A STUDY OF PATIENT SATISFACTION WITH THE HUNTINGTON DISEASE CLINIC AT THE UNIVERSITY OF PITTSBURGH MEDICAL CENTER BASED ON A MAILED SURVEY

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The Huntington Disease Clinic at the University of Pittsburgh Medical Center is dedicated to diagnosing, treating, and supporting patients that are at risk for Huntington disease (HD). This is a progressive disease that causes a multisystem breakdown of the body. Many of these patients grew up knowing the disease and waiting to begin exhibiting symptoms themselves. With the discovery of the gene that causes HD came a predictive gene test that can be performed on symptomatic people or people who are at risk. The test does not come without psychological impacts, though, which is why the clinic was created. The clinic includes a neurologist, a genetic counselor, and at least one social worker. It was formally created in 1999. Before 1999, an informal clinic with rotating doctors saw Huntington patients. It was the desire of the clinic to examine how the services they provide have changed since 1999 and whether they are meeting the patient's needs. This study will allow us to assess the response of the public to the clinic and make changes that will improve the service, thus lending public health relevance to the experience. A mailed satisfaction survey created from the questions of the staff was sent to all of the patients who had been through the HD clinic. Of the two hundred and two surveys sent, forty-one were returned and analyzed according to the logistics of the clinic, the medical staff, and the testing experience. It was found that active patients and patients in the support group were more likely than inactive patients and patients not attending the support group to respond to medical staffing questions. It was also found that age of the participants played a role in the satisfaction with the clinic logistics, while length between the time of testing and the time of filling out the survey played a role in the satisfaction with the physician in the clinic. A final finding of the study is that the genetic counselor and the social workers are generally well liked. Overall, the clinic is meeting the needs of the patient population they are serving.

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PREFACE

I would like to express my gratitude to Elizabeth Gettig, MS, CGC, my thesis committee chair, for her support, help, and guidance through this research. At no point in time was she afraid to get her hands dirty, and she had a personal touch to add to every HD patient that participated in this research. The experience taught me a lot about HD itself, as well as the hardships that go along with a devastating, inherited condition.

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I also want to thank my dad. Although he is no longer with us, he drives everything I do. He was a hard worker and a generous man. He placed his family before anything else in his life. He taught me the importance of education and the importance of loving what you do, as well as making a difference in the world. He also instilled in me the strength to pick up and rebuild when your world crumbles around you. My life would be very different if he were still here – and I would give anything and everything to have him back with us. However, I know that he's looking down on me and giving me the inner strength and quiet grace to go on with my life. I would not be where I am today without him.

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1.0 INTRODUCTION

Huntington Disease (HD) is a fairly rare disease in the general population with an incidence of 3 to 7 in 100,000. For those who live within families that have HD, however, it might not seem so rare. These patients and their families sometimes band together to care for each other and support each other through a person's illness. Unfortunately, this is not always enough for the patient. It is important that there is a knowledgeable medical team that can care for the patient and treat the symptoms of HD in the best way possible. It is also important to encourage the patients and their families to get support outside of the home and the family.

The HD clinic at UPMC strives to meet the needs of the patient population it serves. In this regard, it is important to assess, from time to time, how well they are meeting those needs. This document serves as a formal study of this assessment. The specific aims of this study are to: 1) Assess the patient's satisfaction with the information and care that they received while at the HD clinic, 2) Look at whether satisfaction levels changed between the time of the informal clinic and the time of the formal clinic, and 3) Examine whether or not there is a difference in satisfaction between the patient's who are affected and the patient's who are not affected.

2.0 REVIEW OF RELEVANT LITERATURE

2.1 HUNTINGTON DISEASE

2.1.1 General Information and Clinical Findings

Huntington disease (HD) was first described in 1872 by Dr. George Huntington as a late-onset, progressive neurodegenerative disorder with a hereditary basis (42). It presents with multiple motor, cognitive, and psychiatric or behavioral symptoms. This disease is considered to be panethnic; although, it is found more often in western Europeans than in other cultures. The prevalence of the disease in western Europeans is about 3 to 7 per 100,000, while the incidence in the Japanese is about 0.1 per 100,000. This difference in the prevalence reflects the variation in distribution of HD alleles and haplotypes that are predisposed to mutation (40). Both sexes are affected equally. The mean age of onset is 35 to 44 years, although there is a juvenile form of the disease, which can have an onset before the age of 21. This juvenile form accounts for about five percent of the population of HD patients in the United States. After the onset of symptoms, the survival time is between 15 and 20 years (21).

The progression through the disease is gradual. It begins with subtle changes in coordination, a depressed or irritable mood, minor involuntary movements, and difficulty with mental planning or remembering. At this beginning stage, most people are still able to work and continue their day-to-day activities. The disease will then progress to more involuntary movements and more dependency on others for help. Most patients will eventually have to give up their jobs. There can also be outbursts of aggressive behavior and a lack of social inhibition (21). As the disease progresses into the final stages, behavior problems decrease, but motor

disability becomes more pronounced and patients are often totally dependent on others. They can also be mute and incontinent. While many of these changes are occurring, with the exception of the final stages of the disease, patients are aware of what is occurring to them and to their bodies (44).

The clinical features of this disorder can vary between family members. The most recognizable feature of HD is chorea, or involuntary movement. In an adult, this may present as restlessness, fidgeting, or twitching. The chorea, alternatively, produces irregular movements of the limbs, face, or trunk through the skeletal muscles. Chorea is present in up to 90% of patients and can be made worse by stress (29). It is a continuing symptom when the patient is awake. As the disease progresses, rigidity often replaces the involuntary movement. This, again, will affect the limbs and trunk, and could be seen with spasticity, dystonia, and hyperreflexia (29). There are also problems that occur with voluntary movements. These usually occur early in the disease course, and may involve impaired coordination of movement, dysarthria, dysphagia, bradykinesia, oculomotor problems, and disruptions of gait and manual dexterity (42). There is also a parallel cognitive disruption that causes problems in planning, sequencing, and executing tasks, as mentioned previously. Both of these involuntary and voluntary motor disturbances can impair swallowing, speech, chewing, and ambulation (42). There can also be weight loss and sleep disturbances seen with the diagnosis of HD.

As mentioned, there are also disruptions of cognitive function in HD. In the early stages of HD, this can manifest as forgetfulness, visuospatial and visuomotor problems, deficiency in retrieving learned information, delayed mental processing, problems with concentration and attention leading to impaired verbal learning, and a gradual decline in the ability to communicate (56). The cognitive impairment is not as severe as what is experienced in Alzheimer's disease at these early stages; however in late stages, it has been reported that a patient may not recognize his/her own disabilities (21). Although it is unknown whether cognitive symptoms occur before physical symptoms, it is known that cognitive dysfunction progresses throughout the disease and eventually results in global dementia (21).

Psychiatric disturbances also play a large role in HD, but these disturbances are highly variable (56). There is often a change in the patient's personality, manifesting itself

through irritability, anxiety, apathy, social withdrawal, obsessiveness, aggression, and impulsivity. These changes can result in the occurrence of depression, mania, obsessive-compulsive disorder, affective psychosis, and schizophrenic psychosis, as well as sexual conduct and delusional thought disorders, and substance abuse problems (42; 21). The suicide rate in this disorder is about 12%, although it may be difficult to know whether this is due to the disorder itself or the devastation the person can feel at knowing what occurs during the course of HD (18).

Juvenile HD often presents before the age of 21. It has a clinical presentation that is distinct from adult-onset HD. Frequent falls, clumsiness, poor school performance, attention deficits and behavior problems are often noticed first. This then declines very rapidly to dysarthria, hyperreflexia, seizures, and severe mental deterioration. Chorea is often not observed in patients presenting in the first decade of life, instead they present with rigidity (21). In contrast, teenagers typically have chorea first (21).

2.1.2 Genetics of Huntington Disease

HD is related to a gene that was isolated after extensive linkage analysis and classical positional cloning (24). The gene was localized to chromosome 4p in 1983. This led to the molecular analysis of the DNA at the suspected region on chromosome 4; however, no chromosomal rearrangements were found. Investigators then examined all of the potential genes in the area by isolating them. The gene was finally isolated and identified in 1993 by the Huntington's Disease Collaborative Research Group (24). The gene maps to chromosome 4p16.3 and encodes a protein known as huntingtin. It spans 210 kilobases of DNA and contains 3,144 amino acids. The protein appears to be a DNA-binding protein, although the exact function of huntingtin is unknown (24). In a wild-type copy of this gene, at the 5 prime end, there is a region of about 21 trinucleotide CAG repeats. Each trinucleotide repeat codes for the amino acid glutamine (24). This repeat region of about 21 copies of glutamine can increase to about 40 to 100 copies of glutamine in the disease gene. This expansion of the CAG repeat can be seen to correlate with the age of onset and severity of disease. For example, a person with 100 copies of the CAG

repeat may manifest symptoms at the age of 3, while a person with 40 repeats may not manifest symptoms until the age of 50. This relation can only be used in general terms. For example, a person with 45 copies of the CAG repeat may manifest symptoms before, after, or at the same time as a person with 50 copies of the CAG repeat. Only a slight correlation exists; there is no way to accurately determine the age of symptom onset based on the exact number of repeats (24).

A normal number of repeats is any number below 26 CAG repeats. The region of 27 to 35 repeats is considered an intermediate region, in which an individual will probably not manifest symptoms of HD, but is at risk for a repeat expansion in the next generation. These are known as 'mutable normal alleles' (21). CAG repeats of 36 or more are considered to be mutant alleles. The range between 36 and 39 repeats is known as a reduced penetrant allele. A person with an allele repeat between these numbers may or may not develop HD in their lifetime (21). Because of this uncertainty, this range of alleles can be the most difficult diagnosis for a patient to deal with. It is recommended, in this situation, to rely on the family history to help interpret the results (21). Full penetrance alleles are considered to be 40 repeats or above. These repeats are predictive of the onset of HD at some point in the person's lifetime. The new mutation rate for HD is very low, being only one to three percent, and is rarely seen or reported in the literature (4).

