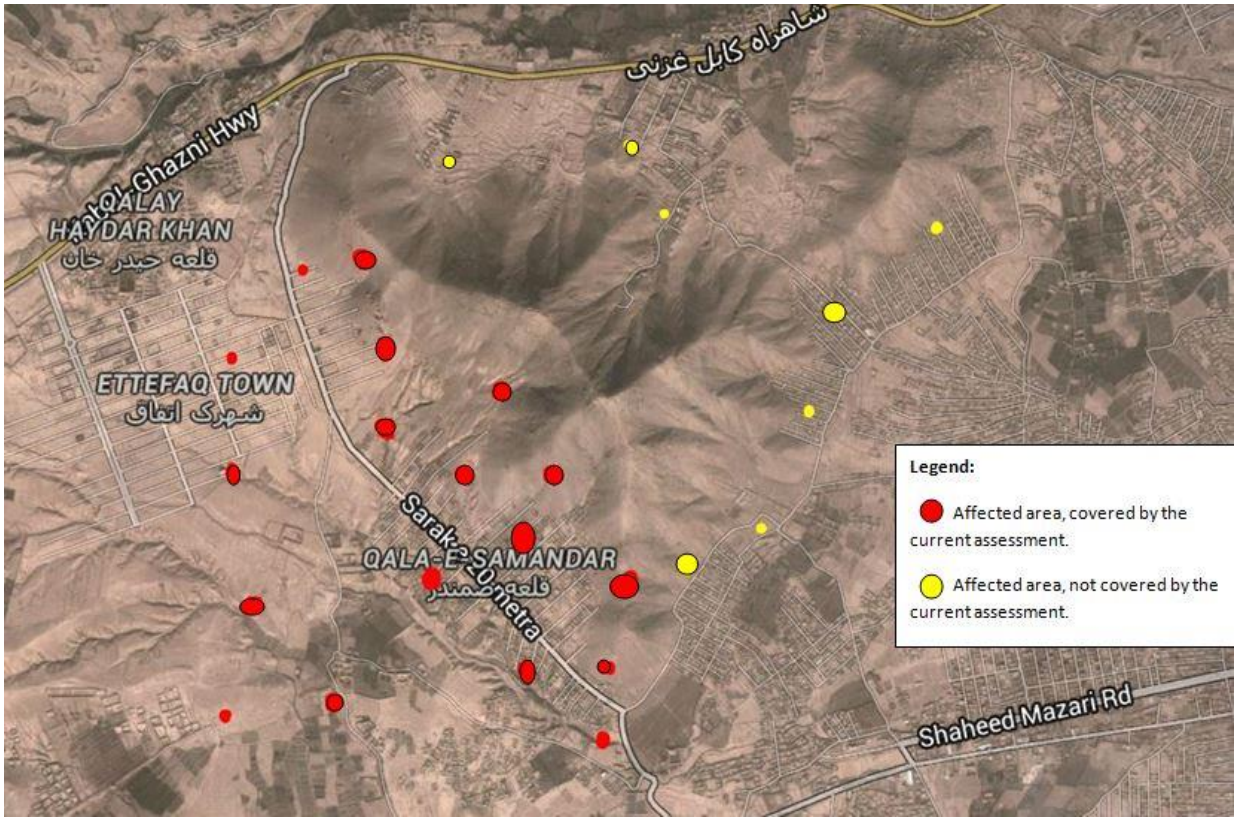
Porsesh Research and Studies Organization

LEISHMANIASIS OUTBREAK IN KABUL: (2016) CASE STUDY OF DISTRICT #13

(Social Science Approach)



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Contents

Executive Summary

Leishmaniasis is a parasitic disease that commonly affects humans. The disease is transmitted from animals to humans via sand flies, which generally results in skin sores. Shahrak-e-Itefaq of the 13th municipal district of Kabul city has witnessed an outbreak of the disease from three years ago.

Porsesh Research and Studies Organization (PRSO) deployed a team of researchers to the field to conduct an assessment of the outbreak and understand the extent of community's awareness of the disease, contributing factors, victims, remedies, and implications of the outbreak. Additionally, based on the research findings, feasible recommendations are provided to address the issue.

Study Findings

Lack of Social Awareness. Despite three years of the leishmaniasis outbreak in the area, people's knowledge about the disease is limited to the name of the disease and the symptoms. To this date, government has not offered any public trainings, notices or announcements from the government to alert and prepare people to respond to the outbreak.

