

STIGMATIZATION OF PERSONS AFFECTED BY LEPROSY IN INDIA
A LEPRÁBAN SZENVEDŐK MEGBÉLYEGZÉSE INDIÁBAN

STIGMATIZATION OF PERSONS AFFECTED BY LEPROSY IN INDIA

MARTIN HEIDINGER, ELISA SIMONNET

Department for Global Health and Development, Medical University of Graz
Geomedizinisches Institut

[DOI: 10.29179/EgTud.2018.1-2.14](https://doi.org/10.29179/EgTud.2018.1-2.14)

Abstract:

Stigma in leprosy results out of complex historical, cultural, physical and psycho-social factors, which makes the disease altogether the most stigmatised of all. In contrary to the stagnant Annual New Case Detection Rate in India, the proportion of Grade-2 disabilities at diagnosis is increasing continuously and therefore projecting life-long care requirements for decades into the future. Historically, the Mahabharata, itself one of the foundational epics of modern Hinduism includes the hero Asvhatthaman, that many leprosy affected persons still believe to be descendants of, showcasing the deep roots of the disease in Indian culture. To tackle stigmatization in leprosy one structural approach exists in the extended bio-psycho-social concept of medicine, broadened by the dimensions of sexuality as well as spirituality, covered by broad education and awareness and an obligatory integrative linkage of all activities. As one best-practice example, the Doctor Typhagne Memorial Charitable Trust is presented, embracing an integrative model of care and caring for thousands of leprosy patients before, during and after treatment each year.

Keywords: leprosy, stigma, Asvhatthaman, bio-psycho-social medicine

Összefoglalás:

A lepra miatti megbélyegzés évszázados történelmi, kulturális, fizikai és pszichoszociális tényezők eredménye, ami miatt a lepra tekinthető a legmegszégyenítőbb betegségnek. Az állandónak bizonyuló indiai éves új esetek arányával szemben, a 2-es fokozatú korlátozottsági besorolások aránya folyamatosan nő, ezáltal előre jelezhető, hogy nő a teljes élethossz alatt igényelt ellátások száma. Történelmileg a Mahabharata, – a modern hinduizmust

EGÉSZSÉGTUDOMÁNY
HEALTH SCIENCE

Közlésre érkezett:

Submitted:

Elfogadva:

Accepted:

2018;62(1-2): 14-28

2018. február 25.

25 February 2018

2018. március 8.

8 March 2018

Levelezési cím/Correspondence:

Martin Heidinger

Department for Global Health
and Development, Medical University of Graz
Geomedizinisches Institut
Attemsgasse 11, 8010 Graz
martin@heidinger.cc

megalapozó egyik eposz, melynek hőse Asvhatthaman, akit sok leprával fertőzött egyén tekint az ősének –, támasztja alá azt, hogy a betegség mélyen gyökerezik az indiai kultúrában. A lepra miatti megszügyenyítés kezelésére egy kulturális megközelítési mód létezik az orvostudomány bio-pszichoszociális kibővített fogalomtárában, a szexualitás és a spiritualitás kiterjesztésével, széles körű oktatással és az elkötelezettség növelésével, továbbá minden egyes aktivitás kötelező, integráló összekapcsolásával. A legjobb gyakorlat egyik példájaként bemutatjuk a Dr. Typhagne emlékére létrehozott Kegyes Alapítvány (Doctor Typhagne Memorial Charitable Trust) integráló ellátási modelljét, amelynek keretében évente leprás betegek ezreiről gondoskodnak a gyógykezelés megkezdése előtt, alatt és utána is.

Kulcsszavak: lepra, megbélyegzés, Asvhatthaman, bio-pszichoszociális orvoslás

Introduction

In this second part of the three-fold series on leprosy in India the focus lies on stigmatization and discrimination of leprosy affected persons. Throughout the cooperation entitled “Leprosy on the Road” of the Department of Global Health and Development of the Medical University of Graz and the Doctor Typhagne Memorial Charitable (DTMC) Trust in Salem, Tamil Nadu, India affected persons were visited, interviewed and examined, especially regarding the stigmatization and discrimination they face. This paper ought to give insights into the current situation of people affected by leprosy in India, the historical, cultural and legislative background of stigmatization and discrimination in India and to extrapolate current efforts and future steps to reduce stigma in leprosy.

