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The Effects of Gender on Resiliency for Children when a Parent has Huntington's
Disease

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 research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university 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.

Abstract

The experience of children who are raised in a family where a parent has Huntington's Disease (HD) is complex. The purpose of this project was to explore the resiliency of those who were raised in a family with a parent who had HD, explore the effect the gender of the child had on their resilience, and whether or not the gender of the parent who had HD impacted resilience. Using a quantitative design, 107 adults who were raised within a family with HD responded to an anonymous online survey answering questions on gender, resilience, and experiences growing up in a family affected by HD. The findings indicated that the gender of the child and the gender of the parent were significant in terms of the likelihood of the child showing resilience. The male respondents tended to have higher resiliency results than their female counterparts, although the vast majority of the respondents were female. In this study, a correlation between the age of the respondent when their parent began showing symptoms of HD and resilience was not supported. These findings highlight the significance of gender, impact of attachment with parent caregivers, and the importance in supporting the children who are being raised with a parent affected with HD.

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The Effects of Gender on Resiliency for Children, When a Parent has Huntington's
Disease

Over one million children will have lost a parent due to a terminal illness by the time they are fifteen years old (Mahoney, 2005). This is said to be one of the most traumatic events to be experienced in childhood (Haine et. al., 2008). When someone is diagnosed with a life-threatening illness, life changes forever, not only for the individual, but also for the entire family. The stress that comes along with diagnosis of life threatening illness is even more complicated if the person has dependent children living at home (as cited by Fearnley, 2012). When a child grows up in a family where one parent has a life-threatening illness, stressors exist that make it more complex than being raised in a family with healthy parents. Often when working with the family, professionals focus on the needs of the parent who is ill or the partner, rather than the needs of the child in the family (Fearnley, 2012; Armistead, Klein & Forehand, 1995). Social networks change, and finances become strained as the parent who is ill loses the ability to work and requires expensive medical treatment. The ill parent may also experience psychological and behavioral symptoms, cognitive decline, and gradually requires more and more help with activities of daily living. The dependent child is left vulnerable, due to the constraints of his or her developmental level.

Most research and attention from the scientific community has focused on the parent who is terminally ill, without much consideration of the impact on the children in the family. Children who are raised in a home with a parent who has Huntington's disease have not had much attention in the research community.

Huntington's disease (HD) is a complex disease that impacts not only the person with the diagnosis but also their family members. HD is considered a rare neurological disease. The age of disease onset ranges from two to eighty. The most common age of onset is thirty to forty-five years old. HD impacts the person's psychological, emotional, and physical well-being, and is progressively debilitating. The individual will eventually lose all independence. Currently there is no cure and no treatments to delay symptom onset starting in the person who carries the HD gene (The Huntington's Disease Society of America (HDSA)).

Huntington's disease is a hereditary disease, and each child of a person who carries the Huntington's gene has a 50/50 chance of inheriting the gene (HDSA). This creates complex relationships and experiences for those living in an HD family. A child growing up in a family that is affected by HD may have the experience of seeing a grandparent, aunt or uncle or parent affected with the disease. The child being raised in a family with HD will likely become aware of their own at-risk status for inheriting the expanded gene. Some children in families affected by HD may find their at-risk status difficult as they understand the possibility that HD may be in their own future (Talking with kids about HD).

In families with HD, ambiguous loss is a common experience. Ambiguous loss is the loss of a loved one emotionally before the person is physically gone (i.e. HD, Alzheimer's disease), the loss of a loved one physically before the person is emotionally or cognitively gone (i.e. ALS) (Boss, 2006).

While some children in families affected by HD show resiliency, others experience significant problems (Forrest Kennan et. al, 2007). The term resiliency refers

to the ability to persevere in the face of adversity. According to the National Association of Social Workers (NASW), resilient children are able to adapt to difficult situations, and develop coping strategies, and eventually are able to become contributing members of their communities (www.socialworkers.org).

The purpose of this quantitative study is to better understand the experience of children growing up in a family affected by a parent who has Huntington's disease and it will look to determine whether the gender of the child affects resiliency. More specifically, the research question is to determine the relationship between gender and resiliency for children who were raised in a household where one parent had HD. The effects of a terminal illness on a family are significant. Little research has been done on the effects on the children in the family (in particular within families who have HD.) This analysis is significant for the HD community, for HD social workers and for other professionals who serve HD families.

This study began by conducting a review of past studies that pertain to children's experiences of growing up in a family where one parent has a life-threatening illness. Information and studies pertaining to children's experiences growing up in a family with HD are also included. The data collection methods and safeguards for research with human subjects are outlined. Data was collected from completed questionnaires and analyzed using Statistical Package for Social Sciences version 22, a statistical analysis software. The results of the statistical analysis are discussed in reference to findings from the literature. The discussion section looks at the effect that gender has on resiliency for children who were raised in a household where a parent has HD, strengths and limitations of this research, along with the implications and plans for future research.