Unclear Picture of Leishmaniasis Sources. Generally, people do not have a clear understanding of what causes the leishmaniasis in their area. Majority believe garbage, sewage, swamps, cattle, livestock, slaughterhouses or soil of the area, with an emphasis on the slaughterhouses near the area are the main feeder of lesishmania flies and causes the disease outbreak. Not having a clear picture of the source of parasites leads to the spread of disease and that makes it impossible to have preventive measures at the community level.

Socio-Economic Risk Factors. Poverty is an underlying factor that facilitates the outbreak of leishmaniasis in the area. Poor waste management and open sewerage that are common in poor neighborhoods such as the Shahrak-e-Itefaq, increase sand fly breeding, resting sites, and their access to humans. Open windows, dining outside, and sleeping outside are some of the habits that also increase the likelihood of sand fly contact with residents of the area.

Efforts to Diagnose, Treat and Control Leishmaniasis

Community Response. Residents of the area receive limited professional help from the Leishmaniasis Hospital when it comes to treatment. Homemade remedies and local pharmacies

are the most common community responses. Preventive measures such as using insecticides are rarely known and used by the residents.

Government Response. Participants of the survey rarely recall any response to the leishmaniasis outbreak in the area for the last three years. The only cases respondents recalled was occasional visits from officials from the Ministry of Public Health. The Leishmaniasis Hospital is located in considerable distance that makes commute both financially and time-wise exhaustive for Shahrak-e-Itefaq dwellers. The only considerable government response happened on May 22nd, 2016, with opening a clinic for treatment of leishmaniasis.

Private and Public Hospitals Contribution. Unaffordable private healthcare and inaccessible public healthcare sums up the picture of healthcare provision in Shahrak-e-Itefaq. There is great expectation from the newly opened Leishmaniasis Clinic that opened on May 22nd, 2016, but questions remain whether the clinic meets the great need of the population and whether they remain open.

Leishmaniasis Outbreak Implications on Residents

Social Implications. The result of the 521 recorded lieshmaniasis patients and 138 respondents revealed that children and women are the most vulnerable groups. For all groups, especially women and children, the disease leads to isolation from community and subjects the victims with social prejudices and exclusion. The disease also negatively impacts children's learning. The stain that stays permanently on skin greatly impacts the physical look, confidence and prospects of marriage, which have great implication for unmarried women.

Economic Implications. It is common that the victims of the disease are willingly or forced to lose their job and isolated because of the disease. Also seeking treatment is extremely costly for the local people considering their limited financial capacity. Provided a great number of dwellers are affected by leishmaniasis and are also economically poor, the disease has left the victims and their families in extreme poverty and greater risks.

Health Implications. Leishmaniasis is not considered a fatal disease, however have significant health implications. The pain and itch are believed to stay with the victim for about one year, which later leads to a permanent mark on the skin of the victim.

Recommendations

Considering the research findings, we provide feasible and relevant recommendations to address the leishmaniasis outbreak in Shahra-e-Itefaq. The recommendations are directed to the governmental bodies such as the Ministry of Public Health and the community, separately:

Recommendations to Government and NGOs Government/ NGOs should establish a leishmaniasis healthcare center in the area that provides affordable healthcare, which will also be accessible by all. Raising awareness and preventive measures are other important but appropriate courses of action that government could take that greatly improve the condition. Provision of insecticide-treated nets and insecticide sprays can prove success in preventing the outbreak.

Recommendations to Community. It is important that victims are brought for treatment immediately, which will reduce the negative impact of the disease. Additionally, change of habits that promote preventive measures could greatly improve the condition

Introduction and Background

Leishmaniasis is a parasitic disease that is visceral, cutaneous, and mucosal caused by infection from thespecies of the genus *Leshmania*. These diseases are prevalent where sandfly vectors and mammalian reservoirs exist in sufficient numbers to permit frequent transmission.[1]Leishmaniasis is caused by infection with Leishmaniasis parasites, which are spread by the bite of phlebotomine sand flies.

There are several different forms of leishmaniasis in people. The most common forms are cutaneous leishmaniasis, which causes skin sores, and visceral leishmaniasis, which affects several internal organs (usually spleen, liver, and bone marrow).[2]Cutaneous leishmaniasis usually produces ulcers on the exposed parts of the body, such as the face, arms and legs. There may be a large number of lesions – sometimes up to 200 – which can cause serious disability. When the ulcers heal, they invariably leave permanent scars, which often result in serious social prejudice.

