

Psychological and social burden of Cutaneous Leishmaniasis among the residents of Quetta city, Pakistan

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Abstract

Leishmaniasis is a parasitic disease transmitted by sand-flies and is considered one of the most neglected diseases in the world. It mostly affects the poorest of the poor. People living in poor situations are more susceptible. Leishmaniasis includes several variants. Cutaneous leishmaniasis (CL) presents as a localized lesion at the site of the sand-fly bite after a period of several days to months. The nodule then increases in size and progressively ulcerates. In immunocompetent persons, CL lesions are slowly self-healing but often form scar tissue. The disfiguring scars can lead to substantial psychological disturbance, social suffering, and economic losses. Community awareness on the spread and control of disease, reducing social stigma, vector control, public-private partnership, and substantial surveillance indicators to measure the exact burden of the disease is needed.

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1. Introduction

Leishmaniasis, a parasitic disease of the genus *Leishmania* transmitted by a sand-fly vector, is one of the most neglected diseases in the world, affecting the poorest of the poor [1]. In low- and middle-income countries, the affected population lives in poor and susceptible environmental conditions. Leishmaniasis includes several variants: cutaneous leishmaniasis (CL), mucocutaneous leishmaniasis (MCL), zoonotic cutaneous leishmaniasis (ZCL), and visceral leishmaniasis (VL) [2]. Except cutaneous leishmaniasis, other forms are beyond the scope of this discussion. Cutaneous leishmaniasis (CL) usually presents as a localised lesion at the site of the sand-fly bite after a period of several days to months. The lesion starts as an erythema that gradually develops into a papule and later to a nodule. The nodule then increases in size and progressively ulcerates. The whole process generally takes between two and six months. Infection most often occurs in summer, hence lesions manifest later during the winter months. In immunocompetent per-

sons, CL lesions are slowly self-healing but they often lead to scar tissue. As sand-flies most commonly bite the face or other exposed parts of the body, these disfiguring scars can have substantial psychological, social and economic impacts. Lesions affecting the central area of the face are more severe than on any other site.

2. Epidemiology

2.1 Global profile

In 2019, 90 countries were confirmed to either have endemic CL and 3 countries that have had previously reported cases of CL [3]. As of today, more than 1 billion people live in areas with endemic leishmaniasis and are at risk of infection. It is estimated that more than 1 million cases of CL occur every year in these regions [4].

2.2 Regional profile

Different species of leishmaniasis are prevalent across South Asia. Anthroponotic species are found in Sri Lanka,

Nepal, India, Afghanistan and Iran [5]. So far, no cases of CL have been reported in Nepal, Bhutan, Bangladesh and the Maldives [6]. New cases have been reported in the different regions of Iran recently with highest incidence in Kerman province in South-eastern region [7]. Similarly, on the border areas of Afghanistan, several cases of CL have been reported [8]. There are underreporting issues but according to WHO observations, Afghanistan has about 38,407 cases, Iran has 15,485 cases, and Sri Lanka has 2,189 cases of CL as of 2018 [9].

2.3 Country profile

According to the WHO's 2018 profile for Pakistan, there are an estimated 19,361 active cases of CL and the incidence rate is 0.33/10,000 population [10]. The disease is believed to have been imported from Afghanistan. Several outbreaks have been observed in Afghanistan, especially in refugee settlements along the border, that also included northwest Pakistan during and after the Afghan war. After the war, millions of refugees with their luggage migrated into Pakistan. Their luggage comprised of carpets, sheets and other furniture that may serve as a contributing cause of disease spread here in Pakistan [11][12]. In Pakistan, CL is endemic to the northern areas, Sindh, Southern Punjab and Balochistan. Balochistan province exhibits most cases in capital city, Quetta, and areas surrounding it. CL is mostly associated with poverty and underprivileged areas with limited access to health care.

