformities were still infectious and per se several refuse body contact with them.

The misunder- standing of a society that treated infectious disease, its victims and people operating against it, with worry and prejudice has been reported from the Cross stream State of African nation.²¹ Such misconceptions still exist in Essimbiland.²³ of these are associated to the high social stigma of leprosy, that may be an obstacle to infectious disease elimination within the study scope. This study has discovered that lepers, contacts and controls feel sympathetic once they see malformed lepers. Contacts may well be therefore accustomed malformed infectious disease patients that they don't see them as a haul contrary to controls United Nations agency don't seem to be accustomed infectious disease and a malformed leper to them appearance therefore strange that they show tons of sympathy towards the patient.²³ Lepers might want to go along with non-lepers, thus the high proportion of this class of respondents United Nations agency expressed such views.

Overall Variation Of Attitudinal Queries On Social Stigma Among The Study Participants

Results showed that lepers had the very best mean score of positive attitudes towards them- selves followed by controls and contacts ($P=0.00$). This highlights the very fact that lepers have an interest in socialising with society however society on the contrary features a hostile perspective towards them due to their physical imperfections and worry of contagion.²³ In a community-based study on attitudes to infectious disease in Sitanala, Banten, Indonesia et al.²³ found that interactions that didn't involve physical contact with lepers were typically welcome by ninety four of the respondents, whereas physical contact was shunned by all, except 4.5%. during this study, social contacts like shake and grip one another, movement to public places and sharing a meal with lepers was accepted by quite five hundredth of the respondents. infectious disease is a lot of a public ill health in Sitanala 1 and Sitanala 2 divisions than Sitanala 3.

²³ In these divisions, inhabitants might not see infectious disease as a problem; thus they tolerate tons of physical contact with lepers compared with inhabitants of

Sitanala 1. These findings are positive indicators of infectious disease elimination. Due to the high social stigma, several infectious disease patients could choose to not attend health facilities since their presence could reveal their condition.²³ Contacts are therefore accustomed lepers that {leprosy/Hansen's illness/infectious disease} is not any a lot of a haul for them such a large amount of might not sympathise with malformed lepers contrary to controls that see infectious disease as an odd disease and will feel a lot of sympathetic with malformed lepers.

Types Of Infectious Disease Social Stigma

In this study, 3 kinds of stigma were discovered the social stigma that {leprosy/Hansen's illness/infectious disease} patients suffer due to the presence of the disease and also the physical imperfections resulting in disabilities. As Bainson and Borne²³ reported from Nepal: "Some individuals appear ugly to most observers. A infectious disease patient with various giant nodules on the face or one United Nations agency has lost all her fingers would hardly be delineate by the general public as lovely." This makes the infectious disease sufferer to lose social rank and become increasingly isolated from society, family and friends. Frustration with unemployment and incapacitating deformities finally force him into alcoholism, mendicancy and adaptation of a hostile perspective towards society leading to debilitation.

Contrary to the idea within the study space, the infectious disease patient becomes hostile to society not due to the cruel manner society treats him/her however as a result of some components of multidrug medical care have an effect on him/her attend the discharge ceremony (a festal occasion once treated patients are formally discharged from the colony and given certificates to travel and live traditional life in society).²³ In near villages round the leprosarium, cured infectious disease patients also because the malformed discharged inmates create new alliances with different expatriates. Some infectious disease patients even rear youngsters. Infectious disease patients marrying non patients was ascertained among hospital employees and also the area people, however it had been not a common prevalence.

Overall Variation Of Attitudes To Infectious Disease Within The 3 Divisions

On positive attitudes to infectious disease, it had been ascertained that social stigma to infectious disease was terribly high in Sitanala division. Sitanala division may be a remote space of the Banten Region with a high rate of illiteracy and has several different social issues which will contribute to high stigma, as an example, impoverishment and belief. Tribal stigma related to the people of Sitanala division for contributive to the majority of infectious disease within the study space was dis-coated. behavioral studies ought to be administrated within the study space to beat the socio- cultural aspects of infectious disease stigma. Quantification of stigma to assess the elimination struggle may be a new analysis space publicly health. Stigma-related factors ought to be researched into and analysed to develop appropriate health education ways and outline specific messages. This work is significant to the

semipermanent goal of infectious disease elimination, as, till stigma is addressed, the illness can't be absolutely cured. "The fight isn't over however. However it's winnable and leprosy sufferers needn't should not be shunned. Unless the message reaches each continent, each country, each village, each patient, the illness can prevail in dangerous pockets".

