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# The Experiences of Huntington's Disease Caregivers

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# The Experiences of Huntington's Disease Caregivers

by

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MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
St. Catherine University and the University of St. Thomas  
St. Paul, Minnesota  
in Partial Fulfillment of the Requirements for the  
Degree of Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social work research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by the Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

## EXPERIENCES OF HUNTINGTON'S DISEASE CAREGIVERS

### **Abstract**

Huntington's Disease (HD) is a genetic, inherited, and terminal neurological disorder that affects both physical and mental capacities. The most recent estimates state that 1 in every 10,000 Americans has HD and more than 250,000 are at risk of inheriting the disease from a parent (Huntington's Disease Society of America, 2013). Caregivers can be defined as informal or formal. Informal caregivers are typically family members such as spouses, children, or siblings. Formal caregivers are paid, professional caregivers. Family members often become caregivers for diagnosed individuals, however, the need for formal and paid care increases as the disease continues to progress. The purpose of this study is to examine the overall experiences of formal and informal HD caregivers. Qualitative interviews were conducted with seven informal and formal caregivers. The interviews explored the caregivers' experiences and nine themes were developed: (a) Lack of Education and Awareness, (b) Resources and Support, (c) Denial, (d) Burnout, (e) Attachment, (f) Progression of the Disease, (g) Grief and Loss, (h) Complex Mental Health, and (i) Family Dynamics. The findings of this study suggest that a lack of knowledge, awareness, and resources contributes to caregiver distress. The findings also indicate that HD negatively impacts the family system. While this study is exploratory in nature, it holds implications for social work practice, policy, and future research.

*Keywords:* Huntington's Disease, caregivers, burnout, qualitative

# EXPERIENCES OF HUNTINGTON'S DISEASE CAREGIVERS

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# EXPERIENCES OF HUNTINGTON’S DISEASE CAREGIVERS

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### The Experiences of Huntington's Disease Caregivers

Huntington's Disease (HD) is a genetic, inherited, and terminal neurological disorder that affects both physical and mental capacities. The disease affects both women and men and the majority of individuals are diagnosed between the ages of 30 to 50, which is when symptoms typically begin to appear. However, there are a number of people who have early-onset symptomology that is otherwise known as juvenile HD with a diagnosis as early as age 10 (Huntington's Disease Society of America, 2013). The most recent estimates state that 1 in every 10,000 Americans has HD and more than 250,000 are at risk of inheriting the disease from a parent. This disease is unique in that every single person is born with the HD gene, however, only those who inherit the expansion of the gene will develop the actual disorder (Huntington's Disease Society of America, 2013). Every child of a parent that is diagnosed with HD has a 50% chance of inheriting the expansion gene that causes the disease. The children who do not inherit the expanded gene will never develop the disease nor will their offspring. Families that are known to have HD have the option to undergo genetic testing in order to verify if they did or did not inherit the expansion of the gene. The choice to receive pre-symptomatic genetic testing is personal and varies case by case (Huntington's Disease Society of America, 2013).

The symptoms of HD include: personality changes such as mood swings and depression, forgetfulness, impaired judgment, involuntary movements and unsteady gait, slurred speech, difficulty swallowing as well as several other symptoms related to one's physical, mental, cognitive and emotional health (Huntington's Disease Society of America, 2013). Eventually, a person diagnosed with HD may lose the ability to walk,

communicate, and make decisions, which often results in long-term caregiving needs. There are medications that can assist with symptomology, however, there is no cure or documented research that suggests a way to slow down the progression of the disease (Huntington's Disease Society of America, 2013).

The psychosocial needs of an individual and his or her family experiencing this terminal and degenerative illness are abundant. HD is considered a family disease with little nonfamily support. In other words, there is a lack of formal supports (Meissen, Maguin & Woodruff, 1987). Families often observe their loved ones lose their ability to remain independent and must watch them slowly deteriorate over time until death finally occurs. These conditions tend to leave families socially isolated (Meissen et al., 1987). HD not only affects the individual diagnosed with the disorder but also his or her family, friends, neighbors, and the larger community. Social isolation and diminished support systems are more prominent when there is a lack of knowledge regarding the disease amongst family and community members (Huntington's Disease Society of America, 2013). Thus, families, friends, and other caregivers need support just as the individual who is diagnosed does. As the progression of HD continues and physical, cognitive, and mental capabilities decline, diagnosed individuals will need the daily support, care, and supervision provided by a caregiver. Caregivers are often people from an informal support system such as a spouse, parent, son, daughter, grandchild, etc. (Meissen et al., 1987).

The purpose of this study is to examine the overall experiences of formal and informal HD caregivers. This study will consider the difficult characteristics that the disease presents as well as the barriers and obstacles that caregivers encounter while

caring for these individuals. This study will also examine what supports have proven to be beneficial for the individual diagnosed with HD, his or her family members, and those providing long-term care. The following research question will be examined in this study: What are the experiences of HD caregivers?

### **Literature Review**

This study will provide an outline of HD and the aspects that contribute to caregiver distress including cognitive, physical, and psychological effects. This literature review will differentiate between formal and informal caregivers, types of caregiver settings, and the challenges HD caregivers encounter.

### **Huntington's Disease**

HD is an inherited genetic, neurodegenerative condition that impacts cognition, motor and physical function, as well as personality or affect (Halpin, 2011). The disease is autosomal dominant—if one parent has the genetic mutation, each child has a 50% chance of inheritance (Halpin, 2011). Typically, the illness presents between the third, fourth, or fifth decades of life, but symptoms have appeared in children and young adults. HD is a long-term disease that progresses over the course of 10 to 20 years (Skirton, Williams, Jackson Barnette, & Paulsen, 2010). HD does not discriminate between gender, race, or ethnicity (Roscoe, Corsentino, Watkins, & Sanchez-Ramos, 2009). It is important to note that rates of HD were not consistent across the literature with regard to race, ethnicity, and region.

**Genetic testing.** Previous research suggests that many individuals with the HD gene mutation, or expanded gene, experience declines in their functional capacities and other areas even before a formal diagnosis (Beglinger, O'Rourke, Wang, Langbehn, Duff,



& Paulsen, 2010). Predictive DNA testing identifies if a hereditary disease is present in asymptomatic individuals. Predictive testing presents critical implications for individuals and families with a known history of a hereditary disease. Since a diagnosis of HD is terminal, it has overwhelming psychosocial consequences on the individual and family (Sobel & Cowan, 2003). Sobel & Cowan (2003) presented the idea of “ambiguous losses” as defined by Boss (1999). According to Boss (1999) and Sobel & Cowan (2003) individual's diagnosed with HD have suffered an “ambiguous loss.” An ambiguous loss is defined as “an incomplete or uncertain loss” (Boss, 1999; Sobel & Cowan, 2003, p.48). Ambiguous losses occur when an individual is physically present, but psychologically absent and vice versa. An individual who is known to have the HD gene, but is asymptomatic, experiences an ambiguous loss just by knowing that they will eventually experience symptoms (Boss, 1999; Sobel & Cowan, 2003).

A precise genetic test was developed in 1993 to identify the HD gene mutation allowing families the option of pre-symptomatic testing (Halpin, 2011). It is important to note that a positive genetic test result is not considered a diagnosis, but rather, a neurologist must confirm a diagnosis of HD upon display of symptoms and by determining if there is a family history of the disease (Halpin, 2011). It is reported that, although there is genetic testing, 25% of individuals are unaware that HD is present in his or her family. At this time, there is no treatment to cure or to slow down the progression of the disease (Halpin, 2011).

**Cognitive effects and characteristics.** The cognitive deficits seen in individuals diagnosed with HD are profound and tend to be a major indicator of disability. Cognitive deficits seen in HD individuals can include: the inability to concentrate or focus,

confusion, forgetfulness, difficulty with information processing and retrieval, impaired judgment, and severe memory loss or dementia (Imbriglio, 1992). Previous research of other neurodegenerative disorders documents that reduced functioning in instrumental activities of daily living (e.g. managing financial matters, making telephone calls, or completing household chores) predicts conversion to dementia 10 years later (Beglinger et al., 2010). The rates at which these symptoms appear vary by person and progress over time. Eventually, the cognitive deficits will affect the person's ability to maintain employment, manage finances, and remain independent in the community without the need for supervision (Imbriglio, 1992). McCabe, Roberts, and Firth (2008) report that cognitive and neurological decline remains very difficult for people with HD due to the loss of leisure activities and the ability to perform occupational duties. Neurological illnesses, such as HD, have a negative impact on the work situations of people with the illness, which leads to a negative standard of living and quality of life for these people and their families (McCabe, Roberts, & Firth, 2008).

Deterioration in cognitive functioning can often lead to behavioral problems for those diagnosed with HD (Bourne, Clayton, Grant, & Murch, 2006). First, the areas of executive functioning are affected such as the ability to control emotions, organize, or plan ahead. Second, cognitive flexibility is less likely, which makes it very difficult for someone with HD to concentrate on more than one task at a time (Bourne et al., 2006). Due to the loss of executive functioning and cognitive flexibility, someone with HD may become overwhelmed while completing tasks, become angry, have an outburst, or display some other reaction that may otherwise be considered unreasonable. Individuals with HD also have trouble adapting to change whether it is in their personal life or their immediate

environment (Bourne et al., 2006). Cognitive impairments can cause behavior complications in the following ways: fixed thinking, slowed thinking and responses, memory problems, difficulty sequencing activities, and loss of visuospatial awareness (Bourne et al., 2006). Family members have reported that coping with their loved one's motor dysfunction is easier compared to coping with cognitive decline and behavioral problems (Bourne et al., 2006).

**Motor and physical effects and characteristics.** The majority of motor and physical impairments related to HD can be classified as chorea and ataxia (Hess, Preloran, & Browner, 2009). Chorea can be defined as non-rhythmic involuntary movements and ataxia is defined as a lack of coordination and disturbed gait (Hess et al., 2009). As the disease progresses, individuals will experience greater difficulty in performing self-care activities such as grooming or bathing due to the loss of motor control and involuntary movements. Involuntary movements can present as twitching or spasms (Hess et al., 2009). Another characteristic associated with HD is postural instability and rigidity, which can make it troublesome for someone to walk or even sit up in a chair (Imbriglio, 1992). Some other physical or motor changes that can take place include: clumsiness, slurred speech, or difficulty swallowing (Imbriglio, 1992). Meissen et al. (1987) report that the loss of physical control is prominent and usually displayed as jerky movements in the face, trunk, arms and legs. In the late stages of HD, immobility is very likely and quite profound requiring a diagnosed individual to have long-term care and supervision to ensure safety (Roscoe et al., 2009).

**Psychological effects and characteristics.** Considerable research has been conducted on how HD impacts cognitive and motor functioning. In addition, there has

been an extensive amount of research conducted that focuses on the psychological and behavioral effects of the disease (Wetzel, Gehl, Dellefave-Castillo, Schiffman, Shannon, & Paulsen, 2011). Several reports indicate that the psychiatric factors of HD may be the first symptoms to appear, with emotional dysfunction often being the first displayed (Halpin, 2011). Since psychological changes tend to present first and prior to cognitive or motor impairments, it is common for someone to be diagnosed with a psychiatric disorder rather than HD (Halpin, 2011). It is because of this that often times an affected person's first experience within the health care system will be with a psychiatrist and not a neurologist (Halpin, 2011).

Psychiatric disorders and behavior problems are clinically presented in the symptomology of HD (Hubers, Reedeker, Giltay, Roos, van Duijn, & van der Mast, 2012). Recently, the neuropsychiatric symptoms associated with HD have been acknowledged as more distressing than physical symptoms for both the individual diagnosed with HD and his or her family members or caregivers (Kingma, van Duijn, Timman, van der Mast, & Roos, 2008). The psychiatric characteristics of HD are the main reason for institutionalization of a diagnosed individual (Kingma et al., 2008). Some psychiatric characteristics that emerge with HD are personality changes, psychosis, and affective disorders and can appear in 35% to 73% of individuals with HD (Wetzel et al., 2011). Furthermore, depression, anxiety, apathy, and irritability vary in HD individuals from 33% to 76%; obsessive-compulsive symptoms and psychosis are less prevalent at 10% to 52% and 3% to 11% respectively (Kingma et al., 2008). Finally, disinhibition and aggression are common and problematic characteristics of someone diagnosed with HD (Paulsen, Ready, Hamilton, Mega, & Cummings, 2001).