Stigma can be differentiated into public stigma, which is defined as a general or group-specific, negatively rated characteristic that in turn leads to social defamation and disadvantage (*Picture 1*).



Picture 1: Setting of a dispelled, leprosy affected person. Source: Authors' Photo - Martin Heidinger

And on the other hand, self-stigma concerning the internalization of the social aspect (1). Discrimination is defined as prejudice towards a group with certain characteristics,

whereas these characteristics in turn become triggers of the discriminatory process and can be described as enacted stigma, which restricts access to social structures and resources (2). Leprosy has widely become a metaphor for stigma and is described as the most stigmatised disease of all (3). It is one of the oldest diseases known to mankind with recordings available from ancient civilisations in Egypt, China and India, referenced in the oldest Hindu and Ayurvedic texts from 6 BC as well as in the Bible, always accompanied by discrimination (3–5). The broad picture of ‘lepers’, a term itself stigmatizing, was one of contagious persons, who in the course of the disease were disfigured and therefore visible as well as distinguishable and with traditional medicines incurable. Therefore, they were stripped off their rights and freedoms and expelled from their respective homes, families and communities to secure the unaffected. Today the disease is still seen as a curse and divine punishment, which results in the paradoxical utilisation of health services, which are not consulted at first signs of the disease because of the generally prevailing internalized stigma (3,5,6). Factors contributing to higher perceived stigma amongst leprosy affected persons were found to be illiteracy, perceived economical inadequacy, change of occupation due to the disease, and lack of knowledge about leprosy and its treatment (7).

Leprosy is primarily visible through hypopigmented, anesthetic skin lesions, and can result in complications such as neuritis, disabilities and deformities. Therefore, the disease itself is stigmatizing through visible skin lesions, yet the irreversible complications leave affected persons marked for life, oftentimes unable to work and therefore an outcast of society. The best cure for disabilities is to prevent them first-hand. Early diagnosis of leprosy as well as prevention and early treatment of reactions thus are key issues. The indicator of cases with Grade-2 disabilities at Diagnosis (G2D) (*Table 1*) (8) is therefore primary in regard to measure the disease burden, because in contrary to solely infected patients, disabled and deformed persons need lifelong care and measures of social equality and integration.

Table 1: Disability-grading of leprosy-associated disabilities in eyes, hands and feet. The sum of each inspected part results in the Eyes, Hands, Feet (EHF)-Score [0-12] (Adapted after Brandsma et al., 2003) (9)

| Grading of disabilities in leprosy according to WHO's three-grade system | | | |
|--|--|--|--|
| | Eyes | Hands | Feet |
| 0 | No eye problem due to leprosy; no evidence of visual loss | No anesthesia, no visible deformity or damage | No anesthesia, no visible deformity or damage |
| 1 | Eye problems due to leprosy present, but no vision impaired (can read fingers at 6 metres distance) | Anesthesia present, but no visible deformity or damage | Anesthesia present, but no visible deformity or damage |
| 2 | Severe visual impairments (can not read fingers at 6 metres distance), lagophthalmos, iridocyclitis, corneal opacities | Visible deformity or damage present | Visible deformity or damage present |

In contrast to the stagnant national Annual New Case Detection Rate (ANCD) over the last decade, G2D increased on a global, regional, national and even provincial scale in India as presented in *Figure 1* (10).