Anthroponotic cutaneous leishmaniasis is a major public health problem in Afghanistan (WHO).[3]For almost a decade, Kabul, Afghanistan, has had the highest incidence of cutaneous leishmaniasis in the world, with an estimated 67,500 to 200,000 cases each year (PMC)[4]. Kabul is currently the largest focus of anthroponotic cutaneous leishmaniasis worldwide (WHO).

Though Kabul is the largest leishmaniasis affected area in the world, people in some suburban areas in Kabul city like Dasht-e-Barchi (District 13) are highly vulnerable. As WHO described, the disease affects some of the poorest people on earth, and is associated with malnutrition, population displacement, poor housing, a weak immune system and lack of financial resources.

[1]Berman, J. D., "Human leishmaniasis: clinical, diagnostic, and chemotherapeutic developments in the last 10 years," *Clinical infectious diseases* 24, no. 4 (1997): 684-703.
[2] "Parasites - Leishmaniasis," Center for Disease Control and prevention, accessed on June 1, 2016, <http://www.cdc.gov/parasites/leishmaniasis/>
[3] "Neglected tropical diseases: Cutaneous leishmaniasis in Afghanistan," World Health Organization, accessed June 1, 2016,<http://www.emro.who.int/neglected-tropical-siseases/countries/cl-afg.html>
[4] World Health Organization Cutaneous leishmaniasis, Afghanistan.WeeklyEpidemiol Rec. 2002;77:246

In 2005, total of 252 and 108 persons were surveyed in the House Hold Survey (HHS) and FGDs respectively which confirms the prevalence of cutaneous leishmaniasis in Kabul. 128 of 252 HHS respondents reported a family member with leishmaniasis.[5]

After huge intervention by national and international organizations in Kabul, since 2007 the incidents of Leishmaniasis have been reduced to almost zero in high and middle class areas of the city.

However, since 2014 the disease has spread in one of the remote areas in west of Kabul. No serious intervention has been undertaken by any national or international organizations to address this issue. The Leishmaniasis Hospital in Shahrak-e-Itefaqhas recently been established to provide services. PRSO has undertaken this research to provide solid evidence from the area.

Socio-Economic Background

District 13, located in the western part of Kabul, is a suburban area in Kabul city. The outbreak of leishmaniasis diseases in the area has challenged the normal life of affected citizens over the last three years. This area is over-populated and disadvantaged as compared to other parts of the city.

There are estimations of the District 13's population but no valid record exists to reflect the affected community's socio-demography and population. Shahrak-e-Itefaq contains approximately 7,000 households and the population peaks to more than 50,000 people, according to a community elder.[6]

The affected area is one of the marginalized parts in Kabul and lacking in terms of social services, education, transportation, sanitation, hygiene system, health, etc. Ibrahimi's drugstore is the only center people refer to at times of emergency. It is extremely poor in terms of equipment and quality of medicine.

The area is a clusterof minor suburbs, connected by dusty roads, narrow and polluted streets of flowing ditch water and people living there are mostly day laborers, fully dependent on daily wages.

[5]Reithinger, Richard, KhoksarAadil, Jan Kolaczinski, Mohammad Mohsen, and SamadHami, "Social impact of leishmaniasis, Afghanistan." Emerg Infect Dis 11, no. 4 (2005): 634-6, (accessed on May 30, 2016)<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3320322/>

[6] Interview with community elder, Kabul, 27 March 2016

Study Objectives

This research intends to:

a. Understand the extent of community's awareness of the disease.
b. Discover the factors related to the outbreak of Leishmaniasisin the area.
c. Identify what groups are most affected in terms of age and gender.
d. Discover the existing treatments victims have sought.

This research also sheds light on Leishmaniasis outbreak's health, social and economic impacts on residents' livelihoods.

Methodology

The conceptualization of methodology for this study went through a series of activities. First, the research board at PRSO had a brainstorming session on the issue. Secondly, the investigators visited the local people and, based on initial information from the field, investigators took action to draft an appropriate methodology for data collection.

Inthe first phase, relevant documents on leishmaniasis were reviewed withmajor emphasis on Kabul cases. Also, researchers reviewed school registration, health and clinic records as supportive resources.

