



Human Rights and Leprosy: A Bibliometric Analysis

Putri Shafarina Thahir¹, Diah Lusi Agustina², Haris Tofly^{3*}

^{1,3} Master of Law, University of Muhammadiyah Malang (UMM), Malang, Indonesia

² Wahyu Husada 2 Clinic, Kediri, Indonesia

*Corresponding author. Email: haris_thofly@yahoo.co.id

ABSTRACT

Leprosy, is a chronic infectious disease caused by *Mycobacterium leprae* that has been known for centuries. Leprosy is often associated with strong social stigma, which can result in human rights violations against sufferers. Many studies show that discrimination against leprosy sufferers still occurs in various parts of the world, despite efforts to eradicate this stigma. Bibliometric analysis is an effective tool for understanding research trends and patterns related to human rights and leprosy over time. Since 1972, research has been carried out on leprosy and human rights. Although there is a wealth of research on leprosy and human rights, little is known about how global trends in this research have developed since their inception. This research analyzes publications about leprosy and human rights from 1972 to 2024. The findings of this study show that the number of publications has increased rapidly, especially in the last 2 decades, with several prominent journals identified. A fair distribution of eight connected articles was found among four research publishing clusters identified by the VOSviewer analysis. The main related topics include neglected disease and isolation policy. Leprosy and human rights research is increasingly important, but knowledge gaps remain. Further research is needed to address stigma, discrimination, and access to health for people with leprosy. This research is important for understanding how research on human rights and leprosy has developed globally, which can help guide future research. Identifying emerging topics and underexplored areas will help researchers focus on the most pressing and relevant issues.

Keywords: *discrimination, Hansen's disease, stigma, VOSviewer analysis*

1. INTRODUCTION

One of the so-called "neglected tropical diseases," leprosy is mostly prevalent in Africa, Asia, and South America and is caused by *Mycobacterium leprae*. Leprosy is still misdiagnosed and feared by the public due to the hideous deformities it may produce, despite the availability of oral antibiotics that can cure the condition [1]. By 2010, most nations have achieved leprosy elimination as a public health issue (prevalence of less than one leprosy case per 10,000 persons). Nevertheless, the WHO reports that this neglected tropical illness is present in more than 120 countries and accounts for more than 200,000 new cases each year [2].

If leprosy or Hansen's disease is not treated appropriately and quickly, afflicted individuals may experience long-term physical impairments as well as psychological issues. A human rights-based approach must be adopted and followed, discriminatory laws must be revoked, healthcare workers must be educated and trained, new therapies and techniques to diagnose and treat Hansen's disease without side effects and to lower the risk of disabilities must be developed, and stigmatizing terminology must be eliminated. These actions are necessary due to the complex and multifaceted nature of the stigma surrounding Hansen's disease and the discrimination that results from it [3]. According to the World Health Organisation (WHO), 51 nations reported one or more cases of discrimination in 2020 [4].

Leprosy has only just been publicly acknowledged as a human rights concern by the international community. A resolution on "Elimination of discrimination against persons affected by leprosy and their family members" was first accepted by the UNHRC in 2008. The United Nations General Assembly unanimously adopted a resolution in 2010 praising the principles and guidelines for the abolition of discrimination against leprosy victims and their families, which give governments a path forward in addressing the problem. More recently, in September 2017 the UNHRC designated a United Nations Special Rapporteur on the abolition of discrimination against individuals afflicted with leprosy and their families. This mandate was extended by an additional three years in July 2020 [5].

Furthermore, the original purpose of the bibliometric technique was to investigate information science and library science. One benefit of the bibliometric method is its ability to categorize bibliographic materials from literature sources. Numerous authors have used bibliometrics as an analytical tool while composing articles for journals, later publishing on assessing the effect of journals, and articles on university rankings. Eventually, bibliometric techniques were used in many other fields of study, such as the social sciences and law. When it comes to giving researchers research data that they may utilize to raise the caliber of their work, bibliometrics is often a useful tool. Nevertheless, bibliometric analysis on the evolution of leprosy and human rights research has not been conducted [6].

This article aims to conduct a bibliometric analysis of literature focused on leprosy and human rights by analyzing trends in leprosy and human rights research over the last few decades, identifying the most dominant journals and research topics in this field, and determining knowledge gaps in leprosy and human rights research.

2. METHODS

To perform this study, a search of the Scopus database (<https://www.scopus.com/>) was conducted.

I. DATA EXTRACTION AND SCREENING

The data utilized in this study comes from worldwide publications that were found through the Publish or Perish (PoP) application. The search was carried out on July 11, 2024, in the "Document search" field of the Scopus database using the keywords "human rights" and "leprosy" for the years 1972–2024.

