THE SOCIAL CONSTRUCTION OF HUNTINGTON'S DISEASE CAREGIVERS IN COLOMBIA, SOUTH AMERICA

Clara Giraldo, B.A., M.S.

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APPROVED:

Erma J Lawson. Major Professor
David Williamson, Minor Professor and Chair of the Department of Sociology
Dale Yeatts, Committee Member
Ami Moore, Committee Member
Sally Stabb, Committee Member
David Hartman, Dean of the College of Public Affairs and Community Service
Sandra L. Terrell, Dean of the Robert B. Toulouse School of Graduate Studies
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This study is a multi-method, two-city, intensive, in-depth qualitative study of Huntington’s disease (HD) caregivers (HDCs) in Colombia. I explored the Colombia HDCs’ experience through the Hispanic culture of caring. I develop the theory of the subrogate agency based on 5 functional stages of HD from Shoulson and Fanh (1979).

This study was conducted in two different regions of Colombia, Medellin and Juan de Acosta, in which high rates of HD cases have been identified. The data were collected through three methods: (a) 56 interviews with HDCs and 8 with physicians; (b) 28 participant observations of Huntington’s disease sufferers (HDSs); (c) 4 interviews and 8 focus groups of 6 members each with HDCs of late HDSs.

Human agency is the ability to monitor one’s own action. This study showed that the gradual and serious loss of all capabilities in HDSs has a social effect on the HDSs’ agency. HDSs’ survival depends on the subrogation that the HDC offers to the HDS. The HDS retains self-hood, i.e. agency, through the HDC’s action. This subrogation causes a paradoxical consequence, resulting in both negative and positive effects on the caregiver.

The theory of surrogate agency is supported by the data. Through the progressive phases, the capacity of the sufferer for expressing suffering, and social embarrassment, as well as the capacity to fight against the illness and provide reciprocity to their caregivers, deceases. The reason is that physical and cognitive impairments, as well as depression and anger, continue to increase.

The study also documented important socio-cultural differences among the study regions. For instance, HDC’s solidarity was based on blood and friendship; in larger cities, HD fragmented families. The study also found that HD is taking an immense toll on caregivers, sufferers and families because they are excluded from the Colombia’s Basic Health Plan.
ACKNOWLEDGMENTS

In memory of my mother Carmen and my sister Lucia through whom my ideas on subrogate agency were crystallized. I also thank to those who support me with love and encouragement

My admiration for all participants of my study, those who are my relatives and those who became my friends. I hope that this study may help to change their destiny and those future generations with Huntington's disease (HD). In acknowledgment of both HD sufferers and caregivers whose lives are examples of human tenacity.

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CHAPTER 1
INTRODUCTION

Background

This research is a qualitative case study of two Colombian communities to examine home caregiving of Huntington’s disease sufferers (HDSs). One city, Juan de Acosta is an agricultural town and the other, Medellin is, an urban city. The research focuses on a special type of care in Colombia, home care. This type of care is informal since it is performed by relatives who are also at risk for HD, and by non-trained caregivers. Qualitative research included in-depth interviews and focus groups of caregivers, field observation of HDSs, and interviews with physicians to explore Huntington’s disease caregivers (HDC).

The view underlying this research is that to understand caregiving, one must understand it from the caregivers’ point of view. Thus, it is necessary to take the role of those whose behaviors are being examined. Behind the rates, correlations, and presumed causes of behavior are real human sufferers of HD and their caregivers who try to make sense of their lives.

The Definition of Huntington’s Disease

Huntington’s disease (HD) is an inherited neurological disorder which used to be known as HD chorea (Harper, 2002). It is characterized by a progressive neurological deterioration of cognitive processes. The abnormal neurological movements include uncontrolled, irregular, rapid, jerky movements of the hands, feet, face and trunk (Kremer, 2002). A major feature of HD is dementia, which includes confusion,
personality disintegration, impairment of memory, diminished control, and restlessness, as well as agitation. Therefore, caregiving to HDSSs is stressful.

Families with the disease have frequently cared for more than one member and consequently, nearly every member of a family has been a HD caregiver (Pollard et al., 1999). Caregivers of HDSs cope with the idea that one day they may need the same care. A distinguishing factor of HDC is the knowledge that they might develop HD themselves, and as a result, they often contemplate the future while caring for a sister, brother, or mother with HD (Pollard et al., 1999).

George Huntington in 1872 published the first medical description of the disease. He reported that it was a hereditary disease. According to Harper, (2002), the Guthrie and Wexler families increased the awareness of the disease. Marjorie Guthrie, widow of singer, songwriter and HDS Woody Guthrie raised funds for research. In 1968, The Wexler family set up the Hereditary Disease Foundation which performed a large study in Venezuela that made it possible to locate the HD gene (Harper, 2002).

**Physiology of HD**

Individuals with HD possess an abnormal repeat of the triple CAG\(^1\). The genetic defect for HD is chromosome 4. Harper of the University of Wales notes that HD is a large gene that is active throughout the body and produces a new protein. In HD patients, a change occurs at one end of the gene (Harper, 2002; Leffler et al., 2005). Kremer (2002) reports that HD has been documented in individuals as young as 2 years and as old as 80. The age of onset tends to decrease in the following generation, with each generation experiencing an earlier onset of HD. The average age of onset of

---

\(^1\) Gene contains many repeats of base triple CAG (cytosine, adenine, and guanine); normal persons have 11-34 copies; affected persons have 42-120 or more copies.
HD is 40 years in males and 39.8 in females. The onset is earlier if the gene is received from the father rather than from the mother (Foroud et al., 1999).

Studies have reported that the aggregation of neurons is responsible for the neuronal damage in HD (Wanker & Anja, 2002). The damage is in certain cortical and subcortical areas, and in the basal ganglia in the brain. Necrology studies have reported atrophy of the spinal cord, brainstem, cerebellum, and cerebral hemispheres (Gutekunst et al., 2002; Leffler et al., 2005). See figure 2 in Appendix A p.209).

**Genetic Testing and HD**

The discovery of the gene made possible a test for the presence of HD. It is definitive, and can be administered to fetus. However, mental health professionals have voiced concern about the adverse effects of genetic testing for those without symptoms (Almqvist et al., 1999; Brouwerdudokde Wit et al., 2002; Brown University, 1999; Cox, 2003; Pakenham, et al., 2002; Tibben, 2002). Sociologists also question the discriminative social practices that can occur due to genetic testing. In fact, Bird (1999) reports the risk of suicide in sufferers who undergo genetic testing for the disease. HDSs are 5.7 times more likely to commit suicide than non-sufferers (Bird 1999.) Paulsen (2005) reports a suicide rate of 7 to 12 times higher than those from the normal population (Paulsen, 2005). As result, researchers are concerned that pre-symptomatic DNA testing can result in devastating effects instead of enhancing the quality of life (Bird, 1999; Paulsen 1999; Wexler 1993).

Some sociologists also report concern that genetic testing may result in numerous societal discriminative practices (Silvers et al.; 2003; Somek, 2003). For instance, Novas & Rose (2000), document the fact that employers often use genetic
testing as a basis to exclude individuals from health insurance due to pre-existing conditions. Moreover, it is a strain on families who receive positive results, and who must then decide whether to have children.

Tortell (1994) also opposes pre-symptomatic HD testing since little knowledge exists about the psychosocial implications of positive testing results. Often people believe, “What’s the point in facing the fact that there’s HD in the family when there is no cure? I’ll do something about it when there is a cure” (Tortell, 1994 p. 29).

Indeed, receiving a positive pre-symptomatic HD test can catapult individuals into a crisis. For instance, an ordinary healthy adult may become transformed into a person anticipating an unbearable experience, characterized by inflexibility, aggressiveness, and often inappropriate social behavior. Currently, genetic testing is unavailable in Colombia except for those families who participate in the HD program at the Neurosciences Institute (Lopera, 2004). Blood samples are sent overseas for testing and the Institute of Neurosciences discloses positive results only to those individuals who already show HD symptoms.

_Prognosis of HD_

Currently, there is no cure for HD. It is fatal. HDSs may live from 10 to 25 years following the onset of symptoms. Life-threatening complications may result from pneumonia or other infections as well as from injuries and falls (HDAS, 2001).

_HD and Caregiving_

HD is also devastating for caregivers for many reasons:
(1) It is a progressive degenerative brain disorder that affects individuals in the prime of life. (2) It is a socially embarrassing and disabling disorder. Consequently, a caregiver
may be stigmatized by dealing with the social reactions to the ugliness of the illness, the rejection of the uncontrolled behavior of the sufferer and the suspicion that he may be the next person in the family to be affected by the disease. (3) There is no known cure or effective treatment for HDSs, which increases the anxiety of caregivers. HDSs require assistance with activities of daily living and instrumental activities, and since there is a progressive loss of intellectual, motor, and social abilities, they required long-term-care (Krane et al., 1987).

The stress of caring for HDSs is demonstrated by several high profile mass-media cases. In 2002, Carol Carr cared for her mother-in-law, husband and two adult sons who all had HD. She killed both of her sons, stating that she wanted to stop their misery. A Georgia court charged her with mercy killing instead of homicide. In 1985, a similar case occurred to Glenda Caldwell, who was at risk of developing the disease. She killed her 19-year-old son and attempted to kill her 18-year-old daughter Susan, who testified against her mother, resulting in a sentence of life in prison. While in prison Glenda developed HD. After Susan Caldwell herself developed the disease, she said that it “took her more than 17 years to understand her mother's suffering” (Rimer, 2002).

HD is a hereditary disease that never skips a generation. Each child of an affected parent has a 50% chance of inheriting the disease. According to Pollard et al. (1999), if someone who has the gene lives long enough, he will manifest symptoms. Until recently, because families have considered HD as a socially unacceptable and embarrassing disease, they have often remained secretive about the disease to the public and even to other family members (Wexler, 1996; Gray, 1995).
Additionally, there is a juvenile form of the disease which is more aggressive than that which strikes adults (Pollard et al., 1999), and which poses numerous challenges to family caregivers. One researcher describes HD as the most terrifying disease on the face of the earth because its victims are doomed to absolute dementia as terrible as Alzheimer's disease (Gray, 1995).

The Disease Experience

Investigating the clinical phases of HD can be helpful in exploring the caregiving experience. These phases overlap; they are not discrete stages. HDSs go through the phases at different rates of speed, and therefore, periods overlap.

Phase 1 is a period from onset to 8 years. The symptoms vary among individuals. In the early phases, sufferers typically suffer depression because they are aware of their condition. They understand their impending physical and mental decline leading to dependence on others and the unavoidable loss of their future. Depression is also related to knowledge of the prior deterioration of other relatives (Paulsen, 1999; Pollard et al., 1999).

According to Paulsen (1999), phase 2 is from 3 to 13 years from onset. In this intermediate stage, HDSs are irritable and angry. They are likely to attempt suicide as they struggle to maintain control over the loss of their ability to manage everyday life. For instance, they often struggle to participate in daily activities, such as managing finances. They are often unable to make simple decision, such as selecting a flavor of ice cream. HDSs are aware of the loss of physical control, which is similar to muscular dystrophy, and a wasting of the body as in the very worst of cancers.
Phase 3 is from 5 to 16 years following onset of HD symptoms. Movement and speech are severely affected. HDSs cannot control the volume of their speech and experience difficulty in coordinating breath and speech simultaneously. Their speech, involves grunts and meaningless sounds, which creates frustration since it is difficult to understand. Because of the cognitive impairment, the content of the speech, the word order, sequence, and capacity for conversation is greatly diminished (Paulsen, 1999; Pollard et al., 1999). The ability to start a conversation, to synthesize information, and to focus on a topic is lost. Such conditions create serious impairment which often results in loss of employment as well as the inability to care for oneself (Paulsen, 1999).

Phase 4 may last from 8 to 21 years from onset of symptoms. Phase 4 is a more disabling phase than the earlier ones. According to Pollard et al., (1999), behavioral changes at this phase are often misinterpreted by caregivers as lack of motivation and laziness, rather than as symptoms of the disease. The most important emotional change is the increased depression, which includes irritability, agitation and disinhibition (Paulsen, 1999).

The physical changes in phase 4 are dramatic. For instance, patients appear drunk because small movements extend from fingers and eyes to major muscles. Often, HDSs stop speaking. Their speech becomes unintelligible and they often express emotions and needs through a few simple words and sounds. When they are no longer understood, many lose their sense of control (Pollard et al, 1999). In this stage, HDSs communicate with caregivers through facial expressions, eye movements, and subtle actions understood only by those close to them (Pollard et al., 1999). The inability to relate to others as well as the cognitive deterioration results in HDSs becoming
inflexible. They often insist on adhering to routines pattern and appear unwilling to adapt to altered situations. Often, HDSs demand objects, food, etc. immediately and often fail to realize the repercussions of their own actions. According to Snowden, (1996) “HDSs may no longer experience feelings of embarrassment, guilt, or shame which under normal situations constrain behavior” (Snowden, 1996, p. 5).

According to Snowden (1996), HDSs are not deliberately obstinate. The brain changes that occur impair their ability to behave flexibly and to adapt to new surroundings. As a result, their caregivers need to impose routine and structure to enhance HDSs’ comfort level.

Phase 5 extends from 11 to 26 years following the onset of symptoms. In the last phase, HDSs require padded side rails to avoid bruises and to protect them from uncontrolled movements. They develop problems which require a special diet and often assistance is required to eat, bathe, and dress. They cannot control their bodies; they cannot maintain an upright position and require the use of a wheelchair (Pollard et al., 1999).

Some sufferers of HD develop Parkinsonism, although these symptoms are not responsive to anti-Parkinsonism medications. Such issues present enormous difficulties for caregivers of HDSs. HD is a disabling condition which damages selective portions of the brain, resulting in specific problems in thinking and behavior. Therefore, HD represents a great challenge for caregivers (Craufurd, & Snowden, 2002).
Significance of the Study

HD caregivers live a paradox; while caring for a HD family member they also may carry the gene. This research is extremely significant since to my knowledge there are no published studies that have explored the multi-dimensions of home caregiving to Colombian HDSs who might be at risk for the disease. The study is also important because it explores caregiving in a culture where there is little research in the sociology of caregiving of HDSs. Overall, this study explores the social construction of caring in a Hispanic culture where family is the main source of support for those who might be at risk for HD.

This study is extremely significant. First, this is a highly incapacitating disease that alters daily family interaction. Second, while in advanced countries, most of the advanced HDSs are placed in nursing institutions; Latin-American families must cope with the disease at home. Third, the rate of HD in Juan de Acosta (JDA) is approximately 500 people per 100,000 while in the United States, the rate is 10 person per 100,000 (Huntington’s Disease Society of America, 2005). Furthermore, HD is an illness that strikes Western European descendants, among whom the rate is 3 to 7 people per 100,000 population (Haigh et al., 2005). Wexler has reported a higher prevalence rate in Venezuela with around 5,000 people per 100,000 (Harper, 2001). Finally, added to this unusually high rate of incidence in JDA, the study focuses on 2 particular communities of HDSs and their caregivers in two different settings because these places represent geographically and culturally two completely contrasting settings.
**Research Sites**

This study occurs in the two sites of Juan de Acosta and Medellin. These sites represent Ferdinand Tonnies's (1887) models of gemeinschaft and gesellshaft. A detailed discussion of Tonnies will be included in the final chapter detailed. Juan de Acosta represents the organic life as described by Tonnies. It is an agricultural town without social diversification. Most of the residents are dedicated to rural activities. The average income is low and is more evenly distributed than in Medellin. According to the Project for the First Conference for Colombian’s Huntington Families (2004), Juan de Acosta is known as the “Most Spanish town of Colombia” (FUNPEHJUA, 2004). The residents are proud of their Spanish ancestry because the population has not mixed with other races in the same proportion as has occurred in other cities in Colombia, and their phenotypes and surnames still resemble those in Spain. They are highly religious and rely on their faith for coping with HD, according to the project for the first Conference for Colombian’s Huntington Families, 2004. Families often live in Juan de Acosta from birth to death (FUNPEHJUA, 2004).

On the other hand, Medellin is a complex society with population diversity and social inequalities. In Medellin, there are technological and scientific resources for those who can afford them. Medellin is a competitive society in which everyone strives for upward mobility. As a result, solidarity is limited to specific family circles. In Medellin, traditional values are challenged and the pace of life is faster than in Juan de Acosta.

**Medellin Social Situation**

Medellin has 105 km$^2$ of urban area and 270 km$^2$ of rural areas. Medellin’s most important demographic tendency is toward expansion. (Alcaldia de Medellin, 2005).
Medellin’s birth rate is 16 per 1000, and the rate of growing is 11 per 1000. In 2003, overall life expectancy was 67 years, with women’s life expectancy (72) being ten years more than men’s (62) (Alcaldia de Medellin, 2005).

A world-wide quality of life survey conducted every year by Mercer Human Resource Consulting from London measures overall quality of life based on ranking evaluations of 39 criteria. These criteria are very comprehensive. They include political and social environment, economic environment, socio-cultural environment, medical and health considerations, schools and education, public services and transportation, recreation, consumer goods, housing and natural environment. By assessing only conditions of personal safety and security, Colombia’s major metropolis score was lower than any other Latin American capital; furthermore, Medellin was ranked 205th and Bogota 210th, only 5 positions above Baghdad. The report states that Colombian’s major capitals have some of the highest indices of crime, kidnapping and homicide in the world. It also found a growing unemployment and political instability (Mercer Human Resources Consultants, 2005). As a result, the safety of HDSs is a major factor that influences caregiving in Medellin.

Gaviria (2005) states that Medellin has dealt with the obnoxious realities brought about by centuries of severe social inequality and the disproportionate distribution of wealth. The imbalance has significantly contributed to the level of violence and degree of hopelessness, which increases the stress of caregiving (Gaviria, 2005). Caregivers often experience suffering in three ways: They cope with the danger of the family being crime victims, being at risk for the disease, and caring for a HD family member.
Moreover, the social disarray affects the mental health of a population which experiences daily threats to physical safety.

*Juan De Acosta Social Situation*

Population is 14,500, 53% in the urban area and 47% in the rural area. The number of dwellings is 2,500, six percent sub-standard; overcrowding rate is 11.1%, population in economic dependency 14%; population in high poverty 11%, illiteracy rate 16%; population with access to running water 70% (Gobernación del Atlántico, 2000).

Men outnumber women, comprising 53% of the population. Indeed, it is estimated that in the next 20 years the population will grow about 48% or more (Diagnosis Municipality of Juan de Acosta, 2000). Around 50% of the population is in an economically productive age, which is considered to range from 15 to 65 years. The rural area is an important base of the economy in this municipality, primary economic activities being agriculture (49%) and cattle raising (20%). Approximately 50% of the population work in rural activities (Diagnostico de la Municipalidad de Juan de Acosta, 2000).

Educational facilities are largely absent. In public education, there are 8 daycare centers and primary schools, 2 high schools and 1 center for vocational education. Total school enrollment is 3,400 students. The teachers are often unqualified and they, like the students who live outside of the town, have problems getting to school (Diagnosis Municipality of Juan de Acosta, 2000). The lack of adequate and comprehensive transportation and a failing health care system creates a difficult situation for caregivers of HD sufferers.
According to Colombia’s government studies, Juan de Acosta lacks industry and commercial establishments that can provide health benefits to its population. This means that most of the population meets the criteria to be served in the subsidized health care system, creating an overload upon the health services. The health service available in JDA is very basic. The health center has only 6 general physicians and 4 nurses for serving the whole population. The center has 11 beds, 6 stretchers, and 1 ambulance for serving people in the rural area. In the rural area the health service is insufficient, lacking both facilities and personnel. Health demands are higher than the capacity of service in the hospital, and those who require transportation in emergency cases will not obtain it promptly because of the considerable distance to a hospital (Diagnostico de la Municipalidad de Juan de Acosta, 2000). Therefore, HDSs in Juan de Acosta sometimes die due to the lack of transportation to medical care facilities.

Statement of the Problem

Previous studies have used quantitative methods to investigate caregiving. Such studies have overemphasized the negative effects of caregiving and have often failed to measure the positive experiences of caregiving considering various social cultural and contexts. This study explores the way in which values and beliefs of the Hispanic culture are embedded in the social construction of caregiving. Using a multi-site qualitative research method, it investigates the way in which caregivers and HDSs develop a connective relationship, thus generating knowledge about the disease as well as the sufferers, and extending beyond the clinical description of the disease.
The concept of human agency underscores this research. Unlike previous studies, it emphasizes the fact that caregiving is an active response to the demands of illness. Specifically, this study investigates whether the caregivers and HDSs experience phases in which there is a change in the type of care as well as in the sufferer’s condition, requiring changes in the way of looking after the sufferer. HDSs confront the most extreme and overarching form of agency loss. Their present state of being bears little resemble to that of their lost identity. Therefore, an HDS requires a surrogate agency from caregivers, in which a human dialectic occurs. The deterioration in the HDSs results in an increase in caregiving activities.

This research focuses on the following questions of HD caregivers, which test the author’s theory of caregiving:

1. What types of caregivers exist in Colombia; is caregiving burdensome, and are women better caregivers than men?
2. Can the relationship between sufferer and caregiver be described as an agency relationship? (As described in the theoretical model).
3. What are the differences in caregiving between Juan de Costa and Medellin?
4. What are the perceptions of HD from the perspective of physicians?
5. How does the Latin culture of reciprocity among family members influence the caregiving experience?
6. What is the impact of HD on the function and roles of family members?
7. What is the social stigma of HD caregivers and patients?

The purpose of this research is to explore family informal caregiving of HDSs in two cities in Colombia. Using the concept of agency, the study investigates the way in
which the clinical phases of the disease influence HD sufferers’ and caregivers’ personal agency. As a result, a new theoretical model is developed to explain the psycho-social issues linked to the stages of the disease.

The Importance of Caregiving Studies in Colombia

Since 1960, Latin America (LA) has experienced an important development in the field of social medicine (LASM) in both methodology and theory that have impacted Latin American micro-and macro-politics in the health field. Most of the theoretical production is unknown among American medical sociologists (Iriart et al., 2002). LASM has studied ways to improve the health indicators of the population and the workers’ welfare. LASM has also been interested in studying the coexistence of a double epidemiological profile with tropical disease and chronic diseases.

Marx’s main categories of social reproduction and production have also been used for describing health conditions in LASM such as the effect of working conditions upon mental and physical health (Iriart et al., 2002). LASM has also criticized the effect of imperialism and macroeconomic politics, such as managed medicine upon the access to health. Inequities as causes of mortalities and the effect of social movement on social politics on health are also studied in LA. An important branch of social medicine has studied the mental and physical effects of torture, repression and violence (Iriart et al., 2002). Nevertheless, caregiving studies from a social medical perspective have been few. De la Cuesta (2003) studied family caregiving of individuals with advanced dementia. She concludes that in Colombia the proportion of informal caregivers who care for people with dementia may be higher than 20%, for the reason
that in the cultural context, caregiving is assumed as a family responsibility rather than a state responsibility. She also reports that there have been very few studies performed in this area in Latin America, but that based on caregiving studies from Europe and the United States, the future will show an increase in the number of people who receive care at home in LA (De la Cuesta, 2003).

Significantly, studies on caregiving in Colombia have often failed to focus on HD, an illness more burdensome to caregivers than other types of neuro-degenerative diseases. The economic, social and emotional burden upon the caregivers is ignored and assumed as family responsibility. There are no resources such as a HD society or organized support groups for these families. For all these reasons, HD families and caregivers desperately need the attention of the state, and support for those affected by HD.

This study has important political, sociological, and theoretical implications. First, to my knowledge, this is the first study to explore the psycho-social aspect of HD. Most studies have focused on the physiological aspects of the disease with quantitative methods. Second, through the exploration of HD, researchers might also explore the psychosocial dimensions of other diseases in Colombia. Third, the integration of multi-qualitative methods allows for a broader exploration of HD caregivers. Such information might form the basis for health-enhancing activities targeted to caregivers in Latin America, which could be extended to caregivers of various diseases such as Alzheimer’s and cancer. Finally, I hope that this study will increase the awareness of HDs and their female caregivers, who routinely experience unbearable situations.
Many of the HD caregivers receive low compensation because caregiving is undervalued by society.

If sociology is action, sociologists cannot be indifferent to social problems such as caregiving problems in Colombia. Sociologists have important roles in changing the status of caregivers and patients in Colombia. Creating the conditions for including HD as part of the basic plan of health seems the most urgent need in terms of policy implications.

The study is divided into the following chapters: Chapter 2 reviews the literature on caregiving and discusses caregiving in Colombia. Chapter 3 reviews the following theories to explain caring behavior among Hispanics: reciprocity theory, feminist theory, and Gidden's concept of agency, as well as the author's theory. Chapter 4 discusses the methods employed. Chapter 5 describes the respondents' profiles, Chapter 6 presents the results of the study. Chapter 7 discusses socio-cultural aspects of HD care in Colombia and finally, Chapter 8 presents the conclusions.
CHAPTER 2
REVIEW OF THE LITERATURE

This literature review begins with statistics on informal caregiving at home and caregiving for long-term-care people in the United States. It also reviews the most relevant literature on Huntington’s disease (HD). The review includes studies on caregiving burden among Hispanics and reviews values and beliefs about caregiving. The review also includes studies on Hispanic caregivers for Alzheimer’s sufferers, the influence of religious beliefs in the support of elders and disabled family members that can hold true for Huntington’s disease sufferers (HDSs) in Colombia. It also reviews religiosity as an important in dementia caregiving that also applies to Huntington’s disease caregiving (HDC).

Caregivers Statistics

HD is considered a long-term-care impairment in which the sufferers steadily lose their capacity to carry out activities of daily life (ADLs) and instrumental activities of daily life (IADLs)\(^2\) encompassing personal care, feeding, and household chores. Although it is assumed that people with disabilities are cared for by institutions, in reality, communities and families care for a large proportion of them (Moroney et al., 1998).

In the United States, 52 million relatives and friends provide care for disabled people, and approximately 26 million provide personal assistance and care to adults with disabilities (Family Caregiving Alliance, 2005). In the US, data from the National

\(^2\) This is a standard classification used for describing tasks of self-maintenance and activities for maintaining a home. The first are known as activities of daily life (ADLs) and the second are classified as instrumental activities of daily life (IADLs).
Family Caregivers Association (NFCA) show that in 1999, 26.5% of the adult population provided care to dependents and 32.5% will become caregivers in the future (Mintz, 1999).

The General Household Survey in 1985 shows that in Great Britain there were 6 million caregivers, 3.5 million women and 2.5 million men. The same data showed that 1.3 million were involved with the most personalized forms of care, being responsible for the dependent’s personal hygiene and grooming habits (Nolan et al., 1996).

The typical caregivers are married women, aged 46, who care for aging parents living nearby. Caregiving also varies among ethnic groups. For instance, middle-aged Asian Americans provide more care to parents than any other ethnic group (42%), and non-American “baby boomers” provide two times more caregiving (43%) than do the American boomers (FCA, 2005).

Caregivers spend at least 18 hours a week caring for their parents, and at least 55% of the caregivers provide an intensive level of care, providing assistance in all the ADLs (Mintz, 1999). These data are consistent with other sources. Abel & Nelson report that women dominate in all caregiving occupations (formal and informal care), 70% of caregivers to the elderly being wives and daughters of the sufferers (Abel & Nelson 1990; Family Caregiver Alliance, 2005).

However, Kramer (2002) reports that 30% of all caregivers are men, and for her, this is a substantial number of providers that deserve closer scientific scrutiny. Indeed, she finds that in some contexts, men provide more care than women; for instance, in the US, 41% to 53% of the primary caregivers of AIDS patients are young men. Most of the men who provide intensive care are husbands (70%) who help wives with personal
care and hygiene (Kramer, 2002). Thus, it is important to avoid stereotyping men as caregivers.

Long Term Care and Caregiving

Long term care (LTC) has increased in the US. Approximately 12.1 million Americans need long-term care. Although 56% of these people are older than 65, there is also an important percentage of people with LTC impairments (44%) who are of working age. Thirty percent of the LTC population has 3 or more limitations for performing their ADL. Forty percent of them have an income 150% below the poverty level. In only 10 years, from 1984 to 1994, the number of people suffering disability and cognitive impairment rose from 35% to 43%.

There are 5 million informal caregivers who care for dementia patients aged 50 or more. Approximately 80% of these are family members who provide LTC to the elderly at home (Abel & Nelson, 1990; Family Caregiving Alliance, 2005). For those LTC people cared for at home, families and friends are often the only source of care (64%), regardless of the level of impairment.

There is also an important tendency to prefer community-based care over nursing homes, evidenced by the increase of assisted living and care facilities from 24,600 in 1998 to 32,900 in 2000 (Family Caregiving Alliance, 2005). Unfortunately, such facilities do not treat individuals with moderate or severe need of care or with cognitive impairments (Family Caregiving Alliance, 2005). One aim of this study is to understand HD and its associated cognitive impairment with the hope that it will assist in the development of assisted living facilities as well as of informal caregiving interventions in Colombia and the United States.
Age and Type of Care

Studies report that age is related to the type of care. For instance, older individuals are more likely to be in nursing homes than younger individuals. Severely disabled people who are older than 85 are twice more likely to be placed in a nursing home than younger disabled are (Doshi, et al., 2005). It has also been estimated that all together, the cost of informal care in LTC is $196 million, which is more than the combined expenditure of nursing homes ($83 million) and home care ($32 million). For 2000, from all the alternatives available to LTC, adult day care is the cheapest and most effective alternative type of care, at $13,000 per year.

Financial Consequence of Chronic Diseases

Chronic diseases pose a heavy financial burden in the United Sates. For example, 66% of health expenditures are used to treat chronic conditions. In the next 40 years, LTC expenditure will be tripled, increasing from $115 billion to $346 billions (Family Caregiver Alliance, 2005). Dementia is the third most expensive illness to care for after heart conditions and HIV. It is estimated that, depending on the stage of the illness, the cost of caring for someone with dementia ranges from $18,500 to $36,000 per year. This calculation does not include the cost associated with the decrease of income of the caregiver and the associated pain and suffering for family members (Alzheimer Foundation of America, 2005).

Although statistics have not been collected in Colombia to examine caregiving or long-term-care, it may be assumed that the statistics will follow the same patterns as those in developed countries. De la Cuesta (2003) also states that those statistics might
be even proportionally higher, because in Colombia, care for the disabled is considered a family obligation rather than a state responsibility (De la Cuesta, 2003).

**Burden and Caregiving**

Some general perception about caregivers is that care is a burdensome experience and that women assume more caring roles than men do (Mockus & Novielli 2000; the 10/66 Dementia Research Group, 2004). Both claims have been researched, and with some exceptions researchers accept both assumptions. This study explores to what degree these general assumptions are applicable to care ideas in the Latino culture.

Caregiving burden refers to the emotional, physical and financial cost of providing care. Caregiving burden is widely measured through the “Zarit Burden Interview” (ZBI) (Carrasco & Artaso, 1998). The scale was developed by Zarit et al., in 1982 to assess burden in caregivers of older people with senile dementia (Mockus & Novielli 2000; Zarit et al., 1980).

There are some agreements among researchers for explaining what factors play an explanatory role in caregiving burden among Alzheimer’s and frail elders’ caregivers. The factors most studied are the intensity and the length of time which a caregiver spends to assists the sufferer, the level of cognitive and functional disability, the patient’s behavioral problems, perceived social support, ethnic background and religiosity. The only agreement among researchers is that perceived social support seems to buffer burdensome effects, and that the caregiving burden leads to the development in the caregiver of physical and mental illnesses, stress and depression. It has been reported that the depression rate for caregivers ranges between 17% and
47% (Carrasco & Artaso 1998; Gallagher-Thompson & Powers, 1997; Mockus & Novielli, 2000).

HD shares with Alzheimer’s disease a common feature, in that in both cases, patients suffer dementia. Unlike other patients who are cared for at home. Studies have documented the stresses of caregivers. In Spain, Carrasco & Artaso (1998) studied stress in Alzheimer’s caregivers. They found that patients’ psychiatric symptoms, incontinence, mindlessness, and more demanding behavior are associated with an increase in caregivers’ depression and stress. In Latin America and the Caribbean, the ZBI scale has been applied in a few studies on caregiver burden to caregivers of the elderly and of individuals with dementia (Scazufca, M et al., 2002). One study was conducted at Sao Pablo and the other was a multi-region study from 10/66 Dementia Research Group (2004). Both studies found that caregivers in these developing societies also experience burden.

Chesire (2003) conducted a quantitative study about caregiving burden in HD. She studied the relation between the level of impairment in Huntington’s disease sufferers (HDSs) and caregiver burden. She used a specific scale for measuring the HD level of impairment (UHDRS) and compared the results with those from a Caregiver Burden Interview (CBI). The mean total capacity in HDSs was 7.1 (+/- 3.4) which is equivalent to a mid-stage in HD. Caregiver burden score was 35.8 (+/- 17.5) which is equivalent to a moderate level of burden. She found an inverse correlation between different indicators of total capacity scale in the HD person and the caregiver burden. Caregiver burden was also predicted by the caregiver’s own perception of stress but was not correlated with the caregiver’s age, gender, education or the duration of the
caregiving. Chesire (2003) is conducting a follow-up study with the same sample to assess longitudinal effects of HD caregiving (Chesire, 2003).

In England, Aubeeluck (2005) developed an instrument to measure caregiver burden among HD caregivers. Huntington’s Disease Quality of Life Battery for Carers (HDQoL-C). This new battery is considered a reliable instrument and is being used in England to assess HD caregivers’ quality of life and to develop therapeutic intervention (Aubeeluck 2005) Both Chesire (2003 and Aubeeluck (2005) stress the fact that HD caregiver have been rarely studied (Aubeeluck, 2005; Chesire, 2003).

### Factors which Buffer Caregiving Stress

Factors such as the closeness in relational attachment can influence the emotional connection and the social support that the caregivers experienced, and can buffer some burden effects (Hooker et al., 2000). On the other hand, Pavalko & Woodbury found that caregivers’ anxiety and stress increased in proportion to the number of years dedicated to caregiving for the patient (1995). Later, Pavalko & Woodbury (2000) observed the effects of caregiving on physical health and psychological distress in a USA longitudinal study of a nationally representative sample of almost 3,000 women in midlife. They found that caring for a disabled relative at home is associated with emotional distress. The relationship with physical illness was weaker. The negative effects were higher for women with employment, but some of the employed women had no choice but to abandon their jobs because of the impossibility of combining the caregiver and work roles (Pavalko & Woodbury, 2000).

In 1996, Lim et al. compared caregiving burden between Mexican-American and Anglo populations. They found that there is no documented literature of burden among
Mexican Americans, but two studies (Cox & Monk, 1993; Monk & Cox, 1990) reported data on burden among Hispanics of Puerto Rican descent using the Zarit Burden Interview (ZBI) (Zarit & Toddt, 1996). They found that “individuals who ascribe to situations such as caregiving are embedded in their cultural values and beliefs. In addition, the meaning of caregiving mediates the caregiver's perception of burden and the cultural norms and standards for expression of burden” (Lim et al., 1996, p. 3).

Lim et al. (1996) state five cultural assumptions about family caregiving that have strong representation in the Latin culture: Latino people admire those who endure suffering because it dignifies human existence; they foster the sense that family well-being is more important than the individual’s well-being, and they tend to perceive caregiving in a more important way because it strengthens family cohesion. Caregiving among Hispanics is still tied to the traditional gender role in which caregiving is considered a woman’s activity. Finally, Latinos are more reluctant to describe caregiving as a burdensome experience and to openly express negative feelings about the experience because of the strong cultural expectation of acceptance of caregiving roles without question. Another study on Alzheimer’s caregivers also agrees that in traditional cultures “the duty of care and veneration of elders […] make it difficult for a caregiver to acknowledge strain where it exists” (The 10/66 Dementia Research Group, 2004 p. 170).

A study from Knight et al. (2002) with a cross cultural sample of family caregivers shows that Latinos with a high sense of family membership are usually less acculturated, although they reveal less burden and depressive symptoms. According to Knight et al., (2002) a sense of family membership is an important factor in explaining
the role of caregiving, but it does not play an important factor in preventing the distress. This study replicates Cox and Monk (1993) results that although Latinos are caring, they cannot avoid the distress of caregiving (Knight et al., 2000).

Caregivers Stress

A number of studies on caregiving are focused on the caregiver burden; they are especially interested in the effects of caregiving on the levels of stress, depression, anxiety and physical illness of the caregivers (Yates et al., 1999). Burdensome effects are part of the caregiving experience, but the caregiving experience goes beyond negative effects. Caregivers and patients develop a connective relationship (Abel & Nelson 1990, Yates et al., 1999) that generates knowledge about the patient and the disease. This knowledge is beyond clinical descriptions. Neena & Colin (2002) studied the relationship between burden and well-being in caregiving and arrived at similar results. According to Yates, “social support is a mediating factor for the caregiver’s well-being, but social support does not affect burden. This study reported that “caregivers’ quality of life could be improved […] and that the overwhelming focus in caregiving research on burden should be supplemented with an emphasis on quality of life” (Neena & Colin, 2002 p 776).

Pearlin et al. (1990) found that although the increasing dependency of the patient increases the stress, most of the intervening variables that are associated with stress outcome have not been satisfactorily tested (Pearlin, 1990). In addition, they found that some caregivers under similar conditions of stress cope better than others. In fact, stressful situations often result in the caregivers’ achieving “competence and inner growth” (Pearlin, 1990, p. 587). The authors report that there are some underlying
coping factors that should be disaggregated to understand how the following three mechanisms work together, the management of the stressful situation, the management of the meaning ascribed to the situation and the way in which individuals manage the cause of the situation (Pearlin, 1990).

Qualitative Studies on Caregiving

Reinardy et al. studied, in 1999, the caregiver’s burden, using two samples and two different methods: a classical scale appraisal and an open-ended questionnaire (quantitative and qualitative methods). They found significant differences between the results from the two methods: while the scale tends to capture negative aspect of caregiving, the open-ended questions allow respondents to reflect on the impact of caregiving on their relationship with the care receiver.

Qualitative methods offer more positive aspects of caregiving, such as caregiving mastery and satisfaction (Reinardy et al., 1999). Harwood et al., (1999) measured caregiving burden, and the level of satisfaction among Cuban American caregivers of ALZ sufferers. They found that positive and negative factors of caregiving can be predicted by perceived emotional support (Harwood et al., 1999). Gallegher-Thompson & Powers (1997) also distrust the conventional objective measures of stressor and depressive factors in caregivers of dementia patients. By using both objective measures such as the appraisal scales and subjective measures of burden, they found that the subjective caregiving measurements were strong predictors of caregiving stress. The researchers reported that neither ethnicity nor religiosity were included as mediating factors in their research model (Gallegher-Thompson & Powers, 1997). All these
findings suggest that a qualitative research design might better capture the HD caregiver experience.