Along with this region of expanded CAG repeats comes a phenomenon known as 'genetic anticipation'. This means that the number of CAG repeats can change from generation to generation. For example, a father may have 45 CAG repeats, but when his son or daughter is tested, they may be found to have 65 CAG repeats. This phenomenon is more commonly seen in paternal transmission of the gene, due to the instability of the CAG repeat during spermatogenesis (21). This increase of CAG repeats generally adds about 7 repeats or more to a sequence (21). Most often, this is how a juvenile onset of HD occurs – through paternal transmission of an expanded CAG repeat.

Huntington disease is passed through families in a dominant mode of transmission, so that a positive family history for the disease is seen in almost 100% of cases. These families have dealt with the diagnosis and the disease for many years, and often know what the signs are

and can identify them in others, and sometimes, in themselves. Each person with HD has a 50:50 chance of passing the HD gene on to their children. This gene can come from either the mother or the father. Nevertheless, as mentioned previously, expansions in the allele generally come from the paternal side. After the age of 20, the risk of having the HD allele decreases with each year that passes where the patient shows no symptoms of HD (56).

2.1.3 Diagnosis of Huntington Disease

A clinical diagnosis of HD is considered when there is progressive motor disability involving both involuntary and voluntary movements, cognitive changes including mental decline and changes in personality, and a positive family history showing an autosomal dominant inheritance pattern (21). Using these clinical criteria, the diagnosis rate is as high as 93% (21). Neurological and psychological exams can also be done to identify these clinical symptoms (56). There are several other tests that can be done to help investigate the diagnosis of HD. These include magnetic resonance imaging (MRI), x-ray computerized tomography (CT), positron-emission tomography (PET), and single photon emission computed tomography (SPECT). Although these tests do lend support to a diagnosis of HD, they are more often used to rule out other causes of neurologic dysfunction (21). MRI and CT scans can show the characteristic degeneration of the caudate and the putamen. A PET scan can show decreased glucose uptake in the brain often before tissue loss in the brain is evident (32). Finally, a SPECT scan can examine the profusion status of the basal ganglia in the brain (11).

Molecular testing for HD is used to clinically confirm a diagnosis or to test a patient presymptomatically. This testing can be particularly helpful in situations where patients have an unknown or negative family history, or when patients have a positive family history but atypical symptoms (56). Testing itself, on the other hand, is not enough to establish a diagnosis in the absence of a clinical exam (56). Targeted mutation analysis through PCR-based assays can detect most mutations up to about 115 CAG repeats. Southern blots can be used occasionally to identify large expansions that cannot be picked up on the PCR assay or for the confirmation of homozygous normal genotypes (21). The detection rate using these test methods is 100% and is

available clinically. Results that come back with a CAG length of less than 26 is considered 'negative'; a repeat length about 40 repeats is considered 'positive'. Inconclusive results fall in that mutable allele range of 27 to 39 repeats (56).

2.1.4 Presymptomatic Testing

Presymptomatic testing is performed using the same tests, but is generally done for different reasons. This type of testing is often offered to asymptomatic patients with a positive family history who want the information for planning their futures (42). This test is generally only done in the presence of extensive pre and post-test genetic counseling, psychosocial and neurological examinations, and post-test follow-ups. Interpretations of this testing are often analyzed through comparison to a family member who is affected and has been tested as well (42). This comparison allows the patients to be sure that negative results are true negatives. At-risk individuals are not tested when they are below the age of 18, based on an international consensus. At the age of 18, patients can go through all of the counseling and make the decision about testing for themselves. Due to the psychological impact that testing can have on an at-risk person, it is believed that the decision to test is a very personal choice that can only be undertaken by an adult (7). The only time this generally accepted guideline is ignored is when a young person is showing symptoms of HD, in which case the test is used to help make a clinical diagnosis (42).

2.1.5 Prenatal Testing

Prenatal testing can also be performed for HD, again using the DNA methods previously discussed or using linkage analysis. The DNA methods are used for babies that are at a 50% risk of having HD. Linkage analysis can be used for babies that are at 25% risk, in cases where the parent does not want to know if they carry the HD gene (56). The test is performed on DNA that is obtained from a chorionic villus sampling or an amniocentesis. Markers that travel with HD

through the family are looked for – if they are found, this puts the child at an increased risk for HD. If these markers are not found, the child is at a decreased risk for HD. Both procedures obtain DNA from the baby, which can then be grown in a lab and tested for an expanded region of the HD gene. Prenatal testing is a controversial issue in the medical community, though. This is because HD is an adult-onset disease, and some people are not comfortable performing abortions for diseases that will not present until later in life (56). In these cases, careful genetic counseling is required (56).

2.1.6 Management and Treatment

Evaluation at initial diagnosis can be rated on a scale that has been set forth by the Huntington disease study group in 1996. This baseline measurement can allow for measurements to follow the progression of the disease (27). At this time, there is no effective cure for HD, although research into a cure continues. Treatment is often palliative and consists of symptomatic treatment for the disorder. Medications change often due to the progression of symptoms and how well the medication controls the symptoms. Chorea is often helped by neuroleptics and benzodiazepines. Rigidity can be treated by anti-parkinsonian medications, yet L-dopa medications can increase chorea (21). Psychiatric disturbances may respond to psychotropic drugs or some types of anti-epileptic drugs (21). Clonazepam can be used for sleep disturbances (56). As the disease advances, supportive care for the patient may need to be put in place, including nursing, diet, special equipment, and eligibility for state and federal benefits. Therapies can help to monitor meals and train patients in safe and effective eating strategies to help improve swallowing problems that can occur in HD. Speech therapy, cognitive behavioral therapy, and relaxation therapy can also be helpful for patients and their families. Psychosocial support for making end of life decisions and care giving, as well as an emotional outlet, are all very important services to have in place as well.

2.1.7 Research

Genetic anticipation in trinucleotide repeat disorders has long been believed to be due to a DNA slippage model. Recent research, however, has begun to find that this is not actually what is occurring in the body that causes the repeat to increase in number. Instead, it is now believed that mistakes in mismatch repair genes (MMR) are causing the increase (20). The proposed new mechanism has to do with the fact that an increase in the number of repeats causes a small loop that should be recognized by the MMR proteins (19). It is believed that the MMR genes have mutations which cause the proteins not to recognize these small loops, so that the increase in repeat number is incorporated into the DNA (19). This new information and the information that is known about chemical and genetic modifiers leads to some new theories about reducing the number of repeats in an HD patient, and thus treating or curing the disease (19).

The function of the protein huntingtin is also under constant study. It has been found that huntingtin is responsible for the transport of brain-derived neurotrophic factor (BDNF) along the microtubules (16). BDNF protects striatal neurons in the brain. Downregulation of BDNF by mutant huntingtin is dependent on the length and levels of expression of the CAG repeats in cell cultures (8). "Decreased levels of this neurotrophin advance the onset of motor dysfunctions and produce more severe uncoordinated movements" (8). Specifically, the decreased levels of BDNF are known to cause degeneration of the striatal neurons in the brain, which are the most affected cells in HD (8). This also leads to the hope for treatment by exogenous BDNF (8).

2.2 ESTABLISHMENT OF THE HD CLINIC

2.2.1 Informal Clinic

In March of 1993, the HD gene was discovered. Elizabeth Gettig joined the Graduate School of Public Health in November of 1993. In the face of this knowledge, and in her new setting, Ms.

Gettig realized that she had a great opportunity to offer the laboratory testing, medical evaluation, genetic counseling, and psychiatric assessment of patients who were at risk for HD (17). The laboratory testing, which Ranjan Deka, PhD, offered from his research lab, was offered on-site. In 1997, the laboratory testing was transferred to Dr. Jeffery Kant's, lab, because his lab was CLIA certified. Before either Dr. Deka or Dr. Kant could offer the testing, both had to go through the Quality Assurance and Proficiency Testing Program. This was offered from the laboratory of Harry Orr, PhD at the University of Minnesota (17). Both Dr. Kant and Dr. Deka had laboratory scores of 100 on the testing, where the margin of error is plus or minus one CAG repeat (17).

David Kupfer, MD, the chair of Psychiatry, assigned the HD psychiatric assessments to a variety of psychiatrists. One of these psychiatrists included Mayada Akil, MD, who had been a fellow of Anne B. Young, MD at Massachusetts General Hospital. Massachusetts General Hospital is the center that identified the HD gene location on chromosome 4 via linakge and direct gene testing for the disease (17). The initial geneticist for the clinic was John J. Mulvihill, MD. When he left the University of Pittsburgh, Susan Bayser, MD, and Lydia Bayne, MD, both neurologists, provided the neurologic exams for the HD patients. Ms. Gettig saw patients in neurology along with the doctors and provided counseling at that time (17).

During the time that there was not a formal clinic, the location changed several times. The sites included Montifore Hospital, Western Psychiatric Insitute and Clinic (WPIC), the General Clinical Research Center, the Falk Clinic, and the Neuropsychiatry Clinic in Montifore (17). During all of this change, there was a lot of frustration felt by Ms. Gettig, as well as by the HD patients. The consensus was that a fixed location and a fixed medical team was needed to provide quality care (17).

In 1998, Ms. Gettig was on a sabbatical at the Center for Disease Control. While she was away, Erin O'Rourke, MS, CGC, took over the genetic counseling for the HD patients. She shared the same frustration that Ms. Gettig had with the current neuropsychiatry staff assigned to the HD service, and elected to stop testing in 1999 (17). Ms. Gettig returned in 2000 and proposed a one-year moratorium on testing until a formal HD clinic could be established (17). It took several meetings with Steven DeKosky, MD, the Chair of Neurology, before an agreement

was reached. It was decided that Ms. Gettig would provide genetic counseling at no charge, while Dr. Kant would charge for the laboratory testing. Additionally, Robert Moore, MD, would step in as the medical director of the HD clinic, and Peggy Polito, an MSW from the Western Pennsylvania Huntington Disease Society of America chapter, would provide social worker services. Ms. Polito is a social worker who has facilitated the local support group and oversees a helpline that is organized through the Western Pennsylvania Chapter. Ms. Polito, Ms. Gettig, and Dr. Moore were appointed Co-Directors of the HD Clinic (17). On February 6, 2001, a statement was released from the University of Pittsburgh about the creation of the formal clinic (See Appendix A).