Definition of Terms

In this study, **gender** refers to male or female due to the lack of literature about transgender youth being raised by a parent who has HD. To respect transgender individuals, the research survey allows participants to identify themselves with the gender options of “male”, “female”, and “transgender or other.”

Literature Review

Gender

Gender impacts emotional response to parental illness. Early in development, boys and girls are socialized to express emotions consistent with their gender roles. Girls are socialized to emote internally, show empathy towards others, have a positive affect and be nurturing to others (Zahn-Waxler, 2010). Boys are socialized to express emotions in an externally directed manner, such as such as acts of aggression, control and dominance (Zahn-Waxler, 2010). There is little research about the role of fathers and their role in the development of a child’s emotional socialization (Root & Denham, 2010). Although when discussing emotions with their child, for both mothers and fathers, the socialization style did differ from son to daughter (Root & Denham, 2010). Denham, Bassett, & Wyatt (2010) found that mothers showed emotion more frequently than fathers. The mothers in their study were seen as the “emotional gatekeeper” and through modeling and socialization were often the parent who taught their children about emotional competence (Denham, Bassett, Wyatt, 2010).

Research suggests that adolescent girls are more likely to assume caretaking responsibilities for their parent who is ill (Compas, Worsham, Epping-Jordan, Grant,

Mireault, Howell & Malcarne, 1994). In addition, research suggests that boys ages 9-17 who had a parent with a life threatening illness tended to avoid home, pursued extracurricular interests outside of the home, and distanced themselves from the close contact they used to enjoy from their parent who is terminally ill (Christ & Christ 2006). In contrast, research by Vannatta, Grollman, Noll and Gerhardt (2008) found that sons of mothers with breast cancer were viewed as emotionally sensitive and lonelier than compared to their female counterparts.

Gender of the ill parent impacts resiliency. Research suggests that the gender of the terminally ill parent impacts the amount of distress in the child. Compas et. al. (1994) found that the child who was the same sex as the terminally ill parent had a more challenging experience. Compas et. al. (1994) found that adolescent girls, more so than adolescent boys, showed emotional distress around the mother having cancer.

Resiliency

Social supports impact resiliency. Evidence indicates that children who are living with a parent who has a life threatening illness are better able to function in their daily lives when they have strong support systems in place (Christ & Christ, 2006). Strong support systems would include being a part of a religious community, athletic group, recreation organization, friend or family groups that foster open communication and support each other during good times and bad. Research suggests that in families who are able to find and utilize therapeutic resources (i.e. individual or group counseling, support group meetings) find that the children are more able to adjust to the family's new normal (Christ & Christ, 2006).

Communication about illness supports resiliency. Research suggests that communication about the parent's illness is key to a child's resiliency when living with a parent with a life-threatening illness (Fearnley, 2012). If the "well" parent is open in discussing illness, losses, and allows the children to be informed on symptoms or changes in the parent's illness, the child is found to have better emotional resiliency (Christ & Christ, 2006).

How told about HD. Research suggests that communication on how HD is discussed or not discussed in a family makes a difference on the resiliency of the children growing up in the family (Keenan et al, 2007; Williams et. al., 2009). Keenan et. al. (2007) noted that children who knew about HD from an early age were better able to cope. In 2013, HDSA's Talking to Kids About HD provided age appropriate ways to have a conversations with children about HD and what effects it has on the person with the disease. Children that knew about HD at a younger age were found to have a closer bond to their affected parent more so than their counterparts (Keenan et. al., 2009). Children raised in a home where HD was not discussed often felt isolated, angry and afraid (Keenan et. al, 2009; Williams et. al., 2012).

Experiences growing up in family with HD. Children growing up in an HD household "differ from adults in a family affected by HD particularly due to their cognitive and psychosocial differences in development and socialization (Keenan et. al., 2007). " Keenan et. al. (2007) and Williams et. al. (2013) found that some children raised in families affected by HD coped successfully and were incredibly resilient but some experienced significant problems, putting them "at risk for physical or emotional harm (Keenan et. al., 2007, p. 126)." Keenan et. al. (2007) looked at protective factors

and risk factors. Protective factors include having someone to talk to about their feelings, a strong support system, an emotionally supportive relationship with the parent who is not ill, and knowing about HD at a young age (Keenan et. al., 2007). Risk factors include avoidance of home, consuming thoughts about inheriting HD themselves, taking on significant caregiver roles, self-harming behaviors (i.e. using drugs or participating in risk taking behaviors)(Keenan et. al., 2007).

