

# **The psychological aspects of polio survivors through their life experience.**

Aspects psychologiques du vécu de personnes vivant avec des séquelles de poliomyélite

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**Prevalence of Post Polio Syndrome** differs according to various studies going

From 20 % (Dalakas 1995)

31 % (Ragonese 2005)

36% (Trojan 1995)

to 60% (Nollet 2011)

showing how badly understood the nosological and semiological aspects of this syndrome are.

None of the PPS symptoms are polio-specific

PPS does not sum up all the possible complaints of patients with polio sequelae,

In the literature, PPS recovers sometimes the real PPS, but often all the complaints from patients with polio sequelae.

It is preferable to use the term “**polio survivors**”.

The term “*patient with late onset sequelae of poliomyelitis*” including problems from other cause (Nollet 2002 60% of the polio survivors).

Fatigue, of any type, and pain are largely encountered in the general population.

**Physical and psychological symptoms are strongly entangled**, a natural obviousness which is not polio-survivor specific.

Before vaccination, fighting the acute disease and limiting its sequelae monopolized the entire medical attention.

The issue of coping with motor deficits, was considered almost out of the medical framework.

Later on when polio survivors report symptoms of fatigue and muscular weakness, physicians sometimes related them to “simple” psychological disorders or patients refusing to cope with the natural aging process, by carelessness or lack of knowledge.

## Two aspects of this issue:

- The frequency of some psychological symptoms.
- The life experience of many polio survivors, lightening some comportments which must be known by the physicians and therapists, through literature and our clinical experience of post-polio consultations *at the Raymond Poincaré Hospital (Garches) and at the Fernand Widal Hospital (Paris).*



## **Depression and anxiety:**

Prevalence of depressive symptoms in polio survivors varies greatly according to the studies.

\* Conrady et al 1989: 93 polio survivors (San Francisco), 50% showed depression, irritability and anxiety.

\* Tate et al 1993: 116 polio survivors (USA Michigan) 15.8 % showed symptoms of depression.

The depressed patients reported a more severe physical deterioration, more pain, a lower coping behavior, a lesser quality of life and frequent loneliness.

## Depression and anxiety:

Kemp et al (1997, 1999) 121 polio survivors (USA Rancho Los Amigos Medical Center, California),

symptoms of depression were reported in 28.2 % subjects.

The risk factors were:

- \* physical changes linked to their polio sequelae,
- \* but even more so the quality of the support brought on by their family, as well as their own attitude towards their disability.

Overall these percentages do not seem so different than the one from the general population (Lepine et al 2005).

Personality of polio survivors suffering from PPS did not seem different than the ones from the general population (Conrady et al 1989).

## Fatigue

3 categories usually described: General fatigue, Mental or brain fatigue and Physical or peripheral fatigue.

Fatigue is strongly entangled with psychological disorders.

This is one of the PPS symptoms, often the first and is also one of the main symptoms of depression.

Mental fatigue is source of physical fatigue and physical fatigue is source of anxiety and depression.

## **General fatigue**

The only characteristics distinguishing 118 polio-survivors with severe fatigue from those with mild/no fatigue were psychological characteristics (depression, anxiety) rather than physical one.

Schanke et al 2002 (Norway) among 266 polio survivors

## General fatigue

- \* Depression was associated with General fatigue, as well as max inspiratory pressure, fibromyalgia and muscle strength (Trojan 2009 among 52 PPS not severely depressed)
- \* Physical as well as “psychologic distress”  
= independent factors associated with fatigue  
(Tersteeg et al 2011 Netherlands, among 168 subjects with “late onset sequelae of poliomyelitis”)

**Physical fatigue** is one of the most pronounced problem of PPS (Schanke et al 2001, Nollet et al 2003, Ostlund et al 2008).

There is evidence for the link between fatigue and weakness:

\*loss of motor neurons starting directly after the acute polio  
(Gordon 2004)

\*normal neuron loss in healthy subjects over 60 also ongoing in PPS patients

\*increasing speed of loss of the motor neurons, incapacity to maintain large motor units in polio survivors muscles  
(Grimby 1998)

## **Physical fatigue: Low resistance to minimal physical exercises**

fatigue was exacerbated by minimal physical exercises

in 18% of the PPS patients,  
none of the controls.

