

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

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Background

Huntington's disease (HD):

- an autosomal dominant **inherited neurodegenerative disease**¹,
- causes motor (e.g., chorea), cognitive (e.g., attention deficits) and neuropsychiatric symptoms¹ (e.g., apathy)¹.
- deprives the ill person of autonomy, who progressively needs help for the daily life^{1,2}
- In most cases, this help is provided by the **spouse**²

Numerous challenges for the spouses:

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

- Some limits to these results:
- No distinction made between the different stages of HD
 - 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)¹¹
 - Living with the romantic partner for at least 5 years
 - Being able to communicate

Procedure:

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

Data analysis:

Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009)¹²

Results

The infernal spiral

It's hell on earth

- Invasion of the HD in the daily life (psychiatric symptoms)
- Emotional burden
- Being trapped in the relationship with the partner with HD who is not the same person as before

"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

- 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
- Feeling of isolation, loneliness and being abandoned by everyone

"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.

Abandoned to our fate

- 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 care

"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.

Need to know, but not too much

- Be the sole guarantor of the maintenance of stability in the daily life → refusing external help
- Pushing the limits of the care

"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.

Being the rock of the family

Discussion

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

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