3. Addressing the issue

Cutaneous leishmaniasis is often neglected, affecting population health indicators, especially social stigma and quality of life index [13]. CL should be considered in patients who have a history of living in CL-endemic areas or recent travel to such areas one to six months prior to scar development [14]. Although the morbidity associated with CL is not that significant, and the disease may not turn out to be lethal, the disfigurement and social stigma is a major cause of psychological disorders [15][16]. CL can occur in any age but is more common in children and young individuals [17].

4. CL impact on gender

CL is detrimental for women and young girls in poor, underprivileged and illiterate societies. Studies have been conducted in Afghanistan, Pakistan, Syria and Iran that demonstrate serious social consequences of CL for young women [13]. They are involved in households, working in open areas, taking care of cattle, handling waste and cleaning muddy areas [18][19]. Affected young girls are left unmarried or separated from their partner after marriage [18]. Some do not even consider sharing a meal with them [17]. Pregnant women are victimised, separated from their

children and also prevented from breastfeeding babies due to the perception of disease being transferred via breastfeeding or physical contact [20]. It adds to their depression and they are socially isolated from everyone leading to suicidal tendencies or mental breakdown. The fear of being the “cursed” one is incorporated into their minds for the rest of their lives. Young children affected by CL only become aware of their disfigurement in adolescence. They are often bullied, seriously enfeebling their mental health. Indeed, perception of the body, more precisely the self-perceived beauty of the face, is a major factor influencing self-awareness not only in women but in males as well [21]. A young boy quoted, “I had to postpone my marriage because of the lesion on my nose. I can no longer go out in public and play sports with my friends. They make fun of my disfigured face [22].” CL has been termed as ‘beauty scar’ in many communities. People hide themselves to avoid harsh comments.

5. Community not seeking medical care

Community knowledge about disease severity is lacking. In the rural areas of Pakistan, CL is known as ‘*kal dana*’, which means “one-year lesion”. Hence, sufferers often wait for 6 months to 1 year rather than seeking medical care, unless the scar grows and causes disfigurement. Many people in the area who actually want to seek medical care are often deterred by others claiming that treatment is of no use and that the lesion will heal itself. What they fail to acknowledge is that, if left untreated, lesions may be superinfected and cause extreme disfigurement, with physical, mental, social, and psychological consequences. In many instances, women do not seek medical care during hospital hours due to their housework demands [23].

6. Unaffordability of medical treatment

When patients decide to seek medical care, they face the issue of unaffordable medical treatment for CL. Pakistan is a middle- to low- income country, where 24.3% of the population lives below the national poverty line (24,25). In some areas, quack practices are common. There are some religious beliefs suggesting that disease can be healed if patients visit spiritual healers every week for about six months. Unaffordability of medical treatment leads them to seek care from quacks. They usually have some past observations about some diseases and their time period. Uncomplicated CL usually heals between 3-18 months [26], which is advantageous for quacks. This may not directly affect the population, but aids to imprint the idea of seeking quack care instead of medical care.

7. Environmental and behavioural practices

People living in rural areas usually live in mud houses with poor indoor conditions. Such houses are usually overcrowded. People who are looking after cattle and other animals are usually at higher risk. All these may act as harbour for sand-flies, which has been confirmed by various studies [19][23]. A study showed that house ceilings made up of old wood might act as shelter for the sand-fly and significant CL cases were observed in such houses [27]. Few people in rural areas like using impregnated nets while sleeping due to its unpleasant smell. Others find it unnecessary to use the nets. Many people in CL endemic areas commonly sleep outside which increases their likelihood of being bitten by sand-fly or other vectors that have the potential to cause vector-borne diseases. Sleeping on the ground is a known risk factor for the disease as it increases the likelihood of being bitten by the sand-fly, which cannot fly high and prefers to stay low on the ground [28].