2.2.2 Formal Clinic

The HD clinic now takes place on the second Wednesday of each month by Dr. Moore, Ms. Gettig, and Ms. Polito. Ms. Humbert, who is a part of the HD support group, and a genetic counseling student are also often in attendance during a patient's session. The clinic sees several types of patients. Some patients are coming for follow-up -- these patients have often either been tested and are positive, or they have not been tested but have obvious symptoms of HD. They undergo a neurological exam by Dr. Moore. The exam includes a variety of smaller tests for the patient, such as extraocular muscle testing, cerebellar function testing, balance testing, and observing for a gait disorder (25). These tasks allow Dr. Moore to assess whether there is a movement disorder and, if so, how advanced it is. At this time, Dr. Moore can prescribe any necessary medications that could help control the movement, or can refill any medication prescriptions that have expired. After the neurological exam, Dr. Moore and Ms. Gettig talk to the patients about their lives and any concerns that they may have (25). They discuss activities that the patient and the family are involved in, as well as jobs and living situations. They try to be a support system outside the patient's family, friends, and everyday life; a place that the patient can always turn to with questions and concerns.

Another group of patients seen at the HD clinic are patients who are getting tested for HD or who have been tested and are receiving results. Testing is not a decision that is made lightly

by these patients, and the initial visit is a time for everyone involved to discuss the various outcomes of the test and how it will affect the patient's life (18). Both a positive and a negative result in this case will invoke a response from the patient (18). If the result is positive, the person now knows that they will very likely develop symptoms of HD, and often they know the course of the disease well. Most of the time, these patients have grown up watching and taking care of family members with HD, and they know what the illness and ultimately, the death, involve (18). This in itself can be a difficult reality to deal with and even though these patients may have grown up knowing about this disease and expecting to get it, it is still a different reality to know that they have the disease as opposed to knowing that they might get it (18). On the other hand, getting a negative result can also be difficult news to hear. In these cases, many patients feel survivor guilt. They feel as though they should not be spared when others in their family are not (18). Sometimes, these people also feel that if they do not have the gene, it is more likely that someone else in their family will, even though the chance is 50:50 for anyone with a parent with HD (18). Also, it has been stated that people who get a negative result may have escaped the disease, but they are never free (18). These people still have to watch and take care of their family members with the disease.

Due to these various emotions, it is important to assess how the patient has been thinking about the testing, why they are being tested, why at this point in time, and how they might respond to the different test results. It is also important to be sure the patient has a support system in place for receiving the results. Once all of these factors have been assessed, the test is performed by sending the patients to the lab to have blood drawn (25). The patients are usually seen back at the next HD clinic meeting, which is about a month from the date that their blood is drawn. Between these two visits, Ms. Gettig asks the patients to think about how they want their results given to them. For example, if the result is over 40 repeats, the patient could ask her to say "the result is positive" or "the result is that you will get HD". In this way, the patient gets to pick the wording that Ms. Gettig and Dr. Moore use, so that there is no confusion about what the test results are and what they mean (18). The HD clinic tries to minimize confusion and maximize support, so the patients feel as though it is a valuable resource (25).

2.3 PATIENT SATISFACTION

2.3.1 Patient Satisfaction

Patient satisfaction is supposed to be a goal of health care, but many studies have been conducted to determine exactly what patient satisfaction is, and whether or not the concept even exists. The content of a patient survey can allow the collection of knowledge about the different levels of 'patient satisfaction', but it does not define what 'patient satisfaction' means (33). For the information to be of any use, one must define what is meant when they say that they are 'satisfied'. Also, to make any changes to the service that is being evaluated, one must try to understand what patients believe what they believe and how they arrived at this view (55).

Several theories have been set forth as to the origin of patient satisfaction. One theory set forth by Fishbein and Ajzen, states that expressions of satisfaction or dissatisfaction are a result of attitude (qtd. by 33). In this case, the measure of patient satisfaction is the positive attitude of the patient regarding their care (33). Another theory is that patient satisfaction has to do with the patient's expectations of an outcome and whether or not their expectations are met (Fishbein and Ajzen, qtd. by 33). People tend to evaluate events in reference to their moral standards or values. This can mean that culturally diverse groups of people may evaluate their visits differently, based on their unique group of values. A well-known example of this phenomenon is the idea that older people are generally more satisfied with health care than younger generations (28). Under the above, this could be because satisfaction comes from the ability of the heath care system to meet the patient's desires. Dissatisfaction, therefore, would result from the actual care that was delivered not measuring up to what the patient expected. Operating within these definitions, the younger population may be more dissatisfied with health care because they have higher expectations for what health care should be able to do for them, whereas older generations are more in awe of the possibilities of health care offers and are, therefore, more accepting of inadequacies (28).

After an extensive literature study on patient satisfaction with general practice care, Wensing, Grol, and Smits state that "Patient satisfaction can either 1) be a means of achieving

quality care, 2) be the outcome of the provided care, 3) be an indicator of those aspects of care that can be improved (in case of dissatisfaction), or 4) be used for evaluating the quality of care by means of previously determined target values" (52). Fitzpatrick offers four advantages to getting patient feedback for physicians and health care in general; understanding patients' experiences with treatment, identifying problems in health care, promoting cooperation with treatment, and evaluation of health care (qtd. in 45). Ten categories that appear to be included in most studies to evaluate patient satisfaction are accessibility/convenience, availability of resources, continuity of care, efficacy/outcomes of care, finances, humaneness, information gathering, information giving, pleasantness of surroundings, and quality/competence (34). Keeping all of these various categories in mind, one can start to construct a tool to measure patient satisfaction.

2.3.2 Problems with Patient Satisfaction

Probably the single most striking finding in patient satisfaction research conducted both here in the United States and in Britain is that all but a minority of respondents are generally satisfied (14). Conversely, considering the statistic that only four percent of customers with a problem complain, perhaps this finding is consistent with what should be expected in a patient satisfaction survey. A patient's views are treated as an attitude, which can be placed on a continuum of 'favorable' to 'unfavorable' with some degree of stability (14). Although there has been no long-term study of the stability of a patient's outlook of past medical experiences and how it affects the expectations of their future visits, it is generally believed that the judgment of satisfaction is determined by expectations that are based on past experiences of the patient (14).

Although it is helpful for a center to hear what they are doing well, it is often more beneficial for the center to hear about what they are not doing well. Dissatisfied customers often hold the information that is needed for a center to succeed (48). Understanding where and why this dissatisfaction occurs can lead to changes that can help to satisfy the present patient population, and hopefully, increase the future patient population (48).

The study conducted by Fitzpatrick and Hopkins looks at dissatisfaction and its origins, based on the theory that satisfaction is related to expectations (14). They examined patient satisfaction with a headache clinic, focusing mainly on the physician and less on other parts of the clinic. This decision was based on several reviews they had found previously. One mentioned that "…recipients of care are more concerned or dissatisfied with the manner and means of the process of health care delivery…than with the outcome of care or competencies of health care personnel…" (Kelman, qtd. by 14). Often, more critical responses are received on the manner, friendliness, and accessibility of care rather than the technical quality of care (14). For this reason, the satisfaction of a patient often relies on the physician's ability to treat his/her patient as a person and not as a case. Larsen and Rootman also put forth the theory that "the more a physician's role performance meets a patient's expectations, the more satisfied a patient will be with the physician's services" (qtd. by 14).

Upon completion of the study, Fitzpatrick and Hopkins examined reasons for the patient's dissatisfaction. One was inadequate investigation. Patients felt as though the physician had decided upon their diagnosis and treatment before he had obtained an adequate picture of their problem (14). Many of these patients made the comment that the physician had not asked enough questions, performed enough tests, or discussed the situation enough with the patient to fully understand the position of the patient. The second category was inadequate explanation. In this case, the patient felt as though the doctor did not give enough details as to what caused the situation or what the future implications of the diagnosis might be. Patients felt as though they left with the same amount of information they had when they arrived. The third category is inadequate treatment. In this situation, patients felt that they did not receive any treatment or that the treatment they did receive was inappropriate.

Overall, in this study, Fitzpatrick and Hopkins were struck by the differences between the patient's expectations of what should occur during the session and the dissatisfaction they expressed after seeing the physician. Although when questioned at the beginning, patients did not seem committed to very specific views of how the specialist should act, it is obvious from the comments made after the sessions that there were some expectations that were not met (14). They also found that, although some people believe that patient's do not comment on technical

aspects of the job, patients do actually base their opinions on what a doctor does (for example, testing) in relation to what they think a doctor should be doing (14).

These observations suggest that measuring patient satisfaction can be challenging. Other problems include the differences between other socioeconomic factors that may play a role in response bias. These can include age, gender, education, social class, income, marital status, and race (22). Often, physicians or centers feel as though the data is unreliable, or that being measured for the sake of being measured is not an adequate reason to perform such a study (43). Still, it is still important to survey a patient's opinion. As John Rollet, MD, a family physician in Chatham, Ill. says: "It shows your staff and community that you're interested in quality. It demonstrates you are looking for ways to improve" (qtd. by 53). A.C. Myers, the president of Myers Group, an Atlanta-based firm specializing in health care surveys and data analysis, says: "Recognize that this is just a snapshot of how your patients view you right now. Then take that feedback and organize improvement projects around those comments or scores" (qtd. by 53). "Whether you think patient satisfaction surveys are good or bad, the fact of the matter is that the marketplace you work in is demanding the data on patient satisfaction be used to empower consumers", states Lenoard Fromer, MD, a family physician in group practice in Santa Monica California, and a member of the AAFP's (American Association of Family Physicians) Commission on Health Care Services. "You have to put quality up front," he continues, "It must be the core of your practice's vision, values, and goals" (qtd. by 53).

