



Leprosy-Info

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Stigmatization refers to the social perception of individuals with certain diseases as being unworthy of social investment due to factors such as their behaviour or noncompliance with medical treatment. The victims of Hansen's Disease have been particularly prone to stigmatization. The Old & New Testaments picture the victim of 'leprosy' as being spiritually and morally impure and hence needed to be withdrawn from the 'spiritually healthy' society. This viewpoint was countered by the Cappadocian Fathers of the Church during the 4th century A.D. who contrastingly promoted a responsibility of care of the victims of leprosy by the community much in line with what was taught by Jesus in the Parable of the poor leper. This responsibility of care was assumed by the European Christian world with particular care being offered by the Monastic [e.g. Franciscans] and Crusader [e.g. that of St Lazarus] Orders.

Stigmatization was again introduced after the discovery of the infecting microorganism by Gerhard Hansen in 1873. This led to the introduction of legislation requiring that leprosy-affected people be segregated to stop them from communicating the disease to others see the sprouting of several leprosaria and leprosy colonies. With the introduction of effective Multiple Drug Therapy, the fear of infection transmission should have been nullified. HOWEVER, stigmatization of the victims of Hansen's disease still exists. In the developing world where leprosy is still prevalent, this fear of being labelled a 'leper' still prevails keeping victims away from seeking timely medical treatment. Since 2000, the pharmaceutical company Novartis has been providing MDT free of charge to all leprosy patients through the WHO. This altruistic measure has reduced the global burden of leprosy by 95% - BUT what about the remaining 5%? Can we encourage them to present early for treatment?

Maltese term for leprosy - ġdiem

The Maltese word for leprosy is *ġdiem*, a word derived from Arabic. This word is also used to denote anything that is foul, dirty or soiled. The word is therefore used in such terms as '*ġiddem il-libsa*'=you have soiled your dress; '*għandek idejk imġiddmin*'=your hands are very filthy; '*il-fniek iġġidmu*'=the rabbits have become mangy; '*kelb marid bil-ġdiem*'=scabby dog; '*ġdiem tas-siġar*'=scale-insects or bark-lice. The word is also used to mean dire dearth or great scarcity, cf. '*għaks imġiddem*'. These alternative meanings for the word *ġdiem*, originally referring to the disease known as leprosy, reflects the traditional outlook towards the disease and its victims.

Malta was the first country to systematically eradicate endemic Hansen's disease with the widespread use of MDT. However, in spite of having no active local cases being reported since the 1990s, the pretreatment victims who now carry the chronic stigmata of the disease are still shunned by society. Maltese legislation, too, has continued to stigmatise those with Hansen's Disease by retaining legislation specifically targeting these victims. While the legal segregation has long been repealed from the legal book, Maltese legislation still retains the Lepers Ordinance Cap. 45 and the lepers Regulations on its books. A move was made in May 2024 by the Minister for Inclusion and the Voluntary Sector to completely repeal the old legislative acts thus elevating these individuals from a stigmatised status of victims of a specific disease to simply sick individuals like any other infection without distinction. The jurisdictions of the Order of St Lazarus in Malta – the Grand Priory of the Maltese Is. and the Grand Commandery of the Castello, have awarded the Order's Companiate of Merit to the Minister for Inclusion and the Voluntary Sector the Hon. Julia Farrugia Portelli for this initiative.

Proposed Grand Hospitaller's Flagship Project

Belfort Leprosy Village in Antalaha, Madagascar:

In April 2024, Cyclone Gamané hit the island state of Madagascar destroying the leper village of Belfort together with its supporting services. The Grand Bailiwick of Germany wishes to support the project of ONG-CALA (the Committee for the Support of Lepers in Antalaha) aiming to re-establish the services supporting this village and its essential services including educational establishments for the children of the families living in these communities. The targeted funds needed amount to about €10,211 to cover: 1. The digging & construction of a well construction and to rehabilitate the present water source (€2,663); 2. Construction of buildings (€6,148); and onsite project management (€1,400). The Office of the Grand Hospitaller of the Order has proposed this project to serve as the International Flagship Project for the Order for 2025 and has donated the sum of €5,000 to support the initiative. Other jurisdictions have also supported the project on their own independent initiative with donations amounting to €4,150.



The Belfort Leprosy Village in Antalaha, Madagascar has been devastated and destroyed by Cyclone Gamané in April 2024.

The ONG-CALA (Committee for the Support of Lepers in Antalaha) needs funds [about €10,500] to rehouse the victims and set up the needed medical and educational services.



We make a life by what we give



The Office of the Grand Hospitaller on the recommendation of the Grand Bailiwick of Germany would like to propose that the Flagship Project for 2025 will support these suffering individuals to better their lives and circumstances.



For further information, contact: grandhospitaller.mhosj@gmail.com

ABSTRACTS

Kesumawardani N, Alfrisa B, Hanafi M, et al. *Stigma in Leprosy Patients in the Community: A Systematic Review*. International Journal of Public Health. 2024.

