The psychosocial burden of localised cutaneous leishmaniasis, A viewpoint

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Leishmaniases are vector-borne diseases caused by protozoan parasites from the genus *Leishmania*.

Transmitted to humans through the bite of a female sand fly.

The history of leishmaniases can be traced back to 2,500 B.C.

The leishmaniases are now considered as neglected tropical diseases by the World Health Organization.

Main clinical forms: visceral, cutaneous and mucocutaneous leishmaniasis.

Annual incidence of Cutaneous Leishmaniasis is estimated at 0.6 to 1.0 million cases.

**We focused in this presentation on the Localised self-healing cutaneous leishmaniasis form (LCL) that exists in Morocco.**
In Morocco, two main causal species for cutaneous leishmaniasis, with different transmission cycle

Cases of the zoonotic form seem to follow a five to ten years cycle.

A more stable caseload of anthroponotic cases continues to persist.

Source: MoH Morocco
Clinical forms of CL in Morocco

- Ulcer
- Macule
- Papule
- Nodule
The facial lesions are the worst

Based on the official MoH data, overall number of CL patients notified in Morocco since 1998 is over 66000 persons

>>> How many persisting facial scars due to this disease ????
The official MoH HEALTH EDUCATION message:

• LCL is a non-fatal, self-healing disease.

• The only treatment that exists against CL is fully available and provided free of charge in all public health facilities.

• No official resistance against (Glucantime*) is right now documented.

• However, the MoH want to update soon the overall leishmaniasis control program.
Our research questions

What is the perception of CL by the affected population?
- In school population in Morocco
- In community in rural Morocco
- In Mediterranean region (scoping literature review)

Map showing Tinghir and Errachidia Provinces located in Deraa-Tafilalet Region, Morocco (Source www.hcp.ma)
CL perception in Adolescents

A cross sectional study, was done within the boarding high school adolescents students living in endemic *L. major* areas.

This survey, done in 2015, was based on a self-administered questionnaire developed to assess the students’ general knowledge about CL composed by 18 closed-ended questions.

Concluded with one open-ended question about the perceived psychological effects of CL scars.

The open-ended question was analysed qualitatively by NVivo 10 software.

All participants were from rural districts where CL outbreaks happened between 2008 and 2010.

258 boys and 190 girls (448 in total) participated in the study. 18.1 years ± 2.3 for boys and 17.2 years ± 1.6 for girls.

Eighty-eight participants (19.6%) reported they personally suffered from CL (38 girls, 50 boys) and among the others, 159 knew at least one person who was affected by CL.
What boys said

“What am I the person who has this disease and carries this mark on the face?” (MR153).

“The psychological state of the affected person could become worse after receiving treatment because the problem is that scars never disappear [even after treatment],” (MR116).

“... Also it causes the patient psychological and dermatological effects over a long period of time, which requires a visit to a psychiatrist.” (MR121).

What girls said

“The sequelae of leishmaniasis negatively influence the condition of the affected person. A psychological complex will develop, and she will be ashamed to appear in front of friends because it is a mark of shame and contempt.” (FT265).

“The fear and worry regarding the lack of treatment for this disease is the real problem for a person affected by it,” (FR011).

“Is there a way to heal the scars?” (FR068).

I am obliged to put cream to try to hide it before going anywhere.” (FR035).
Stigma emerged as a central concept from student text data.

The indelible CL scars lead to self-stigma and social stigma, and to negative psychological effects in this age group.

Preventing the avoidable burden of CL and mitigating its dermatological and psychosocial consequences should be a priority for health authorities.
The content analysis gathered from the 251 adult participants (total of 128 Women & 123 Men) in our 28 focus groups discussions stratified by gender and tradition of medicine (users of folk versus allopathic medicine) and living in endemic CL areas.
Main results

Most participants know CL as a **not deadly** disease.

The impact of CL lesions and scars is important and similar to that of **burn scar** tissue.

People usually try a long list of **folk remedies** on the active lesions, but none was felt adequate.

There was a strong demand for earlier and **better treatment** for CL lesions and their scars.