Along with studies that have been performed on patient satisfaction within the context of physicians, there have also been many studies that have been done on patient satisfaction within the genetics field and, more specifically, with genetic counselors. It was found that recall after a genetic counseling session is relatively good, measuring between 65 to 86% overall (38). Being that imparting information is a goal of genetic counselors, this is an indication that this goal is being met. The recall has been found to be similar to the recall shown by other outpatients of hospitals (38). It was also found that information regarding family planning and family implications was remembered well, measuring 100% in the surveys (38). However, it was stated that patients tend to remember this information in a personal frame of reference. For example, many patients remember a recurrence risk as being "small" or "large" and do not remember the

exact number that was given (38). Research issues were recalled at a much lower rate, while technical issues were measured at 68-78% (38). Surprisingly, there was a lack of association between the information that is recalled and the satisfaction with the information given (38).

As with other patient satisfaction studies, it was found that patients reported greater satisfaction when all of their expectations were met (5; 37). A difference is that many patients do not understand the role of a genetic counselor and their place in a team of medical professionals (5; 35). Often, patients reported being surprised by the role of the genetic counselor, which they found to include emotional and psychological support, time, attention, ability to bring complex information down to their level, and being an advocate for the patient (5). Due to the fact that patients were often surprised at the extent of the genetic counselor's role, they reported a great deal of satisfaction with genetic counselors (5).

There are some parts of genetic counseling, however, that patients reported less satisfaction with. One is that many patients wanted the genetic counselor's opinion on their options (47). Another is that the mode of counseling (whether individual or group counseling) had an effect on whether a patient was satisfied (1). Other patients reported that they were hoping for something more definite from their counseling session, whether it was answers to questions or tests (35). Overall, however, most patients found the counseling process useful and reported a great deal of trust in their genetic counselors (5; 47).

2.3.3 Mailed Surveys

In most cases, decisions about the mode of testing, as well as the place, the time, and the answer format, are made by the researchers (51). There are only a few that allow the patients to be involved in the selection process for the aspects of care that are examined (51). There are different options that can be picked, such as an interview, a questionnaire given in person, and mailed questionnaires. It can be given before the visit, after the visit, or independent of the visit. They can also be given at the practice or health care center or at the patient's home. The questions can be in the form of satisfaction, opinion, and agreement/disagreement, while the answers can be dichotomy or scale ranges (51).

When constructing a survey, it is important to consider about the sample of people that should be studied. The method of surveying should attempt to ascertain the largest group possible to increase the chances of getting an adequate response number (53). Mailing surveys is often the best way to get feedback. This is because drop boxes are too often ignored, and because physically handing out the surveys can influence the results (53). Two examples of how this could occur is if a survey is supposed to be handed to every fifth patient, but one of the patients is angry, the staff may skip this patient, which would bias the results (53). It is also possible that the patient would be concerned about someone seeing their answers on a survey. Thirty to thirty-five percent is an expected response rate for a mailed survey (53). The more responses received, the more valid and reliable the results are likely to be (53).

2.3.4 Response Rates

Response rates to any kind of survey, especially a mailed survey, are a topic that is consistently being studied to identify the best way to get a high response rate. In one study, Asch *et al.* examined studies containing mailed surveys that had been published in medical journals. Using these studies, they found that there was a mean response rate of 59%, plus or minus 20%. They believe that higher response rates increase if subjects are offered monetary incentives, or if surveys are delivered by certified mail or non U.S. Postal Service Carriers (2). It has also been found that response rates can be improved by using stamped instead of metered return envelopes, by using different types of outgoing envelopes, or by prepaying financial incentives rather than paying subjects on completion (2).

It was also found that response rates were lower when the surveys were anonymous (2). Normally, anonymity would make the researcher think that the patients would be more comfortable when responding, thus increasing the response rate. Nonetheless, Asch *et al.* believe that patients are more comfortable not responding when they know that their failure to respond can remain undetected (2). Response rates are also affected in the way that they are calculated. The measure can include several different numbers. One can use the crude statistics, which divides the number of surveys received by the number of surveys sent (2). Then again,

this number includes the number of surveys that came back due to bad addresses, the number that can not be used for the subjects fail to meet the criteria, and the number considered unusable because they are not complete. Therefore, the true response rate can be difficult to accurately assess (2).

There have also been studies performed on the effect that a reminder has on mailed response rates. These studies, however, can have conflicting reports. In one study alone, Wensing *et al.* found that reminders affected response rates in various ways, depending on the country (51). In some countries, reminders made a large impact on response rate, increasing it by up to 20%. Yet, in other countries, there was no difference between the response rates of people who received reminders and people who did not receive reminders (51). Another study found that the rate of responses was the highest with a mailed survey, and that the differences between people responding with reminders and people responding without reminders was very small (51).

Response rates have also been studied in relation to the length of the questionnaire. Many general studies put forth the finding that shorter questionnaires are returned more often than long questionnaires. One study in particular looks at the response of physicians to a questionnaire of varying lengths. This study found that there was a decline in response with the increase in length of the questionnaire. The response rate for a questionnaire that was 849 words long was 60% (31). This decreased to a 16.7% response rate for questionnaires over 1,800 words in length (31). This finding was based on questionnaires that questioned the same information, just worded in different ways to make the length vary. The main finding of the study was that questionnaires that are under 1,000 words have a better response rate (59.4%) than questionnaires over 1,000 words (38.0%) (31).

A final component that researchers conducting a mailed questionnaire should consider is non-response bias. It has been found that older persons, women, people from upper social classes, and people with higher educations are more likely to return mailed surveys (qtd. by 12). Also, Ettter *et al.* found that people who respond are more likely to have a better health status and more positive health-related behaviors than people who do not respond (12). Therefore, being aware of who responds to the survey and who does not may also reflect on the study itself

and the center being evaluated. Etter *et al*. found that the people who responded and the people who did not respond were similar in age, sex, and total refundable health expenditures (12). On the other hand, they did find that people who did not respond had differed in their health expenditures from each other (12). For this reason, it is important to note that not all people who do not respond are the same. It may be useful to send refusals out with the surveys, so that one can better study the reasons for outright refusal as opposed to people who simply ignore the mailing (12).

2.3.5 Reasons to Conduct Patient Satisfaction Research

It has been found that only four percent of all customers with problems complain; the average person with a problem eventually tells nine other people; satisfied patients and customers tell five other people about their good treatment; and the cost of acquiring a new customer is usually five to seven times greater than retaining the current customers or patients (48). Consequently, as medical care is more carefully scrutinized by economic and clinical criteria, patient opinions begin to play a much larger role in the measure of satisfaction than ever before (45).

Considering this and all the previous literature reviewed on patient satisfaction, it seems appropriate to examine the satisfaction of the HD population. This can allow the clinic to improve problem areas to better deliver care to the HD population, as well as their families and friends.

3.0 METHODS AND PROCEDURES

3.1 METHODS

3.1.1 Participants

Any person who was or is a patient at the Huntington disease clinic was eligible to be included in the survey, unless there was a specific indication by the patient that they did not want to be contacted. For the most part, these patients are not contacted by the clinic unless they are active in attending the support group that is organized by the Western Pennsylvania chapter of the Huntington Disease Society of America. Then, the people active in the support group are generally only contacted through the support group. Contact information is kept in the clinic, available to the clinic directors, or in the patient's chart, which is kept in Ms. Gettig's locked office. At no time is any of this personal information given out to anyone not in contact with the clinic without the patient's direct permission.

3.1.2 Active vs. Inactive Patients

Patients who attended the clinic before it was formally organized are considered inactive patients. This will be anytime before January of 2001, when the clinic was appointed to the care of Dr. Moore, Ms. Gettig, and Ms. Polito. These patients received a survey that was printed on salmon colored paper. Patients who attended the clinic after January of 2001 will be considered active patients. These patients received a survey that was printed on blue paper (Appendix B).

The two different colors were used to allow the researcher to easily distinguish between the inactive and active patients. Within the survey itself, there is a question for the patients as to whether they consider themselves 'active' or 'inactive'. In this case, it refers to whether they are active with the support group. It does not have any bearing on whether they are considered active or inactive by the researchers.

3.1.3 Assessing the Patients' Responses

The purpose of this study is to assess the patient's satisfaction with the HD clinic. This study was funded by the Hungtington Disease Clinic, and received approval from the University of Pittsburgh Institutional Board of Review (IRB) in January of 2006. The specific aims of this study were to: 1) Assess the patient's satisfaction with the information and care that they received while at the HD clinic, 2) Look at whether satisfaction levels changed between the time of the informal clinic and the time of the formal clinic, and 3) Examine whether there is a difference in satisfaction between the patients who are affected and the patients who are not affected.

3.2 PROCEDURE

3.2.1 The Survey

The survey itself was adapted from a format that was developed by the Sickle Cell Disease Association of America, Inc. This survey was sent to the various staff members of the HD clinic for feedback, and questions were changed and added to the survey to adapt it to the patient population. The survey was evaluated several times before landing in the researcher's hands, and found to be somewhat long, confusing, and inconsistent (Appendix C). It was reformatted and reorganized to produce a more consistent pattern of questions. This survey had to be easy

enough that patients with some cognitive issues could still decipher the questions and answer them. After one more evaulation by the HD clinic staff, the survey was finalized.

Prior to mailing, the surveys were printed on two separate colors of paper – salmon and blue. As stated previously, each color indicated whether a patient seen before the formal HD clinic was formed or after it was already formed. A cover letter was also printed and signed by Ms. Gettig and myself stating the purpose of the research and giving an approximate date that the surveys should be returned. This letter was printed on University of Pittsburgh letterhead. A random number was assigned to each patient by Ms. Gettig and only she accessed the patient charts to complete this process. The cover letter and numbered survey were put into an envelope with a business reply envelope and postage already paid. These letters were then sent from the Department of Human Genetics.

As the surveys were returned, they were collected and the data put into an Excel spreadsheet. The spreadsheet was updated each time a new survey was received and the data entry was rechecked. Comments were also placed in a special section of the spreadsheet. All of the answers were kept with the patient's personal identification number at all times.