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Abstract

The increasing incidence of leprosy in the community causes individuals with leprosy to experience psychological stress. This pressure can come from the individual's internal perceptions such as feeling insecure, feeling embarrassed, and feeling afraid of being shunned. Apart from that, the psychological pressure experienced by individuals can originate from external factors such as discrimination from society, labeling, and isolation in social life. The method used in preparing this article is the PRISMA method with database searches including Google Scholar, Digital Reference Garba, and Science Direct. There are 15 articles selected based on the criteria, namely published in 2018-2023, can be accessed in full text, articles in Indonesian and English, and are qualitative research using the keywords stigma, leprosy sufferers, and community. The articles analyzed were selected according to criteria with results showing that the stigma experienced by leprosy sufferers in the community consisting of self-stigma and public stigma. These two stigmas cause psychological problems in leprosy sufferers.

Beatriz Miranda-Galarza. *Leprosy (Hansen's disease) in the 21st century: A human rights approach oriented by ethics of care*. United Nations Human Rights - Office of the High Commissioner, 2024.

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Abstract

The present report, submitted by Beatriz Miranda-Galarza, the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members, is her first since her appointment in November 2023. The report provides an overview of the progress made by the mandate since its establishment in 2017, assesses the current state of discrimination against persons affected by leprosy, and outlines the Special Rapporteur's vision and priorities for the upcoming years (2024–2026).

Pertiwi ANAM, Syahrul F. *Risk factors for leprosy: a systematic review*. The Indonesian Journal of Public Health. 2024.

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Abstract

The present reportIntroduction: In 2021, the global prevalence rate of registered leprosy cases stands was 16.9 cases per one million people, with a case detection rate of 17.83 new cases per one million people. This indicates a 10.2% rise in new cases compared to the previous year.

Aims: This study aims to examine the risk factors associated with leprosy.

Methods: The inclusion criteria for this study were articles published in the last five years, available in full-text, and written either in Indonesian or English. Articles that were literature reviews, systematic reviews, metaanalyses, or classified as grey literature were excluded. The exclusion criteria were established to determine which studies to include in this study.

Results: This study found that leprosy is associated with household density, personal hygiene, history of contacts, ventilation, humidity levels, BCG vaccination history, flooring type, house lighting, temperature, and wall type. Personal hygiene was identified as the primary risk factor for leprosy based on individual characteristics and behaviors, while household density was identified as the most significant risk factor based on the physical environment of the occupants. Therefore, poor personal hygiene and high residential density increase the risk of leprosy.

Conclusion: The key risk factors for leprosy include household density and personal hygiene, while a history of BCG vaccination serves as a protective factor. This study provides valuable information for governments and stakeholders to assess healthy household indicators and promote clean and healthy living practices in communities.

Hambridge T. *Shortening leprosy case detection delay: Narrowing the window of transmission and disease progression.* Department of Public Health. Erasmus University Rotterdam. 2024.

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Abstract

Leprosy is an ancient disease that persists as a source of immense suffering worldwide. Although the vast majority of leprosy cases can be effectively treated, delays in diagnosis frequently occur that lead to negative outcomes over time, including irreversible disability, stigma and ongoing transmission. In this thesis, factors that contribute to longer delays are estimated through Bayesian analysis and the epidemiological impact of interventions to enhance early case detection are explored using individual-based modelling. The insights revealed through this work will build on our understanding of the underlying epidemiology of leprosy and identify targets for active case finding more effectively, thereby contributing to leprosy elimination worldwide.

Fitriani , Loukaky L, Tyas L. *The Relationship between Community Knowledge and Attitudes towards Lepra Stigma in the Working Area of Malawei Public Health Center, Sorong City.* Mulawarman Nursing Indonesia Journal. 2024.

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Abstract

Background: Lepra creates a significant stigma within society, leading to the social rejection of people with lepra, which often results in discrimination. According to the Ministry of Health of the Republic of Indonesia in 2022, West Papua is the province with the highest incidence of Lepra in Indonesia, with a rate of 9.89 per 10,000 population. The aim of this study is to investigate the relationship between community knowledge and attitudes with the stigma surrounding Lepra in the working area of Malawei Public Health Center, Sorong City.

Method: This research is a quantitative study with a cross-sectional design. The statistical test used was the Chi-square test. The research instrument was a questionnaire. The study was conducted in the working area of Malawei Public Health Center in Sorong City, specifically in RT 3/RW 4. The population in this study consists of 90 residents from RT3/RW4, with samples of 74 respondents calculated using the Slovin formula.

Results: The study found a significant relationship between knowledge and the stigma of Lepra with a p-value of $0.000 < (\alpha = 0.05)$. Additionally, there was a significant relationship between attitudes and the stigma of Leprawith a p-value of $0.000 < (\alpha = 0.05)$.

Conclusion: There is a relationship between community knowledge and attitudes with the stigma surrounding Lepra in the working area of MalaweiPublic Health Center, Sorong City.