The findings of this report are mainly derived from primary data, collected through conducting FGDs with female and male residents of the area and in-depth interviews with key informants: Darulaman Leishmaniasis doctors, community elders, responsible individuals fromthe clinic and health centers located at the area. Each team, consisting of male and female members, was led by a team leader who ensured the quality control in the data collection process. Additionally, case studies and researcher observations, were used to support field data collection.

Considering representativeness, respondents and interviewees have been selected based on Multistage Random Sampling which is constructed by taking a series of random samples in stages. The affected area was divided into four different sub locations. Therefore, FGD participants and key informants were randomly selected with respect to gender, age group and being affected by leishmaniasis.

Total 138 number of affected male and female residents were questioned through FGDs and 7 Key Informant Interviews (KII) were also conducted with community elders and doctors of health centers.

Limitations

1. This research would be more complete and comprehensive if it was conducted a door to door survey. In that way, data collection on the disease would have been supplemented with information about the socio-economic condition of the residents. However, since most of the families have similar economic conditions, the FGDs and direct field observation of the sample population represents the majority.

2. The assessment was conducted by volunteer researchers. While planning, the whole research team was enthusiastic to contribute to a larger assessment to draw a methodology with wider sample coverage. Porsesh did not have enough financial resources to hire the field researchers and investigators for a longer term which limited the sample size and coverage of the assessment which caused methodological circumstances and small sample coverage

Challenges

1. The survey teams were received very well in the field. However, due to lack of understanding among the people, there were financial expectations in return for data collection.
2. The community leaders expected PRSO to deliver them services and did not understand that PRSO is a research organization and does not deal with provision of services.

Ethical Considerations

The formulation and implementation of this study adhered strictly to the ethical principle of "do no harm" as well as the research ethics protocols of PRSO. The field staff were briefed on the ethical considerations before designing the analytical framework for the study. In particular, the researchers sought to balance the optimization of participation with the risks inherent in local community members being seen to be interviewed by external actors. Deep knowledge of the local cultural and social context was provided by PRSO leadership. PRSO staff and the extensive experience of the research team, combined with the transparency with which we explained the

research, helped to ensure that no additional risk was created and that no harm came to those participating in Focus Group Discussions or interviews. Furthermore, this research was conducted in line with the law of the land. PRSO explained the agenda of research clearly to the affected community. Permission to interview minors were taken from their guardians and also photographs were taken with full permission of the target.

Study Findings

Factors Causing Leishmaniasis Outbreak in the Area

1. Lack of Social Awareness

As a result of conducting six FGDs and seven Key Informant Interviews (KII) with affected people, community elders and doctors in the area, we came to realize that, despite the fact that the prevalence of diseases in Shahrak-e-Itefaq dates back three years,[7] the community's awareness regarding the disease is minimal. Except the disease's name and symptoms, people had very little information about the disease. A significant number of interviewees called it *Saldana* describing it as a painless red spot at the beginning that grows and starts itching and causing pain. Then it changes to long lasting skin ulcers creating scars that remain for a long time. The interviewees claimed they have seen the fly (phlebotomine)and described it as thin and gray with long wings and longer legs that are active during the night. However, people barely knew how to prevent or treat the disease. There have not been any public trainings, notices or announcements from the government to alert people. They do not understand that homemade medication is insufficient and even could lead to further diseases.

2. Unclear Picture of Leishmaniasis Sources

Leishmaniasis parasites are transmitted through the bite of phlebotomine and infected female sandflies. Including humans, 70 animal species have been found as natural reservoir hosts of leishmaniasis. Phlebotomine are found in areas where houses are frequently constructed with mud walls and earthen floors, and cattle and other livestock live close to humans. It also can be found in villages and mountainous areas where dogs and domestic animals coexist with humans. Socially, the epidemic of leishmaniasis is associated with migration and the movement of non-immune people into areas with existing transmission cycles.

[7]Interview with a pharmacist in Shahrak-e-Itefaq, Kabul, 20. 05. 2016

AtShahrak-e-Itefaq, a considerable number of participants guess that the source of the parasites could be garbage, sewage, swamps, cattle, livestock, slaughter houses and soil of the area, with an emphasis on the slaughter houses near the area as the main feeder of *lesishmania* flies.[8]People living in higher places are among the more affected group. Residents guess that it might be due to the "nature of soil" or "mice" in that area that acts as vector for parasites.[9]

Not having a clear picture of the source of parasites leads to the spread of disease and that makes it impossible to have preventive measures at the community level.