**Social Constructions of Hispanic Culture**

According to Levkoff et al. (1999) ethnic identification helps to explain the perception of individuals seeking social support. Ethnicity has three major implications for individuals: “(1) a set of local cultural resources, available for constructing identity and developing behavioral strategies, (2) a means for negotiating differences in interpersonal and institutional settings and (3) a form of identity” (Levkoff et al., 1999. p.8).

The cross-cultural study that compares Mexican-American and Anglo family caregivers of Lim et al. (1997) describes the social construction of caregiving in the Hispanic world in which there is a positive view of a family caregiver as a self-sacrificing, devoted, and protective human being who values family over individual, who enhances interdependence and ignores his or her needs in favor of the needs of care recipients. The caregiver is often a woman with traditional expectations of care roles. In short, the study demonstrates that in the Hispanic culture the general construction of caring seems positive and emphasizes the family as a main source of social support (Lim et al., 1997).

**Caregiving among Hispanics**

Studies have tried to depict the social conditions in which caregivers live and to understand how the cultural values of Hispanics shape their caregiving behavior.

Levkoff et al. (1999) conducted a study among four different minorities in the USA, namely African-Americans, Chinese-Americans, Puerto-Ricans and Irish-
Americans, to understand how minority families seek care for their elders affected with Alzheimer’s Disease and Related Disorders (ADRD) (Levkoff, et al., 1999). They concluded that in caring for an ADRD family member, Caucasian families are less likely than ethnic minority families to take care of the patient in their own residence (Levkoff et al., 1999; Yeatts et al., 1992).

Other factors seem to influence the search for support services, such as the psychosocial attitude of the family, the accessibility to care for providers, and the nature of the contact with them (Levkoff et al., 1999). Among minorities, religious beliefs and affiliations are potential sources of social support by providing ethnically oriented organizations and by strengthening the feeling of self-worth and the value placed upon them by others (Levkoff et al., 1999). In addition, supporting elders is a Christian mandate (Levkoff et al., 1999).

**Religious Coping Mechanism and Christian Ethic in the Latino Caregiving Culture**

According to Navaie-Walise et al. (2002) religiosity is an important variable in this phenomenon because caregivers who seek religious relief carry on their care regardless of the degree of its intensity (Navaie-Walise et al., 2001). Levkoff et al. (1999) notice that religious organizations and religiously oriented services are an important source of support for families taking care of Alzheimer patients (Levkoff, et al., 1999). Giraldo (2002) found that religion is an important coping mechanism among Hispanic caregivers. Those caregivers who are religious appear more self-denying, and less prone to complain about their situation. When they are unable to get rest, they search for inner strength from religious beliefs. One important belief that provides comfort to
Hispanic caregivers is that the life of a good Christian includes service to needy individuals (Giraldo, 2002).

Caregivers also encourage the sufferer through their religious beliefs, (Giraldo, 2002). In religious families, the meaning of this experience is viewed from a Christian perspective. Although caregiving experiences are not always understood for Latino people in religious terms, there are underlying religious values even in those who do not identify themselves as believers (Giraldo, 2002).

Navaie-Walise et al. (2001) conclude that among Hispanic caregivers, religion is an essential factor for dealing with caregiving tasks, and Hispanics are less likely than Caucasians to perceive unsatisfied needs (Navaie-Walise et al., 2001). Regardless of this evidence, there are also studies that give less importance to religiosity in the Hispanic culture as a buffering factor. Zunzunegui et al., (2002) conducted a longitudinal study in Spain that tested the role of both social and psychological resources in the evolution of depression in caregivers of elders with ADL problems. They found that religiosity does not buffer a caregiver’s depression and they concluded that health and psychological factors affect the caregiver’s depression (Zunzunegui et al., 2002).

**Latino Preference of Care**

There are some differences between Hispanics and North American cultural practices. Hispanics are more likely to have “co-residence” of different generations in the same household, and this is also true for Hispanic elders (Knight et al., 2002; Magilvy et al., 2000). The sense of duty reciprocal help and cyclical intergenerational support among relatives explain this social feature. Hispanics and, to some extent,
African-Americans rarely question the emotional and instrumental forms of care that are seen as unquestioned responsibilities (Magilvy et al., 2000).

The system of formal support does not adequately provide services to caregivers, which increases caregiver overload (Navaie-Walise et al., 2002). Although it is unknown to what degree cultural preferences influence the perception and decision about the use of the formal system of support, prior studies show families’ resistance to use unknown service agencies (Johnson et al., 1997; Navaie-Walise et al., 2001 p. 240).

Magilvy et al. (2000) report some of the reasons that prevent minorities, especially Hispanics, from using the formal system of health care. This population is hindered by many social and physical barriers such as a lack of personal resources, different cultural beliefs, language, poverty, and physical impairments for accomplishing IADLs that make long-term care facilities undesirable places to stay for most of the elderly Hispanic population (Magilvy et al., 2000).

Magilvy et al. (2000) found a pattern of under-utilizing long-term care services among Hispanics. It has also been shown that the more traditional the elder, the more likely that he/she would rather be at home, living by herself/himself, or staying with family members, than to be placed in nursing-care institutions (Magilvy et al., 2000). In addition, studies have shown that elders with disabilities often delay decisions to be moved to a nursing home. They will only agree to be moved if their primary family caregiver has serious problems that keep them from giving care to their relatives (Cox and Monk, 1993; Crist, 2002; Dilworth-Anderson & Burton 1999; Magilvy et al., 2000; Wallace et al., 1999).
Hispanic Reciprocity

The concept of altruism and reciprocity are related to caregiving experiences in Colombia because informal caregiving is a non-profitable activity. Altruism refers to “actions performed voluntarily to help someone when the actor has no expectation of receiving a reward” (Howard & Hollander 1997). A case study conducted by Giraldo (2002) among Colombian immigrants in Texas, who care for their elderly disabled father, showed that these family members share a strong sense of reciprocity.

Importantly, they care for their father as their parents did for their grandfathers. However, they were unsure if the generation raised with American values will honor this model, although they have inculcated these values in their children (Giraldo, 2002). Among Hispanics, parents and children expect to reciprocate among each other. Also, a complex pattern of social solidarity among relatives exists, which is the root of social cohesion in the Hispanic culture (Giraldo, 2002).

Liebler & Sanderfur (2001) conducted a study for understanding Hispanics’ gender and social support exchange. They observed that minorities often live in the same household with children, which is a favorable factor for fostering inter-generational social support (Liebler & Sanderfur, 2001). Indeed, the Hispanic system of reciprocity is expected to be intergenerational (Magilvy et al., 2000). In this system, the next generations will reciprocate the help given to former generations. This is an ongoing system of support (Magilvy et al., 2000).

Researchers often called “familism” the tendency of Hispanics and other traditional cultures to view the care of “a frail older relative as a natural part of the family life” (Knight et al., 2002). The findings of Magilvy et al. (2000) of rural elderly Hispanics
have been observed among other elderly Hispanic groups, regardless of gender, location, socio economic status or health condition, etc (Cox & Monk, 1993; Crist, 2002; Dilworth-Anderson & Burton, 1999; Magilvy et al., 2000; Wallace et al., 1999).

Hispanic Culture and Dementia Caregivers

The most prominent feature in HDs dementia. In a study conducted by Cox & Monk (1993) on Hispanic caregivers of patients with dementia, the researchers found that Hispanic systems of support are centered around close relatives such as parents, spouses and adult children (Cox & Monk, 1993).

The studies have reported that the type of instrumental help provided for other relatives is sporadic. Therefore, many Hispanic families rely on a single primary caregiver, who often does not feel confident leaving the patient to be cared for by another caregiver or by using institutional services of caregiving. In many cases, if the primary caregiver can no longer take care of the relative, he/she may not be able to find someone else who can subrogate his/her functions (Cox & Monk, 1993). Other studies comparing Caucasian, Hispanic and African-American informal caregivers also show similar findings. Such studies conclude that family members are the source of caregiving among Hispanics, while Caucasians receive support from other types of close relationships (Cox & Monk, 1993; Navaie-Walise et al., 2001).

Navaie-Walise et al. (2001) measured the level of intensity in caregiving. They report that the overload of caregivers is not equal for all races and ethnicities, and that this racial disparity will increase because minorities will assume the care of uninsured relatives (Navaie-Walise et al., 2001). Cox & Monk (1993) documented that among Hispanics, external help for coping with, or relieving the caregiver burden is an almost
unthinkable alternative. They concluded that regardless of evident stress, most of the caregivers do not ask for professional aid. Cox & Monk (1993) suggested that among Hispanics, family problems are not discussed out of the home. They also deny fatigue and are less likely to admit that taking care of a close family member is difficult (Cox & Monk, 1993).

**Latinos as Main Providers of Informal Paid Care**

In Colombia, the care of frail elderly and the disabled is performed through two types of informal caregivers: family caregivers and non-trained paid caregivers. Therefore, a brief description of what is known about these caregivers is included. Caregiving is associated with care services provided by relatives at home; however, as Abel & Nelson explained, there is an unknown number of “unaffiliated” caregivers who provide help in many different settings. They are under-counted in economic reports and ignored by researchers. Such women perform home care as providers for a wide range of care to recipients. Untrained midwives and private preschool also provide care services (Abel & Nelson, 1990). Domestic workers such as nannies and home attendants provide a large range of care services for different members of the family (Abel & Nelson, 1990).

Informal home care providers do not have credentials for institutional work; therefore, home-based work is the only choice (Abel & Nelson, 1990). Often, informal paid caregivers provide services that according to the American Social Security system, are not covered by the benefit plan, but are necessary for disabled individuals (Abel & Nelson, 1990). The higher the informality, the higher the probability that the care provider does not receive a fair compensation (Abel & Nelson, 1990).
Often informal home providers, paid or unpaid, base their practices on personal experience and lay knowledge that may seem as though they are providing a high quality of care. Often they are considered to be a member of the family (Abel & Nelson, 1990). This affective connection is essential to care, but, the emotional connection is exploitative in that the workers are asked to perform far more tasks than should be expected of them (Abel & Nelson, 1990).

Researchers have also argued that the emotional involvement leads to devaluation because the provider views the care-recipient as a friend who cannot be charged as a business relationship (Abel & Nelson, 1990). Informal caregivers often work for families with low income levels and do not receive benefits; and they are sometimes unemployed for weeks at a time while their employers overcome their financial crises (Abel & Nelson, 1990).

Evidence from prior research (Donovan1989) shows that many paid home caregivers lack training, and usually they receive minimum pay. For instance, data from New York by Donovan (1989) show that 99% of home caregivers are women 98% from minority groups and 50% immigrants. Often these women are single mothers with more than three children, unable to afford adequate lodging and often dealing with hunger (Abel & Nelson, 1990).

Hispanic Culture Rationale for Caring

Magilvy et al. (2000) report that restricted access to the health care system among Hispanics is another factor for understanding how they solve their needs of care through family members (Magilvy et al., 2000). Nevertheless, Cox & Monk (1993) maintain that beyond the economic barriers, there are also values and beliefs that
explain why Hispanics under-use formal sources of care and over-rely on family care (Cox & Monk, 1993; Magilvy et al., 2000). The research evidence also suggests that the available type of support is not merely a matter of cultural preference, but rather is a contingent response of people to the economic conditions in which they live. Rich countries with budgets for social support will create an array of institutions that perform the function of social support that sometimes crowd out the function of families support. On the other hand, poor countries over-rely upon the intergenerational support among family members and untrained paid-helpers without implementing any services of social support (Cameron, 2002; Generations United, 2004; Rajulton & Ravanera, 2001; Wallace, 2001).

Disabled Colombians as part of the Hispanic culture satisfy their emotional, financial and material needs through the help of close relatives and untrained paid helpers (De la Cuesta, 2001). Researchers have no conclusive answer about the future of the Hispanic family and their patterns of support. Researchers point to intergenerational families among Hispanics as a model (Generations United, 2004). But other researchers are less convinced that the traditional intergenerational family can survive and maintain its function of support in the future (Rajulton & Ravanera, 2001).

Colombians, as part of the Hispanic population, are undergoing a process of transformation in which the number of elders will increase at an enormous rate. The eventual assimilation of the American culture can impede the functions of support that have prevailed in previous generations (Gutierrez de Pineda, 1996). Very little research has been conducted to investigate this possibility. Hispanics are also increasingly questioning the traditional gender role which can potentially transform the meaning and
patterns of care. When close family members cease to be the main and unique source of social support for elders, the Hispanic culture will be challenged (Marks & McLanahan, 1993). This study proposes to explore the changes of caregiving of HDS in Colombia.

**Colombia’s Socio-Economics Indicators**

Colombia’s overall Gross Domestic Product (GDP) for 2000 was $97 million (World Resources Institute, 2002) and the Global Public Good (GPG) per capita income $1,850, (ONU 2003). The inequality in income and consumption is alarming. Those in the lowest 10% earn 3.5% while the richest 10% earn 46.5%. Consequently, the Gini index\(^3\) is 58% (Organization of United Nations, 2003). According to the Ministry of Social Protection, 60% of the population live below the poverty line. Colombia’s index of human poverty\(^4\) is 10.6. This index is important because 23% of the population live on less than $2 daily, and 8% live on less than $1 a day. The unemployment rate is 16% (Ministry of Social Protection, Colombia 2003). Therefore, home caregiving for HDS is often provided within the context of extreme poverty and unemployment.

Public health expenditure is 3.6% of the GDP and the private health expenditure is 2% of the GDP. The Health Expenditure per capita is $354. The population with access to affordable essential medications such as pain killers, antibiotics and anti-inflammatory medications ranges from 80% to 94% \(^.\) For HD sufferers, medications are

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\(^3\) The Human developmental reports from ONU 2003 defined the Gini Coefficient a “measurement of the extent to which the distribution of income among individuals or households within a country deviates from the perfectly equal distribution […] A value of 0 represents equality and a value of 1 represents total inequality” (Human Development Report, 2003)

\(^4\) The Organization of United Nations defines HDI as “a composite of three basic components of human development: longevity, knowledge and standard of living. Longevity is measured by life expectancy. Knowledge is measured by a combination of adult literacy (two-thirds) and mean years of schooling (one-third). Standard of living is measured by purchasing power, based on real GDP per capita adjusted for the local cost of living (purchasing power parity, or PPP).” The scale is expressed as a value between 0 and 1. (United Nation, 2003):
not covered. Colombia also has good indicators for sanitation, nutritional status, and access to improved water. Eighty-six percent of the population has access to improved sanitation, 94% have access to improved water, and only 13% of the population has malnutrition.

The expenditure on education is also low. It is estimated that 18% of the total government expenditure is invested in education (Human Development Report, 2002). Although the rate of literacy is high (92%), the percentage of people who achieve higher education is low (18%).

Gender is a major source of social discrimination which is apparent through the index of gender-related development (Human Development Reports, 2003). Only 48% of the women over 15 years of age are employed. Approximately 76% work in services, while only 17% of industry employees are women. Female work in families represents 58% of the work force; therefore, caregiving is considered to be female work.

Colombia Demographics, Health Indicators and Health System

The population of Colombia is about 45 million people, of which about 32 million live in urban areas and 13 million in rural areas (Ministerio de Protection Social, 2003). Life expectancy is 73 years for men, and about 5 years longer for women. Women account for 51% of the population while men account for 49.5% (Ministerio de Protección Social, 2003). According to Departamento Nacional de Estadísticas (DANE), the fecundity rate is 2.6 per woman. The annual population growth projected for 2000 to 2015 is 1.4% (ONU, 2002).

In 2001, the overall mortality rate was .43% while mortality rate among children was 2.56%. Men are twice as likely to die as women; in fact, for every 100,000 men
there are 541 deaths, for every 100,000 women there only 346 (Ministerio de Protección Social, 2002). The reason is linked to an internal situation that affects more men than women. In fact, the leading cause of mortality is homicide, 15% of deaths being caused by violence (Franco, 2000). The second major cause of mortality is ischemic heart disease, 12%. The conditions of internal violence create a situation in which .77% of Colombians are displaced (ONU 2002). In the states of Antioquia and Atlantico where the research was conducted the major cause of mortality is homicide. In Antioquia the rate is as much as 41 per 1000 deaths, while in Atlantico, only 3 per 1000 deaths (DANE, 2004).

In 1993, the Ministerio de Proteccion Social implemented the most important reform in the system of health care in the past century, known as the law 100 from 1993. The major purpose of the reform was to increase the number of Colombians enrolled in the health care system, especially the underserved people such as rural and poor populations. However, as will be shown in the following research, the health care reform has failed HD sufferers. The health care reform will be addressed in Chapter 7.

Approaches to HD from Social Sciences

In Colombia, before Daza’s 1996 study in Juan de Acosta and Lopera’s 1999 study in Medellin, HD had not been diagnosed by genetic testing, but through clinical observation (Daza, 1996; Lopera, 1999). Since this first study, Lopera has conducted two more collaborative studies with Arango-Lasprilla & Moreno (2003), two neuropsychologists. These studies applied neuro-psychological testing in the population that Lopera had identified as HDS and carriers. The objective of these studies was to
establish differences between cognitive abilities of HDSs and healthy relatives at risk. They found that those with HD show the same cognitive problems as those patients with a similar type of subcortical dementia (Arango-Lasprilla et al., 2003; Arango-Lasprilla et al., 2003).

Most studies have focused on finding a cure for HD and very little has been conducted to address the need of care of those whose extreme disability required knowledgeable intervention by those who care for the sufferers. Edmund Chiu (1989), Senior lecturer in psychiatry from Australia claimed, "Caring takes precedence over curing when no cure is available." In the United States, as well as Australia, too much emphasis is placed upon curing a disease and not enough on caring for a disease" (Chiu 1989). Hardt (2001) agrees with Chiu (1989). He claims "I believe we are overlooking many HD-affected individuals and families who are "bleeding in the trenches," at this very moment while focusing primarily on finding a cure" (Hardt, 2001, p. 1). He called for a reform in this situation. After 35 years of intense studies on HD, few studies focus on caregiving issues. For that reason, those who care for the HDSs create and improvise personal strategies for dealing with the illness. There is little knowledge about how Huntington’s disease caregivers’ (HDC) experience affects their life, health and professional careers.

Caregiving Issues in HD

The challenges, problems and fears that HD Caregivers deal with have been addressed in the HD literature as guidelines for dealing with the illness, but to my knowledge researchers have not conducted a scientific study of HD caregiving up to this time. Unlike Chesire’s (2003) and Aubeeluck’s (2005) recent studies on HDC
burden, most literature on Huntington’s disease caregiving (HDCg) did not include or cite scientific evidence for studies on HDCg. Chiu (1989), after dealing 18 years with HDSs and caregivers, acknowledged that the caregiver perspective and knowledge is essential knowledge about the illness. He also intuited that much is demanded of caregivers and that those able to cope with this illness develop high level of maturity; but Chiu (1989) never conducted a scientific study to test his intuition. The current study in HDCg is filling this gap.

As was shown, family caregiving is a neglected area of study, and because the majority of caregivers are women, they often care for a sick relative as well as for children. The studies documented that family caregivers must coordinate many factor of care, including issues of management, disability, mobility and dressings. While dealing with such issues, family caregivers often feel tired, isolated, and overwhelmed. They often lack support, training, information, and a sympathetic ear. The lack of support may be more pronounced for caregivers of HD sufferers, since there is little awareness of the cause of HD beyond its genetic predispositions. Thus, HD not only affects the lives of those suffering from the disease, but also those family members who care for them. The impact of HD on family caregivers is important because the physical and emotional health of family caregivers also influences the health and welfare of the HDSs.

The health of HD caregivers is also of importance since they may be carriers of the gene, and may wonder about their life with HD. The studies mentioned above document the impact of caring on the multiple aspects of caregivers’ lives. These effects are physical, psychological, and social. Research reports that caregivers may
experience increased stress, anxiety and depression that cannot be expressed in the Hispanic culture. The following chapter proposes to use social theories to support a theoretical explanation of the different challenges and processes that the HD family caregiver experiences.
CHAPTER 3
THEORY

Background

Caregiving is one strategy that society uses to cope with chronic illness. Such coping mechanisms are expressed through social expectations which are revealed through the social construction of the caregiving experience. Two common social expectations are: (1) people should care for dependent family members and (2) family members should help to maintain an ongoing circle of reciprocity. This chapter shows that in Colombia, informal home caregiving of chronic sufferers can be explained by three elements: the social construction of illnesses, the expectations about helping behavior, and gender expectations.

*Social Constructions of Chronic Illness in Medical Sociology*

Sociologists and healthcare professionals suggest that illnesses possess sociological effects that must be understood in a frame of meaning. Such a frame work, emphasizes the hegemonic interpretation of illnesses, in which “normal” and “pathologic” are within a contextual interpretation defined as “social constructions” (Wellard, 1998, p. 49).

Contrary to acute illnesses that are sudden and have a fast and dynamic course, chronic illnesses remain over long periods, and require extended adjustments (Lubkin, 1998). In such cases, an illness is part of an individual identity or social stigma (Goffman, 1963; Lubkin, 1998).
Researchers report that the most compelling medical definition of chronic illness is “a recurrent and persistent debilitating condition, which creates a permanent impairment for the individual” (Bradford, 2002 p. 3; Lubkin, 1998, p. xvii). An important feature of chronic illnesses is the illness fluctuations, the occurrence of remissions, exacerbations and stabilization. In consequence, chronic illness sufferers are treated but never cured, and they often suffer for long periods of time (Bradford, 2002; Lubkin, 1998). The variability of a chronic illness influences the level of care or assistance that sufferers may need during their lives (Bradford, 2002; Lubkin & Morof 1998).

Individuals can be stricken by a chronic illness during childhood, adolescence or adulthood (Bradford, 2002; Lubkin, 1998).

Researchers such as Strauss (1975), Alonzo (1995) and Mechanic (1995) emphasize an individual’s own definitions of a chronic illness. They suggest that a chronic illness is defined by the individual in terms of its social and psychological consequences. However, in the health field, there is an absence of subjective responses to the illness (Thorne, 1999). According to Thorne (1999), an illness is experienced as a social and emotional event, rather than solely as a clinical reality. Illnesses are more than body impairments and physical pain. Illnesses change lifestyles and alter identities as well as family relationships. According to Thorne (1999), the sufferer of a major illness seeks an explanation as to its cause and to the physiology of the disease.

However, health professionals often ignore or neglect sufferers’ construction of illnesses and the experience of suffering (Gerhardt, 1993). Moreover, health care professionals may not understand the depth of the sufferer’s torment and agony. As a
result, the sufferer is often perceived as a non-human being without a social role or identity. Mechanic (1995) also acknowledges that the literature fails to focus on the sufferer.

According to Mechanic, (1995) illness is not only a physical experience, but it has a social component. For instance, it can be used for potential advantages, to excuse failure, and to explain disappointment. It can also be used to justify release from expected social roles and obligation. In short, illnesses have an implicit nature that individuals use both to adapt and to influence behavior (Cockerham, 2004; Conrad 2001; Mechanic, 1995).

The previous concepts apply to Huntington’s disease (HD), which is one of the most excruciating and torturous chronic illnesses. HD changes the identity of an individual and creates a catastrophic life crisis. HD involves major physical impairments and tribulations for caregivers (Harper, 2002; Kremer, 2002). In sum, HD is a progressive and gruesome illness trajectory, which exhausts the sufferer’s emotional, intellectual and physical resources. As a result, individuals with HD depend on external sources of psychological, sociological and material support.

*Theories of Social Support*

As described in the literature review, altruism underscores the caregiving motivation in the Latino population. This section presents the theoretical explanations for intergenerational reciprocity as a basis for the caregiving relationship in Colombia.

*Social Network and Social Exchange*

Lee (1985) in the “Theoretical Perspectives on Social Networks” poses the social exchange formulated by Emerson (1958), Homans (1962), and Stolted (1970) as the
main explanation of the unequal social support that is given to the elderly. Social exchange theory asserts that human behavior is oriented towards the expectation of receiving a reward while minimizing one's cost. People evaluate their relationships according to “a subjective calculation of profit” (Lee, 1985 p. 27). For Lee, a satisfactory exchange among people requires the possession of similar resources. When there is not a balance in the exchange, the person who has the more valuable resources gains power over the other person, and it creates a dependent relationship.

For instance, according to Lee (1985), the person who is more emotionally dependent in an unequal relationship depends on the gratification of the other, and thus permits exploitation from the more powerful. This applies in situations that cared-for persons confront daily. In a society where work status and income are highly valued, retired people, the elderly, and dependents often are without symbolic value, which allows them to make a social exchange with caregivers in the act of reciprocity. As a result, dependents appear less resourceful, regardless of their real status. Therefore, exchange theory suggests that disadvantaged elders are regarded as extreme dependents by their family and by society.

Resource Theory

Another theory which may explain caregiving in Colombia is resources theory.

Resource theory is a derivation of exchange theory. This theory suggests that in a relationship, the ability to make decisions is controlled by the person who has the most valuable resources. Elders and disabled, for many reasons, are considered to have less valuable resources; therefore they remain in an unequal exchange with other members of the community and the family. Their nets of social support become weaker
(Lee, 1985). In Colombia, resource theory does not apply, since caregiving is motivated for altruistic reasons. Consequently, a new theoretical model to explain caregiving in Colombia should include the issue of reciprocity.

**Concern about the Concept of Reciprocity**

After discussing the role of reciprocity in human relationships from the social exchange theory, it is important to discuss other perspectives of reciprocity. For example, Kittay’s perspective (1999) on reciprocity is based on the social principles of justice and fairness. It also promotes cooperation as the best for society. However, in relationships of dependency such as between caregivers and cared-for people, this model fails to fit, because many dependents are unable to reciprocate caregivers for the social support that they receive (Kittay, 1999). For that reason, it is necessary to broaden the concept of reciprocity to, “Someone who cares for those who care”.

According to Kittay (1999), the concept of interdependence links those who help others and those who require assistance (Kittay, 1999). The author (1999), proposes a broad definition of reciprocity, which can be understood as “generalized reciprocity” similar to that of Neufal and Harrison. The definition suggests that there is a cosmic justice which is translated, “What goes around comes around.” According to Neufal & Harrison (1998), most of the people who care for others never will be reciprocated by the same person that she or he cares for. However, this person will be reciprocated by receiving caring from the next generation. According to Kittay, generalized reciprocity is a public acknowledgement of the value placed on those who care, and the commitment to uphold the principle of care in current society (Kittay, 1999). Nolan et al. (1996) support the philosophical and ethical formulation of Kittay, when they accept Griffin’s
statement that caring is “the most basic way of being in the world” (Nolan et al., 1996, p. 30). As a result, people care because they value and respect human beings (Nolan et al., 1996).

**Defining “Care for” and “Care About”**

Fisher & Tronto (1990) explored care based on the prevailing ideals of caring. They concluded that caring is a process with four phases: “Caring about, taking care of, caregiving, and care-receiving.” The first action, “caring about” is undertaken when individuals are aware of the need of protective actions required for caring. “Taking care of” involves accepting responsibilities to improve the situation. “Caregiving” entails concrete actions upon the cared for individuals. “Care-receiving” is the feedback that the recipient gives to her/his caretaker (Fisher & Tronto, 1990). Care-recipients often complain of the care that they are receiving (Fisher & Tronto, 1990).

Caring activities often require various individuals to perform complementary tasks (Fisher & Tronto, 1990). Furthermore, caring is an activity accomplished under certain preconditions and depends on a combination of “ability factors” such as skills, knowledge, time and physical resources. Although women caregivers possess sufficient ability factors, they are usually not allowed to make decision regarding care. Thus, an inefficient process of care result (Fisher & Tronto, 1990).

Judgment is the main skill for “taking care of” because it requires choosing one action over another, in order to predict the outcome. The possession of resources provides power to caregivers (Fisher & Tronto, 1990).

Nolan et al. (1996) have criticized the traditional assumptions of caring since most of them have emphasized instrumental tasks of caregiving without grasping the
“dynamic nature of family caregiving” (Nolan et al., 1996, p. 2). For these authors, there is a difference between “care about” and “care for”. Although the first is a concern for another person, which is expressed by financial and emotional support, the second type of care involves the care of another person, physically (Nolan et al., 1996).

Nolan et al. (1996), expand Bowers’ (1987) model for understanding caregiving. For Nolan et al., caregiving should be classified by purpose, rather than by task. According to Nolan et al. (1996), the most extended function of care is the anticipatory care. It is performed “before and throughout the period of caring”. The protective, preservative, and reconstructive care describes ongoing steps in the process of caring. Nolan et al. (1996) and other authors (Neufeld, & Harrison, 1998) consider that this model should reinforce the aspect of reciprocity since research findings indicate that even in situations of extreme mental limitations, some caregivers are able to decipher subtle and diffuse reciprocities (Neufeld, & Harrison, 1998; Nolan et al., 1996).

For Bowers, there are five different but often overlapping types of care: (1) anticipatory care (“just in case”), (2) preventive care (hidden care), (3) supervisory care (minimizing awareness of help to dependants), (4) instrumental care (dependent needs total assistance but maintains emotional reciprocity with carer), and (5) protective care (preservation of the cared-for person’s sense of self) (Nolan et al., 1996).

Feminist Perspective

Abel & Nelson (1990) agree that caregiving demands material and emotional support, but they conclude that society devalues emotional work, giving preeminence to instrumental activities (Abel & Nelson, 1990). Selma Sevenhuijsen (1998) describes the emotional qualities of caregivers as intimacy, serenity, understanding,
thoughtfulness and above all, the ability to obtain satisfaction through the fulfillment of small services (Sevenhuijsen, 1998); nevertheless, for Sevenhuijsen, caring first and foremost comprises human agency (Sevenhuijsen, 1998).

Feminist authors, such as Waerness (1983), stress the fact that caregiving is one human activity in which the traditional division between emotion and reason is blurred. Since caregiving entails both emotional and intellectual functions, people provide care to those who are emotionally close (Abel & Nelson, 1990). Waerness suggests that the “rationality of caring” is the same sense that Ruddick (1983) defines as “maternal thinking” because the caregiver is guided by emotion, and develops knowledge through caring (Abel & Nelson, 1990). However, according to Kittay (1999), caregiving is a female function, involving the dependence of one person on another.

**Women’s Caregiving and Unequal Division of Labor**

Various feminist authors (Abel & Nelson 1990; Lorber, 1997; Sevenhuijsen, 1998) describe different settings and roles in which women perform caring labors, such as family care for frail elderly, children and disabled people. Women are also in the majority in other healthcare settings such as hospitals, hospices and nursing homes, where they carry on most of the menial work of caring. Nurses, gerontologists and midwives have professional training for caring and receive payment for such activities. However, female professional caregivers undergo the same powerlessness as do informal caregivers (Abel & Nelson 1990). Sevenhuijsen remarks that the problematic issue in caregiving is the uneven distribution of payment among caregivers, and the way in which care as an activity is under-valued in society (Sevenhuijsen, 1998).
Fishers & Tronto (1990) formulate a feminist theory of caring. They suggest that early feminist theoreticians such as Mayerhoff (1971) and Noddings (1984) assume that women are naturally endowed for caring. For them, caring is a matter of motivation (Fisher & Tronto, 1990).

“Caring” is considered by current society as a dual value system. One part of society strives for rational and bureaucratic types of public care while another part of society advocates private care, in which uncompensated labor and personal relationships are circumscribed. Those two settings are identified as opposite spheres dominated respectively by males or females (Fisher & Tronto, 1990). According to the division of labor, women are portrayed as less or more involved in their role of caring. Those who only care for themselves are “selfish carers;” yet others involved in caring are models of caregivers (Fisher & Tronto, 1990). Women often experience care as a labor of duty and love since they provide emotional and material support to their children (Fisher & Tronto, 1990).

Prior to feminist theory, sociologists ignored the way in which the material conditions and relations of power affect caring (Fisher & Tronto, 1990). In the nineteenth century, with the expansion of the market-oriented society, the growing “White middle-class”, and the “cult of domesticity” provided an ideology for maintaining a division of labor between men and women. Such a framework suggested that the moral endowment of women caused them to develop an affinity for caregiving. However, times changed and that model of woman was replaced by one whose moral imperative of care for her family conflicted with her role as a full-time worker outside the home (Fisher & Tronto, 1990).
Social scientists often agree that caring is a social activity because society needs care to continue to exist. Indeed, without caring, society has a low chance of survival (Cancian, & Oliker, 1999; Fisher & Tronto, 1990; Kittay, 1999; Sevenhuijsen 1998). Nevertheless like any other social activity, caring has “potential for conflict” (Fisher & Tronto, 1990). For instance, caring for the environment when boundaries are defined often causes cultural and class confrontation (Fisher & Tronto, 1990). In short, as Fisher & Tronto (1990) have reported, “We should come to understand the rich and knotty texture of our caring experiences, why caring can be both so rewarding and so exasperating” (Fisher & Tronto, 1990, p.40).

Theoretical Framework

Different studies (Alonzo 1995; Mechanic, 1995; Strauss, 1975; and Wellard, 1998) demonstrate that reality does not have an independent and objective existence; members of society construct it. Every society defines illness and care based on moral values, beliefs, interactions and experiences within a social setting; but those values and beliefs are ideological tools that every society utilizes for legitimizing their macro-economic and macro-political conditions (Bourdieu, 1999; Giddens 1986; and Habermas, 1999) Although the interactions and experiences of caregiving are shaped for particular social constructions (Lobers, 1997) these constructions are negotiated through power (Fisher & Tronto, 1990; Scambler, 2004).

This study acknowledges that HDSs demand from their caregivers both instrumental care and emotional care. However, those who take care of sufferers with HD acknowledge that there is a progressive loss of personhood and agency in the care-
receiver. Most important, caregiving is first and foremost a special way of human agency as Sevenhuijsen asserts.

In contrast to Sevenhuijsen (1998), who considers caregiving as a moral imperative, this study defines caregiving, as a form of social agency, as Giddens (1996) defines agency. Caregiving is a special type of relationship creating a subrogate agency.

Such a definition of caregiving is essential since HD causes a loss of agency. Human agency is the ability for monitoring one's own action (Archer, 2000; Callinicos, 2004). The gradual and serious loss of all capabilities in HD has a social effect on the sufferers' cognitive, conative and physical abilities. They forget who they are, where they are, where they are from, what institutional memberships they hold, and what personal relationships they possess.

Due to the loss of all these abilities, they have problems using their bodies. They lose the ability to speak in a coherent manner and their rational actions fade, their position in society and physical abilities are crippled. They no longer can determine their position in society, what kind of personality they have as well as any other personal information such as gender, age or sex preferences (Archer, 2000; Callinicos, 2004).

The ability to understand the human condition is diminished, sufferers cannot exercise particular religious or moral beliefs, and their communication with others ceases. In short, the result for sufferers of HD is a veil of ignorance about the self and a lack of all elements that provide human agency. Their volition and existence as human

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5 Conative: The aspect of mental processes or behavior directed toward action or change and including impulse, desire, volition, and striving. (Dictionary.com, 2005).
beings are threatened, and their weakened agency (i.e. loss of being human) can only be restored through the caregiver. This research argues that the caregiver acts as a surrogate agent of the sufferer's action and volition (Archer, 2000; Callinicos, 2004).

The sufferers’ survival depends on the subrogation that the caregiver offers to the HDS. The HDS conserves a small degree of self-hood, i.e. agency through the caregiver’s action. This subrogation causes a paradoxical situation. On one hand, there are constraints to the caregiver, including stress and burden. On the other hand, the HDS experiences psychological rewards, such as a sense of mastery, purpose and maturity. Often in the Latin culture, HD caregivers experience social enhancement and sympathy. Caregiving for sufferers with severe loss of agency creates a type of human relationship that cannot be replicated in any other care situation such as that of mother/child.

Caregiving is a special type of surrogate agency in which there are only two parties, sufferer and caregiver. The caregiver, by default, replaces the sufferer’s lost agency. This type of caregiving is defined by Simmels (1908) as a dyadic relationship. In the dyad, the two do not attain a super-individual life and they develop inseparability as well as intimacy (Simmel, 1964). Researchers often suggest that caregiving combines instrumental and emotional action. However, Sevenhouijsen (1998) emphasizes that caregiving is a social practice which produces knowledge. The ability to provide care can be seen as a special form of “resources” described by Giddens.

Symbolic interactionism (Berg, 2001; Blumer 1993) suggests that the meaning of the caregiving experience should be studied in consultation with caregivers and
sufferers. Using this assumption, both caregivers’ experiences and sufferers’ experiences should be studied equally. In addition, two important theoretical branches in qualitative theories, phenomenology and ethnomethodology (Creswell, 1998; Maynard, & Clayman, 1991) suggest that the caregiving experience should be studied inside the daily life of caregivers and sufferers.

The caregivers can respond to questions such as “What is the meaning of care for a long-term care sufferer?” “What are the skills and tasks of care?” “Who is the sufferer?” “What are the sufferer’s feelings and needs?” Caregivers can depict phases in the process of the disease. Caregivers also learn about themselves. They learn to cope with their stress and anxiety and they learn from mistakes. Caregivers also may capitalize on their personal history, experience and social context for creating awareness about sufferers’ conditions and needs. In short, caregiving is a twofold experience, in which constraining and enabling elements are intertwined.

The following theoretical model proposed for conducting the study explains how subrogation of agency is tested, within the context of HD.

**Theoretical Model of this Study**

This study uses a model of the sufferer and caregiver relationship to formulate questions and to analyze the data. This is an inclusive model that uses the concepts discussed in the literature review (See figure 2, Appendix A, p. 209).

This study assumes that the relationship between sufferer and caregiver is an asymmetric relationship with a great degree of dependency from the sufferer to the caregiver. Previous research demonstrates that caregiving is a complex task that involves instrumental and emotional care. The literature also shows that families
negotiate their caregiving agreement and that an unequal division of labor makes women believe that caring is natural to them.

The categories that compose this model and guide this study are divided in two realms: sufferers’ categories and caregivers’ categories. In sociological terms, caregivers give agency to the sufferers who struggle to preserve their personhood despite their losses. In the model (See figure 3, Appendix A, p. 210) each person is represented as a scalene triangle. Both triangles form a square. The square represents a complementary relationship between HDS and HDC. The caregiver supplants the sufferer’s functions that she/he cannot perform. The triangle upside down represents the HDC, while the triangle supported by the base represents the HDS.

These two figures represent an essential element in this relationship. In the gradual process of physical and mental deterioration, the caregiver provides more and more means to support the sufferer’s agency and thus to allow personhood. However, these resources are limited by the HDS’s capacity for taking advantage of this support. When physical and mental conditions have deteriorated, the sufferer loses his/her capacity for enjoying the resources received from certain types of care.

_Huntington’s Disease Phases and Caregiving Phases_

I created this model for describing the experiences of caregivers of Huntington’s disease sufferers (HDSs). The five phases included correspond to the five medical phases of Huntington’s disease (HD) that are based on an exploratory study of caregivers in the United States.

