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المدرسة الوطنية للصحة العمومية
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Ecole Nationale de Santé Publique

The psychosocial burden of localised cutaneous leishmaniasis, A viewpoint

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Introduction

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.

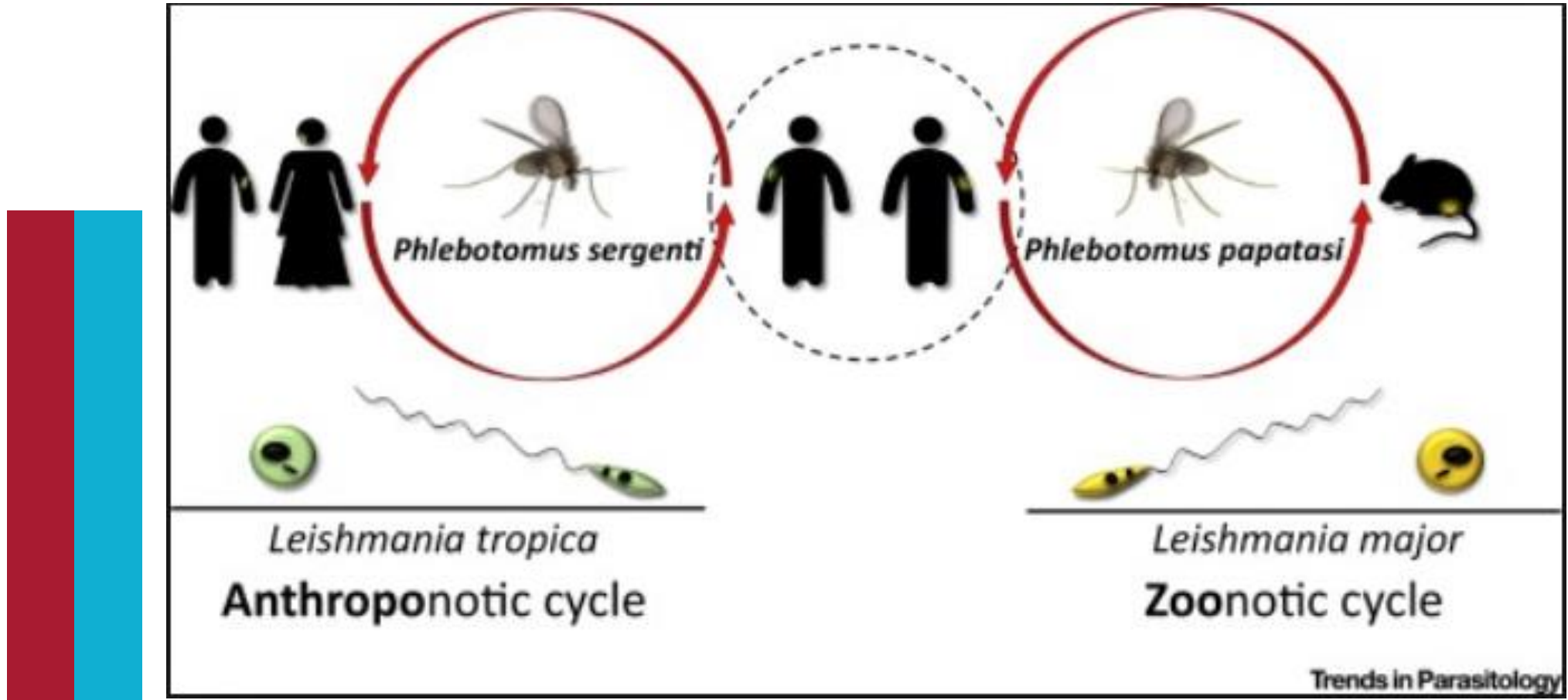
The leishmaniases are now considered as neglected tropical diseases by the World Health Organization

