

CASE REPORT

Stigma and Prosthetic Rehabilitation Challenge for Leprosy Survivor in Pandemic Situation

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ABSTRACT

Introduction: Disability in Leprosy Survival (LS) is generally irreversible and burdensome, although the leprosy itself had been cured. The case report will describe the stigma, medical, and socioeconomic challenges facing by LS while dealing with prosthetic replacement in the pandemic situation.

Methods: A 38-year-old man with bellow knee amputation, left side, was diagnosed with leprosy in 1990, completed Multi Drug Therapy (MDT) treatment and was declared cured within 2 years. Amputation was performed in 2006. Having stump maturation, the patient got the prosthesis that had not been replaced until now. The stigma attached to LS made patient felt the difficulty of getting a job and worried about losing his current job. This made patients reluctant to ignore the need of a new prosthesis for years. The damaged prosthesis caused repeated injuries to the stump.

Result: When a pandemic occurs, the patient's concerns came true, the patient was fired. But on the other hand, this created an opportunity for patients to focus on prostheses replacement, especially with the support of Universitas Indonesia community engagement grants. Patients were prescribed a new prosthesis with similar construction the old one, except endoskeleton and the inner liner part; which should be using silicone gel, replaced with a double inner liner.

Conclusion: Pandemic gives social economic impact to the patient; loosing job, regional lock down and resistancy to go to public area as hospital. Stimulations and supports in order to help him and his family to go through the pandemic are needed in order to maintain their independency in daily life.

Keywords: leprosy, pandemic, prosthetic, rehabilitation, stigma

ABSTRAK

Latar belakang: Disabilitas pada Orang Yang Pernah Menderita Kusta (OYPMK) umumnya ireversibel dan memberat, walaupun penyakit kustanya sendiri telah lama sembuh. Laporan kasus ini akan menjelaskan tantangan stigma, masalah medis, serta sosial ekonomi yang dihadapi oleh OYPMK yang telah mengalami amputasi, selama menjalani rehabilitasi terkait pemeliharaan dan penggantian kaki palsu di masa pandemik.

Metode: Seorang pria 38 tahun dengan amputasi bawah lutut kiri, didiagnosis kusta *borderline* pada tahun 1990, menyelesaikan pengobatan MDT dan dinyatakan sembuh dalam 2 tahun. Amputasi dilakukan pada tahun 2006. Setelah *punctum matur*, pasien mendapatkan prostesis yang sejak saat itu belum pernah diganti sampai sekarang. Stigma yang melekat pada OYPMK membuat pasien merasakan sulitnya mendapatkan pekerjaan dan sangat khawatir kehilangan pekerjaannya saat ini. Hal tersebut membuat pasien cenderung mengabaikan kebutuhan akan prostesis yang baru dan menunda penggantian prostesisnya yang telah rusak selama bertahun-tahun. Prostesis yang rusak menimbulkan cedera berulang pada *punctum*.

Hasil: Saat pandemi terjadi, kekhawatiran pasien menjadi kenyataan, pasien dipecat. Namun di lain pihak, hal ini menciptakan kesempatan bagi pasien untuk fokus pada penggantian prostesis, terlebih dengan adanya dukungan hibah pengabdian masyarakat dari Universitas Indonesia. Pasien diresepkan protesis baru dengan konstruksi yang mirip dengan prostesis lama, kecuali bagian *endoskeleton* dan *inner liner*; yang seharusnya menggunakan *silicone gel*, namun diganti dengan *inner liner* ganda.

Kesimpulan: Pandemi memberikan dampak sosial ekonomi bagi pasien; seperti kehilangan pekerjaan, pemberlakuan pembatasan kegiatan masyarakat dan kesulitan untuk pergi ke area publik seperti rumah sakit. Stimulasi dan dukungan untuk membantu diri sendiri dan keluarga melewati masa pandemi sangat dibutuhkan untuk menjaga kemandiriannya dalam kehidupan sehari-hari.