_HD Phase 1:_ HDSs have agency. They fight against the illness. In this phase, they try to slow down the progress of the disease. There is suffering because the onset
is accompanied by the self-awareness of the final outcome of the disease. Depression is common in this phase, caused by neurological damages and reactive response to unresolved family and personal conflicts.

Individuals are aware of their involuntary movements, physical limitations and other symptoms of the illness. They feel embarrassment and anger because of their slurred speech or of their appearance of drunkenness or craziness. They deal with negative social reactions to their illness. However, no matter how difficult the task may be, individuals typically do not request help to perform them.

If the HDSs have a primary caregiver in this phase, they will reciprocate for their services in multiple ways, such as doing little tasks for them, or giving gifts. They have a lot of verbal interaction with the caregiver, creating a symmetric relationship. There are physical changes that affect movements, conversation, feeding and many other activities, but the physical impairments are functional. An important feature is that HDSs have the capacity to understand who they are, what they should do and to exercise their volition and to act by themselves (see figure 4 Appendix A, p. 211-213).

Caregiving Phase 1: The Huntington’s disease caregiver (HDC) provides very little “instrumental care” and a great deal of emotional support because HDSs preserve most of their psychological functions and are able to enjoy emotional support. They need encouragement, assurance and support to preserve their sense of personal value and meaning. HDCs in this first phase begin to develop, little by little, a sense of mastery and connectedness that become essential features as the illness advances. HDCs perform very few tasks for sufferers in this phase, and their energy is undiminished; therefore, they experience little or no fatigue. There is suffering caused by the onset of
the illness because it is the beginning of the expected illness trajectory. Also, some caregivers who are at risk anticipate their own future. HDCs experience embarrassment because of people’s reaction to the HD person’s physical appearance, but the embarrassment is less than that experienced by the HDSs themselves.

The most salient feature is an inner process in which the caregivers position themselves in relation to the family and gender expectation on care. There is a conscious or unconscious process of questioning about why they should assume this role and why others with the same care responsibility manage to avoid this commitment. One paradox is that, at the same time that caregivers question their role assumption, they develop a certain sense of pride for assuming a role that entails a positive cultural sanction (see figure 4 Appendix A p. 211).

**HD Phase 2:** The HDS still has energy and emotional resources for “fighting against her/his illness” but these resources have decreased. Sufferers still reciprocate the caregiver, but there is no longer a symmetric relationship. Physical impairments become more evident. There is more depression, more anger and more social embarrassment linked to both the physical impairments and the neurological deterioration. Cognitive problems are clear and serious, and sufferers begin to demand and accept more help from others (see figure 4 Appendix A p. 211).

**Caregiving Phase 2:** HDCs provide less emotional support and more instrumental help, and this tendency increases during the following phases. This change is related to the nature and extension of the HD impairments. There is a higher sense of mastery, connectedness and sense of care. Suffering and fatigue increase, but they are still bearable. Social embarrassment rises. The HDC still questions the assumptions of her
or his role as caregiver, but the feeling is balanced in some way because of the positive sanction that the caregiver receives from friends and other family members (see figure 4 Appendix A, p. 212).

**HD phase 3:** Depression, anger and shame caused by neurological damage are present. In deed, in this phase, many HDSs have clear symptoms of dementia. The capacity to express suffering decreases because HDSs lose their consciousness of the illness and have severe speech problems. They require a caregiver skilful enough to recognize their unpleasant experiences, sores and pain. Suffering remains because the sufferer endures the adversity and hardship of having one of the longest and most catastrophic chronic diseases. Sufferers become unaware of their physical and mental limitations as well as injuries and associated conditions. HDSs need permanent care and require assistance for all their activities. In short, agency decreases and dependence increases (see figure 4 Appendix A p. 212).

**Caregiving Phase 3:** Care becomes instrumental. The HDS is not able to enjoy emotional support but the caregiver still is able of experiencing emotional connection with the sufferer, and his or her sense of love and care also increases. These emotions act as buffering against the fatigue, stress and burden that increase when dementia and the physical impairment become a permanent condition in the sufferer. There is suffering because the illness trajectory in the HDS is full of uncertainty, uneasiness and watchfulness. Social embarrassment at this phase is related to both the physical appearance and the unconventional behavior of the HD people in public settings. A lot of the stress experienced comes from dealing with the HDS: behavioral problems. Nevertheless, HDCs also develop a higher sense of mastery and are able to make good
impression of their roles as caregivers within their families and social circles. There is less conflict in assuming the role of caregiver because the caregiver’s commitment increases when the sufferer loses his or her agency (see figure 4 Appendix A, p.212).

**HD Phase 4:** HDSs’ abilities decrease; they are disconnected from their emotions. They have lost the ability to look after themselves. They need permanent and protective help because their involuntary movement and lack of judgment create a risk to themselves of injury or even death. They are shadows of their former selves. There is more depression, more crises, accidents and in most cases, advanced forms of dementia. All of these elements together make their existence very miserable (see figure 4 Appendix A, p. 212).

**Caregiving Phase 4:** HDCs are exhausted since they have dealt with stress, burden and suffering. The amount of instrumental actions of care begins to grow. Embarrassment increases because sufferers develop many behaviors that are frowned upon. Another reason for feeling some increasing stigma is that some people know the caregivers will develop similar symptoms if they are HD positive. Often, caregivers require help from another person to perform care tasks such as feeding or cleaning, because the sufferer is no longer able to keep his/her bodies in vertical position. HDCs increase their mastery as well as a sense of care, since HDSs are unable to express their needs (see figure 4, Appendix A, p. 212).

**HD Phase 5:** HDSs are close to death; they cannot swallow or perform any tasks by themselves. They need to be cared for simultaneously by two or three HDCs. They can recognize their names, but there is no awareness of who their relatives are, who they were or where they are. They are in limbo, unable to express their emotions,
needs and pain. They live because someone helps them to do so, but without the constant care of other human beings they will soon die (see figure 4, Appendix A, p. 213).

**Caregiver Phase 5:** HDC develops a strong sense of connectedness. The HDC finds that his/her relationship is smoother and closer in the last phase, when the HDS is less combative and seems more vulnerable. The emotional support that the sufferer receives is often conditioned to his/her mental skills; therefore, in the last phase, she/he requires very little emotional support. The sense of mastery increases even more when the caregiver feels that she or he is dealing with death. Fatigue, stress and suffering reach their highest point. In this phase, the social embarrassment remains stable or decreases because the sufferer remains at home or in an institution with very little or no exposure to the external world. The condition of total dependency makes the caregiver forgives and reconciles all the rage caused by the sufferer’s demanding and offensive behavior from prior phases. The level of positive sanction is higher because of what the caregiver has been going through. Sometimes, for this phase, another relative has decided to perform some of the caregiving tasks that have become too cumbersome for a single HDC (see figure 4, Appendix A, p. 213).
CHAPTER 4
METHODS

Procedures

The objective of this study is to use two communities to study Huntington’s disease caregiving (HDCg) in Colombia. The study uses 35 semi-structured interviews with current Huntington’s disease caregivers (HDCs), 4 semi-structured interviews with former HDCs, 8 focus group with former HDCs, 28 observations of Huntington disease HDSSs (HDSs) in interaction with their HDCs, 7 interviews with neurologists and physicians, 1 interview with a neuro-psychologist and 2 interviews with key informants. A summary of methodological steps in the study is provided in Appendix B, table 1, p 218.

The study was conducted in two regions: Juan de Acosta and Medellin. The first region is Juan de Acosta and vicinity (JDA). In this region, Daza et al., (1995) identified the largest population in Colombia with HD. This population is spread in various towns in the north costal region of Colombia, but the study only includes families from Juan de Acosta rural and urban areas, Baranoa, Piojo, Usiacury, Puerto Colombia, Turaba and the fourth major city in Colombia, named Barranquilla. Map 1 shows this first region (see figure 5, appendix A p. 214) The second major region included in the study corresponded to the population identified as Huntington disease carriers for the Institute of Neurosciences (IN) in La Universidad de Antioquia (1999), The population identified by the institute is located in Medellin, the second largest city in Colombia, Entrerrios rural and urban area and Sopetran. The Institute also assists families from a large town called Yarumal and from our capital city, Santa Fe de Bogotá, but they were not
included in the study. Figure 6 shows the second region included in this study and the location of our capital city (see figure 6, Appendix A, p. 215) Figure 7 show both regions (Appendix A, p. 216).

Recruitment of Participants

The vice-president of FUPEHUJAC (Fundacion de Pacientes con la Enfermedad de Huntington Juan de Acosta) was vital to the study in identifying and gaining access to the families with HD in the JDA region. She was the gatekeeper to the Juan de Acosta community. The foundation requested a copy of the study results as compensation for its providing information and helping me to find the participants. In Medellin, I used family contacts and the HD families' database from the Institute of Neuro-sciences at La Universidad de Antioquia. The institute provided information from 21 kindred and required the researcher's confidentiality about the genetic testing confirmation from those HDSs, who still do not know the results.

In Juan de Acosta, families and HDCs of HDSs have requested attention and help because they consider themselves a marginalized population. Nevertheless, participants in both regions were enthusiastic about the study and were able to talk in both sessions about their experiences as HDC.

The sample was complemented by information from experts who have studied Huntington's disease in Colombia, some who treat HDSs, some others who are relatives of HDSs and others who are knowledgeable of the social conditions and population with HD. They were considered key informants. HDSs were also observed as part of the study.
Key Informants for Recruitment

FUPEHUJAC provided detailed information about the HDSs from the JDA region, and the neuro-psychologist at the Institute of Neurosciences helped me to classify participants prior to contacting them. They assisted in selecting the most appropriate participants to be included in the study who could meet the requirements that I was looking for in the purposive sampling criteria. I used the sheet of socio-demographic data for collecting information about each HDS prior to the interview, making a census of the features in the population allows me to select a rich sample from the information provided.

In JDA, the number of families registered in the foundation is 76, but only 24 of them were included in the sample. In MED, from the 21 family pedigrees collected in the Institute of Neurosciences, 9 were selected to participate. In the selection of particular cases, the key informants and a snow-ball technique were used to identify deviant, disconfirming and critical cases. In the JDA region, participants were recruited face-to-face because most of them do not have telephone. In MDE, most of the interviewees were recruited by phone. In this initial contact they were informed about the purpose of the study, the kind of activity in which they would participate, the issues related to the consent form and the specific time and location for the coming meeting. I requested permission to observe the interaction of the HDSs and their HDCs.

Sampling Criteria

This study includes primary HDCs. The HDC must be the person who provides the basic material and financial needs of the HDS. He/she also was selected because of his capacity to recognize the HDS’s emotional needs and to assure that the HDS
receives the necessary care to carry on his or her life safely and with dignity. Most of those who were chosen as primary HDCs live with the person or have living arrangements that allow them to provide care on a daily basis. Although it was proposed that in order to be part of this sample, the HDC must have fulfilled this role for at least 6 months, those studied had served for more than 1 year. Most of the primary informants interviewed are close relatives who care for their parents or spouses with HD. In those cases in which the primary HDC is a paid helper, the helper was included in the study since she/he may know a great deal about the HDS’s condition. One criterion for selecting the cases studied was the exclusion of those HDCs who are alcoholics, drug users or who have psychiatric disorders. Two HDCs were deaf and required a proxy to participate in the study.

Restrictive Sampling Criteria

HDCs in the focus group were required to meet the same criteria as those HDCs for living HDSs. In this case, the participants were former HDCs for HD relatives who had passed away in the last four years. In the field this criteria was difficult to meet and for that reason 12 out of 25 HDSs had died more than 4 years ago.

HDSs included in this study were those who have been positively identified by either a neurologist or a geneticist as HDS, either through genetic or clinical testing. Genetic testing is still not available to all HDSs in Columbia. A combination of criteria from two different neuro-pathological assessments of HD, the Physical Disability Rating Scale from Myers et al., (1988) and Shoulson & Fahn’s (1979) functional scale indicate that at the onset of the illness, the symptoms are mild and the need of care is probably less. It was estimated that the HDCs included in this study will be taking care of HDSs
who will reach at least the second phase of the illness, in which the HDS begins to require assistance in daily living. In the practical field, the number of HDSs in each phase increases gradually from one phase to the next one. The study includes HDSs in all of the five phases because that method gives a true picture of HD as it progresses.

The criterion for including the experts was their knowledge concerning HD and HD’s caregiving. These experts have two categories: 5 of them work as researchers, professors and therapists of families with HD, and 3 of them acquired their knowledge through direct and close experience with the illness. The three physicians, who are involved with the treatment and care of their parents and grand-parents, were all at risk to develop the illness themselves.

Data Collection

I collected the data in Spanish and over a period of 3 months, between June 15, 2004 and September 2004. I lived in the JDA region for 1 month which gave me a good perspective of the community. Table 2 shows (See appendix B p. 221) the number of observations, interviews and focus groups conducted in each city and the type of informant, number of sessions and average duration of each session.

HDCs Interview Guide

This study inquired into the motivations and circumstances that lead HDCs to assume the role and to question what they learn from their practice as HDC. The questionnaire includes two categories of issues: those related to the perception of the HDC about the HDS, and those related to the perception of the HDC’s own role.
The first category, the HDS’s self-consciousness, was explored along with the HDS’s self-awareness about his/her physical and mental impairment and the HDS’s awareness of negative reactions toward them. To understand how the HDS’s level of physical impairments influence the caring relationship, I explored the HDS’s capacity for adjustment to these impairments in order to determine what behaviors are more problematic for the HDC. The HDS’s reciprocity with the HDC was examined in terms of emotional response and gratitude expressed. The caring relationship was also depicted in terms of the “need to be cared for.” This feature varies from HDS to HDS and from the earliest to the latest phases. HDSs, as a result of the illness, undergo drastic changes in personality and moods that affect the caring relationship. For that reason, the HDS’s emotion also was included as an observational category. The increase in the severity of the illness increases suffering, and the HDS’ level of suffering was studied through the HDC’s subjective perception. The capacity of the HDSs to fight against the illness also was explored through the HDC’s narrative account.

The second category describes the most relevant elements of the caring experience to the HDCs. Caregiving requires a great amount of instrumental activity. This is explored in three different aspects: changes in the family routine, organization of personal time, and availability of external help. Emotional support provided from the HDC to the HDS is explored through the availability of other family members for decision making, and the capacity of the HDC for describing his/her role beyond any instrumental task. The sense of connectedness investigates the self-reported sense of emotional closeness as a result of the caregiving relationship. Emotional stress investigates challenges and problems faced by the HDC: self-reported emotional
resources, the meaning of the illness and experiences of regret. The HDCs also have been described as dealing with considerable fatigue. The category of struggle against fatigue was explored through four issues: self-reported fatigue, time and energy expended, social life effects and coping mechanisms against fatigue. The category “altruism” explores the expectations of compensation, the willingness to provide care for others and the perception of the moral dilemma of searching for institutional alternatives of care. “Personal growth of the HDC” will involve two different elements: sense of life accomplishment and mastery. The last element, carrier awareness, allows the researchers to consider all the categories of analysis with the perspective of the HDCs’ possibility of developing the illness. All the areas of observation mentioned above were developed in accordance with the theoretical model of this study.

The instruments applied in the interviews (See Appendix D, p. 231-238) include 37 semi-structured questions. I used part of this questionnaire in a pilot test conducted in 2002 with Colombian immigrant HDCs in Texas (Giraldo, 2002). In addition to these areas of concern, some questions were taken and adapted from a classic study in caregiving and stress from Pearlain et al., (1990). These questions were also tested by a quantitative study from Moore and Williamson (2002) to gather information about HIV HDCs in West Africa in 2002. The areas of observation and respective questions that were taken from those studies are as follows: HDS’s problematic behavior, HDC’s overload, family conflict, and issues related to having the dual role of caregiving and working outside.
In-Depth and Structured Interview

This study includes 35 current HDCs. Thirty of them were interviewed twice, and 5 were interviewed in a single long session because of the limited means of transportation in rural areas. A total of 70 semi-structured in-depth interviews with current HDCs were accomplished, 19 participants were from MDE and 16 from JDA. The average duration was 1.5 hours and the transcripts from the interviews comprise 1,200 pages.

The questions were stated as topics that are relevant to discussion, but they only were asked if the interviewee did not introduce these topics during the session. In addition, I scheduled two different interview sessions that allowed her to cover the topics related to the questions. Both interviews and focus group sessions were videotaped, audio-recorded and transcribed verbatim. They were recorded, checked for accuracy, and later typed for the subsequent analysis.

The interviews were designed to be 1 hour per session; however, in those cases in which important topics emerged, I explored the meaning of those topics, extending the interviews by a maximum of 30 additional minutes. In those cases in which the informant requested to postpone the interview, the interview was rescheduled until it was completed.

Participants with only a few years of education exhibited more difficulty in understanding the questionnaire when the questions were formulated. I used two strategies to solve this problem: rephrase the question using local expression and terminology, or ask the HDC to talk about the HDS’s illness. In that way the care issues that arose were used to further the dialogue.
I planned that in both interviews and focus groups, the information would be complemented by notes and descriptions about individuals’ gestures and surrounding settings, emotions, voice tones, etc. This complementary qualitative technique was not needed because the video tapes allow me to observe the scene over and over and to capture more details than could be captured in a single view.

Only one interviewee could not finish the second session because she was concealing from her children her suspicion that her husband had experienced the onset of the disease. This same interviewee refused to be videotaped but allowed me to make an audiotape.

After the first session, I went over the videotape data identifying unconcluded topics that should be readdressed in the second session. The second sessions in most of the cases were used to answer part of the main questionnaire and to extend and to clarify information from the first session. In some cases because of the short time and the considerable distance involved, it was impossible to reschedule additional appointments to complete the data collection, these interviews were far-reaching. In fact most of them are approximately 100 pages of transcription.

Most interviews were conducted at the interviewee’s home, although one interview was conducted at the University because the interviewee felt more comfortable talking in the university setting. Most interviews were accomplished while the HDSs were present because many of them could not be left alone for their own safety. In some other cases, they wanted to listen to the interview as it took place. Children and other family members went in and out of the room, but it did not disrupt the dynamic of the interview. This is the idiosyncratic way of life in the Hispanic population,
among the poorest people. Family privacy is scare, and anyone can interrupt without being considered impolite.

*Field Observation*

Fourteen HDSs from MDE and 14 from JDA compose the sample. Observation sessions of each HDC were performed, varying from 1 to 3 hours. Seventeen HDSs were observed twice and 10 of them only once. Most were observed for 2 hours before or after the interview sessions. Most of the observations were conducted in the HDC’s home (95%) while 5% were observed in the home of other close relatives. One HDS could not be observed because since the onset of the illness she has refused to be seen by anybody except her sons, her husband and her neurologist. Approximately 50 hours of observation were done.

I collected 300 pages of field notes from HDS-HDC interaction observation; these notes were not translated into English but they are used as part of the data for the analysis. The observation was an open one in which I interacted a little with the HDC and HDS while they were performing their routine activities, such as feeding the HDS. The reason is that non-interacting observations were very uncomfortable for the HDC, and some interaction allowed the HDC to act spontaneously and reduce reactive effects. Observations were valuable to assess the HDS’s phase and to understand the HDC’s answer in semi structured in-depth interviews.

I gained access to the caregiving setting through the consent of each HDC who participated in this study. The HDCs signed a written consent form in which he/she expressed understanding of the nature of the observation and the possible benefits and risks (See Appendix C p.238). Field notes were taken. One of the most important
strategies used in this study was to record key words and key phrases while in the field, to make notes about the sequence of events, to limit the time of observation and to write full notes after leaving the field.

Some HDSs socialized with me. For instance, a HDS who is a nun was allowed to travel with me from Medellin to a rural area in which her other sisters and brother with HD live. This family hosted me over a weekend, during which every one of her relatives with HD was interviewed and observed, via consent form. Her mother, the former HDC of her husband was also interviewed. In the JDA region, the opportunity to observe the normal interaction of HDCs and HDSs went beyond the 45 minutes expected for the observation.

Participants were enthusiastic about the research process. HDSs in the earliest phases were not passive subjects of the visit. They wanted to be groomed for my visit, and they wanted to listen and to ask questions. A particular occurrence happened with one of the nun’s sisters. She came by herself from another town during the weekend that was scheduled to collect data from her family. I talked with the HDS as a gesture of appreciation of her effort to come to the meeting, and the I took her back home in order to interview her husband, via consent form.

**Focus Group Interview Guide**

I had created a questionnaire with seven questions from the main interview with current HDCs, including questions from each area of interest of this study: the HDS’s behavior and the HDC experience (See Appendix D, p. 238). A special consideration for using focus groups in this research is that HD HDCs constitute a very small group. In addition, in Juan de Acosta, participants have low levels of education.
Focus Group

Eight focus groups were conducted, each comprising 6 former family HDCs. Half of the focus groups were in MDE and half in JDA. The HDCs cared for 25 HDSs who died with HD, making a total of 46 HDCs in the focus group. Four participants from a sample of current HDCs were also included in the focus group because they have the dual status of current and former HDCs. Another 6 caretakers participated in two focus groups for two different reasons: three of them were inhibited by the presence of other participants to speak candidly and 3 of them acted as gatekeepers to access other participants.

Focus groups five and six included only 3 participants because participants live in different cities. In addition, 4 individual interviews were done with those former HDCs who lived too far away to attend the focus groups from these interviews, 2 former HDCs from MDE and 2 from JDA. Adding the former HDCs from the focus groups (46) with the former HDCs interviewed alone (4) the overall total was 50 former HDCs. Transcripts from focus groups are 500 pages.

Each focus group lasted, on average, 2.5 hours. I set the location in the home of some of the participants, acted as moderator of all the groups, and provided food during the breaks. The date and down-time among sessions was set according to the convenience of most participants.

A fortuitous and successful outcome resulted from the use of the consent form. According to the consent form “the questionnaire will be given to participant at the beginning of the meeting, so you will know the questions that follow” (See appendix C page 224). By this means, participants in the focus group were better able to
concentrate on the topic of discussion and to make a more organized participation and presentation of their own ideas.

Despite the fact that this study lacks a research assistant, I did not take field notes after each interview or focus group because the videotapes provided richer data than audiotapes. Notes were not judged to be needed. The use of videotape allowed me to analyze all non-verbal communication and preserve all the nuances of particular situations during the session as well as to recall observations, impressions and intuitions that were be valuable for later analysis.

**Physician’s In-Depth Interview Guide**

The questionnaire created for interviewing physicians focused on obtaining information about the medical construction of HD, and their viewpoint about the major challenges that families deal with in caring for an HDS at home. This instrument also includes a question for identifying the type of stigma that HDSs, HDCs or medical practitioner encounter in the Colombian society because of the illness. The questionnaire also explores to what degree home care is the proper kind of health care needed for a HD HDS. Both questionnaires for physicians and HDCs include questions about institutional care and genetic testing that according to the HD literature are major concerns with this specific population.

**Physician’s In-Depth Interview**

The study includes face-to-face interviews with 7 physicians, including 4 neurologists; 2 general practitioners and 1 dermatologist-epidemiologist in addition to 1 neuro-psychologist. Each interview lasted an average of 45 minutes. Three interviews were conducted in their offices and 5 of them in their homes. Two physicians were from
JDA and 6 from MDE. The interviews generated 170 pages of transcripts. Two neurologists had conducted the largest neurological and genetic testing of HD in Colombia in different cities. Two others are neurologists who treat HDSs; 1 is a neuropsychologist who conducts neuropsychological tests for HDSs and keeps the pedigree trees of affected families. Three more physicians are relatives at risk who care for and treat relatives with HD.

*Key Informants Interview Guide*

There was not a pre-established interview for these informants. The content was established after I was in the field for some time and I identified issues of the local culture and popular knowledge that I needed to understand.

*Key Informants Interview*

A total of 6 hours of face-to-face interviews were conducted with 2 key informants from JDA, the vice-president of the HD local foundation and the elderly woman who can recall the pedigree and personal history of all those in the region who had HD. The transcripts of this activity generated 100 pages. The first key informant described in detail the situation of the HD HDCs and families who participated in the study. She provided information about the language and local mindset about the disease among those families who suffer the illness and those families who do not. She also described the socioeconomic and health conditions in the town and the local view of social solidarity.

The second key informant described the history of those who suffered from the disease in the past generation, discussing the treatment, beliefs and tribulations of
families affected by the disease 50 and 60 years ago. Both informants signed consent forms for this activity.

*Demographic Questionnaire*

From each of the 85 HDCs and 53 HDSs was collected demographic information through a questionnaire. It includes information on the HDC’s age, gender, marital status, social status, religious affiliation, education, occupation, health status and other common socio-demographic indicators. It also includes, among other questions, demographic information about the HDS, the phase of the illness process, the length and number of people involved in the caregiving, and the number of disabled people and children at home (See appendix D, Socio-demographic questionnaire, p. 239).

*Sampling Technique*

The sampling technique combines three main types of purposive sampling: particular cases, sought features and contrasting features (See figure 1 Sampling techniques p. 77). The combination of three techniques produced a clearly stratified sample. Although this is not a random sampling, it is larger than most of the typical qualitative studies and the combination of the three types of techniques produce a large array of features that enhance the sample quality (See appendix B, table 3 p. 222).

The number of HDSs in this study is 53, but the number of HDCs is larger (75) for three reasons: the length of the disease, its disabling nature, and a larger number of family members living in each household. The unit of analysis for describing how the three purposive sampling techniques were used for enhancing the sample is the number of HDSs.
Figure 1: Sampling Technique

Sampling for Particular Cases

The sample was selected from the population using the three purposive techniques proposed: particular cases, contrasting features and features sought. The most obvious type of particular cases included in the sample are the experts. Some of them are individuals who study or deal with HDSs and some others have specific knowledge about the affected people in each region. Two the experts, I looked for two types of particular cases in the HDCs sample: antithetical cases and key cases. In addition, two types of key cases were also sought: intensity cases and critical cases. Table 3 in page 236 makes a summary of the particular cases identified and used in the sample.

Sampling Features Sought

The study consists of a proportional number of HDCs in the six social classes existing in Colombia. It includes both genders and includes HDCs with educational levels consistent with those in the Colombian population. Other features take into account different care arrangements, such as in the number of HDCs per HDS. The HDS’s age and the HDC’s age are important aspects of variation as well as the type of
relative who cares for the HDS - brother, sister, children, parent, etc. Table 4 (Appendix B, p. 222) allows the observation that all cases included in the sample satisfied the criteria of maximum variation.

**Contrasting Sampling Features**

Half of the sample studied is people from cities and half, from small towns. The sample includes informal home care and paid caregiving. Those paid HDCs who were identified by relatives as primary HDCs were characterized according to different levels of training. The sample includes HDSs who are institutionalized and those kept at home, although this case is in some way deviant in terms of the Colombian cultural expectation. Another contrasting feature is length of the care period. The sample includes individuals who were HDCs from 6 months to more than 20 years.

Different living arrangements were also included in this sample, whether or not the cared-for individual lives in his/her own home or lives in his/her children’s or relative’s home and whether or not the primary HDC lives in the same household or lives nearby.

Differences in race and ethnicity were not found. I expected to include HDCs and HDSs in each of the five phases of the illness, but in the field, it was difficult to find an equal proportion of HDSs in each illness phase. The general tendency is for the number of HDSs to increase from one phase to the next.

The sample also included HDCs who have cared for HDSs still living and for those who have died. I expected to exclude those HDCs who cared for people who died more than 4 years ago, but this criterion was impossible to satisfy in the field with the
existing population. Twelve of the HDSs who passed away died in the last 4 years, and 13 of them died more than 4 years but less than 12 years ago.

The sample included HDCs with different family structures as well as families with different numbers of disabled members and with children under 12 years who also require care. I incorporated in the sample HDCs who were more oriented toward either an instrumental or an emotional type of care. It also contrasted the prevalent type of care provided, such as home care or institutional care. The sample includes HDCs with different health conditions, identifying and contrasting HDCs who have been tested with those who have not yet been tested. It contrasts cases in which HDSs have excellent care conditions with those HDSs who are neglected or mistreated. After performing the interviews the table of contrasting features of the sample was enlarged with two factors that were identified in the field: whether those at risk were interested in being tested and whether or not the HDC had prior experience in caring for other HD family members. Appendix B shows table 5 the contrasting features that were accomplished in the sample selection (see p. 223).

Analysis

During the data collection, videotapes were used as a theoretical sampling tool because after every session I had the opportunity to go over the session, looking for patterns that identified how participants solve their concern on caregiving. This means that each interview’s revision provided more clues about the direction in which the following interviews and focus groups should be directed or emphasized.
Transcriptions

The first step was to transcribe the Spanish audiotapes to text and then translate the text into English. The transcription was one of the most challenging steps in the study. For lessening human mistakes in the transcription of audio-records and videos, I used two Colombian assistants with prior experience in transcription. The technique for decreasing the number of human failures in the transcription was to provide transcribers with the audiotapes for bringing the interviews into text. After the transcriptors completed the transcriptions of the audiotapes, I used the videotapes for going over every transcription, correcting and adding all the details that were missing from the original transcription.

The auditory portion of the transcription allowed me to be aware of possible pitfalls in data collection. Audiotapes often have technical problems. There were at least five interviews in which one cassette side or both sides ran without recording, and there were no signs of malfunction during the interviews. Some audio recorders do not emit any sound when the cassettes reach the end and I spook into the recorder for minutes before being aware of this. The degree of fidelity of the audiotape is very low, and it is worsened by noises in the background, echoes and many other technical problems.

In this case I was able to solve all these problems because there were videotapes that served as backup of the data. The videotapes were used to complete and rectify the missing data from the audio. Videotapes do not have the technical problems of the audiotape; there is a clear signal of the beginning and end of the tape, and the researcher can remedy any type of malfunctioning immediately. In addition, the
accuracy of the videotape for capturing the human voice is far beyond that of audiotape. Transcriptions from audiotape may lose from 10 to 20% of the words in the dialogue.

Translation

Another step of data preparation was translating the data from Spanish to English, which took about 5 months. I and a Hispanic-American student with a major in Translation and Interpretation at California State University Long Beach did the translations. The translation of both were audited by an English-Spanish speaking editor at the writing center at the University of North Texas; and finally, a native English speaker (who volunteered her time) checked the overall meaning of the test with the perspective of an English speaker. My major professor was also able to check the data by reading some of the translations that according to her criteria were rich and valuable data.

Issues of credibility in the translation were addressed by using external auditing to approve the accuracy of the translations; it can never be exact, but only as close as possible to the original meaning. For preserving the vividness of some expressions, many key Spanish words and phrases that illustrate the richness of the culture will be kept in parentheses. I was literal with the narratives, writing every single word, in order to reflect the free speech and use of language contractions of the interviewee, to reflect voices pitches, and to use different symbols or prints for enhancing the meaning of the transcripts. Nevertheless, to convey the meaning in English, many paragraphs require modification and adjustment from the original sentences. Although translation of the research is accurate, translation always brings turns of phrases in which the readers miss the idiomatic expressions.
Data Processing

The codes were written in English but part of the codification was performed with Spanish transcription and part with the English translations because I codified the data while the translator was still working on the translations. The data were also organized into several major categories and finally a major theoretical model that will be presented in the results. Another important step was the cross-codification that was performed in Spanish for an expert qualitative researcher who provided an external auditing to the data analysis. After the information was reduced by codification and categorization, I created a conceptual scheme that showed the relationship between all major categories in the findings. A graphical display of this relationship will be presented in the results.

The data were codified using the regular word processor, and the qualitative researcher program of data analysis called "Ethnograph" was used for testing axial codification. The analysis of the demographics presented at the beginning of chapter 5 was performed through the statistical packet SPPS. After reducing the data, I performed the literature review in order to find other studies that support or contradict the study findings and wrote its results, including testimonies of informants to support my findings.

Credibility and Trustworthiness

The credibility of the study was enhanced by using four types of methodological triangulations; first, sampling triangulation; second, triangulation of instruments for collecting information; third, informants' triangulation and four, cross-codification.
The combination of sampling techniques described in tables 3, 4 and 5 (See appendixes B, pages 222 to 223) increases the richness and reliability of the study. The use of interviews, focus groups and observations also enhance credibility. The use of four different types of informants also boosts methodological triangulation. Another important instrument for increasing credibility in the findings is the use of cross-codification of two interviews and 1 focus group that allows me to compare the topic identified as relevant for another researcher.

Data Storage Issues

For enhancing methodological trustworthiness, the following methods were employed: The focus group sessions were spaced at least two days apart. Question sequence, electronic data recording, participant verification and a debriefing session were done through the use of videotapes. These methods helped me to reconstruct the information and avoided the effect of timing on the trustworthiness of the information because videotape can recall and capture information in full, which allowed me to consider the data during and after the collection.

Ethical Considerations

There was no inherent health or physical risk to those chosen to participate in the focus group, interview or observation as described. The informants were contacted by phone or in person to request their participation. In addition, before the interview or focus group took place, I read aloud to participants the issues of confidentiality and their rights as participants (such as “do not answer personal questions” or “refrain from participating in the study at any time if you consider the questions embarrassing or too
personal.” I explained to those who were not familiar with some of the expressions the meaning of the paragraphs.

Participants’ permission for recording the interview and videotaping the focus group was requested. They were also informed that the videos and audios will not be used for future studies, commercialized or broadcast. The observations of the HDS-HDC interaction were authorized via consent from. The HDCs who participated in the study were informed that HDSs would not be video-recorded and that only field notes would be taken during the observation.

Each participant signed a Spanish version of the informed consent form. In this study, proxies may also be used if is necessary. Three different consent forms were used for three different kinds of participants and activities (See Appendix C, p. 224-230). Each participant received a signed copy of the form. Having a detailed and written consent form helped to create an atmosphere of seriousness and reliance.

Records are kept confidential between me and the participants. The results of the study are compiled in a manner that makes it impossible to identify any single individual from the presentation of the study results. Participants were allowed to ask questions about the consent form, their rights as participants and the confidentiality of their identities and information that they provided. They were not forced to participate in the study, all were volunteers.

There were two minor incidents with participants. One interviewee refused to be videotaped but allowed me to make an audiotape. One HDS would not consent to be seen by me because she considers her illness an unpleasant condition that only very close relatives can see, but her HDC participated in the interview.
The ethical dilemma is that the study’s commitment to authenticity leads to descriptions or findings that create discomfort in some informants who do not feel well portrayed by the study. For instance, anger and aggression are two common traits in HDSs and HDCs may not be pleased to read these descriptions of people they love. Some others may not be pleased to allow relatives to know their resentment that the caregiving of the HD person is delegated to a single member of the family. Families have a facade that they struggle to maintain.

Support Provided to Participants

The participants of both interviews and focus groups received a gift of a Spanish version of a famous caregiving book by Mace and Rabins called “The 36-Hour Day: A Family Guide to Caring for Persons With Alzheimer's Disease, Related Dementia Illnesses, and Memory Loss in Later Life.” The books were provided as token of gratitude, acknowledgment of their spirit and tenacity, and awareness that most of them do not have access to literature vital to the performance of their caregiving roles. Poor families in the JDA region also received some money for groceries, and the Foundation was also given a much-needed computer.

In Medellin, families were less poor, and for that reason they did not receive any economic incentives. Although the idea of giving a book as a source of consultation for the HDC with little support and encouragement was present at the submission of the proposal, it was only when I visited the JDA region that the idea of providing economic support became a moral imperative.

These gifts could be seen as attempts to buy their participation that could bias their testimonies. But the context and manner in which the compensation was given
precluded this possibility. First, the gifts were given after the data collection had been finished; second, people participated voluntarily. They did not know that I would give them something since nothing was offered to participants in order to enroll.

Limitations of the Study Design

There was a problem in the design of one part of the study because I underestimated the HDSs’ skills and reactions to the study. The observation is an appropriate method for those HDSs who are in the latest phases of the illness, but in the early phases, HDSs are able to discuss their situations with me. They may be anxious or looking forward to being interviewed and having their observations heard and valued.

The methods should be flexible in this matter, allowing me to decide whether or not observation or interview was a more appropriate form to approach the HDS, but it was not modified for two reasons. First, to maintain the design for methodological reasons, the proposal must be carried out in a consistent manner. Second, this research would have been enhanced by direct interviews with HDSs, but because of their mental limitations it was impossible to use HD respondents.

The field notes cannot reflect the suffering of someone with HD. For instance, one HDS in JDA was observed through a cage. He lies on the floor, piled as mummies are buried in pots. There were severe bone malformations caused by choreic movements. Another HDS has a severe chorea that keeps her chest and head bent on her knees and her saliva and mucus flowing in her face without control. She can only return her body to a normal position with the help of her HDC, and only for brief
moments while the HDC feeds or cleans her. These are the kinds of situations common to HDSs that field notes cannot describe.

Justification for Methodology

There are many methodological considerations stated by qualitative research theoreticians (Berg; 2000; Creswell 1998, Lofland & Lofland 1995; Patton, 2002) that point out that qualitative methods are the most suitable method for studying HD caregiving in Colombia. An important consideration is the nature of the researcher's questions since all of the proposed research endeavors to represent in detail what is occurring through HD HDCs. Another consideration is the underdeveloped state of HD HDC research in the areas of medical sociology and caregiving theory.

The nature of the disease is still another consideration. HD has a domino effect upon the family, because a single sick individual in the family brings a set of unexpected effects and a chain of individuals whose life is affected for both the spread of the disease and the constant awareness of being at risk. In short, HD is a very intense and disturbing experience that cannot be captured in a quantitative study.

In addition, I consider the size of the population under study. The number of people with HD is lower than the number of those with other chronic conditions such as arthritis and neuro-degenerative diseases such as Alzheimer (Alzheimer’s Association, 2004; National Institute of Arthritis and Musculoskeletal and Skin, 2005). Therefore, a standardized study is not possible. Another factor is the level of education, since some of the participants, such as those from Juan de Acosta, have a low level of literacy and education. Therefore, a survey would be cumbersome and senseless for these JDA
people. Another consideration is the severity of impairment of some HDSs and the consequent increase in the demands upon family HDCs. Family members will experience difficulty participating in a study in which they have to be displaced from their natural environment. Furthermore, HD family HDCs must be studied in their own setting; otherwise, the study results will not be the same.