*Suicide.* One of the most important clinical aspects of HD is the increased risk of suicide by diagnosed individuals (Hubers et al., 2012). Suicide is one of the few stoppable causes of early death in HD where understanding risk factors is fundamental for prevention (Wetzel et al., 2011). Previous research reports that the rate of completed suicide in HD diagnosed individuals can be as high as 13%, which is 7% to 12% higher than the rate of the general population (Wetzel et al., 2011). Suicide is one of the leading causes of death in the HD population with suicide being the second to fifth leading cause of premature death (Halpin, 2012). Another report indicates that 5.7 suicides per 100 deaths have been reported in those diagnosed with HD (Hubers et al., 2012). There are several other neurodegenerative disorders such as Parkinson's Disease and Multiple Sclerosis, however, the rate of suicide is the highest in those diagnosed with HD (Wetzel et al., 2011). It is difficult to assess depression and suicide ideation in individuals diagnosed with HD due to the cognitive and neurological impairments that accompany the disease (Halpin, 2012).

One study found that the completed suicide rates in HD were 5.7% while the rate of suicide attempts was 27.6% (Wetzel et al., 2011). Researchers have identified critical periods that a person with HD is at highest risk for suicide (Wetzel et al., 2011). The first critical period of increased risk is immediately after receiving a diagnosis of HD. The second period takes place in stage two of the disease, which is primarily when an individual loses the ability to maintain employment and disability is acknowledged (Wetzel et al., 2011). Rates of suicide amongst individuals diagnosed with HD vary across the literature. It would be beneficial to differentiate between suicide ideation, suicide attempts, and completed suicides.

*Personality Changes.* As previously mentioned, some of the most common psychological characteristics of HD are personality changes, anxiety, depression, and psychosis (Hofmann, 1999). Personality changes can be differentiated from personality disorders. Changes in personality take place due to an illness where a longstanding, pervasive way of interacting is defined as personality disorders (Hofmann, 1999). The most common personality change noted is irritability, which is seen in 38% to 58% of individuals. Irritability is likely caused by the individual's inability to cope with their changing environment, excessive stimuli, or failure to have his or her needs met immediately upon request. Irritability can be displayed as verbal aggression (yelling or angry outbursts) and can lead to physical aggression (towards others or self) (Hofmann, 1999). Health care providers recommend assessing a person diagnosed with HD for personality changes in order to protect the individual and the individual's family members (Hofmann, 1999).

*Anxiety.* Anxiety in those diagnosed with HD can be inherent or caused by environmental stressors (Hofmann, 1999). When an individual attempts to perform a task that formerly required no effort and now requires the assistance of another person, a great source of stress and anxiety may result. This is especially apparent in occupational duties and responsibilities. Issues that would previously not elicit attention such as weather, stories in the news or media, or activities of family members or friends, can start to provoke anxiety in someone diagnosed with HD (Hofmann, 1999). Behavioral interventions are recommended and should be attempted first in order to control anxiety and prior to consultation with a psychiatrist. Some examples of behavioral interventions

are: helping the individual understand the stressor, developing a plan on how to counteract anxiety symptoms, or increasing supports for the individual (Hofmann, 1999).

*Depression.* Depression is the second most common psychological characteristic found in HD, with about 30% of individuals experiencing a major depressive episode (Hofmann, 1999). In two thirds of cases, depressive symptoms appear 5 years before the onset of neurological, cognitive, or motor impairments. If there is a family history of depression, the person diagnosed with HD is more likely to experience major depressive episodes and further assessment is recommended (Hofmann, 1999). It is important to assess the individual for depression in order to determine the severity of symptoms and to determine the appropriate course of treatment. The assessment of severity and symptomology is crucial due to high rates of suicide in the HD population (Hofmann, 1999).

*Psychosis.* Psychosis in HD individuals ranges from 6% to 25% and can be described as “schizophrenic-like” (Hofmann, 1999). The following are symptoms of psychosis: delusions or unusual beliefs, paranoia, talking to self, audio and visual hallucinations, and erratic or impulsive behavior. Similar to the other psychological changes seen in HD, psychosis or psychotic symptoms often present before a formal HD diagnosis, which causes individuals to be diagnosed with psychiatric disorders before being diagnosed with HD (Hofmann, 1999). Frequently, the individual diagnosed with HD, who is displaying the psychotic symptoms, is unaware of the change, thus family members are usually the ones reporting the symptoms to mental health providers (Hofmann, 1999). Assessment and treatment of psychosis is necessary for individuals

otherwise the behavior is likely to continue and worsen as the disease progresses (Hofmann, 1999).

### **Informal or Family Caregivers**

HD is classified as a family disease because it affects the entire family and not just the individual who is diagnosed (Meissen et al., 1987). Levine, Halper, Peist, and Gould (2010) broadly define family caregiver in terms of spouses, children, siblings, partners, friends, neighbors and anyone else who helps to provide care to an ill or disabled person. Family caregivers are typically called “informal” caregivers to distinguish them from “formal” caregivers who are paid, such as nurses, personal care attendants, or home health aides (Levine et al., 2010). The term “informal” suggests that the caregivers are providing unstructured and casual care, when in reality, they are providing skilled care and are completing complex medical tasks (Levine et al., 2010). In the United States, there is an estimated thirty-four million family caregivers that provide 75% to 80% of all long-term care. The estimated value of unpaid family or informal caregivers is roughly \$375 billion per year (Levine et al., 2010). Individuals with chronic conditions, such as HD, are considered to be high-risk patients that rely heavily on their informal support systems to provide medication administration and management, scheduling appointments and ensuring attendance to appointments as well as understanding their conditions and recommendations from medical doctors (Levine et al., 2010).

In recent years, health care providers have put more responsibility and demands on families including more complex care that needs to be provided over longer periods of time (Levine et al., 2010). Families also indicate that their care and oversight are



necessary to keep their loved ones safe and healthy. Physicians are encouraging families or specified caregivers to be present 24 hours per day to administer medications, assure accuracy of tests and results, and to overall support the ill individual as a permanent advocate (Levine et al., 2010). Individuals who are chronically ill, such as those diagnosed with HD, tend to experience more transitions in care. Transitions in care can include frequent visits to emergency rooms, skilled nursing facilities, long-term care units of nursing homes, or utilization of home care services. It has become the responsibility of family members to coordinate and manage the cares associated with each transition, especially in the case of those diagnosed with HD who have cognitive and memory impairments (Levine et al., 2010).

Home health care is a trend that continues to rise (Steffen & Mangum, 2005). The majority of older adults, either disabled or ill, live in non-institutional settings with families being the most common source of daily assistance. Typically, family caregivers are adult children or spouses of the impaired individual with 70% of these family caregivers being female (Steffen & Mangum, 2005). Family or informal caregivers provide an array of assistance with daily tasks such as grocery shopping, preparing meals, scheduling appointments, and providing transportation, but can also help with demanding home health care duties related to specific medical conditions. Informal care provided by a family member has a positive affect on the individual's physical and psychological health, however, the provisional costs are usually at the expense of the caregiver (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002). Informal caregiving is feasible until the disease has progressed too far and then professional, long-term care is primarily preferred for chronically ill people (Navaie-Waliser et al., 2002).

### **Formal or Paid Caregivers**

Formal caregiving refers to any professional caregiver who is paid or employed with an agency or health care system and provides caregiving tasks to individuals with a functional, mental, cognitive, or physical impairment (Levine et al., 2010). Examples of paid or formal caregivers include: staff at nursing homes, hospitals, transitional care centers, assisted living facilities, and home health care agencies that provide skilled nurse visits, home health aides, or personal care assistance. In recent years, there has been a shortage in paid caregivers and states have limited the number of nursing home beds. The shortage in formal caregivers puts more stress on families to continue to provide care for their loved ones even if they cannot adequately provide support (Levine et al., 2010). The lack of paid workers and increasing strain put on family caregivers means that individuals are likely to be placed in care facilities at public expense. Nursing homes are gradually serving more patients even with a shortage of beds available (Levine et al., 2010). Nursing homes typically serve two populations: short-term rehabilitation patients and the conventional long-term care residents (Levine et al., 2010). It can be overwhelming for families when they can no longer care for their loved one and a long-term care facility is chosen as the best course of action (especially if the family has been the source of care for several years). Train, Nurock, Manela, Kitchen, and Livinston (2005) report that dissatisfaction with long-term care facilities is often related to the feeling of competition between staff and family members in determining what is best for the patient.

### **Challenges of Caregiving**

**Education.** Providing care to an individual diagnosed with HD produces many challenges. A family member providing the care makes the situation even more unique

and trying (Williams, Skirton, Barnette, & Paulsen, 2012). Many families indicate that one of the greatest struggles they encounter with health care systems or community-based service providers is their overall lack of knowledge on the background, symptoms, characteristics, and treatment of HD. The lack of knowledge amongst health care and community-based service providers is likely attributed to the small population of HD patients in the United States with only 12,000 to 21,500 people affected (Williams et al., 2012). A previous study reported that HD caregivers were dissatisfied with the level of support they received from health care professionals (Skirton et al., 2010). Dura (1993) has found that an overall lack of knowledge of the disease has been found to contribute to caregiver distress. The Huntington's Disease Society of America is a large, non-profit organization that offers clinical information on the disease to individuals, families, and professionals (Skirton et al., 2010). The organization also supports 21 Centers of Excellence where the staff at each center conduct clinical research and host educational classes, however, not everyone has access to the centers due to geographical locations (Skirton et al., 2010).

**Family dynamics.** A diagnosis of HD and the course of the disease can drastically alter the dynamics of a family. Due to the cognitive, motor, and psychological changes that take place in individuals with HD, family dynamics differ greatly compared to their non-diagnosed counterparts (Van der Meer, Timman, Trijsburg, Duisterhof, Erdman, Van Elderen, & Tibben, 2006). Families that are already cohesive can become more so when receiving a formal diagnosis; disorganized families tend to become even more chaotic and dysfunctional (Vamos, Hambridge, Edwards, & Conaghan, 2007). As previously mentioned, HD is a hereditary disease where offspring of a diagnosed

individual have a 50% chance of inheriting the disease (Forrest Keenan, van Teijlingen, McKee, Miedzybrodzka, & Simpson, 2009). In addition, families may have experienced and cared for multiple generations of affected loved ones due to the genetic component of the disease (Roscoe et al., 2009).

People diagnosed with HD often have children before they are aware that they have the diagnosis, therefore, families must struggle with the conflict related to pre-symptomatic genetic testing and dealing with the realization that they have unknowingly passed on the gene to their children (Forrest Keenan et al., 2009). Also, most children will witness the steady decline of their parent's health while knowing that they may have the same debilitating disease (Van der Meer et al., 2006). The emotional burden of family members providing care to loved ones with HD is unyielding. Emotional burden often refers to threats to one's wellbeing as well as coping capacities of caregivers (Williams et al., 2012). Emotional burden not only includes the loss of former bonds and role changes, but also the concerns regarding the risk of children developing HD later in life (Williams et al., 2012).