Young caregivers. It is common for family members to participate in varied levels of caregiving tasks at home when one member is sick or disabled. Williams et. al. (2012) found that of the thirty-two teens in HD families that participated in their study, 77% described participating in caregiving activities. Williams et. al. (2012) found that of these young caregivers, they had a greater quality of relationship with the ill parent. The quality of the relationship between the ill parent and child was greater in quality in that the child had gained opportunity to spend more quality time with the parent, and had a sense of serving their parent. In providing care to their affected parent, some young caregivers experience emotional distress about their own awareness of having a 50/50 chance of inheriting the disease (Williams et. al., 2009). Keenan et. al. (2007) similarly found that although some young people in HD families avoid the family or family member who is affected with HD as a protective measure, many were participating in caregiving for their HD affected parent and household help for the family. Taking on a caregiving role for a parent while still a child can have lasting negative effects on the child's own development and health (Kavanaugh, Noh, & Studer, 2015). Negative effects on the child's development may include: loss of childhood, confusion in roles or role reversal, decline in academic performance or work performance.

Coping Strategies. When faced with difficult life experiences, people find ways to cope, which may lead to resilience. Some coping strategies are beneficial, some protective in nature, and some not very beneficial to one's well-being. Research by Williams, Driessnack, Jackson, Sparbel, Leserman, Thompson & Paulsen (2013) looked at coping strategies used by teens growing up in a family with HD and the effectiveness of the strategies used. They found that learning about their parent's disease, thinking and doing something that was not associated with their parent or their disease, and advocating for or helping their parent were rated the most common of coping strategies used and were rated to be the most helpful. Keeping emotions and feelings suppressed was a coping strategy that was common, but not found to be helpful. One of the strategies noted in the study was participating in HD specific support group and attending HD conferences. This was noted to be a helpful coping strategy, but one that they tended to underutilize (Williams et. al., 2013).

Mental Health

Mental health concerns in children of parent with a life-threatening illness.

Research has tried to understand the relationship between childhood experiences of a terminally ill parent and the mental health repercussions that follow. Christ and Christ (2006) suggest that children were found to have a higher risk of mental health symptoms given the challenges, loss and accompanied stressors associated with parental illness. Children that have a parent who is terminally ill were also found to come from families with greater strains on financial resources and potential for instability depending on the presence of co-current stressors on the family (Christ & Christ, 2006).

There are multiple stressors for children that have a parent with a life threatening illness. Adolescent girls who have a terminally ill parent were found to have higher rates of anxiety and depression than their female counterparts (Compas et. al., 1994). Christ & Christ (2006) found that children who were open in communicating their feelings and emotions, particularly to their surviving parent, showed better psychological outcomes.

Research has found that school age children with a terminally ill parent often struggle with being separated from the parent who is ill with fears that the parent will not be there when the child comes home. The anxiety and difficulty detaching from the parent is often amplified on Mondays after the weekend together, after summer break, or any extended periods of time together (Christ & Christ, 2006).

Conceptual Framework

Using the theoretical framework of attachment theory, the author will ask the research question, “Is there a relationship between gender and resiliency for children who were raised in a family with a parent who has HD?” The attachment theory will help frame the issues about a child’s resiliency.

Attachment Theory

Attachment theory is based on the collaborative works of John Bowlby, a child psychologist and Mary Salter Ainsworth, psychologist. Bowlby originally formulated the theory with his curiosity about maternal absence and personality development. Ainsworth supplemented the work of Bowlby through her work on security theories. The theory of attachment was able to be tested through Ainsworth’s methods and foundational concept of the attachment figure. The attachment figure is a child’s caregiver/parent which when

a secure base is established, allows the child to explore the world. The two began collaborating in the 1950s and continued research and deepening understanding of the theory through their lifetimes (Bretherton, 1992).

The theory focuses primarily on emotional bonds established or not established between children and their parents or caregivers. It is believed that emotional bonds that are established early on in childhood between a child and their caregiver assist the child in healthy development. When the adult caregiver provides a healthy sense of security for a child through providing and being responsive to the child's basic needs, a sense of security is developed. Once a secure attachment is established between the child and caregiver, the child is able to trust and depend on the caregiver. When a child and caregiver have a secure attachment, the child is then able to explore the world and develop healthy attachments to others later in life. (Harris & White, 2013). If secure attachment is not established, a child may experience separation anxiety if their attachment figure is not available to them in times of emotional distress or physical need (Bretherton, 1992).

Attachment theory was chosen as the conceptual framework for this project as it aligns with the significance of a child-parent relationship, and particularly when a parent is ill. Armistead, Klein and Forehand (1995) found that there is a very relevant connection between having a parent with a life-threatening illness and their child's ability to form attachments. Research by Schmidt, Nachtigall, Wuethrich-Martone and Strauss (2002) suggests that attachment has an impact on an individual's ability to cope and to be resilient, and will likely impact emotional and physical well-being when faced with a chronic illness.