3. Socio-Economic Risk Factors

According to WHO, "Poverty increases the risk for leishmaniasis. Poor housing and domestic sanitary conditions, such as a lack of waste management or open sewerage may increase sand fly breeding and resting sites, as well as their access to humans. Sand flies are attracted to crowded housing as these provide a good source of blood-meals. Human behavior, such as sleeping outside or on the ground, may increase risks."[10]The area is over populated at Shahrak-e-Itefaq, additionally houses are mud-built, sanitary conditions are basic and all sources of meals to feed sand flies exist.

Efforts to Diagnose, Treat and Control Leishmaniasis

According to World Health Program's findings, Leishmaniasis can be prevented by:

1. Early diagnosis and effective case management that reduces the prevalence of the disease.
2. Vector control that helps to reduce or interrupt transmission of disease by controlling sandflies that includes insecticide spray, use of insecticide–treated nets, environmental management and personal protection.
3. Effective disease surveillance is important. Early detection and treatment of cases helps to reduce transmission and to monitor the spread and burden of disease.
4. Control of animal reservoir hosts

[8] Interview with medical technologist, Atayee Hospital, Shahrak-e-Itefaq, Kabul (27.05.2016) and FGD with women in Shahrak-e-Itefaq, Kabul (20.05.2016)
[9] Interview with pharmacist in Shahrak-e-Itefaq, Kabul, 25.05.2016)
[10] *"Leishmaniasis Fact sheet N°375".World Health Organization. January 2014. Retrieved 17 February 2014, accessed on June 3, 2016,*http://www.who.int/mediacentre/factsheets/fs375/en/

5. Social mobilization and strengthening partnerships – mobilization and education of the community with effective behavioural change interventions considering the context.[11]

No adequate measures have been taken to prevent prevalence of the disease in Shahrak-e-Itefaq. However, there are some basic actions taken by the community and recently a mobile hospital has been installed in the area by the government to treat the diseases.

1. Community Response

Leishmaniasis is diagnosed in the hematology laboratory and its treatment can be determined by species of *Leishmania* and the type of infection. In Shahrak-e-Itefaq, however, grave poverty has limited the possibility of admittance to a private hospital to cure the disease. In response to the open-ended question on what actions have been taken by the community to treat/prevent the disease, respondents answered as follows:

Homemade[12] medicine	Often
Installing nets (without insecticide)	Often
Insecticide–treated nets (private providing)	Sometimes
Visiting private hospital and pharmacies	Very frequently
Visiting DarulamanLashmaniHospital	Often
Visiting other public clinics	Often
Covering body	Occasionally
Insecticide houses, gardens and yards	Rarely
Visited hospital outside Afghanistan	Seldom
Praying without scientifically dealing with diseases	Seldom
Have not visited any hospitals	Very Rarely

It was evident that the community is using a homemade medicine called *NillTotia,Safari Totia,*[13]*Patas and* Olive Oil[14] to fight the virus since they are not financially able to go to any government health facilities (due to distance) or private clinics (due to cost of medicine and fees). According to a woman in an FGD, "Each single injection costs between 100 to300

[11]Ibid
[12]"Homemade" is the word used in FGDs but it means natural medication
[13] FGH with group of men, Shahrak-e-Itefaq, Kabul, Afghanistan, 27.04.2016
[14]Interviw with Medical Technologist, AtaiHospitial, Shahrak-e-Itefaq, Kabul, Afghanistan,30.04.2016

AFs"[15]which is more than a poor family can afford. Use of such medicines iseither unhelpful or might lead to other health problems.[16]

As mentioned in the section on the preventive measures, the people who tend to cover their body mentioned that they do this because the *Leishmaniasis* ulcer mostly appears on the uncovered parts of the body. Other measures they have taken includes, but is not limited to, praying, wearing veil (Chadari), using net for doors and windows. However, increasing numbers of victims shows that community efforts have not led to betterment of the situation.

Disappointingly we also found cases with a few affected patients who did not visit any of the hospitals. They only stayed home to get result of homemade medications.

2. Government Response

According to the community, the disease has spread in the area for three years but no significant measures have been taken by the government to provide a timely and sufficient medicine to prevent the outbreak of the parasite. However, recently a mobile clinic has been installed, but considering the enormous number of affected residents, the capacity is very limited. This was evident in most of FGDs with participants who were denied any kind of support from the Ministry of Public Health (MoPH). Some women, however, in one of the FGDs mentioned that a few officials from the MoPH visited them recently but did not take any practical stepsto fight this sickness. According to women FGD participants, "The government just clicked videos, pictures and conducted some interviews."[17] The same information was confirmed in a KII with a doctor who hasa private health center in the area.