From the theoretical viewpoint some researchers report (Reinardy et al., 1999; Sheehan, & Donorfio, 1999) that the major body of research in caregiving has been done through quantitative methods in which the burdensome aspects of caregiving have been over-represented. Caregiving also has positive elements that only qualitative methods have recently captured. This is another reason to choose a qualitative design, since it will allow the exploration of both negative and positive dimensions of the process of surrogate agency and the theoretical model proposed (see page for more details on surrogate agency). Another reason for choosing a qualitative design is the selected topic, “social constructions of caregiving.” A qualitative design allows me to understand the perspective of interviewees, their life experiences and personal situations, expressed in their own words (Berg, 2000).
CHAPTER 5
RESPONDENTS' PROFILES

Characterization of the Participants In-Depth Interview

Thirty five current Huntington's disease caregivers (HDCs) participated in the interviews. Nineteen were from the JDA region and 16 from the Medellin region. Most of the current HDCs in the study were women, 87% in JDA and 91% in MDE. Current HDCs’ average age was 44 years in JDA and 49 years in MDE. In both regions, majority of HDCs (66%) are married or live in cohabitation. The most common type of family in both regions is the nuclear\(^6\) family (52%). In JDA, 48% of the families are extended\(^7\) while MDE has more variety in family structures, such as a single mother family (11%).

MDE HDCs have on average 9 years of education while JDA HDCs have on average 6 years. All current HDCs in JDA are low income workers while in MDE there are 36% with high income occupations. The most common HDC occupation in both regions is housewife (36%) and other occupations that allow the HDC to stay at home such as self employment and sewing. In MDE, on average, people have cared 6 years for the HD family member while in JDA the HDCs had served for about 12 years. All HDSs in JDA receive home care while in MDE only 83% receive home care (See table 6, Summary Socio-demographic In-depth Interview p. 90).

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\(^6\) Nuclear Family: “A nuclear family consists of a mother, father, and their biological or adoptive descendants, often called the traditional family” (Family Ties, 2005).

\(^7\) Extended Family: Two or more adults from different generations of a family, who share a household. It consists of more than parents and children; it may be a family that includes parents, children, cousins, aunts, uncles, grandparents, foster children etc. The extended family may live together for many reasons, help raise children, support for an ill relative, or help with financial problems (Family Ties, 2005).
Table 1
Summary Socio-Demographic In-Depth Interview

<table>
<thead>
<tr>
<th></th>
<th>Juan de Acosta Region (n=19)</th>
<th>Medellin Region (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Women 91%</td>
<td>Women 87%</td>
</tr>
<tr>
<td>Average age</td>
<td>44 years</td>
<td>49 years</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married 52%</td>
<td>Married 52%</td>
</tr>
<tr>
<td>Average years of education</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Occupational status</td>
<td>Low income occupation 100%</td>
<td>High income occupation 36%</td>
</tr>
<tr>
<td>Average number of caregiving years</td>
<td>12 years</td>
<td>6 years</td>
</tr>
<tr>
<td>Proportion of HDS cared for at home</td>
<td>100%</td>
<td>83%</td>
</tr>
<tr>
<td>Assistance for a paid HDC</td>
<td>20%</td>
<td>50%</td>
</tr>
<tr>
<td>Perceived Health Status</td>
<td>Healthy 73%</td>
<td>Healthy 67%</td>
</tr>
<tr>
<td>At risk</td>
<td>33%</td>
<td>33%</td>
</tr>
</tbody>
</table>

Seventy three percent of JDA HDCs reported that they enjoy good health, while in MDE only 67% report good health. In JDA, most of the families do not have paid helpers (80%) while in MDE 50% have a paid- for helper at home. There is a similar percentage of HDCs at risk in both cities (33%) as determined by the family relationship (see Table 6).

Characterization of Participants of Focus Groups

The sample for the focus groups includes 23 former HDCs from MDE and 20 from JDA. Women are the most common HDCs in both regions; the proportion being above 85%. In JDA, 90% are Catholics, while in MDE, participants were less
homogenous. Some of them defined themselves as non-practicing Catholics (17%) or Christians (12%). In both regions around 52% of the participants are married.

In MDE, the average age is 48 years while in JDA it is 40 years. The average years of education is higher among MDE former HDCs (12 years) than JDA former HDCs (8 years). In addition, MDE does not have illiterate HDCs; furthermore, there are some current HDCs with undergraduate (18%) and master’s degrees (13%).

All former HDCs in JDA work in low status occupations while in MDE, 30% of them have high income occupations. In JDA, only 55% of them are employed while the remaining percentage has a less restrictive occupation such as independent professions (10%) and housewives (25%). In MDE, 60% of former HDCs are employed and have high income occupations. 33.3% of the sample in JDA declared themselves as unemployed, against 7.9% in MDE, a 5 times higher rate. In JDA, former HDCs are compressed in three intermediate social classes, namely, lower class (55%), upper lower class (25%) and middle class (20%) while in MDE 52% of former HDCs are from the three highest social strata.

In JDA, 45% of them do not have children under 12 while in MDE, 30% are also caregiving for children under 12 years of age. In all JDA households, the HDS is the only member with disabilities, while MDE has two or more disabled people. Ninety five percent of JDA families have two or more primary HDCs while in MDE this percentage is lower (87%).
Table 2  
Summary Socio-Demographic Focus Groups

<table>
<thead>
<tr>
<th></th>
<th>Juan de Acosta Region (n=20)</th>
<th>Medellin Region (n=23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Women 85%</td>
<td>Women 85%</td>
</tr>
<tr>
<td>Average age</td>
<td>40 years</td>
<td>48 years</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married 52%</td>
<td>Married 52%</td>
</tr>
<tr>
<td>Average years of education</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>Occupational status</td>
<td>Low income occupation 100%</td>
<td>High income occupation 60%</td>
</tr>
<tr>
<td>Average number of caregiving years</td>
<td>12 years</td>
<td>8 years</td>
</tr>
<tr>
<td>Proportion HDS care at home</td>
<td>100%</td>
<td>83%</td>
</tr>
<tr>
<td>Assistance from a Paid-HDC</td>
<td>20%</td>
<td>50%</td>
</tr>
<tr>
<td>Perceived Health Status</td>
<td>Healthy 75%</td>
<td>Healthy 82%</td>
</tr>
<tr>
<td>At risk</td>
<td>65%</td>
<td>65%</td>
</tr>
</tbody>
</table>

In both cities, daughters are the most frequent HDCs (70% in JDA and 52% in MDE). In both regions, people have cared, on average, 13 years for the HD family member. In the MDE region, 50% of the people hire informal HDCs to help in fulfilling their HDC functions, while in JDA 20% of the families had a paid helper. In MDE, 7% of the HDSs are placed in nursing homes while in JDA all Huntington's disease Sufferers are cared for at home. In both regions, most of the HD patients are cared for, in their own home (66%) while a remaining 34% are cared for at the HDCs' home.

Among MDE former HDCs, 82% perceive themselves as healthy while in JDA only 75% report good health. In both regions, 65% of the former HDCs are at risk.
From those at risk in JDA, 50% want to be tested, while in MDE only 26% want to be tested (see Table 7, p 92).

*Characterization Experts in the Sample*

The sample includes 10 experts of whom 7 were physicians and 1 was a neuropsychologist. Two of them were key informants for the JDA region. This part of the sample is composed of 50% men and 50% women. Mean age is 45.5 years. 50.0% of them are married and 82.5% live in nuclear families. All of them are White upper class (70%) and upper middle class (30%) people, and all of them are Catholics. 6 experts come from MDE and 4 from JDA. The specialists have more than 19 years of education, general practitioners have 17 years of education and the key informants only 12 years.

In JDA the sample includes 2 White male experts. The clinical neurologist's reaches education is equivalent to a master degree, and he works as professor and researcher in La Universidad del Atlántico, He is also the health provider in hospitals and he has a private consulting practice. He conducted the largest study of HD in this region in 1992 and he is still linked to the population providing free consulting to HDs. However, his assistance is occasional because he resides in Barranquilla (1 hour from the HD population). He is a former chief the of the Secretaría de Salud del Atlántico (Atlantico’s State Health Office). Currently, he is involved in politics and has played a leading role in making HD families in JDA aware of the unfair exclusion of HD from the Basic Plan of Health in Colombia.
The second primary care physician resides in the town. He would like to be the primary physician for the HD foundation but he cannot afford to volunteer his work for the foundation because he is a new physician working in solo practice. He is at risk of developing the illness himself, coming from a family with more than 10 individuals who are affected by the illness. His grandmother is 88 and had has the illness for 20 years. The rate of progression of her disease is very low and she is still functional and the leading figure of her family. The physician has a highly significant and close relationship to his grandmother but he is not involved in her care. The key informants from JDA are White women age 32 and 82. Both of them are recognized by the JDA as local leaders. Both of them come from families with multiple individuals affected by HD. One of them has been confirmed as positive HD.

In Medellin, one of the neurologists is the chief of the Institute of Neurosciences of the Universidad de Antioquia. He is the first researcher who published a HD study supported by genetic testing in the state of Antioquia. Another neurologist is also
member of the institute. The third neurologist is the director of Clinical Neurology Department in la Universidad de Antioquia. The Dermatologist- Epidemiologist is a consultant for the Pan-American Organization of Health in diverse pathologies.

Among these physicians who had relatives with HD, 2 are women closely involved in the instrumental care of their parents. Their relatives’ disease had developed slowly, since three of them have suffered HD for more than 15 years are functionally in the early and middle stage of the illness. These relatives have required care only in the last 6 years. All HD relatives live in their own home and have primary HDCs different from the physicians (see Table 8. p 94).

Social Characteristics of the HDCs

The following shows the social characteristics of the entire sample, including in-depth interviews and focus groups. Without exception the HDCs are White, approximately 85% are women, and 90% are Catholics. The overall HDC mean age is 45 years. Age range goes from 17 to 84 years.

Among Colombian families, HDSs often have more than one primary HDC. One family alternated their HDC function among 7 women who cared for their father over a period of 17 years. In this study, patients often have two primary HDCs (33%); but there is a good proportion of HDCs who receive no support from other people in the family for caregiving (30%).

Age: the mean of caregiving years is 5.5 years; nevertheless, participants some have difficulty in determining the number of years that they have cared for their relatives. Many of them consider only the years in the late phase in which the patient is severely disabled or even bedridden. Nineteen percent of the participants in this study
cared for another relative with HD who had already died. The types of relationships with the patients were varied including at least 14 different relationships. But traditional HDC such as daughter (36%) and wife (16%) still predominate. In both regions, women outnumber men as HDCs. It is common for sisters to take care of their ill brothers; however, not one brother was taking care of a woman. In the same fashion, fathers were not caring for their ill children. Men in the sample are mostly sons (9%) and husbands (7%)

**Social/economic characteristics:** The distribution of the social strata matches the overall distribution of social strata\(^8\) in Colombia. In important to emphasizing the fact that taxes, services and prices are divided into 6 levels rather than the 5 levels used in the United States. Seventy six percent of the HDCs are from the lowest social strata, 12% are middle class and only 13% are from the upper classes. In the overall results, it was found that HDCs’ occupations influences their ability to perform this activity, the most common occupation being housewife, about 25% are housewives, 12% are house keepers and 12% are salespeople who usually have more flexibility in their working schedules. The spectrum of occupation is wide, 90% of them are not qualified occupations, but all of HDCs have work arrangements allow them have time for caring. For instance, the aesthetician, the optometrist, the salespeople, the dressmakers and the fashion designer run their businesses at home. Only 20% of the group work for

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\(^8\) The social stratification in Colombia uses a scale of 6 strata according to a classification of dwelling areas. This classification takes into account the following factors: habitat, physical environment, landscape, social prestige and quality of life in this neighborhood. Quality of life includes economic, social and cultural conditions inherent to the area. Nevertheless, the stratum of each household is revised and adjusted when it is superior or inferior to those in a particular zone (Departamento Administrativo Nacional de Estadisticas, DANE 2005).
other people while 80% have current jobs status that allow them the time to take care of their HDSs.

Marital status: Many of the HDCs were married (42%). Two types of families are highly prevalent, nuclear (50%) and extended (48%). There is a very small percentage of HDCs who are illiterate, 12% of them has less than 5 years of education. Most of the HDCs have either primary school (20%) or some years of secondary education (22%).

People at the household who need care: Forty eight percent of the HDCs care simultaneously for the HD person and either their children, the patient's children, or other children in the family. This is true for those HDCs who live in extended families and who take care of the children of young HD single fathers. Many participants of the focus groups relate how children become HDCs informally without a deliberate plan. Children from HD households are incidental HDCs for their ill relatives. They often run errands, prepare meals, do housework and watch over the HDSs when needed.

Most of the HDSs (56%) were the only person with disabilities at home while they endured the illness. Two HDCs (from both regions) cared simultaneously for two severely disabled people with two different pathologies. Another woman in MDE dealt with three HD siblings in a period of 10 years. This woman is in the first stage of her own illness but she is not aware of her condition. In another case, a wife reports herself as disabled because of her advanced state of arthritis and scoliosis.

Health status: HDCs were asked to report their perceived health status, and in the overall results, 75% described themselves as healthy. The remaining percentage represented all types of conditions; one of the HDCs was deaf from birth, another
became deaf as she got older. Four HDCs were undergoing the onset of the illness as was evident from their involuntary movements, and from their relatives who perceived them as sick. One of these HDCs with HD was the sister who cared for two brothers and one sister over a period of 10 years. Some others reported fatigue and stress, whereas others had chronic conditions such as high blood pressure or arthritis.

**HDS’s living arrangements:** Many HDSs were cared for in their own homes (65%), while the remaining 35% lived in the HDC’s home, for different reasons. Three mothers and 3 fathers in advanced states of the illness were taken to their relatives’ homes because they could not express their wishes as to where they were to be placed. Three HDSs were single brothers and sisters who needed assistance from a sister or another female relative who cared for them in their household. One HDS lived at the HDC’s home in a financial arrangement with other relatives finally, 1 HDS is a man whose estranged wife and children did not want to be responsible for his care because of a family history of domestic abuse. For that reason, he lived at the HDC’s home.

**Paid HDCs**

Seventy three percent of the participants did not pay for care. Only 28% paid for informal HDCs. It was difficult to characterize paid HDCs. Some families, although they had a maid or informal paid HDC who provided some care to the HD person, did not consider her as the primary HDC because the family still lived in the household and assisted these helpers. Some other families, regardless of living at home with their HD
relatives, considered that the primary HDC was the paid helper because she was the person who has a permanent and close contact with the HDS.

Some families had a maid who was expected to assist the ill person as part of her work duties, without any prior training or arrangement; some others hired maids as HDCs and instructed them to prioritize the HDS’s care over any other household duties. There were also families whose closest relatives (7%), such as sisters and cousins were very poor, and who receive small stipends for their care assistance. But what these women received did not compensate for their commitment and assistance.

Risk Factor in the Sample

In the overall results 60% were relatives at risk, but from this group only 1 person had had a positive test result. There were also 5 participants (7%) in the illness onset but who were not aware of their condition. The remaining were HDCs who were not at risk (41%) but were often concerned for the at-risk condition of their children. Among the 40 people at risk in the study, 75% had not been tested; 35% had been tested but did not know the results, while 5% (1 person) knew her result. There was no unanimity about whether people want to be tested. 35% of the people did not want to be tested and 45% wanted to be tested and to know the results of the test. Only one person was undecided about this option, and three of the HDCs, although they were at risk, were not aware of their statuses.
The specificity in the data will be determined by two crucial sociological features: namely, whether the Huntington’s disease caregiver (HDC) is at risk, and the region from which the data was collected. Both features are compared and contrasted through in-depth interviews with HDCs and physicians, focus groups, and observations integrated in a whole analysis. The end of each interview states the participant pseudonym, the region from which this interview comes (MDE region or JDA region), the type of instrument of data collection (In-depth Interview: II, Physician’s Interview: PI, Focus Group: FG, Observation: OB and Key Informants Interview KI), whether or not the participant is at risk (at risk: AR, non at risk: NAR) and the page from which it comes.

The results explore HDC’s phases that are tied to the changes and losses experienced by the HDS. Therefore, results are structured into the 5 HDC phases to explore the surrogate theoretical formulation. Each phase explains those components in the theoretical model that describe the most important issues faced by HDCs in each phase.

An Overview of HD Phases Expressed by HDC

The following excerpt demonstrates the dialectical theoretical relationship between the phases of HDSs and the HDC. Dario is a 26 year old male who cared for his mother for ten years in the JDA region. He watched the deterioration of his mother who would not allow others to see the ugliness of the disease. Dario shares his household with his father, his brother and his partner, who is expecting Dario’s first son.
He is currently employed, but he has not been able to find a job that commensurate with his education. He expressed ideas about the caregiving phases, and responded to different challenges that HDCs deal with throughout the illness; he reported:

[Phase 1] In the beginning, I did blame them a lot... because I would say, why me, why me? I mean, why do I have to do this and I don't know what I'm doing, I don't know what this is... ah? Like I was telling you, the most logical... both of them come, sit down, there is an illness, it is how it is called, this is what will happen [...] instead of that I saw how my mom was deteriorating, then... as it happened, I was learning everything, but as it happened... man if, what's more, in the future this is going to happen [...] but no, it was when I was 16 years old, I have... no idea... so I blamed everyone in the world because you say, why me? If I'm just a kid, I'm young, I should be playing soccer in the Atlantic league [...] but it was a short period, thank God... from the blaming to the learning... right away (Dario, JDA, II, AR, p.40).

Dario's comments reveal that in phase 1 as a HDC he did not understand the deterioration of the disease. He began to learn about the disease at age 16, following the wasting of his mother's body. He felt conflicted as an adolescent who desired to play soccer, but was trapped in the caregiving role. He continued to talk about phase 1:

[Phase 1] So my first process we can call it... let's say... the process of ignorance... for me... I didn't have a clue about anything, I didn't have a clue about anything and everything was a question... then it was the phase of blame, [...] Why me? Why did this happen to me... why me, because I am the oldest? So, it's my responsibility. Why my brother didn't care much? [...] Besides, I felt fear that I could also get sick, oh my God! What an inheritance... that I will receive! And that is the most difficult phase, and the longest... it took me almost... two years, that Phase... two years, from the time that I didn't want to know anything about anything, I would go crazy a lot (Dario, JDE, II, AR, p. 40).

In phase 1, Dario became overwhelmed by the stress of the disease. He did not know what to expect and questioned “Why Me”. Leal (2001) in her portrait of HD shows that many HDCs answer themselves this question through faith, because they think that the HDC role is predestined by God (Leal, 2001)
Dario also questioned his own mortality and sadness about his inheritance. Register (1999) found this permanent sense of potential threat in chronic patients because they do not know how soon they will become worse or die (Register, 1999). Dario continues expressing his feeling about phase 1. He remarked:

[Phase 1] I started studying for a career, I didn’t care about anything, right, I dropped my studies, ah... and it was a very difficult phase... very hard, you pull away from the whole world, you are too alone... (Dario, JDA, II, AR p. 40).

When Dario and other interviewees such as Blanca and Rosa allude to phases and emotions such as denial, anger, bargaining, depression and acceptance for describing how they see dynamic changes in their roles as HDCs, they may be recalling some of the main elements from the popular grieving theory formulated by Kubler-Ross (1969). Nevertheless, Kubler-Ross’ theory does not reflect the complexity of issues tangled in the HDCs experience as Dario stated:

[Phase 2] Then comes the phase of acceptance, where you are like... things are like this and you have to face them... then when you face them, then everything that comes next is learning. It’s all learning and whatever comes down the road... to go... after that it’s not your phases... your own... then it is the patient’s phases... (Dario, JDA, II, AR, p, 41).

Dario’s words allow us to understand that as a HDC he is aware that caregiving is a process. This process is not merely a series of inner processes that he recognizes in himself but rather is a contingent answer on the patient’s needs. The pace of the illness phases also will force the HDCs to change their attitudes, roles and perceptions about themselves as he expresses in this paragraph:

[Phase 2] When you enter the phase of learning, it is because the patient is very ill. She is really needy. In the phases of... of blame and in the phase of... of solitude, that is... of fear... the patient is still a little able
himself, right? but the phase of blame ends when the patient really needs help, then you forget about your former feelings (Dario, JDA, II, AR, p. 41).

Dario is stating that in his second phase as HDC he is pressured to fulfill his mother’s needs. He describes the type of concern as a HDC he experienced in the first phase. He felt guilty, afraid and isolated but the HDS performed her personal activities, by herself. When it is evident to him as HDC that his mother is starting a new phase in which she need more effective help, Dario’s first caregiving phase ended. The following comments reveal the process through which Dario passed to phase 2. In this phase, Dario struggles to maintain control, despite the fear, pain and apprehension. He stated:

[Phase 2] It was a sudden process, I mean, it’s like that start of that phase in the patient kills your phase… I mean, like it touches you… yes, I mean, you have fear, but that phase of needing you begins to kill that phase of fear… I mean, like it… I still continue feeling fear, suddenly, at times, I am attending the patient with fear, with, with a lot of apprehension, with a lot of pain inside… but… you have to be aware of the patient, so that phase begins to kill your phase of fear (Dario, JDA, II, AR, p. 42).

Dario uses the expression that “the patient phase kills your phase.” This means that he sees his own phases triggered by the needs and challenges that his mother places upon him as HDC. This is clear evidence that caregiving is a dialectic relationship in which the HDC is interpreting things such as physical and functional deterioration as signals that require a new contingent action. In short, as Blumer (1937) states, in the symbolic interactionism perspective, HDC’s actions “are always joint, in which the mutual response and adjustment of the actor and others are considered” (Blumer, 1937). Dario’s description of the HDC’s phases also shows that among those HDCs at-risk, the most striking factor of suffering is the awareness that in the long run the illness will also beat him:
[Phase 3] You reach a moment in which you suddenly do, you fear that you might become ill, you fear that you may be the next one, yes, but when you start learning about the needs, that fear begins to diminish...You become aware that the illness exists, and that you don't have adequate medical treatment, although there isn't a vaccination, a cure, or whatever, there is a process of care that can begin to tranquilize you, right? If you can count on a person to be at your side, to be aware of the illness, to be aware of everything you are living, ah... you calm down a little... (Dario, JDA, II, AR, p. 43).

Dario talks about his main concern, being at-risk for a disease in which there is neither treatment nor cure, and the only source of certainty is the safety net that an individual creates with relatives, who are also at risk. If he can rely on someone to care for him as he is caring for his mother, then there is hope. This means that in countries like Colombia without resources for Huntington's disease sufferers (HDSs), the care pact among relatives is the most important source of emotional stability. Nevertheless, Dario's words also demonstrate that for those HDCs at risk, the possibility of developing the illness is a constant threat. This awareness is part of the process that HDCs go through during the earliest phases, as Dario stated:

[Phase 3] The fear begins to fade, begins to stop, it is inside... obviously... the fear is inside... ah... ah... that fear that causes you a rush to live... to live now, thinking about the future, but to live now... because you don’t know in the future... right? For example, I have an uncle, the uncle... a... he got it when he was young, he was very young... I think he was my age, a little more... my mom was forty-three years old... right...if you calculate, you say, well, I have twenty, when I am forty-three... I still have twenty-three years... some calculations that can be illogical, right, but they give you a little hope, that I have so many years to do something, to leave something, to not go through life unprepared, yes? (Dario, JDA, II, AR, p. 44).

In his interview, Dario also said that through the time he had served as HDC he had learned to interpret signs of his mother's deterioration. HDCs know when the HDSs
are moving to a more critical phase of the illness, in which they will require more instrumental help. Darios explained his entry into phase 4:

[Phase 4] So… and that phase… you start the phase of learning and the patient begins the phase of deterioration, and the first thing is the touch, well? It’s the… the motor skills, in the hands, what you loose… yes, you can’t hold things very well, or with too much strength, you can’t eat, you can’t do manual activities; the legs are ok, you can walk, yet you can’t control your hands completely, so… a phase begins when you have to help them grab things, without humiliating the patient, because I have learned that… I mean, never… the… the worse thing you can do is treat a patient like an invalid, yes? Like an invalid, man, it’s just that a person who has lived their whole life, who has taken care of themselves… for you to come and treat them like an invalid… it’s an illness that you have to treat with a lot of… astuteness, that’s one way of saying it, yes, to help them… (Dario, JDA, II, AR, p. 45).

Dario also showed that as HDC he has developed mastery for assisting his mother. Through the phases he has become self-reliant and proud of his accomplishments as HDC. HDSs require a very skillful HDC who is able to interpret their signs of discomfort; otherwise, HDSs begin to engage in disruptive behaviors. HD HDCs must also be extremely tactful in helping HDSs to perform activities that have become difficult for them, as Dario reported:

[Phase 4] To help them, but do not … take away… that activity, well, if they can do certain manual activities, you are going to help them, you are not going to tell them move I’ll do it, no, you are going to help them with that activity, right, this… it’s the act of not taking away the activity but, to instead help them, right, after that, then comes the motor skills in the legs… that is very difficult you know… they begin to trip, they begin to fall, it’s not the same, it’s not the same… first it’s the hands, then the legs… well, that’s what I have experienced, first with the hands, then the legs. So, you have to… that exercise, right, the let’s go, let’s walk, let’s go around… (Dario, JDA, II, AR, p. 46).

Dario describes phase 5 as the phase in which the mental abilities and self-consciousness are seriously affected, increasing the complexity of HDC tasks. As a
HDC, he finds this new phase far more challenging because his mother often focuses her aggression upon him and other close relatives.

[Phase 5] We arrive to have her sitting in a place... Those are suddenly things related to age, I don’t know when... when you become an invalid, no, right, but you do begin losing your abilities periodically, progressively... the hardest phase comes... with the consciousness... with the mental part... when you suddenly begin not to recognize things, when you suddenly... there is a phase... when you don’t recognize many people of today, but you do remember people from the past. [...] After that appear aggression (Dario, JDA, II, AR, p.47).

Dario’s closing paragraph demostrates his mother’s grief of loss abilities. The most common expression of grievance in HDSs is anger, which should be viewed with the perspective that HDSs lose their ability to express their needs and desires, as Dario reported:

The aggression appears in the beginning of each phase of dependency, right? Because of the fact that they don’t want to accept that dependency, yes, I mean, they become aggressive because they don’t accept that they have to depend on you in some way... They depend on you to get things... no... they depend on you to bathe them... no... they depend on you to brush their teeth... no! It’s at the beginning of each dependency... that aggression... it’s... it’s... but it’s at times more... suddenly because of their pride, because of their dignity... I don’t know... how to describe it... it’s at the beginning of each dependency... then my mom has moments where no... where she doesn’t turn aggressive, she is suddenly irritable, different, irritable, because... things annoy her or they bother her, but not aggressive, she doesn’t hit, she doesn’t kick, no... she doesn’t insult, she doesn’t scream... right? (Dario, JDA, II, AR, p. 48).

After this overview of the phases through the words of a single HDC, I will describe in more detail the phases that other HDSs and HDCs undergo.
HD Sufferers in Phase 1

In this phase, according to the theoretical model, HDSs, fight against the illness, suffer, deal with reciprocity, physical impairments, social embarrassment, depression and anger, and have a low need for care by the HDC.

Suffering

The suffering of HDSs in the first phase is evident through the difficulties of motor coordination, loss of awareness, and changes in cognitive abilities. Juan, a well-known psychiatrist who suffered HD for more than 20 years and passed away in 2004, would, at the illness onset, forget where he placed his wallet or documents (Patricia, MDE, GF, AR, p. 5). Similarly, Blanca, a prestigious physician, talked about the suffering of her mother. She observed that “at the illness onset her mother was grieving because she could not participate in physical exercise or perform tasks which required complex coordination” (Blanca, MDE, IP, AR, p.7).

The data showed that physical limitation was a major source of suffering for a number of the respondents. For instance, Regina, a 56 year old HDC from a rural area in the JDA region, has cared for her husband Ariel, who suffered from HD for more than 7 years. The illness has not advanced at the same pace as other HDSs in JDA. He still retains mental capacities. Ariel was one of the HDSs who was alert and, therefore he could be interviewed. During the observation, he put on his best clothes. While I observed, he talked to his wife Regina and Alicia, the vice-president of FUPAEHJDA. He told Alice that “he is not sick, it is just that when you get older you are worn out” (Ariel, JDA, OB, AR, p. 1). Ariel’s opinion is partially true since the limitations and restrictions that he has confronted now that he is 60 years old are outcomes of getting
older. Nevertheless, there are limitations for working that he does not realize are caused by HD. Ariel’s behavior is characteristic of an anosognosic HDS, in that, he is unaware of HD symptoms. Regina’s recalled the difficulty Ariel faced while he lost physical abilities, and his breadwinner role. She remarked:

The last Christmas, he went to the countryside to collect some yucca (comestible root) and he did not bring any yucca…. he fell and got broken his arm. Now he constantly argues because we do not let him go to the countryside to clear bushes, because he can cut himself. That is the reason that he does not go out to work. His son does not allow him to go to the countryside because he can cut himself or fall over there, but my husband does not give up easily, always searching for something to do” (Regina, JDA, II, NAR, p. 1).

Other interview revealed that one HDS who had been suffering for twenty years never believed that he was ill, even though others saw his deterioration. One extreme example was Hector in the JDA region. He was 74 years old and a retired surgeon who was unaware of his illness. His wife, Lucia, reported the following, “I am tired of looking after him, I have to stay behind him like a small kid because you never know what damage he is doing, and there is no point in scolding him. Talking to him is like talking to this chair. He does not think that he is sick, but that the only sick person in this house, is me” (Lucia, MDE, II, NAR, p 87).

Paulsen, (1999) and Pollard et al., (1999) have described this phase as severe depression due to the awareness of the losses caused by HD. Studies have shown that HDSs develop progressive anosognosia. Often HDSs fail to recognize their physical and cognitive deterioration due to brain dysfunction. Ibarra, a neurologist from the JDA region, explained that anosognosia makes it difficult for HDCs and physicians to interpret signals of suffering and Ibarra stated:
Most of the patients who suffer from dementia, among them HD, do not realize their deterioration. They begin to lose capacities and many times it is the family who notices it. [...] The patient does not have insight about his pathology. We call this also the sense of illness in the patient. The patient may have anosognosia or no sense of being ill [...] If there is no sense of illness, there is no anguish about the illness, but this can be merely our observation. We do not know if any of the behaviors that the patient presents, such as the exacerbation of symptoms, insomnia and somatic complaints, are manifestations of the patients' anguish. What we call anosognosia or loss of the sense of being ill, perhaps it is a way to show suffering but neither the HDC nor the physician can recognize it (Ibarra, MED, IP, NAR, p. 6).

Nikolinakos (2004) studied how anosognosia affected the unity of consciousness. Consciousness integrates both non-reflexive and reflexive consciousness. Non-reflexive consciousness is the way people experience phenomena, while reflexive consciousness is the awareness of how a phenomenon is experienced by the self. Reflexive consciousness is the mechanism that allows people to be aware of feelings, desires, sensory experiences and beliefs. This also involves certain capacities such as the capacity to interpret, recall information and make plans.

Giddens (1986) also suggests that reflexivity is a core feature of human agency (Giddens, 1986). Patients with anosognosia develop problems with non-reflexive consciousness and a complementary loss of reflexive consciousness because they are unaware of their physical losses. Although anosognosias suggest that both types of consciousness are disjoined, fragmentation varies among HDSs (Nikolinakos, 2004).

According to Nikolinakos (2004), monitoring ability is a central feature to understand human beings as agents. When the monitoring processes decrease, the ability to understand the condition is also decreased. In short, a person whose capacity for monitoring is decreased suffers an important loss of human agency (Nikolinakos, 2004).
According to Nikolinakos, anosognosic patients fail to realize that their agency has been diminished. Such an observation is important for two reasons; first, because it provides evidence of the surrogate agency theoretical model, which suggests that the agency of HDSs has been diminished. Second, anosognosia is a common feature among psychiatric and neurological patients. In fact, the National Alliance for the Mentally Ill of New York reported that 40% to 50% of the NY homeless population experience anosognosia.

Often programs for the homeless fail to recognize that such people are unaware that they suffer a mental illness (The National Alliance for the Mentally Ill of New York City Metro, 2005). Nikolianos’ and the National Alliance for the Mentally Ill’s observations are important because HDSs often comprise the beggars or homeless population. Consistent with Nikolianos’ finding, in a JDA focus group, Alicia reported the stigma of her father, an HDS who begged without feeling shame. She reported:

He would start begging in the shops, give me a banana, then the man in the shop one day said, “You don’t give any food to that man, he is… eh… he’s like a mad man, I don’t know,” I told him, “No sir, what’s wrong is that he is ill, with HD, and you do not need to pay much attention to him.” If you don’t want to, don’t give him anything, because he eats at home […] I would then tell him not to go to the shop, because… the people in the shop didn’t want to give him anymore, because… so he ended up as a beggar, begging… a hundred pesos to smoke, a hundred pesos for a banana an so on (Alicia, JDA, FG, AR, p. 15).

The data showed that anosognosia was common in this sample. For example, Antonia, 59-years old, who had two brothers and two sisters with HD, and who is also at the beginning phase of the illness, reported that her bothers were well educated and outstanding citizens. However, following the diagnosis and progression of HD, they were homeless and street beggars. Antonia explained:
My other brother, Alexander, lived in the street and sold newspapers to get some money. Imagine that he was standing there until four or five p.m. [...] and I said to him, “look it is five p.m. People are not going to buy them.” The newspapers were totally black and destroyed and nobody would buy that newspaper. He didn't have any notion of the time (Antonia, MDE, FG, AR, p. 96).

Antonia reported that another brother, Martin, went to church nude to beg for charity. She reported the disheveled and disorganized lifestyle that occurred following the progression of HD. Antonia described the incident. She reported:

Martin went nude to the church to beg for charity. Then, people said to us, "Look "Martin is naked at the San Cristobal's church begging for charity." We went there and we found him nude, begging. He didn't take a shower. He had the room full of urine. He lived in the most terrible condition that you can imagine, because he didn't have anyone to look after him, except when I went there. He did not have someone who stood by him all through the illness. He lived in the most terrible filthy place in the world; he lived with all the drug users who took over his home (Antonia, MDE, FG, AR, p. 15).

The finding that anosognosia is a characteristic of HD places even more psychological stress on HDCs.

**Cognitive Impairment**

Patients from both regions exhibit cognitive loss, obviously affecting their productive lives. Alexandra was unable to perform simple mathematical operations such as knowing the cost of two bags of milk. (Blanca MDE. IP, AR,. P. 3) Wilmer and Eduardo at the illness onset lost their employment because their work consisted of counting money and they were unable to balance the books correctly (Magnolia, MDE, IE, AR, p 80; Flor, JDA, II, AR, p 36). Juan forgot the names of common objects and tried to take a shower without taking off his clothes (Adriana, MDE, FC, AR, p. 4). In this
period, there is a fluctuation of the cognitive capacity. Often they seem to behave rationally. Javier’s HDC recalled in a focus group in MDE. Juan’s daughter, a 50 year old well-educated HDC gives a good lay definition of dementia. She stated: “Dementia is the loss of capacity for judging things that you managed before, like knowing how much a bag of milk costs” (Rebecca, MDE, FG, AR, p.1)

In the first phase of the illness Juan experienced suffering because he was aware of the cognitive changes. Adriana the 45 year-old daughter of Juan explained:

Juan was anguished because when he began to lose his capacity to express himself I went to him with a paper and said to him, “Father, come and write me something that I know you are capable of writing.” Then, he began and he wrote a paragraph in four languages [...] The only word that was coherent and I understood was “anguished” (Adriana, MDE, FG, AR, p. 31).

Juan’s remarks also demonstrated the variety of patterns within the theoretical phases

*Fight Against the Illness*

An interesting finding showed that region influenced the way in which HDSs fought against the illness. For example, HDSs in the rural area fight against the illness by trying to maintain their former life. There is certain passivity about the illness. They work in farming activities as much as they can, but they do not understand that new strategies are needed to improve their quality of life. Gerardo, a 42 year old farmer who is caring for his 39 year old wife Karina claimed: “Well, there is no reason for not moving, my wife wants to do things that must be done at home” (Gerardo MDE, IE. p. 6). In contrast, people in the city strive to be active agents fighting against the illness, searching for reasons to do so and developing strategies for combating the illness.
Lorna, a 23 year-old HDC who cared for her late grandfather Jaime since her childhood, recalled him as a man of enormous strength. Lorna recalled:

My grandfather said that he had to train every day so that the illness did not defeat him. Every day, he went out and made everything by himself. He made self-examinations because he wanted to know if he was alright or wrong that day. He called me and told me: “Look, I still have good balance” because he was still able to stand up on one leg. He tried to overcome the disease. Day by day, he ate alone and made everything alone. Nevertheless, he could never urinate without spilling, he didn’t calculate well and I think that he was always anxious because of his illness… (Lorna, MDE, FC, AR, p. 130)

In the same focus group, Julian, a 30 year old HDC who cared for Jaime’s sister, who also was affected by HD, related the power of his mother Caridad to overcome a lymphoma, and later, HD just because of the strength of her spirit,

My mom was a special case because what preceded HD was a lymphoma. This cancer weakened her, greatly. I think that she wanted to fight because her children were young. She said to herself, “I have to take care of them,” and because of that she did not give up (Julian, MDE, FC, AR, p.132).

Julian also reported that because his mother was a lymphoma survivor. She suffered a lot but she fought against HD. Julian explained:

Her children were a motivation to live because she wanted to care for us. The doctors said that she would not survive this cancer more than five or six years, but the lymphoma never recurred […] She overcame her cancer but she never imagined that in the following years she would develop HD, and for 20 years she would go through more terrible pain and suffering than the lymphoma had caused her (Julian, MDE, FC, AR, p.132).

Adriana also emphasized that her father Juan suffered, but he did not want to die. In spite of the fact that had he HD and diabetes for many years, in the first phase of the illness he struggled actively against it and tried to preserve his capacity to enjoy life.
Strauss (1975) found that patients fight actively to overcome illness crises (1975).

During certain chronic conditions there are periods of recovering and periods of exacerbation. However, in HD, the trajectory, the course of disease is always downward, with no periods of recovery.

Co-morbidity: This study also found that HDSs such as Juan and Caridad had more than one disease. This condition has been chiefly observed in the medical field (Lubkin, 1998) and has been the object of interest to medical sociologists (Bisschop et al., 2003; McQueen and Siegrist, 1982), Among HDSs, comorbidity increased the complexity in caregiving assistance.

Reciprocity

According the surrogate theoretical framework, in phase One, HDSs possess emotional connections that allow reciprocal HDC relationships. In this study, however, seven HDCs described HDSs as apathetic. Leon from MDE and Pedro from JDA, two middle-aged HDCs, described their wives as sexually apathetic (Leon MDE, II, NAR, p. 30; Pedro, JDA, II, NAR, p. 8). Some others, such as Johnny and Eduardo were described as having a lack of interest in work (Julia MDE, II, AR, p 16; Flor JDA, II, AR, p 40).

Others, such as Hector and Gregorio were described as lacking interest in family relationships and leisure activities (Lucia, MDE. II, p 45; Sarah, MDE, II, p 40), Nevertheless, those HDSs with young children such as Doris, Leonardo, Jaime, Esteban, Gloria and Martha cared for their children and their partners, and performed housework as much as the illness allows. The ability to develop connective relationships
with other relatives and friends is evidence that they have a degree of reciprocity with their HDCs and family which allow them to have social support in this phase.