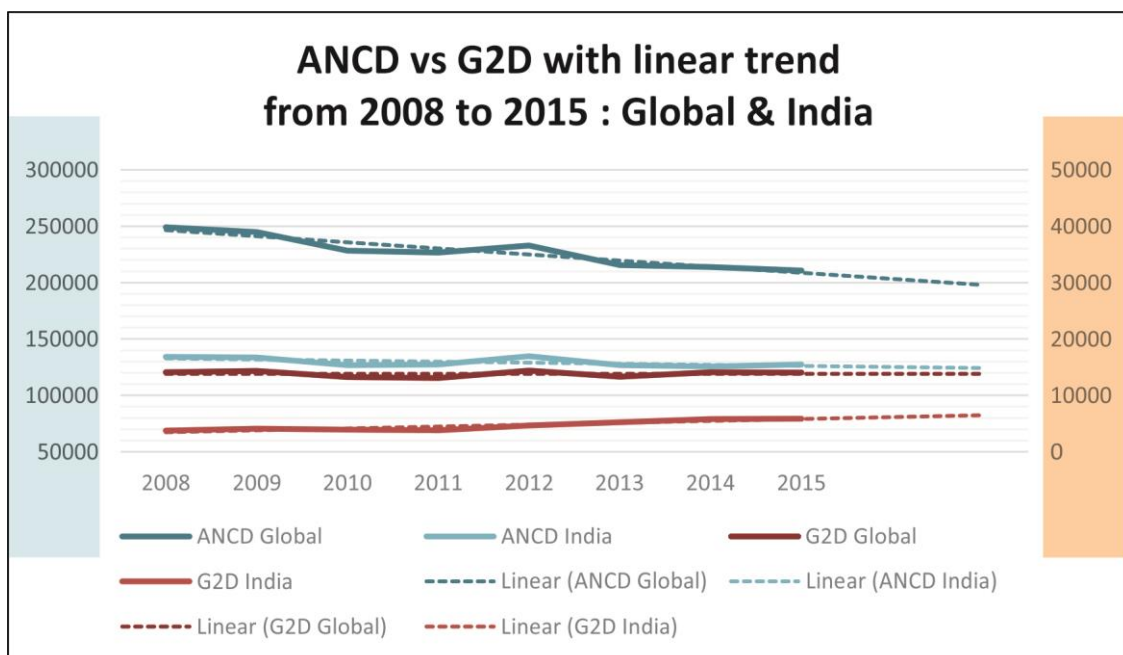


Figure 1: Reduction in global ANCD (blue lines) from 2008 to 2015, and stagnant national trend in India. Increasing G2D (orange lines) globally and nationally. Linear extended trend lines (dotted) to highlight the contrary evolution.

As leprosy is a disease of poor socio-economic standards, the non-reversible status of disabilities is striking doubly as most affected countries have no means to deliver measures of integrative medical, psychological, social and rehabilitative care for disabled and deformed persons. They, however, can not subside in their mainly physically arduous daily routine, which guarantees them income and ability to feed themselves and their families.

Historical background – Asvhatthaman: legend of a cursed hero

By the middle of the first millennium BC the Brahmins, the most superior group of priests and scholars, controlled the northern part of the Indian Subcontinent. The Vedas, as their oldest testament, were thereafter put into coexistence with the Mahabharata, supposedly being the greatest Indian epic and foundation of India's national religion – Hinduism, containing the famous Bhagavad-Gita. It came about in a time in which new world-views gained momentum, and was extraordinarily, not directed towards the Brahmins but rather for Ksatriyas, warriors and rulers, addressing ethical queries within the scope of violence, killing and karma. The Mahabharata can be said to be a standard scripture for Hindus and Indians alike, who will generally be able to outline the most central parts especially since Doordarshan, the Indian state television screened a 94-episode series of the tale in the 1980s (11).

The story in brief, consists of a war between two lines of cousins, who rage over power and succession with several Hindu deities supporting either one or the other side of warriors. In the end both sides are exterminated and encounter each other in heaven (11–13). In concern of the stigmatization of persons affected by leprosy one hero and villain of the Mahabharata is of interest. Asvhatthaman, a warrior of the Kauravas family-line, with a powerful jewel on his forehead is one of only three warriors of his family still alive after an 18-day war. Through the help of the god Shiva, one night he enters the camp of the Pandavas, the concurring cousin-line, and kills every present soldier. As he is pursued by the Pandavas after the massacre he releases a weapon out of this jewel, which devastates all wombs of Pandava women. For these two impious acts Asvhatthaman has to cut out his gem and is cursed by Lord Krsna himself (11–13). “You shall wander this earth for 3000 years, ... without companions, ... for you shall have no place in human society, you vile and wicked man. Stinking of pus and blood, ... you shall live ... plagued by every disease” (14). In general perception, Asvhatthaman especially contracts leprosy, forming sores and ulcers that will never heal (15). Even today, Indians connect Asvhatthaman with leprosy and persons affected

by the disease believe themselves being descendants of him, living in isolation and social exclusion, branded with their signs of the disease for as long as they will live and through incarnation even within their next lives.