Methodology

Research Purpose and Design

Schroder developed the Coping Competence Questionnaire (CCQ) in 2004, to measure resilience from learned helplessness for a person despite repeated stressors in his or her life. Schroder and Ollis (2012) argue that the CCQ fills a previous gap in measurement tools that explores “emotional well-being, stress resistance and mental health (p. 1).” The CCQ has been shown to be highly reliable in replication studies. The CCQ score will be reflected in this study to signify level of resilience of respondents (Schroder & Ollis, 2012).

This quantitative exploratory research study utilizes similar research methods. The researcher provided the participants with a link to the online survey. He or she was asked to complete the survey at a convenient time for them. The participant was asked to read the consent form and check a box to verify that they had read and agreed to participate. He or she was then asked to answer the 27-item questionnaire. CCQ was chosen for this study due to its accessibility, correlation to resiliency despite adversity and focus on emotional well-being.

The purpose of the study was to identify the relationship between gender and CCQ score, which will be utilized to signify resiliency. The research question was analyzed through the perspective of attachment theory. Consideration of gender of the parent who had HD, the gender of the adult raised in a family with parent who had HD, recognition of support system while growing up and outlets to talk about HD were examined in the data collection process.

Data Collection Instrument and Analysis

Schroder's (2004) Coping Competence Questionnaire (CCQ) was included to capture the resiliency or lack of resiliency among adults who grew up in a family with a parent who had HD. This 12-item scale was incorporated in the beginning of the measurement tool created for this research study. In order to interpret the CCQ score, all scores are reversed (1=6, 2=5, 3=4, 4=3, 5=2, 6=1) and added up together. The CCQ score will be reflected in this study to signify level of resilience of respondents (Schroder & Ollis, 2012). Schroder (2004) equates resilience to coping competence. Coping competence is the ability to persevere in the face of stressful life circumstances.

Schroder (2004) used the CCQ instrument with chronic disease populations to assess coping competence and to find predictors of depression. For the purpose of this study, the CCQ was utilized along with include other questions to better understand the relationship between gender and resiliency among children of a parent who has HD. A Likert scale was used, to be consistent with the CCQ format. The main variables being examined were the gender of the adult that was raised in a family with a parent who had HD, the gender of the parent who had HD and resiliency as defined by the CCQ results. Other questions that were on the survey include: Did you grow up in the United States?, How old are you currently?, How old were you when your mother or father began showing symptoms of HD?, How old were you when your parent was diagnosed with HD?, Did you live with your parent who had HD throughout your childhood?, Did you provide care for your parent who had HD (i.e. making meals, cleaning the house, buying groceries, providing hands on cares)?, Did you live with your non-affected parent as well as your parent with HD growing up?, Were there other adults in your household growing

up besides your parents growing up? Did you often have someone you could talk to about HD or your parent with HD?, If you did have someone you could talk to about HD and your parent with HD, what was your relationship to that person? A statistical analysis was done to explore a relationship between the variables.

Sampling Method and Data Collection Process

The researcher of this quantitative analysis employed judgment sampling. Judgment sampling is a “nonprobability sampling technique in which investigators use their judgment and prior knowledge to choose people for the sample who best serve the purposes of the study” (Monette, Sullivan, Dejong & Hilton, 2014, p. 498). The use of judgment sampling provided the researcher with a homogeneous group, which indicated more specifically whether gender impacted resilience among children who are raised in a family where one parent has HD (Monette et. al., 2014).

Recruitment of participants took place by the researcher with assistance of The Huntington’s Disease Society of America (HDSA), The Huntington’s Disease Youth Organization (HDYO), social media, and local individuals within the Minnesota Huntington’s disease community. Between fall of 2014 and spring of 2015, the survey was administered to 120 individuals who were raised in a family where one parent was affected with HD. Potential participants were asked if they would consider answering a questionnaire regarding their experience being raised in a family where one parent had HD. If the participant agreed, he or she clicked on the link provided, read the Letter of Informed Consent and clicked to agree or disagree to participate, and completed the self-administered questionnaire. All participants’ data was utilized in this quantified research study.

Measures for Protection of Human Subjects

A *Letter of Informed Consent* was designed to commit to ethical standards and ensure they were met in the administration and reporting process of the questionnaire results. The online survey format for collecting data allowed the participants to remain confidential. The voluntary nature of the study along with contact information was provided if any questions or problems occurred.

Confidentiality. All data that was collected for the purposes of this research study was not identifiable. The participant's identity was anonymous; identifying information was not asked of the participants. The participants were asked to click a box, rather than sign their name to consent to their participation in the study. There was no identification of the participants in any written reports or publications. This was crucial for the protection of the participants due to the sensitive nature of the study. The statistical analysis of the relationship between gender and resiliency among people raised in a family where one parent had HD was used solely for the purpose of this study. It will be available to the general public on the world wide web and will be published on St. Catherine's "SOPHIA" website.