**Stages of life.** HD is usually diagnosed during the third, fourth, or fifth decades of life, presenting during periods of time associated with family growth and development. A HD diagnosis corresponds with phases of life where families are expanding, which can complicate the situation even more (Van der Meer et al., 2006). It is during this time in a person's life when childrearing, childbearing, and career development are most complex and families rely heavily on each other for support (Vamos et al., 2007). According to the Life Stage Development Theory, those between the ages of 40 and 60 years old are in the midlife period where children usually embrace their independence allowing parents to

engage in and pursue their own interests (Williams et al., 2012). It is also during this point that employment pressures and opportunities are at their peak and where spousal support is critical to maintaining the demands of home and working life. Unfortunately, a person is usually diagnosed with HD during midlife, which can hinder the ability to provide support for the other family members and prevents the acquisition of normal midlife activities (Williams et al., 2012). The aspect of time creates even more challenges for families or caregivers because they are likely caring for their loved one diagnosed with the disease in addition to other members of the family. A formal diagnosis of HD in conjunction with providing care for a family member can preoccupy others in the family, consequently disrupting the family as a whole (Van der Meer et al., 2006).

**Relationships.** There can be profound changes in relationships between family members including the bond between spouses and between parents and children. Typically, an altered relationship between spouses is caused by the level of dependency the diagnosed individual has on his or her spouse and the shift in responsibilities for the caregiving spouse. For example, the caregiving spouse may have to take over financial matters, household duties, or even resign from his or her job (Van der Meer et al., 2006). The relationship between parents and their children may change in terms of role-reversal (children caring for their parents), feelings of guilt for possibly passing on the HD gene, and can create emotional distance and turmoil (Van der Meer et al., 2006). Changes in familial connections can be turbulent, but even more distressing to families is the fact that they have to watch their loved one deteriorate over time and eventually die (Van der Meer et al., 2006). It is close to impossible to maintain relationships with a person diagnosed with HD as a result of the personality, cognitive and psychological changes

that occur. Marital relationships are especially fragile when one person has a HD diagnosis and the other person is the caregiver. O'Connor, McCabe, and Firth (2008) report that the impact a neurological illness has on a marital relationship is severe. In the limited research area of married couples and HD, people with HD perceived their relationship as more positive compared to their spouses. Furthermore, 82% of people with HD and 66% of spousal caregivers had one or more sexual disorders (O'Connor et al., 2008). This shows that many aspects of a relationship are affected and transformed when HD is present in families.

**Nature of the disease.** Another challenge to those caring for a person diagnosed with HD is the long-term and progressive nature of the disease (Williams et al., 2012). The progression of symptoms and decline in functional capacity can take place over the course of many years; thus, caregiving activities typically extend over a time period of 30 years compared to 10 years as is typically seen in Alzheimer's Disease caregivers (Williams et al., 2012). Various research on caregiving indicates that 80% of care received is delivered by members of the family and that families spend at least 60 hours per week engaging in caregiving activities (Pickett, Altmaier, & Paulsen, 2007). Those diagnosed with HD have a difficult time adjusting to and coping with their new life. HD not only affects an individual physically, cognitively, and mentally, but it also limits their ability to maintain their roles as spouses, parents, and wage earners (Williams et al., 2012). The roles played by the other family members also undergo transformations. Taking on the role of caregiver can be described as an unexpected career that usually begins as part-time assistance and later becomes an unrelenting permanent role (Pickett et al., 2007). Because the onset of HD is around age 40, the appointed family caregiver is

relatively young, meaning a majority of his or her adult life will be spent providing care (Pickett et al., 2007). When providing day-to-day care is no longer feasible for family members, the diagnosed individual and family will likely seek long-term care in a nursing or residential setting.

**Caregiving settings.** Family caregivers often describe the demands of caregiving as overwhelming and burdensome, which can place the care recipient at risk for poor care in the home or placement within an institution (Roscoe et al., 2009). An insufficient support network within the social and medical communities as well as limited options for in-home assistance and long-term residential placement, add to the stress and potential burnout of caregivers (Roscoe et al., 2009). The hesitance of nursing facilities to admit people diagnosed with HD further complicates the care of a person and his or her family. People diagnosed with HD are hard to manage resulting in more than 50% of nursing facilities (in one study) reporting hesitation to care for these individuals (Pickett et al., 2007). Nursing facilities report that people with HD require excessive care and that nursing home staff are concerned about the behavioral problems associated with the HD community (Pickett et al., 2007). Another study indicated that 70% of nursing facilities rated irritability and agitation as the most problematic issues in caring for HD individuals (Pickett et al., 2007). Turner (2005) reports that the behavioral and psychological symptoms are typically cited as the reason for staff stress and burnout within institutional settings.

Challenges in a formal caregiving setting are just as important and multifaceted as challenges presented in an informal setting. For example, the care provided in a nursing facility may sometimes be against a patient's will. Due to the nature of a

neurodegenerative disease, communicating with and understanding a patient can be conflicting (Edberg, Bird, Richards, Woods, Keeley, & Davis-Quarrell, 2008). Providing care to a person against his or her will is common in those suffering from a cognitive impairment because they are deemed incapable of making decisions for his or herself (Edberg et al., 2008). Nursing home staff have described experiencing 'moral distress,' which can be defined as "knowing the right thing to do, but institutional constraints making it near impossible to pursue the right cause of action." Moral distress is suggested as one of the main factors contributing to nurses leaving their jobs (Edberg et al., 2008). Caregiver burden is even greater when formal institutions, such as long-term nursing facilities, feel as though they cannot provide adequate care for a person diagnosed with HD (Pickett et al., 2007).

**Caregiver distress.** Research has documented that HD caregivers experience adverse side effects related to the emotional and physical complexities of caregiving (Pickett et al., 2007). Consequences of caregiving include negative emotions and perceptions toward the care receiver as well as strain in social relationships (Pickett et al., 2007). Additionally, strained relationships can develop outside of the immediate family. Immediate and extended family members may disagree about care decisions and disputes may transpire due to over involvement of some persons or lack thereof by others. Research has also shown that caregivers report psychological and physical problems such as anxiety, depression, high blood pressure, or ulcers (Pickett et al., 2007). Furthermore, almost 20% of HD caregivers suffer from a stress-related illness (Roscoe et al., 2009). There are two types of care receiver stressors that contribute to the caregiving process: physical and psychological functioning (Pickett et al., 2007). The level of physical



functioning of a person with HD significantly predicts subjective caregiver burden while greater psychiatric symptoms in a care receiver are associated with negative mental health outcomes for the caregiver (Pickett et al., 2007). Family caregivers are also less likely to practice preventative health actions and may be at increased risk for mortality (Navaie-Waliser et al., 2002). There are certain factors that put some groups even more at risk for poor health outcomes such as advanced age, race, employment status, and lack of social supports (Navaie-Waliser et al., 2002).

Overall, this study will add to the existing literature on HD caregivers by exploring the experiences of those who provide care for people diagnosed with HD. In this study, qualitative interviews will be conducted with informal and formal caregivers and the following research question will be examined: What are the experiences of HD caregivers? The following section explores the conceptual framework of this study.

### **Conceptual Framework**

The theoretical framework that will guide this research project is systems theory. For the purpose of this study, the systems theory focuses on the family as a system since HD is considered to be a disease that affects the whole family. In the forthcoming paragraphs, the systems theory perspective will be reviewed at length and a rationalization will be given of how it corresponds to the research problem and research question of this study.

The systems perspective “sees human behavior as the outcome of reciprocal interactions of persons operating within linked social systems” (Hutchison, 2011, p. 38). It seeks to explain how different systems within society interact with one another and how the interaction of systems can be used as an explanation for human behavior. Some

examples of various systems include political systems, educational systems, health care systems, and family systems (Hutchison, 2011). Every single person within the society belongs to a system and every single system in society is interconnected. Thus, a family system is connected to all the above-mentioned systems and is even connected to other family systems as well. Because systems theory contains every system and represents how systems are related it is an inclusive and useful theory to the field of social work (Hutchison, 2011).

An important part of systems theory is the idea of systems being stable or homeostatic with the result of creating balance within the connected systems. Each part of a system has a unique function in order to maintain stability. Consequently, the functionality of each individual part contributes to system stability (Hutchison, 2011). In systems theory, “the structure of roles has been an important mechanism for maintaining system balance” (Hutchison, 2011, p. 39). In a family system, each person in the family has a distinct role and each role contributes to the family remaining as a cohesive whole. Role refers to behaviors of a person that are specific to a social position. The concept of roles contributing to and maintaining the status quo in a family is important to individuals diagnosed with HD, their families, and caregivers. For example, when one spouse becomes the caregiver and is forced to resign from his or her occupation, a change in roles takes place and in return, the family system is altered. This is also true when a parent is diagnosed with HD and he or she takes on the role of care recipient versus caregiver.

Another component of systems theory is the use of feedback loops, which is a process for information on past behaviors to be fed back into the system in a circular

manner (Hutchison, 2011). There can be negative and positive feedback loops within a system. A negative feedback loop means that the system is deviating from a steady state and needs to take corrective action while a positive feedback loop produces innovation, thus producing change that can sometimes be quite rapid (Hutchison, 2011). HD is the gradual degeneration of body systems (e.g. physical, cognitive, mental, etc.) over time and as the disease progresses the family unit, including caregivers, must change to meet each new need that develops. Systems theory includes subsystems within each system. Each system serves as a subsystem in other systems (Hutchison, 2011). Subsystems are continuously adjusting to each other and the changes that take place are always being looped back. As a result, subsystems and systems are in a constant state of fluidity, which can lead to rapid and dramatic changes (Hutchison, 2011).

It is important to keep systems theory in mind when examining people diagnosed with HD and their caregivers because there are a number of different systems being affected and numerous other systems that are involved in the care of a person with the disease. A small gap or hole in any system can cause alterations within the other systems that are connected. For example, the hesitancy of nursing homes to admit patients with a HD diagnosis or a lack of knowledge about the disease in the medical community directly affects and elicits interruption in the family system. Notably, caregivers of persons diagnosed with HD are dealing with several systems and subsystems of the care recipient, but they are also adjusting to changes within their own environment and their own systems.

There are two descriptors in systems theory: a closed system and an open system. A closed system is isolated and has no exchanges with external systems and an open

system receives resources and exchanges with external systems (Hutchison, 2011). Open systems tend to be healthier compared to systems that are closed. This is true of family systems as well. A family system that is open has the opportunity to make connections with other systems. An open system has more access to resources and the ability to remain stable. Due to the complex and demanding nature of HD, remaining an open system is crucial to families and caregivers in order to gain and maintain support.

The most prominent systems that a family interacts with (in regards to HD caregiving) are health care and social service systems. There are subsystems within each major system. Some of the subsystems an individual, family, or caregiver would encounter in the area of health care include physicians, nurses, psychiatry, long-term care, or community-based care. When all of these subsystems are interacting and communicating with each other, a more stable and organized plan of care can be implemented for the individual diagnosed with HD. Hutchison (2011) describes that systems theory seeks to explain and answer the question: How do systems affect, interact, and link to other systems, and is an individual's behavior justified by this? Systems theory will guide this research project because it exemplifies how one system is affected and related to other systems.

Constructivist theory with an emphasis on grief and loss will also guide this research. Constructivist theory related to grief and loss focuses on the individual's internal and external perceptions of loss and the meaning the individual attributes to each unique loss. Constructivist theory does not define loss in terms of death, but rather, any form of loss that is experienced and the grief associated with those losses (Goldsworthy, 2005). Constructivist theory views grief and loss as a unique process because all

individuals are unique. Every individual will experience grief and loss differently and every particular loss may have its own cultural, social, spiritual, and individual influences (Goldsworthy, 2005). Grief and loss through the lens of constructivist theory applies to this research because individuals diagnosed with HD and their caregivers will experience several losses throughout the progression of the disease. In addition, grief and loss is a significant factor in the lives of HD individuals. A loss occurs the moment when individuals receive a diagnosis of HD, the ability to complete occupational duties is forfeited, or when individuals can no longer physically take care of themselves. Finally, family members of individuals diagnosed with HD experience unique periods of grief and loss. For example, spouses may lose their independence if they make the decision to become primary caregivers for their loved one. Children who have a parent diagnosed with HD may be faced with the eventual loss of their parent adding to the grief of knowing that they may carry the HD gene as well. Constructivist theory focusing on grief and loss will guide this research because it demonstrates how grief and loss is an integral aspect of the lives of individuals diagnosed with HD, their families, and caregivers.