Kata kunci: kusta, pandemi, prostetik, rehabilitasi, stigma

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INTRODUCTION

Leprosy is a disease caused by *Mycobacterium Leprae*. It is a mildly infectious disease that is thought to be transferred through infected respiratory droplets. The cure for leprosy is a course of antibiotics known as MTD (Multi Drug Therapy). Rifampicin, dapsone, and clofazimine are used in combination with each other to cure a person of leprosy. The World Health Organization (WHO) supplied MDT for free for anyone who needs it.¹ The purpose of MDT treatment is to

break the chain of transmission, prevent drug resistance, shorten the treatment period, improve the regularity of taking medicines and prevent the onset or worsening disability.

Indonesia ranks third in terms of countries with the highest number of leprosies in the world, after Brazil and India. This fact hasn't changed in the last 20 years ago.² This shows the magnitude of leprosy management problems, both at the world and national level.

Leprosy founded first time on January 31 1924. Today, it is celebrated as World Leprosy Day (WLD). Not like other celebration day, WLD is held in order to campaign global leprosy awareness.¹ Pandemic gives new situation in WLD in 2021.

Some medical staffs of Medical Faculty, Universitas Indonesia - Cipto Mangunkusumo Hospital made collaboration in order to campaign and participate in leprosy awareness and elimination. The collaboration was called KATAMATAKU. It was founded in 2017 and ever since, it annually became executive member of Universitas Indonesia for community engagement program in leprosy. In 2019, the collaboration was developed, not only in medical faculty but also to other faculty in Universitas Indonesia. Katamataku held medical examinations and training to leprosy survivors and sufferers. Trainings were also given to medical personnel or cadres who work with leprosy. Training was not limited in medical aspect, but also vocational.

Along pandemic, Katamataku had made some adjustment in community engagement program. Trainings were given through online webinars

and meetings. Patients who need treatments were asked to come to the hospital since covid-19 screening and prevention protocol at hospital are strictly applied, it was safer for both patients and clinicians.

Actually, leprosy and covid-19 as infection disease are sharing same pattern in elimination management; early detection and contagion prevention.^{3,4,5} But, most stake holder will have more attention in lethal disease rather as covid-19 than disabled disease as leprosy. Since all health resources are intended for the handling of covid-19, leprosy detection and treatment activities are very likely to decrease or even stop altogether. This will be a time bomb; there will be an increase in new cases of leprosy or more disability in leprosy survivors after the pandemic.⁶ At our last online meeting on August 2020 with medical officers of Primary Health Services around endemic areas of leprosy in Malang, they stated that routine coaching activities for leprosy sufferers or survivors had to be stopped since covid-19 pandemic. It was not only because of the covid bustle, also to avoid crowd during the pandemic and impossible to hold online meetings because of infrastructure and economic limitation. In this situation, some support and stimulations for leprosy-continuing medical services was needed, even though with limited sources and more challenges.⁷

This case report will explain the journey of leprosy survivor who has been amputated and has rehabilitation related to the maintenance and replacement of leg prosthetic in pandemic situation. It will describe the stigma, medical, and socioeconomic challenges that he has to go through. This case report is expected to be an inspiration in improving public, academics,

policy makers, and stakeholder awareness, related to leprosy handling problems in Indonesia, both problems for patient and survivors. Thus, it is ultimately expected to reduce the level of disability, promote equal rights for people with disabilities, and support the realization of leprosy elimination nationally and internationally.

CASE PRESENTATION

A 38-year-old man with amputation bellow knee sinistra, was diagnosed Leprosy in 1990. He had borderline tuberculoid leprosy (BT), finished MDT medication and declared cured in 2 years after. He was amputated in 2006, bellow knee level, left limb. Ever since, he used his prosthetic, never had the new one until now.

