

Huntington, the disease that transforms everything in its path: Narratives of family caregivers from the Colombian Caribbean coast

Huntington, la enfermedad que transforma todo a su paso: Narrativas de cuidadoras familiares de la costa Caribe colombiana

Elsy Cecilia Puello-Alcocer^a

 <http://orcid.org/0000-0003-0914-1857>
E-mail: epuello@correo.unicordoba.edu.co

Nydia Nina Valencia Jiménez^a

 <https://orcid.org/0000-0003-2414-2276>
E-mail: nnvalencia@correo.unicordoba.edu.co

Auri Cristina Quiceno Espitia^b

 <https://orcid.org/0000-0003-1663-8562>
E-mail: aquicenoespitia@gmail.com

^a Docentes Programa de Enfermería, Facultad de Ciencias de la Salud, Universidad de Córdoba. Córdoba, Colômbia.

^b Egresada del Programa de Enfermería. Integrante del Semillero de investigación Mostaza de la Facultad de Ciencias de la Salud. Universidad de Córdoba, Colombia.

Abstract

Qualitative study to explore the transformations experienced at an emotional, physical, and social level by family caregivers of patients with Huntington's disease on the Caribbean coast of Colombia. Participants were selected from the Factor H Foundation database, obtaining a theoretical saturation point with 10 life stories telling from the caregiver's voice, gathered between August 2020 and May 2021. The driving question was refined by a panel of experts and was used with the consent of the participants. The main category, "Huntington, the disease that transforms everything in its path," was divided into three subcategories: "Transforms my world," "Transforms my heart and soul," and "Transforms my body." These subcategories unveiled that caregivers are mostly women who experienced losses in different aspects of their lives: educational, social, work, affective with strong impacts on their physical and emotional health, and, therefore, in their daily life. It is concluded that Huntington's disease has adverse signals for the patient, their caregiver and the family; hence the need to focus collective efforts for its comprehensive approach.

Keywords: Caregivers; Huntington's disease; Personal narrative.

Correspondence

Nydia Nina Valencia Jiménez
Cra. 15 a No. 47-20. Montería, Córdoba, Colômbia. 230002430.

Resumen

Este estudio cualitativo pretende explorar las transformaciones experimentadas a nivel emocional, físico y social por cuidadoras familiares de pacientes con enfermedad de Huntington en la costa Caribe de Colombia. Las participantes se seleccionaron de la base de datos de la Fundación Factor H, lográndose un punto de saturación teórica con 10 historias de vida narradas desde la voz del cuidador y recolectadas entre agosto de 2020 y mayo de 2021. La guía de preguntas se refinó mediante panel de expertos y se empleó bajo el consentimiento de las participantes. La categoría central “Huntington, la enfermedad que transforma todo a su paso” se desagregó a partir de tres subcategorías: “Transforma mi mundo”, “Transforma mi corazón y mi alma” y “Transforma mi cuerpo”; a partir de las cuales se obtuvo que el cuidado es ejercido en su totalidad por mujeres, quienes experimentaron pérdidas en diferentes esferas: educativo, social, laboral, afectivo con fuertes impactos en su salud física, emocional y, por ende, en el cotidiano de la vida. Se concluye que la enfermedad de Huntington está permeada por señales adversas para el paciente, su cuidador y la familia; de ahí la necesidad de centrar esfuerzos colectivos para su abordaje integral.

Palabras-clave: Cuidadores; Enfermedad de Huntington; Narrativa personal.

Introduction

To explore Huntington’s disease (HD) is to enter a world of suffering, helplessness, resignation, and pain for patients, caregivers, and family members. Given this precept, two aspects mark the symbolization of this pathology: as part of a group of incapacitating, degenerative, cruel, and incurable diseases that gradually take away the tranquility, joy, being, living, and existing of the people who suffer from it and their caregivers. It is characterized by a triad of signs and symptoms: cognitive, motor, and behavioral, which pose a challenge to those who live it because of the transformative impact on their ways of existence (Migliore; Jankovic; Squitieri, 2019; Paz-Rodríguez; Chávez-Oliveros; Bernal-Pérez et al., 2021).