7.1 Governance issues

In Pakistan, there is a designated national level Malaria Control Programme. Leishmaniasis is included in this program as a part of vector-borne diseases. This merits discussion because sand-fly morphology is considerably different compared to other vectors. Mosquito repellent nets are usually disbursed for sand-fly control as well, however sand-flies are only 1-4mm in size compared with mosquitoes that are about 10mm in size. Sand-flies can therefore easily pass through the impregnated nets. Public health programs are mostly focused on other issues and therefore CL is being neglected at many platforms. Currently, Médecins Sans Frontières (MSF), a non-profit humanitarian organisation, is working on leishmaniasis and has set up three leishmaniasis centres in Quetta. They educate local communities in catchment areas about the spread and prevention of CL. The World Health Organization (WHO) is also working on treating leishmaniasis in Pakistan and provides medicines to government authorities. In 2002, WHO actively recognised CL as an issue in the country and a joint assessment mission of the Ministry of Health (MoH) and WHO was sent to the Northwest Frontier Province. Alarmingly, they identified 5,000 cases of CL in the area. The disease was first recognised in refugee camps but quickly spread to the neighbouring villages. The local community of the area, due to lack of knowledge about the disease, had no preparedness against it, propagating the risk of a severe epidemic. WHO identified an immediate need for almost 15,000 vials of pentavalent antimonial (first-line drugs) to treat CL cases. This mission also recommended a plan of action that involved the MoH, United Nations High Commissioner for Refugees and other Non-Governmental Organisations (NGOs), to train local health workers, translate CL guidelines into local languages, and strengthen

surveillance and aggressive vector control activities to prevent further transmission [29]. Still there seems to be some gaps in public-private partnership and coordination.

Another major issue is the high cost of medicines available on the market. Injection of sodium stibogluconate is used for the treatment of CL, the retail cost of which is PKR 285 (USD 1.73), while the treatment is quite exhaustive and may take several weeks. In Pakistan, the out-of-pocket expenditure on health is 60.24% as of 2017 [30], 24.3% of the population lives below national poverty line and 2.3% of the employed population has a purchasing power parity of PKR 314 (USD 1.90) a day [24]. CL is called a disease of the poorest, and keeping above the statistics in mind, it becomes merely impossible for an individual below the poverty line to access medical treatment for CL.

Another reason for the spread of CL is lack of awareness among the remote populations living in CL endemic regions. Unavailability of a trained dermatologist in peripheral areas makes the diagnosis of CL significantly difficult. Lack of laboratories to detect CL lesion results in delay of diagnosis and, thereafter, treatment of the disease. It is crucial for the readers and researchers to comprehend that leishmaniasis surveillance is weak and there is lack of reporting not only in Pakistan but worldwide (30,31,32) which makes it difficult for both local government and international NGOs to formulate necessary guidelines and policies.

8. The way forward

In some regions, CL is referred to as ‘flesh eating disease’ while in other regions, it is referred to as ‘little sister’ for the fact that CL is a common part of families now. Therefore, it is of great importance to educate the masses to normalise stigmatisation related to this disease. Community-based outreach sessions should be conducted on monthly or quarterly basis in disease endemic areas to educate communities about the risk factors associated with CL and infection prevention. For any community-focused intervention, involvement of key influencers and elders of that community is of great prominence and can substantively increase the likelihood of intervention success.

There is also a mental health policy in Pakistan which focuses on primary health care of young children, adolescents, men and women. They are given mental health education through formal sessions, community outreach and in-patient departments [33, 34]. Educating people on reducing the stigma about dermatological manifestations such as CL can be incorporated into such programs. Women who are not allowed to come out of their houses to partake in the community sessions can be attended by lady health workers (LHWs). LHWs educate women of the community on different health aspects, and they can also counsel and educate the public at their homes. Cross-referencing the impact of similar proposed programmes

tackling other psychological and social burdens can prove to be beneficial in reducing CL scar stigmatisation.

The use of lemon essential oil is also suggested as a sand-fly repellent; however its use is debatable. A study found that people who used such oils without scientific basis were four times more likely to have CL than those who did not [23]. As sand-flies cannot fly high, they bite people who tend to sleep on the ground. Therefore, sleeping on higher ground or on the first floor if available is favourable to prevent sand-fly bites.