His educational level was elementary school. He worked as a janitor at the pharmacy, but had fired since pandemic. Patient is a hard worker, never late or skipped, because according to the patient looking for a job is very difficult, he is worried about being fired if behave assorted. This makes the patient never replace his prosthetic leg, even though it has been damaged. Because replacing prosthetic legs, meaning the patient has to go to the hospital, take care of social national insurance (BPJS), on weekdays, ditching from his job.

Using broken prosthesis, patient actually had tried to fix or adjust simple the prosthesis by himself; replace bolts or small parts. Even his neighbors who are also amputees and using prosthetic often ask him to repair minor damage to their prosthetic legs. In short, he is an autodidact prosthetic repairman.

He married in 2004 with other Leprosy survivors. His wife was diagnosed leprosy in 1995, got MDT medication, on and off, and declared cured in 5 years after. His wife had bellow knee amputation in 2002. From the marriage, they had 3 children, none of them infected by *mycobacterium leprae*.

Patient and his family live in Sitanala Leprosy Village. It is an old village that was once inhabited only by leprosy survivors, but is currently inhabited also by workers in Sitanala public hospital. Patient's home is located at RT 01 RW 13, which is inhabited by 163 families, there are 437 residents in total and 51% (n=437) of them are leprosy survivors.

With the stigma attached to OYPMK, patients found it difficult to get a job and have fears of losing their job. This makes patients reluctant to ignore the need for a new prosthesis and delay the replacement of their prosthetic that has been damaged for years. Such delays often cause injury to the stump. When a pandemic occurs, the patient's concerns come true, the patient is fired. But on the other hand, it creates an opportunity for the patient to focus on replacing his prosthesis.

Patient's chief complain is loosening of prosthetic leg. He needs to use 5 layers of socks to make the prosthetic leg feel tighter and more comfortable to use. Thus, he can sit to stand, walk, go up-down stairs and work without injuring his stump.

His stump is mature. There is scar and hypotrophy. The hypotrophy made the socket loosening. The circumference of the limbs below knee is 8 cm different, the left side is smaller than the right

one. His old prosthesis construction components are Patellar Tendon Bearing (PTB) socket, supracondylar suspension and sleeve, inner liner 70 cm, exoskeleton, and Solid Ankle Cushion Heel (SACH) foot. The prosthesis could be easily donned.

Patient was prescribed new prosthesis with construction parts similar with the old one, except the inner liner and skeleton. The new one would use endoskeleton and silicone gel inner liner. But, due to limited budget, the silicone gel was replaced with double layer inner liner. Prosthetic leg replacement financing source was community service grants from University of Indonesia.

DISCUSSION

Leprosy is a chronic bacterial infectious disease that attacks skin tissue and peripheral nerves. It is usually characterized by weakening or numbness of the limbs, legs, and followed lesions on the skin. Until now Indonesia has not been granted leprosy elimination status. Though leprosy is a disease that has long spread since 1873 ago. Director of Direct Infectious Disease Prevention and Control Ministry of Health stated that out of a total of 34 provinces in Indonesia, there are still 8 provinces that have not managed to obtain leprosy elimination status. They are North Sumatra, South Sulawesi, West Sulawesi, Gorontalo, Maluku, North Maluku, Papua, and West Papua. The definition of leprosy elimination is the number of leprosy cases less than 1 person per 10 thousand inhabitants. Indonesia is targeted to reach total elimination status in 2024.^{2,8}

Jakarta Province has already reach elimination status, leaving problems in leprosy survivors that also need serious treatment. Impairment status of leprosy survival deteriorated significantly after release from treatment (from 59% to 77%). (9) Just like this patient that had bellow knee amputation in 14 years after release from treatment. It is in line with the mean time for progression of the physical disability grade was 162 months (13.5 years) for Paucibacillary Leprosy (PB) and 151 months (12.5 years) for Multibacillary Leprosy (MB) leprosy patients.¹⁰