Huntington’s disease is an orphan, neurodegenerative, and chronic disease caused by an abnormal cytosine-adenine-guanine (CAG) repeat in the Huntingtin protein located on the short arm of chromosome 4p16.3. It has an autosomal dominant characteristic that makes descendants of the diseased person have a 50% chance of suffering from the disease (Santana et al., 2021); likewise, the repeats of this protein are considered normal between 6 to 26 triplets of (CAG), but it starts to develop from 36 repeats on (Roth, 2019). This pathology has different stages in which the patient suffers a progressive worsening that makes them dependent on family members and caregivers.

Caregivers of patients with Huntington’s disease face changes at the biopsychosocial level, due to the dedication and time spent caring for their diseased relative. They are forced to abandon their occupational, recreational, and cultural activities and even their emotional life. Thus, the daily life of these people becomes a circle of attention focused on their HD family member, leaving aside intentions, expectations or personal projects, such as the dedication and devotion to the patient that family caregivers suffer from caregiver overload syndrome. In this inexplicable context, the lack of knowledge by the caregiver and the surrounding community can be commonly identified as the enabling forces in the complications of this condition, which can be misinterpreted and

even stigmatized (Pino Melgarejo; Trejos Herrera; Orozco-Ospino, 2016; Castagna, 2020).

HD represents a before and after in the life of the patient-caregiver dyad, due to the diversity of events that begin to develop from the first signs and symptoms, especially when the genetic, neurodegenerative and chronic nature compromises the present and future of patients and their caregivers. Although the severity of signs and symptoms varies from one individual to another, the levels of need for help and support are always present; even from the onset of symptomatology, people with HD become dependent on their caregivers (SIERRM, 2020). Therefore, within families in which a case of Huntington's disease is diagnosed, new responsibilities and roles inevitably arise; roles that are assumed by a member of the family nucleus, that is when informal caregivers emerge when an illness occurs or when a family member needs attention and care.

In this regard, Valencia Jiménez, Puello Alcocer and Amador Ahumada (2020) point out that caregivers almost always start their work suddenly, unexpectedly (especially when it is the first case in the family), with denial, emotional pain and, most of them, surrounded by environments of poverty, few support networks, functional illiteracy related to little or no knowledge and management of the disease. In spite of that, responsibility, love, and the desire to help give way to different coping mechanisms in caregivers that provide them with resilience and the ability to adapt to all the transformations that accompany their role as caregivers.

All of the above constitutes the inputs to propose an investigation in one of the areas with the highest prevalence worldwide—the Colombian Caribbean coast—aiming to explore the life histories of HD caregivers residing in some municipalities of the departments of Magdalena and Atlántico (Colombia) to reveal the physical, psychological, and social transformations and to make known the problems experienced by these caregivers in their daily lives.

Methodology

This is a qualitative research with a biographical narrative approach, conducted between June 2020 and May 2021. It was developed in the personal and

day-to-day environment of the caregivers, thus allowing for an in-depth understanding of the social, physical, and affective aspects immersed in the participants' narratives that provided the researcher with the necessary tools to enter these experiences and interpret them.

Data collection was carried out through a semi-structured interview, assessed and refined by a panel of experts. Ten caregivers participated in the study, and were chosen through the convenience sampling technique and selected based on the following inclusion criteria: The person in charge of the HD patient must be a primary caregiver of legal age (18 years of age, as established in the Colombian Constitution); the caregiver should have been taking care of the HD for at least one year; the person in charge of the HD patient had to be a beneficiary of the Factor H Foundation (a non-profit organization that seeks to mitigate the suffering of individuals, families, and communities affected by Huntington's disease) and voluntarily grant consent to participate in the study. This last criterion was due to the fact that the institution provided the database to facilitate communication with and access to the participants.