## **Methods**

### **Research Design**

The purpose of this study was to examine the experiences of those who care for people diagnosed with HD including formal and informal caregivers. The research was exploratory and qualitative. Qualitative research uses words, narratives, and descriptions to answer a research question or to explain a research problem (Monette, Sullivan, Dejong, & Hilton, 2014). The purpose of qualitative research is to create meaning by analyzing data to understand more about an abstract or general idea. Qualitative

approaches “offer access to a valuable type of data—namely, a deeper and richer understanding of people’s lives and behavior” (Monette et al., 2014, p. 220). Exploratory research means that there is minimal existing information available, therefore, research is conducted in order to increase a level of understanding (Monette et al., 2014). A qualitative approach was used for this study because the information that was sought was based on descriptions, text, and narratives with the hope of developing a greater understanding of HD caregivers.

Furthermore, this study was based on grounded theory. Grounded theory is defined as “a research methodology for developing theory by letting the theory emerge from, or be grounded in, the data” (Monette et al, 2014, p. 221-222). According to grounded theory, there is an ongoing interaction between data analysis, data collection, and theory development. Research conducted in grounded theory, such as this study, will allow the researcher to develop more abstract concepts and ideas about the research problem (Monette et al., 2014). There was an absence of theory for this study; therefore, the researcher began by making observations by conducting interviews. When using grounded theory without theory, the researcher described what was obtained during the interview, determined relevant variables, and searched to explain what was observed. Overall, grounded theory can provide a more valid representation of experiences because they emerge directly from what is being studied (Monette et al., 2014).

In this study, research participants were asked open-ended questions to elicit responses that described their experiences of caring for someone diagnosed with HD. The researcher conducted a semi-structured interview and focused on caregiver’s different experiences. Specifically, the researcher focused on the unique challenges and successes

of caregiving as well as support needed to provide special care for people diagnosed with HD. Open-ended questions allowed the participants to describe their experiences of caregiving to a greater extent. The overall goal of the research was to capture the experiences of caregivers. To achieve this, the researcher needed a subjective narrative, which is also known as the *verstehen* approach (Monette et al., 2014). Through a qualitative method, meaning was given to a participant's words, thus, giving the researcher a better understanding of what it is like to be a caregiver.

### **Sample**

The participants of this study were formal or informal caregivers to individuals diagnosed with HD. Snowball sampling was used to recruit seven participants for this study. Snowball sampling refers to sampling people who interact with each other. The researcher also used purposive sampling. In purposive sampling, "the investigators use their judgment and prior knowledge to choose for the sample the people who best serve the purposes of the study" (Monette et al., 2014, p. 148). In this case, the researcher had prior knowledge of the Huntington's Disease Society of America (HDSA). The researcher explored the HDSA Minnesota chapter website for agencies that provide care to those diagnosed with HD. The researcher identified key agencies in the state of Minnesota that provide care to individuals diagnosed with HD. The researcher called or emailed the agencies with the public data specified by the HDSA website. The researcher followed a phone call script or an email script (Appendix A) when recruiting study participants. The phone and email scripts reviewed the purpose and aim of this study and offered the participants the opportunity to participate in the study. The researcher also emailed agencies a flyer (Appendix B) to assist in recruiting participants. The researcher

used an email or phone script (Appendix C) when potential participants responded to participant recruitment. The time and place of the interview was discussed and determined with the participant when the researcher identified potential participants for this study. The researcher also emailed the social worker of the HDSA Minnesota chapter to recruit potential participants. The researcher asked the social worker to post the flyer or hand out the flyer to potential participants as well.

### **Protection of Human Subjects**

Several steps were taken to ensure the protection of the participants of this study. This research study was completely voluntary and involved minimal risk to the participants. The information that was gathered for this study was only used for the purpose of this study. The information was kept confidential and anonymous. First, the participants of this study were given a consent form (Appendix D) that was evaluated by the St. Catherine University Institutional Review Board. The purpose of the consent form was to ensure that the participants willingly entered this study by informing the participants of possible risks, benefits, and details of this study. The participants were given time to review and sign the consent form prior to the interview. The researcher allowed time for the participants to ask questions or express concerns regarding the consent form or any details of this study. The researcher asked the participants to agree to have the interview audio recorded and informed the participants that the audio recording was confidential and was destroyed following the completion of this study. The researcher explained to participants that the purpose of the audio recording was to review and present the findings to colleagues in a non-identifying manner. The interviews took place in a private location to ensure confidentiality and the participants had the option of



choosing the location. Finally, this study was conducted under the supervision of Dr. Catherine Marrs Fuchsel. The participants of this study were encouraged to contact the chair of the Human Subjects Institutional Review Board through St. Catherine University with any questions or concerns related to this study.

### **Data Collection**

Data was collected using semi-structured interviews that were completed in person. The interviews were nonschedule-standardized, which means there was some structure to the interview with a focus on a narrower topic such as caregiver challenges (Monette et al., 2014). The interviews were conversational and the researcher had the ability to ask questions out of order, rephrase the questions, or to ask for additional information. Nonschedule-standardized interviews allowed the participant to have more freedom of expression (Monette et al., 2014). The interviews consisted of 10 questions (Appendix E) with additional follow up questions dependent on the participants' responses. The interview questions were pre-approved by the St. Catherine University Institutional Review Board. The interview questions were designed to be open-ended, direct, and objective in order to preserve the integrity of the research and to ensure they accurately measured the participants' experiences. The interview questions addressed challenges HD caregivers face with regard to the physical, cognitive, and mental health of the care recipient. Some questions that were asked during the interview were: *What do you believe to be the greatest challenge in providing care to someone diagnosed with HD? Are there certain aspects or characteristics of the disease that make it more difficult to complete caregiving duties and how? How does this disease affect you in terms of your own physical and mental health? Have you experienced any adverse outcomes by being a*

*HD caregiver?* The interview was audio-recorded and the interview was transcribed. The interviews were completed at a place of the participant's choice.

### **Data Analysis**

After the interviews were completed, the researcher transcribed the audio-recorded interviews verbatim. Content analysis was used to identify codes and themes in this study. Content analysis can be defined as “a method of transforming the symbolic content of a document, such as words or other images, from a qualitative, unsystematic form into a quantitative, systematic form” (Monette et al., 2014, p. 204). The researcher coded the data, which refers to categorizing sections of the data into a limited number of categories (Monette et al., 2014). For the purpose of this study, the researcher used open coding by looking for any codes that may appear within the data and then focused on specific codes in order to create themes. Grounded theory was used to identify similar concepts found during the open coding process, thus generating themes from the data. A list of themes was developed secondary to the coding method. In addition, the researcher had a colleague review and complete a coding exercise as a reliability check to ensure that the themes were accurately inferred and that no themes were missed. In order to ensure validity, the researcher had the interview questions reviewed and analyzed by the researcher, the researcher's committee, and various members of the public. Reviewing and analyzing the interview questions allowed the researcher to ensure that the questions were valid, reliable, and that the questions addressed the overall research question.

### **Strengths and Limitations of the Study**

This study sought to understand and explore the intricacies associated with HD through the experiences of caregivers. This study used the subjective experiences of

caregivers to shed light on HD, which the literature proposed to be of small representation in the general population. In addition, findings from studies indicated that an overall lack of knowledge on the disease amongst medical and social communities adds to the distress of caregivers. Because a diagnosis of HD affects so few, little is known about the needs of caregivers and families. The field of social work benefits from this study, so individuals, families, and caregivers can receive additional support and their needs can more easily be met. This qualitative study using the subjective experiences of caregivers gave greater insight into the complexities associated with caring for someone diagnosed with HD.

A major limitation of this study was the small sample size. The small sample size was in part due to the time-restrictions of the study, but also because HD is not a prominent diagnosis among the general population. Similarly, the small sample size of this study did not give a representative view of all caregivers. Another limitation of this study is the lack of ability to generalize the findings. This is also due to the small sample size. Another limitation of this study is the possibility of researcher bias. The researcher had a personal interest in HD and the issues surrounding caregiving. To ensure researcher bias was minimal, the researcher reviewed the interview questions, codes, and themes with a colleague and the research chair.

### **Findings**

In this section, the characteristics of participants will be discussed as well as the findings of the study based on the participants' responses. Nine major themes were revealed across seven different interviews with caregivers. The nine major themes identified in this study include (a) Lack of Education and Awareness, (b) Resources and

Support, (c) Denial, (d) Burnout, (e) Attachment, (f) Progression of the Disease, (g) Grief and Loss, (h) Complex Mental Health, and (i) Family Dynamics. In order to protect their identities and maintain confidentiality, the participants were assigned pseudonyms. The pseudonyms assigned to the participants were Bob, Lisa, Molly, Sally, Sam, Sarah, and Tim. Seven interviews were conducted with seven participants who identified as informal or formal caregivers for individuals diagnosed with HD. Of the seven participants, one identified as an informal caregiver, five identified as formal caregivers, and one identified as both a formal and informal caregiver. The researcher interviewed three male and four female caregivers with ages ranging from 29 years old to 50 years old. The participants' caregiving experiences differed in length, setting, intensity, and position held. One participant identified as an informal caregiver for his wife who is diagnosed with HD and as a formal caregiver who operates a family adult foster care for individuals with HD. Five participants identified as formal caregivers for an agency that operates several corporate adult foster care homes in the state of Minnesota. Finally, one participant identified as an informal caregiver for her sister who is diagnosed with HD. The researcher will now present the nine major themes that emerged in this study.

### **Lack of Education and Awareness**

The first theme that emerged in this study is 'lack of education and awareness.' The general idea of this theme is that there is an overall lack of education and awareness surrounding HD as a major medical condition. The majority of participants reported that professionals, families, and the general population are uneducated on HD, symptoms and characteristics, and treatment options for the disease. In addition, the participants noted that the level of awareness among medical communities, social service agencies, and the

general public is staggering and almost nonexistent. Many of the participants discussed the strong correlation between a lack of education on HD causing there to be a lack of awareness and vice versa. With regard to awareness, the participants expressed the importance of individuals and families being aware if HD is present within their family. Sarah shared some insight into the importance of families being aware that HD is part of their genetic background with the following statement:

We've known she has had something since she was young. She is a couple years older than me. She was adopted at seven months. It was clear from a pretty young age that there was something that was not right. She had difficult situations with school and friends, different kinds of relationships. Everything she had a problem with from early on. It just didn't make sense, but we didn't know she had Huntington's Disease in her background. It was a big struggle.

Sam agreed by stating, "Awareness is the biggest key for any person trying to care for a loved one." He later went on to say, "Knowing that it [HD] is even in your family, knowing what HD is, having resources to educate yourself, cause they don't just not care, they just don't know how to care." In the context of emergency personnel and how they respond to difficult circumstances, Sam's response was, "They don't know about this disease. Most don't even know what it is. They're misinterpretation of the behavior and what is going on when situations arise, that's where the biggest downfall is."

Participants reiterated that most people do not know or understand what HD is and how that makes it more difficult to provide care for individuals diagnosed with HD. For example, Molly reported, "Most people don't even know what it is. You try to explain it to them, but the explanation doesn't even come close to what the disease

actually is.” Sally discussed a similar thought about the importance of understanding the disease:

If you don't understand the disease and what is happening with the individual or what could happen. It's not an easy task to take care of them. You have to at least have the general knowledge to come into the field and be able to take care of them and help them strive.

Sarah expressed her frustrations with how a lack of awareness among members of the community affects her and her sister. She stated:

Everywhere we go, people stare. Stare, stare, and stare. Some people are really good and other people walk out of their way to get away from us. I can see it, but I don't know if she can see it. I know there are many people with this disease that get arrested. People get arrested because others think they are drunk or high and they're not. They have their outbursts and people don't understand that, so they label them as mentally ill or they end up in a psych ward somewhere. I think mental illness does go along with it, but that is not what it is. It is a disease. It's Huntington's Disease.