A second mailing was performed about two weeks after the first mailing was performed. At this time, all the surveys that had been come back as undeliverable were the focus of the second mailing. For the surveys that were returned, an attempt was made to identify the change of address or a phone number for the patients of the surveys that were returned. If a phone number was found, the patient was contacted to get the correct address. If a new address was obtained, a survey was sent to the new address. The social workers of the clinic helped with this process.

3.2.2 Statistical Analysis

All of the data were saved in the Excel spreadsheet before the analysis took place. Each specific aim was examined specifically, with tables being made to show the number of people who were satisfied with each factor on the survey and the number of people who were not. These tables were then used to create two by two tables. This information was put into Stata®, a statistical

package created by StataCorp LP. In Stata®, Fisher's exact test was performed on the two by two tables to examine whether the comparison was significant.

4.0 RESULTS

4.1.1 Survey Demographics

Two hundred and two surveys were mailed out to the participants of the study. Of these, forty-four surveys (21.7%) were returned as being undeliverable at the end of the study. Forty-one surveys (20.2%) were returned with answers. This leaves one hundred and seventeen surveys (57.9%) that were never returned. Not considering the surveys that had incorrect addresses, this is a return rate of 25.9%, which is only 5% less than what was expected.

Of the surveys that were returned, thirteen (31.7%) were from patients who are affected with HD and twenty-seven (65.9%) were from unaffected patients, with the last survey (2.4%) being from a patient with a repeat number in the intermediate region. For the purposes of the analysis, the person in the intermediate region will be considered affected, even though this is not technically a medically correct assumption.

Of the 70 surveys that were not returned, thirty-two (45.7%) were sent to patients who were affected with HD, and thirty-two (45.7%) to patients not affected with HD. The remaining 6 (8.7%) were also in the intermediate region.

4.1.2 Overall Survey Answers

The first section of the survey analyzes the demographic factors of the participants in the study. The first question asked the participants whether or not he/she was married. Of the forty-one participants, thirty-nine answered this question. Of these thirty-nine, twenty-four (61.5%) are married, seven (17.9%) are single, six (15.4%) are divorced, and two (5.1%) are widowed.

Twenty-four of the forty people who answered the next question have children, which is 60%, and therefore, 40% of these patients do not have children. Twenty-three (57.5%) of forty people are still working, while six (15%) are on disability. Twenty five percent of people (10) are not working and one person is retired (2.5%). The final question in this section is whether or not these patients participate in the HD support group. Twelve people in this population (30.7%) participate in the support group, while twenty-seven (69.2%) do not attend the support group.

Table 1: Rating program

Program	Excellent	Good	Fair	Poor	Not Answered	Total
Rate quality of service	26 (63.4%)	5 (12.2%)	3 (7.3%)	0 (0%)	7 (17.0%)	41
Patient got kind of service expected	27 (65.9%)	5 (12.2%)	3 (7.3%)	0 (0%)	6 (14.6%)	41
Program met patient's needs	24 (58.5%)	6 (14.6%)	3 (7.3%)	0 (0%)	8 (19.5%)	41
Would recommend program to family or friends	29 (70.7%)	4 (9.8%)	1 (2.4%)	1 (2.4%)	6 (14.6%)	41

The next section of questions is summarized in Table 1. These numbers represent the number of respondents. In this secttion, the participants were asked four questions which asked them to the clinic a rating. The ratings, in general, were four for excellent, three for good, two for fair, and one for poor. The overall ratings for the group from each question were excellent or good, however the occasional fair was also reported. There was one report of a poor outcome in the recommendation question. There were also some people who did not answer these questions – those numbers are also shown in the table.

In the questions following this first section, the participants were asked about their experience with some of the logistics of the appointment, including ease of making an appointment, ease of parking, helpfulness of the staff at the front desk, and the availability of the staff outside of the clinic. These questions were asked in a yes or no format, with space left for comments. Again, overall satisfaction was seen for each question, with a few people reporting that they were unsatisfied. There were also a number of people who did not answer the question. These results are summarized in table 2.

Table 2: Logistics of Staff

Logistics	Yes	No	No Answer
Appointment	35 (85.4%)	0 (0%)	6 (14.6%)
Parking	27 (65.9%)	4 (9.8%)	10 (24.4%)
Front Desk	32 (78.0%)	1 (2.4%)	8 (19.5%)
Availability of Staff	30 (73.2%)	0 (0%)	11 (26.8%)

The third section of questions had to deal with the co-Directors of the HD Clinic. These people were rated on their interactions with the patients during the session, as opposed to how the clinic actually runs. For example, the survey asked whether or not the patient was satisfied with Dr. Moore, and the patient could respond saying yes or no. Again, there was space here for the patient to make comments. This section of questioning also had an overall satisfaction; though, there was a higher level of satisfaction with the genetic counselor and the social workers than with the physician. These results can be seen in Table 3.

Table 3: Medical Staff

Medical Staff	Yes	No	N/A	No Answer
Dr. Moore	22 (53.7%)	5 (12.2%)	4 (9.8%)	10 (24.4%)
Betsy Gettig	34 (82.9%)	0 (0%)	0 (0%)	7 (17.1%)
Social Workers	33 (80.5%)	0 (0%)	0 (0%)	8 (19.5%)

The participants were also asked why they had decided to proceed with testing. They were given a list of choices, such as planning for the future, reproductive decisions, reducing uncertainty, and doctor recommendation. Each participant could check off as many reasons as they wished. Tables 4 and 5 show the break down of reasons given. Table four shows how often each answer was given – whether by itself or in a group. Table five shows the groups of answers that were chosen, and how often they were chosen together. Often, a specific group of answers was only chosen by one person or two people. It can be seen that planning for the future and reducing uncertainty were the most popular answers overall. These are closely followed by reproductive decisions and thought I had symptoms.

Reasons for testing:

1) Planning for the Future
2) Marital Decisions
3) Reproductive Decisions
4) Clarifying Risk for Children
5) Employment Decisions
6) Reducing Uncertainty
7) Doctor Recommendation
8) Thought I Had Symptoms
9) Other

Table 4: Summary of Answers

Reason	Number	Percentages
1 – Planning for Future	17	20%
6 – Reducing Uncertainty	16	19%
4 – Clarifying Risk for Children	13	15.5%
8 – Thought I Had Symptoms	13	15.5%
3 – Reproductive Decisions	7	8.3%
9 - Other	7	8.3%
7 – Doctor Recommendations	5	6%
No Answer	4	4.8%
5 – Employment Decisions	3	3.6%
2 – Marital Decisions	0	0%

Table 5: Groups of Reasons and how often they were seen

Reason	Number	Percentages
8 – Thought I Had Symptoms	5	13.9%
9 – Other	4	11.1%
4 – Clarifying Risk for Children	2	5.6%
6 – Reducing Uncertainty	2	5.6%
7 – Doctor Recommendations	2	5.6%
1, 4 – Planning for Future; Clarifying Risk for Children	2	5.6%
6, 8 – Reducing Uncertainty; Thought I Had Symptoms	2	5.6%
1, 3, 4, 6 – Planning for Future; Reproductive Decisions; Clarifying Risk for Children; Reducing Uncertainty	2	5.6%
1, 4, 6, 8 – Planning for Future; Clarifying Risk for Children; Reducing Uncertainty; Thought I had Symptoms	2	5.6%
1 – Planning for Future	1	2.7%
1, 3 – Planning for Future; Reproductive Decisions	1	2.7%
3, 4 – Reproductive Decisions; Clarifying Risk for Children	1	2.7%
7, 8 – Doctor Recommendations; Thought I had symptoms	1	2.7%

Table 5 continued

Reason	Number	Percentage
1, 3, 6 – Planning for the Future; Reproductive Decisions; Reducing Uncertainty	1	2.7%
1, 4, 6 – Planning for the Future; Clarifying Risk for Children; Reducing Uncertainty	1	2.7%
1, 4, 8 – Planning for the Future; Clarifying Risk for Children; Thought I had Symptoms	1	2.7%
1, 5, 6 – Planning for the Future; Employment Decisions; Reduce Uncertainty	1	2.7%
6, 7, 8 – Reduce Uncertainty; Doctor Recommendations; Thought I had Symptoms	1	2.7%
1, 3, 5, 6 – Planning for the Future; Reproductive Decisions; Employment Decisions; Reduce Uncertainty	1	2.7%
1, 3, 5, 8 – Planning for the Future; Reproductive Decisions; Employment Decisions; Thought I had Symptoms	1	2.7%
1, 3, 6, 9 – Planning for the Future; Reproductive Decisions; Reduce Uncertainty; Other	1	2.7%
1, 3, 4, 6, 9 – Planning for the Future; Reproductive Decisions; Clarifying Risk for Children; Reduce Uncertainty; Other	1	2.7%
1, 4, 6, 8, 9 – Planning for the Future; Clarifying Risk for Children; Reduce Uncertainty; Throught I had Symptoms; Other	1	2.7%
2 – Marital Decisions	0	0%
3 – Reproductive Decisions	0	0%
5 – Employment Decisions	0	0%

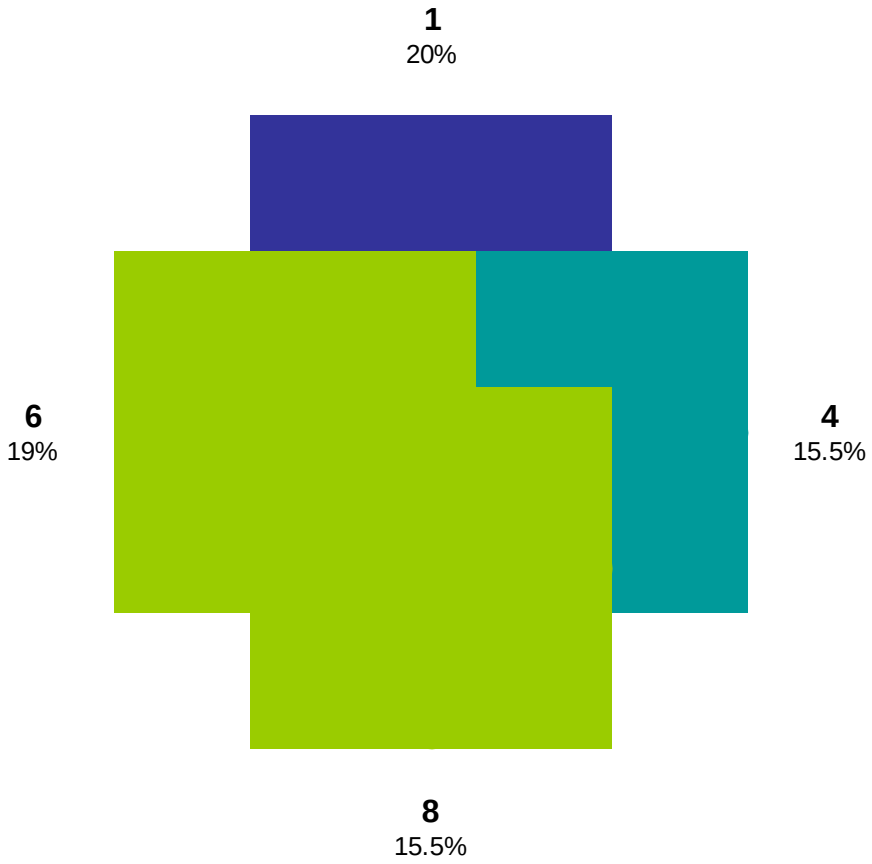

Figure 1: Top 4 Reasons for Testing and How Often They Overlap.