WHO measures against stigmatization of leprosy affected persons

As one of the first steps to end discrimination and allow inclusion, the WHO tried to assess how many of the reporting countries in its Global Leprosy Update 2015 stated to have discriminatory laws against persons affected by leprosy. Out of 136 countries reporting, 38 answered the questionnaire, with 33 stating not to have any discriminatory laws, four reported the existence of legislation that might restrict persons affected from social entitlements and one country reported to have discriminatory law, which is not enforced. Unfortunately, the reporting countries were not particularly mentioned (16). In its newest “Global Leprosy Strategy 2016-2020 – Accelerating towards a Leprosy-Free World”, the WHO targets on (i) zero grade-2-disabilities in pediatric patients, (ii) reduction of new leprosy patients with grade-2-disabilities to less than one case per one million persons and (iii) zero countries with legislations allowing discrimination against people affected by leprosy by 2020. One pillar of this strategy, comprising aspects of integration and socio-economic improvements, composes itself of goals and activities for the promotion of societal inclusion by addressing all forms of discrimination and stigma, the empowerment and capacity-enhancement of persons affected by leprosy to participate in leprosy services and the inclusion of communities in the improvement of the situation. Furthermore, networks of persons affected by leprosy shall be encouraged, the integration of such organizations with other community-based organizations fostered and community-based rehabilitation for people with disabilities through leprosy supported. Finally, access to social and financial support services shall be facilitated, discriminatory laws abolished and replaced by policies for the inclusion of persons affected by leprosy (17).

India’s legal situation concerning leprosy

Contrary to general conception of Indian laws, and also contrary to India signing the UN Resolution to End Discrimination Against People Affected by Leprosy, laws discriminating persons affected by leprosy still exist on the statute books of India. The legislation of a country in this respect does not just form the legal framework of a nation, but to some extent

shows the official attitude towards this matter. The far-reaching consequences of such laws directly and indirectly influence a country and its people. Persons affected by leprosy are officially, historically and culturally as well as out of knowledge-gaps, misunderstandings and partly irrational social dynamics discriminated, which fuels the fire of social stigma associated with the disease. The National Law Commission of India in its 256th report in April 2015 denounced Indian legislation and called for a remake of several laws (18).

The approach of the Indian people as well as the Indian government over the decades was described as “benign neglect” by Navin Chawla (3). Today the affected persons are still outcasts of society and discriminated physically, as well as psychologically. A publicly known diagnosis of leprosy covers the whole range of consequences from none to separate housing-situations (*Picture 2*), over the inability to ever marry again to permanent unemployment.



Picture 2. Separate housing of family members on the right (including electricity, brick wall and iron sheet roof) and the leprosy affected grandfather on the left (no electricity, open space, thatched roofing). Source: Authors' Photo - Martin Heidinger

The official legal perspective was originally represented in the installation of the Lepers Act of 1898. This law was based on the premise that people affected by leprosy would remain so for their entire life, which was true at that time due to lack of medication. The act largely employs for:

- segregating beggars suffering from leprosy from unaffected persons,
- disallowing leprosy patients from preparation, handling or selling of food, drinks, drugs and/or clothing,
- forbidding leprosy patients from using public wells, tanks, taps, etc. for purpose of bathing or washing,
- restricting leprosy patients from working as barbers, cooks and domestic servants,
- disallowing leprosy patients from using public vehicles and public transport,
- debarring leprosy patients from inheriting ancestral properties.

Further national Indian laws addressing the incurable lepers, discriminating them directly as well as indirectly and making social stigma and inclusion acceptable from a legislative to a societal point of view, were the Indian Divorce Act 1869, the Indian Christian Marriage Act 1872, the Dissolution of Muslim Marriage Act 1939, the Special Marriage Act 1954, the Hindu Marriage Act 1955 and the Hindu Maintenance and Adoption Act 1956. Also in 1956 the Life Insurance Cooperation Act was passed, which permits higher rates to be charged for persons affected by leprosy due to their supposedly higher mortality risk. More recent legislation includes the State Beggary Act, in which persons affected by leprosy are categorized together with lunatics, the Motor Vehicles Act 1988 and the Railways Act 1989, which deny people affected by leprosy the right to obtain a driving licence or to travel by railway. The Lepers Act, even though repealed by the States of Gujarat, Assam, Nagaland, Meghalaya, West Bengal, Tamil Nadu, Tripura, Punjab, Karnataka, Orissa, Himachal Pradesh, and Maharashtra, and the Union Territories of Delhi, Andaman and Nicobar Islands, Lakshadweep, Dadra and Nagar Haveli and Chandigarh, existed on the statute books of the nation until mid-2016 (18,19).