Close relatives and HDCs are aware that most people cannot notice the effects of the illness, but merely view the symptoms as a movement disorder. Julia, a 17 year old HDC of her father, states that “When people see him the town, they think that my father only has involuntary movement; they do not notice his other problems, for instance that he does not know when people do not give him the right amount of change” (Julia, MDE, II, AR, p. 21).

Apathy affects seriously the capacity to reciprocate the HDC because HDSs loses emotional warmth. They fail to see different points of view, and lose interest in everything once held dear.

*Physical and Mental Impairments*

HD affects physical and mental abilities. The changes are noticed in phase 1. Often they converse poorly and repeat themselves, as was observed in both regions. For instance, Alexandra was observed interacting with her paid HDC.

Her paid helper was trying to talk to her about different issues but she always came back to the same issue that occupied her mind this day. She was bothered because the researcher invited her to go out and she did not park her car in Alexandra’s parking place. Although the researcher and HDC explained to her that her car was parked two blocks away, she could not understand that explanation and refused to go out (Alexandra, MDE, OB, AR, p. 1).

In this period, HDSs are aware of their physical impairments, and compensate for such behaviors. Leon remarked: “Now, when she comes here she goes all the way around avoiding this steep street, and if it is raining she chooses another street. She is afraid because she has fallen three or four times (Leon, MDE, II, NAR, p. 17).” In this
phase, regardless of their limitations, HDSs are able to stay at home alone, perform routine activities and go out alone, which implies very little need of instrumental help. Flor, a 36 years old female who supports her three children and her 47 year old brother Eduardo, said about him, “He is not bedridden; he cannot work, but he can clean the dishes and help with the housework” (Flor, JDA, II, AR, p. 23).

Coping with Stigma

Through all the phases of the illness HDSs experience social embarrassment. Carolina’s interview showed how the stigma of the disease affected her husband's behavior and social interaction. She is a 42 year-old HDC from MDE who cared for three different generations of HDSs: her late grandmother, her late husband, and his 21 year old son who has had HD symptoms for three years.

Carolina reported the stigma attached to the illness as she cared for an abusive HDS. She said that her husband, a highly qualified professor, was abusive before and after the illness onset. However, the stigma of the illness also involved Carolina’s son addiction to marihuana following the diagnosis of HD, which created social embarrassment.

Carolina’s husband died three years ago, but she recalled the social stigma of the illness. She stated: “His personality, in combination with the physical impairments, hindered his role as a faculty member. In fact, that’s why he retired from the university, because the students thought that he was always drunk, because he was clumsy. I think that he kept working for eight years after the illness became evident” (Carolina, MDE, II, NAR, p. 51).
The data indicated that HDSs often reacted negatively to health care facilities, doctors, nurses and various health care personnel. Often they demanded the constant care of HDCs or they refused medical assistance and procedures when hospitalized. The respondents reported that a sense of hopelessness and distress caused the refusal of medical treatment. For instance, Carolina reported, “When Tiberio had an appointment with a neurologist, he would say, ‘quit bugging. If I knew that I was going to get better, well, I would go, but I’m worse all the time” (Carolina, MDE, IE, p 14).

This rejection increased through the phases and caused emotional stress. For example, Tiberio, even in the last two phases of the illness, opposed medical treatment. Carolina explained:

When he was very ill, too disabled to go, I would tell him, ”Dear, will you go with me to this place,” but it was to take him to the doctor, I would deceive him to take him there. When I took him I had to take him in a wheelchair because it was on the top floor, and he didn’t like that. He didn’t like people to see him in the state he was in (Carolina, MDE, IE, p. 14).

Carolina also told about the films that the neurologist made of her husband. “When he was ill, it was like he would dream that they were filming him, and he would say, “ no, I don’t want them to film me.” I don’t know why, but it was later when he was really impaired. (Carolina, MDE, II, NAR, p. 54)

Goffman’s (1961) concept of stigma describes the processes that Carolina recalled in the interview. Her late husband, Tiberio, resented the stigma of HD disorganized movement as well as the changes in physical appearance. As Goffman observed (1961), deformity increases the visibility of the stigma because this feature attracts attention (Goffman, 1961).
Indeed, HDSs experience great social stigma. For instance, they cannot be seen in public, without being noticed by others. Additionally, Chiu (1996) suggests that in social settings HDSs have more involuntary movements because their level of anxiety increases (Chiu, 1996). HDSs cannot conceal their spoiled identity. Carolina remembered: “When Tiberio quit his job as professor he was intellectually productive, but he hated that students paid more attention to his involuntary movements and slurred speech, than to his lecture” (Carolina, MDE, II, NAR, p. 55).

Importantly, Tiberios’ story is typical of the social stigma of HD, although however, experiences of stigma vary among HDSs.

In short, the first stage, HDSs show more energy and emotional resources for fighting against the illness than they do later. Depression, anger and shame are strong emotions among HDSs, but these emotions dim through time in accordance with the functional phases.

HD Caregivers in Phase 1

Suffering

Suffering is a central feature of HD- and HDCs’ experience. It is the believe in the culture of Latino caregivers that only blood relatives can experience the concern for HDSs. Responsibility, concern and attachment to identify with the relative’s suffering. Therefore, being sick, going through crises and coping with uncertainty are the major reasons that make HDCs experience the care concern as an unique way of suffering.

Caring about, as Fisher and Tronto (1990) state is the clearest expression of connection with others, but this connection is simultaneously a source of sorrow. HDCs
experience mental suffering and pain. Flor described this experience “What I said is that other people won’t hurt for them (worry) in the same way that I feel their pain. If this person is blood from your blood, you care about this person and you feel that you are connected to this person” (Flor, JDA II, AR, p. 3).

In the first phase, both HDSs and HDCs experience denial and grievance, especially those HDCs who have never before cared for this type of illness. In the JDA region, Pedro, a 45 year old HDC, is taking care of his 40 year old wife, Pilar. Pilar was an orphan from early childhood, and never knew her father and his other children. She moved to Barranquilla with her mother’s sister and never knew until the illness onset that her father, her half-siblings and half-cousins had HD.

Pedro, as well as other interviewees, had little knowledge of HD and for that reason, he expected his wife to recover. He claimed: “She is suffering because she does not want to be like that; she wants to be a normal person. I tell her that she is going to recover, that she has to trust. She prays to God, she prays for her cure. We have faith that God will cure her” (Pedro, JDA, II, NAR, p. 9).

HDCs in the early phases often expected a cure, but hope disappeared when the patient deteriorated. Data also found that HDCs expressed hope that the illness would progress slowly and smoothly. For example, Julia, from a rural area in MDE, was married at age 17 and she lived in an extended family, including her father, Jonny, a 43 year-old farmer, had been sick for 4 years. At the end of the interview she stated, “I hope that someone will soon find a cure, but if they do not find a cure I hope that this illness does not make my father become bedridden soon” (Julia, MDE, II, AR, p. 23).
The findings also revealed that close relatives and HDCs often were reluctant to admit the disease's onset. In a rural area of the JDA region, Gerardo described his wife's illness. He reported: “Well, I do not know because I see that she is not really incapacitated. She is not sick as her sister is [...]. She cleans the house, she washes clothes (manually) and does everything at home I do not notice anything unusual in her” (Gerardo, MDE, IE, NAR, p. 1).

Gerardo refused to acknowledge his wife's sickness despite the fact that in neurological examinations at the Neurosciences Institute had that confirmed this fact Gerardo's denial was an unsuccessful method of coping with the anxiety and depression caused by his wife's diagnosis.

During the interviews, some respondents were uncomfortable with I named HD. For example, I observed Karina in her little cabin in a rural area. The field notes for this visit stated:

Karina was intimidated by my visit, and did not know how to react. Her voice was reduced almost a groan. Her reactions to the questions that I asked her husband caused me to choose my words very carefully in order to avoid increasing her discomfiture. I sat down on a bed and complimented her on the neatness of her home and the beautiful view from the cabin. She could not relax, I tried to not make her feel that she was being observed, but all through all the interview I realized that the mere mention of the disease made her more confused. She also clasped her hands tightly in an effort to hide her involuntary movements from me, revealing her suffering as she tried to deny her illness (Karina, MDE, OB, AR, p 1).

HDCs cope with the sadness and disappointment of a relative's life ended in the prime. Studies have shown that HD often strikes during the most productive periods of a person's life (Krane et al., 1987).
Magnolia, a 59 year-old woman from the JDA region, comes from a family in which more than seven members have been affected by HD. Although she supports her family financially, her 88 year old mother cared for the two children who had HD. One child died, and the other child, Wilmer, was 48 years old. Magnolia declared: “It was a pity that a man as young as Wilmer got sick and lived a life of confinement and isolation” (Magnolia, MDE, II, AR, p. 81). According to Magnolia, Wilmer was relocated to Medellin following the illness onset since none of his relatives in the town where he lived would take care of him.

This study found that some HDCs also coped with HDSs who were drug or alcohol addicts. For example, Carolina and Martha were frustrated because the HD relatives that they cared for had little willpower to overcome their addiction (Carolina, MDE, II, NAR, p 5; Flor, JDA, FC, AR, p. 85). HDSs, in advanced phases, from the JDA region and the JDA region were described by their HDCs as heavy smokers and alcoholics (Leonisa, MDE, FC, AR, p. 56; Martha, JDA, FC, AR, p. 57).

HDCs of HDSs whose illness onset was not connected to involuntary movements related that they took years to figure out what illness the person was suffering from, despite the fact that other close relatives had experienced similar onset. In the JDA region, Mirna a 29 year old female described, in a focus group, her mother Elvira who was sick from her early adulthood, and who committed suicide 12 years ago. Mirna reported,

I think that my mother suffered from HD since she was born, is it true Nelly? She would suddenly start dancing with a broom. But we did not notice it. When I was young, my mother was already very ill but we did not know. She did not want to go out and she didn’t like people. She would say that when she went out they mocked her.
Mirna did not notice the depression associated with her mother’s illness. She explained:

She began shutting herself in, not going out anywhere. She burned herself twice. The first time that she burnt herself we took her to the doctor and she said: “I burnt myself.” Well we made some remedies for her and we took care of her. We did not realize that she needed psychological treatment (Mirna, MDE, FC, AR, p. 7).

Karp and Tanarugsachock (2000) found that prior to the diagnosis, HDCs experienced emotional anomie and only when the patient receives an appropriate diagnosis does the HDC change his initial feeling into compassion, sympathy and hope. The diagnosis is a frame that allows the HDC to understand that the condition is permanent, which permits the HDC to modify her anger and resentment.

Additionally, the diagnosis allowos HDCs to avoid guilt feelings due to the lack of control over HDS’s behavioral problems. Karp and Tanarugsachock’s (2000) findings documented the onset of the HD without involuntary movements, but with behavioral problems. In Mirna’s case, her family failed to understand that her mother’s behavior was caused by HD until decades later. As a result, they had expressed anger, resentment and guilt.

Social Enhancement

Colombians’ cultural ethos emphasizes that caregiving hardships and confronting the adversity of illness. Gerardo and others, claimed; “Well, things should be faced as they come, and regardless of anything, you should keep going” (Gerardo MDE, II, NAR, p. 17). There is cultural value in experiencing hardships. In the MDE region, Fanny a 70 year-old HDC care for her husband Gilberto who died in 2002. He choked on a fruit from
his own backyard, a place in which he used to escape to pick fruits. Fanny exemplified the concept that God gave her the mission to care for her husband. She stated,

> I say to myself, he is a human being like everyone else and who gives us everything is God. I always think that it is God who gives those things [...] I don’t want to be a person who doesn’t feel pain for people. I like to serve people and more so when it’s family [...] I always try to help whether it is a nephew or a brother [...] I would never have consented to place him in a nursing home. In the final years he died there was the mayor of our town who was very nice to us, and she would tell me, “Look Mrs. Fanny, I will help you get him admitted,” and I, “would say, no. What sorrow, him in a home thinking all day about me while I was somewhere very well just because I don’t want to care for him. I will care for him while I can, and I would ask my God, ‘blessed Lord, don’t leave me sick or put me in a way that I cannot care for him, no, give me life and health and I hope I can deliver him to you quickly.’ I don’t want to leave him in someone else’s care (Fanny, MDE, IE, p. 33)

Fanny’s views were consistent with those of Lim et al., (1997) because the construction of her role as HDC was positive, and she embodied sacrifice, devotion and protection. Fanny also exemplified Lim’s at al., (1997) observations that a Latina HDC ignores her needs, to favor that of the care recipient’s. The HDC in the Latino culture embodies the gender expectation of care roles.

This study also found that children are involved in caregiving roles at early ages. For instance Gerardo stated, “the one who really worries me is my 12 year old daughter. She is studying in town, and she says that she wants to quit school in order to come back home, but I will not allow her to do it” (Gerardo, MDE, II, NAR, p. 18).

**Mastery**

From the early phases, HDCs develop strategies, mostly by observation and common sense, to help HD relatives. For instance, Blanca mentioned some of the
methods that she used to handle her mother’s illness. She said “before we had a double bed, now we have a single bed; before, we had porcelain and decorations, now we have stored them; before, she ate with a fork now we give her a spoon. The key is to be flexible” (Blanca, MDE, II, AR, p 121).

This study also found that a common idea among Colombian HDCs was that HD patients should fight the physical disability and they should perform daily activities as much as possible. Flor stated this knowledge, she said: “I scold my brother Eduardo, I tell him, ‘you are not useless’” (Flor, JDA, FG, AR, p. 47). The fact is that in this phase HDSs can remain at home alone and perform activities, making the HDC’s burden and stress bearable. Care as described in the first phase often was supervisory.

Additionally, a large percentage of the HDCs reported that they conduct their own usual activities. In the JDA region, Amanda, a 23 year-old HDC, who shared the care of her late father with her mother described why her father’s care was never a burden. She explained.

Sometimes I arrived home and I helped my mom, other times I took care of him while my mother went out. In spite of that, I feel that I lived an ordinary life. We lacked many things as children, but we were not kept from living a normal life. I had my daughter, I studied and I had a partner as other people do (Amanda, JDA, FG, AR, p 100).

The data found that the prior quality of marital relationships influenced the perceptions of the caregiving role. For example, Rosa, a 42 year-old HDC from the JDA region who cared for a young husband with HD, William, talked about her former married life,

He would have his social life on the weekends, he would drink a lot, but I also have to say that [...]he liked the family life a lot... We went out a lot, we used to travel a lot, we went to Medellin or to Cartagena, to San Andres,
we traveled a lot, because he was... he was very joyful, although he didn’t show it a lot. He liked going out and…. he didn’t like to stay at home. So, the tables have turned. Now, I’m the one that goes out, to do the errands and all, because he doesn’t want to go out (Rosa, JDA, II, NAR, p. 23).

Indeed, Carrasco and Artaso (1998) reported that previous marital closeness buffered the HDC’s burden (Carrasco & Artaso 1998). It is important to mention that different from most of the HDSs in the JDA region, Rosa and Wilson moved to a large city close to Juan de Acosta, and their background corresponded more to that of an upper-middle class family.

**Struggle Against Fatigue**

Impoverished HDCs confront additional stressors associated with the lack of financial resources. For instance, HDCs in Colombia deal with HDSs who do not receive medications due to the lack of money. Additionally, they often have limited understanding of medical prescription. An example was Mara. Mara, a 82 year-old illiterate HDC, from the JDA region, reported, “We do not have money for buying these pills. I have some pills that the doctor prescribed, but I did not want to use them so I gave them to Camilo, but he did not want them either. He complains all night that he has pain in his neck so I am giving him dolex (popular name of acetaminophen tabs in Colombia) (Mara, JDA, II, NAR, p. 83)

The data demonstrated that HDCs often prefer traditional treatments to that of western medical practices. Leon from a rural area in MDE region stated, “I do not trust pills, I really never go to the doctor myself. Every time than I am sick I use herbs and homemade remedies” (Leon, MDE, II, AR, p. 36). As a result, HDCs cope with HDSs who are depressed and compulsive.
One respondent reported the stress of caring for her brother who was not medicated. Antonia reported: “My bother Martin began to hate me deeply and every time that I visited him he insulted me, spit at me and even tried to hit me” (Antonia, MDE, FC, AR, p. 96). Despite of this fact, HDCs develop tolerance and patience to deal with the HD patient, understanding that the emotional changes are effects of the illness. Fanny stated: “Every time my husband urinated in his pants, he got angry with me and said to me “Your obligation is to clean your husband, that’s why you are here” I never humiliated him and tried to change his underwear quickly so he would get comfortable again” (Fanny, MDE, II, NAR, p 75).

Gallegher-Thompson & Powers (1997), Harwood et al., (1999) and Reinardy et al., (1999) reported that caregiving has both positive and negative effects. As a result, Fanny simultaneously coped with fatigue, and developed mastery.

*Instrumental Help*

Consistent with the surrogate theoretical framework, this study found that HDCs were watchful, and closely observed the activities of the HDSs. This attention to the HDS was especially important because they often became lost, had accidents at home, and often hurt themselves.

For a large percentage of HDCs, the insistence of the HDS on performing risky activities is perceived as stubbornness. Mar is a 55 year-old HDC from MDE who cared for her brother Dario, a 49 year-old former businessman. Dario’s former associate and his wife took advantage of his condition. According to Mar, Dario was extremely stubborn. Mar explained:

I told him not to insult the police officers when they mistakenly take him out of the metro because they assume that he is drunk, but my brother
always gets in trouble with them. I also told him not to go by himself to hire a lawyer for recovering his lost fortune, but he never follows my advice. Every day he goes downtown trying to find a lawyer who will represent him (Mar, MDE, II, AR, p. 39).

Pollard (2000) reported that “HD can create an appearance of selfish, demanding and egocentric. However, this conceals the person who was generous or selfless. Difficulty controlling impulses and inhibiting the expression of feelings, especially negative ones, creates a demanding, imposing figure” (Pollard, 2000 p. 1)

HD Sufferers in Phase 2

In this phase Colombian HDSs have visible limitations for writing, walking, swallowing and talking but they are still functionally able to carry on activities of daily life. The physical appearance change, because of the change in the physical appearance, HDSs seem more clearly sick because they present more involuntary movement, less coordination, and more facial changes, and their bodies are more cachectic. Nevertheless, they do not face serious dangers such as choking or life-threatening falls.

Fight Against the Illness

In addition, in this phase, HD individuals still use compensatory strategies for dealing with their impairments. Blanca relates, “my mother had difficulties in walking forward, but not in walking backward. Then, before the fracture, she walked backward in her room because it was faster than walking forward” (Blanca, MDE, IP, AR, p. 3).

HDCs notice that HDSs have memory loss, especially of those things that they have learned recently. Dario states about his mother’s memory losses
When you suddenly begin not to recognize things, when you don’t recognize many people of today, but you do remember people from the past let’s say a name… for example, Claudia… I would ask my dad, who is Claudia? It’s a girl who studied with in high school… imagine that… How strange is this? (Dario, JDA, II, AR, p 47)

Their ability to write is seriously affected, but they are still able to read. For instance I observed that sister Lucero has a notebook in which the other sisters of the community make her practice her handwriting. It is full of scribbles. Nevertheless, sister Lucero still watches TV and reads the newspaper (Lucero, MDE, OB, AR, p. 3). HDCs also described the HDS as more uneasy, anxious, with difficulty in falling sleep. The symptoms deteriorate. Clemencia reported the condition of her father Jaime, “He always had trouble sleeping at night. He spent the night listening to the radio at an incredible volume, talking to the street watchers and walking around the neighborhood” (Clemencia, MDE, II, AR, p. 56). In this phase, HDSs accept little help in performing complex tasks.

HDSs spent more time at home than they did in the first phase. They began to like television and spend a lot of time in this way. Julia explained, “My father work less and less every day. Right now he spends almost the whole day watching television” (Julia, MDE, II, AR, p. 32). They often wake at night to go to the bathroom. For a poor family that shares the same sleeping space, this can be disturbing.

Physical Impairments

In this phase HDSs try to work, but it becomes increasingly difficult. They often forget what they were doing and have to be reminded by their HDCs to continue working. HDCs are highly distressed when the HDS gets lost, a frequent occurrence in
this period. However, many HDCs dealt with the opposite problem when they urgently tried to convince an HD person to quit working. There were physicians, drivers, cashiers, and engineers in processing plants whose families knew that an error in judgment by the ill person could kill someone or cause financial troubles for a company. In all these cases, families took months or years to dissuade them from working. Fanny, whose husband drove a jeep for transporting people and merchandise, convinced her husband’s mechanics to remove a part of the engine. When her husband wanted the car repaired, they agreed to trick him, telling him that the part broken was no longer available. This was the only strategy for making him stop driving. Fanny’s husband never considered himself ill. HDCs realized that convincing an HDS to quit driving is difficult. Many of them are described as aggressive and imprudent drivers when they get sick.

During the first three phases of the illness, HDSs feel hungry constantly and eat everything that is in front of them. Among poor families of both regions, this was a constant concern. They exhausted all their resources feeding the HD person, who seemed insatiable. In this phase, HDCs did not prepare special meals for the HD person. Most of the poor HDSs, competed with children or other disabled members, and were aggressive if they did not receive the food they wanted.

Mara related how her late husband, who usually was kept in a cage, managed to escape from the cage and ate a container of leftovers that the family had saved for feeding pigs. The container was full of rotting corn shells and kernels, watermelon shells and seeds being decomposed. As a result her husband became sick and vomited for days (Mara, JDA. II. NAR, p 90). This man survived, but not every HDS lives.
example, Fanny’s husband who suffered HD for only 7 years, choked and died from swallowing fruits without chewing them (Fanny, MDE, II, NAR, p. 45).

**Cognitive Losses**

Cognitive losses affect the HDSs in this phase, and they are also less aware of themselves and their surroundings. Consequently, they fail to notice when someone gives them the wrong change. They often mislay important objects such as documents, keys or money. HD individuals are unable to cook and to help with household chores. They do not remember recipes and have multiple accidents while cooking or engaging in other activities. Through breaking objects, they often hurt themselves and others.

**Need to be Cared For**

In this phase, HDSs require some help in dressing, eating and performing other activities. HDCs report that the HDSs might put on their shirt or shoes backwards or mismatch buttonholes and buttons in a shirt. For that reason they watch more closely. However, in this period HDSs are very selective about the people from whom they will receive help and for what type of activities. Sandra, a 34 year old HDC from the JDA region, talked about her late mother who passed away in 2002. She remarked,

Well... my mom always... she would practically not allow anybody to help her because, when she walked, I would tell her, “mom, come here, I’ll hold you.” “No, let me go, I know how to walk, do you think I’m going to fall!” It was not easy ... she wouldn’t allow me to help her... In the beginning she wouldn’t allow us to bathe her. At first, she would say that she had her own hands and would not allow us to help her. It was impossible, because I would notice that.... she would drop pitcher when she was pouring water, Sometimes she would come out with soap in her ears and sometimes in brushing she would put deodorant instead Colgate on the toothbrush....She would ask, come, help me out here, or grab this here, do this, but since she was always obscene in her words, she would say “son of a bitch, pick this shit up for me!” That was all she would say (Sandra, JDA, II, AR, p.36-37).
The previous comments demonstrate the increased deterioration of the HDS’s mental status while refusing instrumental help, and creating mental anguish for her daughter and family.

**Reciprocity**

In this phase, HDSs are still able to reciprocate their HDC with verbal gratitude as, Ernesto a 41 year old HDC who cares for his mother Betty who has been sick for ten years. He narrated,

She thanks me […] She won't have breakfast until I have breakfast […] She realizes if I get hurt or if I have sometimes, a cold, do, you know, what she does? She says to me, "Take a pill." She immediately gets worried, but I say to her, "Calm my love, what really worries me is you. Take it easy because for me it is first you, second you and third you" (Ernesto, MDE, II, AR, p. 22).

It is important to stress that Betty’s voice was scarcely understandable, but her son had become skilled at conversing with her.

Nevertheless, HDCs and family members notice that HDSs are more selfish, and do not like, to share food or things that they like, such as cigarettes. In this phase, they spend their money foolishly, squandering it on unnecessary purchases for their own whims. Other HD suffers become generous, giving their money away without restraint.

Emma from the JDA region reported a story about her father giving away money. She explained: “Before getting sick my father brought home all that we need but after he got sick when my dad would go out to the street to look for something, if there wasn’t any you had to look for it because if a person would not give it to him he would have the biggest fit” (Emma, JDA, FC, AR, p. 47).
Sarah, a 59 year-old HDC from MDE region recalled that her husband had suffered with HD for more than 5 years, and his generosity was more than good heartedness. She stated,

In his childhood, he never received toys and other things, and that's why he was always a generous man. We filled our suitcases with dozens of things for giving to poor people during Christmas and it was ok. Then, his religiosity awoke and he began to pray and to go to mass every day. I was really concerned because he donated $100 dollars every day to the church. I knew that something was wrong with him (Sarah, MDE, II, NAR, p. 3).

Suffering

HDCs interpret the emotional suffering in this phase. Dario described this aspect in his sick mother, “She is suffering a lot because she can't take care of herself and because of the solitude. Because… we all work, so we spend very little time with her, ah, you can tell, in her face, in the small amount of time that we spend with her you can see the changes in her face” (Dario, JDA, II, AR, p. 4)

HD Caregivers in Phase 2

In the second phase, HDSs' income often is reduced, which causes family members to search for alternative sources of income. Additionally, HDCs gradually assume a greater amount of agency as the HDS's agency is decreased.

Struggle Against Fatigue

In the beginning, families were concerned chiefly with the physical effects of the illness. Then, they became more aware of the financial burden and the danger of becoming destitute, especially if the HDS is the family provider. As an example, Lucia was a 74 year-old HDC from MDE region who experience great stress in dealing with
her husband’s care. She suffered advanced stages of osteoarthritis and her husband was anosognosic. She detailed a description of the way in which families of HD confront the financial crises. She remarked:

I noticed that he did not dress well, he did not do his best to look well groomed […] For instance, he carried his medical equipment in a plastic bag. It really came to my attention because he was someone who has always been concerned about his physical appearance […] He always handled the money, bought groceries, paid bills […] One day, I began to notice strange things. We began to receive notices of unpaid bills. He owed 6 months of salary to his secretary; he charged merchandise on his credit card and never paid the monthly installments. We also received notice that our utilities would be disconnected. He owed more than 2 years of property taxes and our house was in the process of being foreclosed (Lucia, MDE. II, AR, p 6).

Lucia continued discussing the turmoil of the financial crisis; she stated:

I almost went crazy, so we had to begin to save on everything. We used only a single light bulb in the house. My son who was a student told me “we are so poor that I am going to drop out of school and go to work” but I said to him “No, because if you do not finish school. You will be qualified to do only the most menial work” […] We were short of food, we had no new clothes, we had to wear the same shoes for years, putting cardboard inside them to kept them dry. But finally my son graduated as a physician (Lucia, MDE. II, AR, p 6).

The impact of the cognitive losses in the financial situation of an HD person’s family varied because most HD families from JDA were poor, while, in MDE region, there was a wider range of social classes. Wealthy families were afraid that the lack of judgment in an HD person would result in losing money (Ibarra, MED, IP, NAR, p. 3)

In the JDA region, although poor families experienced shortage of food because of the lack of employment, Julia claimed that: “Even now that my father cannot have his own tomato plants we have not had to adapt to the situation because we never have had comforts; therefore, things really have not changed a lot” (Julia, MDE, II, AR p. 15).
Prior studies (Covinsky et al., 1994; Covinsky et al., 1995; Emmanuel et al., 2000) have demonstrated that serious illness is correlated with adverse economic effects. In the Covisky studies, 20% of the subjects were obliged to quit their jobs, 31% of them lost their life savings, and 29% lost the main income provider. This situation was stronger for those severely disabled, poorer, and younger than 45 years. Additionally, serious illnesses often caused bankruptcy. According to Ezekiel et al., (2000), often families took loans and extra jobs to ease the financial burden of medical expenses. In such families, patients were more likely to requeste assisted suicide, and HDCs showed higher levels of depression.

**Instrumental Help**

In this phase, HDCs identified physical and functional impairments. They also noticed that the HDSs had minor accidents, and the HDCs were forced to implement selective strategies of help. At this point, HDCs noticed little changes in behavior that signaled the onset of the illness. These were not recognized at that time as symptoms of the illness because many HDSs “had a normal life” (Julia, MDE, II, AR, p. 27).

The data showed that when HDSs demonstrated errors in judgment, HDCs nagged them. HDCs assumed that HD people had normal mental capacity. Neurologists and physicians suggested that that “recognizing the illness onset saves much suffering for he HD patient and the HDC” (Blanca, MDE, IP, AR, p. 4; Lemus, MDE, IP, NAR, p, 17; Silvia, MDE, IN, NAR, p. 29).

**Suffering**

HDCs also reported that sadness and distress increased at this time because they began to realize that at the end, the HD person would become bedridden. HDCs
also coped with the question of why they had to take care of their relatives while other relatives avoid the responsibility. Such questions resulted in mental turmoil while the HDCs gradually assumed agency of the HD.

_Tension between HDCs:_ A number of respondents reported tension between themselves and relatives who were uninvolved with the patient care, but who nevertheless denigrated those who cared for the HD suffer. Often the respondents reported outsiders who viewed HDCs as negligent, unloving, cruel and even responsible for hastening the progress of the illness. For example, Emma, the HDC who was beaten by her sick HD father declared her HD sick aunt killed herself. She explained:

> Sometimes I think that maybe she made that decision and maybe one shouldn’t be unhappy but maybe she did the right thing because if she were alive at this time in her life, who would be looking after her? Her sisters never looked after her. They are so weird. They didn’t like my mom or us. They are still like that, they don’t visit us. (Emma, JDA, II, AR p. 51)

The suspicion of mistreatment is bi-directional. For instance, Ruth reported that her father’s sister mis-treated her mother, which she described in detail. She stated:

> My mom endured a lot from my aunt Carol. They would say that my dad had become ill because of her, and my mom would say, “It’s not my fault that Albeiro has fallen ill with this illness,” so, they would go all the way to the wild country (local name for undeveloped properties) and they would fight with my mom and insult her. Or if they saw my sister, they would insult her too (Ruth, JDA, FG, p. 27).

_Hexing and Caregiving:_ Three HDCs were accused by other close relatives of placing a hex on their husbands. The relatives believed such suspicion for decades, until a neurologist informed the family about HD. The data showed that a large number of families only became aware of the diagnosis HD at the end of the HDSs’ life, or after they died, when they consulted with neurologists. Furthermore, neurologists and HDCs
reported that general physicians often provided a wrong diagnosis, such as Parkinson’s or Alzheimer’s. An interesting finding of this study was that a large number of respondents did not know the name of the illness, the natural course of the illness, and the genetic risk associated with the illness, even among HDCs who were also at-risk.

**Social Embarrassment**

HDCs such as Rosa, Blanca and Dario stated that they “felt marked by the stigma associated with the HD.” They stated that people fail to understand the illness and those close to the HD person. They also reported that the public over generalize about the relatives, assuming that all of them will have the same end. As a result, the respondents reported that families prevented teenagers from friendships with those at risk for developing HD. The friendships were particularly forbidden when families suspected the possibility of marriage. The respondents also reported that they would face discrimination when seeking employment or health insurance.

Perceptions of HD: In the JDA region, participants perceive HD as a movement disorder rather than a type of dementia. Alicia, who is a key participant from JDA, stated, “here we see very little dementia; people with HD do not have dementia; they retain their faculties until he end” (Alicia, JDA, KI, AR, p. 1). Nevertheless, the data collected in the town showed that HDSs after reaching the intermediate phases exhibited manifestations of dementia. Dr. Duran claimed,

> In reality, dementia is uncommon in JDA. We have observed patients in advanced stages of HD and we did not observe dementia. We observed severe psychosis in 60 or 70% of the patients […] Nevertheless, we never have seem any patient who has forgotten his identity.(Duran, JDA, IP, NAR, p. 42)
Dr. Duran’s remarks are problematic considering the International Alzheimer’s Association’s (2005) definition of dementia. It states, “The loss of intellectual functions (such as thinking, remembering, and reasoning) of sufficient severity to interfere with a person’s daily functioning. Dementia is not a disease itself but rather a group of symptoms that may accompany certain diseases or conditions. Symptoms may also include changes in personality, mood, and behavior” (International Alzheimer Association (2005)). Psychosis is a personality disorder that is part of dementia.

Not only JDA participants have this misperception, as other participants from MDE also perceived HD as a movement disorder in which people still preserve their mental capacities. This ignorance of the illness caused other effects. Because HD was not given the status of insanity, the HDSs are held accountable for their behaviors. The lack of medicalization of HD in Colombia suggests that HDCs do not understand that medical practice is the proper mechanism for controlling, modifying, and treating HD. An interesting study would explore folk medicine and other remedies HDCs used to treat HD.

**Inner Negotiation with Social Expectations**

The results found that inner negotiation with social expectations centered on whether family members were involved or not involved with caregiving. As the HDC assumed more of the HDS’s agency, more family HDCs were needed. Family members agreed that the HD person required company and more financial assistance and most HDCs concluded that an HD person should not suffer in solitude or loneliness.

A common feature in the Colombian HDCs’ belief system was the perception that family members should not protest when other relatives do not participate in the
care of the HD person. However, Rosa was an exception. She expressed displeasure because relatives refused to visit them. Rosa reported,

> They come sometimes, but I think they should come more often. He’s here locked up, but they come and they do not take him out. I think all the people think that I am quite sufficient to take care of him. So, His family as much as mine have decided that I'm sufficient (Rosa, JDA, II, NAR, p. 43).

The care of the HD person caused quarrels and polarizations within and between families, often for decades. Families discussed the type of care that HDSs must receive and from whom, and how to distribute the cost of care. Often such discussions caused severe family discord.

The respondents also reported that caregiving issues were influenced by power and gender, and economic disparities. The powerful members of the family often imposed the care conditions for the HD person. Women with money were in a better position to negotiate care agreement with male relatives than those without economic resources. Blanca, a prestigious medical specialist, commented on how she persuaded her siblings to develop equal responsibility for caring for her mother during weekends, Blanca stated,

> Then I said to myself, “This a very big problem, because they do not want to help. I am stuck with it all that the responsibility falls on me. The one who doesn't want to solve it gets screwed” You know what I am going to do, I am going to make a list of weekend shifts because it is not fair that my male siblings never have to look after my mom, my dad and Elvira during the weekends. I work the whole week, and right now my dad is angry because this weekend I will leave for Santa Fe de Antioquia with my son whom I have not seen in the last six months, I have a right to go out this weekend with my children (Blanca, MDE, IP, AR, p 36).

She also hired a permanent paid HDC for her mother. She reported,
I told them, “Now we have two employees; one of them on the weekend and the other from Monday through Friday. But in the future I know that my mom is going to need a person during the day, another at night and another on the weekend. And where is this money coming from? It has to come from us because we cannot change that; that is what we have to go through.” That day we agreed on an amount that each person gives for his share of these girls’ salaries (Blanca, MDE, IP, AR, p. 32).

The data showed that a paid helper is the solution for a family in which every child wants to keep his independence and lifestyle without having to deal with feelings of guilt for knowing that his sick mother is losing her standard of living.

Another serious conflict among relatives occurred when a member of the extended family detected the illness onset in another family member. Julia explained the behavior when her mother suggested taking two daughters to the neurologist: Julia reported:

My mom had a hard time convincing them to take Martha and Karina for treatment; when that happened, they treated her badly, saying that they were not ill, that there’s nothing wrong with them, that she was a meddler. So we left them alone and afterwards they started to realize it and they became interested in the issue. We would ask for the appointments, and if they wanted to go, good, and if they didn’t want to what could we do? It was their own business (Julia, MDE, II, AR, p. 26).

**Stress and Burden**

Colombian HDCs seldom expressed stress and burden due to the care of an HD relative; they rarely believed that God was unfair to them. They claimed that it just happened and it was no one’s fault. Some even claimed that it was genetic and worried that they, or their children would develop the illness. They also wondered who would take care of them.
Most of the HDCs considered that HD patients are better cared for at home simply because care is given with affection. Colombian HDCs rarely believed that they are losing an important part of their lives because of taking care of an HDS. Most of them accomplished their goals, such as motherhood and marriage despite assuming the caregiving role.

Those HDCs who felt that they missed out on life were concerned about the lack of time for studying or working. However, some of these HDCs were young daughters who were also caring for their babies. This means that the HD parent was not the only reason for dropping out of school. Soledad a 26 year old HDC who cares for her mother in MDE stated: “The reality in my case, what I could not do anything with my life because I had my daughter. It’s my daughter who really does not allow me to study; it was not because my mother got sick” (Soledad, MDE, II, AR, p. 36).

**Mastery**

In phase 2, the respondents did not express sadness or stress for losing a pleasant life. Although they lost their temper or were easily irritated with the HD person, a large percentage rated themselves as “good HDCs” because they believed that they did their best for the HD person. Nevertheless, Daniela, a 41 year old HDC from JDA who cared for her late mother 10 years ago described the situation. She remarked:

I give myself a score of five [...] I feel now that my care could have been better. There were moments in which she needed me and I did not look after her. There were many moments in which I felt angry when she soiled the bed without asking me for help. It made me mad, It really bothered me to have to wash the blankets and mattress. On these occasions I assisted her by obligation [...] Sometimes I think that things would have been different if I had not had a little baby but I guess I am lying to myself because I developed a certain revulsion to my mother for such a long period of care. I was also tired of giving her so much of my care but she never expressed gratitude (Daniela, JDA, II, AR, p. 108).
The respondents reported that HDCs had to develop patience. This advice clearly showed the social representation of HD and the HDC’s role. The data demonstrated a tacit acknowledgement that the patient’s condition was not easy to handle, but that the role of a model HDC was to endure the hardship, the difficulty and inconveniences without complaint. For example, in MDE, Maryluz a 45 year-old HDC from MDE region, who cared for her deceased mother for 5 years following 15 years of suffering from HD, discussed the caregiving role. The caring changed her life. She stated:

I feel so sad to remember that time. I thought that I was not going to be able to continue. It is very hard. Day and night without sleep constantly looking after her. I did everything for her, she was not able to use the chamber pot, walk to the bathroom or other things. By the time that I cleaned her, my mother would be dirty again. She was like a decayed body but she was still alive, she smelled like a cadaver smells. My home was smelly, so my three daughters and my husband moved away. They didn't even like to come to our home. Regardless of this, I was looking after her and I could not abandon her. The solace and peacefulness that I have is that I was with her and it didn't matter how she smelled. I was with her and said to her “I love you” and I caressed her face.

Mariluz emphasized the character traits which developed as a result of caregiving. She reported:

I learned many things, such as tolerance, humility and patience. There were times when I believed that I was not going to be capable, that this was very difficult but I was wrong because I was capable. It has been 5 years since she died. I remember her with nostalgia and also simultaneously with serenity.