Young women with CL scars in the face are stigmatized and will often be rejected for marriage in these communities.
The psychosocial burden of CL in the literature

Limitations of the published studies

- Cross-sectional quantitative survey designs
- No specific stigma or quality of life scales adapted to LCL
- Small sample size
- Lack of appropriate control groups
- Not all studies distinguished the LCL lesion from the LCL scar.
- Potential confounding factors not assessed:
  - Physical aspect of the lesion or scar,
  - The socio-economic position of the LCL person
  - Factors determining the CL-related knowledge, attitudes and practices of society)
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year of publication</th>
<th>Country of the study</th>
<th>Methods</th>
<th>Study design</th>
<th>Timing</th>
<th>Study Population</th>
<th>Sample size</th>
<th>Sex ratio (M/F)</th>
<th>Age range (years)</th>
<th>Patients with CL scars included</th>
</tr>
</thead>
<tbody>
<tr>
<td>Al-Kamel et al.</td>
<td>2017</td>
<td>Yemen</td>
<td>Qualitative</td>
<td>Interview</td>
<td>May 2016</td>
<td>CL patients</td>
<td>11</td>
<td>0.10</td>
<td>12-60</td>
<td>Yes</td>
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<tr>
<td>Bennis et al.</td>
<td>2017</td>
<td>Morocco</td>
<td>Qualitative</td>
<td>Questionnaire</td>
<td>April 2015</td>
<td>Boarding school students</td>
<td>448</td>
<td>1.36</td>
<td>16-20</td>
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<td>Chahed et al.</td>
<td>2016</td>
<td>Tunisia</td>
<td>Quantitative</td>
<td>Questionnaire survey</td>
<td>Not defined</td>
<td>Women with CL scar</td>
<td>41</td>
<td>All female</td>
<td>12-53</td>
<td>Yes</td>
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<tr>
<td>Ramdas et al.</td>
<td>2016</td>
<td>Surinam</td>
<td>Qualitative</td>
<td>Ethnography</td>
<td>Sep 09 to Dec 10</td>
<td>CL patients. General population</td>
<td>205</td>
<td>8.3 &amp; 1.4</td>
<td>20-49</td>
<td>Yes</td>
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<td>Turan et al.</td>
<td>2015</td>
<td>Turkey</td>
<td>Quantitative</td>
<td>Questionnaire survey</td>
<td>May 11 to Apr 13</td>
<td>Paediatric CL patients and healthy controls</td>
<td>54</td>
<td>1.16</td>
<td>7-18</td>
<td>No</td>
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<tr>
<td>Handjani et al.</td>
<td>2013</td>
<td>Iran</td>
<td>Quantitative</td>
<td>Questionnaire survey</td>
<td>2013</td>
<td>Relatives of dermatological cases</td>
<td>50</td>
<td>0.85</td>
<td>20-65</td>
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<tr>
<td>Vares et al.</td>
<td>2013</td>
<td>Iran</td>
<td>Quantitative</td>
<td>Questionnaire survey</td>
<td>Not defined</td>
<td>CL patients</td>
<td>124</td>
<td>0.59</td>
<td>16-80</td>
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<td>Abazid et al.</td>
<td>2010</td>
<td>Syria</td>
<td>Quantitative</td>
<td>KAP-survey</td>
<td>Nov 06 to Oct 07</td>
<td>CL patients or the caregiver seeking treat</td>
<td>70</td>
<td>0.46</td>
<td>≈32</td>
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<td>Fernando et al.</td>
<td>2010</td>
<td>Sri Lanka</td>
<td>Quantitative</td>
<td>KAP-survey</td>
<td>Sep 06 to Feb 08</td>
<td>CL patients</td>
<td>120</td>
<td>2.75</td>
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<td>Niforouzadeh et al.</td>
<td>2010</td>
<td>Iran</td>
<td>Quantitative</td>
<td>RCT</td>
<td>2007</td>
<td>Female CL patients</td>
<td>2 groups of 20</td>
<td>All female</td>
<td>&gt; 10</td>
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<td>Kassi et al.</td>
<td>2008</td>
<td>Afghanistan</td>
<td>Qualitative</td>
<td>Case report</td>
<td>Not defined</td>
<td>Woman with CL scar</td>
<td>1</td>
<td>All female</td>
<td>28</td>
<td>Yes</td>
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<tr>
<td>Simsek et al.</td>
<td>2008</td>
<td>Turkey</td>
<td>Quantitative</td>
<td>Questionnaire survey</td>
<td>2006</td>
<td>Women in general population</td>
<td>247</td>
<td>All female</td>
<td>15-47</td>
<td>Yes</td>
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<td>Reithinger et al.</td>
<td>2005</td>
<td>Afghanistan</td>
<td>Mixed</td>
<td>KAP &amp; FGD</td>
<td>Oct 2002</td>
<td>KAP: household head; FGD: women</td>
<td>252; FGD: 108</td>
<td>FGD All female</td>
<td>Not defined</td>
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<td>Yanik et al.</td>
<td>2004</td>
<td>Turkey</td>
<td>Quantitative</td>
<td>Questionnaire survey</td>
<td>Sep 02 to Aug 03</td>
<td>CL patients, persons with CL scar, healthy controls</td>
<td>3 groups of 33</td>
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<td>12-35</td>
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<tr>
<td>Reyburn et al.</td>
<td>2000</td>
<td>Afghanistan</td>
<td>Qualitative</td>
<td>FGD</td>
<td>Feb to Jul 1998</td>
<td>CL patients and unaffected spouses</td>
<td>8 groups of 6 to 10</td>
<td>1:1</td>
<td>≈28</td>
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</tbody>
</table>
Overview of the main study results