Even though India has signed the UN Resolution to End Discrimination Against People Affected by Leprosy, so “that persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all basic human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws;” calling for governments to “take effective measures to eliminate any type of discrimination against persons affected by leprosy and their family members”, limited

action has been taken to modify national legislation to date (20). These principles have to be followed ought a legislative stop of discriminating people affected by leprosy be put in place, which will act as a regulation, guideline and “role-model” to the broad society of India in ending its stigmatization, discrimination and exclusion of this group of people.

Women, children, leprosy and discrimination

Globally, one billion people are affected by Neglected Tropical Diseases (NTDs) including leprosy, due to poor socio-economic standards. Two populations rank within the bottom spots of the one billion: women and children (21). Poverty, poor education, discriminatory laws and policies – in short their marginalised position, are the reason for their respective vulnerability. Two-thirds of the world’s illiterate are women, (22) who also make up the majority of poor and landless persons as well as the largest number of globally poor living on less than one US-Dollar a day (23). Women with leprosy therefore experience discrimination because of their gender as well as their disabilities. A survey in Kolkata found that women delayed visiting medical care centers for diagnosis and/or follow-up, until their guardian/spouse felt it was necessary and possible besides their household-duties, which easily led to conflicts and demotivated them from seeking medical help. Medical advice particularly for patients with leprosy, as not walking long distances and not working with hot utensils were not practical (24). The triple jeopardy “Leprosy – Gender – Discrimination” therefore needs special addressing and a focus on the inequalities especially of women and children affected by leprosy, which will only be reducible by tackling their general vulnerability.

Tackling stigmatization in a bio-psycho-social approach

In a bio-psycho-social (BPS) approach to medicine (25), the biological disease burden identifies the source of enacted stigma and the practiced discrimination, which in turn leads to perceived stigma, that can be defined as fear by the affected person, and the psychological burden of the disease. Finally, the internalized stigma, resulting out of the above mentioned, leads to the loss of self-esteem, dignity and will expose oneself to the discriminating environment. Social exclusion leads to isolation, depression and perceived helplessness, which finally produces ignorance, lacking compliance and self-care (26).

A way to tackle this vicious cycle is to adapt one’s approach to the BPS model, whereas an integrated approximation, including all three aspects is key to success. To minimize stigma

in the first place, the disease burden per se ought to be reduced, and early reporting promoted. This requirement itself shows the obligatory consideration of all three BPS components, as early reporting is often hindered by the anticipated stigma, and can therefore only be achieved by well executed integration and social rehabilitation programmes, that finally minimize stigma. Additionally, early diagnosis is the only way to reduce the number of disabilities at diagnosis, and the first step in the three-fold cascade of prevention, protection and self-care to minimize the final stages of disabilities, namely deformities, ulcers and subcutaneous infections, which can be life-threatening and are the easiest comprehensible branding-factors. Concerning the psychological aspects of the disease and its stigmatization, self-help groups and other group-based activities are a way to raise self-esteem and weave a network amongst affected persons as well as service providers. This is also part of a social rehabilitation, which should be fostered mainly by the reintegration into working environments, to give purpose and value to each individual. A comprehensive visualization of this approach is presented in *Figure 2*.

