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# "We live two lives separately": an interpretative phenomenological analysis of spouses' experience facing Huntington's disease.

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### Background

### (A) Huntington's disease (HD):

- an autosomal dominant inherited neurodegenerative disease<sup>1</sup>,
- causes motor (e.g., chorea), cognitive (e.g., attention deficits) and neuropsychiatric symptoms<sup>1</sup> (e.g., apathy)1.
- deprives the ill person of autonomy, who progressively needs help for the daily life<sup>1,2</sup>
- In most cases, this help is provided by the **spouse**<sup>2</sup>



- **Experience of the genetic diagnosis:**
- Disbelief/denial (discovery of the disease)<sup>2</sup> VS resentment/hostility (guilt and worry for the children)<sup>2, 3</sup>
- **Burden:**
- Exhaustion due to the duty of care, the lack of respite and the constant evolution of the disease<sup>3, 4</sup>  $\rightarrow$  neglect of their own needs and health<sup>3,5</sup>
- Loss of the marital relationship:
- Anticipatory grief and loss of the partner<sup>5, 6, 7</sup>, identity upheaval for the spouse<sup>5,8</sup>
- **Needs of support:**
- Lack of understanding from the medical staff, feeling of isolation and loneliness <sup>3, 9 10</sup>

Some limits to these results:

1)No distinction made between the different stages of HD

2 Few focus solely on spouses

This study is the first part of a project aiming to understand the experience of spouses at the three stages of the disease and the specificities of each.

#### Method

# Objectives:

To better understand the experience of spouses facing the 1st phase of Huntington's disease To identify the difficulties and needs of spouses in the management of the daily life

# Participants:

- 10 spouses, recruited in the Reference Centre for Huntington's disease of Lille University Medical Centre (Lille, France)
- **Inclusion criteria:**
- Being the spouse of a person diagnosed from HD, at the 1st stage of HD (measured by the Total Functional Capacity Score, Shoulson & Fahn, 1979)<sup>11</sup>
- Living with the romantic partner for at least 5 years
- Being able to communicate

- Characteristics of the spouses:
- $\bar{x}_{age}$  = 54 years
- $\bar{x}_{relationship duration} = 35 years$
- $\bar{X}_{patient's TFC} = 9$
- (n.b.: 1<sup>st</sup> stage of HD range: 13-7)

#### Procedure:

Individual interview with the spouse, at the spouse's home.

-- Data analysis:

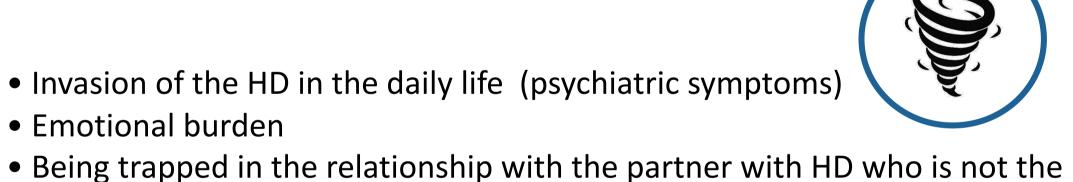
Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009)<sup>12</sup>

#### Results

### The infernal spiral

same person as before

• Invasion of the HD in the daily life (psychiatric symptoms) • Emotional burden



"It's hell on earth... (cries) I'm exhausted(...) I hate my life right now... I thought that I would have a better life, a better retirement than... That." Isaac.

"It's, like we say, 'for better and for worse', but now...It's hard for me." Eric.

#### Escape, whatever it takes

- Bad habits for health, to avoid negative emotions
- Taking refuge with children: a source of both relief and stress
- Disengage from the couple's relationship

"Well, when I drink... I drink a lot. And if I let myself go, I can drink every day." Daniel. "Sometimes, I think... to leave and never come back, but .... I don't say it, but I thought about it..." Adele.

#### No happy ending for us

It's hell on

earth

- a bleak future for me...
- ... For our couple...
- •... Which could become even darker if the children have inherited the disease

"We don't wish such a life... And we don't want our children to be sick (cries). If my daughter is also positive, I realise that I will have to live with it... (cries)." Helen.

#### Alone in the world

• by the laboratories, administration and healthcare systems Abandoned Feeling of isolation, loneliness and being abandoned by everyone

to our fate

"I'm in a lawsuit against the social security, which refuses to put her on disability. (...) It's unfair, she worked for 25 years... but she doesn't fit into the boxes er, it's, purely administrative and they don't do it; they should know that it's a neurological disease anyway and that... it's not cheating, she's sick, she's condemned..." George.

• the need to better understand the disease to better control the daily life

 needing to know about children's transmission, only if they not inherited it • The fear of knowing that the disease is real and will require a greater amount of

**Needing to** know, but not too much

"It may be the fact to not... Not see... Maybe there is a problem, but... You know, you close your eyes. Maybe it's the fear to say...'Well, yeah, there is this problem and... That the disease is there, it is starting'..." Bruno.

 Be the sole guarantor of the maintenance of stability in the daily life -> refusing external help

Pushing the limits of the care

Being the rock of the family

"My best friend reprimanded me on the phone... That I was doing too much, that I had to be careful and so on... But well... I know I do a lot, but I can't see myself doing less... It would seem abnormal to do less. Not for the moment..." Jules.

#### Discussion

- This study confirms the results of previous researches on experiences of carers facing HD<sup>2-10</sup>
  - Our study underlines that, even at the first stage of HD (some patients were almost at the maximum of the TFC scale), the experience of spousal caregivers is coloured by distress  $\rightarrow$ exacerbated by psychiatric symptoms <sup>4</sup>
- These results would have to be put in perspective with the results of studies focusing on the 2<sup>nd</sup> and 3<sup>rd</sup> phase of HD = to identify the specifities in the experience and the needs across the evolution of HD <sup>13</sup>

## Clinical perspectives:

- A systematic consideration of spousal carers' experience during medical appointments
- Offering help and respite as soon as possible after the first symptoms of HD
- Therapeutic Education for spouses: explaining the changes and symptoms of HD: better preparation for the daily life.
- **Development of interventions for spouses** based on Compassionate focused therapy 14 or **Emotionally Focused Therapy** 15

#### References

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