Bolded numbers are the Reason Number and numbers underneath are how often they were quoted. Clockwise: Reason 1 – Planning for the Future; Reason 4 – Clarifying Risk for Children; Reason 8 – Thought I had Symptoms; Reason 6 – Reducing Uncertainty.

Figure 5 shows the top four reasons that were quoted as reasons for testing. It also shows the overlap between each answer and the answers together in groups.

4.1.3 Affected versus Unaffected

Each factor was evaluated comparing affected participants responses with those from non-affected patients responses. This was done by counting the responses from each person and comparing them using Fisher's exact test. Whether the questions were answered was also evaluated, since only surveys that answered all of these questions could be used. Though answers varied on each question, the overall satisfaction between the two groups was not significantly different. These tables and p-values can be seen in Appendix D.1.

4.1.4 Active versus Inactive

Again, each question that was asked in the three different sections of the survey was analyzed separately to see whether people who attended the clinic before it was formally organized had a significantly different satisfaction rating. As seen before, there was no real difference between the two groups. The only category that approached significance was whether or not the participants answered the questions regarding the medical staff. It was found that the active participants were more inclined to answer the questions about the medical staff than the inactive participants. These data can be found in Appendix D.2.

4.1.5 Other Comparison Groups

The questions were also analyzed by looking at whether participants who attended the support group had a different view of the clinic than those who do not attend the HD support group. Again, there seemed to be no difference in the satisfaction rating, but there was a significant difference in the answering of the questions. People who attend the support group were more likely to answer the questions pertaining to the medical staff than the people who do not attend the support group. Also, people who attended the support group were more satisfied with Dr. Moore than people who do not attend the support group.

Another comparison that was performed was to determine whether married participants were more satisfied with their experience than people who were single, widowed, or divorced. There did not seem to be a difference in their satisfaction with the experience. Married people seemed to have a better experience with parking and also with having someone attend the disclosure session with them than the other groups, but this result did not approach significance. There was a significant difference as to which group was more likely to answer the questions about testing and the testing experience. Married participants were more likely to answer questions pertaining to the testing than people who were single, divorced, or widowed.

Another factor that was studied was the differences in satisfaction of patients who are over the age of 45 and participants under the age of 45. The age of 45 itself holds no medical significance; it was the median of our population. People over the age of 45 were more likely to fill out all of the questions pertaining to the logistics of the HD clinic, whereas people under the age of 45 were more likely to not complete these questions.

A final category that was evaluated is whether five years or more had passed since the participant had attended the HD clinic. Again, it was found that there was no major difference between the reported satisfaction of the two groups.

All of these tables and p-values can be found in Appendix D.

4.1.6 Response Verses Non-response

The final analysis examined the differences between the response rate and the non-response rate in terms of whether the subjects were affected with HD. It was found that unaffected people were more likely to respond to the survey than people who were affected with HD, as opposed to the non-response group which had equal numbers of affected patients and unaffected patients. These numbers did not fall into a significant range, though. Patients who fell into the intermediate region were also recorded. Although only one responded to the survey, and there were only seven total that were contacted. These numbers did not reach significance.

Table 6: Affected/Unaffected vs. Response/Non-response

	Affected	Unaffected	Intermediate Region
Response	14	27	1
Non-response	32	32	6

p-value: 0.140

5.0 DISCUSSION

5.1 DISCUSSION OF STATISTICS

This study was performed to allow the Huntington Disease Clinic of the University of Pittsburgh Medical Center to ascertain whether their patients are satisfied with the care provided by the clinic. It was also conducted to determine whether anything is lacking in the program that the patient population may desire. The data analysis suggests that the respondents were satisfied with their experience. Many of the patients that responded to the survey provided positive comments about services that the clinic does well.

5.1.1 Medical Staff

Two major factors that were rated as being excellent in all cases were the genetic counselor and the social workers. No one responded that they were unsatisfied with these health care professionals, and no one felt as though the counselor or the social workers were not available when the patient needed them. In fact, there were many good comments on the survey about these people. One person said that “Betsy and Peggy were great” and that they “…made it easier to accept the results (believe it or not)”. Many other people mentioned that “Betsy was wonderful” and that the social workers were “very compassionate”. In no cases were there any negative comments about this part of the medical staff.

Dr. Moore, on the other hand, had a more divided reaction. As can be seen in the tables, Dr. Moore did have some negative comments. Some of these comments include that he was not compassionate or humble, and that he was unapproachable and arrogant. However, if the overall

results are examined carefully, his approval rating overall is still relatively good. It is also important to note that the data on Dr. Moore is less complete, because he joined the clinic after both the social workers and the genetic counselor. He may have had a few negative comments, but he also had less people to evaluate him, which can make the numbers look more significant.

Another possible reason for the lower rating is due to the fact that he is the physician performing the exam. As mentioned in a previous study, patients often arrive at an appointment having some idea of what they expect in the visit (15). Dr. Moore's exam may appear rather simple to a non-medically trained individual. One may think that more complex testing would be necessary, such as an MRI or a CT scan, to look for more definite information. In spite of this, Dr. Moore does a short physical exam that gives him the medical information necessary to make a diagnosis. In fact, one patient did write that they "were not satisfied with the exam of balance and walking issues", while another patient commented that the doctor "only spent fifteen minutes" with them. Another patient stated that her cousin did not recognize the diagnosis of HD in herself (the cousin). The patient was surprised at this until after her own physical exam, which she considered minimal. Often, these patients have lived in HD families for a long time and have watched many people with the disease. It is logical that they would expect a much more in depth exam from a doctor, and could be confused and concerned when they do not receive what they anticipate.

As a medical staff, on the other hand, there were many positive comments from the participants of the survey. Many people described the members of the clinic as being supportive, kind, caring, and patient. They feel confident that the clinic and the patients are in good hands, and that the members of the clinic have the appropriate knowledge to be a good resource for the patients and their families.

5.1.2 Logistics

Overall, the logistics of the HD clinic did not seem to be the focus of this group of patients. The general feeling was that the front desk was good, and the availability of appointments was satisfactory as well. One person commented about the parking situation, but this has been

improved since the formal clinic was established. A few patients did comment on the cost of the clinic and the testing, which is something that was not formally asked on the survey. One patient mentioned that it is $100 per month to see a doctor to be told that they had HD plus the cost of testing that was paid out of pocket. Another patient mentioned that people on a fixed disability income can not afford to pay $400 for a doctor's visit, and suggested considering out of state patients for charity care. Cost can be a real issue for these patients, since genetic testing is expensive. These patients often choose to pay for testing out of pocket so as to avoid insurance discrimination. Still, it is something that the clinic could consider looking into, to see if there are ways to reduce the cost to the patients.

5.1.3 Significant Findings

Through the statistical analysis, it was found that people who are considered active (attending HD clinic after the formal clinic was organized) were more likely to answer questions regarding the medical staff than people who are considered inactive. As mentioned previously, only people who answered all of the questions about the medical staff (so the questions pertaining to Dr. Moore, Ms. Gettig, and the social workers) were analyzed. This may give a slightly biased result for this group of questions. The reason for this is because Dr. Moore did not start working with the clinic until 2001, when it was formally organized. Before this, patients had a different doctor. This would lead to the active participants being more likely to answer all three questions, as opposed to the participants who may have had a different doctor. This confounding factor may be the reason for this significance.

It was also found that people who attended the support group were more likely to answer the questions about the entire medical staff and were more likely to be satisfied with Dr. Moore, as opposed to people who do not attend the support group. It is possible that people who are likely to attend the support group are also more likely to have been tested recently and know Dr. Moore. This conclusion can be supported by the fact that, of the 13 people who reported being involved in the support group, only one is considered to be inactive (being tested before 1999). It is also possible that because these patients are in the support group, they are more invested in

the clinic as a whole. This is possibility is harder to assess because only 13 people reporting that they are involved in the support group which leaves 68% of the participants in the study who do not attend the support group, but still returned the survey.

Married participants were also found to be more likely to answer the questions about their testing experiences than participants who were single, divorced, or widowed. It is difficult to know whether this is an arbitrary result, or if there is something significant in this finding. It is possible that having a partner there during the testing process makes the experience easier. On the other hand, there are other participants who have brought other family members or friends who have been satisfied with their testing. There have also been couples that break up or get divorced due to a testing result. These reasons make it difficult to determine the implication of this finding.

Another result is that participants who are over the age of 45 were less likely to answer all of the questions about the logistics of the clinic. This seems to be in direct contrast with research that found that older people are more satisfied in general than younger people (31). Younger people may be able to remember these parts of the clinic better than older people. They may also be more inclined to give their opinion on the seemingly "smaller" parts of the clinic to express their overall satisfaction with the clinic. Then again, it is possible this is an arbitrary finding.

