

ISSA, PARIS,
*CHRONIC DISEASES TAMED BY SPORTS AND
PHYSICAL ACTIVITIES?
THE CASES OF PEMPHIGUS AND HIV, NOWADAYS IN
FRANCE*

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Introduction: interest of comparison between...

... two types of disease* :

- PV = autoimmune (?), non-inheritable (?), remission (?)

- HIV = infectious (!), transmissible (!...? undetectability of virus - question of fiability of tests...)

All of two with severe morphological implications

With new
biological,
epidemiological
(sociological?!)
investigations,
some
characteristics
are changed

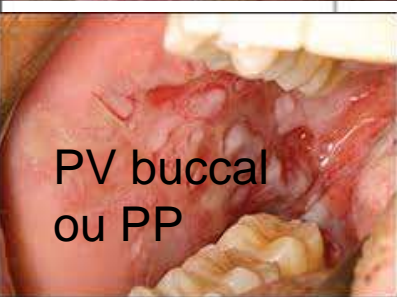
Bullosa Diseases (Pemphigus)



PB



PE/S



PV buccal
ou PP

- (MBAI in French) are more and more various (+10*)... against only 3, few years before
- Varied Prevalence : from 1/3000 to 50.000 pregnancies for *P. gestationis* to 2/M. hab./y. for PV (average of: **0,6/100 000***)
- An heterogeneous medical support among centers:
 - proximity,
 - competence,
 - reference (only 2 in France),
 - ... let alone outside the university hospitals

Rare and unknown... so, few shared

According to
type of
Pemphigus
the skin is
more or less
net

- Absolutely unknown by general population, even by lots of (para)medicine professionals
- The social silence is often combined by an individual silence: the PLWP don't tell anybody about their suffering
- Vulnerable lives reinforced by symptomatic treatment with severe consequences*

HIV and correlate' infections: a paradox of social presence vs. absence

Several groups of HIV patients, caregivers or researchers are organized and mediatized : AIDE, Act Up, Actif santé, Seropote, etc.

- Chronical treatment with less and less secondary (visible) effects
- Opportunistic infections ⇔ Sword of Damocles
- Stigmatized infection even nowadays in spite of Sidaction (dedicated Day, 27-29 march)
- Real and “fantasystic” Risk and Fear* of contamination (self and other)

Recent survey: PLWHIV Discrimination and... Exclusion of Care: 1/3

*“We want
health
democracy
on this
issue”
(A.I.D.E.S.*)*

The third of HIV testers were refused in the consultation of dentists (148 out of 440)... that have not complied with the law. Refusals were often disguised beneath:

- discouragement strategies
- reorientation towards some colleagues... under the pretext of a lack of knowledge of pathology

<http://sante.lefigaro.fr/actualite/2015/06/04>

A) Rare* diseases and... chronic

Different levels
of sociological
understanding

- a) Various experiences of diseases**
- b) Old paths/difficult life with Pemphigus or VIH => ambivalent relationship with the medical and sporting worlds**
- c) The mobilizations:
 - Caregivers
 - Treated patients
 - Political institutions
 - Associations, etc.

One Research question:

With the
notions of
“biographical
disruption”
(Bury, 1982) +
capabilities to
react, to
empowerment

What impact of diagnosis and treatment
to these people’s sporting participation?

B) Combined methods

A national survey by questionnaires* (n= 619) and non-structured interviews (n = 50) on access for PLWHIV to physical activity and sports**

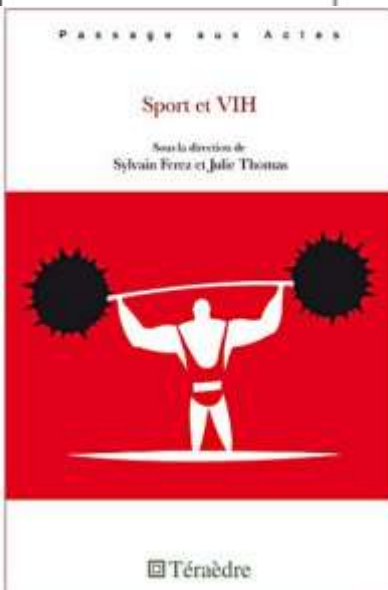
Done

Direct Observations into national association (Paris, 2013-)

Interviews with PLWP, close people, medicine professional (n= 36) in France

Participation into therapeutics workshop (Rouen, 2014-)

Content analysis is in progress (13/36)



Researches with long latency periods. A necessity or...

... a consequence
of **medical
obstruction**
because of
illegitimate
investigation
by/for sociologists
or sport
researchers?

With different **savage's roles***, assumed or endorsed by us:

- Psychological support
- Therapeutic counseling
- To make talking (*catharsis* effect)
- Take time to listen « *without clinical interest* » (*dixit* one medical specialist)

C) The practical consequences of the disease



« Wounds flow into the mouth as dressings when it resumed normal life, and it smells very bad. This complicates much intimate and collective relations! (...)