People from distant areas who want to seek medical care have to travel long distances which is costly. They have to endure vehicle, accommodation and medical costs in the city. There is an urgent need to establish leishmania centres in disease endemic areas with affordable, sustainable, and equitable diagnostic as well as curative services available to the people. One way to make it possible is by building a strong synergy between public-private sectors.

Using the One Health approach, health departments along with other concerned departments like Livestock and Municipality should devise and implement CL prevention and control strategies relative to their departmental roles, for instance rodent control, sanitation and hygiene along with health education sessions. In areas where availability of dermatologists is difficult, LHWs can be trained to identify CL lesions and offer necessary basic care.

CL treatment should be made simple and affordable. Currently, medicine is directly injected into the lesion and duration of treatment takes about 4-8 weeks. There is a dire need to look for other affordable, less invasive treatment options. The government should procure it through the Provincial Medical Store Depot along with other medicines annually, so that each district gets its fair share of medicines according to the number of cases, and it should be included in the annual budget as this disease is now endemic in Balochistan. A concerted effort at the national, provincial and district levels is needed. Leishmania control programmes at the provincial level can prove to be useful in addressing this neglected issue.

Epidemiologists should be posted in every district to provide evidence-based information by improving surveillance indicators. Recognition of the lack of evidence-based information on CL epidemiology for better understanding it and its control is needed as the actual magnitude of CL and its exact prevalence are still not known. For this purpose, significant research is needed on CL with adequate funding in the research and development sector to encourage researchers to approach CL with innovative ideas and conduct baseline and extensive studies with donor support. This will help policy makers and international NGOs to implement disease-specific programmes.

Insecticide-treated nets and indoor residual spray should be made available to every household, especially as mosquito nets are not useful to prevent sand-fly bites. To address this, nets should be constructed according to the diameter of the

sand-fly. The authors would like to conclude the discussion with a WHO quote, “Small bite, Big threat” (World Health Day, 2014).

9. Conclusions

Community-based programmes focused on reducing stigma in the society and provision of social mobilisers in CL endemic areas to educate the public about disease prevention and importance of early treatment can prove to be useful. Effective mental health service delivery in CL endemic areas can be beneficial. The One Health approach should be used to control the disease risk, incidence and related stigma, which can also be addressed through banners, charts, and community sessions. Training of LHWs should be carried out to help them detect the CL scar at early stages in CL endemic areas. Affordable treatments for CL should be ensured while CL related research should be updated within the existing national malaria control programme to tackle it more effectively.

References

- [1] Ayub S, Khalid M, Mujtaba G, Bhutta RA. Profile of patients of cutaneous leishmaniasis from Multan. *J Pak Med Assoc* [Internet]. 2001 Aug [cited 2019 Aug 1];51(8):279–81. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/11715889>
- [2] TDR | Leishmaniasis. WHO [Internet]. 2019 [cited 2020 Oct 5]; Available from: <http://www.who.int/tdr/diseases-topics/leishmaniasis/en/>
- [3] WHO | World Health Organization [Internet]. [cited 2021 May 23]. Available from: https://apps.who.int/neglected_diseases/ntddata/leishmaniasis/leishmaniasis.html
- [4] Leishmaniasis [Internet]. [cited 2020 Oct 5]. Available from: <https://www.who.int/news-room/factsheets/detail/leishmaniasis>
- [5] Overview of Leishmaniasis with Special. 2018 [cited 2020 Oct 13]; Available from: https://doi.org/10.1007/978-3-319-68493-2_1
- [6] GHO | By category | Status of endemicity of cutaneous leishmaniasis - Data by country. WHO.
- [7] Ghatee MA, Taylor WR, Karamian M. The Geographical Distribution of Cutaneous Leishmaniasis Causative Agents in Iran and Its Neighboring Countries, A Review [Internet]. Vol. 8, *Frontiers in Public Health*. Frontiers Media S.A.; 2020 [cited 2020 Oct 13]. p. 11. Available from: www.frontiersin.org
- [8] Qureshi NA, Ali A, Rashid U, Tayyab-Ur-Rehman, Ali N. Prevalence of *Leishmania tropica* in