Main clinical forms : visceral, cutaneous and mucocutaneous leishmaniasis

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

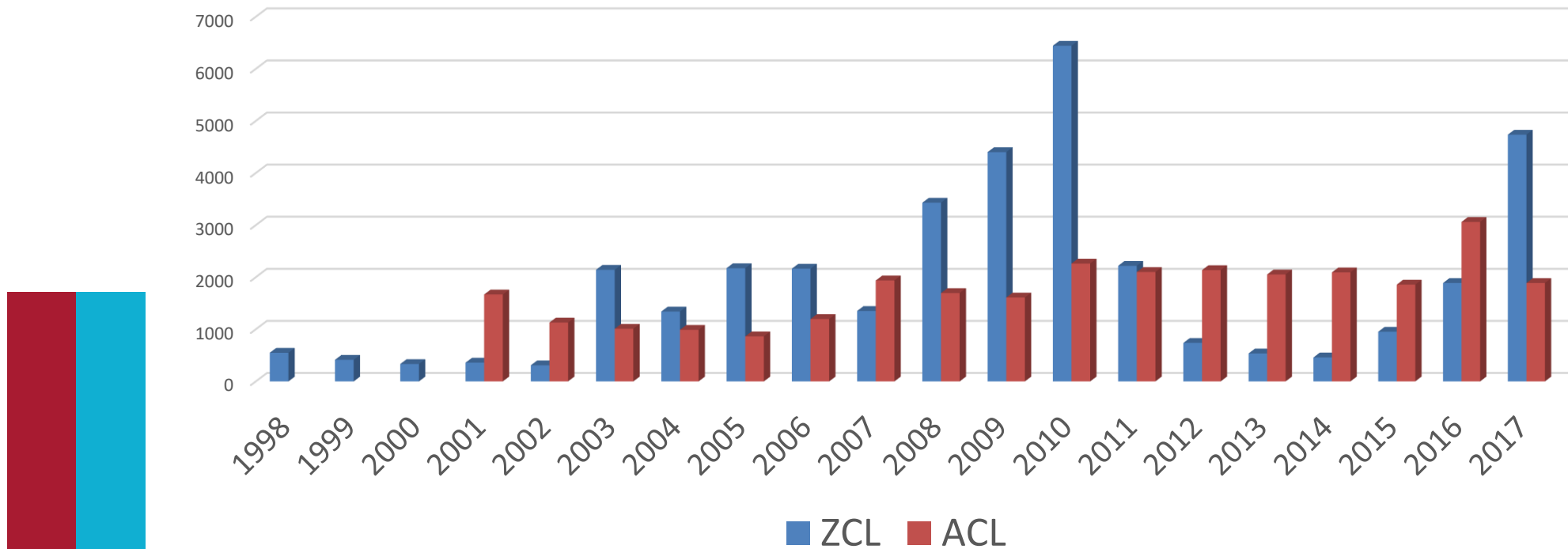
We focused in this presentation on the Localised self-healing cutaneous leishmaniasis form (LCL) that exists in Morocco

In Morocco, two main causal species for cutaneous leishmaniasis, with different transmission cycle



Source 2016: Mondragon-Shem, Karina et al. Cutaneous Leishmaniasis: The Truth about the 'Flesh-Eating Disease' in Syria. Trends in Parasitology , Volume 32 , Issue 6 , 432 - 435

Recent trends in ZCL & ACL in Morocco



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

A more stable caseload of anthroponotic cases continues to persist.

Clinical forms of CL in Morocco

Ulcer



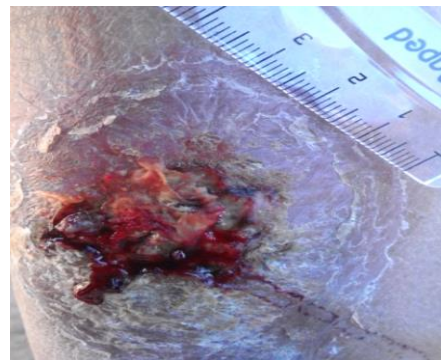
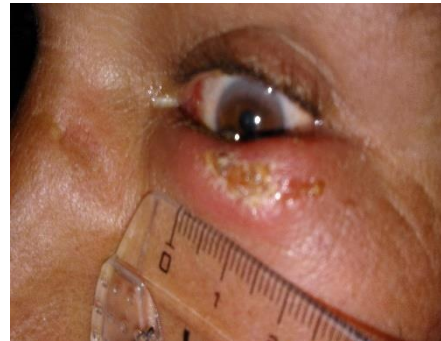
Macule



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 \pm 2.3 for boys and 17.2 years \pm 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

*“**Why 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?**” (FR 068).*

*I am obliged **to put cream** to try to hide it before going anywhere.” (FR035).*

Emerging themes in text analysis

Self-concept		Body image	
Self-confidence	Self-esteem	Body beauty	Face appearance
Self-awareness	Self-contempt	Scars cosmetic effects	
Social stigma		Self-stigma	
Family relationship	Avoidance by others	Embarrassment	Shame
Social contempt	Marriage difficulties	Anxiety	Sadness
Fear		Depression	Suicidal ideas
Health seeking behaviour			
Traditional remedies	Conventional treatments		
Spiritual healing	Coping strategies		

- 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.