Risks and benefits of being in the study. The study has minimal risks to participants but may bring up some difficult memories/feelings. Participants were asked to answer questions regarding their personal resilience, questions regarding their gender, questions that relate to their parent with HD and the support or lack of support they received raised in a family affected by HD. Participants had the choice to stop the questionnaire at any point with no repercussions. The study had no direct benefits to participants. Increased knowledge regarding the experience and impact of having a parent

with HD on children is significant for the field of social work and HD community. It gives a voice for the children in the family who are at times not well represented in research and clinical settings. This study may also inform social workers and other professionals working with families affected by HD.

RESULTS

Data was analyzed using Statistical Package for Social Sciences version 22.

Respondent demographic distribution was gathered to analyze frequencies and a cross-categorical comparisons were also used in a chi-square test.

Participant characteristics

A total of 120 participants completed the survey, all of whom self-identified as having a parent with Huntington's Disease. This was a large sample size. The majority of respondents (41.1%) were in the 26-35 age range with 26.2% reporting their age between 18-25, 9.3% aged 36-45, and 24.3% 46-79 years of age. Four respondents reported their age younger than 18, with the remainder confirming they are of adult age and old enough to consent to participation in the survey.

Of the respondents, 20 (18.7% of the sample) identified themselves as male, 87 (81.3% of the sample) identified themselves as female, one identified themselves as transgender. Due to the use of gender in terms of strictly male vs. female in this study and throughout the review of the literature, the transgender respondent's response was not used for the purpose of this study. Four respondents were under the age of 18 and their responses were also not included in the study as the required participant age was 18 years or older. Seven other responses were not used in the study as their responses were incomplete. 107 responses were analyzed for the purposes of the study. There were a relatively equal number of respondents that had a father with HD (n=55, 51.4%) versus a mother with HD (46.7%).

The age of the respondent when the parent who had HD began showing symptoms ranged from the respondent's age 1-50 years old. The majority of respondents

(64.5%) reported their parent with HD showing symptoms before the respondent was eighteen years old, 15.8% (n=17) reported being 21-30 years old, 7.5% (n=8) were 31-40 years old, 4.6% (n=5) were 41-50 years old, and one responded N/A to this question.

The number of respondents that grew up in the United States was seventy-two (67.3%), with 33 (30.8%) from outside the US. The study used an online format to make it accessible to participants around the world.

The distribution of selected sample demographics is displayed in Table 1.

TABLE 1
Sample Demographic Characteristics

Age			Age When Parent Began Showing Symptoms of HD			
	n	%	n	%	n	%
18-25	28	26.2	0-10	37	34.5	
26-35	44	41.1	11-20	35	32.7	
36-45	10	9.3	21-30	17	15.8	
46-79	26	24.3	31-40	8	7.5	
			41-50	5	4.6	
Respondent Gender	n	%	N/A	1	1	
Male	20	18.7				
Female	87	81.3				
			Grew up in U.S.		n	%
Parent with HD Gender	n	%	Yes	72	67.3	
Father	55	51.4	No	33	30.8	
Mother	50	46.7				

The relationships between variables were evaluated with chi-squared analyses. Significance was evaluated with the two-tailed probability level of .05. Results of cross-tabulations between age of respondent when their parent began showing symptoms of HD and resiliency, gender of respondent and resiliency, gender of respondent as it relates to gender of parent and resiliency are displayed in Table 2.

Age and Resiliency

Age of respondent when their parent began showing symptoms of HD was not statistically significant in relation to resiliency, through the CCQ score ($\chi^2(1632, N=107) = 1586.52, p=.786$). Due to the age at which most affected individuals develop symptoms of HD, the age of the respondent when their parent began showing symptoms was a fair representation of the population. 67.2% (n=72) of the sample was under the age of 20 when they remember beginning to see symptoms of HD in their affected parent. When considering the importance of parenting and attachment from childhood through teenage years, disruptions in attachment due to HD may be apparent for children being raised by one parent with HD. The parent with HD may show some impairment related to the stage of HD requiring care of the parent and they may be unable to provide adequate emotional and physical care for their child.

Gender and Resiliency

To determine the relationships between variables, data from several variables were cross tabulated and evaluated using chi-squared variables. Results of cross tabulations between the respondent's gender and parent with HD's gender and CCQ score to reflect resiliency are displayed in Table 2.