Mariluz described assuming the HDC role. She said:

My siblings also took care of her, but at the times when it was most difficult, nobody wanted to do so. All of them were saying, “let's take her to a hospital, or to someone else’s home,” and I was saying to them, “no, I
want to stay with her.” In this moment, I still have this satisfaction; I still have calmness and inner peace that has no price. I feel very proud about that… I learned from this illness that one has to face up to the final consequences (Mariluz, MDE, IE, p. 27).

According to Rehnfeldt and Eriksson’s (2004), participants’ interpreted suffering as an existential sign that demanded an ontological encounter between the HDS and the HDC. For these authors, the HDC and patient have an existential encounter in which they share meaning that makes an unbearable situation bearable. This process of signification allows HDCs to care for the HDS (Rehnsfedt & Eriksson, 2004). HD HDCs, therefore, develop connection and mastery that allow them to overcome the suffering and fatigue produced by the HDS’s condition.

Social Enhancement

The data documented that daughters expressed the intention to care for parents; mothers expressed the intention to care for their children, and some people were willing to care for anyone in the family. Among older women in the sample, three of them cared for two or three HD members, as well as other disabled family members.

In general the Colombian HDCs support intergenerational reciprocity or generalized reciprocity within the family. Lucila, a 60 year-old HDC in the JDA region, who had cared for three members of her family with HD recalled her caregiving experiences. She reported:

Baryon is very different from Federico; he only gets angry if you do not give him food and cigarettes, while Federico was so aggressive that we had to lock him in a little cubicle. Sometimes we had to tie him to a tree. My mother took care of him until she died and then I began to look after him. My father was also sick. My mother and I took care of him on our primitive farm, I was only twenty years old” (Lucila, JDA, II, AR, p 16).
Lucila simultaneously cared for her brother Bayron, and her 9 year-old autistic and blind grandson at home by herself. She reported caring for two people. She recalled:

Bayron lived with me for many years after my mother went to work in el Valle (another state). Then, he got sick and I began to care for him. My grandson Carlos was left here by his mother, she told me that Carlos was my son’s son so it was my responsibility as well. Sometimes I said to my granddaughter. “Come and cared for him and you will see what this is all about.” I have him here because my son works far away. Carlos does not speak but he hears when I call his name. Sometimes, he also gets angry and breaks things. He broke my mirror and flower jar. He gets angry if he hears a sound in the kitchen and I do not give him food immediately (Lucila, JDA, II, AR, p. 4).

Paradoxically, women in Colombia are oppressed and feel caretaker overload, while at the same time experiencing social enhancement.

*Love and Sense of Connectedness*

In phase 2, HDCs provide a lot of emotional support as Ernesto revealed in his interview. He recalled the emotional support he provided for his mother. He said:

I told her, “I know that those things hurt” I try to avoid painful things but this is the reality of life and they are necessary,. But I said to myself, “for what reason is one on her side?” So I say to her, “Mom I am here! Do I matter to you? Keep fighting and take it easy me dear” (Ernesto, MDE, II, AR p. 31).

Not all HDCs talk openly with the patient about their condition. This means that there are HDCs such as Fanny, Leila, Martina and Emma who never confront the HDS in relation to his or her sickness. Those who adopt this strategy think it is effective because it avoids stress and depression in the HDS. In addition, they believe that the HDSs have little consciousness of the illness.
HD Sufferers in Phase 3

In this Phase, HDSs have more disabbling movements, physical impairments and accidents but they are no longer aware of them. Therefore, they experience less distress, although those around them experience great of distress. The increasing dementia makes all their losses invisible in a certain way.

Physical Impairments

They have important problems of coordination that hinder all their activities. One of them is brushing their teeth. I observed that after reaching this phase of the illness the HDSs have severe dental problems or become toothless, which makes their difficulty in swallowing worse. In this phase, they experience motor difficulties feeding themselves and swallowing. Many of them are undernourished. They can eat by themselves, but require special preparation of meals and special eating utensils plus supervision during the meal.

HDSs from rural areas and little towns have worse dental problems than those from the cities. HDSs with strong involuntary movements are able to wear out a pair of shoes in one week and ruin their clothes, sheets and personal objects as Maria in the JDA region related about her brother. She recalled:

He smashed one of his shoes and now he no longer has anything. Since he always smashes the same shoe we made a new pair with a brown shoe and a black shoe. He smashes it from this side, because this is the side where he holds his gate. His shoes don't last long. The clothes that he has are those things that you see there (I see 3 changes of clothing, ragged and dirty). We had a bathroom here but he destroyed it. He has turned it into crumbs because he always falls there (Maria, p 13) The Indian has broken more than 10 thermos flasks. He catches the black coffee and lets it fall. I said to him: "this thermos flask that you have now is a gift from my daughter, don't break it.... All the cigarette ashes fall about him, all his pants are burnt. He is suffering a lot, mainly at night, I listen when he complains, but there are moments in which I can hear him
and I go and I find him snoring. When I listen to him snoring, then I think: "He is sleeping already, he stopped hitting himself (Maria, JDA, II, AR, p. 33).

Involuntary movement can be reduced with medication, but poor families cannot afford it and other families do not give it because these medicines increase apathy and disconnection in the HDSs. Neurologists also agreed that sedative medication reduces the little alertness that they still have; therefore, the better treatment involves physiotherapy, cognitive stimulation and affection (Ibarra, MDE, IP, NAR, p 37).

**Depression and Anger**

The data showed that HDSs had considerable cognitive losses. They were unable to recognize the difference in the value of bills, and their capacity for processing information was slowed down. As a result, their conversation is very repetitive. This is another behavior that easily angers HDCs. HDSs lose inhibition and frequently use obscenities and slurs to refer to other family members and their HDCs when they feel frustrated or angry. This is a disturbing behavior for HDCs and families.

Many HDCs described the HD person in this phase as someone who has total apathy for his family and things that used to be important to them. Lucia said in her interview, “He does not accept that he is sick. He no longer cares about anything. He does not care about good and bad things that happen in the country, what happens at home or what happens to his friends, and he even does not care about what happens to him” (Lucia, MDE, II. NAR, p. 79).
Need to be Cared For

In phase 3, the data showed that the HDSs gave up activities that were important to them because of cognitive losses and physical impairment. There were problems in walking and families used wheelchairs for taking them out. HDSs after reaching phase 3 required permanent cognitive stimulation to prevent a total cognitive loss. They could no longer write or read and their periods of concentration were extremely short. Company was a crucial issue to the HD person through all the phases, but the purpose changes. At the beginning the aim was to provide emotional support, in the intermediate phase it was to provide cognitive stimulation, and at the end it was to watch to protect them and assistance for all activities.

The level of self-awareness decreases drastically, and that frequently HDSs did not notice or alert HDCs about injuries. In short, in this phase HDSs have important losses of agency. HDCs noticed, as Blanca observed that her mother became obsessive about small details but she is no longer able to retain a sense of identity. She reported:

My mom does not suffer. My mom worries about small things perhaps, because we have not bought workout pants for Daniel’s birthday, or because the girl did not go dye her hair, but my mom does not have an image. She does not say to herself, “I am Alexandra Morales, the Alexandra Morales who was able to make things, who was the boss of this organization, who ruled, who did, who had, who had money, who gave or did not give, who did what I wanted, who raised six children and who has four grandsons, and look who I am now” No, she does not know that (Blanca, MDE, IP, AR p. 53).

Blanca stated that her mother no longer recognized herself. Blanca clearly observed how HDSs lose the capacity to see themselves as human being, to have
reflexive monitoring that allows them to understand a past identity and a current awareness of self.

HD Caregivers in Phase 3

Struggle Against Fatigue

Teresa is an 85 year old HDC taking care of her 49 year old son Wilmer. This case is paradigmatic because Wilmer is an HDS in the third phase of the illness who is rebellious. His HDC reported enormous stress in dealing with a HDS who refused to do anything that the HDC requested. Teresa stated,

He is always hungry. I have never struggled with a person like that who is never full [...] I cannot wash him in the bathroom but rather in the patio[...] I bathe him on another patio but because it does not have a lock bar, well when I took him there he immediately escaped [...] In addition, the finger nails and toenails.... He scratches himself with his nails at night and I see him laying down and sleeping but, look, he scratches himself. [...] I have to make him go to bed and he does it but around six or six thirty he is already awake, so every day I have to wake up myself around six thirty [...] I say, “Wilmer, Wilmer sit down, please sit down here on any of the furniture that you want.” Sometimes he sits down and other times he does not. Then, I am giving him food and he makes like this (she shows with her body how he crosses his legs). He crosses his legs which makes it harder for me to reach his mouth. I force him to eat all the food here and he crosses his legs pleasantly. It takes time to give him all his meals: breakfast, lunch and supper. If you give him anything soft he throws away more than he eats [...] (Magnolia, MDE, II, NAR, p 3-5).

Teresa also expressed suffering because she had to deal with a man of whom she is afraid. She asserted:

Besides, he pushes me, if I say anything he walks over and pushes me. If I give him a chance to hit me, he will hit me. He does not give a damn if he is naked walking through the house[...]: He no longer brushes his teeth [...] If you could have seen him when he was healthy, he was really polite to me, he had that pure respect with everything (Magnolia, MDE, II, NAR, p 6-8).
Teresa struggled against her feelings of fatigue and searched her inner strength for dealing with what she considered an unique burden. She stressed:

Sometimes I say to myself ... that I cannot bear him, “sit down Wilmer because I am getting dizzy, sit down Wilmer.” I have a strong mind, because I am able to cope with something like this!! It is because God is great and compassionate and gives us a good shelter because you might see something like this in your son..., this is too hard. You see, I am eighty five, I am going to reach eighty six and look I am not crazy yet!! (at this point Teresa began to cry and wept for some minutes in the following part of the interview) Sometimes I begin to cry looking at my luck because there are many younger women and they do not have to tolerate the martyrdom that I have here, nevertheless I love him and I do not want him to leave (Magnolia, MDE, II, NAR, p 9-10).

Teresa’s case demonstrates of the tacit expectation of most HDCs. A good HDS is a HDS who obeys both the HDC and the medical regimen; nevertheless, in practice, most HDSs get what they want and how they want it. They only eat the food and wear the clothes that they choose, even if this selection is wrong or is not available. They can fight bitterly with a HDC who wants to force them to do anything that they dislike or does not provide what they want immediately.

This expectation of obedience was explicitly discussed by Daniela, another HDC in JDA who resented the invasion in sufferer’s personal life, and the need to control the decision making power that the HDC exercises upon the HDS ,even in the earliest illness phases. She stated: “We have a problem in this town, we want to rule their lives, we tell them what to do and how to do it. Look at Doris, everyone wants to give their opinion about her life” (Daniela, JDA, II, AR, p 120). One of the neurologists denounced the restriction of an HDS with dementia. He stated: “HD patients usually deal with a lot of restrictions since the HDC many times does not have enough time and capacity for
offering the things that they need such as leisure, exercise and personal assistance (Ibarra, IM, MED, NAR, p. 3)

Mastery

In a focus group, Julian a 32 year old HDC from MDE region narrated an anecdote about his late mother that may seem hilarious, but in reality reveals a lot about the kind of stresses and complexities that HDCs for HD patients deal with:

Her mother who was taking vacation on a remote beach began to cry and stamp her feet when their daughters told her that they do not have milk for her dessert and she only stopped crying two hours later when the family was able to drive back to the closest store. The next day, the family had a new chest cooler full of milk boxes for supplying milk when her mother asked for it again (Julian, MDE, II, AR, p. 86).

This was one of the most distressful and difficult issues of caring for an HD person. In this study, HDCs often talk about “being humorous with the HDS” These HDCs who were able to be humorous with the HD irrational behavior were considered more skilled in caring for HD person. Magnolia regretted that her oldest daughter gets angry easily at Wilmer’s stubbornness. She stated, “It will be important that she listens to this conversation because she loses her temper very quickly (the equivalent idiomatic expression in Spanish is she “accelerates too much”). She lacks patience; she loses her temper too quickly, and then, he gets angrier (Magnolia, MDE, II, Ar, p. 16). Mara from the JDA region also has the same perception, she criticizes the reaction of people to her son’s tendency to quarrel and fight with everyone. She reported:

I have bad luck, I am salted like people say (In English a person may say “I am jaded or jinxed”) . He is going to put them in bad mood. Sometimes I wonder why he fights and puts people in bad mood. The Indian fights because he is reckless. He goes there and says that he has not been
given food, that my mother has not given him food and that he is hungry. “Give me food” and then they give him food. The Indian goes to his brother’s home looking for trouble. He breaks his beer bottles and drinks his sodas. What can we do? Like my son says, “There is nothing to do. I cannot force the Indian.” Sometimes, when the Indian goes there, he picks up some sticks and knocks down his brother’s home because he says that these buildings belong to him, that all these properties are his. He exposes himself. He gets all these flying corks (injuries) because he seeks confrontation, but people should ignore him (Mara, MDE, II, NAR, p. 15).

Magnolia and Mara are from two different regions, but they have in common that they are elderly women, without literacy, who have been caring for more than two generations of HD in their families. Both of them show mastery because their common sense tells them that confronting an HDS can increase the level of aggressiveness in the HD person and the level of stress for themselves and their family.

Sutton & Feil (1999) have been validated the strategy of being humorous with the HDS. They suggested ways to deal with patient with dementia. The authors developed a method for decreasing stress among HDCs. This method is called validation, based on three ideas: first empathize rather than contradict, second avoid conflict even if it involves lying to the dementia patients, and third, try to discover what is the underlying emotion when you feel angry with the dementia patient (Sutton and Feil, 1999).

*Inner Negotiation with Social Expectations*

There is a social expectation to keep the family together through adversity. HDCs, therefore, struggle to preserve a family unit. The reality is that the family unit is highly affected when a main figure is affected by HD. In Barranquilla, Dario recalled the patience required to maintain a home. He reported:

> It is very stressful. You have to have a lot of patience and the home environment, the feeling of a home, is lost because everyone has his own
Data from the interviews revealed that HDCs often sacrificed their own lives. This issue created inner questions as to whether they should value family survival over their own interest. In Dario’s case, he coped with this situation by bringing his partner to live in his parent’s home, simultaneously performing his role of caretaker and spouse.

**Instrumental Help**

In third phase three, HDCs were concerned by the increased level of dependency and the demands that were placed upon the HDC both in terms of length and intensity of care. They were aware that an HD person has an accelerated loss of cognitive abilities which requires more help that the HDC can objectively provide. Blanca in her closing statement about her advice for a family who is dealing with an HD person states, “Stimulation, stimulation and more stimulation” They need someone who will talk to them, play with them, read to them, and who will keep their brain active but this stimulation is almost impossible (Blanca, MDE, IP, AR, p. 160). Silvia, the only neuropsychologist who participated in the study, stated:

All the HDSs that we have observed have three main disorders: motor problems, behavioral problems and cognitive problems. We have seem a lot of HD patients with cognitive losses that affect their praxis and memory problems not at the level of storage but not at the level of evoking events. The cognitive loss worsens over time; we try to explain to our families about this process (Silvia, MDE, IN, NAR, p. 12).

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9 Praxis “is the ability to interact successfully with the physical environment; to plan, organize, and carry out a sequence of unfamiliar actions; and to do what one intends, wants, and needs to do in an efficient, satisfying manner. It is a broad term which actually includes: Ideation – the thought, planning an idea in the mind, ability to visualize the activity, motor planning – making a plan for the action, and execution – actually doing the activity or executing the action” (Lighthouse project, 2005).
In phase 3, HDSs need more help than the HDC can provide, creating feeling of exhaustion. Often, HDCs can no longer provide for the patients needs. Therefore, the HDC feels insecure in the caregiving role.

**Suffering**

The HDCs mourn for the losses of HD individuals, they loss of their former selves and their inability to have a social life. Blanca said, “My mom was a person that everyone loved, my mom had charisma [...] now I see that she has lost her relationships with everyone. It is very painful for me (Blanca, MDE, IP. AR, p. 5) Blanca’s grieving for her mother’s capacity extends for more than 10 pages in the interview because it is totally shocking for a HDC to witness a massive surrender to all that represented her mother’s former life. Witnessing this massive surrender and losing a former life causes a lot of pain and fatigue. Rosa recalled,

> It’s not fair. I feel that... I get tired mentally, no... I mean.. I feel an emptiness, I feel that I’m alone... First, as a sexual partner I feel that I lost him a long time ago and also feel that I’m alone, because I can't share certain worries with him. For example, I can't even share with him something as simple as talking about every day life. I can't, because he... not even in the every day things does he respond to me [...] Lately, about fifteen days ago and since, I notice that he is more submerged, more quiet, he turns over and goes to sleep (Rosa, JDA, II, NAR, p. 44).

The data showed that in phase three the suffering was more intense. One reason was the HDCs’ awareness that HD was irreversible and that the patient will continue to deteriorate every day.

**Love and Sense of Connectedness**

Despite these negative outcomes, despite her feeling isolated, tired and frustrated, this experience enhances the HDCs' self-esteem, sense of life purpose and
tenacity. For instance, Rosa views herself as providing agency, and to a husband who can no longer survive by himself. Rosa described her late husband’s loss of self. She reported the following:

If I weren’t here, and he were here on his own, I think it would be very terrible for him because I am everything for him, everything, everything. Although he doesn’t tell me, I feel that it’s like that. I’m the person who gives him his meals. I’m the person who is attentive with his doctor, about his medication, eh... I think that he knows that... I’m going to be with him... I mean, that I won’t leave him alone at any time; I think he knows that, I tell him, I think he knows it, that he’s aware that the only person that could deal with all this is me. I think that... he never tells me, nor is he going to tell me, but I think so. I think that if he were alone, if I wasn’t around, who knows, probably... he wouldn’t be here either! (Rosa, JDA, II, NAR, p. 45)

Rosa’s words demonstrated a sense of connectedness, this inner knowledge that her husband’s existence depends on her own existence.

HDCs also develop mastery because they learn to interpret from little gestures, words and attitudes that the HDS is irritated and angry and they also know how to solve the issues in quickly. HDCs also can recognize what things from their former life are still vital for the HD person and what persons, activities, and preferences are still providing an emotional meaning for the HDS. HDCs learn how to interact with someone who has changing moods and can get distressed very easily about little details. They learn the specific situations that cause that reaction and try to avoid them. They know what things their patients still enjoy. They develop skills to maintain conversations according to the HDS’s pace and topics of interest. In short, they are highly creative and resourceful in dealing with the HDS’s limitations, behavioral and cognitive problems.

The data showed that HDCs of HDSs are always at-risk, and every day something new and unexpected may happen. Most of the time this is a source of stress
for the HDC but some situations can also be humorous. HDCs always laugh recalling memories from hilarious situations. Blanca laughs through the interview recalling her trip to Europe with her sick mother. Blanca reported:

I went with her and my dad to Madrid [...] one day I said to mother, “Stay here in the room; I am going to leave with dad and I will bring your breakfast. Please do not leave because you can get lost [...] I said to my mom, “I will leave the television turned on.” When I returned with the coffee, she was watching porno movies and to watch these movies you have to pay [...] She pressed and pressed and finally she made it to that channel [...] We took a small service elevator in order to avoid the lobby because she has a lot of difficulty walking; as soon as we entered the elevator, she said to me, “My dear, where do you urinate in this bathroom?” ha, ha ha, But it was an elevator, my mom is funny, Ha, ha, ha. [...] I paid for a taxi. You know how many dollars it costs? When we arrived at the cathedral I said to my mom, “Let’s go down to see the Cathedral” and she said, “No I won’t, I already saw it yesterday, I do not want to see more Cathedrals.” “No mom, yesterday we saw the one at Seville; this is Toledo’s Cathedral.” She said, “They are all alike,” so she did not want to see it (Blanca MDE, IP, AR, p57-60).

The data indicated that there was a strong sense of love and connectedness between the HDC and the HDS, which contributed to their emotional well being.

HD Sufferers in Phase 4

When an HDS reaches phase 4 they no longer know what is happening around them, they cannot be hurt by their past memories or current conditions. They forget about themselves and the surrounding world. They do not show a strong connection with their life, body and loved ones. They no longer keep time and space orientations. In this phase, the level of impairment increases, and they need total assistance with all activities.
Physical Impairments

When they walk, they need someone who takes them; the same is true for every activity. They start to spend more time in bed or sometimes sleep during the day and wake up at night. In phase 4, all physical and cognitive functions are severely affected. This fact will increase burden and stress in the HDC.

Suffering/Need to be Cared For

In phase 4 HDSs cannot express a lot of affection, but they respond positively to affectionate gestures. Elena was a paid HDC of Lucy’s brother. Elena was remarkably perceptive to his need to be cared and loved. She described how Eliezer, regardless of his limitations expressed the need to be cared for, Elena stated,

I think that he tries to express gratitude because he hugs me sometimes. Sometimes he puts his hand on my cheek here and it’s more when he puts his hand like this. He needs a lot of love, because look, yesterday I got close to him, I would caress him and he would relax, he is always with someone, that’s the good thing about him. When I tell Mrs. Lucy, “Look he is restless, then Mrs. Lucy gets close to him, and plays with him. That’s the good thing, that he is never, never alone. (ELENA, MDE, II, NAR, p 39)

Elena was a woman with little education, but she is very skillful a, committed and clever HDC. For example, she finishes her answer by stating that this kind of ill person must never be alone, which is true. HDSs require company and watching 24 hours a day. In this case she sleeps in the same room with Eliezer and she also manages to help with the household chores.

I observed her interacting with Eliezer. “When I was there she was holding Eliezer’s penis in a urine bottle. I asked her what are you doing? And she answered, “we do not use pampers I use this urine pot every hour and I wait until he urinates. Sometimes he can urinate faster and sometimes he takes more time, but I know his
body very well. I never let him urinate in the bed” (Eliezer and Elena, MDE, OB, NAR, p 2). This observation shows to what extent Eliezer is impaired, but also show the caliber of Colombian paid helpers. She was saving Lucy a lot of money on diapers and cleaning expenses. What kind of salary can compensate an employee with this degree of commitment to her job?

HD Caregivers in Phase 4

Suffering

After caring for an HD person for a long time, HDCs understand deeply the uniqueness of the HD person. Dario talked about the uncertainty and suffering associated with the deterioration caused by HD. He stated:

[…] If you get AIDS or cancer, you know what will happen... you know how much time you have... you know that if they operate or if they don’t operate, how you will be... you have a medical diagnosis... that is... exact in some way... you have this many years to live, ready, etc. but with HD you don’t know when the illness will begin, you don’t know how quickly the illness will progress, you don’t know when the illness ends. Something about it is very wearing[…] This is very wearing as much for the patient as for the caretaker (Dario, JDA, II, AR, p 76).

Dario related how he dealt with his mother’s crisis:

My mom has been ill for nine years... and who knows if we still have ten more years... right... or maybe one year, I don’t know, you don’t know at what moment... you have to be attentive day to day... there was a time when ... in nine years, it was the most difficult time I have ever lived... when it fell out of my hands... I... she was coming from the bathroom, I was helping her... then suddenly, there was my mom, with the whites of her eyes, not breathing and... she wouldn’t react... and... “wake up,” and nothing! I mean... it was personally my hardest moment in the... in these nine years because she wouldn’t react to anything. I mean, I got scared, I cried, I ran out crying, I called an ambulance (Dario, JDA, II, AR, p 77).

Dario stressed the high level of uncertainty attached to the HD trajectory:
This is something that you don’t know, when the moment ends… you lie down to sleep and you don’t know if it’s a pulmonary problem, respiratory… I couldn’t get her to wake up… do you understand? It’s something very difficult… very difficult… you don’t know when that moment starts and you don’t know when that moment ends… you don’t know how the illness will progress, different from other illness… (Dario, JDA, II, AR, p 77).

Dario’s observations of suffering and uncertainty were also expressed by Alicia, Amanda, Emma, Flor, Rosa, Ruth, Leonor, Patricia, Blanca, Sofia, and Carolina. Repeatedly HDCs reported HD as unique because of the level of suffering, deterioration and uncertainty attached to the illness. Both HDC and HDS experienced exhaustion of their physical, emotional and financial resources for dealing with the disease.

Love and Sense of Connectedness

The following incident describes an example of love and sense of connectedness which was a pattern in the data. The love and sense of connectedness also demonstrates the way in which HDCs assume agency while dealing with the conflict of the suffering. Blanca took her HD mother to the hospital to consult the gynecologist and while she was there a lady in the reception area that told her, “Ah if one gets this illness one will die. Why does one want to live like that? Oh, what boredom, one would die,” (Blanca, MDE, IP, AR, p. 20).

This anecdote exemplifies the daily conflict that HDC deals with. They are taking care of someone whom from an outsider’s perspective is reaching a degree of deterioration in which life is a misery, but there is a strong sense of care and connectedness that has grown after many years of caring for an HD person. Therefore, HDCs begin to do anything in their power to improve the situation of their relative or to
restore their lost agency and Blanca pointed out in her interview that HDCs care for people who society no longer values, she reported:

I remember that when Caridad died Laura said, “I could have still looked after her for some years. I would have been able to continue looking after her as she was. I didn’t want her to die.” And you would think objectively that Caridad no longer had a possibility of living or anything. Why did Laura say, “I would look after her, I could have looked after her another three years. It doesn’t matter to me, I lift her, I change her diapers,” But then people look at a person like my mom as a thing that doesn’t have any value. They are disposable to society. Why do these people waste so much energy with a person who is no longer worth anything? (Blanca, MDE, IP. AR, p. 107).

The data shows that HDCs from both regions, in phase 4 have a strong attachment to the HDSs because in the final phases HDSs are less angry, more depressed and seem more vulnerable.

*Instrumental Help*

HDCs related that in this phase, many HD patients developed co-morbidities that are extremely challenging to manage and treat because the HDS is not cooperative and is unable to follow medical regimens. How can you explain to an HD person that he has a fractured femur and he must remain in bed in order for it to heal, or he will not be able to walk normally? How can you explain to an HDS that he has diabetes and that he eats sweet food he will go into shock and die?, How can you explain to an HD person that she or he has a feeding tube, and should not pull it out it because it is the only means to keep him from dying of starvation. When HDSs reach this point, they require a HDC twenty four hour a day. How can you care for someone who needs help twenty four hours a day? The dilemma of many HDCs when they reach this phase is: How can
I work? How can I sleep? How can I come to an agreement among those who are responsible for the HD person?

*Inner Negotiation with Social Expectations*

Another problem that HDCs discussed in phase 4 is that even if the HD person objectively needs institutional care, HDCs are highly afraid of taking this step. Most HDS still seem to recognize their homes and to behave more peacefully at home. When they are taken on vacation or to a hospital they have extreme negative reactions and are more confused. HD people sometimes do not allow strangers to help them or have only certain others from whom they will receive help even from the earliest phases of the illness. Dario described this issue in his mother’s case. He reported:

> Should I tell you how she has taken the illness? I tell you that sincerely, she has received it with a lot of stubbornness. Because the assimilation was very difficult since the beginning, no, she didn’t want to accept that she had the illness, ah... and currently and it’s very difficult for her to accept help. It has all been very gradual, by steps, step by step, first give her food, help her with her necessities [...] She didn’t try. Although she worked in the medical field, she didn’t try to assimilate in the best way, I think, because after years it’s still difficult for her (Dario, JDA, II, AR, p, 1.).

Dealing with this situation increases fatigue, stress and suffering in the HDC.

*Struggle Against Fatigue*

The data showed that HDCs deal with dementia and rejection of help. This was why many paid helpers quit their jobs. HDCs named this feature as one of their most fatiguing issues. Martha, a 41 year old HDC from the JDA region explained how difficult it was for her mother and for her to assist her late father, she stated:

> “I had him here for two years. Before that my mom had him over there in the little farm. But then I brought him here because my mom was going to Venezuela. Before, I had to go my mother’s home every day. My mom would say that she couldn’t bathe him over there. My mom couldn’t assist
him because she was scared of him. My dad had immense strength and he would hit her. Fifteen days before he died I had to scream out to my husband because dad was choking me, he was breaking my neck. He was telling me I'll kill you! His favorite phrase was “I'll kill you.” I care for him because he was my dad, but he can hurt another person. I know it’s the illness making him hit me or I wouldn’t have the heart to take care of him. It is dangerous to take care of patients like that, because they get very aggressive...They can kill their own mother, their own siblings, themselves... but I had the power of God. He almost choked me one time. If I hadn’t screamed! My husband took him away (Martha, JDA, II, AR, p. 55).

Similar situations were described for other families. In Martha’s case, poverty was a key factor in understanding how demanding it is to care for a patient who is aggressive and who is extremely selective about the person from whom he would accept help.

Martha’s father did not receive medication. He was demanding, aggressive and incontinent and his care was delegated to the poorest woman of the family whose siblings support her with groceries to feed her family and late father. She was taking care of a person who needs two or three HDCs but she had to do it by herself. She could not change this situation and she knew that the next day she will still have the same responsibility. She prays, asking for strength to get through the next day. Fatigue is closely related to the HDS’s aggressive behavior.

*Mastery*

Of interest, the data revealed that regardless of the extreme impairments and cognitive losses of HD people, Colombian HDCs understand care in terms of keeping the HD person groomed. They spend a lot of time on personal cleanliness. They believe that good care is largely about grooming the HD person. According to the HDC, this aspect is important for both HDCs and HDSs. Ernesto, a male HDC reported:
I do her fingers and toes. I polished them yesterday [...] She reminds me to do it. I know that I need to maintain her hands beautifully [...] If it is necessary to dye her hair, I do it myself. She is a little gray-haired, you can see how it is growing out again. She loves the beauty salon. She loves manicures and pedicures because she is a beautiful woman. She is still very proud of herself. We still buy body lotions, moistenings and wrinkle drops. I always put some drops on her and she feels herself, she likes to feel fragrances in her body. She loves dresses and skirts, she likes to be elegant anytime. I try to dress her with these things that she likes [...] In reality we get anything we need for taking care her’. Later we can go and I will show you all the things that I have to groom her (Ernesto, MDE, II, AR, p. 18 – 20).

In the advanced phases, HDCs know that the HDSs’ loss of interest in their personal cleanliness is a signal of greater deterioration. HDCs all through the phases are aware that it is the illness trajectory that makes the HDS get worse. Strauss’ (1975) studies on chronic illness can be applied to HDCs; HDCs perform on behalf of the HDS what he calls confrontation strategies that help the HDS to solve multiple problems caused by the disease.

The main task for the HDC and family was to solve problems that patient’s behavior created and to avoid consequences such as stress and family breakdown that Strauss observed chronic patients causing (Strauss, 1975).

Different from other chronic patients, HDSs are HDCs learn how to deal with medical crises, problems of social isolation, control of symptoms and adherence to prescribed regimens. The HDC is who learn the course of the disease, strive for normality, and find financial resources (Strauss, 1975). In this case, it is the HDC who finds different social support sources on behalf of the HD person. Strauss’s theory applies to those patients who do not lose agency and when it is transferred to the HDCs’ realm these strategies of confrontation described a single issue: HDCs’ mastery.
HD Sufferers in Phase 5

The results demonstrated a large percentage of HDSs died in the early phases from accidents related to the illness. Two women killed themselves in the second or third phase of the illness. They were from different regions and there is no relationship between them. However, both of them killed themselves by pouring gasoline upon themselves, sitting in a chair and burning themselves without expressing fear, pain, or regret. Both women died in the following days from advanced sepsis. Paulsen (2005) has linked suicide in an HD person to depressive processes that are 7 times higher than in the general population. She also states that medication in most cases effective therapy for an HDS (Paulsen, 2005). Nevertheless the HD population in this study was highly un-medicated. Only six out twenty eight HDSs that were observed used a permanent medication (Field notes, 2004). None of the HDCs reported attempted of suicide.

Physical Impairments

In spite of these early deaths, there was a good proportion of HDSs who reached this advanced illness phase. After reaching the last phase of the illness, the most prominent feature is the level of physical impairments. Carolina relates some of the feeding problems of her husband:

After he got sick, Jose would eat half a chicken for lunch, a pound of meat in a single meal, [...] there comes a time when they can’t eat. Jose spent three months being fed through a tube, he couldn’t eat, he could only drink Ensure every three hours. I would pour one of those disposable cups of water around his mouth. That’s not what the doctor would prescribe, because he couldn’t even drink water through his mouth, because he would throw it up. When he felt thirsty, I would wet his lips with cotton, because he needed to taste food once in a while [...] Liquid would choke
him, and he spent eight days unconscious due to a pulmonary infection that he got, because he would throw up the liquids, his lungs got filled with liquid, and so afterwards, they prohibited all liquids through the mouth (Carolina, MDE, II, NAR, p 35).

HDSs are described in the last months of their life as extremely emaciated, unable to perform any action, incontinent and bedridden. Some of them developed bed sores. They were also described as extremely apathetic and disconnected from outside life. This phase can last around two years.

HD Caregivers in Phase 5

Suffering

HDCs from both regions were concerned about how they would deal with the late phase of the illness in which the patient would be bedridden, because the level of complexity and demand for the HDC exceeded their knowledge and vigor. Flor stated,"I do not feel tied up now because my brother is still active, he is not lying in bed yet when he is in a bed and can no longer take care of himself, I will be tied up" (Spanish expression that means to be in a big trouble) (Flor, JDA, II, AR, p.4) Magnolia, expressed the same concern about her brother's disease in the ability of her old mother and family to manage her brother care. She stated:

I am terrible at attending people in bed. I feel revulsion when I see people brushing their teeth. I cannot see it, that’s just me. Then, if I manage them, it is with a lot of effort. I will not do it in a consistent manner. I know that I will not do it well but I will not let my mother go if she gets sick. I do not think I will, I believe I will not take care of her. It means that the solution will be to hire someone at home, someone who takes care of my brother and mother at home but I will never put her in an institution. No way! (Magnolia, MDE, II, R, p. 51).
There is a strong social expectation that the sick people should be cared for at home. Magnolia suffers because she feels trapped in a maze. She has an agreement with her mother in which she provides financial support, and her mother performs the instrumental care, but this agreement is frail because her mother is a very elderly person who will soon need care herself. Magnolia will strive to support her mother and brother at home in compensation for her mother’s devotion as HDC. Magnolia’s story is evidence of how Colombians sacrifice their own well-being to maintain the family’s well-being.

*Love and Sense of Connectedness*

In this phase, HDCs develop a higher sense of care and connectedness; a new form of emotional communication since conversation and other types of communication are limited by the advancement of the illness. Most of the communication with an HDS is through tactile language gestures and body postures. Some HDCs claimed that when they touch or give hand or massage to an HD person, while talking to them there is an emotional communication. Although HD people may not understand, conversations, they are aware of the tone of the voice, they seem more comfortable and they calm down.

When HDSs press or hold a hand and weep a bit, HDCs receive messages. From these details, HDCs often are aware of an affective sphere. Adriana talked about communication with her father. She reported:

> Four days before he died, I saw he was very restless. Then I would lie by his side, put my arm around him and he would grab my hand and that is how he got calm. But during the other hospitalizations, when they cut his foot and when he had gastric problems, I had to close the door and lay down with him on some occasions because he could not be quiet and he was not tranquil […] There were times in which the nurses would enter
and they would say, “‘This can’t be done.’ And I would tell them, ’Well, I am very sorry for violating the rules of this institution, but for me, he is first’” (Adriana, MDE, FG, AR, p. 23).

The interviewees reported communication with the eyes and movements that express rejection and other emotions.

Mastery

The interviews revealed that HDCs also developed mastery. Families managed to make adaptive devices and accommodations for helping the HD person to perform their daily life activities and to be safe at home. For example, an extremely poor family from JDA whose father was unable to walk at night to urinate created a male urinal from disposable oil plastic containers removing a small piece in the upper part of the container and keeping the handle and the lower part. Families with more resources installed safety handrails, and bedrails. They padded rooms, acquired unbreakable dishes and cup. Most of the people removed objects that could hurt the HD person and found more comfortable clothes and shoes that were also resistant to their movements.

Poor families have fewer resources for getting these devices and making accommodations. Poor families deal with incontinent HDSs without diapers by constantly cleaning urine and excrement spillages. In the JDA region, families who have HDSs in advanced phase of dementia and who are extremely aggressive, build cages and maintain the HD person behind bars. Martha related her struggles in these paragraphs. Martha recalled:

He would say “water, give me water," but even if he asked for water what he really wanted was food. So every night I had to lay out the small mattress in his enclosure, and wash it because he would soil himself there, completely, completely. So I would feed him here. [..]So, this is the room, I made it… I made this bed of concrete because he couldn’t use the
wooden bed anymore [...] this is special because it was strong enough for him and I put this small mattress on top. So he could urinate and all at night [...] I put cement because it was easier to clean than wood. [...] I would pour water, every day I had to clean it and the stream of urine and feces would run over there every day. That was three, four times if he soiled himself I had to bathe him. I would take him over there on the patio. I would bathe him on a wall, but he managed to throw me down and run over here and he would fall [...] I had to force him to bathe, I mean, he would fight with me, he would throw blows at me and I would grab him until I could take him back but he would fall here (Martha, JDA, II, AR, p. 1-2).

Locking her father behind bars was her strategy for controlling him and protecting herself from being hurt. She stated:

I put in these little bars because he was very hyperactive, because he lost his memory. He would sometimes call me Ana, and when he would really look at me he would call me Negra (term of endearment meaning dark one). [...] So when I would take him out to bathe him and to clean the room I had to lock myself in like this and leave him there, eh, sitting. [...] When this place was clean I would bring him over here inside, so I always had to have this gate closed when he was here. He would stay in here during the day (Martha, JDA, II, AR, p. 3).

Martha’s mastery and strength is evident also in this paragraph, as she added:

I would struggle with him, I would fall here on the floor, I would fall with him and... better said, he was a person that didn’t know what he was doing; [...] He was my dad, but sometimes I would think twice about bathing him, uh! And sometimes it was on my own, alone! [...] When he would soil himself three, four times sometimes I would take him over there, Ay! It’s just that, better said! I would tell my God, “Pick him up my Lord,” because Uh! That was something!! Just like I asked my God, my God took him away (Martha, JDA, II, AR, p. 5).

Martha’s interview documented mastery because her capacity to tolerate a situation like this for two years and because to have her father in a cage is a good alternative for keeping an un-medicated HDS who can assault at any moment their relatives and HDCs. In this region they build cages for aggressive HDSs; 3 of the
current HDSs and 5 late HDSs were caged. In addition to the mastery, her interview also shows how deep her suffering and fatigue are since she begs God, “God take him away.”