CL perception in Community (adult population)

RESEARCH ARTICLE

“The mosquitoes that destroy your face”. Social impact of Cutaneous Leishmaniasis in South-eastern Morocco, A qualitative study

Issam Bennis^{1,2,3}, Loubna Belaid⁴, Vincent De Brouwere², Hind Filali¹, Hamid Sahibi⁵,
Marleen Boelaert^{2*}



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.



**Young Vs Older
Stigmatised Vs Stigmatiser**

Diminished marriage prospects

No stigma



The psychosocial burden of CL in the literature

RESEARCH ARTICLE

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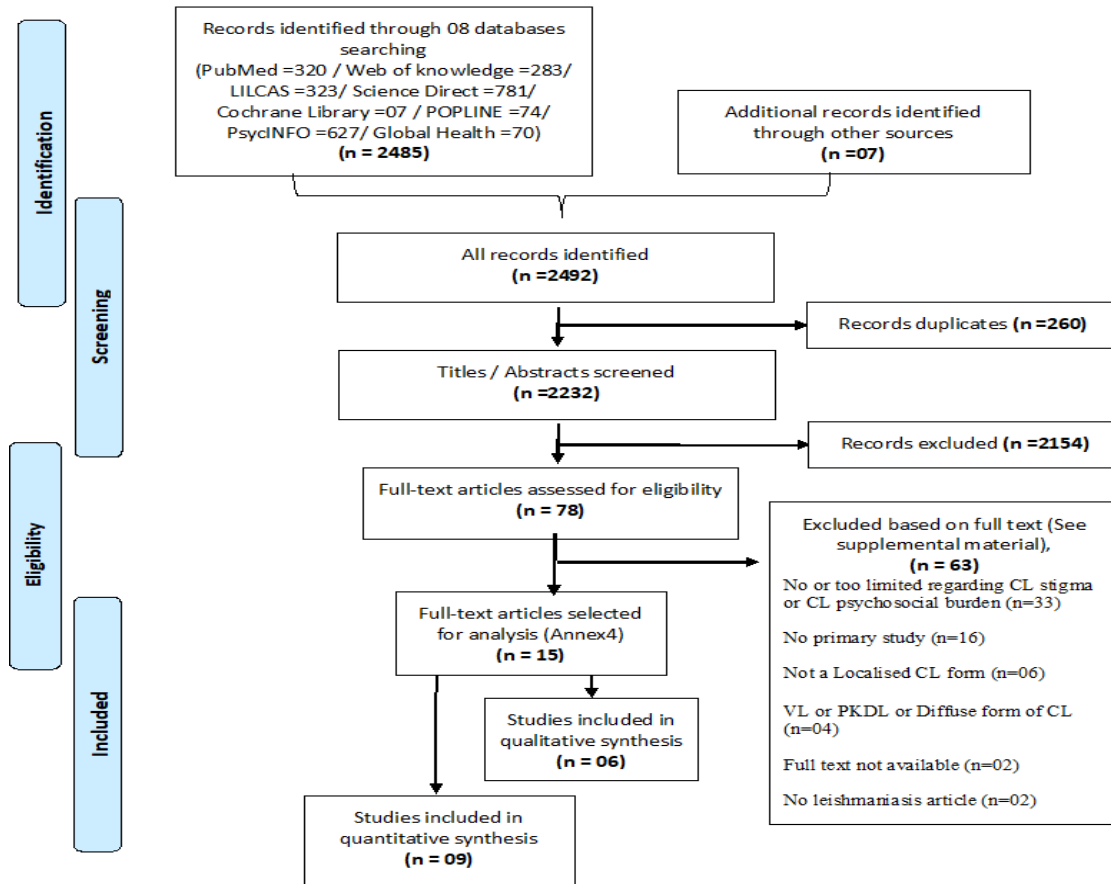


Psychosocial burden of localised cutaneous Leishmaniasis: a scoping review

Issam Bennis^{1,2,3*}, Vincent De Brouwere², Zakaria Belrhiti^{1,2,4}, Hamid Sahibi⁵ and Marleen Boelaert²

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)



Flowchart of the number of literature searched and selected for psychosocial burden of Cutaneous Leishmaniasis