Each interview lasted 45 to 60 minutes. Before asking the questions, the interviewer introduced himself, explained the purpose of the research to each caregiver, read the informed consent and waited for the respective approval. Interviews were recorded in MP3 format for subsequent reproduction and manual transcription, since the transcribers found were not intuitive and could at some point obviate, distort or fail to convey the information provided by the participants.

Data were recorded in transcription grids, which were then coded in an open and selective manner in order to generate categories and subcategories that would be construed along the study. The saturation point was determined with interview number 10 at the moment when the sufficiency of content was verified, which allowed answering the problem question of the macro study.

For the analysis of results, the guidelines of Bardin (2002) were taken into consideration in three stages: 1) Pre-analysis: in this stage, the narratives of caregivers adjusted to the central purpose of the study were chosen; subsequently, the baseline

document was designed considering completeness, representativeness, homogeneity and relevance. 2) Exploratory: this moment of the analytical process made it possible to organize the narratives with the support of coding operations and categorical system, allowing the transformation of primary data into units of registration and context. 3) Categorization and interpretation: it was proposed through the finding of pure “*a priori*” categorization procedures by means of categories established in the documentary review and the theoretical baselines. Once the life histories were transcribed, several comprehensive readings were made and the categorical attributes homogeneity, completeness, exclusivity, replicability, and relevance were pointed out. The coding matrix made the codes visible in vivo and the similarities and differences that gave rise to the subcategories were segmented by means of colors.

The baseline study for this article considered the ethical and legal aspects and principles that support the Research Committee of the *Facultad de Ciencias de la Salud* of the *Universidad de Córdoba*, Colombia (Code 2021-2A), and was classified as minimal risk for the participants. Researchers were informed about the need to have trained personnel available to provide support and to try to control the participants’ emotions if these emerged. Likewise, the research adhered to the regulations of Resolution No. 8430 of 1993 of the Ministry of Health and Social Protection in Colombia, which contains all the guidelines for research in health areas.

Results

Research participants were 10 informal caregivers of HD patients attached to the Factor H Foundation; eight with primary residence in the department of Magdalena and two in the department of Atlántico (both located on the Colombian Caribbean coast), distributed as follows: El Difícil (1); Santa Marta (2); Sabanas de San Ángel (3); Algarrobo (2). Regarding the department of Atlántico, caregivers from Juan De Acosta (2) participated.

The changes experienced by these caregivers were placed in the category “Huntington, the disease that transforms everything in its path,” which contains three subcategories “Transforms

my world,” “Transforms my heart and soul,” and “Transforms my body.” In the first subcategory, the diseased person is placed as the central axis of the caregiver’s life, causing the caregiver to put aside their personal development, autonomy, the processes inherent to the stages of their life, and their plans and projects; their expectations are reduced to the daily chores related to caring for their sick relative with HD, which is evident in the following comments:

Well... it changed me a lot because when he was healthy, I could work, for my children, for me and for the needs of the house, but at the time of his illness and as he got worse, my whole world changed, I could no longer go out to work, I could not leave the house, I could not do anything at all, I had to be at home, looking after him, take care of him and take care of him every day. (E2)

... I mean, for me it changed everything, absolutely everything. I didn’t have a childhood, I didn’t know what it was like to be a child, because I became the caregiver of my mother and practically of my sisters because they were small and I had to take care of them too, I had to leave school, I didn’t have time to go out to play or talk with my friends, I practically have no time for myself. All that was very hard, and it is still very, very hard, taking care of her and taking care of the housework... There are days when I wake up with no spirit, I don’t even want to think or do anything, but I keep going, I keep going, I keep taking care of them, fighting and giving everything for them, because I love them and because they need me. (E3)