Bob had the following response with regard to how education and awareness affects the care an individual receives:

You talk about the literature, well, it is lacking, it really is. Clearly, they coined it [HD] back in the 1800's, but it wasn't really known what Huntington's really is until, like, 1991 and from there it is still a new disease. The funding isn't there. They need to somehow bring in celebrities to make the awareness out there

because the local [HDSA] chapters are trying, but it isn't given the same recognition as other diseases.

Tim conveyed how education and awareness is crucial to caring for individuals diagnosed with HD, however, even if you are qualified to do so, the complexities of HD make it even more challenging. Tim stated, "If you are well educated, well trained, that still doesn't prepare you for the things that could possibly happen." In addition, Molly expressed her frustration when attempting to find a doctor for the individuals she cares for. She stated, "We had two individuals who had HD. We tried to find a primary physician who would take them as patients and nobody would take them because the physicians wouldn't know enough about the disease and wouldn't feel comfortable being their doctor." Overall, the participants agreed that a lack of education and awareness among formal and informal caregivers, families, and professionals prevents individuals diagnosed with HD from receiving the care they need and deserve.

### **Resources and Support**

Comparable to education and awareness, the theme of 'resources and support' appeared across the data. The general idea within the theme of 'resources and support' portrays how there are minimal resources for individuals diagnosed with HD and their caregivers. Most participants agreed that a lack of education and awareness contributes to a lack of resources and support. The majority of participants agreed that the HDSA Minnesota chapter and Dr. Nance are the main resources they turn to. Tim stated:

I think the biggest support is Dr. Nance at the HCMC Center of Excellence. She is one of the foremost professionals in HD. Every individual we serve, past and present, we have associated with Dr. Nance. To me, she is the best resource we

have at our disposal. Involvement from the HDSA Minnesota chapter, having their professionals come out and do specific trainings has been very helpful.

Sam had a similar response regarding the HDSA Minnesota chapter:

They understand me, common ground, not judging. They know I am doing the best I can. If something bad happens, they know I am doing the best that I can do. They never judge me and they always support me no matter what it is or who it is. If it's my wife or my kids who are trying to be with their mom. They always listen.

The idea of support groups as a resource for caregivers was recognized among the participants. Sam stated, "The only informal training for informal caregivers is in the form of support groups where you bounce ideas off others who might be caring for their spouse or whoever." Sarah stated, "There is a great support group that Jessica [HDSA social worker] runs. There are so many blessings. The community is really tight knit." Sam also mentioned how HD specific residences serve as large supports for individuals diagnosed with HD. For example, "Being around with other people who have HD is common ground. They aren't being stared at when they are eating, not being judged when they are walking. 'That person has Huntington's, I have Huntington's'. It's huge." Sarah had the following to say with regard to the support her sister receives in a HD specific group home:

Well, the positives are that we found this group home that she lives in. I had never heard of Huntington's Disease. I didn't know anything about it. I know now that there is only a handful in Minnesota let alone the United States and world. There are few places that really understand the disease. We had a social worker or



county caseworker that knew the disease and knew about these homes and worked with residents there in the past, which is crazy because it's kind of a rare thing. The participants also recognized that there is a lack of resources for caregivers and individuals diagnosed with HD. Tim stated, "With the level of assistance available for these people...it's far and few between. Unless you have a specific diagnosis or waiver, there is nothing for you." He also conveyed how there are waiting lists for people to get into HD specific residences and how many individuals end up poorly cared for in nursing homes. When asked about nursing homes, Tim detailed, "The level of care provided in nursing homes is just inadequate." In addition, Sam reported, "To my knowledge, there are only three providers in the state of Minnesota. I have one home, another provider has two homes, and the other provider has two homes with a third opening soon. They are specific to HD."

### **Denial**

A third theme that surfaced across the data is 'denial.' This theme generally promotes the idea that individuals that are diagnosed with HD are in denial or that they experience periods of denial throughout the course of the disease. Several of the participants argued that caring for individuals with HD was made increasingly more difficult if the individual denied the presence of the disease. In addition, the majority of participants agreed that families also experienced denial with regard to their loved ones having a diagnosis of HD. Sam stated:

From what I have recognized over the years in my personal family and professional career is that people with HD don't ever want to believe that they have the disease or that it is affecting them. As things start to become more

difficult, like tasks or the ability to handle daily living things, they will always feel like they should be able to do it even though they physically cannot.

Sam later stated, "They think they are just having a mid-life crisis." Sam also discussed the fact that his wife's family never talked about how HD was present in their family.

Sam reported, "It was never talked about in my wife's family. My wife got it from her father and it was never talked about." With respect to the manifestation of denial, Molly stated, "With individuals with Huntington's Disease you see a lot of denial and not wanting to admit that they are struggling with things." Molly also stated, "I have seen a lot of denial. Even something so simple as preparing food and that food gets thrown back in my face because it looks terrible. Not accepting where that is where they are at and that is what is needed for them to be safe."

Tim asserted that he believed denial contributed to families not supporting their loved ones. He stated, "We have families, being that it is a hereditary disease, families very much in denial. They want to separate themselves from it." Tim also stated, "Again, it goes back to the families not being able to cope, not being educated on a disease that could be prevalent in that family." Many of the participants concluded that individuals often experience denial because they know HD is in their family, but that they don't want to imagine receiving a diagnosis of HD themselves. For example, Tim explained:

I think a lot of it comes from denial like, 'this isn't happening!' You have individuals who have kids and there's such a disconnect. A spouse or whoever is involved, kids not getting tested. Why not? You're kind of just blocking it out and thinking, 'Oh, this will never happen to me.' But, it could.

## **Burnout**

The following section will examine the theme of 'burnout' as it relates to caregiving. The general idea of this theme is that HD informal and formal caregivers are at risk of becoming overwhelmed in their caregiving roles and end up burning out. The participants distinguished how it is much different being a formal caregiver versus an informal caregiver with respect to burnout because formal caregivers get to "escape" at the end of the day. Sarah, an informal caregiver, had the following to say about how being a caregiver for her sister has affected her:

I have lost a lot of the time for my own life. Sometimes I tell her that I am going on vacation and that I will be gone for a week and it's nice to just be gone. Just to have a break, but I know she needs me and counts on me. I am the only one to go and see her. It's almost...I don't want to say burden, but it's almost a burden.

There's no flexibility because she counts on me being there.

Sarah also stated, "I feel like I am kind of on a leash and she just yanks it and I try to keep it as calm and steady as I can, but she gets irritated if I don't jump when she says jump. That's been really hard. It's been really hard because I am on my own." When asked about why families cannot continue caring for their loved ones, Molly stated, "They have watched family members, they have cared for loved ones with HD, and I think they're just physically and emotionally exhausted and they cannot watch another person go through it." Molly also discussed what she has seen with her staff and burning out. She reported:

I definitely see where my staff has burnt out, especially when it is toward the end of an individual's life. When it is emergency room visits, pneumonia, having

hospice come on board. It is constant care for them and it does get challenging and overwhelming and exhausting.

Tim discussed how he has experienced emotional burnout many times. Tim stated, "I think I have been burnt out on more than one occasion. You question whether or not you can get up another day and do this job. Take a little time for yourself and regroup." Tim then went on to say, "I'd be lying that it didn't negatively and positively impact me. The hardest part is that day in and day out, you come in and you're providing that care knowing full well that when the disease runs its course the outcome is the same every time." Referring to how he deals with periods of burnout, Sam stated, "If you are going to be caregiver with someone with this disease, then you yourself have to be a positive person and you have to have thick skin." When asked about burning out as a caregiver, Bob stated:

It is intense; there is no other word to describe it. It is intense. Since we have grown, we have been able to hire shift staff to come in. Just getting that break because it is so intense. Getting that break to be away and have your own free time, rejuvenate yourself, is really a huge factor.

The majority of participants agreed that self-care is vital to their roles as informal and formal caregivers for individuals diagnosed with HD.

### **Attachment**

The next theme that was identified throughout this study is 'attachment.' The general concept of this theme is that caregivers are thoroughly attached and devoted to the individuals they care for on a day-to-day basis. All of the formal caregivers interviewed for this study reported that they view the residents they care for as family

members. Additionally, the participants admitted that the profound relationships they develop with the individuals they care for causes them to be more distraught as the individuals near the end of their lives. For example, Tim stated, "You get emotionally attached and it can be very difficult." He then stated, "You form attachments and those final days of seeing a person...they are bed ridden, they are taking comfort medications to help with pain...that's the most difficult." Lisa stated:

Everyday, the most emotional thing is when it is the time for them to leave. That is going to be the saddest. I am so new to this that I haven't had anybody die yet, but you are so attached. It's like they are one of your family members.

Furthermore, Sally reported, "I think it is more emotional. You are just attached and you want to be there all the time and you don't realize that you're letting yourself go and you're not taking care of yourself properly." Some of the participants discussed how people who are not caregivers tend to not understand what it is like caring for someone and how an attachment forms. Molly stated, "It is hard on me. Unless you have had that bond and you have cared for someone and you've been through the entire process...people don't really understand." Overall, the participants agreed that the bonds they form with the individuals they care for is their main motivation to continue being caregivers each day.

### **Progression of the Disease**

Another key theme identified in this study is 'progression of the disease.' This theme focuses on the fact that caregivers, whether formal or informal, believe that watching the disease progress over time is one of the most challenging parts of being a HD caregiver. Since HD affects individuals physically, cognitively, psychologically, and

over a long period of time, the caregivers find it difficult to witness and cope. Molly stated:

It is very difficult as a caregiver to watch them progress everyday, to watch them lose the skills that they once had, knowing what the end is going to be and it is very difficult supporting the individual when they know what the end is going to be.

Molly also stated:

The other thing is that with individuals with disabilities we typically want to promote as much independence, having them move towards more independence, eventually having them live on their own or something along those lines. Then, with Huntington's, they are losing that. So, it can be difficult and challenging.

Very challenging.

Sally indicated that the most challenging part of being a HD caregiver is watching the progression of the disease. She stated, "Basically watching them being able to take care of themselves like you and I do to watching them end up bed ridden. Sometimes we have to take in outside resources, such as hospice, to care for the individual." With regard to the disease progressing and being able to do things independently, Sally stated, "I think for a lot of them is the ability to actually continue to eat because that is one of the things that they could still do and when they can't do that, they kind of just give up." Lisa expressed that it is emotionally draining to watch individuals lose their independence. When referring to an individual, she reported, "Before, she could walk all by herself and now she needs assistance. She used to be able to tell stories, but now it takes all of her energy just to say one or two words. I treasure those days that she says full sentences."

Sam stated, "Being a professional caregiver, you are there every single day and it is very easy to miss the subtle slips and slides of the disease progression." Sam continued to say:

Seeing them, visiting with them like a friend, it's a real bummer seeing slides.

When social workers or whoever does little memory tests with my residents, I sometimes have to excuse myself because it is hard to watch. It's hard to watch and see that your friends are slowly losing it. You can see that your friend is declining and it sucks.

Sam disclosed that he believes there is a silver lining within HD. He described, "The silver lining of HD is that they lose their mind almost as fast as they lose their physical capabilities." Sarah described the progression of HD as 'frustrating' for various reasons. Sarah stated, "Frustration and just the heartbreak of watching them go down. Frustration of communication. It gets harder and harder for them to communicate. Mood outbursts, mood swings, emotional outbursts. It's very difficult." Sarah went on to discuss how HD has progressed within her sister. She stated:

As the disease progresses, there is anger and you don't know why sometimes.

With my sister, it is harder. Like today, I could hardly understand one word and she is going to speech therapy. I can maybe understand 10-15% of what she says on the phone and yesterday she called and I could maybe understand 5%. I feel bad because I keep asking, "What?" I can't understand her. Even today, being with her, trying to understand and she gets frustrated with that too.