- school boys of khyber agency, FATA near Pak-Afghan border. *Acta Trop* [Internet]. 2016 Dec [cited 2019 Aug 1];164:90–4. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/27593497>
- [9] GHO | By category | Number of cases of cutaneous leishmaniasis reported - Data by country. WHO.
- [10] World Health Organization. Leishmaniasis country profile- 2015 Pakistan. World Heal Organ [Internet]. 2017;2015:1–2. Available from: https://www.who.int/leishmaniasis/burden/Ethiopia_2015-hl.pdf?ua=1
- [11] Kassi M, Kassi M, Afghan AK, Rehman R, Kasi PM. Marring leishmaniasis: The stigmatization and the impact of cutaneous leishmaniasis in Pakistan and Afghanistan. In: *PLoS Neglected Tropical Diseases*. 2008.
- [12] Afghan AK, Kassi M, Kasi PM, Ayub A, Kakar N, Marri SM. Clinical manifestations and distribution of cutaneous leishmaniasis in Pakistan. *Journal of Tropical Medicine*. 2011.
- [13] Weiss MG. Stigma and the social burden of neglected tropical diseases. In: *PLoS Neglected Tropical Diseases*. 2008.
- [14] Uzun S, Gürel MS, Durdu M, Akyol M, Fettahlioğlu Karaman B, Aksoy M, et al. Clinical practice guidelines for the diagnosis and treatment of cutaneous leishmaniasis in Turkey. *Int J Dermatol* [Internet]. 2018 Aug 1 [cited 2020 Oct 5];57(8):973–82. Available from: <http://doi.wiley.com/10.1111/ijd.14002>
- [15] Kassi M, Kassi M, Afghan AK, Rehman R, Kasi PM. Marring leishmaniasis: The stigmatization and the impact of cutaneous leishmaniasis in Pakistan and Afghanistan. In: *PLoS Neglected Tropical Diseases*. 2008.
- [16] Simsek Z, Ak D, Altindag A, Günes M. Prevalence and predictors of mental disorders among women in Sanliurfa, Southeastern Turkey. *J Public Health (Bangkok)* [Internet]. 2008 Dec 1 [cited 2020 Oct 5];30(4):487–93. Available from: <https://academic.oup.com/jpubhealth/article/30/4/487/1508269>
- [17] Bilgic-Temel A, Murrell DF, Uzun S. Cutaneous leishmaniasis: A neglected disfiguring disease for women. *Int J Women's Dermatology* [Internet]. 2019 Jul 1 [cited 2020 Oct 5];5(3):158–65. Available from: [/pmc/articles/PMC6637076/?report=abstract](http://pmc/articles/PMC6637076/?report=abstract)
- [18] Bennis I, Belaid L, De Brouwere V, Filali H, Sahibi H, Boelaert M. “The mosquitoes that destroy your face”. Social impact of Cutaneous Leishmaniasis in South-eastern Morocco, A qualitative study. *PLoS One* [Internet]. 2017 Dec 1 [cited 2020 Oct 5];12(12). Available from: [/pmc/articles/PMC5738074/?report=abstract](http://pmc/articles/PMC5738074/?report=abstract)
- [19] Bamorovat M, Sharifi I, Aflatoonian MR, Sharifi H, Karamoozian A, Sharifi F, et al. Risk factors for anthroponotic cutaneous leishmaniasis in un-responsive and responsive patients in a major focus, southeast of Iran. *PLoS One* [Internet]. 2018 [cited 2019 Aug 6];13(2):e0192236. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/29415078>
- [20] Reithinger R, Aadil K, Kolaczinski J, Mohsen M, Hami S. Social impact of leishmaniasis Afghanistan [2] [Internet]. Vol. 11, *Emerging Infectious Diseases*. Centers for Disease Control and Prevention (CDC); 2005 [cited 2020 Oct 5]. p. 634–6. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3320322/>
- [21] Ramezankhani R, Hosseini A, Sajjadi N, Khoshabi M, Ramezankhani A. Environmental risk factors for the incidence of cutaneous leishmaniasis in an endemic area of Iran: A GIS-based approach. *Spat Spatiotemporal Epidemiol* [Internet]. 2017 [cited 2019 Aug 1];21:57–66. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/28552188>
- [22] The only option for cutaneous leishmaniasis treatment | Pakistan | MSF [Internet]. [cited 2020 Oct 2]. Available from: <https://www.msf.org/only-option-cutaneous-leishmaniasis-treatment-pakistan>
- [23] Gijón-Robles P, Abattouy N, Merino-Espinosa G, El Khalfaoui N, Morillas-Márquez F, Corpas-López V, et al. Risk factors for the expansion of cutaneous leishmaniasis by *Leishmania tropica*: Possible implications for control programmes. *Transbound Emerg Dis* [Internet]. 2018 Dec [cited 2019 Aug 1];65(6):1615–26. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/29806200>
- [24] Poverty: Pakistan | Asian Development Bank [Internet]. [cited 2020 Oct 2]. Available from: <https://www.adb.org/countries/pakistan/poverty>
- [25] Poverty headcount ratio at national poverty lines (% of population) - Pakistan | Data [Internet]. [cited 2020 Oct 2]. Available from: <https://data.worldbank.org/indicator/SI.POV.NAHC?locations=PK>
- [26] Burza S, Croft SL, Boelaert M. Leishmaniasis. *Lancet*. 2018;392(10151):951–70.
- [27] Reithinger R, Mohsen M, Leslie T. Risk factors for anthroponotic cutaneous Leishmaniasis at the household level in Kabul, Afghanistan. *PLoS Negl Trop Dis* [Internet]. 2010 Mar 23 [cited 2019 Aug 1];4(3):e639. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20351787>
- [28] Croft AM, Taylor NA, Rodenhurst KE. Sandflies and leishmaniasis [10] [Internet]. Vol. 367, *Lancet*. Elsevier; 2006 [cited 2020 Oct 6]. p. 112. Available from: <http://www.thelancet.com/article/S0140673606679609/fulltext>