...You can’t let go of this disease, even if you want to, I am always aware of it at all times, in all the situations I live, that it is not only my mother with the disease, it can also be my siblings, my cousins. So everything I do, I do it for my future, I do it thinking about the disease, what if I am the one who later gets sick or my brother gets sick, I know I am going to be their caregiver, because obviously, I am not going to leave them, I am not going to abandon them; I am always focused on

everything I am going to do in the future is for them, to be aware of them, I know that if someone gets sick I am the one who will take care of them, I am going to be responsible for their care? Or what if I am the one who gets sick? I am always talking to my brothers, telling us, if we get sick, we are going to support each other in this or that way, we are always going to be there for each other, we will not abandon each other and so... (E4)

The second subcategory, “Transforms my heart and soul,” describes the transformation suffered by the emotional and affective environment of caregivers, in which emotions that are very hard to face such as sadness, anguish, and pain, come to the surface. However, self-motivation processes also emerge driven by love and the desire to obtain the knowledge that will allow them to care adequately, because the only thing they want is for their relative to maintain a proper quality of life despite the circumstances, the place where they live, the apparent oblivion that the disease generates in their minds. Likewise, they perceive that their diseased relative is aware of who takes care of them and loves them until their last days, which can be observed in the following narratives:

...This disease destroys everything, it produces a lot of sadness, it hurts to see a loved one who was well and suddenly everything changes and gets worse every day, to see her with those strange movements, to know that nothing will be the same, to see that she can no longer fend for herself. My mother has moments of despair, restlessness, apathy, bad temper, it is not easy for her to feel good or to be happy. Living this situation is very difficult both for the patient and for those of us who care for them. It hurts my soul to see everything that is happening, to see and think about her suffering, it gives me a lot of sadness, depression, stress, it makes me anguish to think that I cannot cope with all the responsibility I have; the only thing that helps me to get the strength to continue caring for her is the love I feel for her. (E4)

...Well, what can I say, I don't know how to describe all the pain I carry inside, sometimes I cry a lot

because it makes me sad that nobody can do anything for her, that this disease has no cure, that is, to see her like this, it makes me very sad and depressed, to see that although I take care of her, I can no longer share with her, that she is there but at the same time it is as if she were not there, she is sitting without doing anything, without speaking, looking far away, lost. So... this disease took my mother away from me, this disease is very ugly. It is horrible that all this is happening to us. (E8)

...Before all this I had a normal life, but since I had to face this disease and become a caregiver, everything changed, what I used to do every day is left behind because in order to take care of the diseased person I had to make changes in my life; one has to change many things for their wellbeing, to try to make them well, even though inside I am devastated, full of pain, sadness, and depression because I know that I will never recover. (E6)

The third subcategory, “Transforms my body,” shows how the 10 study participants who have the role of caregiver suffer changes at the biopsychosocial level. Taking care of a diseased person involves drastic modifications, carrying along many health problems that affect the caregiver's quality of life.

Being a caregiver causes changes in the person. The first thing I got was pain in my neck, arms, and then in my whole body, I forgot things, sometimes I feel that I forget everything, I get desperate, I get very stressed, I get very tired, I would like to have help and support to recharge my energy, to be a little more rested, calmer to be able to continue caring for him and continue working as before to help with all the expenses of the house. (E2)

My day as a caregiver is active, it doesn't stop, many times it is stressful because I have to do everything and try to understand what the patient needs. They get anxious, they get tired, and just as the patient gets tired I also get tired as a caregiver and I get stressed, my head hurts, the back of my neck,

my body; so I think that, although we do things the best we can and with pleasure, it is not easy, it is hard work and yes...life changes a lot, there is a before and an after this disease. (E6)

Well, I used to live my life well, calmly, but since my mother's illness appeared, I am the one who takes care of her and that brings responsibilities and work. Although I do it with love, I get tired, I get exhausted, it makes me sad and anxious because taking care of her all the time is stressful, many times one reaches the limit, I feel burdened, I think I can't give any more and I don't know what to do. Sometimes I explode and cry because the truth is I don't even know what to do with her, even if I take care of her, she doesn't get better, that gives me a lot of powerlessness, anger, sadness, and pain. (E8)