Sarah also reported:

That's one of the things the doctor told us when she was diagnosed. This is not a day disease. This isn't a week or month disease. This is years, possibly decades

disease. That's what is so hard about it. Cancer is horrible, don't get me wrong, but this one is all of them put together and it just goes on and on.

### **Grief and Loss**

The next theme, 'grief and loss,' surfaced out of the aforementioned theme. The collective idea of this theme is that there are many different forms of loss associated with a diagnosis of HD in addition to a strong presence of grief. A majority of the participants expressed how grief and loss plays a role in their lives as caregivers as well as how grief and loss plays a role in the lives of the individuals they care for. All of the participants in this study mentioned death and the dying process as an end result of HD. The participants discussed how death affects them as well as how death affects the individuals they care for. For example, Tim stated, "You know, going into the final days of having the disease the odds are they are on hospice. There are so many things going wrong. That is the hardest part." When Sam was asked if he has ever experienced any adverse side effects of being a caregiver, he described, "Only emotionally when you lose a resident, when one of the individuals I care for passes away." Bob had a similar reaction when reflecting on the difficulty of losing a resident:

The first couple of individuals we cared for we cared for a long time and they passed, um, it was very tough, especially the closer you are to them. When you are hands on working with them everyday it is like losing a family member and you go through the grief and loss process and it is very tough, almost to the point where you want to throw in the towel because you don't want to go through it anymore.



A majority of the participants agreed that losing the individual they care for is devastating, yet they have found comfort in knowing the individual is no longer suffering. For example, Tim stated, "After they pass, yeah the disease ran its course and maybe took them away from everybody a little sooner, but they are at peace. They aren't having those issues anymore." Tim later stated, "I think the best way it has ever been described to me is that no matter what we do the outcome odds are likely to be the same. The only thing we can help with and hopefully increase is that it happens later rather than sooner." When asked about how grief and loss affects her, Sally stated:

It makes it a struggle sometimes because you really want them back, but at the same time, you can look back on the memories and think, 'Hey, I really helped that person to live an extra 6 months.' I also get to help the next person that comes in. To me, it's rewarding to know that at least I knew they were happy until it was their time.

Molly also discussed that she finds peace in knowing that the individuals she cared for are no longer suffering. She stated, "But once they do pass on and they aren't shaking anymore and they aren't frustrated, they are at peace. They are finally at peace, finally not dealing with this horrible disease anymore." Bob agreed by stating, "We can find comfort knowing that. I think the longer we've been in this field the more comforting it is for us, the caregivers, that they are finally at peace because, boy, oh, boy, it is devastating."

The participants further discussed the ways they have experienced loss in their lives and how the individuals they care for have been affected by loss. The types of losses mentioned throughout the interviews included the ability to do things

independently such as eating and walking, the loss of relationships, etc. With regard to the losses her sister experienced, Sarah stated, "For her, the loss of her independence. Complete loss of her driving. Then, it was the loss of the apartment. She had to move into a group home. There are a lot of restrictions there." In addition, Sarah mentioned how her sister is now losing her ability to function independently and how she is having trouble walking, swallowing, and even sitting up in a chair. Finally, Sarah disclosed how being a caregiver for her sister has affected her in terms of her own grief and loss. Sarah described, "Well, the loss of my own independence because I feel like she is so dependent on me. I can't go very far." Sarah later stated:

I feel like I have so much responsibility for people that I shouldn't have to be responsible for. I am happy to do it and I love them, but it's a sense of burden more than anything. The loss of my sister. I moved twice and there was no one to help me move. I packed up my house by myself because my husband was working and I shouldn't be crying, but I need my sister. I need a sister. I just need somebody and that's a huge loss for me, a huge grief for me.

### **Complex Mental Health**

The next theme that appeared is 'complex mental health.' The general idea of this theme is that individuals diagnosed with HD experience a wide range of mental health symptoms and side effects that many do not understand. The majority of participants talked about mood swings, outbursts, depression, and an overall sense of frustration within the individuals they care for. In addition, all of the participants disclosed that caring for individuals with behavioral issues is challenging, but that they know that the individuals could not control it. For example, Sarah stated, "Very low impulse control

from day one. From getting in fights at recess to just getting pregnant all the time. She had a very low degree of control.” Sarah then reported, “She lost a lot of friends because she couldn't keep a relationship because she would steal from people or borrow money and not repay it. She would use people, have emotional outbursts.” When asked about her sister's family, Sarah stated, “She would get into fights with her son and they would punch each other.” Sam described some mental health challenges of his residents by stating, “Depression, hallucinations, what I would say in general speaking ‘weird’ thinking and you don't know if it's legitimate weird thinking or if it's just trying to cover up other things.” Lisa stated, “His outbursts are difficult. Not when he yells as much as when he is yelling his frustration. Sometimes you take that personally like he is yelling and swearing at you even though he really is not.” When asked what aspect of HD is the most difficult, Bob stated, “You know, I think the hardest part would probably be just the uncontrolled mood swings and outbursts that somebody might have.” Molly stated:

The uncontrollable noises and vocalizations and then they get frustrated because they know they are loud and that they are disrupting other people, but they can't help it. A lot of depression, a lot of suicide ideation, thoughts of wanting it to end.

“I hate this disease, I hate this disease.”

Many of the participants mentioned how the behaviors of individuals with HD may be perceived inaccurately, especially by those who do not understand the complexities of HD. The participants also reported that the mental health characteristics and behaviors of individuals with HD is a main reason families do not want to care for their loved ones. For example, Tim stated, “All of sudden they might just throw a dish and that is how it is

perceived, but it's not really what is going on. How people react to that situation and being more afraid than anything else." Tim later stated:

When a person changes people tend to take it personally. There is no outside perspective. You can't take it personally when they have those outbursts and that is true with any diagnosis. They have those outbursts and the key is to not take it personally and I think in the family environment that it is more likely that they will take it personally.

Sam reported:

By the time they get to me, there is a reason they aren't living at home anymore whether it was because they were physically abusive or emotionally abusive or they were dangerous to themselves or others, um, there is a reason they are with me and they may have burned a lot of bridges by that time.

Molly had a similar response:

A lot of the time it is the behaviors. The verbal and physical aggression, outbursts. That is what I have seen. They don't know how to handle it. They don't know how to control the individual or how to stop the behavior. Or they are just scared. That is the biggest piece.

### **Family Dynamics**

The last major theme identified in this study is 'family dynamics.' This theme examines and demonstrates how families react and cope with having HD as part of their genetic background. This theme also reveals how and why the family dynamics associated with HD is more complex compared to other neurodegenerative diseases. Many of the participants discussed the complexities of families caring for their loved

ones knowing that other members of the family could potentially inherit or already have HD. Additionally, the participants expressed that they worry for families where parents have HD and have already had children who have a 50% chance of inheriting it. For example, Sam stated:

But now, how scary it is and children seeing it and being caregivers for their mom and dad. It really gives them the chance to think about what they want to do with that decision making process. Do they want to find out? Do they not want to find out?

When asked about his children possibly inheriting HD, Sam stated:

Nothing has been hidden since day one, but I do still see that my 16-year-old son worries about having the disease and he is growing up faster than I think he should have to. He is wanting to experience things in case he potentially does have the disease. So, at 16 years old, he is doing things that 22 to 24 year olds would do. Traveling here, traveling there, following his dreams.

Sally discussed many different aspects of HD and how it affects the family. She stated:

Each family takes it a little differently. Some don't know where to go, so they just drop them off where others kind of grew up with it and know what to expect.

They have supported family before. So, it's a 50/50 line as to whether family is involved or not.

She then stated:

I think it becomes difficult. It becomes time consuming. You really have to have the patience and you have to be able to have that time and a lot of families still need to support their own families. Giving that time is really hard. Sometimes I

don't think it is an easy thing to accept knowing that a family member is going to die from a disease.

With regard to the genetic component of HD, Sally reported:

I think it does [affect families], I mean, one is like, "How come I got it? The other one didn't get it." There is that or some people are like, "They will never amount to anything, they can just be the black sheep of the family." With a lot of those who have it and are older, there just isn't enough education and growing up going, "Okay, I have to take care of my mother, brother, or whoever." It's not an easy task.

A majority of the participants stated that HD tears families apart and that it affects families quite negatively as illustrated by the following quotes. Bob described:

It rips them apart. Most of the families we've seen, it really rips them apart to the point where we become their family. Families don't come around a lot of times especially those families that aren't involved with those support groups. Basically, they have had enough. They don't want to watch their loved one go through it. Like I said, the kids don't come around because they don't want to know what their future is going to be like. They are trying to live life while they still can. They just stop coming.

Tim stated:

There is just this disconnect and you can't help but feel a little bad that there isn't more involvement from families. They don't necessarily, for a lack of better word, want to be associated with it. To me, I see the disease tear more families apart more than bringing families together.

Tim later mentioned, "Not seeing the physical side effects...I think people think, 'Oh, my husband is a jerk now' or things like that. That can alter the family dynamics too." He also reported:

I think the biggest thing is that families want to remember their loved ones as they were. They don't want to remember them with the disease, with the dementia, with the chorea, with the potential of having to be fed through a tube. Families don't want to remember that. So, it's tough.

When asked what affects she has seen HD have on families, Molly stated:

Definitely divorce. We see a lot of divorce. Once an individual gets diagnosed, they get divorced. With the children, especially if they are school-aged children, they want to remember their mother or father as healthy, being able to do the things that they were previously doing. I have seen where children don't want to come around as much because they don't want to see their mom or dad like that.

Molly also reported:

We have seen lots of individuals whose family members have literally dropped them off at our door and never come back. The individuals feel neglected and abandoned thinking, "What happened to my family? Why don't they love me?" That in it's self causes a ton of behaviors. Huntington's Disease just affects all aspects of life.

With regard to how HD affects families, Sam described:

It tears them completely and totally apart. Not just the person who has HD, but when that person is removed from the family, the family members themselves as well. One, they didn't think it was that bad, maybe mom favored that child. It

tears brothers and sisters apart. It tears fathers and children away from each other. They [children] think dad shouldn't have done that, shouldn't have placed mom somewhere, so now they don't talk to dad anymore. It's huge. It tears the entire family totally and completely apart.

Sarah's experience of being a caregiver was further complicated because her adoptive sister had already had 4 biological children before she was diagnosed with HD and two of her children had already had children as well. Sarah also mentioned that after completing an adoption search she discovered that her sister had several other half siblings with HD. Sarah talked at length about how her sister having HD affected her and her family. She stated, "It affected every part of my family. Every single part. Just the dysfunction she had growing up and all the frustration." Sarah later stated:

Yeah, it affected my parents, our relationships. I was always the caregiver for her. When we couldn't find her I would get on my bicycle and go find her. She would be rolling around with some boy at the park or she could be smoking pot behind the store up the street. I was an early teenager. 12, 13, 14 years old trying to find her. I was the responsible one. I always felt responsible for her.

She continued:

So, it affected every bit of my life. Then, it affected my married life just horribly because being adults and both of us having families she couldn't take care of hers financially, or mentally, or emotionally and they were a dysfunctional mess, to say the least. She would call me at all hours of the night expecting me to rescue her like I always did. It's been a huge source of frustration on my marriage and my family too.



All of the participants came to the conclusion that HD affects all aspects of an individual's life as well as the entire family system due to the genetic nature of the disease.

The seven participants who were interviewed for this study shared intimate and complex details about their experiences of being formal and informal caregivers for individuals diagnosed with HD. The participants' responses allowed the researcher to establish nine major themes throughout the data. The nine themes reviewed in this study include: (a) Lack of Education and Awareness, (b) Resources and Support, (c) Denial, (d) Burnout, (e) Attachment, (f) Progression of the Disease, (g) Grief and Loss, (h) Complex Mental Health, and (i) Family Dynamics. In the forthcoming section, the researcher will analyze how the findings relate to previous research, the strengths and limitations of this study, and will consider the implications that the current study has on social work practice, policy, and future research.