Authors	Year of publication	Country of the study	Methods	Study design	Timing	Study Population	Sample size	Sex ratio (M/F)	Age range (years)	Patients with CL scars included
Al-Kamel et al.	2017	Yemen	Qualitative	Interview	May 2016	CL patients	11	0.10	12-60	Yes
Bennis et al.	2017	Morocco	Qualitative	Questionnaire	April 2015	Boarding school students	448	1.36	16-20	Yes
Chahed et al.	2016	Tunisia	Quantitative	Questionnaire survey (scale)	Not defined	Women with CL scar	41	All female	12-53	Yes
Ramdas et al.	2016	Surinam	Qualitative	Ethnography	Sep 09 to Dec 10	CL patients. General population	205CL patient & 321 people	8.3 & 1.4	20-49	Yes
Turan et al.	2015	Turkey	Quantitative	Questionnaire survey (scale)	May 11 to Apr 13	Paediatric CL patients and healthy controls	54 CL patients	1.16	7-18	No
Handjani et al.	2013	Iran	Quantitative	Questionnaire survey (scale)	2013	Relatives of dermatological cases	50 relatives	0.85	20-65	No
Vares et al.	2013	Iran	Quantitative	Questionnaire survey (scale)	Not defined	CL patients	124	0.59	16-80	Yes
Abazid et al.	2010	Syria	Quantitative	KAP-survey	Nov 06 to Oct 07	CL patients or the caregiver seeking treat	70	0.46	≈32	No
Fernando et al.	2010	Sri Lanka	Quantitative	KAP-survey	Sep 06 to Feb 08	CL patients	120	2.75	02-70	No
Nilforoushzhadeh et al.	2010	Iran	Quantitative	RCT	2007	Female CL patients	2 groups of 20	All female	> 10	No
Kassi et al.	2008	Afghanistan	Qualitative	Case report	Not defined	Woman with CL scar	1	All female	28	Yes
Simsek et al.	2008	Turkey	Quantitative	Questionnaire survey (scale)	2006	Women in general population	247	All female	15-47	Yes
Reithinger et al.	2005	Afghanistan	Mixed	KAP & FGD	Oct 2002	KAP: household head; FGD: women	KAP: 252; FGD: 108	FGD All female	Not defined	Yes
Yanik et al.	2004	Turkey	Quantitative	Questionnaire survey (scale)	Sep 02 to Aug 03	CL patients, persons with CL scar, healthy controls	3 groups of 33	1:1	12-35	Yes
Reyburn et al.	2000	Afghanistan	Qualitative	FGD	Feb to Jul 1998	CL patients and unaffected spouses	8 groups of 6 to 10	1:1	≈28	Yes

Overview of the main study results

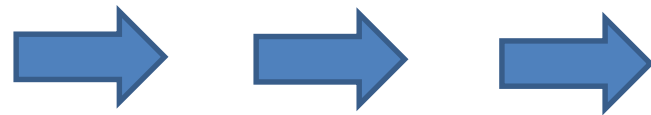
LCL is a source of psychological suffering, stigmatisation and reduction of quality of life.

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.