Having knee amputation made him had grade 2 disability. Grade 2 disability means visible impairment on hand, feet or eyes. As the patient had BT leprosy, he had more risk in having physical disability. The risk of Grade 2 disability was 16.5-fold higher in patients with lepromatous leprosy, and 12.8-fold higher in patients presenting the borderline form, compared to patients presenting indeterminate leprosy.¹¹

He only finished his elementary school and didn't continue his formal education. It means that he had only 6 years of formal education. This fact also put him in risk of physical disability. Having none, 1-3 years and 4-7 years of formal education presented 5.6, 3.51, and 2.47 odds of developing physical disability.¹¹

The stigma surrounding leprosy can be a major burden and affects many dimensions of a person's life, including intimate relationships, such as marriage.^{12,13,14} Body image impairment due to skin lesion and deformity is one of problem in intimate relationship.¹⁵ Beside that, they meet difficulty in getting spouse because the stigma of leprosy survivors had already attached to each

of them, no wonder marrying fellow survivors becomes more preference. Even though he and his wife are leprosy survivors, none of their children had leprosy. It is showed that leprosy is curable. It also shows that leprosy survivors are not contagious.¹⁶ This fact often misperception by community, family, even survivor^{17,18} and then make stigma.¹⁸

Living in leprosy village, like Sitanala Leprosy Village, had become preferences for most of leprosy survivors including our patient. In leprosy village, they would have more opportunity in housing and employment, especially for those who have family. Even though, better opportunity in employment does not mean sufficient income.¹⁹

Leprosy community will also give direct access to medical services.¹⁹ Sitanala village is side by side with Sitanala Hospital, that used to know as Leprosy Hospital. MDT availability and leprosy-reaction treatment would be more likely than general hospitals.

Most of leprosy survivor in Sitanala were unemployed.²⁰ Our patient work as Janitor, like most of the survivors who had grade 2 disability were blue collar worker. Those with least disability more likely to be white collar worker.²¹

Discrimination in finding job and education is some of problems faced by leprosy survivor,²² as this patient also had. A study to leprosy patient in 2018 at Medan, Indonesia, said that 19% of respondents were refused for employment. It also said that they were forced to leave school (21%) and commonly experienced mild depression (63%).²² It makes sense, then, that

patient concern about losing job was very high.

What was feared by patients regarding the low of employment for LS became a reality. Stigma and the impact of economic conditions are the reasons for patients being laid off. Although the pharmacy owner did not explicitly disclose the reason, the patient has long been aware of his very vulnerable position to dismiss, related to the stigma that throughout life must be borne by the patient. So when getting a job as janitor, patients were very careful and fully dedicated in working, in order to maintain his fragile position.

During pandemic, unemployment rates increased whole over the world and reached the peak in April 2020. In a study in Columbia, Workers with primary educational level, like this patient, experienced worse unemployment rates in the first period of pandemic (21.2%). In the early months of the recession, unemployment was concentrated in industries that provide in-person services. Notably, the leisure and hospitality industry experienced an unemployment rate of 39.3% in April, before declining to 16.7% in December. Other services, including pharmacy in which the patient work for, also reached the highest unemployment rate in April 2020, although not as high as the leisure and hospitality industry.²³

Those who lost their job or business during pandemic had higher levels of depression, stress and anxiety. But Mental Toughness (MT) protects individual from depressive symptoms. MT as a stable, narrow, personality trait. MT is genetically appeared as personality but could be modified by environmental factors. MT has four components; control, confidence, commitment and challenge. Our patient had all components

of MT; from the way he takes challenge to work outside the village, his commitment in dealing with his previous job, taking good control on his job performance. But as previously stated, environment could modify MT.²⁴ Supportive environment would give positive impact and unsupportive one would give negative impact. Support could be given in aspects of medical, economic, social or psychological. Direct community needs are the most favorable support.