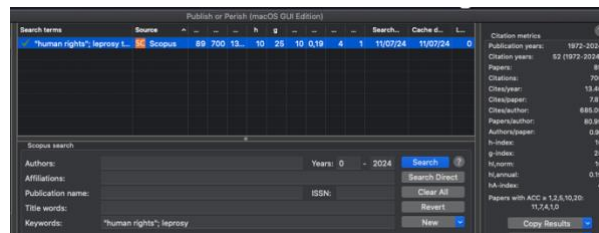


Fig. 1 shows the search results for the terms "human rights" and "leprosy" in Publish or Perish (POP) for papers that Scopus indexed over the 1972–2024 study year.

II. DATA ANALYSIS AND VISUALIZATION

The analysis of the bibliographic data was done with VOSviewer (1.6.17). VOSviewer was used to carry out the co-occurrence analyses of journals and keywords. The maps associated with the aforementioned analysis were created.

3. RESULTS AND DISCUSSION

Following our search strategy, we extracted 89 articles on human rights and leprosy from the Scopus database via PoP application. The bibliometric analysis carried out in this study provides a comprehensive overview of research focusing on leprosy and human rights. This analysis shows several important findings:

I. TRENDS IN SCIENTIFIC PUBLICATIONS ON HUMAN RIGHTS AND LEPROSY

The Scopus database search results indicate that the field of leprosy and human rights studies started to take shape in 1972. Up till 2024, 89 articles in total were published. Figure 2 displays the number of publications per ten years. Over the past 20 years, there has been an upsurge in publications. This shows that this topic is increasingly receiving attention and interest from researchers.

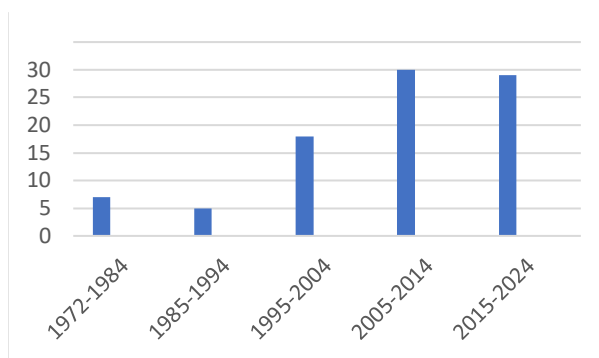


Fig 2. The number of publications of each decade in this area.

Research on human rights and leprosy was first conducted in 1972 with an article document published in Scopus [7]. Historically, leprosy has been known in Japan since the eighth century and was thought to be inherited; individuals avoided being married into families where there was a leprosy-affected member. To eradicate leprosy, the Japanese government implemented a lifelong quarantine policy at the start of the 20th century. This deliberately spread false and negative beliefs about the disease, portraying it as fatal and extremely contagious, and helped to create a persistent stigma against those who were afflicted. The authorities kept patients in quarantine until 1996, even after efficient therapies were available. Since then, the administration has expressed regret to the patients for infringing on their human rights, which are guaranteed by the Constitution. The policy also affected children who had leprosy and children born to leprosy parents [1]. Meanwhile, according to research conducted in Indonesia, people descended from lepers faced discriminatory treatment, exclusion, stigmatization, exile, and inequality since they were seen to pose a threat to their offspring's existence. This might harm their dignity [8]

According to a recent study, human rights advocacy, education, and awareness campaigns are crucial in reducing stigma and improving the lives of those who have leprosy. In order to promote social engagement and well-being, the study also supports the reintegration of impacted persons into their communities [9].

II. CORE JOURNAL OF SCIENTIFIC PUBLICATIONS ON HUMAN RIGHTS AND LEPROSY

Search results through the Scopus database using the Publish or Perish (POP) application show that the journal in first place with a total of 19 articles published in *Leprosy Review*. Thus, the leading Journal in this field is *Leprosy Review*. It is followed by the *Japanese Journal of Leprosy*, *Star*, *Indian Journal of Leprosy*, *PLoS Neglected Tropical Diseases*, *The Lancet Infectious Diseases*, *International Journal of Leprosy and Other Mycobacterial Diseases*, and *Medecine/Sciences*.