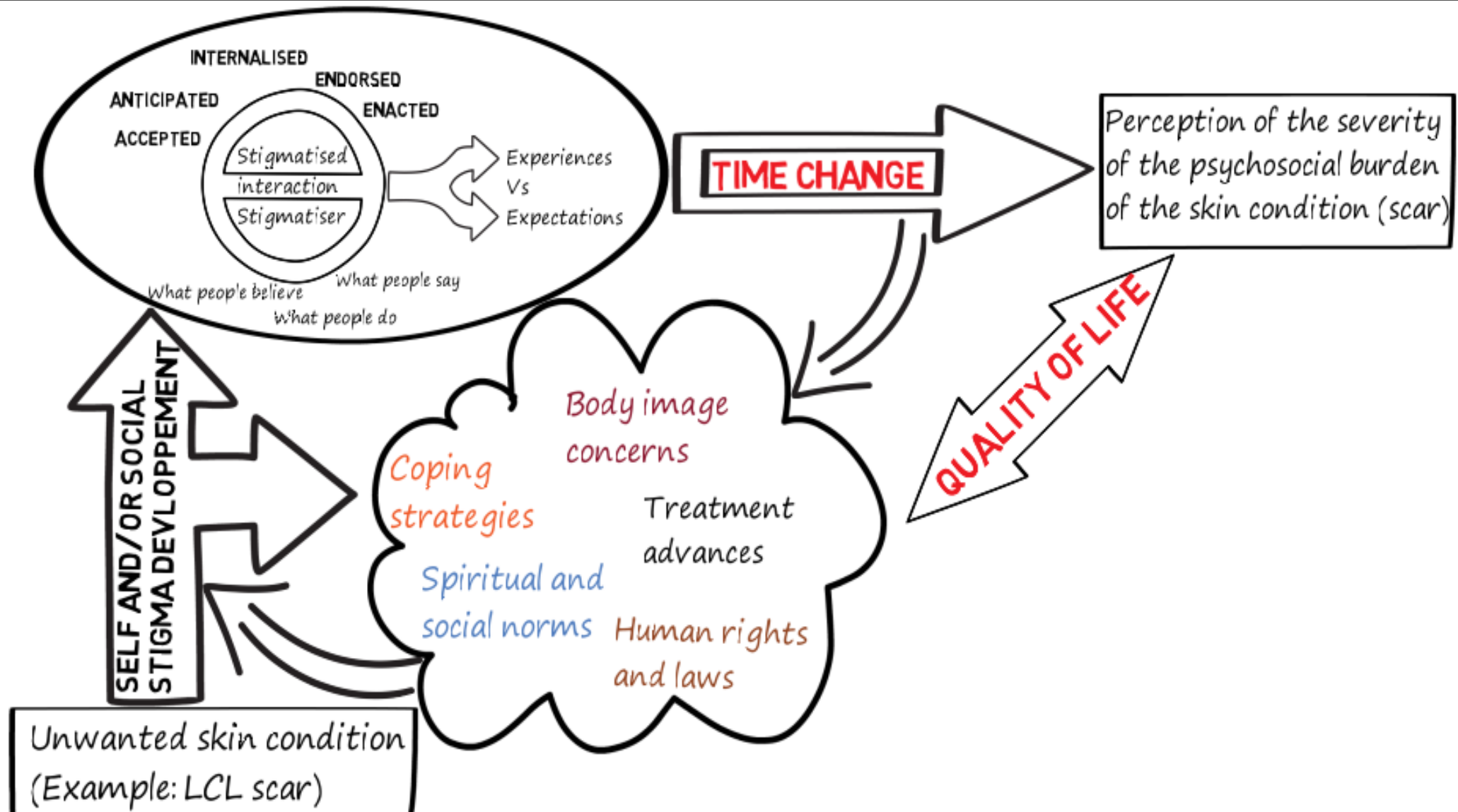
Extreme self-isolation and self-contempt can sometimes even lead to suicidal ideation.