On the other hand, the long distance of Leishmaniasis Hospital in Darulaman, District 6from District 13 made it difficult for women and children to reach it. Some of the affected women complained about expensive transportation to the hospital in Darulaman considering the fact that they are suffering from extreme poverty. Many cases reported by the community that women have walked two hours to Darulaman where they needed to visit a doctor. As of22 May 2016,after frequent requests from people and their repeated follow ups[18], a branch of Darulaman Leishmaniasis Hospital has started operating in District 13 that might be effective if sustained.

[15]FGH with group of women, Shahrak-e-Itefaq, Kabul, Afghanistan, 28.04.2016
[16]Interview with pharmacist,Shahrak-e-Itefaq, Kabul, Afghanistan, 27.04.2016
[17] FGH with group of women, Shahrak-e-Itefaq, Kabul, Afghanistan, 28.04.2016
[18] Interview with Rah-e-Marefat school principle, Shahrak-e-Itefaq, Kabul, Afghanistan, 30.04.2016

3. Private and Public Hospitals Contribution

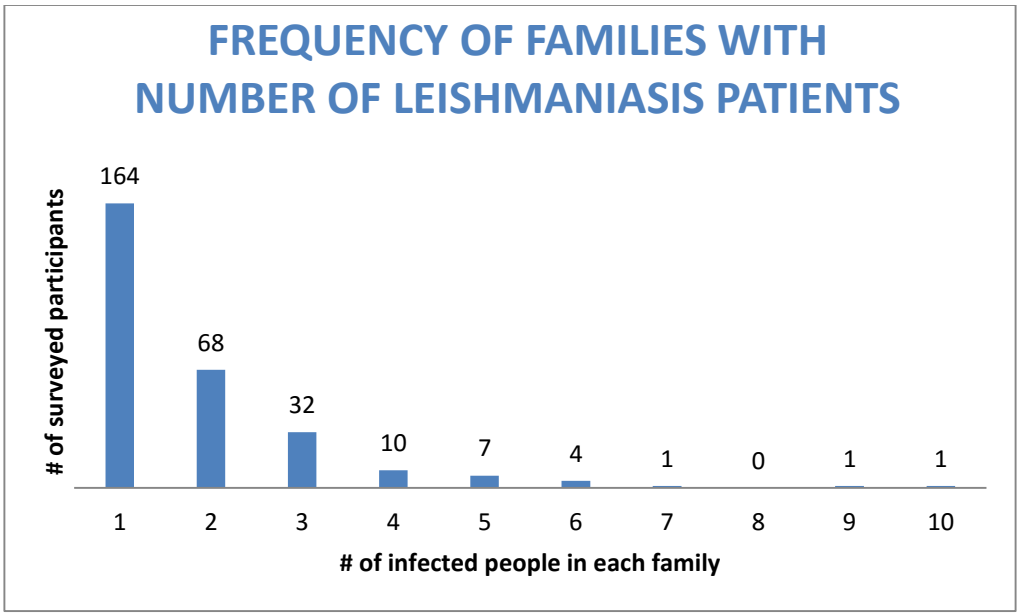
According to the people in the area, they had no access to onsite Leishmaniasis Hospital until 22 May 2016.They needed to refer to the private hospitals located in the area to seek treatment for the disease. Considering the amount of population in District 13, there are few government hospitals and healthcare clinics where local people can seek treatment. The cost of visiting a private hospital and the required medicine to treat leishmaniasisis beyond what peoplecan afford. In many cases, patients paid 1000-1500 Afghani in the private hospitals which presented a financial burden on those who are barely able to feed their families.[19]In a few cases, community members were referred to pharmacies to eliminate the cost of doctor's fees. There is a direct correlation between the family's economic profile and the way they seek for cure. The wealthier the families are, the more likely they are to seek treatment at a private hospital.

Leishmaniasis Outbreak Implications on Residents

1. Social Implications

The PRSO field team recorded 521 *leishmaniasis* incidents and interviewed 131 patients including male and female of all age groups and conducted 7 KIIs . These patients had at least one *leishmaniasis* mark on their skin, mostly on their faces and hands. In terms of how infection is spread among families, the team found that two-thirds of the recorded incidents (357 patients, 68.5%), have another infected family member. While less than one-third of the recorded incidents (164 patients, or 31.5%) of the recorded incidents are the only member in their families to report infection. Overall, based on the survey results of 521 individuals, an average of 1.8 people is suffering from the*leishmaniasis* infection in a family, ranging from one patient to ten patients. The graph below illustrates the families and number of *leishmaniasis* patients.