Berlly et al (1991 San Francisco) 86 PPS / 20 healthy subjects

## **Physical fatigue and depression?**

Patient's vitality,

defined by the presence of energy and lack of fatigue,  
seems to essentially depend on physical factors and not  
on psychological fatigue.

(Ostlund et al 2008 on 143 Norwegian polio survivors)

## Mental fatigue and depression ?

Mental fatigue could have a pathophysiological component / lesions of the reticulating activating system

(Bruno et al 1993-94).

- attention, recent memory and consciousness disorders,
- no changes in their cognitive abilities.
- and mental fatigue did not seem to be related to the depressive symptoms.

Further studies did not find cognitive impairments in PPS nor Polio survivors

(Hazendonk et al 2000, Schanke et al 2002, Ostlund et al 2005).

Relation between mental fatigue and vitality has been emphasized (Ostlund et al 2011).

## Pain

one of the symptoms with a high psychological component

- \* high relation between pain and the degree of daily physical activity (Willen and Grimby 1998 Sweden)
- \* high interference between pain and psychological functioning among 63 PPS (Hirsh et al 2010 Washington).

To summarize:

**Frequency of depression seems to be**

- \* not very different in polio survivors than in general population;
- \* higher in the PPS patients but the diagnosis criteria for PPS are often poorly described.
- \* depression does not seem to be related to cognitive impairment but rather to physical fatigue, decreasing of the physical abilities and the own environment of the subject.

## **Life experience and restricted participation (social impairments)**

Greater deterioration of their physical and/or psychological condition,  
with a negative impact on their ability to participate in social activities.

(Grimby 1994; Lund and Lexell 2008, 2009; Ivanyi 1999, Nollet 2003)

## Life experience and restricted participation (social impairments)

In France the GLIP (*Liaison and Information Network on Poliomyelitis*), study for the conference on poliomyelitis in Paris 2006 = four major issues for their members:

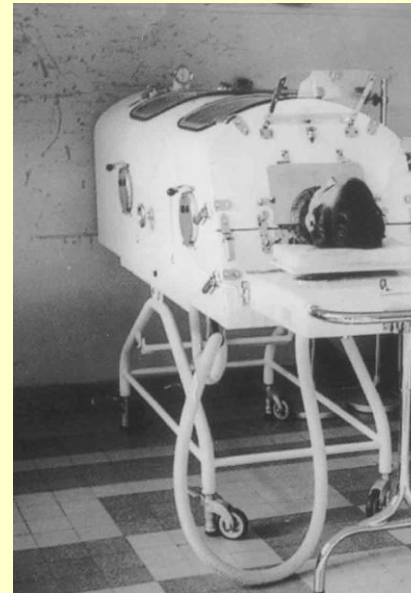
- \* The fear to see their spouse facing a health problem and not being able to deal with it;
- \* The difficulty to cope with an aggravated loss of autonomy;
- \* The feeling of being treated like a child;
- \* The lack of comprehension and attention that can lead to depression " .

To understand what questions polio survivors ask themselves we need to understand what their life experience was.

## Childhood

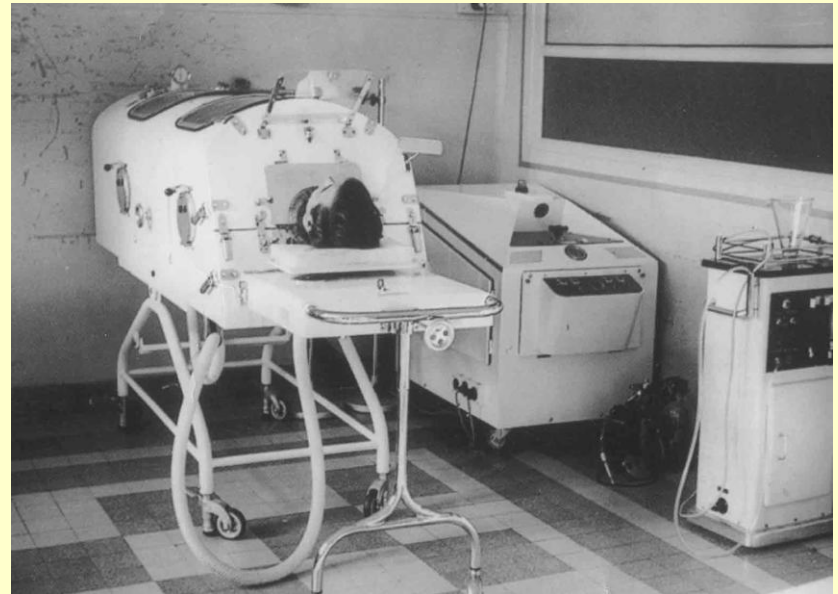
Poliomyelitis has a definite impact on these patients' lives,