TABLE I. CORE JOURNAL OF SCIENTIFIC PUBLICATIONS ON HUMAN RIGHTS AND LEPROSY

Journal Name	Number of Publications
<i>Leprosy Review</i>	19
<i>Japanese Journal of Leprosy</i>	7
<i>Star</i>	5
<i>Indian Journal of Leprosy</i>	4
<i>PLoS Neglected Tropical Diseases</i>	3
<i>The Lancet Infectious Diseases</i>	3
<i>International Journal of Leprosy and Other Mycobacterial Diseases</i>	2
<i>Medecine/Sciences</i>	2
<i>Total</i>	89

III. BIBLIOMETRIC MAP OF RESEARCH DEVELOPMENT ON HUMAN RIGHTS AND LEPROSY INDEXED BY SCOPUS BASED ON KEYWORDS

Analysis from VOSviewer (version 1.6.17) obtained co-occurrence map network visualization with the following results:

The results of network visualization, overlay visualization, and density visualization of co-occurrence maps of research developments on human rights and leprosy are divided into 4 clusters with 8 keywords that are consistently connected to each other with the table and image display as follows:

TABLE II. CLUSTER ON DEVELOPMENTS IN HUMAN RIGHTS AND LEPROSY RESEARCH 1972-2024

Cluster	Item
First	Human rights, Hansen's disease
Second	HIV, Hansen's disease
Third	Leprosy, neglected disease
Fourth	Isolation policy, medicine

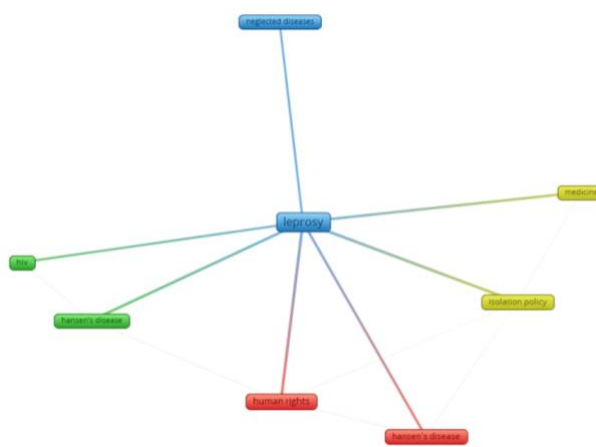


Fig 3. Network visualizations on the development of Human Rights and leprosy research from 1972-2024

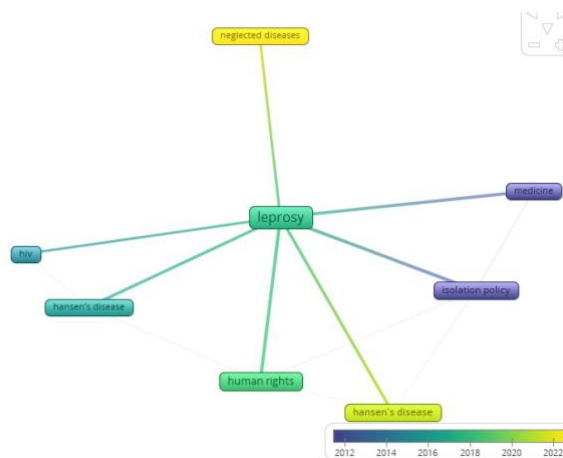


Fig 4. Overlay visualizations on developments in Human Rights and leprosy research from 1972-2024

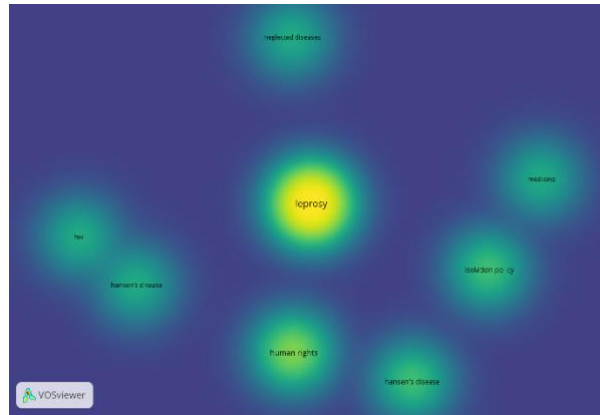


Fig 5. Density visualizations on the development of Human Rights and leprosy research from 1972-2024

Overlay visualizations can for instance be used to show developments over time. Density visualizations provide a quick overview of the main areas in a bibliometric network.

From the above images, several themes in papers on the evolution of leprosy research and human rights have not received enough attention up to this point. The research areas that have received little attention are indicated by subtle color changes and decreased font sizes. A few of these have to do with HIV, Hansen's illness, neglected illnesses, and medications. An item (label) in the cluster density view has the same markings as the visible item. The color of each item point varies according to the item's density at that moment. This shows that the number of objects connected to other items determines the color of the points on the map. This section is beneficial in providing a broad overview of the bibliometric map's overall structure by highlighting the things deemed significant for the study.