Bio-Psycho-Social Dimensions of Stigma in Leprosy

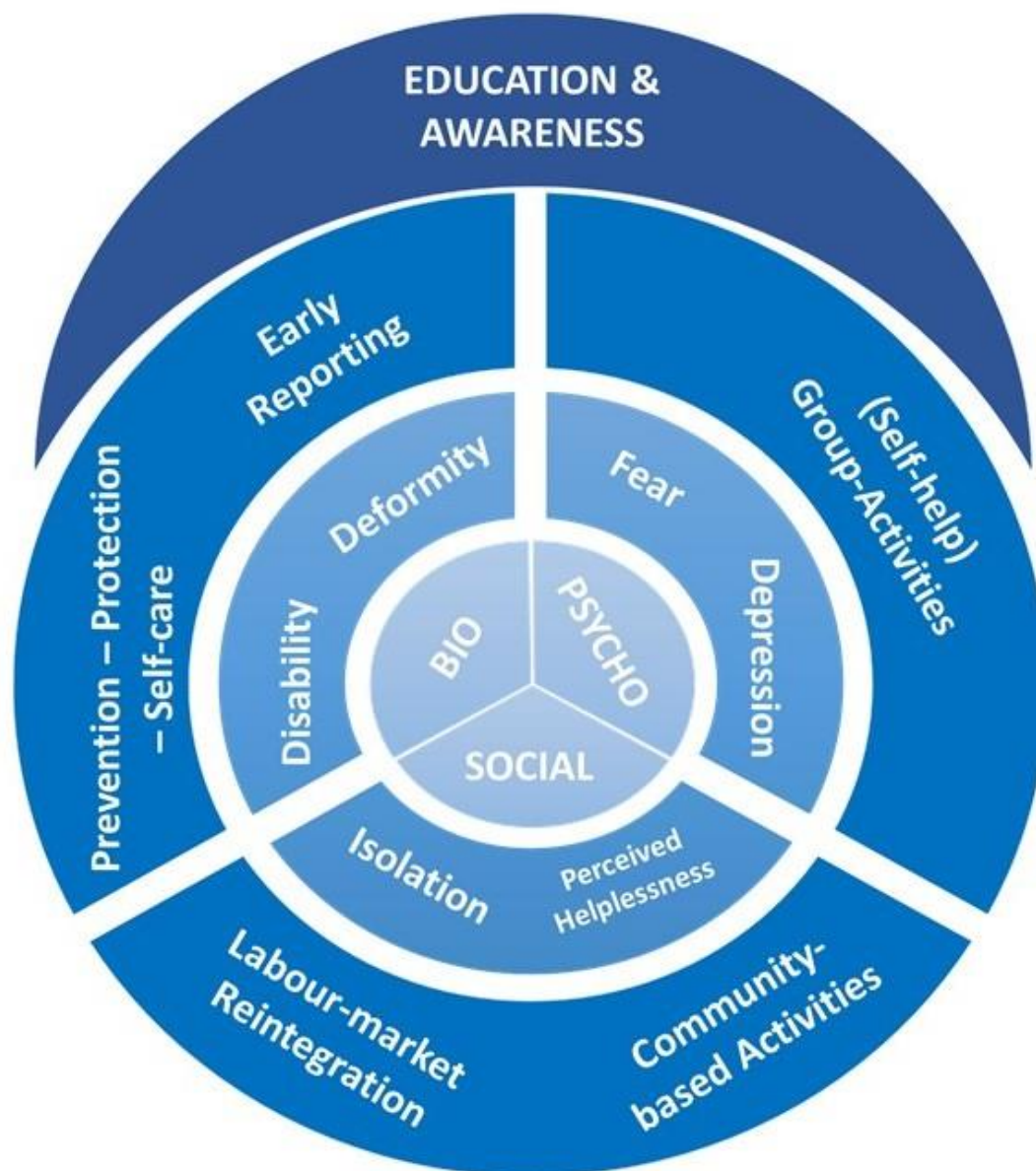


Figure 2 Bio-Psycho-Social Approach to tackling stigmatization and discrimination regarding leprosy. Stigmatizing factors, as well as stigma-reducing ones can be divided into the 3 dimensions. Education and awareness towering above all, and an integrative link of all activities an obligatory cornerstone to success.

Two facultative, additional components of the BPS model – spirituality and sexuality – should also not be ignored, as two sections of this paper demonstrate. The integration of religious and spiritual backgrounds, including its historical roots and contemporary interpretation and practice must be considered, as much as gender and age specific approaches for women and children, shall the programme be inclusive and successful.

Towering above all these actions is awareness and education of affected and unaffected persons in respect to the current knowledge of the disease and recent research findings. The promotion of success-stories and role-models dedicating themselves to the integration of affected persons should also be published under the consideration of medical over-information, which poses a threat especially concerning poorer socio-economic classes, which are regular targets of uncoordinated campaigns concerning prevalent diseases like leprosy, tuberculosis, HIV and Dengue fever amongst others.