- LCL is a source of psychological suffering, stigmatisation and reduction of quality of life.
- LCL generates mental ill-health, as shown in several countries.
- LCL leads to social stigma that eventually causes self-stigmatization, which amplifies the feelings of fear, anxiety, and depression in those affected.
- Extreme self-isolation and self-contempt can sometimes even lead to suicidal ideation.
- Some people will tend to heavily personalize negative social and self-images within age identity and global wellbeing.

The emotions and memories change within time and interact across lifespan. >> influence the psychological state of the CL affected persons in a variable way.
Time adjustment of stigma types and psychosocial impact of unwanted skin conditions adapted from Deacon et al., Weiss, and Thompson et al., applied to Localised cutaneous leishmaniasis (LCL)

From a qualitative view

Unwanted skin condition (Example: LCL scar)

Coping strategies
Spiritual and social norms
Human rights and laws

Body image concerns
Treatment advances

Perception of the severity of the psychosocial burden of the skin condition (scar)

INTERNALISED
ENDORSED
ENACTED
ACCEPTED
ANTICIPATED

Stigmatised interaction
Stigmatiser

Experiences Vs Expectations

What people believe
What people say
What people do

TIME CHANGE

QUALITY OF LIFE

SELF AND/OR SOCIAL STIGMA DEVELOPMENT
Three categories of patients with CL scars (inactive without relapse) from a quantitative view

If we consider the time dependence as the major modificative factor (The person holding CL scar will not remain depressed forever).

>>> What is the coefficient linked to time depression dependence?

Which standard scales shall we use/develop for assessment of psychosocial suffering?

>>> Shall we build specific CL stigma and CL QoL scales?

Who do not accept or not ready to accept this new skin condition harassing their live

Who will change their mind depending on the future consequences due directly or indirectly to the new skin condition (e.g.; development of skin cancer, treatments advances)

Who accept or are positively ready to accept living with this new skin condition as part of their live
“The fact that the psychosocial burden generated by LCL is time-dependent makes it hard to measure”

In absence of a standardized and validated tool for CL to assess the depression psychosocial impact or the quality of life impact linked to CL and other NTD how it could be possible to estimate the burden?

The tool needed should assess really the quality of life and the psychosocial impact or shall we look for another parameter like the “Resilience” scales?
Conclusion: Urgent need of better prevention, diagnostic and treatment of LCL.
Acknowledgements

For further questions or interactions: issambennis@gmail.com

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