



IMPACT ON THE GRANDPARENTS-GRANDCHILDREN RELATIONSHIP IN HUNTINGTON'S DISEASE



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EUROPEAN
HUNTINGTON'S
DISEASE
NETWORK

Introduction

Huntington's disease (HD) is a hereditary neurodegenerative disorder of the central nervous system.

It is transmitted from parents to children, producing emotional and structural changes in family life. It is categorized as a minority disease because of its low global prevalence. The positive or negative results of the genetic analysis suppose an impact on family dynamics, with the grandparents-grandchildren relationship being one of the subsystems affected by the risk or the reality of suffering the disease.

There are studies on the relationships between grandchildren and grandparents with a neurodegenerative disease, but few when it is the grandchild who has or is at risk of developing the condition. The relationship between grandparents and grandchildren hasn't been studied as much with HD.

This study is about how being at risk of developing or having symptoms of the disease affects the grandparent-grandchild subsystem.

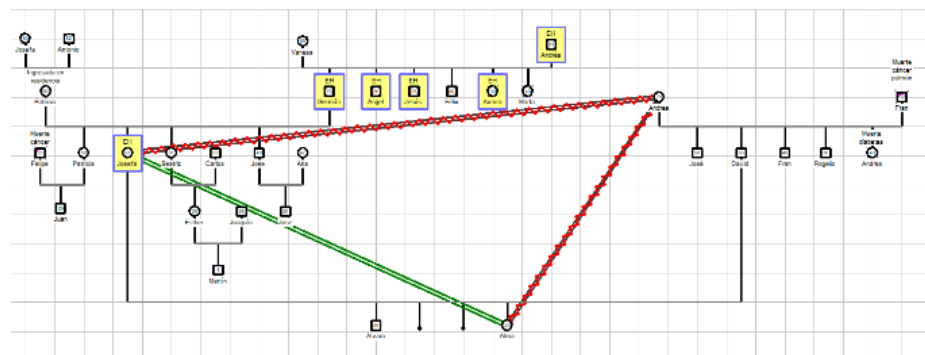
Methodology

A qualitative case study methodology was used. The work is based on Systemic Family Therapy, closely tied to the notion of the Family Life Cycle.

The double objective of the research presented in this study is: (1) To obtain an in-depth understanding of the emotional process of coping with being at risk of having HD or being symptomatic of the disease, as well as its effect on the relationship between grandparents and grandchildren, and (2) To explore the impact on grandparents of the risk or diagnosis of HD in their grandchildren.

Participants: Seven grandparents and seven grandchildren belonging to six families affected by HD participated in this study. They were identified by Castille and Leon Huntington's Chorea Association (Burgos-Spain) as being "suitable" candidates for the study. They comprise 6 integrated cases (one unit -person with HD- and several subunits - grandchildren- make up one case).

Instruments: Interviews and genograms were used as data collection instruments.



Data analysed: analysis of themed content, narratives, conversations and discourse.

Results

Five categories emerge for the grandparents and five for the grandchildren:

Results of interviews with the grandparents:

- They learned about HD in the family by observing associated behaviours in relatives.
- They reveal emotional distance between grandparents and grandchildren, and a lack of activities together.
- The grandparents' feelings about the fact that their grandchildren have or can develop HD are sadness, worry and upset, but concealed.
- The grandparents don't hold their sons/daughters-in-law responsible for having offspring and passing along the family disease. In 2 cases, they would have chosen not to have children in order to not pass HD on to their grandchildren.

Results of interviews with the grandchildren:

- They miss having more contact, more time together and more displays of affection.
- Some grandchildren relate emotional distance or cold relationships; others feel closer to the grandparents they do activities with.
- The current relationship between grandparents and grandchildren compared to 2 years ago improved in 2 cases, stayed distant in 1 and worsened in 1.
- The grandchildren's reactions to the chance of having HD go from not being affected and not thinking about it, to being aware and wanting to make the most of their time.

Conclusions

- Confirmation of the impact of HD on the grandparent-grandchildren subsystem in the family dynamic. Knowledge of the existence of HD influences relationships between grandparents and grandchildren, with emotional and behavioural changes like avoidance, denial, blame and inhibited sadness.
- Avoidance of open conversation about the presence of HD is observed. Grandparents and grandchildren avoid speaking directly about HD, and the lack of communication on this topic leads to affective distance in the relationship.
- Greater knowledge is needed about the specific coping strategies employed when faced with HD in the grandparents-grandchildren subsystem.

The limits of the study are related to the lack of studies on grandparents and grandchildren affected by the disease. The informants' point in the life cycle also affects the study. It would be interesting to study the ties between grandparents and grandchildren from the viewpoint of other family members.

References

Armas Junco, L., y Fernández-Hawrylak, M. (2021). Estudio cualitativo sobre el impacto en la relación abuelos-nietos ante la enfermedad de Huntington/A qualitative study on the impact on the grandparent-grandchildren relationship in Huntington's disease. Medicina de Familia-SEMERGEN. <https://doi.org/10.1016/j.semerg.2021.01.008>