Best-practice example

With over 85 years of experience in treating leprosy patients, the DTMC Trust today has an integrative and comprehensive approach to achieve its goals in the respective fields. Five permanent health-workers and medical professionals are covering the primary front of representatives, together with one lab-technician, while two accountants, one managing director and one CEO build the institutional foundation.

- IEC – Information | Education | Communication and Training Programmes are designed for the general public and especially the poor, patients and health staff to raise awareness and knowledge about leprosy and steps to eliminate the disease as a priority measure.
- Deformity Prevention and Medical Rehabilitation Camps according to NLEP (India's National Leprosy Eradication Program) standards are carried out monthly. Patients and family members undergo IEC and group education, create networks, get to know community volunteers and are provided with medical services, ulcer care, physiotherapy and counselling as well as nutritional incentives. Individually fitted Microcellular Rubber (MCR) footwear is distributed and repaired. Patients are assisted in applying for government welfare schemes.
- Nutritional assistance to leprosy patients is provided for the neediest amongst patients, consisting of 10kg of rice and 2kg of nutritional powder per month.
- Medical care for leprosy patients on an outpatient basis is assigned bi-weekly for each patient under leprosy and/or leprosy reaction treatment. Furthermore, patients are screened during in-field activities as well as Prevention of Disabilities Camps and referred from District Health Centres. Inpatient care is provided for ulcer cases, patients with deformities, for reaction cases and for post-operative care. Wound care with daily dressings is carried out as well as antibiotic treatment for infected wounds and

physiotherapy including wax baths and supervised exercises. Voluntary occupational group therapy covers the psycho-social aspects of care.

- Community volunteers are the link of villages to the institution, reporting of suspicious symptoms, keeping records of new cases, disabled persons, material needs and welfare schemes. Together with these volunteers, reintegration into the local labour market is processed.
- Since social exclusion is still a huge problem for people affected by leprosy the DTMC Trust focuses on rehabilitation of people affected by leprosy and affected families by educating them and their surroundings in their respective settings. Annually 1.300 patients and their villages are seen, including an examination of their personal as well as living condition, the recording of their welfare-schemes and material needs. The education of surrounding inhabitants is carried out based upon the social dynamics of the setting.

As a registered Leprosy Care Facility, the DTMC Trust strongly cooperates with public health institutions. Once new cases are detected they are referred to these facilities, where treatment is distributed free-of-cost. However, after finishing their treatment, the re-referral of potentially needy patients is not routinely installed yet. Many patients are being *lost* due to defective communication.

Conclusion

Stigmatization and discrimination of leprosy affected people in India presents itself as one of the most complex constellations in socio-medical terms. An immense historical, spiritual, mythological and cultural foundation is further complicated by India's social structure and social ethics, which clash on one of the oldest disease known to mankind. In terms of its long history, it has only recently become curable, which has not yet reached all stakeholders and the broad public. To untangle all twists, one must structurally approach the disease, its history, pathophysiology and finally its implications in a broader context than the sole bio-medical side. Best-practice examples exist; however, it is not just the integration of care into the public health service, but also the coordination of this sector with non-governmental stakeholders, that currently contribute to public awareness, early diagnostic, treatment of leprosy reactions and life-long care of leprosy affected people. With leprosy case detection campaigns in endemic micro-areas the biological cycle of the disease can be hindered, yet for

the human care of persons affected, and especially those found with disabilities at diagnosis, the integrative care of stigma and discrimination needs to be improved.

Acknowledgements:

We thank Dr. Sr. Francina Karippadathu for her tireless work for those affected by leprosy.

Financial support:

This research received no external funding.

Conflict of interest:

The authors declare no conflicts of interest.