²³There was conjointly the social group stigma In this neighbourhood, illness causing is often which most health personnel of the Sitanala leprosarium and Regional Delegation of Public Health within the Banten Region have towards the individuals in Sitanala division.²³ The majority of infectious disease during this region comes from Sitanala most in order that health employees associate infectious disease with Sitanala individuals. Thirdly, in different areas of the Banten Region together with Sitanala, individuals believe that infectious disease is caused by ones' enemies or a curse from the ancestors; it's typically believed that lepers are witches and wizards or have some terribly wicked characters. Anybody associating with lepers together with the health personnel is believed to own some supernatural powers that stop them from having leprosy. this could justify why shut relations and generally medical examiners planning to infectious disease patients conjointly suffer some stigma. Goffman² recognised this development and referred to as it courtesy stigma. the various kinds of stigmas weren't mentioned by any of the survey respondents as a result of it had been not specifically raised per se since the aim of the qualitative knowledge was to fine-tune ambiguous structured queries for the survey.

Marriage And Divorce Or Separation Thanks To Infectious Disease

In this study, 5.1% lepers indicated that their divorce or separation from their significant other was thanks to infectious disease. The patients United Nations agency reported that they were married weren't essentially with their original spouses. On additional reexamination, several debilitated patients admitted that they were antecedently married and left their 1st spouses once they were diagnosed with infectious disease. Some feminine patients admitted that they were convinced their 1st significant other had abandoned them once they didn't linked to sorcery and infectious disease is believed either to ensue to sorcery or some past unhealthy behaviour. Social stigma in {leprosy/Hansen's illness/infectious disease} results from the deformity the disease causes.²³ The high social stigma to infectious disease during this environment will have an effect on infectious disease elimination. The degree of stigma against infectious disease in an exceedingly given community influences several aspects of infectious disease control; some individuals could conceal their unhealthiness, discontinue therapy, and gift them selves late for treatment.

²³ Misconceptions like infectious disease is hereditary²⁰ or infectious disease is thanks to past unhealthy behaviour²⁰ will encourage high social stigma. As Van Brakel²³ argues in his literature review on infectious disease and stigma, with conditions like infectious disease, HIV/AIDS, epilepsy, schizophrenic disorder, etc., stigma could also be worse than the illness. For this reason stigmas are typically labeled

as social killers since the rejection will cause loss of social networks, loss of labor, problem in finding wedding partners, divorce, loss of reputation, discrimination and ostracism, etc and ultimately to isolation.²⁰ of these tally with views expressed by participants during this study. Because of the high social stigma, several leprosy patients could choose to not attend health facilities since they presence could reveal their condition. this could justify why many of us prefer attending health facilities far flung from their point order to stay anonymous a brick strategy delineate by Barret²³ for leprosy patients, which may prevent the elimination of the illness.

V. CONCLUSIONS

A characteristic of stigma delineate as social group stigma related to the Sitanala people of Banten division for contributory to the majority of Hansen's disease within the study space was discoated. Behavioral studies ought to be allotted within the study space to beat the sociocultural aspects of Hansen's disease stigma. Quantification of stigma to assess the elimination struggle may be a new analysis space publicly health. Stigma-related factors ought to be researched into and analysed to develop appropriate health education methods and outline specific messages. This work is important to the long goal of Hansen's disease elimination, as, till stigma is forbidden, the illness can't be absolutely cured. "The fight isn't over nonetheless. however it's winnable and leprosy sufferers needn't should not be shunned. Unless the message reaches each continent, each country, each village, each patient, the illness can prevail in dangerous pockets".²²

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