



Living nowadays with a pemphigus in France.

Added Values of a qualitative research

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Plan

Introduction: Sociological focal

- 1) A Body hypervigilance?
- 2) An upset biography?
- 3) Family-conjugal relations (impacted) negotiated: the gendered differentiations
- 4) Dominant Female *care* : a familial empathy into APPF and by APPF

A “distanced” posture/analysis... negotiated every day (Elias*, 1993)

- No medical action
- No (psycho)therapeutical attributed action... even if we are presented, sometime, as psychologists!
- A **punctual** role into hospital, into APPF’s events
- **Affective relations controlled** by methodological experience and protocol (with doctors, PLP, close relations patients...)

Complementary Investigations about Pemphigus (PV)

- Medical Protocol : FMR, CHU Rouen-RC of bullous diseases, Pr. P. Joly (dir.), QOL questionnaires...

Sociological protocol: (n= 64, including 9 caregivers), all transcribed interviews (>1000 pages),
Direct observations (>100 h) : APPF, TE, FB®...

Social,
medical, etc.,
varied
situations

- Active File et **outside AF** (via national association and by large call for testimony)
- Average Life with PV: ~ 6 y (0,1* to 20 y)
- Average undiagnosed period: 7 month (0,1 to 90 months)
- Average Age : ~ 54 y (22 to 90 y), 14 males
- Δ Profession : to Legal Minimum Wage (RSA) to University Professor or managing director
- Pemphigus only or PV with psoriasis, esophagus cancer, ankylosing spondylitis, Parkinson's, antecedent of thyroidism...

To analyze **varied experiences** of disease and sickness which are...

More than the consequences of biochemical process

More than a subaltern or inferiorized situations...

Experiences of life with PV are **also**:

- Active (individually and collectively)
- Efficient (with consequences +/-)
- Intimate, collected with benevolence, without judgment, above all without medical power

Type of P. are (always) interpreted PV and PLP are **subject** and **object** of various interpretations:

... scientific ←-----until-----→ profane
... objective ←-----until-----→ subjective
... universal ←-----until-----→ singular
... generalizable ←-----until-----→ anecdotic

With:

- Balance of power, domination
- Different values, interests between each "actor"

Complete analysis of:

Disease: biomedical definitions (MBAI)

Sickness: political definitions (FMR)

Illness: experiential definitions (life with...)

... all these are ideally **combined with competing definitions: situational, interactive, affective, cultural, social, etc.**

A specific context of... **medical contest**

- The adhesion of biomedicine approach was/is never total
- **Defiance exists about medications risks**
- *“after educator and politic man, medicine practitioner is touch by a **confidence crisis...** with one acceleration of this phenomenon” last decades (Raude, 2017)*
- Associations of patients took/take a “new” place in the medical system (1980-)

Presentation of four sociological focus with some detailed analysis



Verbatim
as they
are!

1) A Body hypervigilance?

Not so much and not necessarily by the rare disease

□ No or few "obsessive" behaviors :

« Afterwards, I keep an eye on myself as every woman has to do it I think. Gynecological level all this (...) I am more aware perhaps than some people who have had nothing. Obviously afterwards, you see things a little differently anyway. **We*** understood. »



GÉRALDINE, 34 yo, 2008-

□ Sensitivity “refined” by fear of relapses:

« That illness, as I have been told, is asleep in us. We have it in us. She's asleep. Professor X spoke that if she heals, she is still there. She is still in us. If I get well, she's asleep. She may wake up. »



BÉNÉDICTE, 63 yo, 2009-

Skills acquired post/via Pemphigus

- a beneficial food hygiene!
- an "armed" medical experience of knowledge (technical, relational, biological, in terms of network, etc.)!
- a singular "face-to-face" between PLP and SP/GP
- an intimate domestication of human vulnerability
- a reinforced *carpe diem*... sometimes

Verbatim
as they
are!

Examples of unrealistic expectations, confusions*

«It started by an eczema and then they said it was the *Findus* (dixit) I would like to hear about operations (No. They do not do that) So ... (sigh of discouragement) this disease there, one in a thousand ... we're sixty million or eighty, I do not know.