REFERENCES

1. Warmbrunn A. Stigma. In: Pschyrembel online. Medizinische Fachredaktion Pschyrembel; 2017.
2. Wied S, von dem Knesebeck O. Diskriminierung. In: Pschyrembel Pflege. 3. Auflage. Pschyrembel Pflege; 2012.
3. Chawla N. Vocational Rehabilitation and Social Reintegration of the Leprosy Affected in India [Internet]. [cited 2017 Mar 28]. Available from: <http://www.navinchawla.com/pdfs/Vocational%20and%20Rehabilitation%20and%20Social%20Reintegration%20of%20the%20Leprosy%20Affected%20in%20India.pdf>
4. World Health Organization. Leprosy Fact Sheet [Internet]. 2016 [cited 2017 Mar 28]. Available from: <http://www.who.int/mediacentre/factsheets/fs101/en/>
5. National Leprosy Eradication Programme India. Strategic Framework For Reduction Of Stigma & Discrimination [Internet]. Available from: nlep.nic.in/pdf/Stigma.pdf
6. The Nippon Foundation. Leprosy in Our Time [Internet]. Tokyo; 2013. Available from: http://www.nippon-foundation.or.jp/en/what/projects/leprosy/Leprosy_in_Our_Time2014.pdf
7. Adhikari B, Kaehler N, Chapman RS, Raut S, Roche P. Factors affecting perceived stigma in leprosy affected persons in western Nepal. PLoS Negl Trop Dis. 2014 Jun;8(6):e2940.
8. Alberts CJ, Smith WCS, Meima A, Wang L, Richardus JH. Potential effect of the World Health Organization's 2011-2015 global leprosy strategy on the prevalence of grade 2 disability: a trend analysis. Bull World Health Organ. 2011 Jul;89(7):487–95.
9. Brandsma JW, Van Brakel WH. WHO disability grading: operational definitions. Lepr Rev. 2003 Dec;74(4):366–73.

10. *Heidinger M, Simonnet E.* Leprosy in Southern India. *Egészségtudomány - Health Science*, 2017;61/4:35-45. <http://egeszsegtudomany.higi-enikus.hu/cikk/2017-4/2017-4.pdf>
11. *Smith JD.* The Mahabharata. London: Penguin Group - Penguin Classics; 2009.
12. *Ganguli KM.* The Mahabharata [Internet]. 1896 [cited 2017 Mar 28]. Available from: <http://www.sacred-texts.com/hin/maha/>
13. *Chopra R.* Mahabharat. India: DD National; 1988.
14. *Smith JD.* The Mahabharata. In London: Penguin Group - Penguin Classics; 2009. p. 579.
15. *Shyamsunder G.* Ashwatthama [Internet]. 2013 [cited 2017 Mar 28]. Available from: <http://shyamer.in/data/documents/Ashwatthama.pdf>
16. World Health Organization. Global leprosy update 2015: time for action, accountability and inclusion. *Wkly Epidemiol Rec.* 2016;91(35):404–20.
17. World Health Organization Regional Office for South-East Asia. Global Leprosy Strategy 2016-2020. Accelerating towards a leprosy-free world [Internet]. World Health Organization; 2016. Available from: http://apps.searo.who.int/PDS_DOCS/B5233.pdf
18. Government of India, Law Commission of India. Eliminating Discrimination Against Persons Affected by Leprosy [Internet]. 2015. Available from: <http://lawcommissionofindia.nic.in/reports/Report256.pdf>
19. Indian Ministry of Law and Justice. The Repealing and Amending Act, 2016 - No.23 of 2016. New Delhi; 2016.
20. United Nations Human Rights Council. Human Rights Council Resolution 8/13. Elimination of discrimination against persons affected by leprosy and their family members [Internet]. United Nations; 2008. Available from: <http://www.mofa.go.jp/files/000078245.pdf>
21. *Hotez PJ.* Forgotten People, Forgotten Diseases: The Neglected Tropical Diseases and Their Impact on Global Health and Development. Washington, DC, USA: American Society for Microbiology Press; 2008.
22. UNESCO. EFA Global Monitoring Report 2015 - Education for All 2000-2015: Achievements and Challenges [Internet]. 2nd ed. Paris: UNESCO; 2015. Available from: <http://unesdoc.unesco.org/images/0023/002322/232205e.pdf>
23. United Nations Department of Economic and Social Affairs. The World's Women 2015 Trends and Statistics [Internet]. New York: United Nations; 2015. Available from: https://unstats.un.org/unsd/gender/downloads/WorldsWomen2015_report.pdf
24. *John AS, Rao PSS, Das S.* Assessment of needs and quality care issues of women with leprosy. *Lepr Rev.* 2010 Mar;81(1):34–40.
25. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science.* 1977 Apr;196(4286):129–36.
26. *Van Brakel WH.* Measuring health-related stigma—a literature review. *Psychol Health Med.* 2006 Aug;11(3):307–34.