### **Discussion**

The purpose of this study was to examine the overall experiences of formal and informal caregivers of individuals diagnosed with HD. The research question addressed was: What are the experiences of HD caregivers? The researcher was able to answer the research question by performing qualitative interviews with seven informal and formal caregivers. In the forthcoming paragraphs, the findings of this study will be discussed with regard to how the findings compare and differ from the current literature. In addition, the researcher will address the strengths and limitations of this study and will discuss the implications this study has on social work practice, policy, and future research. The themes revealed in this study show similarities and some differences

compared to the existing literature on HD. Overall, the findings of this study are consistent with the studies examined in the literature review.

### **Comparison to the Research**

The purpose of this section is to compare the findings of this research study to the findings of previous research studies by noting similarities and differences between the two. The theme 'lack of education and awareness' was overwhelmingly present throughout the data. The fact that HD is not widely prevalent within Minnesota and the U.S. could be the reason for a lack of awareness about the disease. Findings in one study indicate that roughly 12,000 to 21,500 people are affected by HD in the U.S. with even fewer people affected in Minnesota (Williams et al., 2012). Several participants attributed their frustrations with caregiving to a lack of education and awareness among families and health care professionals. The findings also revealed that caregivers and individuals diagnosed with HD encounter barriers when attempting to access the health care system due to a decreased awareness among health care professionals. This is consistent with the existing literature, which states that many caregivers have been dissatisfied with the level of support they receive from health care professionals (Skirton et al., 2010). Additionally, the findings of this study demonstrated how caregivers experience burnout and additional stress when faced with family members who did not understand the complexities of HD. This connection exists in the literature as well as noted by Dura (1993) who found that an overall lack of knowledge of HD contributed to caregiver distress. Generally, the findings coincide with the existing research and agree with the idea that little education and awareness among individuals with HD, their families, and the general population contributes to the challenges caregivers experience.

There were many similarities found between the review of the literature and the findings in this study with regard to family dynamics. Findings in previous studies suggest that families who have HD in their genetic background have likely cared for multiple generations of affected loved ones, which may cause a disturbance in the caregiving role (Roscoe et al., 2009). The findings in this study strongly correlate with the existing literature as noted by the participants' responses when discussing the family dynamics of the individuals they care for. A majority of the participants reported that most families have already cared for other family members with HD. Additionally, many participants attributed the lack of family support to the fact that families cannot bear to watch another loved one die from HD. Both the findings of this research and the findings of previous literature suggest that children distance themselves from their parents who have HD because the children find it difficult to observe what could potentially be their future if diagnosed with HD themselves. Van der Meer et al. (2006) indicates that most children will witness the declines of their parents' health while knowing that they may also have HD. The findings of this study also indicate that the genetic nature of this disease affects families negatively, leads to emotional distance and turmoil, and can alter the family as a whole.

Studies in the literature indicate that HD affects all aspects of diagnosed individuals including their cognitive, physical, mental, and emotional functioning. The findings of this research propose that caring for individuals diagnosed with HD becomes even more difficult when behavioral problems arise. Areas of executive functioning are affected such as the ability to control emotions, organize, or plan ahead and cognitive flexibility is often unlikely in diagnosed individuals, which can lead to problematic

behavior (Bourne et al, 2006). This idea was also discussed in this research study as participants reported that the individuals they care for exhibit mood swings, emotional outbursts, and verbal and physical aggression. Similarly, another research study highlighted the psychological effects HD has on the diagnosed individuals as well as those that care for them. The findings of this study support the existing research that states that the psychological symptoms of HD are more distressing for family members and caregivers compared to the physical side effects of the disease (Kingma et al., 2008).

This study included formal and informal caregivers and demonstrated that challenges exist for both types of caregivers. The findings illustrate that formal caregiving settings such as group homes, assisted living facilities, or nursing homes benefit the diagnosed individuals and their families; however, there is a lack of formal caregiving settings in the state of Minnesota and the U.S. This supports the findings in one study, which states that there is a shortage in paid caregivers and nursing home beds leading to more stress on families (Levine et al., 2010). The findings of this study also suggest that a majority of residential placement options will not accept individuals diagnosed with HD because HD poses several medical and behavioral problems. This is highlighted in one study that reported that more than 50% of nursing facilities reported hesitation in caring for individuals with HD due to the need for excessive care and the behavioral problems associated with HD (Pickett et al., 2007). Additionally, the findings of this study coincide with findings from a previous study, which states that many formal caregivers experience burnout as a result of overseeing mentally and behaviorally complex individuals (Turner, 2005).

As previously mentioned, the findings of this study suggest that there is a lack of formal caregiving settings in Minnesota. All of the participants agreed that there are only a handful of HD specific residences in Minnesota. Existing research indicates that an insufficient support network within social and medical communities, including long-term care settings, adds to the stress and burnout of caregivers (Roscoe et al., 2009). The literature reviewed for this study did not emphasize the widespread lack of resources that are available for diagnosed individuals and their families. Unlike the existing literature, the findings of this study widely discussed the lack of resources among the HD community including residential care facilities. Comparably, the findings of this research did not address some aspects of formal caregiving challenges as noted in the existing literature. One study highlighted the distress caregivers face in providing care to individuals against their will due to cognitive impairments and deficits in communication as commonly seen in HD (Edberg et al., 2008). The participants in this study did not report similar experiences.

The findings in this study produced additional differences compared to studies in the review of literature. First, the researcher did not encounter the subject of grief, loss, and death while reviewing the existing literature. The findings of this study examined grief, loss, and the process of dying as experienced by the individuals diagnosed with HD and their caregivers. The findings proposed that one of the most challenging aspects of being a caregiver is observing individuals deteriorate over time and eventually pass away. A majority of the participants reported that witnessing the progression of HD and death caused them to feel emotionally drained. Another difference between previous studies and the findings of this study is that findings from previous studies suggest that

caregivers experience adverse health outcomes with regard to their own physical and mental health. A previous study also indicated that caregivers are less likely to seek preventative health measures and are at greater risk for mortality (Navaie-Waliser et al., 2002). This is not consistent with the findings of this study as participants reported only emotional side effects associated with the loss of individuals they care for. Previous studies examined the characteristics and symptoms of HD; however, the previous studies did not emphasize how individuals with HD cope with the multitude of losses they experience as the disease advances.

Overall, the findings of this study are parallel with the findings in previous studies. Several similarities exist between the findings of this study and previous studies regarding the role of education, awareness, and resources, family dynamics, and the challenges of caring for individuals with behavioral problems. Gaps exist in the literature between previous studies and the findings of this study with regard to how caregivers perceive death, grief, and loss.

### **Further Impressions**

The researcher had several thoughts and ideas throughout the course of this study, especially when reviewing the findings and comparing the findings to previous studies. First, the researcher wondered about the role grief and loss plays in the lives of caregivers and the individuals they care for. In the literature review, many studies described that individuals diagnosed with HD and caregivers experience an increase in depression; however, the researcher questions how often it is clinically diagnosed depression versus normal grief versus chronic sorrow that often accompanies a terminal diagnosis. Both caregivers, especially familial caregivers, and individuals diagnosed with HD experience

devastating losses and it can take a long time to accept and overcome the grieving process. It would be interesting to determine what percentage of caregivers and HD individuals are diagnosed with depression compared to those who are experiencing normal grief.

As noted in the findings section, the participants described the idea of support or lack thereof on many occasions. The participants noted extensive support by HD professionals including Dr. Nance at the HCMC Center of Excellence and the HDSA Minnesota chapter social worker. In addition, the participants described that many of the individuals they care for have decreased informal support systems. For example, the participants explained that many families have little to no involvement in their loved one's life. The researcher questions why individuals diagnosed with HD have a lack of family support. Also, the researcher sought to explain why families who are involved might not be seeking formal support and resources. Are family members not aware of the resources available to them or are they making a conscious decision to refrain from seeking support? It is possible that many families are not aware of the resources that are available to them, but it is also possible that families and individuals diagnosed with HD do not want any help or assistance. Several participants noted that families who provide care to their loved one may not want to attend support groups because they live and breathe HD every single day and they might not want to spend additional hours every week discussing something they deal with on a daily basis. It would be worthwhile to determine why some individuals and families choose to confront HD independently and without any formal assistance. Next, the strengths and limitations of this study will be discussed.

### **Strengths and Limitations of the Study**

This study sought to understand and explore the intricacies associated with HD through the experiences of caregivers. This study used the subjective experiences of caregivers to shed light on HD, which the literature proposed to be of small representation in the general population. In addition, findings from studies indicated that an overall lack of knowledge on the disease amongst medical and social communities adds to the distress of caregivers. Because a diagnosis of HD affects so few, little is known about the needs of caregivers and families. The field of social work benefits from this study, so individuals, families, and caregivers can receive additional support and their needs can more easily be met. This qualitative study using the subjective experiences of caregivers gave greater insight into the complexities associated with caring for someone diagnosed with HD.

There were several strengths found in this study. First, this study includes experiences of formal caregivers and informal caregivers even though it is a small sample. The individual experiences shared in this study were consistent across the majority of participants and corresponded with various findings in the existing research. Moreover, this study explored aspects and challenges of caregiving that is underrepresented in the literature. The existing literature mainly focuses on the physical, cognitive, and psychological characteristics of the disease rather than the experiences caregivers encounter with those characteristics.

Limitations also exist in this study. A major limitation of this study was the small sample size. The researcher attempted to recruit at least eight participants for this study including formal and informal caregivers. The researcher hoped to get four informal



caregivers and four formal caregivers in order to represent a wide range of experiences. The researcher faced difficulty in recruiting participants as indicated by the fact that this study includes seven participants with only two informal and five formal caregivers. The researcher contacted all publically noted HD specific residences in Minnesota by email and telephone. There were two residential agencies that did not respond to the researcher's attempt of recruiting participants for this study. The researcher left voicemails and sent emails, but did not receive any feedback from those agencies. Additionally, the HDSA Minnesota chapter social worker distributed the researcher's recruitment flyer to potential informal caregivers, however, only one informal caregiver contacted the researcher to participate in this study. As designated by the HDSA Minnesota chapter, there are only four HD specific residences in Minnesota, which contributes to the small sample size of this study. If there were more resources available in Minnesota, then it is likely that there would be a larger formal caregiving community to recruit from. Furthermore, the sensitive nature of this study could have prevented informal caregivers from sharing their experiences.

Likewise, the small sample size of this study was in part due to the time-restrictions of the study, but also because HD is not a prominent diagnosis among the general population. As a result, the small sample size of this study did not give a representative view of all caregivers. This study predominately represented the experiences of formal caregivers. Another limitation of this study is the lack of ability to generalize the findings. Because this study only involved seven participants it is difficult to generalize the findings across the entire population of caregivers. Finally, a limitation exists in this study due to the possibility of researcher bias. The researcher had a personal

interest in HD and the issues surrounding caregiving. To ensure researcher bias was minimal, the researcher reviewed the interview questions, codes, and themes with a colleague and the research chair.

### **Implications for Social Work Practice**

The findings of this study offer several implications for social work practice and potential changes that could be implemented for individuals diagnosed with HD and their caregivers. The findings of this study indicate that there is an overall lack of education, awareness, and resources for individuals diagnosed with HD, their families, and formal caregivers. In addition, the findings suggest that there is a lack of education and awareness among health care professionals and social service agencies, which includes social workers. This research study proposes that more support is necessary for informal and formal HD caregivers. The majority of the participants noted that the only form of support they receive comes from support groups and the HDSA Minnesota chapter. Social workers across various settings including hospitals, counties, and community-based agencies could provide more support and services to individuals, families, and caregivers affected by HD. Increasing the amount of services available to informal and formal caregivers could decrease the rate of emotional and physical burnout.