5.1.4 Conclusions

As mentioned previously, one of the problems with a survey is that each participant has a different number of years between when they were tested and when they completed the survey. This could introduce a recall bias into the sample. It is well known that people with HD have cognitive problems, and these participants may not remember exact details about the clinic (21). It is also known that, as time passes, exact details of an event may become harder to remember. This could result in a population that reports more satisfaction, due to the inability to remember details that they may have generated dissatisfaction.

The aforementioned results may not yield important implications. Most of the findings had to do with whether or not a population was more or less likely to answer a group of questions. While this may be an interesting finding, it could also simply be a coincidence related to the small sample size. Without doing a larger study or a more in depth investigation with the participants of this study, it is difficult to know whether this is something that is meaningful or if they are simply arbitrary findings. Also, another reason that these results may be found significant is due to a Type 1 error. This occurs if the null hypothesis is rejected when it is true. It is possible that if the p value was changed, the same conclusions would not be considered significant.

Another problem can be the population that did not respond to the survey. There are several reasons why people may not have responded to the HD survey. One is that people have relocated since the clinic last saw them. This reason could be supported by the number of surveys that were returned to the clinic. There could have been many more that were simply thrown away if the person no longer lived at the address or that may have gotten lost in the mail. Also, many of the surveys that were returned also had disconnected phone numbers. Secondly, many HD patients move close to a family member or friend, or even into a health care facility, so there are people nearby to care for them. A third reason that people may not have responded to the survey is due to the HD itself. Part of HD is not being motivated to begin a task (18). It is possible that many of the patients received the surveys and intended to fill them out, but never actually did so. People who were involved in the support group may have felt that the clinic staff are already aware of their opinions, since several staff members attend the support group meeting. Because they talk to the clinic personnel often, they may have felt as though it was not worth their time to fill out the survey. There may also be a population of patients who tested negative or who only attended the HD clinic once and feel as though they did not know enough to fill out the survey. Finally, there is always a population of people who do not want to fill out surveys for any reason.

There was limited data on the population of people that did not respond to the survey. There were some statistics that were carried out on this population in comparison to the participants of the study. The patients who did not respond did not prove to be overwhelmingly

affected or unaffected. There were a few who received an indeterminate result. These people may not have responded because of the difficulty of the test results. Yet, without more specific information, it is difficult to know why these patients chose not to respond.

5.1.5 Patient Suggestions

One section of the survey left open-ended questions for the patients to write both positive and negative comments about the HD clinic. The positive comments have already been addressed in the above sections. However, some patients did make suggestions for the clinic. A few patients mentioned that they would like more information on HD during the session. This includes information about the disease itself, as well as the impact of the results of the testing. One patient mentions that the impact of a positive result can never be over-stressed. Another patient states that the psychological impact of a result on the family members should be discussed in depth, as well as the impact on the patient. A third patient mentions that it is important to discuss that HD is not a "death sentence". In other words, HD is an incurable disease but there are medical interventions that can help improve the life of a person with HD and it is possible that a person with HD can die for reasons unrelated to this neurological condition.

Another comment that was covered by a few patients related to the disclosure session. One patient mentioned that it should be stressed that a support person should come to the disclosure session with the patient. Two other people commented on the people in attendance during the disclosure session. One specifically said that there were too many people in the room, while another mentioned that the student's presence surprised her. This patient said that advanced warning would have been nice. It was not the presence that bothered her as much as not being forewarned about their attendance. Another patient did not like the question that is posed before the disclosure; "are you sure you want the results?". This patient felt as though, since the results were negative, they should have been disclosed without this question asked beforehand. Lastly, one patient commented that more follow-up was needed from the clinic.

The majority of the patients in the survey reported that they trusted the results of the genetic testing. In fact, only one participant reported that they did *not* trust the results of the

genetic testing. Interestingly, several people commented that they had problems believing that they were not developing HD, even after the testing was negative. One patient stated that they "still occasionally get flashbacks of the fear of HD setting in when trip, etc". It may be difficult to accept a negative result when a patient has grown up waiting for the symptoms of HD to begin. However, it is intriguing that more people did not admit to lacking confidence in the test results when several made comments alluding to this later in the survey.

5.2 FUTURE STUDIES

There are several studies that could be pursued based on the findings. One possibility was briefly mentioned above, the option of a survey with open-ended questions. A study done previously showed that open ended questions allow people to express more dissatisfaction than surveys with more formal yes or no questions (44).

Another important facet of surveys is the response rate. The response rate to this survey was somewhat low compared to the expected 30%. On the other hand, this study did not perform a mass second mailing or a reminder mailing. It is possible that these tactics may have increased the response rate by a few percentage points. Another well studied means of improving response rates to a mailed survey is to offer an incentive (2). Whether this incentive is monetary, for example if it includes the participant being entered into a contest, people are generally more likely to respond to something when they get something in return.

Thirdly, as predicted, most of the surveys were returned with the patient being satisfied with their experiences. Although this lets the clinic know that they are doing well, it does not allow them to make the improvements that may benefit patients. It is often more helpful for patients to give suggestions or to let the clinic know why they are dissatisfied, so that the information can be used to make improvements. If this is something the clinic wants to pursue, it may be worth implementing a comment card system. The patients could receive a generic, short comment card before the session and could put it in a comment box on the way out of the

office. This approach, however, may share some similar problems that other research projects have found, such as the fact that people who are anonymous are less likely to respond to surveys, or the fact that a box seems cold and impersonal (2; 53).

Finally, it could be interesting to follow-up on the responses of the various groups of people in a larger sample. Studying whether marriage actually does make a difference in the satisfaction of testing, or if people attending the support group are more or less satisfied than other HD patients. Breaking down any of these factors could lead to some interesting conclusions if studied in a population that is large enough.

APPENDIX A – PRESS RELEASE

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FOR IMMEDIATE RELEASE

UNIVERSITY OF PITTSBURGH ESTABLISHES REGION'S FIRST HUNTINGTON'S DISEASE CLINIC

PITTSBURGH, February 6. 2001 -- The University of Pittsburgh has established the region's first Huntington's Disease Clinic that will offer genetic testing and counseling and conduct research on the disease that affects 30,000 Americans, with as many as 1,500 Western Pennsylvanians considered at risk for developing the disease. Thirty-five years ago, legendary American folk singer Woody Guthrie died at age 55 from HD which had been misdiagnosed for years.

The clinic, which will be housed in the Department of Neurology and affiliated with the Pittsburgh Institute for Neurological Disorders (PIND), will also offer diagnosis, medication for movement disorders, cognitive and psychiatric evaluation and treatment, physical, occupational and speech therapy, caregiver and social services and nutritional counseling.

Robert Moore, M.D., director of the clinic, is engaged in functional brain imaging studies of Parkinson disease and plans to use these techniques to study HD.

A fatal, degenerative brain disorder that primarily strikes men and women between the ages of 30 and 45, Huntington's disease causes involuntary movements, severe emotional disturbance and cognitive decline. As their bodies and minds deteriorate, affected individuals die from complications such as choking, infection or heart failure.

"Although researchers identified in 1993 the gene that causes this devastating disorder, there is still no cure. There is hope as genetic testing is available for family members of Huntington's patients, and only a handful of specialized clinics in the U.S. offer treatment and research," Dr. Moore said.

Affecting as many people as hemophilia, cystic fibrosis or muscular dystrophy, Huntington's disease has been diagnosed in 30,000 Americans, with another 150,000 at risk because family members have a 50 percent chance of inheriting Huntington's from an affected parent.

"The personal stories of HD families are compelling," said Elizabeth (Betsy) Gettig, M.S., director of the Genetic Counseling Program at the University of Pittsburgh's Graduate School of Public Health. "This is a complex disease involving movement, mood and heredity. Even if you escape the disease yourself, you clearly are not free as brothers and sisters, and other loved ones remain at risk for developing HD. The experience of living in an HD family is a powerful one."

Members of the University of Pittsburgh Huntington's Disease program plan to conduct research to better understand and find new treatments for the disease. This will include work on the basic mechanisms underlying the loss of nerve cells in HD and clinical research to help understand the manifestation of HD and develop new treatments.

The University of Pittsburgh has been one of the leading centers for research on late onset neurological diseases including Parkinson Disease and Alzheimer Disease for more than 20 years. Pitt investigators have contributed substantially to our understanding of these diseases and their treatment and look forward to applying this background to HD.

The Clinic will become a member of the Huntington's Study Group (HSG), a non-profit group of physicians and researchers in the U.S., Canada, Europe and Australia that conducts clinical trials of new treatments in HD.

"Our eventual goal is to be a designated Center of Excellence sponsored by the Huntington Disease Society of America," Dr. Moore said.

The clinic will work closely with the Western Pennsylvania Chapter of the Huntington Disease Society of America located in Pittsburgh.

APPENDIX B - SURVEY

UPMC HD Clinic Client Service Opinions

Please help us improve our program by answering some questions about the services you have received. We are interested in your honest opinions, whether they are positive or negative. Please answer all of the questions by circling the answer that best represents your thoughts. Thank you very much.