Respondent gender and resiliency (CCQ Score)

The gender of the respondent was significantly related to resiliency, through the CCQ score ($\chi^2(48, N=107) = 62.26, p=.081$). In this sample, there were more female respondents than male. Although there was a discrepancy between the gender of respondents, it appears that the male respondents (68.4%) had CCQ scores in the 51-71 range on the CCQ, where as the female counterparts had a range from low to high CCQ scores, with the majority (54.1%) of female respondents also in the 51-71 range. This high level of resilience may be attributed to the challenges and experiences that a child within an HD family endures.

Gender of Parent with HD, Gender of Respondent and its role in Resilience

The gender of the parent who has HD was significantly related to the resiliency of the respondents, through the CCQ score ($\chi^2(96, N=107)=160.34, p=.000$). It appears that this sample female respondents were less likely than their male counterparts to score high in resilience after being raised by a parent with HD, regardless of the parent's gender. This is explained in the literature, as girls were found over boys to experience more emotional distress when their mother had cancer (Compas et. al., 1994). There was a slight decrease in resilience score for the male respondents who had the same sex parent who was ill.

TABLE 2

Cross-Tabulation of Gender of Respondent and Gender of Parent with HD with
Resilience Indicator (CCQ Score)

	Gender of Respondent: Gender of Parent with HD							
	<u>Male: Father</u>		<u>Male: Mother</u>		<u>Female: Father</u>		<u>Female: Mother</u>	
	N	%	N	%	N	%	N	%
CCQ Score								
12-20	0	0	0	0	3	2.8	3	2.8
21-30	0	0	0	0	3	2.8	3	2.8
31-40	4	3.8	0	0	9	8.5	4	3.8
41-50	1	0.9	1	0.9	8	7.6	6	5.7
51-60	4	3.8	1	0.9	9	8.5	17	16.2
61-71	4	3.8	4	3.8	9	8.5	11	10.5

Caring for a Parent who has HD

Results indicate that for children in a family where one parent has HD, providing care for the parent with HD is prevalent (Table 3). 65.4% of respondents provided care for their parent who had HD (i.e. making meals, cleaning the house, buying groceries or providing hands on care). It is noteworthy that females of the sample were more likely to have provided care for their parent with HD than the males. 57.9% (n=11) of male respondents provided care for their parent with HD, while 42.1% (n=8) did not. 71.9% (n=59) of the female respondents reported providing care for their parent affected with HD, and 28% (n=23) did not. Since this was a young sample, the findings from this sample confirm that many children in a family with a parent who has HD provide care,

and more female children than male children. This issue of gender socialization, with females being more caregivers and males being more providers, is supported.

TABLE 3

Care for Parent and Support System

	Yes		No	
	N	%	N	%
Care for parent?				
Male	11	57.9	8	42.1
Female	59	23.0	23	28.0
Had Someone could talk to about HD?	43	40.2	60	56.1

Support System

A large number of respondents did not have someone that they could talk to about HD while growing up 56.1% (n=60). Of the total number of respondents, 40.2% (n=43) did have someone that they could talk to about HD. Of those that did have support, there was an option to name their support person. Those that responded to this question acknowledged family members (28), friend (22), a sibling (21), a HDSA specific social worker or counselor (8), teacher (1) and a specific support group (1) as being their support system. The literature supported children being a part of family discussions about HD and the importance of a child having at least one person to which they can turn to discuss their feelings and experiences of growing up in a family with a parent with HD (Fearnley, 2012; Keenan et al, 2007; Williams et. al., 2009).

DISCUSSION

The findings of this study confirmed and contradicted previous research that has been done regarding children raised in a family with HD and provides implications for social work practice and further research. The present study found that females are more likely than males to be connected through social media, likely to speak out and respond to inquiry about and speak to their experience being raised within a family where a parent had HD.

The majority of the respondents were in the age range of 26-35 with 41.1% (n=44). This is important as the format of the survey was online, and recruitment was done through social media. The age when respondents began seeing signs of HD in their parents was when the children were under 20 years old (67.2% or n=72.). The age when most people become diagnosed with HD is between 30 and 50 years old, which explains why the majority of their children would be 20 years of age or younger at onset of parent's disease.

Secure attachment occurs when a child finds security from their mother and primary caregiver (Bretherton, 1992). If the caregiver is affected with HD, there is the likelihood of attachment being disrupted due to the symptoms associated with the disease. Persons with HD may become egocentric, emotionally detached, delusional, paranoid, anxious and depressed due to the symptoms associated with the disease. When the parent begins showing symptoms of HD, the child may not be at the developmental level to be able to understand that the response of the parent may be due to symptoms of the disease and not a healthy parental response.

Male respondents in this sample were more likely to be resilient than female respondents, unless their father was the parent with HD, in which case the males were less resilient than females. Although, of the male respondents, they tended to be less resilient when it was their father who had HD rather than the mother. This is consistent with Compas' et. al. (1994) findings that the gender of the ill parent and the gender of the child impact the likelihood of resilience. Also consistent with Compas' et. al. (1994) female children were more likely to take on caregiver roles with their parent who had HD compared to male children.