[19]FGD with women, Shahrak-e-Itefaq, Kabul, 30.05.2016



Furthermore, in order to identify the victims of the leishmaniasis outbreak, we have examined the gender and age aspects of the affected population. Asking FGD participants and key informants including doctors and community elders, we learned that children and women are the more affected groups.[20]

Leishmaniasis has a serious social impact on the affected community. Although it leads to isolation of the affected person from the public domain, it has a consequence on women in particular. Since the ulcer on patients' bodies, even after recovering, will leave a scar, it has a serious negative impact on girls' future with regards to spouse selection and marriage.[21]Girls with many scars on their face and hands will be considered less desirable by would-be suitors.

Currently some children complain that they can't go to school because other students do not want to interact with them and tease them. "People and friends around you will treat you with contempt and force you to remain in isolation. It leads to serious health and mental consequences," an interviewee said.[22]It was evident that children face humiliation at school when then feel isolated from other friends and classmates. Other students have a fear that they will be infected with the same disease if they approach the infected children. In addition, many children

[20]Interview with District Representative, Shahrak-e-Itefaq, Kabul, 16/04/27
[21]FGD with women, Shahrak-e-Itefaq, Kabul, 10.05.2016
[22]Interview with a patients in Shahrak-e-Itefaq, Kabul, 13.05.2016

who need to receive their medication from Darulaman Hospital need to take frequent leave from school which also has negative impacts on children's learning.

Patients feel ashamed to participate in social gatherings, parties and the public domain. They feel lonely especially when their relatives do not treat them well.[23]

2. Economic Implications

As the doctors in the area indicated, a great number of the population living in Shahrak-e-Itifaq are affected by Leishmaniasis. It results in major economic deprivation of the people.

First, people who are affected will lose their jobs or can't work, since they mostly avoid being in the public domain and prefer to spend their time in isolation. This has a serious negative mental and psychological impact on the affected person and leads to a worsened economic condition for the family putting the whole family in financial jeopardy, which may lead to a crisis if proper measures are not taken by the government.

Secondly, a family with five members affected by the disease has to spend between 1000-1500 Afs per doctor visit including the cost of injections per person. Given the large scale unemployment and underemployment, poor economic situation of the residents of the area, and limited government clinics and other public services, the financial implications for infected people will lead to deprivation of the affected community and major challenges. Adding to aforementioned a few interviewed patients reported itch, pain and burning around the ulcer as health implications. People were also speculating that it leads to other kinds of diseases. One of the participants mentioned that an affected woman died even after going to Pakistan to seek medical treatment.

Conclusions and Recommendations

Leishmaniasis is a serious concern in Shahrak-e-Itefaq and its neighboring areas in District 13. It needs concerted effort by the MoPH, health organizations and the local community to address the leishmaniasis outbreak. Our recommendations are as follows:

[23] FGD with women, Shahrak-e-Itefaq, Kabul, 15.06.2016

Relevant governmental and non governmental bodies

- Establish and maintain a clinic in the area to diagnose, treat and prevent spread of Leishmaniasis in an appropriate, affordable and accessible manner.
- Provide preventive measures via public awareness campaigns in the local communities and in schools, distribute informational brochures and installing public notices in public places.
- Clean the area where sand fly vectors and mammalian reservoirs exist immediately. A plan for sustained cleanliness of the area needs to be developed.
- Check the slaughter house in the area. If the slaughterhouse isfound to be a feeding source of the sandfly, required actions must be undertaken.
- Provide and distribute insecticide-treated nets including insecticide sprays to reduce or interrupt the transmission and spread of the disease.

Community

- Encourage early visit to healthcarecentersfor diagnosis of leishmaniasis after symptoms are observed. Early detection and treatment of leishmaniasis cases help reduce spread of the disease.
- Encourage behavioural change such as avoiding sleeping in open spaces without mosquito nets.
- Participate in public trainings by the MoPH and other stakeholders, reading texts available in print and online on how to treat and prevent leishmaniasis, and disseminate the knowledge to local residents via public forums such as the Friday sermons in local mosques.

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