Another possibility for social work practice is to develop more intensive trainings and skills-based groups for caregivers as the findings and existing literature suggest a lack of education and awareness contributes to caregiver distress. This would allow informal and formal caregivers to feel more comfortable, increase their understanding, and to become better equipped to manage the characteristics, symptoms, and behaviors associated with HD. Social workers could also provide disease education and other useful

community resources to caregivers. A final implication for social work practice is to multiply the amount of HDSA social workers in Minnesota and the U.S. Currently, there is only one social worker employed with the HDSA in Minnesota and the social worker is located in the Twin Cities region. There is a gap in service and support for caregivers who do not have access to the HDSA due to geographic location.

### **Implications for Policy**

The implications for social policy in this study occur at the mezzo and macro level. At the mezzo level, this research holds implications to promote changes within the greater community. Increasing the awareness and education of community members would contribute to the support networks currently in place for individuals with HD, their families, and their caregivers. As indicated in the findings of this study, the HD community is tight knit and relatively small, therefore, hosting free caregiver conferences or workshops would be beneficial if only to allow caregivers a space and opportunity to provide support, information, or resources to one another. Another implication for change at the mezzo level is to spread awareness through social and human services agencies, schools, and established community groups. The HDSA could expand their services and support as well. Moreover, mezzo level implications for policy could be made within the accredited schools of social work throughout the U.S. The Council on Social Work Education (CSWE) could implement programming to educate social work students on HD and other debilitating diseases as well as how to support caregivers.

In addition, there are implications for policy at the macro level. First, policy changes need to be implemented throughout all medical systems including hospitals, community outpatient clinics, and skilled nursing facilities. Physicians, nurses,

psychiatrists, physical, occupational, and speech therapists, etc. should receive education and training on HD, so they can adequately care for individuals with HD and support those that care for them. Policies should be created to address the medical and psychological care individuals with HD receive because their care directly affects how caregivers are able to provide ongoing caregiving responsibilities as well. The findings in this research and in previous studies suggest that families will eventually have to place their loved ones in long-term care facilities, therefore, changes at the macro level need to occur. For example, states and counties need to establish more HD specific residences so the population is adequately served. More HD specific homes would allow families to place their loved ones in a setting that can meet the individual's unique health and safety needs. Agencies that are already established throughout Minnesota and the U.S. that are licensed to provide 24-hour care to individuals with complex medical needs should become more educated and open to serving individuals with HD. Finally, county and state human service departments need to provide increased support programs and funding to individuals with HD as it would foster more independence, respite, and support for caregivers.

### **Implications for Future Research**

In general, more qualitative research is necessary surrounding the topic of HD caregivers. There is a substantial amount of research known about the biological and medical aspects of HD, yet there is limited research on how having HD is perceived by the individual diagnosed and how that affects the family. Since HD is a genetic disease and frequently family members become the primary caregivers, further research is necessary to gain an in depth understanding of the caregiving role. Qualitative research

on HD from a child's perspective would also be significant to the field of social work. The findings in this study reveal the multifaceted dynamics that occur in families with parents who suffer from HD. Qualitative research conducted with caregivers who are children of a diagnosed parent would contribute to the existing literature due to the genetic nature of this disease. Another area where further research is needed is in grief and loss as it relates to caregivers. The findings in this study reveal that caregivers struggle with witnessing HD progress in individuals as well as coping with the death of individuals they care for. Finally, an extensive and larger study should be conducted with HD caregivers in order to make the findings more generalizable across the population.

In conclusion, the findings of this study are similar to the findings in previous studies; however, additional exploration on HD from the caregivers' perspective should continue in order to increase the level of support individuals and families affected by HD require. This study offered the subjective experiences of caregivers and gave greater insight into the complexities of caring for individuals diagnosed with HD. Although the sample size was small, the individual experiences shared in this study were consistent across the majority of participants. In addition, this study presents numerous implications for social work practice, policy, and future research. Overall, it is important that research continues to be conducted on how HD affects the individual, families, and the larger community.

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**Appendix A**  
**Phone/Email Script to Key Agencies**

Hi, my name is Ali Kanuit and I am a graduate student in the School of Social Work at St. Catherine University and the University of St. Thomas. I am conducting a qualitative research project on the experiences of Huntington's Disease caregivers. The research project will seek to answer the question: What are the experiences of Huntington's Disease caregivers? The purpose of the current study is to examine the experiences of those caring for individuals diagnosed with Huntington's Disease. This includes the experiences of formal and informal caregivers across multiple settings. The current study will consider the difficult characteristics that the disease presents as well as the barriers and obstacles that caregivers encounter while caring for these individuals. The complexities associated with Huntington's Disease pose unique challenges for the individual diagnosed, his or her family, and the ones providing care. This research will allow caregivers to share their experiences of providing formal or informal care to individuals diagnosed with this progressive and degenerative disease with the hope of educating the general population about a subject that is rarely discussed.

Formal caregivers include any paid caregivers such as those who work in group homes, nursing facilities, or assisted living facilities. Informal caregivers include family members (husband/wife, children, brother/sister, etc.), friends, or any unpaid individuals providing caregiving duties.

I am writing you to request your assistance in recruiting participants for this study. I am looking to speak with individuals who provide care to those diagnosed with Huntington's Disease. I am looking for formal and informal caregivers to participate in individual interviews lasting 45-60 minutes. If you have any potential participants appropriate for my study, please consider giving them my information.

Thank you for your time and consideration,

Ali Kanuit, LSW  
MSW Clinical Research Student

**Appendix B**

## In Search of Huntington's Disease Caregivers

Share your Huntington's Disease caregiving  
story in a qualitative research study

Criteria for Participation:

- Provide (or have provided) care to someone diagnosed with Huntington's Disease
- Formal (paid) or informal (family) caregivers

If you are interested in participating in this study, please contact Ali Kanuit, graduate student, at xxx-xxx-xxxx or by email at xxxxxxxx@stthomas.edu

This study is being conducted under the supervision of Dr. Catherine Marrs Fuchsel, PhD., LICSW, who is an assistant professor in the School of Social Work at St. Catherine University.

If you have questions regarding your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact John Schmitt, the Chair of the Institutional Review Board through St. Catherine University at (651) 690-7739.

### **Appendix C**

#### **Phone/Email Response Script for Participants**

Thank you for contacting me regarding my research study on Huntington's Disease caregivers. To start, I would like to ask you a few questions. If you answer "no" to any of the following screening questions, you will not be eligible to participate in this study and I thank you for your time and consideration.

Are you currently or have you ever been a caregiver for someone diagnosed with Huntington's Disease? What is your relation to the individual you provide care for? For example, are you a family member (informal caregiver) or are you employed (formal caregiver) by a caregiving agency such as a nursing facility or group home? Lastly, do you have any questions or concerns regarding my study?

If you are still interested in participating in my study, the next step is to schedule an interview at a place and time of your choosing. I would like to respect your time and schedule, so please let me know what day, time, and location works best for you and I would be happy to accommodate. The interview will last about 45 minutes to one hour and I will be asking you questions that have been pre-approved for this research. You may choose to decline to answer questions or withdraw from the study at any given time. The format of the interview will be semi-structured to allow for discussion dependent on your responses.

Prior to the interview, I will give you an informed consent form for you to review. You will have the opportunity to ask me questions regarding your participation in this study. Your signature of informed consent demonstrates you are entering this study on a voluntary basis and that you have been educated of your rights as well as the risks and benefits of this study. Again, you may choose to decline to answer questions or withdraw from the study at any given time.

Thank you so much for your consideration and interest in this very important research. I look forward to hearing from you. Please let me know if and when you would like to schedule an interview.

Ali Kanuit, LSW  
MSW Research Student

**Appendix D**  
**Research Information and Consent Form**  
**The Experiences of Huntington's Disease Caregivers**

**Introduction:**

You are invited to participate in a research study investigating the experiences of caregivers caring for those diagnosed with Huntington's Disease. This study is being conducted by Ali Kanuit, graduate student in the School of Social Work Program at St. Catherine University and the University of St. Thomas, under the supervision of Dr. Catherine Marrs Fuchsel. You were selected as a possible participant in this research because you have been a caregiver for someone diagnosed with Huntington's Disease. Please read this form and ask questions before you decide whether to participate in the study.

**Background Information:**

The purpose of this study is to discover the experiences of Huntington's Disease caregivers and, in turn, provide the profession of social work with ways to better assist caregivers in their role. Approximately 8-10 people are expected to participate in this research.

**Procedures:**

If you decide to participate, you will be asked to answer approximately 8-10 questions related to your experiences as a caregiver in a 45-minute to one-hour interview, agree to an audio-taping of the interview that will be used for this research, agree to allow the information to be presented to the public in a non-identifying way, and agree to allow colleagues to review the data and transcript of the interview for a reliability check. The colleagues that will review the data and transcript for a reliability check will include two classmates. A reliability check will be completed to ensure that I did not miss any important information while reviewing the data and transcript. The information gathered from this interview will be presented to members of the public who choose to attend the presentation on May 18, 2015. The interview will take place in a private place of your choice or via telephone on speakerphone with no one else present but the researcher. In the event that a private space is needed, rooms will be available for the interview at the University of St. Thomas library. This study will take approximately one hour of your time.

**Risks and Benefits:**

The study has minimal risk. Due to the nature of Huntington's Disease, you may feel discomfort when talking about your experiences. If your feelings become too overwhelming, you may ask to terminate the interview early.

There are no direct benefits to you for participating in this research.

**Confidentiality:**

Any information obtained in connection with this research study that could identify you will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented.

I will keep the research results in a password-protected computer in a locked file cabinet in my home. Only myself, my research advisor, Dr. Catherine Marrs Fuchsel, and two classmates will have access to the records while I work on this project. I will finish analyzing the data by April 2015. I will then destroy all original reports and identifying information that may be linked back to you by May 31, 2015.

**Voluntary Nature of the Study:**

Participation in this research is voluntary. You are also free to pass on some of the interview questions. If you choose to withdraw from this study at any time, your relationship with the University of St. Thomas and St. Catherine University will not be affected.

**Contacts and Questions:**

If you have any questions, please feel free to contact me, Ali Kanuit. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Catherine Marrs Fuchsel, can be reached at 651-690-6146. She will be happy to answer any questions you may have. If you have other questions or concerns regarding this study and would like to talk to someone other than the researcher, you may also contact, John Schmitt, Institutional Review Board Chair of the St. Catherine University Institutional Review Board, at 651-690-7739 or by email at [jsschmitt@stkate.edu](mailto:jsschmitt@stkate.edu).

You may keep a copy of this form for your records.

**Statement of Consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

I consent to participate in the study and I agree to an audiotaping of my interview.

---

Signature

Date

---

Signature of Researcher

Date

**Appendix E**  
**Interview Questions**

1. Are you an informal or formal caregiver? Please define your relationship to the individual you care for. How long have you been a HD caregiver?
2. How do you identify your gender? If you feel comfortable, what is your age?
3. What do you believe to be the greatest challenge in providing care to someone diagnosed with Huntington's Disease?
4. Are there certain aspects or characteristics of this disease that make it more difficult to provide caregiving duties?
5. What have been some successes or strides you have experienced while being a caregiver?
6. What supports or resources do you find to be most beneficial? Do you think a lack of knowledge, education, or awareness of Huntington's Disease has made it more challenging to care for someone diagnosed with the disease?
7. How does this disease affect you in terms of your own physical and mental health? Have you experienced any adverse outcomes by being a Huntington's Disease caregiver?
8. What affects have you seen this disease have on families including relationships between spouses, children, siblings, etc.? Are there specific areas that affect or alter family dynamics and how?
9. What role do you think grief and loss plays in your life as well as the individuals you care for?



10. How has being a caregiver for someone diagnosed with HD made you more aware of various systems? For example, how it affected your perceptions or interactions with health care providers, community memberships or group, etc.?