The significant differences between gender of the child and the ill parent are important to acknowledge. As parents in a family with at risk children, the findings in this research may help guide how a parent of a particular gender will guide and support their child. Due to societal and subconscious treatment of boys and girls, attempts to teach and model social and emotional competency may be beneficial for a family facing HD.

Support System

It has been noted in the literature that having a support system and having at least one person to talk to about the parent with HD impacts the resilience of a child who is being raised in a family with HD. The sample reported a surprisingly low number 40.2% (n=43) of those who had someone to talk to about HD, and 56% (n=60) who did not have someone to talk to about HD. It is also important to note that 30.8% (n=33) of respondents were not raised in the United States. HD specific support options and opportunities may be limited or not accessible for those in certain locations in the United States and abroad. These findings may signify that there is a large gap in services for

children who have a parent with HD and their ability to access resources. Williams et. al. (2013) also found that there is a gap for teens accessing resources. The researchers found that even when opportunities are offered in proximity to the teens, they are not always accessing them (Williams et. al, 2013).

Implications for Social Work Practice

The information found in this study can be helpful for social workers working with a family affected by HD. Whether a county social worker, school social worker, HDSA social worker or Huntington's Disease Youth Organization (HDYO) social worker, it is important to acknowledge the role of the child(ren) in the family. Social workers or therapists can utilize this research and literature to inform their practice with families affected by HD . County social workers or child protection social workers could use this research to inform how children provide care in the family affected with HD as this may happen more than in a non-HD family. School social workers could use this research to support students in the school setting to establish support of teachers and friends and to help bridge the gap of knowledge and understanding of HD between family and school. Social workers working within the HD community or service providers could push for more child/young adult specific programming and funding to support such efforts. This may include professionally led youth groups, online support groups, summer camps specifically for children growing up in a family with HD, and youth social activities to meet other children in a non-threatening and fun setting.

Implications for Research

The results of this study have shown that there is a need for further support for children who are being raised in a family with HD, which presents a unique experience and must be assessed from the eyes of the child. Further research could explore how children want to be supported and educated about HD. Training mental health professionals outside of the HD community about HD and its effects on children within the family is important. Helping families access HD specific resources and professionals, as compared to non-HD specific providers, is critical. If respondents were aware of HD specific resources and professionals, did they utilize them or not and for what reasons?

With the current trend of connecting as using social media, this outlet offers anonymity and privacy when wanted for young people to access information and receive support. The traditional support group, where people meet face-to-face and talk about their feelings may actually occur on an internet interface between people. Examples may include through social media websites, phone conferencing programs, blogs or chatrooms. Rather than reaching out to young people through strictly in person educational and supportive opportunities, it may be worth the time and energy investing in alternative support avenues.

Strengths and Limitations of Methodology

There were strengths and limitations that surfaced while conducting this quantitative analysis. A strength of the research study is the reliability of the data collection tool (CCQ). The CCQ has been utilized in several research studies, which strengthen its scope of efficacy.

A strength and limitation of this study was the online format. It was able to reach many possible respondents inside and outside of the United States and allowed respondents to remain anonymous. Since the questionnaire refrained from asking for identifying information, respondents were more likely to respond openly and honestly. The study also may not have reached some that would have liked to participate, due to the fact that some may not have access to a computer or internet access.

A limitation with the survey being quantitative, rather than qualitative, was that because the researcher did not ask the questions in an interviewing or qualitative manner, some of the voice of the participants may not have been gained through this research study. It might be important to access the individual voices, as every person who is raised in a family affected with HD is different, has different support systems and will be impacted differently than other children who have a parent with HD.

The recruitment for this study was done through HDSA social workers, HDYO website, local support groups and the local HDSA Minnesota Chapter Facebook page. For someone who has a parent with HD, he or she may not be engaged with HDSA or HDYO. This limitation did not allow for those not considered to be well connected to participate and share their experiences through the completion of this survey. This may be important due to the fact, that if someone who has a parent with HD and they themselves are affected with the disease, they may not be as savvy online, may not be able to independently utilize computers or the internet, or may not be able to communicate the responses to the questionnaire anymore.

Conclusion

It is common belief that boys will be boys, and girls will be girls. A concern with this belief is that a boy or girl may not be able to grieve the loss experienced or express him or herself in a healthy manner, but rather in a way that is thought to be socially acceptable. As noted, with Huntington's disease there are ambiguous losses that occur as the individual with Huntington's disease is no longer able to participate in relationships in the same way as prior to HD, long before death. The proposed analysis sought to explore the correlation between gender and resiliency for children who were raised in family where one parent had HD. The hope of this study is to honor the experiences of all children who have a parent with HD, and to further understand and to positively impact their experience. For practitioners working with children with a family affected with HD, especially those under twenty years old, this study indicates that attachment theory and gender of parent affected are variables to consider when providing care.