So there are six or eight patients (in France) right? »

(Jean Pierre, retired, ex-employee, recent diagnosis)

2) An upset biography? Not that much and not necessarily by the rare disease

- 2/5 biographical break: social life suspended, stopped
- 2/5 continuity of biography: maintenance of the activity (professional, playful, associative ...)
- 1/5 bifurcation of trajectory with professional changes in particular

Examples of “biobreak”: - recent, + recent



«I was a girl who really go ahead, who was a fighter, and I'm no longer it, and I do not see it coming back in the years to come ... I have moments of unwillingness to do something. This never happened before. »

Danielle, 53 yo, upper class, 2007-

Verbatim
As they are !



« since 2013, me, I do only that : hospital, sick, hospital, sick, I have only that (in my life now). As soon as it goes a little better, paf, there is something else. »

George, 66 yo, ex-employee, 2013-

Exemples of continuity (+, -)



« It does not bother me because I tell to me it's only hazard. It's me, it could be another person. No specific vigilance because I can not prevented it, I have not really changed. It's not like you can prevent then you pay more attention to your actions. »

Clémentine, living with 2 auto-immunes diseases, 2012-



«And I'm not sure what to do with it (relations to parents),if they was dead, I cannot do anything about it. There, they are there and they are never useful to me, they have never be useful me to anything.»

Wendie, 42 yo, divorcee, 2012-

3) Family-conjugal relations (impacted) negotiated: the gendered differentiations

- Male PLP beneficiaries of a “naturalized” female care:

"My wife, she is a housewife. She's taking care of me ".

Charles, 53 yo, 2015-

- Female PLP altruistic"



“At my age, I think I'm still in the death front line, I think it does not matter; if the young are good health. It's ok. And fortunately it happened to me that at my age, now, I'm still in the frontline (facing death) “

Malou, 72 yo, ex-tradeswoman, 2014-

- For female PLP the **male care** is « *inexistent, insufficient* » (*dixit*)... even though **it exists and is observable**

Strong shift in conjugal relationships or everyday tasks: a constant rebalancing

*« With ma wife, we are constantly united for 22 years ... love is making sacrifices on each side; **we got married for the worst** and **for the best**. She had a lot of trouble because it is a physical and psychological illness. It was not beautiful to see. So there was no more sexual relations, there was nothing left. So loss of sexual power too. I was treated for that. I did not even want sex, I did not want anything. Everyone was annoying me. »*

Dany, superficial foliaceus P, 2010-

Risk of exclusion



Marital breakdown... among other ruptures



« I do not understand that there is a lack of humanity at this point, I lived it, I had everything that fell on me, and in addition I lived this non-respect. Nobody respected me, my husband no longer respected me, the hospital no longer respected me ... I could not even pass the hospital without a crisis of tears. »

Danielle, 53 yo, upper class, 2007-

4) Dominant Female care : a familial empathy into APPF and by APPF



« Much more with my daughter than with my son. It is probably easier to talk about between women; yes, we talked a lot, and then my daughter at age 35 stopped the job she was doing to resume studies of psychology, (laughter) if you want, she was on the front row to help me when it was not too good. »

Eloïse, 61 yo, 17 y PVP, ex-teacher

An effective and efficient female care

The association as support and engine... for all?

- Pedagogical role for the PLP and its spouse:



« I missed to tell to you something important the other day: my husband is with me at the APPF meetings, almost every time. And for him too, it proved very useful. »

Aria, 64 yo, public retired, 2008-



- Pedagogical role of association for the caregivers, the researchers: keeping in mind the possible variety of impacts (Sobocinski et *al.*, 2017)

The peer helpers play different roles in the:

- Definition of PLP aspirations
- Facilitation of PLP power
- Facilitation of PLP choices

Then, the progressive organization of patients + « ***solidarisation*** » of caregivers induce them to adopt a **more humble position** (Laval, 2017)

International network



Would you like to help patients get diagnosed faster?

Spread the word as an IPPF Awareness Ambassador!

Awareness Ambassadors are IPPF community members who band together to spread local awareness of pemphigus and pemphigoid (P/P). Their goal is to help P/P patients receive a diagnosis faster. They do this by putting P/P "on the radar" of dental professionals.

What makes a great Ambassador?

Ambassadors are passionate individuals ready to spread awareness of P/P both in the US and abroad (patients, friends, family, healthcare providers, etc.).

Patients become
“ambassadors” of other
patients, and even of one
disease

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THANKS FOR YOUR ATTENTION