- [29] WHO | Pakistan. WHO [Internet]. 2018 [cited 2020 Oct 2]; Available from: <http://www.who.int/leishmaniasis/burden/Leishmaniasis-Pakistan/en/>
- [30] Out-of-pocket expenditure (% of current health expenditure) - Pakistan | Data [Internet]. [cited 2020 Oct 5]. Available from: <https://data.worldbank.org/indicator/SH.XPD.OOPC.-CH.ZS?locations=PK>
- [31] Desjeux P. Global control and Leishmania HIV co-infection. Vol. 17, Clinics in Dermatology. Elsevier Inc.; 1999. p. 317–25.
- [32] Ashford RW. Cutaneous leishmaniasis: Strategies for prevention. Vol. 17, Clinics in Dermatology. Elsevier Inc.; 1999. p. 327–32.
- [33] Ali TM, Gul S. Community mental health services in Pakistan: Review study from Muslim world 2000-2015. *Psychol Community Heal*. 2018;7(1):57–71.
- [34] Upadhyay RP, Chowdhury R, Aslyeh Salehi, Sarkar KK, Singh SK, Sinha B, et al. WHO-AIMS Report on Mental Health Institutes in Pakistan. Anemia [Internet]. 2018;10(5):1–9. Available from: http://www.who.int/mental_health/mhgap/risks_to_mental_health_EN_27_08_12.pdf<http://dx.doi.org/10.1016/j.jad.2012.02.009><https://doi.org/10.1016/j.ajp.2017.03.010><http://www.dovepress.com/risk-factors-associated-with-postpartum-depression-in-the-sa>