Discussion

All participants in the study belong to the female sex and fulfill the role of mothers, daughters, and wives and are dedicated to household chores, thus installing the work of caregiver in the female gender, while the man is usually alien or absent from this type of tasks when the voluntary or forced assignment to women continues to obey the establishment of a private and domestic world, guarantor of the moral values and customs of a traditional society, with a tendency to sacralize the female role in health care. In this sense, authors such as Valencia Jiménez, Puello Alcocer and Amador Ahumada (2020) agree that caregiving roles have traditionally been assigned to women for various reasons: caregivers par excellence, innate abilities to assume decisions related to caregiving, and the adoption of multiplicity of functions with efficiency.

The role of women in the development of health and life is invaluable when they are bestowed with the obligation to sustain a precarious health system, unable to meet the care needs of the subjects demanding care (Massé García, 2017), and to look aside when it comes to caregivers. In this regard, it is worth mentioning the invisibility of an indispensable, active, and valuable work for the family and society, when numerous communities of informal family caregivers are still recorded

with little social recognition, lacking economic retribution and often undervalued, even by their own relatives (Misnaza Castrillón; Armenta Restrepo, 2017; Fernández Tijero, 2016).

The caregivers interviewed perceived the transformation of their world from the onset of the pathology in their lives. When everything began to revolve around the person with Huntington's, this coupled with their living conditions forced them to abandon their expectations regarding education, life projects, and their future in general. In this research, one of the greatest impacts disclosed was school dropout when it comes to caregivers who began their activity in childhood and adolescence; a similar condition was identified with Mexican minors for whom the exercise of caregiving excluded them from the educational system due to lack of time (Gutiérrez Robledo; Jácome Maldonado; González Rivero et al, 2021); and from this event, a life path begins with fewer opportunities to raise the socioeconomic level and contribute to the expected social change as necessary attributes to achieve the well-being of human beings (Venegas Álvarez; Chiluisa; Castro Bungacho et al., 2017).

Furthermore, women caregivers noticed changes at different spheres of their world, especially highlighting the impact on their work life when the illness of their family member forces them to displace their work role, condemning themselves to the exclusivity of caregiving. This feeling of not being able to be, do, feel, and live together is interwoven to create a network that deprives women of their sense of freedom, limiting their possibilities for development. In this light, education is connected to the expansion of opportunities and capabilities that drive the improvement of income, participation, and economic and social development as the basis for achieving well-being and happiness (Sen, 2000; Sen; Kliksberg, 2007).

Caregivers of Huntington's patients also perceive transformations in the emotional sphere when their feelings are permanently associated with pain, sadness, and hopelessness. It is a state of being in which the subject loses autonomy and the management of their own life, feeling the same or even worse than the patient, because they are condemned by their body to be and coexist in an

unwanted world, and long for those realities that were once part of their life (Varela Londoño, 2020). Caregivers, however, live in a kind of prison with invisible bars, having the possibility of going to the outside world and at the same time not being able to do so because of the commitment or the emotional burden that this type of care denotes.

The feelings of the caregivers interviewed are installed in a place where caring for a relative with Huntington's disease hurts in different ways: as part of a sentence of the whole family facing the uncertainty of who will be the next one; because of the losses in different spheres of life; and for caring under a curtain of lost looks into a horizon without return, under the certainty that the body of the relative, their feelings and values are there, but these are overshadowed by a set of signs and symptoms of a rare disease that roams around the house waiting for the opportunity to counterattack them again. These findings are similar to those of Ahmad et al. (2018), who identified how caregivers suffer emotional burdens especially characterized by feelings of stress, sadness, and helplessness when observing no improvement, as well as fear of the future, forgetful memory, impaired concentration, mental exhaustion, anxiety, hopelessness associated with the disease, and the stress of knowing that other family members may develop it.