- \* differences with other children: necessity to wear orthotic devices or braces, inability to play sports like other kids



## Childhood

Sometimes the need to attend school at the hospital for long periods of time leave a strong imprint in their mind, abandonment anxiety, fear of death and sometimes even abuse were awful daily companions.



Later on they will do their best to avoid any further contact with the medical field.

## Childhood

Relationship with the family members had an impact on their life experience growing up in a medical environment: their presence, the family structure, the way they lived and behaved with children in relation to their physical disability:

- sometimes by overprotecting them,
- most often by fighting for their children to be just like others.

Children impaired by their paralysis will learn to leave with their disability,

They often built-up strong personalities



## Cutting the umbilical cord a second time around:

When the growth period comes to an end, it is time to give up and store away chest braces, orthotics and orthopedic shoes, always reminding patients and others around them of their physical differences.

This was sometimes only been possible by taking some assumed risks.

It is a key period, cutting the umbilical cord a second time around, the one linking the patient to the medical environment.



## Cutting the umbilical cord a second time around:

- Once an adult... very intense familial and professional life,
- Without ever requiring any medical help until the embarrassing disorders came up: falls, loss of muscular strength, traumatism...
- Constant intricacy between the consequences of post polio paralysis and other health disorders.
- Unfortunately Polio can too often be accused of all ills, sometimes by carelessness or lack of knowledge.



Poliosurvivors are often supposed to be “type A”  
behavior.

(intense ambition, oriented toward achievement with competitive behavior styles)

The rigid qualities associated with this comportment could be deleterious when ageing and/or PPS occur, because of the inflexibility regarding the life style changes needed (Creange and Bruno 1997).

Actually the coping style of PPS subjects is often adaptative

80% said life was worth living

67% that they had often or all the time been in good spirit. (Ahlstrom and Karlsson 2000 Sweden)

Paradoxically, some patients are not able to “cut the cord” with older practices: the physiotherapist is never competent, the orthotic specialist is incapable of finding the right orthosis and the physician knows nothing about this disorder...



R.Poincaré Hospital Garches in the Sixties

## **Late functional deterioration**

- \* Sometimes wearing again orthotics on the lower limbs can be the only way to enable the patient to walk without any risk of falling, fatigue or exaggerated joint alteration...  
“constraining” and “stigmatizing” for some patients
- \* Difficulties to convince these patients that rehabilitation at the age of 60 is obviously different than the one they experienced as children:
  - muscle reinforcement techniques are different,
  - energy conservation measures are as essential if not more than muscle reinforcement...

## Late functional deterioration

This late setting deterioration is source of many worries, greatly promoted by the uncertainties surrounding the PP Syndrome.



What is the part played by poliomyelitis, lifestyle, natural physiological constitution, new health disorders or natural aging?

But confronting again the medical world brings back bad childhood memories with strong emotions.

Trust and apprehension are often intertwined.

What could be proposed?



Peter Bruegel 1559

## What could be proposed?

- Take time and listen to our patients to untangle the different elements making up the symptoms.
- Listen to the patient with in background the knowledge of these possible heavy histories. the fears and suffering from their childhood are never far away.  
Hope and suspicion towards medical professionals can lead to misinterpreting some of their behaviors.

## What could be proposed?

- The type A behavior when present should be decreased, so the polio survivors complete and comply with a treatment and orthosis and be able to make necessary changes (Creange 1997).



## What could be proposed?

- Future oriented coping related to hope may improve the self perceived mental and physical status of patients with PPS  
(Shiri et al 2011 in press)
- Effect of a multidisciplinary rehabilitation program with physical, psychological benefits at 6 months  
(Davidson 2009)
- Sometimes inciting these patients to seek psychological support is often quite useful.

**Thank you for your attention**