A study conducted by Martos-Casado et al. demonstrated how stigma affects how individuals living with leprosy perceive several health-related processes. Besides being the source and effect of the processes that sustain the illness in endemic nations, it is also seen as a cross-sectional factor that influences the other obstacles that have been found. These could include ignorance, false ideas, cultural norms, and fear of contracting the disease, to name a few. Additionally, these findings are seen in a variety of diseases or illnesses, including mental health, cancer, obesity, and other infectious diseases like HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome). These results are consistent with existing literature currently in publication [10].

4. CONCLUSION

Publications experienced an up-and-down graph from 1972 to 2024. However, there has been a significant increase in the last two decades, indicating that in that year, the interest of the researchers increased. This conclusion is based on the research results and the discussion above. The VOSviewer analysis revealed four research publication clusters with an even distribution of eight linked articles among them. In general, VOSviewer can help researchers choose their study topics more quickly. Relationships, trends, and topic density can all be analyzed with VOSviewer. Using this analysis, we can determine whether the research topic is worthwhile. Further research is needed to address stigma and discrimination for people with leprosy; and it is hoped that this research can make a significant contribution to the understanding of the complex relationship between leprosy and human rights, as well as assist in efforts to overcome stigma and discrimination, and protect the human rights of all people affected by leprosy.

ACKNOWLEDGMENT

Thank you to the parties who have supported the implementation of this research.

References

- [1] Y. Horikoshi and M. Toizumi, "Lessons From the Wrong Isolation Policy Violating Human Rights for Leprosy in Japan," *Pediatric Infectious Disease Journal*, vol. 42, no. 6. pp. E212–E216, 2023, doi: 10.1097/INF.0000000000003897.
- [2] M. Das, "A tribute to the elimination of leprosy," *The Lancet Infectious Diseases*, vol. 24, no. 7. p. 684, 2024, doi: 10.1016/S1473-3099(24)00348-7.
- [3] P. Deps, L. Delboni, T. I. A. Oliveira, S. M. Collin, M. A. Andrade, and E. L. N. Maciel, "Steps towards

- eliminating Hansen's disease stigma," *International Health*, vol. 15. pp. III7–III9, 2023, doi: 10.1093/inthealth/ihad050.
- [4] World Health Organization, "Global leprosy (Hansen disease) update, 2020: impact of COVID-19 on the global leprosy control." <https://www.who.int/publications/i/item/who-wer9636-421-444> (accessed Jul. 16, 2024).
- [5] T. Nanri, "Initiatives to address leprosy as a human rights issue through the mandate of UN Special Rapporteur: Achievements and challenges," *PLoS Neglected Tropical Diseases*, vol. 16, no. 3, 2022, doi: 10.1371/journal.pntd.0010201.
- [6] Ardiansyah, Wandu, Suparto, M. Rafi, and P. Amri, "Bibliometric analysis and visualization of state administrative law in Scopus database from 2017–2021," *Cogent Social Sciences*, vol. 10, no. 1, p. 2310935, Dec. 2024, doi: 10.1080/23311886.2024.2310935.
- [7] J. C. Pedley, "The stigma of leprosy.," *Leprosy Review*, vol. 43, no. 2, pp. 69–72, 1972, [Online]. Available: https://api.elsevier.com/content/abstract/scopus_id/0015349314.
- [8] F. A. Sabri, I. Rosyadi, M. Isfironi, M. N. Hadi, M. Sulthon, and A. M. Khazin, "Navigating Stigma and Discrimination: Betrothal Challenges Faced by Descendants of Leprosy in Madura, Indonesia," *Al-Istinbath: Jurnal Hukum Islam*, vol. 8, no. 2, pp. 553–576, 2023, doi: 10.29240/jhi.v8i2.6905.
- [9] G. I. Oke *et al.*, "Experience of people living with leprosy at leprosy settlements in Nigeria," *Public Health Challenges*, vol. 3, no. 2, 2024, doi: 10.1002/puh2.171.
- [10] G. Martos-Casado, C. Vives-Cases, and D. Gil-González, "Community intervention programmes with people affected by leprosy: Listening to the voice of professionals," *PLoS Neglected Tropical Diseases*, vol. 16, no. 3. journals.plos.org, 2022, doi: 10.1371/journal.pntd.0010335.

Open Access This chapter is licensed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits any noncommercial use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if changes were made.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