Consistent with the social and emotional changes, caregivers also expressed impacts on their body with the appearance of localized pain in the back, neck, arms, hence the exercise of caring for people with HD for prolonged periods of time causes efforts and overload that affect physical health. These findings are consistent with those of Fernandes dos Santos (2018) for whom fatigue and limited opportunities for leisure constitute the grounds of physical and mental exhaustion of caregivers; as well as that made visible by Ahmad et al. (2018) and Misnaza Castrillón and Armenta Restrepo (2017), whose care demands become stronger as the disease progresses and produces strong impacts on the physical and psychological environment of caregivers.

This web of circumstances, overloads, social, emotional, and bodily changes reveals the need for co-responsibility of care on the part of the State and the Health Care Provider Entities (*Entidades*

Prestadoras de Salud, EPS), especially due to the impact of HD on the patient, their caregiver, and the family. Given this, voices are heard pointing out the lack of solidarity for the mitigation of suffering and daily needs faced by these families (Varela-Londoño; Giraldo Mora; Arias Valencia, 2020), and the scarce governmental support due to the lack of specific social protection programs aimed at the main caregiver as a subject of care that deserves psychosocial interventions tending to minimize the overload of the main caregiver (Ahmad et al., 2018).

In Colombia, there are some organizations that support and accompany families in the process of improving the understanding of the disease, as well as guiding them in the institutional care paths, helping them to overcome their fears and difficulties, improving their nutrition, conducting clinical studies, creating conditions conducive to empowering them in care, and generally reducing the suffering of families affected by HD living in conditions of poverty. These include the Factor H Foundation, the Neurosciences Group of the Universidad de Antioquia, and the Vulnerable Communities of Colombia Foundation.

Despite the presence of these organizations, their efforts do not fully meet the needs of a HD patient and their caregivers (Varela Londoño, 2020). Therefore, state presence is urged to manage the biopsychosocial impact of the family caregiver, because this would be easier to cope with if caregivers had constant genetic counseling that avoids the continuity of cases and high prevalence levels in some Latin American regions (Santana et al., 2021). Likewise, they could develop skills and abilities toward a greater understanding of the problems and have those conditions to increase self-care, decrease physical and mental overload, and improve as much as possible their quality of life, which is affected in many dimensions.

Conclusion

The life stories of the caregivers of Huntington's disease patients on the Colombian Caribbean coast follow a path installed in a category whose symbolism is expressed as Huntington's, the disease that

transforms everything in its path. The world as that scenario, in which the episodes of life take place, is no longer the same for any member of the family, because the care of this type of pathology is not assessed by age, expectations or dreams, but by the demand for care usually prolonged and overwhelming.

The girl or woman of these families that carry Huntington's disease in their genes become caregivers without choice, driven only by love and commitment to that loved one who cries out for care. These girls and women are excluded from the educational, labor, social, and even affective system, usually carrying out their life alone, without the support of a partner who can commit to live imprisoned in a painful and permanent life situation.

Emotional changes expressed in fears, depression, sadness, and desolation become a rosary of manifestations that guide the daily life of the caregiver, who needs biopsychosocial interventions and social protection by the State. Healthcare for the patient with Huntington's disease or the support offered by non-profit organizations is not enough, because the caregiver is also a parallel patient with specific emotional care demands that require the support of an entire social, state, private, and humanitarian network.

The expressions of physical pain installed in the body of the caregiver are a call to public policies of the Latin American nations with the highest prevalence of this problem, such as Venezuela, Brazil, and Colombia, to join research, economic and citizen awareness efforts to comprehensively address the demands of this population, and contribute with the necessary actions to find treatments to mitigate the physical, emotional, and social burden derived from orphan diseases such as Huntington's.

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Authors' Contribution

Puello Alcocer: data review and interpretation, critical revision, and approval of the version for publication. Valencia Jiménez: data conception, outlining or review, and critical revision of the article. Quiceno Espitia: data conception, outlining or review, and drafting of the article.

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