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



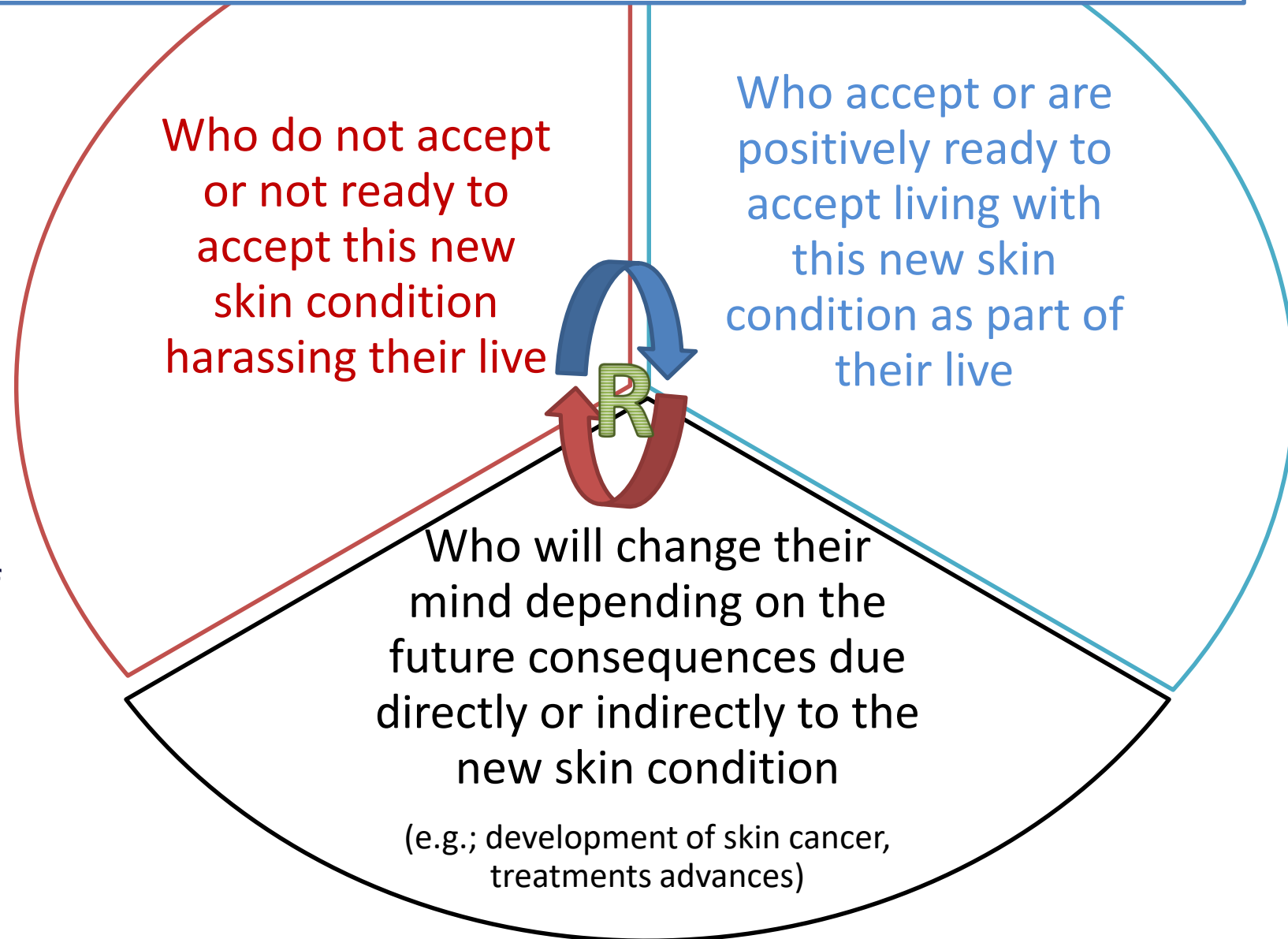
Three categories of patients with CL scars (inactive without relapse) from a quantitative view

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** ?



Are we looking in the right direction ?

"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

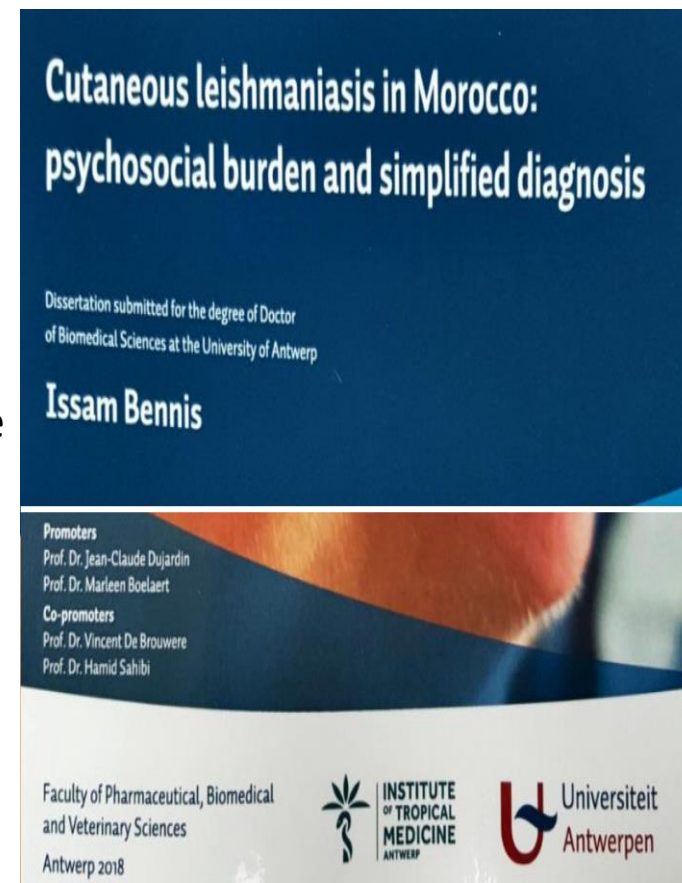
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DNDi

Drugs for Neglected Diseases *initiative*



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