Bhatia R, Kumari N, Tewari V, et al. *Lepromatous leprosy in primigravida with early onset pre-eclampsia in third trimester: a rare case report.* International Journal of Reproduction, Contraception, Obstetrics and Gynecology. Medip Academy. 2024; 13 (12) : 3733-3735.

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Abstract

Although leprosy is infrequently observed during pregnancy but when it occurs, can worsen and in the absence of treatment cause irreversible damage to the skin, limbs, nerves, and other organs. It is therefore necessary to have vigil eye for early diagnosis, management and treatment of leprosy during pregnancy for best maternal and fetal outcomes. We report a case of a primigravida 29-weeks pregnancy, early onset preeclampsia with lepromatous leprosy came to emergency with chief complaints of multiple erythematous papules arising all over the body mainly limbs and abdomen associated with intense pain. A diagnosis of lepromatous leprosy was made on the basis of biopsy report. Patient was treated with multidrug therapy (MDT) as per national leprosy elimination program (NLEP) successfully and delivered a healthy baby boy without any adverse maternal and perinatal outcomes. The infant growth following delivery was normal during follow up period till one year. Multidrug therapy consisting of dapsons, rifampicin and clofazimine is highly effective treatment for leprosy and considered safe for both mother and child hence treatment should be continued unchanged during pregnancy.

Depictions of lepers in sculptured art forms

While post-Medieval paintings depicting the peripheral deformities of leprosy victims are numerous, lepers have rarely been represented in sculptured art. Many of those described are actually dubious and misrepresented. These dubious sculptures include:



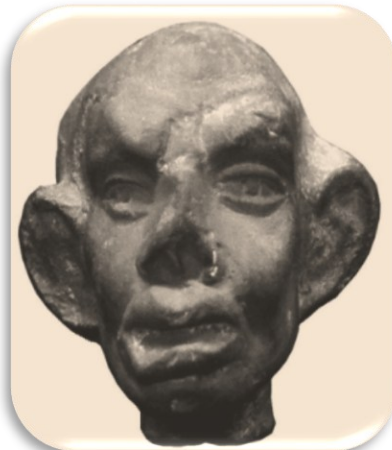
The 15th century sculpture of the figure standing next to St Elizabeth of Hungary kept in the Chapel of the Châteaudun in northern France.



The 'roi lepreux' sculpture in Angkor, Cambodia



The 'Leper Terracotta' figure of Athens



? Leper Terracotta head from Smyrna



Canaanite jar from Beth-Shan representing leprosy

References:

- K. Gron. *Leprosy in Literature and Art*. [International Journal of leprosy](#) 1973, 41(2), 249-283.
- F.E. Hoggan. *The Leper Terra-Cotta of Athens*. [Journal of Hellenic studies](#) 1893, 13, 101-102.
- A. Mitchell. *The Hellenistic turn in bodily representations: Venting anxiety in terracotta figurines*. In: *Disability in Antiquity* [ed. C. Laes], Routledge, 2016, 182-196.
- M. Yoeli. A "facies leontina" of leprosy on an ancient Canaanite jar. *Journal of the History of Medicine* 1955, 10, 331-333.

Some, albeit rare, sculptured-art has been clearly documented to depict leprosy features – the typical *facies leprosa*.



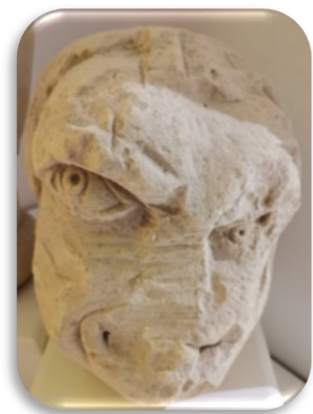
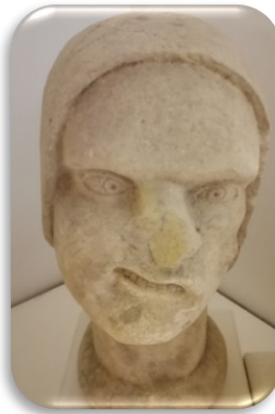
Melton Mowbray 'leper head',
Burton Lazars, England



Lazarus of the Parable holding clapper in the Cistercian Abbaye
de Cadouin, Dordogne Valley, France



Female leper in Nidaros
Cathedral, Norway



Sculptured leprosy heads at Il-Ħaġar Museum
at Victoria-Rabat, Gozo

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- D. Marcombe & K. Manchester. *The Melton Mowbray "Leper Head": An historical and Medical investigation.* [Medical History](#) (1990), 34, 86-91.
- K. Manchester & C. Knusel. *A Medieval sculpture of leprosy in the Cistercian Abbaye de Cadouin.* [Medical History](#) (1994), 38(2), 204-206.
- G.W. Jacobsen & E. Hem. *Sickness in the Nidaros Cathedral?* [Tidsskrift for den Norske Lægeforening](#) (2012), 6(132), 686-687.
- C. Savona-Ventura. *Medically-related sculptures in Gozo.* [The Gozo Observer](#) (2024), 48, 3-6.