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Appendix A

**THE EFFECTS OF GENDER ON RESILIENCY OF CHILDREN WHEN A
PARENT HAS HUNTINGTON'S DISEASE**

INFORMATION AND CONSENT FORM

Introduction:

You are invited to participate in a research study investigating gender and resiliency among adult children who were raised in a family where a parent had Huntington's Disease (HD). Jessica Marsolek, LSW, a graduate student at St. Catherine University under the supervision of Dr. Pa Der Vang, a faculty member in the School of Social Work, is conducting this study. You were selected as a possible participant in this research because you have been identified as an adult, and were raised in a family with one parent who was affected by HD. Please read this form and ask any questions before you agree to participate.

Background Information:

The purpose of this study is to further understand the experiences of children who are raised in a family where a parent has HD and the effects it has on the resiliency of the now adult children. A minimum of 40 people is expected to participate in this research.

Procedures:

If you decide to participate, you will be asked to consent to participating, as well as complete an anonymous online questionnaire. This study will take approximately fifteen minutes from start to finish.

Risks and Benefits of being in the study:

The study has minimal risks. One risk is that you will be asked to answer questions about your parent who had HD and the survey may bring up memories of your upbringing that might be upsetting to you.

There are no direct benefits for your participation in this research. The indirect benefits to participation are to provide further insight on children in a family affected by HD, where little exists.

Confidentiality:

Participant identity will remain anonymous. Any information obtained in connection with this research study that can be identified with you will be disclosed only with your permission; your results 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 locked file cabinet in my home and only Jessica Marsolek and Dr. Pa Der Vang having access to the records while I working on the project. After the data is analyzed by April 30, 2015 the original reports and identifying information that can be linked back to you will be destroyed.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University. You are free to stop participation in the study at any time without affecting these relationships.

New Information:

If during course of this research study we/I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings.

Contacts and questions:

If you have any questions, please feel free to contact me, Jessica Marsolek, LSW at 612-371-0904. You may ask questions now, or if you have any additional questions later, the faculty advisor, (Dr. Pa Der Vang, 651-690-8647) will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or 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. Please know that you may withdraw from the study at any time even after signing the form.

- I consent to participate in the study.
- I do not consent to participate in this study

Appendix B

Questionnaire- Online

Using A Google Form survey

How do you deal with stressful situations? Please read each of the following statements and select the one answer that most closely reflects your own reflections. There are no “right” or “wrong” answers.

Please use the following response options: 1= VERY UNcharacteristic of me, 2=RATHER UNcharacteristic of me, 3= SOMEWHAT UNcharacteristic of me, 4=SOMEWHAT characteristic of me, 5=RATHER characteristic of me, 6=VERY characteristic of me

1. I become easily discouraged by failures.
2. When my performance does not satisfy, I start to question my abilities.
3. I often feel unable to deal with problems.
4. Failures can shake my self-confidence for a long time.
5. When I am confronted with unusual demands, I feel helpless.
6. When I do not immediately succeed in a project, I quickly lose hope for a good outcome.
7. When I can't solve a task, I blame my lack of abilities.
8. When I fail at something, I tend to give up.
9. When my work is criticized, I feel depressed.
10. I often feel overpowered by obstacles or troubles.
11. I lose faith in myself when I make mistakes.

12. If I do not instantly succeed in a matter, I am at a loss.

Note: All items are reversed (1=6, 2=5, 3=4, 4=3, 5=2, 6=1) in order to interpret the sum score of these items as an indicator of “coping competence.”

13. What gender do you identify with? (Female, Male, Transgender or Other)

14. I grew up in a family where one parent had Huntington’s Disease (HD)? (Yes, No)

15. I grew up in the U.S. (Yes, No)

16. I grew up outside of the U.S. (Yes, No)

17. Which parent has/had HD? (Mother, Father)

18. How old are you currently? ---

19. How old were you when your mother or father started showing symptoms of HD?

20. How old were you when your parent was diagnosed with HD? --

21. I lived with my parent who had HD throughout my childhood? (True/False)

22. I provided care for my parent who had HD. (For example: making meals, cleaning the house, buying groceries, providing hands on care) (True/False)

23. I lived with a parent not affected by HD as well as my parent with HD growing up. (Yes, No)

24. There were other adults in my household growing up besides my parents growing up (Yes, No)

25. I often had someone I could talk to about HD. (True/False)

26. I had someone I could talk to about my parent who had HD. (True/False)

27. If you said true to either #23 or #24, what was your relationship with this person?

(Sibling, parent who did not have HD, other relative, friend, neighbor, teacher,
doctor, counselor, social worker, HD specific social worker)