Struggle Against Fatigue

The data showed that without exception, HDCs agreed that most demanding activity was taking the patient to the bathroom, because they asked to be taken there constantly. For those HDCs such as Martha who dealt with incontinent HDSs, the burden reported was even greater. In the JDA region this is a core issue because none of the houses have bathrooms inside. In a focus group, Alicia described what happened when her father tried to defecate in his latrine:

Our bathroom is built in the back (She means back yard with plants and trees), because these houses are old. They are from a village, so people are accustomed to only build the rooms inside and the people in the past eh… used latrines in the back, there aren’t, there isn’t a sewer system here, so the bathrooms have to be built with a cesspit, with a septic tank, so they build them in the back to prevent the home from smelling. When a person is ill and the bathroom is in the back you have to use your creativity to… figure out how he’ll go out there and… or find a way to see how he’ll take it over there! He would soil over there in the back, in the patio but he couldn’t hold himself up in the bathroom, because he would fall. He had to crouch down and smoke but while going to the bathroom he would fall, he would drench himself completely… with feces. They are not able to use it safety and find the way back instead they have accidents along their way back (Alicia, JDA, FG, AR, p. 23).

Despite the fact that she was sharing her HDC labor with her two sisters and mother, she expressed a lot of exhaustion and anger about caring for her late father in the last phase. She stated:

We would take turns, because my mom had to work sometimes… When he soiled so many times a day I would tie on some gloves. Our gloves were plastic bags. Without bags it was more difficult because then you…
that smell wouldn’t go away, it would stay ten days straight dirtying… eh…
eh… then in the end he was soiling himself a little everyday. Many times I lost my patience. Many times… I’m not going to say that I didn’t… I scolded many times. I would tell him many times, “You’ve got me very upset” (Alicia, JDA, FG, AR, p. 61).

The data show that in the JDA region the conditions for caring for an HD person were inadequate and HDCs tolerated unbearable conditions.

*Inner Negotiation with Social Expectation*

HDCs, in the last phase, complained about physicians and other health personnel because they tell families that an HD person is no longer worth the effort to kept the alive. Physicians try to impose their treatments instead of following the family’s and HDC’s desire. Making the decision of using a feeding tube was a difficult decision. HDCs also resented physicians who seemed more interested in conducting research about the illness and were grateful for those who were compassionate and respectful.

The data demonstrated a tension among relatives in charge of the HD care as to whether or not an HD patient in this phase would be better dead. Patricia’s interview revealed that surrogate agency was present, even at the end of a HDSs’ life, and affected the HDC’s well-being; she reported:

My father’s period of required caretaking lasted 17 years and I was his caretaker for 14 years and I can only say something that as a caretaker I got seriously sick in my personal experience is that one goes crazy or it is to say one feels for the patient something that goes further from his control and a pathological dependency is created. One does not want to let them go and everyday one gets closer. You want to give your maximum. Give them all possible and impossible things. This is a characteristic you would see in the caretaker. It is not normal because if one would see him suffer and see him deteriorate, but at the same time reach a strengthened connection. They would lose their speech and can only communicate by gestures at the end will become confused. At then end you practically feel like a derivative of the patient and one can’t tolerate that one day that person is not going be there because one would feel mutilated. The very
thought of that person going to disappear, even if that implies you are going to rest physically and psychologically, your psychological being remains very altered all of the time. You would like to never lose them because you reach a mutual understanding and interdependence with them that is not understandable by people who weren’t a HDC (Patricia, MDE, FG, AR, p. 46).

Patricia denounced the amount of pressure placed upon HDCs and the little assistance that they received. She stated:

One would get seriously ill and even for the gravest illness in our society the HDC doesn’t have psychiatric assistance or medical assistance. You fail mentally and physically. […] Neither do we perceive it nor does the HDC ever have help here. Furthermore, the family begins to punish the HDC, then, you have the load of the patients’ psyche and the load of your own destruction. One’s own emotional load is enormous and you do not have medical assistance. That is why this illness is catastrophic for the patient and the HDC (Patricia, MDE, FG, AR, p. 47-48).

Although Patricia has more scientific basis for claiming that HDCs overload is not properly treated in Colombia, Flor believed that there was a connection between HDC overload and the development of physical illness. In this particular case, the HDC being at risk of HD, sees a path between HDC overload and HD development. Flor stated “when a HDC gets tired, they become even more susceptible to develop HD (Flor, II, AR, p. 12) Flor copes with the idea that her physical maladies may be signals of HD. The amount of coping resources among HDCs at risk is enormous as Flor stated, “.. I say.. what is this exhaustion about, my God, I already got this illness or, then I clear my mind of that because I think, this exhaustion is probably because I’m tired of working, because I don’t sleep well or something […] I’m going to be strong, I’m not tired, there’s nothing wrong with me” (Flor, JDA, II, AR. P.13).
As prior studies have shown, Flor’s perception of fatigue was a sign of HDC’s burden (Chesire, 2003). Nevertheless, as Pearlin et al., (1990) emphasized, HDCs’ burdens vary depending on the socio-cultural context.

Chapter Summary

The data strongly indicate that there is a dialectical theoretical relationship between the phases of the HDSs and the HDCs. Caregiving phases respond to different challenges that HDCs deal with throughout the illness. Those challenges are related to two main issues: taking care of the HD person with their physical and mental disabilities and managing the uneasiness of knowing they or their children can develop the illness in the future.

The results strongly suggest that HDSs’ agency decreases through the phases. In the first stage HDSs show more energy and emotional resources for fighting against the illness than they do later. Depression, anger and shame are important emotions among HDSs, but these emotions dim through time in relation to the functional phases. HDCs reported that as the time pass HDSs in this study are more disconnected from their own emotions.

The study found that HDSs’ awareness and capacity to reciprocate their HDC decreased as the illness progressed. HDCs noted that HDS’s needs in the advanced phases were related to major physical impairments that demanded more intensive care from the HDC.

As the phases progress both HDSs and HDCs experience suffering; but HDCs’ suffering increases, while the effects of the illness decreases HDSs’ capacity to express
their feelings. Many of them, due to brain dysfunction, are not aware of their condition and do not recognize their disabilities. This lack of awareness, called anosognosia, makes it harder for HDCs and physicians to interpret signals of suffering and sorrow. Anosognosic HDSs cannot monitor their inner processes and, therefore, the ability to understand their condition is diminished. People whose capacity for monitoring is decreased suffer an important loss of human agency (Nikolinakos, 2004).

Through the stages, the cognitive and physical capacities of HDS decrease. The loss of mental skills affects their capacity for enjoying the HDC’s emotional support. The most important effect of cognitive deterioration in the HDSs is the loss of their productive lives. HDSs from rural areas fight against the illness by trying to maintain their former lives. In contrast, people in the city strive to be active agents fighting against the illness, searching for reasons to do so and developing strategies for combating the illness.

The data also support that as their physical and mental conditions deteriorate, they lose their capacity for enjoying leisure activities and intellectual stimulation from their HDCs. The data also show that in the first stage, HDSs require less instrumental care than in the latest stages.

The same is true with the “sense of connectedness. HDCs in this study report that their relationships become smoother and closer in the later phases, when the HDSs are less aggressive and seem more vulnerable. HDCs provide emotional support through all the phases but while at first this support is more related to encouraging the HDS to fight against the illness, in the late phases the emotional support is expressed more through gestures and tactile communication. These changes in the type of
emotional support were shown to have been connected with decreases in the mental capacities of the HDS.

Although the expectation of most HDCs is that a good HDS is a HDS who obeys both the HDC and the medical regimen, in practice, most HDSs are demanding persons, creating stress and fatigue in the HDCs. Nevertheless, HDCs in the study are reluctant to express stress and fatigue openly, despite the fact that they deal with burdensome situations and that HDSs tend to get worse throughout all the phases. Most HDCs in Colombia deal with HDSs who do not receive medications.

HDCs in the study ask “Why Me,” and they answer this question through faith, because they think that the HDC role is predestined by God. There is duality in the sense that there are fatigue, burden, embarrassment and even inner struggle with the social expectations. But at the same time, the HDCs achieve mastery, a sense of connectedness and a sense of purpose for assisting HDSs through the phases. They also become self-reliant and proud of their accomplishments as HDCs.

HD in Colombia has a physical stigma attached. The negative reaction to HDSs is even higher in the advanced stages of the diseases when not only the bizarre movements are noticed but also the behavioral disorders. Stigma and social embarrassment affect all aspects of human interaction in HD suffering and they become a hindrance even for receiving appropriate treatment and care from relatives. Family and HDCs’ social interaction is also affected when they withdraw from these associations as well.

Among poor families of both regions, caring for an HDS exhausts the family resources while wealthy families are afraid that the lack of judgment in an HD person
will result in financial loss. Participants feel that the whole family helps either very little or none at all, while acknowledging that the HD person needs more company and more financial assistance. The care of the HD person causes quarrels and polarizations within and between families, sometimes lasting for decades.

Colombians have good cultural mechanisms for enduring caregiving hardship and the adversity of illness. Caregiving is mastery because in the Latino culture, those who handle difficult situations are developing spiritual growth. Caregiving, even with all the cost and burden, allows people to develop self-control, calmness and the ability to tolerate frustration, and to overcome all kinds of obstacles. Therefore, those who care are proud of themselves, and have a positive social sanction.

HDCs expected little compensation because they believed that “to give without receiving anything was the highest human satisfaction.” They knew that few HDSs would reciprocate their help and did not care about it. Furthermore, most of them expressed the intention to take care of other sick relatives. Colombian HDCs rarely believed that they had lost an important part of their lives because of caring for an HDS. Most of them claimed that they accomplished other life-time goals such as having motherhood and marriage, which were important events within the Colombia culture.
CHAPTER 7
THE SOCIAL CONTEXT OF HD CAREGIVING IN COLOMBIA

Introduction

After describing the findings related to the Huntington’s disease (HD) theoretical phases, this chapter presents some findings linked to the social cultural aspect of taking care of an HD person in the Colombia context.

Social and Cultural Aspects of Caring for Patients with Aggressiveness

One of the most stressful situations that Huntington’s disease caregiver (HDCs) deal with, even from the first phases of the illness, is the display of aggressiveness. Among HDSs only two men were typified as extremely passive, in either JDA or MDE, while most women were passive. Most of the men from the JDA region who developed the illness at a young age or as middle-aged adults were described by their HDCs as abusive and violent prior to and after the onset of the illness. Wives, daughters and sons who cared for these people described a family life with much of domestic mistreatment, as Carolina told about her marital experience:

I remember that during my pregnancy with my first girl we had a horrible problem, and I asked him for a separation. It’s just that, imagine it, during twenty-one years of marriage I asked for a separation eight times. I requested it and he never wanted to, he would tell me that over his dead body. I would send the police to the university where he worked. He was very aggressive, wherever he could get me, look, he used to hit me hard and he never wanted the separation, but he was very aggressive [...] He hardly ever hit the children, but when he did it was hard. In fact, when I was sick he began to beat my son (who is suffering HD) because he was the most stubborn one, so he would hit him very hard, but that was his behavior all his life” (Carolina MDE, II, NAR p, 57).
Leila told us about her late husband’s behavior, “Well, before becoming ill, he wasn’t a saint because let’s say, he used to mistreat his daughters. He would very get jealous” (Leila, JDA, FG, NAR p. 4). The illness increases aggressive behavior in these men, as Leila stated “Emma was the girl that received the most beatings from that man. One night, she even fainted, because he had the porch full of corn kernels and while running away she ran and she tripped on a stick in front of her and she fell unconscious.” (Leila, JDA, FG, NAR, p. 5) During a focus group, in a very rural area in Juan de Acosta, an elderly woman related: “He got in a rage every night, we had to take our lamp and escape from the ranch. We slept all together hidden within the bushes. It is a miracle the snakes did not bite us” (Veronica, JDA, FG, NAR p 13).

But in the JDA region, not only sick men mistreat their families. Flor, a female HDC, narrated how during her late mother’s sickness, the father was the one who mistreated them: Flor said:

My dad wasn’t ill, and my dad would beat us[…] My mother was ill and my mom would get involved and also, my mom was beaten. She wasn’t able to defend us. He would get upset with us and he would lock us in, but he wasn’t ill, or anything. And in the time that we cared for my mom; my mom could not protect us or help us because he didn’t allow her (Flor, JDA, FG, AR p. 6) […]. My mom was ill, and she couldn’t go outside to search for us because she was afraid to leave the house. Nevertheless, one day she went out to search for us, but because of her illness when she went out the neighbors stopped her. They said to her “No, don’t go searching for your daughters. Leave them, they are at a party.” But she replied, “No, because their dad will come home and he will harm them.” (Flor, JDA, FG,, AR, p, 9).

In spite of the history of family mistreatment, only 5 out of 25 wives (20%) move in with a new man or get divorced; furthermore, from those divorced, one of them took care of her ex-husband in the last phase of the illness. A late HD man who cheated his
wife with three different women simultaneously and engendered more than 30 children was looked after by one of his oldest daughters and a daughter in-law. At this date, 7 of his children have the disease.

_Men as HD HDCs_

Husbands are less likely to care for a sick wife. After the onset, of the wife’s illness, 7 out of 14 husbands (50%) got a new girlfriend while living still with the HD person. In the overall sample wives are more faithful and able to endure a more stressful relationship with a sick husband than husbands are. Leon, a young man, described caring for a wife who has been sick only three years ago. He reported:

People tell me, you are good man because how many men see their women like that and abandon them [...] People know that I love to drink and I will never quit it [...] Nevertheless, I will struggle with my wife until the end because I knew her healthy and now that she is ill I will not throw her away. This town is full of women in every corner [...] I had a lover four years ago. She used to ask me to leave my wife and I told her, “I am very poor and unfaithful but I am not considering leaving my wife, I stay with her until the end (Leon, p. 11).

Leon continued to talk about the details of caring for a sick wife. He stated:

As a man that I am, I like sex, and my wife does no longer have an interest in sex. Do you understand me? For that reason I know how to manage. I have escaped for two or three days but I told my wife that I was working and she trusts me (Leon, MDE, II, NAR, p, 12).

Leon and other men who cared for wives reported that all a sick wife needs is “food and roof” (Leon, MDE, II, NAR, p, 11). They believed that as long as they provided, they were free to pursue their own interests. In addition, Leon’s sense of reciprocity should be valued in the context of the caregiving, because, as other HDCs
related, the commitment of a husband to a wife who has been sick for more than a decade fades. Flor remembered caring for her mother. Flor stated:

My mom, my mom would get very jealous with my dad, and she would tell him to bring her the bread, and with her illness, and she would talk about the women he had. She would say, “those damn women,” when he had Catalina, and he had Nancy, and she did not like Nancy because she was her own cousin and these women got in her way, the one he lives with now is Nancy (referring to the fathers actual wife). She would say that she didn’t accept that, that she had taken the “daily bread” from her children (meaning that she had stolen the family’s provider). My mother was ill, my father was young and he needed a woman, but my mother did not accept that Nancy was my dad’s woman (Flor JDA, FC, AR, p. 14).

This difference between men and women is the product of still strong traditional gender expectations that were inculcated in little children. For instance, Leon encourages his twelve year old daughter to assume early caring roles. He expressed that “I say constantly to my daughter, wake up! you should learn to prepare meals and to clean the house in order to help your mother, you see how she is” (Leon, p. 14). That is the reason that Blanca is disappointed with Colombian society. She claimed, “HD people are considered a family issue and their care is delegated exclusively to daughters” (Blanca, MDE, IP, AR p. 67). Blanca considered that life in the city changes a lot of the family interaction because people are always busy. Nevertheless, women have assumed new work roles that will hinder them in providing care for those in need. “The problem is that men’s roles in our society have not changed yet, so society still relies on women for proving care” (Blanca, MDE, IP AR p 71-72).

Differences in Social Solidarity among Small Towns and Large Cities.

There is a difference among Colombians in the way that they perceive social solidarity and reciprocity. HDCs from little towns such as Juan de Acosta and Entrerrios
believe in extended social solidarity among the whole population as a base of their social fundamentals and survival. Leon narrated in his interview:

Here, all people are united; if there is a sick person, all people are around that person […]. Before we were like 3,000 people and now we are more than 8,000. Here, everyone is united while in a city a sick person will die. Here, we are very poor but with an illness like this people offer me a lot of resources, like money or anything […].Look, one day I think it was my son Felipe, got sick, and people from the town ask us “what do you need? Do you need money?” […] They immediately carried him to the hospital […]. Despite that I am very poor, here I never come to a standstill about anything (Leon, MDE, II, NAR, p. 28).

Similarly, a key informant in Juan de Acosta recalled his views of social solidarity. She said:

Now we have seen people coming here from other places and mixing with the natives. That have taught the people here to be selfish, but in general, the natives of Juan de Acosta are very noble people with good hearts. In general, the people that come from outside come with a selfish mentality For example, around here, if I have guayabas (fruit), I say ‘Hey Blanquita grab some guayabas,’ and there is no problem for me, ‘grab some lemons.’ grab lemons because that’s not mine”, on the other hand, people that are selfish, that speaks and thinks “I’m going to sell it and I’m going to earn money’ (Alicia, JDA, KI, AR p. 8).

A key informant from MDE expressed different views of social solidarity. Blanca stated:

My mother owns 50% of the community property with my father. And I have my dad like this (she points out with her hand her elbow, which means to become tight with your money). I have him ready: "Dad it is that things are like that." The expenses are these and these and there is not enough money for them, then what are we going to sell? (Blanca, MDE, IP, AR, p. 41)

Blanca also noted that the importance of her mother’s quality of life. She stated:

And what are we going to do and how are we going to support her, but my mom’s quality of life is above the patrimony of the children. I told all of them here: “None of us needs money, they already gave us all the opportunity to enjoy an upper class life. That is the condition that we each have, all of us have work, all of us have a profession and all of us have a
car, a home and their children. So you do not think that what is from my
dad and my mom we are going to keep as patrimony, we have a mom
with dementia who is going to generate all the expenses that you can imagine” (Blanca, MDE, IP, AR, p. 41).

Blanca's interview can seem a little insensitive and money-oriented because her perception of the patient’s quality of life can be perceived as the attempt of an upper class family to maintain its social status. The status is seriously threatened by the cost of support for an HD person in a country in which dementia expenses are not covered by any medical plan or state financial support. The issue of solidarity should not be oversimplified in terms of how people in towns and large cities manage the economic issues of caregiving. The same Blanca’s interview gives evidence that there are many more nuances in the issue of reciprocity:

I don't know how to interpret it but my mom was unconditional with me.
When my mom took care of my children, I took my child with fever at 6.a.m. and she told me, "My dear go to study, he will cry for a while and by the time you get the corner he has already forgotten and he gets calm. Now I am a doctor and a dermatologist and I can do many more things because she always supported me. So, I struggle to maintain her quality of life as much as I can, but the problem is that daughters get more involved. I don't know if it is because I have such a large gratitude debt with her (Blanca, MDE, IP, AR, p. 68).

This means that regardless of the differences in mentality, there is still a unity in the mindset of the Latino culture that makes the care of relatives a main concern. Blanca again underlined that “care here is still a women’s concern” (Blanca, MDE, IP, AR, p. 68).

*Caregiving and Poverty*

Needy HDCs report a dual stress for taking care of the HD person and also for not having work or enough money to provide the family needs. This finding was
consistent in both regions. Interviewees remarked to the researcher that providing employment and money was the most effective way to help them out. The Espinal family with 5 siblings stricken with HD (one of them already dead) declared in a focus group:

If we can get some help. I wish someone could help us because we are unemployed, we are going through a crises [...] here, there are only four months with rain and because of the sun the dirt is dusk we cannot cultivate it [...] We are not harvesting anything [...] I think that because of the illness people do not give us work [...] It should be backwards, when a person has an illness like this and his family members request a job people should give them the job (Alberto, JDA, FG, AR, p 74-75).

Her sister Leonor who is 41 years old, echoes Alberto’s ideas, She states “If the father cannot work, but he has a child who is twenty two years old, give the job to his son or a daughter if they do not want to give it to the father” (Leonor p. JDA, FC, AR, p. 77). As has been demonstrated through the description of the HD HDCs’ worries in small towns, poverty is a factor that has a cascading effect upon HD care conditions.

**Government Abandonment of the HD Family**

Neurologists were highly concerned with three issues. First, Colombian Huntington’s disease sufferers (HDSs) do not have any protective legislation that allows them to receive all the treatment available, at least to improve the quality of life. HD treatments are very expensive and the Colombian system of social security does not provide help to the HDSs. The reality is that those who are enrolled in the subsidized system of health do not receive treatment, and medication for HD is specifically excluded. The second concern among neurologists was the cost of caring for a person with dementia which in Colombia is not covered for anyone.
Two neurologists and one physician claimed the cost of caring for a person with HD in Colombia was more than the sum of 7 minimum salaries per month (Ibarra, MDE, IP, p. 29; Lemus, MDE, IP, p. 29; Morales, MDE, IP, AR, p. 42) which is around $1,086, while Colombia per capita income is $1,850 per person per year (ONU 2003). Neurologists such as Lemus and Duran were also aware that there is not any social policy that facilitates an HD person’s continuing to have a job as long as the HD person is able to do the work (Lemus, MDE, IP, p. 45; Duran, JDA, IP, p. 36).

Neurologists were aware that employees and even coworkers were little aware of HD and instead of helping people to extend their productive life, in practice there is a social stigma that hinders HD people from having a job (Lemus, MDE, IP, p. 46; Duran, JDA, IP, p. 37).

Although HDCs have a high expectation that HDSs can work as a therapeutic measure, the reality is that very few HDSs in this sample are given the opportunity to work. Only those who are in the countryside and have little farms are able to develop an economic activity but they are not able to support their families and themselves with this labor, usually they require income from a complementary source. Julia states about her father Johnny, “My father was a picker of tomatoes, he used to pick the tomatoes of all the people around, but now they give him very little work, he is still working because my mother wants him to make his contributions for the retirement pension but now it is my partner who is buying our groceries every week” (Julia, MDE, II, AR, p 37).

**HDCs at Risk: “Living Under an Avalanche”**

In general Colombian HDCs, both those at-risk and those who are not at-risk, are reluctant to have genetic testing for themselves or for their children. This may be a wise
attitude in a country in which people are not treated with specific HD medicines as noted by many neurologists but rather with generic psychiatric medicines like Haroperidol. The choices for treatment and care are altogether inadequate (Lemus, MDE, IP, NAR, p. 19; Ibarra, MDE, IP, NAR, p. 35; Garcia, MDE, IP, NAR, p. 27). The genetic test is not available to everyone, but only to those who are involved in neurological studies or who can afford to send their blood samples to foreign countries.

Rosa's husband, William, is an HDS. He has an important position in a polymer processing plan that agrees to pay for genetic testing for William and his children. He was tested, but his wife refuses to allow testing her for her children. Rosa’s rationale is:

I have an ill person in the family and I’m dedicated to him So, I would rather hope that my children will live their lives, just as he did. He lived his life, he fell in love, he got married, he had his children and now he has me and I’m taking care of him, I wish for my children also to do that, because if I find out that my children, one of them or the three of them are affected, it wouldn’t even be a life for them, or a life for me, because then, I would think that they wouldn’t get married, or would not have children and any of that. So, my hope is that some day this illness may have a cure (Rosa, JDA, II, NAR, p. 8).

When the doctor sent the test orders, I asked them whether they wanted to have the exam done and they told me that they didn’t. Both of them.... told me "no, no mom, we prefer... we prefer not to know," [...] If some day, they tell me “we want to know whether we have my dad’s illness”, since it is their wishes and they are now a legal age; then I will think they should do it (Rosa JDA, II, NAR, p. 9).

Although people were reluctant to have the genetic testing, most of them were concerned about having some savings or financial provision for themselves and their children if they should get sick. In a country where genetic testing is not yet a routine exam, those at risk cope with the illness with three thoughts in mind: I need to live my life intensively, I hope my onset comes on late in life, and finally I hope that HD affects
me in a benign manner (Blanca, MDE, IP, AR p. 50; Leonor, JDA, FC, AR, p. 95; Dario, JDA, II, AR, p 16).

In the MDE region, a neurologist considers that genetic testing cannot even used to prevent those at risk from having children, since HD still allows people to lead a productive and valuable life (Lemus, MDE, AP, NAR, p. 20). HDCs also reported that children at risk have very little or no knowledge about HD. HDCs accepted that this attitude is linked to the stigma associated with the illness, because going out with a person who has HD is always embarrassing. They know that people are looking at them. When you are with an HD person you cannot be unnoticed.

HDCs from both regions want their children to have genetic testing but most of the time they do not have a clear perception of what the benefit would be. Most of them said “I would like to know if my children are going to develop this illness in order to prevent it” (Leon, MDE, II, NAR, p 23; Pedro, JDA, II, NAR, p. 43). This statement does not really make sense since HD cannot be prevented.

Chapter Summary

Aggressiveness or rage were described as the most disruptive aspect of HD in family interaction, since other family members often react in the same way as the HDS creating extreme distress in the HDC. Aggressiveness in HDSs extends from simple actions such as throwing and breaking objects to more serious bodily attacks on their close relatives and HDCs. Nevertheless, there is a gender difference in HD aggressiveness. Males display more aggressive behaviors while women are less physically aggressive and more likely to use verbal aggression.
In the JDA region, regardless of the father’s mistreatment, the interviewees regarded the refusal of a wife and children to assume the care of an ill father as the worst crime on earth. Infidelity and marital cheating are no reason to lose the privilege of being cared for by a loving wife or daughter. On the other hand, young men who care for their sick wives express more duality between following the high social standard of reciprocity between spouses, but they also feel the need to meet other strong social expectations, such as men having regular sexual intercourse and other types of enjoyment. This difference between men and women is the product of the strong traditional gender expectations that are still inculcated in little children.

Latino culture makes the care of a relative a main concern, especially a woman’s concern. However, there are differences among Colombians in the way that they perceive social solidarity and reciprocity. HDCs from little towns support more extended social solidarity among the whole population as a base of their social fundamentals and survival while families in large cities strive for the survival of the family in terms of being able to maintain their social status and preserve the cohesion through adversity.

This chapter discussed the reluctance of HDCs to take a genetic test, but most of them were concerned about having some savings or economic provision for themselves and their children in the eventuality that they might get sick. In a country where genetic testing is not yet a routinely exam, those at risk cope with the illness through three ideas: “I need to live my life to the fullest, I hope my onset comes late in my life and finally I hope that HD affects me in a benign manner” In the JDA region, genetic tests cannot even be used to prevent those at risk from to having children, since HD allows people to lead a productive and valuable life.
The most disturbing finding in this study was government abandonment of the HD family. Colombian HDSs and HDCs need protective legislation that allows them to receive all the treatment available to at least improve their quality of life.
CHAPTER 8

CONCLUSIONS

Major Findings from the Research

This study explored the surrogate theory of caregiving among Huntington's disease sufferers (HDSs) in two Colombian cities. The findings are in three major areas: The theory of the subrogate agency, socio cultural differences among the regions, and social problems for HD families in the JDA region.

Subrogate Agency

The theory of surrogate agency was validated. The data show strongly that the relationship between Huntington's disease caregiver (HDC) and HDS is a relationship of agency. Researchers have described HD and other neuro-degenerative dementias as threats to individual identity (A Wexler, 1995, De la cuesta 2003). The proofs that the model was supported are:

1. HDC and HDSs experience immense suffering.

2. HDSs experience through the 5 phases anosognosia or loss of capacity to recognize their mental and physical impairments. The degree of anosognosia varies from HDS to HDS, although it increases through the phases. Anosognosia affects the capacity of the HP person to express suffering and sorrow. Those with a lower degree of anosognosia in the first phase of the illness experience more psychological effects such as depression, grievance and denial. HDSs with this condition reject advice and recommendation from HDCs and physicians, and expose themselves and their families to risks, abuse and abandonment.
3. HDCs' suffering increases through the 5 phases for different reason, including the lack of funds, the aggressiveness of the disease, the unfair distribution of care responsibilities among relatives, and the suspicions of outsiders who regard the HDCs as negligent, unloving, cruel and even responsible for hastening the progress of the illness.

4. HDCs' sufferings have still other sources such as witnessing the deterioration of the HDS, dealing with hundreds of crises through the illness and dealing with wandering about the next life-threatening accident or injure that the HDS will experience. They suffer because they feel emotionally affected when people around them began to see the HD person as someone whose life no longer has value. At the end, HDCs' suffering is related to the awareness that complexity of the disease and demands on the HDCs exceed their knowledge and strength.

5. Through the phases, HDSs experience an increasing loss of cognitive and physical capacities that affect their family and social interaction, and lead to social isolation. This isolation is heightened by the stigma associated with the illness.

6. HD in Colombia is stigmatic for HDSs, families and HDCs. Although the HDSs' feeling of embarrassment about their condition will weaken over the phases, families and HDCs experience more stigma for their status as at-risk individuals. The main sources of stigma are: the ugliness of the disease increases, the associated dementia also increases, and other people have more awareness of the at-risk status of the HDCs and other relatives. Stigma is results of ignorance
among the general population about this disease. HDSs with more awareness of their conditions experience more voluntary social withdrawal.

7. HDSs’ cognitive capacities influence the degree to which they can engage in reciprocal behavior with their HDCs. HDSs’ capacity of express gratitude and acknowledgment to their HDCs fades over time, making the HDC’s labor more burdensome.

8. The capacity to fight against the illness decreases through the phases. A higher mental awareness in phase 1 influences the capacity to assume a sick role and to cope with the illness. In the second stage, HDSs’ compensatory strategies for fighting against the illness are reduced. In final stage they expend their energy trying to swallow or express discomfort.

9. Through the stages, greater physical and mental impairment decreases the capacity of the HD person to fight actively and, makes them begin to need more assistance, ant to different degree. In addition, HDSs are very selective about the people from whom they will receive help and in what type of activities.

10. In contrabalance to the stigma because of the at-risk status the HDCs receives great social enhancement because their experiences are full of hardship which is greatly admirable in Latino culture. It is thought that those who endure hardship temper their spirits and achieve spiritual control. This mindset is clearly the product of Catholic doctrine that is still hegemonic and in many ways is still a factor of the homogenization of the Colombians’ mindset.

11. HD HDCs develop mastery through the stages. They capitalize on knowledge gained by experience and by trial and error. They learn gradually to deal with the
medical system and with scientific knowledge about the illness that is being gained little by little. In the first stage, they provide needed encouragement and emotional support for helping the HDS to lead a “normal” life and to perform their own activities as long as possible.

12. HDCs in this study developed sense of connectedness and love that increased with the stages and, obviously, varied among the HDCs. Connectedness in the first stage is expressed verbally, while at the end of the HDSs’ life it becomes more subtle. This sense of connectedness and love compensated for the lack of expression of reciprocity from HD person in stages 4 and 5 when HDSs experienced serious communication limitations.

13. Mastery is also achieved because most of the HDCs deal with HDSs who do not receive medication. This means that the HDCs interact with HDSs who exhibit the coarsest psychiatric behaviors. Regardless of this, HDCs through the phases develop a high degree of tolerance and patience to deal with the HD patient, understanding that the emotional changes are effects of the illness. This is highly admirable because their level of training and the support that they receive is minimal.

14. Mastery is also proven because in a country in which services for the HDSs are almost non-existent, HDCs must solve the needs of their relatives by themselves.

15. In addition to developing mastery by dealing with HDSs without medication, adequate medical care, economic resources and family support, HDCs are also affected negatively by burden, stress and fatigue. Nevertheless, HDCs’ complaints are rarely voiced.
16. Findings also give evidence that HD HDCs experience burden, although Latinos are reluctant to complain about burden or about unfair distribution of care responsibilities among relatives. This finding supports prior studies (Lim et al., 1996; The 10/66 Dementia Research Group, 2004) that HDC’s burden is a private matter.

17. HD HDCs through the stages provide more and more instrumental help because there is increasing apraxia and disabling movements that hinder them from performing the simplest activities. The most challenging and burdensome effect of the illness is the incontinence.

18. HDCs must deal with four social expectations through the phases. The first inner dialogue is about answering the question of “why me?” The second dialogue is about the inconsistency of financial and emotional assistance that they receive from other relatives with similar responsibilities. Third, there is a social expectation of supporting family through adversity even if it means assuming the role of head of the family in order to maintain the unit. This social expectation involves sacrifices of the HDCs’ own life projects and may create many inner questions whether they should consider family survival over their own interests as individuals. Another strong social expectation is that elders, children and disabled family members should been cared for at home. When the HD person arrives at phase 4, the HDC begins to battle with this expectation because objectively the HDS is in need of institutional care but the HDC is afraid of taking this step. These 4 topics are the main sources of inner negotiation with social expectations, all of them part unexpressed.
19. Aggressiveness from the HD person was considered the most unbearable problem of taking care of an HD person. High levels of aggression were found in both men and women but in males it was more physical while in females it was more verbal. Strong gender patterns of education are assumed to be the cause of this difference. High levels of aggressiveness also must be linked to the lack of medication available to Colombian HD’s HDSs.

20. Being at risk of HD increases HDC stress, but also increases the HDC’s sense of connectedness with the HD person.

21. Finally, there is very little awareness of the implications of being at risk among the population. People do not consider that genetic testing can improve their lives in any way. HDCs at risk expect to develop the illness themselves and if they do develop it, they expect to have a late onset, with smooth and gradual progression of the disease.

Cultural Differences among Regions

There are differences in caregiving between both settings related to economic and cultural conditions. Colombian’s perception of reciprocity influences enormously the HDC experience. Catholicism is a source of moral principles defining the mindset of social solidarity among HDC and other people in Colombia.

1. Education, social status and personal history have a strong effect on the strategies that HDSs use for overcoming the illness. HDSs from small towns are more likely to strive to maintain their former life while those in the city engage more in life changes that can compensate for the illness effects.
2. Colombian families still support social solidarity but there is a difference in the patterns of solidarity from a communal or extended solidarity in little towns to a more restricted form of solidarity in cities that revolves around the close family.

3. Findings of this study point out that HDCs from small towns have a very distinctive way to deal with HDSs that is different from that of HDCs from large cities. HDCs in small towns are still linked to solidarity forms that reflect what Tonnies (1987) called organic life while large cities are oriented for patterns of solidarity that Tonnies (1987) describes as mechanical structure.

4. The particularities in the small towns visited in the JDA region and MED region include mutual affirmation of the most intimate relationships, more orientation toward a private life, a tendency to remain from birth to death in the same place and strong religious orientation. The small towns also exhibited an adherence to family life and gender roles such as mutual assistance, obedience of children and patriarchal models of family relationships that gave men more power, preeminence and freedom in all life spheres of life (sexual freedom, economic freedom, and freedom of mobility). In Juan de Acosta solidarity is based on blood, friendship and local unity.

5. Results also show that females still predominate in the HDC role. The few male HDCs who were found in the sample took that role because there was not a close female relative who could do so. There were families that were composed mainly of males, families in which women were living abroad and families in which women were immature.
6. There is a strong socialization that leads women from an early age to assume caregiving roles. Women from small towns express more willingness to assume this role, while women from large cities question openly this assumption and maintain their roles as new workers. This is a change that has occurred in only one generation. Their mothers and grandmother were customarily housewives and most of them are still tied to traditional roles.

7. According to the Colombian’s Project (2000), poverty in little towns in Colombia affects 85% of the population as opposed to 64% in the large cities. These findings of differences among women are related to women’s social and economic status and the Colombia organic culture (Colombia’s Project, 2000).

8. Wealthy families from both regions are able to afford a paid helper who provides an important amount of HD assistance, alleviating the burden and fatigue of the primary HDC. Some of the paid helpers were considered primary HDCs for the relatives.

   **Social Problematic of HD Families in the JDA Region**

Physicians perceive HD as one of the most expensive, least understood and most rarely diagnosed disease in Colombia with an immense toll on HDSs, HDC and family. The way in which HDSs are treated in Colombia is demoralizing and inhumane.

1. The situation for poor families in both regions in terms of health assistance is frustrating because although HDSs from JDA are classified as eligible for assistance by the subsidized system of health care, the medicines that they
require are excluded from the basic health plan. HD patients generally cannot afford them, creating frustration and increasing the progression of the illness.

2. Particularly in the JDA region, sick people are assisted by very few general physicians. Additionally, psychologists and nurses have neither the knowledge nor the training required for treating the HD person; therefore, HDSs are often disadvantaged by the lack of a health care provider while they deal with a life-threatening and debilitating disease.

3. Although HD is the most prevalent disease in the region, sufferers do not have access to a neurologist, clinical trials, medications, diagnostic tests or treatments. As HD progresses with language and speech difficulties, deformities of limbs, the inability to swallow food, drink water, and walk, HDSs in the region do not have access to physical therapies. In short, HDSs and families in the JDA region are unprotected by the state. What is more outrageous is that the incidence of HD is highest among the lowest social classes. (Ochoa et al., 1997). Daza (1991) observe the same phenomenon for HD in the JDA region, HD having the highest incidence among the poorest people.

4. Beyond the health problems caused by HD, there is a social stigma that affects all the people from JDA. Since the mass media has portrayed the whole town as HD carriers, people feel that they can be discriminated against or identified with this particular illness.

5. The poorest families experience frustration in dealing with HDSs who do not receive proper medication because most of the new anti psychotic medications are so that expensive that patients in the town rarely receive it. The newest
medications for HD or even for Alzheimer’s are not available in Colombia and
HDSs receive obsolete medication from the 1960’s and 1970’s. Many times the
effect brings no clear relief to the HDS and in some cases even makes their
condition worse.

6. Support of HDCs is needed in the JDA region in the form of a day care center in
where the HP person can remain during the day while the families work or merely
to serve as a respite service for HDCs.

7. The lack of sewage systems, fresh water and electricity make households
inadequate for assisting the HDSs.

In short, poverty, lack of protective legislation and lack of education makes
conditions for HD families in the JDA region unbearable.

Theoretical Implications for Medical Sociology

The data indicate that HDCs strive to preserve a symbolic interaction with the HD
person. HDCs are aware that people with HD seem to have no perception,
communication and view of themselves as if they posess a self. They no longer interact
with themselves and with others as Mead (1937) assumed human beings do. HDSs lack
reflexive processes that Mead and Blumer (1937) describe. Regardless of this
condition, HDCs act toward HD people in a symbolic manner. Prior researchers had
described HD and other neurogenative dementias as a threat to individual identity (A

De La Cuesta reports from her study on caregiving of patients with advanced
dementia. “The advanced dementia patient’s body is the vehicle that needs to be
endowed with identity and communicative strategies (De la Cuesta, 2003 p. 76). She also states that as caregivers build a system of communication, they also simultaneously build that an identity for the patient and for themselves. They see patients as interacting with them. This interaction is possible because in this conversation the caregiver endows an identity as an individual to the patient. In the communicative interaction between patient and caregiver, the sufferer’s social identity and sense of self is transformed (De la Cuesta, 2003).