Those include distributing food, medicine and other relief supplies, and small loans for livelihood security; providing supplies necessary to continue academic studies and for self-care activities; advising on how to protect against the novel coronavirus, and giving information on leprosy and creating a hotline to serve persons affected by leprosy, and offering counselling.²⁵

Prostheses funding is obtained from Universitas Indonesia community engagement grants. Usually, this community engagement activity is carried out in Sitanala Village directly, but since the Pandemic, residents have closed access, the village was locked down, only local residents who can go in and out. So, Katamataku had to call the prostheses recipient candidate to come to the Cipto Mangunkusumo Hospital.

Few prostheses candidates refused to come to our hospital. Distance became their main consideration not to come to Cipto Mangunkusumo Hospital. They need to spend some money to go with public transportation, quite big expense for them. To overcome this, transportation fee was given, taken from the grants fund. But still, few candidates refused to come because they were worried about Covid-19 exposure.

More candidates also thought, why had to come to Cipto Mangunkusumo Hospital, if they can get a prosthesis at Sitanala Hospital which is located right in their yard. At Sitanala LS hospital can indeed get free prosthetic legs, using BPJS. But limited financing often causes prostheses specifications can not match the needs of patients. By the grants funding, the specification could be fulfilled, taylor made to patient's condition.

Patient had stump sores in weeks before which made delay in prosthetic replacement. It might be caused by stump pistoning due to reduction in stump volume, as the patient reported loosen socket. Stump volume reduction is experienced by most patients with a below knee amputation. Volume changes in the below knee residual limb, is the most problematic and etiology of prosthetic rehabilitation, such as difficulty in fitting and piston movements. These conditions make the stump prone to sores, abrasions, blisters and complicates prosthetic rehabilitation.^{26,27}

Patient used his old prosthesis for 15 years. This is quite long prosthesis period. A study of prosthesis period among trans-tibial amputees showed that they needed 1.4 new prosthesis, 2.9 new sockets, 3.2 major repairs and 14.1 minor repairs over 10-year period.²⁸ So, it is just time for him to have prosthesis replacement. The patient is autodidact prosthesis repairman, so he maintains and does minor repair to the prosthesis by himself. Minor repair included repairs such as adjustments to the socket, adjustments to the knee or ankle, simple replacement of belts or straps.²⁸ Part of his prosthesis that needs major repairment is the socket.²⁹ Socket repair must be done by prosthesis technician, with adequate equipment support. It is impossible to be done

by autodidact repairman as he is. Instead, he deceived it by wearing multiple socks so that the socket fit and the piston did not occur. In the early stages, it worked, as the stump get more atrophy, the wound appears.

Prostheses for amputee increase accessibility to education, employment, and quality of life improvement.^{30,31} Strategic role of prosthesis made it become primary service in some Leprosy Hospital. Few of them may have no orthotic service, but still give pros like Alverno Hospital in Singkawang. One of the primary goals of rehabilitation following lower-limb amputation is the successful fitting of a prosthesis and use of the prosthesis to achieve functional mobility. The principles of amputee rehabilitation, from pre-amputation to reintegration into the work force and community, are reviewed. Exercise techniques, training programs, and environmental modifications that have been found to be helpful in the rehabilitation of the amputee.³¹ The patient has good prognosis in achieving successful prosthetic fitting since he had bellow knee amputation and prosthetic fitting by 1 year following a first major lower-limb amputation due to Leprosy complication. Satisfaction with both the functional utility and cosmetic appearance of the prosthesis is also an important outcome of prosthetic restoration.³² Patient stated that the new prosthetic is better than the old one. But he need to train himself to get familiar with the new one. Especially since he had already compromised and compensated with the loose socket for years, now he has to make adaptation to the new socket that is fit the stump.³³

CONCLUSION

Pandemic gives social economic impact to the patient; loosing job, regional lock down and resistancy to go to public area as hospital. Stimulations and supports in order to help him and his family to go through the pandemic are needed in order to maintain their independency in daily life.

PATIENT CONSENT

Patient had given consent to the authors for making case report based on his medical record and his life experiences.

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