Go to the pool as soon as there is not too much visible stuff on the skin »

(Gertrude, 64 yo, 14 y. of PV)



Morphologic changes with treatments

Pemphigus

- Loss and weight gain (-20kg, then + 30kg)
- Moon face, neck and swollen body:
« When you look at it, you do not recognize yourself (...) you took 30 kg, you can not see with a veil before the eyes, hair everywhere, etc. » (Léa, 23 years of Buccal Pemphigus)

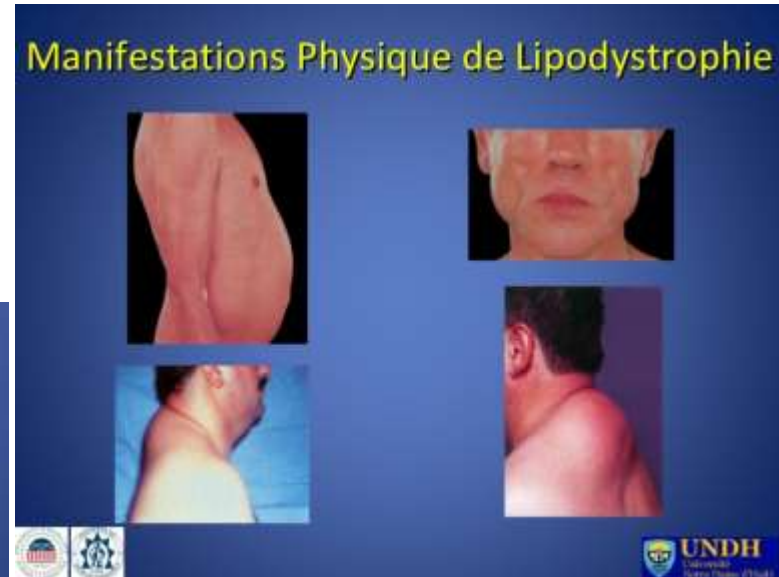


Varied (and obsoleted?) body manifestations

HIV

- Lipoatrophy and lipodystrophy (buffalo hump, etc.) (only for old PLWHIV?)
- Emaciation characterized, including the face

Filling or liposuction techniques are not so democratized



Guesly Delva, M.D.
Post Doc Infectious Disease Fellow
Institute of Human Virology
University of Maryland School of Medicine
November 2011

D) Risk of social and sporting isolations

*« The cortisone gives some vitality. So, I was hiking again, but very quickly I gave up... and I put a hat, because **I was ashamed** »*

*« I picked up with walks again but alone for two reasons, first because I did not want to show my wounds, and then secondly, **I didn't want answer the questions...** I've had sores in the scalp and also on cheeks. »*

(Dylan, 72 yo, 4 year of PV).

<http://zope.dermis.net/e04info/e05copyright/>



Risk of social and sportive isolation

VIH

« Before the illness, I've always been a guy who weighs 75 kilos but of muscles. [...] So I'm a man who has fat thighs, arms, butt, thin legs and the trunk is big. So I'm not very nice to see naked (...) that is this ancient and beautiful body which (HIV) took to me.»

(57 yo, African French)

E) Modulated Participations in sports

Ferez et al. (2014)	Increased n=80	Stabilized n=245	Varied n=87	Disrupted n=38	Reduced n=126
Only statistically significant tendencies					
Sex and sexual orientation	Homosexual Male	Homosexual Male	Heterosexual Female	Heterosexual Female or without sexuality	Under-representation of Gays
Place of birth	North Africa	France	ns	Africa	French islands
Professional Activity	Invalidity or more engaged in activity	Activity, high level of scholarship	Invalidity	Invalidity, without diploma	Without activity or "long illness"
Place of life	ns	ns	Big regional town	suburb of Paris	ns

SPA as means to a relative empowerment

Qualitative indications on 13 interviews

unresponsive	1
Stop sport	3*
Modification	5
Pursuit	4

A **Strong injunction** by medical specialists and the Pemphigus National Association:

« Do Yoga, Sophrology, something that relaxes you; have a normal** life! »

- Physical well-being **rediscovered**, but **frail**
- Revitalization to self-control: « *now I run much more in fact. It's really in this mastery compared to the cortisone, to avoid taking the weight* » (Eva, 41 yo, PV)

Keep “normal” leisure/life or rethink it?

The reorganization of life is impacted by:

- external factors (social and economic resources, symbolic representation of disease, collective mobilization and resistance, etc.)
- internal (capabilities to be positive, to relativize, to protect oneself**, to activate new bonds, new projects)

The Chronic
Diseases disrupt
these
biographies, a
real
ALTERNATION*
(Berger,
Luckmann, 1996,
214)?

Minority of Tough and effective people...

... which can
(with social,
economics
resources)
increased
their self-
constraint and
engagement in
sports

“I managed my disease alone... I do not represent the majority of the cases. I knew many people who try to share the difficulties with a conjoint, a sister. Me, never, ever even with the people closest to me”

(Léa, 62 yo, Oral P. since 13 years)

Hyper physical activity of tough PLWHIV

Héas et al.,
2012, 72

« Adapted sport does not indicate sport soft, still less a sous-sport »

Carlos* is demanding and seeks a high level of sport

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Elements of interviews transcribed and mobilized here

	<i>Pseudonyme</i>	<i>Age et profession</i>	<i>Ancienneté et type de MBAI</i>
n = 23 transcribed on 36	Danielle	53, researcher (stop and return to work)	7 y., PV
	Léa	62, entrepreneur (no stop)	23 y., PV buccal visible, without treatment during 3 years
	Dylan	72 years, retired since 1999, former nuclear engineer	4 y., PV buccal
13 Interviews are mobilized here	Xénophon	64, retired army but continued activity	7 y., PV buccal
	Gertrude	64, halftime and then retired university	14 y., PV/PP buccal with Nikolsky's sign, skin cancer, bowel cancer, stroke...
	Solenn	57, responsible for an IT service company, sick leave	6 y., Pemphigus paraneoplastic, tumor, respiratory failure
	Aria	64 years old, retired, former director of public service	6 y., PV buccal, nothing on the skin
	Eva	41 years, educator (former secretary)	4 y., PV
	Maude	42, part of the local government service	17 y., PV
	Béatrice	22, AVS, recovery study to become a social worker	5 y., PV/PP buccal
	Christine	68, former secretary in the private	20 y., polyarthritis
	Léone	79, former stevedore	14 y., P. Scars
	Eloïse	61, ex-college professor (sick leave)	17 y., Pemphigoïde of mucous