De la Cuesta also states that in cases of advanced dementia, the HDC constructs the patient through the interaction. This construction is essential for the care relationship because it endows the patient with a being and body that can be an object of care (De la Cuesta, 2003). In short, De la Cuesta is supporting the thesis that the HDCs are the vehicle to preserve agency in patients with advanced dementia through interaction as this study has supported. This observation has a twofold theoretical implication for medical sociology: first, dementia hinders important social capabilities in the self, and second, this change requires a new frame of significance with the HDC in order to restore a meaningful interaction.

Policy Implications for HD Patients and HDCs

In Colombia, the neuro-degenerative illnesses such as Alzheimer's, epilepsy, HD, vascular dementias and ataxias are ignored by health legislation. They are also neglected by the manuals of therapeutic procedures produced by the Ministry of Social Protection. Specifically, the Committee of Social Security on Health is the institution that
regulates the formulation of a basic plan of assistance on health. This plan is known as Obligatory Plan of Health (POS).

Many catastrophic diseases such as cancer, HIV/SIDA and renal insufficiency used to be ruled out of the POS but Colombians have fought actively for the inclusion of these pathologies in the POS through a constitutional mechanism called “accion de tutela.” This right includes the right of any individual to dispute a statute or an administrative regulation because of a violation of his or her constitutional rights. It entails the summary regulation of the protection of explicitly determined rights which must be exercised directly on the basis of the Constitution. It does not matter which body carries out the protection or on which proceedings the protection is based; what is important is the subject of protection. In practice there are rights which can be claimed by an affected individual at any time before an ordinary court when such an individual feels that his rights have been violated due to any action or omission by a body of public authority.

The current health reforms, in some degree, were enacted because of a collective action by people from different places who requested the provision of those medicines and treatments essential to preservation of life and health. Medications such as insulin have been supplied for their health services provider or EPS (Health Promotion Provider); but they are excluded from Colombia’s basic plan of assistance.

Colombia’s basic health plan is an imperfect system. It requires immediate legal reform to protect the human rights of Colombians. It specifically needs legislative reform in regard to the neurological diseases so that it will allow more effective pharmacological treatment of HD in all its stages. Also, some legislative changes are
needed concerning the management of clinical complications in HDSs which are very common in Colombia.

HD patients need a health plan that allows some degree of rehabilitation through physical, occupational and cognitive therapy. There are multiple legislative groups such as the Ministry of Social Protection, the President’s office, the governors’ office and mayor’s office that have the legislative power to advocate for the inclusion of neuro-degenerative diseases in Colombia’s health legislation. The local HD association in JDA has consistently requested this inclusion to these governmental entities, but its plea in favor of neuro-degenerative patients has been ignored.

Colombians health concerns are still not being addressed on issues vital to HD families, such as genetic counseling in which both education and artificial insemination become available to the HD population. Those at risk need the genetic test to become available in the country. They also need institutional programs with resources that provide support and information about their condition, and the possibility to choose healthy embryos through artificial insemination because, as it was demonstrated from the data, families at risk strive to preserve the right of the youngest generation to have a fulfilled live even if it might increase the HD-affected population.

The education programs should address issues related to the natural course of the illness, the associated stigma that HDSs and HDCs experience and the grief associated with the deterioration and death that result. Support groups should address three different populations: HDSs, HDCs and people at risk.

The population affected by HD is increasing at an enormous rate, especially in the JDA region, for two reasons; high rates of natality and endogamic families. Although
there is no agreement about whether the HD population should be treated in an
eugenic manner, the reality is that the increase in the number of affected people will
create more expense for both the state and for family HDCs.

Colombia’s basic health plan also needs to become more comprehensive and
include thousands of family HDCs who perform health care services to their relatives,
saving millions of pesos to the government by paying for treatments and house
expenses from their own pockets. Also the loss of potential income of those caring for
relatives with long-term-care conditions must be considered.

More than support groups for decreasing the stress, depression and mental
fatigue of Colombia’s HDCs, what can really constitute a revolution in the Colombian
mindset is that HDCs become aware of their burden and invisibility. They should use la
accion de tutela to reclaim their basic rights such as the freedom for health and life.
They need to become visible to the population and to the government. They need
financial support because they are assuming a responsibility that must be jointly by the
State. Moreover, if it is considered, as neurologist and HDCs reported the expense of
caring for someone with dementia is greater for home care than it is for medical
expenses and treatments.

Finally, there is a strong need for more moneys for medications and for assisting
family members with daily expenses. The government could establish funds for HD
families to assist them financially, and other HDSs could be encouraged to create such
a foundation for families in need.
Limitations of Research

One limitation is that the HDSs were not interviewed. As a result, the HDCs described the HDSs’ experiences. It would have added to the validity of the data if the HDSs had described their own experiences.

The study would have been enhanced if I had had more time and financial support. Having a cross-cultural sample from the United States would also have enriched the study findings since it would have allowed me to contrast and compare different cultural perspectives on care. The study would have also have been enhanced by the application of a quantities instrument such as the Zarit Burden Interview (1982) or HDC Burden Interview (Chesire, 2003) or the HDQuality of Life Battery for Carers (HDQoL-C) (Aubeeluck, 2005) because it would have be allowed me to compare the interviewee’s results with the survey results.

Implications for Future Research

The sample in this study is a Latino population in a developing country. Therefore, while the theoretical model created may reflect a phenomenon that is typical of developing countries, replicating this study in a developed country, or a multi-country sample will be the most important factor for future research. Another important study will be to use the theoretical model of subrogate agency with other populations with dementia or degenerative disease, and determine if the model holds true in these populations.
This study has demonstrated that HDSs have an extreme loss of agency through the phases, the lost of agency in the HDS increase the level of complexity in the caregiving tasks and consequently in their level of stress. It will be important to conduct a comparative study of HDC’s burden and stress among HDCs of different types of dementia patients in order to determine how specific traits of the neuro-degenerative diseases entail different challenges and different levels of burden upon HDCs.

Chesire’s study (2003) on HD caregiving burden correlated the level of functional impairments in the HD person with the level of burden in the HDCs. She found that there is a direct correlation between increases in functional impairments and HDCs’ burden. Nevertheless, Chesire’s study (2003) does not show that HD HDCs have higher levels of burden than do HDCs of HDSs with Alzheimer’s or HDCs of frail elderly people. However, her study was not a comparative one.

It will also be important to study how co-morbidity in HDSs affects the care of HDSs since a significant number of them have co-morbidities. Another important research is on caregiving by the young, since the study found that a great number of participants in the focus groups developed those roles as children. It will also be important to explore the perception held by teenagers and young adults in affected families about HD and HD caregiving.

In both regions, anger and aggression were very prominent features observed by HDCs in HDSs before, during and after the onset. Therefore, an important psychological study will be to determine if anger is a premorbid factor to HD dementia traits. Conde in 1998, found important social and psychological premorbid factors in the development of Alzheimer’s. Among the social factors, low levels of education and poor
social interaction were considered premorbid factors for Alzheimer’s. He also observed that introversion and restricted interaction are factors that increase the risk for developing Alzheimer’s (Conde 1998). Therefore, the cultural elements associated with the expression of anger and aggression in both gender deserve a closer scrutiny.

In the Colombian context, the most important future study will be a statistically representative one that measures the extension of caregiving in Colombia including both family HDC and paid helpers. The second most important study will be on Juan de Acosta’s HD kindred, because although it is a population of only 14,000, 76 families are affected. Only Nancy Wexler has reported a larger kindred of descendents of the same HD ancestor in Barranquitas, Venezuela, a little town in which half the town's 10,000 people posses the gene. In fact, Barranquitas has the world's highest incidence of HD. While the Barranquitas population at risk has been determined through genetic testing conducted by the Hereditary Disease Foundation (Wexler, 1995; Hoag 2000) The Colombian HD population is still identified by the symptomatic members of a family. For comparing the real magnitude of the illness in JDA and Barranquitas it will be necessary to have a massive testing of those at risk in JDA.

This Research is Inspired by My Mother’s Life.

*My Mother’s Situation*

My mother died in July 26, 2000 at the age of 63 after struggle of 22 years. My mother had one of the most difficult lives that I have ever known. Her childhood and adolescence were framed by poverty and family violence. She attempted to escape from those situations through early marriage with a widower 17 years her senior. She
was immensely unhappy, and thought about getting a divorce early in the marriage, but she was worried about her three stepchildren. Compounding the situation, every year she was pregnant again a new baby. Every new baby was another reason to remain in an unhappy marriage. During our childhood, my mother protected her children, even when my father was in a bad mood and often used physical punishment for discipline. By 1977 there were 8 children, and the youngest was only 7 years old.

*Beginning the Illness Career*

In 1977 my mother was diagnosed with Hodgkin’s disease. It was severe, and the physician was unsure whether she would survive. During chemotherapy sessions, I watched her throw up and become delirious. At the same time, my parents separated. Consequently, my mother experienced a life threatening illness, emotional distress and the economic restrictions of her new status. While she struggled to survive, she also tried to parent.

She defeated death, but paid a high cost through a decline in her health. She would not ever be the same again, and she was beginning the most painful and tortuous chapter of her life. She could never have imagined her future. By 1986 my mother was continuing her parenting duties, including cooking, sweeping, mopping, cleaning dishes, and making a comfortable life for her children.

*Signs of Illness*

In 1986, my mother began having frequent accidents. For example she often broke dishes or glasses; she cut or burned her hands, and she worried about making small decisions. For instance, she experienced difficulty deciding what to prepare for
dinner, or solving domestic situations. Additionally, she nodded her head most of the time, as though she was talking to herself. I thought that she was nervous or anxious.

_The Diagnosis_

In one instance, while my mother cooked, she spilled hot oil and burned herself. Her brother, who was a physician, recommended a neurologist. A few weeks later, my mother had her first electroencephalogram and was clinically evaluated by the neurologist. The physician diagnosed HD, and explained the symptoms and evolution of her disease. He stressed that the disease was untreatable and expressed sympathy over her future. He sent us home without any specific instructions about the care of my mother.

_Unexpected Caregiving_

In that moment, my family began a long journey as HDCs. No one provided us any instructions. We were three young children, caring for my mother without help. We changed our life style to become HDCs.

These were demanding times. For 14 years, we dealt with my mother’s multiple functional impairments, and discovered thousands of accommodations that we had to make. Sometimes, my mother’s humor was the only possible response to situations that were out of our control. At other times, we felt overwhelmed and angry when she became repetitive and obsessive in her ideas as a consequence of her increasing dementia. We coped without the support of relatives, with minimal medical guidance, and with the indifference of society and government.

_Illness Aftermath: Sharing the Burden_
HD became a collective family tragedy. Despite the fact that the offspring has only 50% probability of developing the disease, in my mother’s family the genetic probabilities were higher as 10 of 10 siblings experienced HD. Currently most of the children and wives of my mother’s siblings have confronted a similar situations. Certainly my family is a large group of members at risk, but not as large as the families affected in Juan de Acosta region, which positively has the second highest rate of HD in the world. I am deeply disturbed by knowing the burden that the illness has imposed among this under-served population because I am a witness to the lack of solidarity and economic support that families in that region face.

Intellectual Craftsmanship

During the data analysis, I decided to be tested for HD. My results were positive and if I live long enough I will develop HD. Therefore, my research was not conducted from a neutral position. I am perhaps biased by my perspective as a Latin American woman, a former HDC of my mother, and a healthy carrier of HD.

As a carrier of the HD gene, I have the intellectual craftsmanship that Wright Mills promotes (2000). This research is evidence of how my life experience was capitalized in my intellectual work. I feel personally involved with this study which has become the center of my existence for 5 years. I know that this experience will have an imprint on my future development as a sociology researcher. Through this study, I have organized a meaningful whole from the chaos of my past experiences by creating a sociological interpretation. My deep familiarity with the topic (Berger, 1995; Lofland and Lofland 2001) gave me the motivation to rethink my life experiences and to produce a theorization of HD HDCs. I believe that my perspective as an insider gives me a better
understanding of my participants’ perspective and allows me to conduct better interviews and focus groups. The proof of this is in the amount and richness of my data. I also succeeded by interviewing many important informants who trusted me by revealing many of their fears.

This was a painful emotional experience, and hearing the voices of HDSs over and over affected me deeply. Often I saw myself in the research subjects, which again affected the way I thought about the matter, and consequently I cried many nights while working on my dissertation, reading my transcriptions, translations, coding and even when I was putting together my analysis. I could recall vividly how hard my mother’s life was and how painful my sister’s murder. She was an exemplary HDC who I was expecting would enrich my dissertation with her own voice, but now her voice has been silenced forever.

As an individual, I accept that caregiving is burdensome, stressful and that HDCs make many mistakes in the way that they handle situations of HDSs. Nevertheless, I am totally convinced that the tenacity and determination for going through the challenge of a doctoral program are the results of a spirit that was strengthened by adversity.

It is possible that in 10 or 20 years when I get sick I will not be able to understand my own dissertation. Nevertheless, I will feel gratified if my study can enlarge the body of knowledge of HD. In Colombia, HD is still a disease in the closet, needing everything to be done. That is one of the main reasons for going back to a country that cannot offer me appropriate treatment when I get sick.

I combined a genuine humanized interaction with my research perspective to accomplish my study. I attempted to combine my voice as researcher and at risk person
to explore the complexity of HD HDCs. I hope that this theoretical approach contributes
to alleviate the human misery of those who live with HD or are at risk of it.
Figure 2

Major Brain Atrophies in HD

Reproduced with permission from Wisconsin HD Center, 2005.
Figure 3

Caregiver- Sufferer Agency Relationship in Huntington’s Disease

[Diagram showing the relationship between caregiver and sufferer, with phases and factors indicated.]
Figure 4
Observation Areas in Caregiver-Sufferer Relationship
Phases 1 to 2
Figure 5
Observation Areas in Caregiver-Sufferer Relationship
Phases 3 to 4
Figure 6
Observation Areas in Caregiver-Sufferer Relationship
Stages 5

- Suffering
- Fight Against the ill
- Reciprocity
- Physical Impairments
- Social Embarrassment
- Depression, anger
- Need to be cared for

- Suffering
- Love and sense of connectedness
- Mastery
- Social Enhancement
- Instrumental help
- Social Embarrassment
- Struggles against fatigue
- Inner negotiation with social expectations
Figure 7: Map Juan de Acosta Region - Colombia

Source Gobernacion del Atlantico, Colombia, public domain.
Red de Desarrollo Tecnológico y Fortalecimiento para la Pequeña Producción Agropecuaria Bogotá, Colombia, public domain.
Figure 9: Map Regions Studied in Colombian Gobernación del Atlántico, Colombia, public domain.
### Methodological Steps: Steps 1 to 11

#### Decision Making

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Chose type of study: Qualitative Study</td>
</tr>
<tr>
<td>2</td>
<td>Chose a target population: JDA and MDE</td>
</tr>
<tr>
<td>3</td>
<td>Chose a specific research Model: Community Case Study</td>
</tr>
<tr>
<td>4</td>
<td>Chose sampling methods: “Maximum Variation”</td>
</tr>
<tr>
<td>5</td>
<td>Define restrictive criteria for sampling: Definition of caregiver and HD patients</td>
</tr>
<tr>
<td>6</td>
<td>Chose Instrument of Data Collection: Interviews, focus group and observation</td>
</tr>
<tr>
<td>7</td>
<td>Chose Recording Strategies: Audiotapes and videotapes</td>
</tr>
<tr>
<td>8</td>
<td>Plan strategies for increasing credibility and trustworthiness: Triangulations, interaction strategies, data collection and data analysis strategies.</td>
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</table>

#### Design of Instruments

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<thead>
<tr>
<th>Step</th>
<th>Description</th>
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<tbody>
<tr>
<td>9</td>
<td>Instruments Data Collection: Interviews, focus groups</td>
</tr>
<tr>
<td>10</td>
<td>Create demographics questionnaire</td>
</tr>
<tr>
<td>11</td>
<td>Creation of Consent forms: Three forms current caregivers, former caregivers, experts</td>
</tr>
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</table>
(table 4 continued)
Steps 12 to 24

<table>
<thead>
<tr>
<th>Collecting Data on the Field</th>
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<tr>
<td><strong>Step 12</strong></td>
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<tr>
<td>Contact gatekeepers in populations: Vice president foundation and neuro-psychologist foundation</td>
</tr>
<tr>
<td><strong>Step 13</strong></td>
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<tr>
<td>Select the Sample from the population: Purposive sample</td>
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<tr>
<td><strong>Step 14</strong></td>
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<tr>
<td>Contact individuals selected as sample and request participation</td>
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<tr>
<td><strong>Step 15</strong></td>
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<tr>
<td>Protocols and signatures of consent forms</td>
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<tr>
<td><strong>Step 16</strong></td>
</tr>
<tr>
<td>Collected the data: Conduct session according parameters</td>
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<tr>
<td><strong>Step 17</strong></td>
</tr>
<tr>
<td>Collect Socio-demographic data</td>
</tr>
<tr>
<td><strong>Step 18</strong></td>
</tr>
<tr>
<td>Take field notes for observations and conducting a theoretical sampling through the revision of audiotapes</td>
</tr>
<tr>
<td><strong>Step 19</strong></td>
</tr>
<tr>
<td>Give participants books on caregiving and donations</td>
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<table>
<thead>
<tr>
<th>Preparing Data for Analysis</th>
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<tbody>
<tr>
<td><strong>Step 20</strong></td>
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<tr>
<td>Transcription cassettes to text in Spanish</td>
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<tr>
<td><strong>Step 21</strong></td>
</tr>
<tr>
<td>Cleaning transcription from audio with the videotapes</td>
</tr>
<tr>
<td><strong>Step 22</strong></td>
</tr>
<tr>
<td>Translate data to English: Researcher and professional translator</td>
</tr>
<tr>
<td><strong>Step 23</strong></td>
</tr>
<tr>
<td>Auditory of translations: Bilingual editor from writing center at UNT and volunteer native speaker</td>
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<tr>
<td><strong>Step 24</strong></td>
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<tr>
<td>Processing Socio-demographic data: SPSS processing</td>
</tr>
</tbody>
</table>
(table 4 continued)
Steps 25 to 29

Analyzing Data

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<tr>
<th>Step</th>
<th>Description</th>
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<tbody>
<tr>
<td>Step 25</td>
<td>Codification data: Codes in word processor and coaxial coding in Ethnograph</td>
</tr>
<tr>
<td>Step 26</td>
<td>Partial cross-codification Data: Expert Qualitative Research in Colombia</td>
</tr>
<tr>
<td>Step 27</td>
<td>Identification of major categories and its conceptual connection</td>
</tr>
<tr>
<td>Step 28</td>
<td>Analysis of socio-demographics and integration to the results</td>
</tr>
<tr>
<td>Step 29</td>
<td>Presentation of results to committee members and later to participants for a feedback</td>
</tr>
</tbody>
</table>
Table 5  

*Methods of Data Collection and Time Invested*

<table>
<thead>
<tr>
<th>Current Caregiver with Sufferer Alive</th>
<th>Sufferers Observations</th>
<th>Caregivers Interviews</th>
<th>Physicians Interview</th>
<th>Former Caregiver with Deceased Sufferers</th>
<th>Key Informants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sessions</td>
<td>Sessions</td>
<td>Number of Participants</td>
<td>Total Sessions</td>
<td>Average Duration (in hours)</td>
</tr>
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<td>Medellín</td>
<td>Juan de Acosta</td>
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<td></td>
<td>14</td>
<td>14</td>
<td>28</td>
<td>50</td>
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<td></td>
<td>19x 2 = 38</td>
<td>16x2 = 32</td>
<td>35</td>
<td>70</td>
<td>1.5 minutes</td>
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<td>64</td>
<td>56</td>
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<tr>
<td>Physicians Interview</td>
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<tr>
<td></td>
<td>6</td>
<td>2</td>
<td>8</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Former Caregiver with Deceased Sufferers</td>
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<td></td>
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<tr>
<td>Sufferers Mentioned</td>
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<td>10</td>
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<td>N/A</td>
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<td>Focus Groups 6 people</td>
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<td>46</td>
<td>8</td>
<td>2.5</td>
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<td>Interviews with FC replaced group meetings</td>
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<td>4</td>
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<tr>
<td>Key Informants</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>64</td>
<td>56</td>
<td>123</td>
<td>136</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 6 *Particular Cases*

<table>
<thead>
<tr>
<th>Antithetical Cases</th>
<th>Number of cases that meet the criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average Case</strong></td>
<td></td>
</tr>
<tr>
<td>The common type of care</td>
<td></td>
</tr>
<tr>
<td>Deviant case (Break social expectation of caring)</td>
<td>4</td>
</tr>
<tr>
<td>Confirming cases</td>
<td></td>
</tr>
<tr>
<td></td>
<td>66</td>
</tr>
<tr>
<td>Disconfirming cases</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td><strong>Key or Crucial Cases</strong></td>
<td></td>
</tr>
<tr>
<td>Intensity cases</td>
<td>4</td>
</tr>
<tr>
<td>Critical case</td>
<td>2</td>
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</table>

### Table 7 *Features Sought*

<table>
<thead>
<tr>
<th>Maximum variation</th>
<th>Number of cases that meet the criteria</th>
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</thead>
<tbody>
<tr>
<td>Social Class differences (6 strata)</td>
<td>All</td>
</tr>
<tr>
<td>Gender Differences</td>
<td>All</td>
</tr>
<tr>
<td>Schooling Differences</td>
<td>All</td>
</tr>
<tr>
<td># of primary caregivers per sufferer</td>
<td>All</td>
</tr>
<tr>
<td>Sufferers’ age differences</td>
<td>All</td>
</tr>
<tr>
<td>Caregivers’ age differences</td>
<td>All</td>
</tr>
<tr>
<td>Type of relative who care for the sufferer</td>
<td>All</td>
</tr>
<tr>
<td>Maximum variation</td>
<td>Criteria Completed</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Urban vs. small town settings</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Non-paid care vs. paid care</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Trained paid care vs. untrained paid care</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Care Period: at least 6 months to more than 20 years</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Home vs. Institutional care</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Sufferers living in their own home vs. sufferers living in a child’s home</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Primary caregiver living in the same household vs. primary caregiver living nearly</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Ethnic differences</td>
<td>Non accomplished</td>
</tr>
<tr>
<td>Differences in the illness stage</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Caregivers’ narratives of still alive sufferers with already death sufferers</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Family structure</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Number of members disable and/or children under 8 year-old.</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Instrumental vs. emotional care</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Differences in caregiver’s health status</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Intensive sampling</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Better care vs. worse care</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Tested vs. non-tested caregivers</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Interest to be tested vs. no interest</td>
<td>Accomplished</td>
</tr>
<tr>
<td>Prior care experience with a HDS vs. non-prior experience</td>
<td>Accomplished</td>
</tr>
</tbody>
</table>
APPENDIX A

CONSENT FORMS
CONSENT FORM FOR CAREGIVERS

English Version for Caregivers

Title of the Study: The Social Construction of Huntington’s disease (HD)
Caregivers in Colombia

Principal Investigator: Clara Giraldo

Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the proposed procedures. It describes the procedures, benefits, risks and discomforts of the study. It also describes the alternative treatments that are available to you and your right to withdraw from the study at any time. It is important for you to understand that no guarantees or assurances can be made as to the results of the study.

Purpose of the study and how long it will last:
The purpose is to understand the experiences of people in Colombia who care for those who have HD. You will be interviewed twice in your home, and it will set the time and days most convenient to you. The researcher will contact you previously and will explain the purpose and schedule of each session. The first session includes a 45-minutes observation and a 60-minutes interview. In the first part of the first meeting, the researchers will explain you the consent agreement and the activities of this section. The domiciliary visit will consist on an observation of the regular interaction of the caregivers and patient while the researcher will take field notes. Later in the following part of the first session the researcher will collect some demographic data about the caregiver and his/her family. In last part of the session will be administer a questionnaire. In a posterior session, a second interview will be conducted in order to extend and clarify information for the prior session.

Description of the study including the procedures to be used.
You will be asked to respond to questions that will ask you about caring for your relative in the home. The questionnaire will be given before, so you will know the questions that will follow. You will be also request to interact with your relative at home while an observation is performed. You have the right not to respond to questions or to the observation, you deem necessary, and will not be penalized for doing so. While you are completing the interviews, the responses will be tape-recorded and video-recorded. Videotaping may be used as an aid in the transcription process; the tapes will be available for review only the research for the purpose of making a script of the discussion. If you change your mind, and do not want the interviews to be video recorded or tape-recorded, you have the right to do so.
Your name or your family members name will not be used in connection with the study. All the information collected will be kept in a locked box under the supervision of the principal investigator, a graduate student in the department of Sociology at the University of North Texas, Denton, Texas. You understand that all information is confidential, but my dissertation committee at the University of North Texas, Denton, Texas will have access to the information.

**Description of the procedures/elements that are associated with foreseeable risks.**

We see no risks in responding to the interview questions at this time, but some people may experience anxiety in responding to some questions. By signing this form, you release University of North Texas of all responsibilities.

**Benefits to the subjects or others:**

By participating in this study, we will be able to know the problems of those caring for people who have Huntington Disease.

If you have any questions about this research project, please call...Clara Giraldo, or Dr. Erma Lawson, [phone number]. This study has been approved by the University of North Texas Institutional Review Board (IRB). If you have questions about your rights as a research participant, you may contact the UNT IRB at [phone number].

You understand that participation is voluntary; refusal to participate will involve no penalty or loss of benefits. You may discontinue participation at any time. You have given ample opportunity to ask any questions, and had questions answered about this study.

By signing this form, you are giving permission to participate in the study as described above. I will be given a copy of this authorization form after I have signed it.

Signature__________________________________Date________________________

________________________

Print Name_________________________________

**For the Investigator or Designee:**

I certify that I have reviewed the contents of this form with the person signing above, who, in my opinion understood the explanation. I have explained the known benefits and risks of the research.

Principal Investigator’s Signature________________________

Date________________________
UNIVERSITY OF NORTH TEXAS
COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS

CONSENT FORM FOR FORMER-CAREGIVERS

English Version for Caregivers of Huntington’s disease (HD) Patients who already died

Title of the Study: The Social Construction of HD Caregivers in Colombia

Principal Investigator: Clara Giraldo

Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the proposed procedures. It describes the procedures, benefits, risks and discomforts of the study. It also describes the alternative treatments that are available to you and your right to withdraw from the study at any time. It is important for you to understand that no guarantees or assurances can be made as to the results of the study.

Purpose of the study and how long it will last:
The purpose of this research investigation is to employ a series of 6 focus group discussions to gather data on the experiences of people in Colombia who cared for those who had HD and died during the last 4 years. It will take about 90- minutes to answer the questions. You will be offered a break as needed and refreshment will be provided at the close of the session.

Description of the study including the procedures to be used.
Each group will include 6 participants both males and females of different ages who cared from a HD close relative who pass away within the last 4 years. Each member will be invited to participate in the discussion of 7 questions about your caring experience with patients with HD. The questionnaire will be given at the beginning of the meeting, so you will know the questions that will follow. The place selected for the focus group will be at a convenient location that is easy to find. The day and time will be also selected according to the convenience of the most of the participants.

You have the right not to respond to questions, you deem necessary, and will not be penalized for doing so. The discussion will be video-recorded and tape-recorded. Videotaping may be used as an aid in the transcription process; the tapes will be available for review only the research for the purpose of making a script of the discussion. If you change your mind, and do not want the interviews to be video recorded or tape-recorded, you have the right to do so.

Your name or the name of those who you identified during the interview as HD patients
will be not disclosed. All the information collected will be kept in a locked box under the supervision of the principal investigator, a graduate student in the department of Sociology at the University of North Texas, Denton, Texas. You understand that all information is confidential, but my dissertation committee at the University of North Texas, Denton, Texas will have access to the information.

**Description of the procedures/elements that are associated with foreseeable risks.**
Participants will be able to rely on the moderator’s quality of respect and sensitivity as a basis for their responses. The moderator will do everything in her power to help generate a setting that is conducive to discussions concerning conditions that can be somehow personal in nature. The moderator will display both tolerance and respect for the participant and exhibit interests in both the participants and their viewpoint, regardless of personal experience.

We see no risks in responding to the interview questions at this time, but some people may experience anxiety in responding to some questions. By signing this form, you release University of North Texas of all responsibilities.

**Benefits to the subjects or others:**
By participating in this study, we will be able to know the problems of those taking care of people who have HD.

If you have any questions about this research project, please call...Clara Giraldo, or Dr. Erma Lawson, This study has been approved by the University of North Texas Institutional Review Board (IRB). If you have questions about your rights as a research participant, you may contact the UNT IRB at.

You understand that participation is voluntary; refusal to participate will involve no penalty or loss of benefits. You may discontinue participation at any time. You have given ample opportunity to ask any questions, and had questions answered about this study.

By signing this form, you are giving permission to participate in the study as described above. I will be given a copy of this authorization form after I have signed it.

Signature__________________________________Date__________________________

Print Name_________________________________

For the Investigator or Designee:
I certify that I have reviewed the contents of this form with the person signing above, who, in my opinion understood the explanation. I have explained the known benefits and risks of the research.

Principal Investigator’s Signature________________________

Date____________________
English Version for Physicians

Title of the Study: The Social Construction of Huntington’s disease (HD) Caregivers in Colombia

Principal Investigator: Clara Giraldo

Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the proposed procedures. It describes the procedures, benefits, risks and discomforts of the study. It also describes the alternative treatments that are available to you and your right to withdraw from the study at any time. It is important for you to understand that no guarantees or assurances can be made as to the results of the study.

Purpose of the study and how long it will last:
The purpose of the administration of the questionnaire is to determine the experiences of people in Colombia who care for those who have HD. It will take about 45- minutes to answer the questions. You will be interviewed once in your office and will set the time and days most convenient to you.

Description of the study including the procedures to be used.
You will be asked to respond to questions that will ask you about caring treating patients with HD. The questionnaire will be given before, so you will know the questions that will follow. You have the right not to respond to questions, you deem necessary, and will not be penalized for doing so. While you are completing the interviews, the responses will be video-recorded and tape-recorded. If you change your mind, and do not want the interviews to be video recorded or tape-recorded, you have the right to do so.

Your name or the name of those who you identified during the interview as HD patients will not be disclosed. All the information collected will be kept in a locked box under the supervision of the principal investigator, a graduate student in the department of Sociology at the University of North Texas, Denton, Texas. You understand that all information is confidential, but my dissertation committee at the University of North Texas, Denton, Texas will have access to the information. In addition, the main researcher agrees to credit properly those documents written by the interviewed practitioners that they may freely supply to the main researcher as part of the research data.
Description of the procedures/elements that are associated with foreseeable risks.

We see no risks in responding to the interview questions at this time, but some people may experience anxiety in responding to some questions. By signing this form, you release University of North Texas of all responsibilities.

Benefits to the subjects or others:

By participating in this study, we will be able to know the problems of those treating people who have HD.

If you have any questions about this research project, please call...Clara Giraldo, or Dr. Erma Lawson, __________. This study has been approved by the University of North Texas Institutional Review Board (IRB). If you have questions about your rights as a research participant, you may contact the UNT IRB at __________.

You understand that participation is voluntary, refusal to participate will involve no penalty or loss of benefits. You may discontinue participation at any time. You have given ample opportunity to ask any questions, and had questions answered about this study.

By signing this form, you are giving permission to participate in the study as described above. I will be given a copy of this authorization form after I have signed it.

Signature_______________________________ Date________________________
APPENDIX B

QUESTIONNAIRES
Caregiver Interview Questions

Title of the Study: The Social Construction of Huntington’s disease Caregivers in Colombia

Principal Investigator: Clara Giraldo

Thank you for taking time from your busy schedule to talk with me. Your opinions will help to understand the care of HD patients. Thank you for taking time from your busy schedule to talk with me. Your opinions will help to understand the care of HD patients. I encourage you to answer openly and honestly and every time that you think what I should answer to this question please consider that what is important to this study is your viewpoint regardless any difference of criteria that you might have with others.

Category
Introductory Questions
- How did you come to be a caregiver for (name of relative)?
- Why did you become a caregiver for (name of relative)?
- Tell me about your experiences as caregiver

Patients Behavior
Self- Consciousness
- Some people are aware of their mental or physical problems while others are not. How aware do you think (name of relative) is about his/her problems?
- Patients with severe illnesses deal with the reaction of people around to their illness. What is your perception about the reaction of people around when see someone with Huntington?
  - PROBE In your opinion how much is your relative awareness of this social stigma?
  - PROBE Tell me about the stigma that you as caregiver and families has experience?
  - PROBE If so, how do you deal with it?

Physical Impairments
- What type of adjustments has your relative made to deal with his/her (specific illness or symptoms that have the patient)?
- What are for you the most problematic behaviors from your (name of relative)?

Reciprocity
- I would like to know if you can describe any behavior or situation in which you feel that your (name of the relative) express his/her gratitude or attempt to get an emotional connect with you?
Need to be cared
- Some people accept that another person helps them perform those activities that they cannot do by himself/herself, some others refuse to be helped. How is it in your case?

Patients’ Emotions
- How would you describe the general mood of (name of relative)?

Suffering
- Some people think that person with long history of illness suffer a lot. What happened in the case of (name of relative)?

Fight against the Illness
- Please describe how (name of relative) has coped with his/her illness in the period that he/she has been affected?

Caregiver Experience
Instrumental Tasks
- In some families there are a lot of changes in routines when a relative becomes ill. How has this been in your family?
- Think for a minute in your life; talk to me about how do you manage to work and take care of your relative?
- What type of support do you receive from your relatives and friends?

Emotional Support
- In addition to the physical care, is there any other form of care you think you provide to (name of relative)?
- Tell me how your family makes decisions about the patient?

Sense of connectedness
- Describe how close and connected you feel you and (name of relative) might be.

Emotional Stress
- What are the main challenges or problems that you face when you take care of (name of relative)?
- What type of emotional resource do you use for coping with the patient’s situation?
- What is the meaning of this illness for you?
- Do you have any regret about anything?

Struggle against Fatigue
- Many people consider that caring for other causes a lot of fatigue. How do you feel about it?
  - PROBE Please told me about the energy and time that you expend taking care of your relative?
  - PROBE How is your social life?
- **PROBE**  When you feel tiered what type of strategies do you use for decreases this sensation?

**Altruism**
- What are you expectations, if any, about what you might get back from your relationship with (name of relative)?
- Would you consider to be a caregiver for others or not?  Please tell me a bit about your decision
- Other countries have places in which HP receive institutional care. If those places would exist here would you put your relative in the care of the institution?

**Personal Growth**
- Some caregivers feel that they lose important things in life because of their relative illness. How do you feel about this issue?
- In overall how do you rate yourself as caregiver?
- What have you learned from the experience of caring for (name of relative)?

**Carrier awareness**
- Can you tell what your thoughts about the testing of Huntington are?

**Closing Questions**
- Tell me what would you say to someone in your position?  What advice would you give them?
- Is there anything important that I have missed?

Thanks for your information and time. I would like to count with your future help if through my analysis any of your information requires further clarifications.
Questionnaire for Former-caregivers

Title of the Study: The Social Construction of Huntington’s disease (HD) Caregivers in Colombia

Principal Investigator: Clara Giraldo

English Version
Thank you for taking time from your busy schedule to talk with me. Your opinions will help to understand the care of HD patients. Thank you for taking time from your busy schedule to talk with me. Your opinions will help to understand the care of HD patients. I encourage you to answer openly and honestly and every time that you think what I should answer to this question please consider that what is important to this study is your viewpoint regardless any difference of criteria that you might have with others.

Category
Introductory Question
• Tell me about your experiences as caregiver

Patients behavior
Self-Consciousness
• Some people are aware of their mental or physical problems while others are not. How aware do you think (name of relative) was about his/her problems?

Physical Impairments
• What were for you the most problematic behaviors from your (name of relative)?

Suffering
• Some people think that person with long history of illness suffer a lot. What happened in the case of (name of relative)?

Caregiver Experience
Fight against the Illness
• Please describe how (name of relative) has coped with his/her illness in the period that he/she has been affected?

Emotional Stress
• Do you have any regret about anything?

Closing Questions
• Tell me what would you say to someone in your position? What advice would you give them?

Thanks for your information and time. I would like to count with your future help if through my analysis any of your information requires further clarifications.

Questionnaire for Physicians
Title of the Study: The Social Construction of HD Caregivers in Colombia
Principal Investigator: Clara Giraldo  
English Version

Thank you for taking time from your busy schedule to talk with me. Your opinions will help to understand the care of HD patients. I encourage you to answer openly and honestly and every time that you think what I should answer to this question please consider that what is important to this study is your viewpoint regardless any difference of criteria that you might have with others.

Categories:
Introductory Question
- Tell me when you see a HD patient, what comes to your mind?

Caregivers
- Think about the HD patients for a second, and those people who care for them, talk about the problems that you think that they may confront.
- What are the major problems and challenge of families who care for a HD patient?
- Many people do not know what HD is, tell me about the stigma you think that HD patients have
  - PROBE Tell me about the stigma caregivers
  - PROBE Tell me about the stigma physicians encounter when they care for HD
    - If so, how do you deal with it.?
- What would be an ideal care for someone who has HD?

Patients
- The patients whom you have seem or treated with Huntington, discuss their medical treatment issues?
  - Probe; Do you have any thought about the social issues that they deal with.
- Think about the home care in our country, do you think H. patients should be cared for in institutions, like they are in other countries.
- Other countries have more genetic testing, talk to me about your beliefs about testing.

Culture and Institutional Factors
- Do you see in our culture some positive factors that help HD caregivers to cope with (to deal with) this challenge?
- How being a carrier of the gene influences those who care for HD patients?
- What advice would you give to someone who cares for HD patient at home?
- What advice would you give to a physician who takes care of a HD patient?

Thanks for your information and time. I would like to count with your future help if through my analysis any of your information requires further clarifications.
Socio Demographic Information aout Participants

Title of the Study: The Social Constructions of Huntington’s Disease (HD) Caregivers in Colombia

Before starting the interview please provide some information that will allow the researcher to understand better your current situation.

Respondent #
Date __/__/______
Place ______________________

1. Age in years ________
2. Gender: Male ______ Female __________
3. Marital Status __________
4. Highest level of education achieved _________________
5. Number of years of Schooling _________________
6. Occupation _________________
7. Current labor status _________________
8. Social Strata _________________
9. Type of family structure __________
10. Ethnicity _________________
11. Religion _________________
12. Number of Children at home under 12
13. Patient still alive _____ patients who already died _____
14. Number of disabled people at home _________________
15. Type of Relationship with the patient _________________
16. Age of the sick person _________________
17. Number of years that your relative has been diagnosed with HD __________
18. Number of years that you have taken care for your relative _________________
19. Use paid-care: yes _____ No _____
20. Training level of the paid care _________________
21. Number of caregivers at home _________________
22. Home ______ vs. Institutional care ______
23. Patients living in their own home _____ vs. patients living in a child’s home ___
24. Can establish the stage in which your relative is currently ______
25. Caregiver’s health status ______
26. Tested vs. non-tested caregivers__________
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