Personal
Are you: ____Married/Cohabitating Divorced Widowed Single

Do you have children? Yes No If yes, how many? _____

Are you employed? Yes No On Disability

Do you continue to attend (or go to) the HD clinic? Yes No If yes, how often? _____

Program – Choose the best number

1. How would you rate the quality of service you have received?

4	3	2	1
Excellent	Good	Fair	Poor

2. Did you get the kind of service you wanted?

4	3	2	1
Yes, definitely	Yes, generally	No, not really	No, definitely not

3. To what extent has our program met your needs?

4	3	2	1
Almost all of my needs have been met	Most of my needs have been met	Only a few of my needs have been met	None of my needs have been met

4. If a family member/friend were in need of similar help, would you recommend our program to him or her?

4	3	2	1
Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not

5. Did you find it easy to schedule an appointment? Yes No

6. Did you find it easy to find parking near the clinic? Yes No

7. Did you find the staff at the front desk helpful? Yes No

8. Did you find your meeting with the doctor (Dr. Robert Moore) helpful?

Yes No If no, why? _____

9. Did you find your meeting with the genetic counselor (Betsy Gettig) helpful?

Yes No If no, why? _____

10. Did you find your meeting with the social worker(s) (Peggy Polito/Peggy Humbert) helpful?
Yes No If no, why? _____

11. Outside of appointment times, did you find the doctor/counselor/social workers to be readily available? Yes No

If no, would you like them to be? Yes No

12. Do you have any other comments or suggestions for us to improve the clinic?

Testing and Support

If you had a gene test for HD, please complete the following- otherwise you have finished this survey. Thank you

Date of testing: ¬¬¬¬¬¬¬¬¬¬¬¬¬¬¬¬_____

13. Why did you decide to have genetic testing? (Check all that apply)
Planning for the Future Employment Decisions
Marital Decisions Reducing Uncertainty
Reproductive Decisions Doctor Recommendation
Clarifying Risk for Children Thought I had Symptoms
Other: _____
_____

14. Are you satisfied with your decision to be tested? Yes No

15. Do you trust the test result? Yes No

16. Now knowing the test result, would you have taken the test in the first place?

Yes No

17. Did you find the pre-test counseling session useful (review of risks, family history, discussion of how to prepare for both a positive or negative test)? Yes No

18. Did you find the disclosure (telling of the result) session useful? Yes No

19. Did you bring someone with you for the disclosure session? Yes No

Was that helpful? Yes No

20. Do you have suggestions that might help our program or people considering testing?

21. Please tell us one thing that went well with your testing experience and one thing we could improve:

APPENDIX C – OLD SURVEY

Today's Date: _____

Please fill out the following survey by circling the most accurate choice for each question. There are no right or wrong answers and you may have help from your caregiver.

Background

1. What is your current marital status? Married/cohabitating Single Divorced

2. Do you have biological children? No Yes If yes, how many_____

3. What is your current employment status? Employed Unemployed On Disability

4. Do you attend the HD Clinic? No Yes If yes, how often_____

Genetic Testing: Decision making and satisfaction with your visit

5. What were the reasons why you decided to have genetic testing?

	Not at all	Somewhat	A good deal	Very much
Planning for the future	1	2	3	4
Marital decisions	1	2	3	4
Reproductive decisions	1	2	3	4
Clarifying the risk for children	1	2	3	4
Employment decisions	1	2	3	4
Reducing uncertainty	1	2	3	4
A doctor recommended it	1	2	3	4
I thought I had symptoms	1	2	3	4
Other reason _____	1	2	3	4

6. Are you satisfied with your decision to take the test? Yes No

7. Do you trust the test result? Yes No

8. Now that you know the result, would you have taken the test in the first place? Yes No

Counseling

9. What is your opinion about the counseling you received? Please check the appropriate box.

Counseling sessions were easily comprehensible and I have NO improvements to suggest

Counseling sessions were easily comprehensible but I would like to suggest the changes concerning the counseling sessions _____

I did not like the counseling session, but have no suggestions

10. Did you consider the pre-test counseling session useful? Yes No

11. Did you consider the disclosure (telling of result) counseling session sufficient? Yes No

12. At what moment did you experience the greatest need for psychological support?

Decision making phase
Waiting for the result
Test disclosure session
Soon after the test disclosure
One month after the test disclosure

13. Did you seek psychological help/services after hearing the genetic test result? Yes No

14. How do you estimate the risk of other family members to be carrying the HD gene now that you have had counseling and have been tested?

Your mother:	no risk	small risk	moderate risk	great risk
Your father:	no risk	small risk	moderate risk	great risk
Your son(s):	no risk	small risk	moderate risk	great risk
Your daughter(s):	no risk	small risk	moderate risk	great risk
Your spouse:	no risk	small risk	moderate risk	great risk

15. Are you satisfied with your life in general at the moment?

Extremely satisfied
Rather satisfied
Neither satisfied nor unsatisfied
Rather unsatisfied
Extremely unsatisfied

Clinic staff and facility

16. How easy was scheduling an appointment?

Very easy and timely
I wanted to come in sooner
My ideal appointment time was unavailable

17. How easy was it to find parking near the location of your appointment?

Very easy
Reasonable for a hospital setting
Too difficult

18. How satisfied were you with the staff at the front desk?

Very satisfied

Satisfied
Unsatisfied
If unsatisfied please explain _____

19. At an HD meeting you meet with three professionals, a doctor (Dr. Robert Moore), a genetic counselor (Betsy Gettig), and at least one social worker (Peggy Polito and/or Peggy Humbert). We are interested in how satisfied you are with the HD team.

The doctor:	extremely satisfied	satisfied	unsatisfied
The genetic counselor:	extremely satisfied	satisfied	unsatisfied
The social worker(s):	extremely satisfied	satisfied	unsatisfied

If you would like to comment on one or more of the individuals mentioned above, please do so below:

_____
_____
_____
_____
_____
_____
_____
_____
_____

APPENDIX D - TABLES

D.1 AFFECTED VS. UNAFFECTED

Table 7: Logistics - Not Affected

Not Affected	Yes	No
Appt	14	0
Park	12	2
Desk	13	1
Answered	14	4

Table 8: Affected - Logistics

Affected	Yes	No
Appt	16	0
Park	14	2
Desk	16	0
Answered	16	6

Table 9: Appointment - Aff vs. Unaff

Appointment	Yes	No
Affected	16	0
Unaffected	14	0

Table 10: Parking - Aff vs. Unaff

Parking	Yes	No
Affected	14	2
Unaffected	12	2

p-value: 0.648

Table 11: Front Desk - Aff vs. Unaff

Front Desk	Yes	No
Affected	16	0
Unaffected	13	1

p-value: 0.467

Table 12: Answered - Aff vs. Unaff

Answered	Yes	No
Affected	16	6
Unaffected	14	4

p-value: 0.503

Table 13: Medical Staff - Not Affected

Not Affected	Yes	No
Moore	2	1
Gettig	10	0
SW	10	0
Answered	10	8

Table 14: Medical Staff - Affected

Affected	Yes	No
Moore	12	2
Gettig	14	0
SW	14	0
Answered	14	8

Table 15: Dr. Moore - Aff vs. Unaff

Dr. Moore	Yes	No
Affected	12	2
Unaffected	2	1

p-value: 0.465

Table 16: Ms. Gettig - Aff vs. Unaff

Ms. Gettig	Yes	No
Affected	14	0
Unaffected	10	0

Table 17: Social Workers - Aff vs. Unaff

Social Workers	Yes	No
Affected	14	0
Unaffected	10	0

Table 18: Questiions Answered - Aff vs. Unaff

Answered	Yes	No
Affected	14	8
Unaffected	10	8

p-value: 0.422

Table 19: Not Affected - Testing

Not Affected	Yes	No
Decision	15	0
Trust	15	0
Retest	14	1
Pre-counseling	14	1
Disclosure	13	2
Bring someone	12	3
Help	12	0
Answered	15	3

Table 20: Affected - Testing

Affected	Yes	No
Decision	13	1
Trust	14	0
Retest	13	1
Pre-counseling	13	1
Disclosure	13	1
Bring someone	11	3
Help	11	
Answered	14	8

Table 21: Decision to be tested - Aff vs. Unaff

Decision	Yes	No
Affected	13	1
Unaffected	15	0

p-value: 0.483

Table 22: Trust Test Results - Aff vs. Unaff

Trust	Yes	No
Affected	14	0
Unaffected	15	0

Table 23: Take Test Again - Aff vs. Unaff

Retest	Yes	No
Affected	13	1
Unaffected	14	1

p-value: 0.741

Table 24: Pre-counseling session helpful - Aff vs. Unaff

Pre-counseling	Yes	No
Affected	13	1
Unaffected	14	1

p-value: 0.741

Table 25: Disclosure Staff Helpful - Aff vs. Unaff

Disclosure	Yes	No
Affected	13	1
Unaffected	13	2

p-value: 0.235

Table 26: Bring Someone to the Session - Aff vs. Unaff

Bring Someone	Yes	No
Affected	11	3
Unaffected	12	3

p-value: 0.639

Table 27: Questions Answered - Aff vs. Unaff

Answered	Yes	No
Affected	14	8
Unaffected	15	3

p-value: 0.151

D.2 ACTIVE VS. INACTIVE

Table 28: Logistics - Active

Active	Yes	No
Appt	17	0
Park	14	3
Desk	17	0
Answered	17	5

Table 29: Logistics - Inactive

Inactive	Yes	No
Appt	13	0
Park	12	1
Desk	12	1
Answered	13	6

Table 30: Appointment - Act vs. Inact

Appointment	Yes	No
Active	17	0
Inactive	13	0

Table 31: Parking - Act vs. Inact

Parking	Yes	No
Active	14	3
Inactive	12	1

p-value: 0.409

Table 32: Front Desk - Act vs. Inact

Front Desk	Yes	No
Active	17	0
Inactive	12	1

p-value: 0.565

Table 33: Questions Answered - Act vs. Inact

Answered	Yes	No
Active	17	5
Inactive	13	6

p-value: 0.387

Table 34: Medical Staff - Active

Active	Yes	No
Moore	14	2
Gettig	16	0
SW	16	0
Answered	16	5

Table 35: Medical Staff - Inactive

Inactive	Yes	No
Moore	8	1
Gettig	9	0
SW	9	0
Answered	9	10

Table 36: Dr. Moore - Act vs. Inact

Dr. Moore	Yes	No
Active	14	2
Inactive	8	1

p-value: 0.713

Table 37: Ms. Gettig - Act vs. Inact

Ms. Gettig	Yes	No
Active	16	0
Inactive	9	0

Table 38: Social Workers - Act vs. Inact

Social Workers	Yes	No
Active	16	0
Inactive	9	0

Table 39: Questions Answered - Act vs. Inact

Answered	Yes	No
Active	16	5
Inactive	9	10

p-value: 0.060

Table 40: Testing - Active

Active	Yes	No
Decision	16	0
Trust	16	0
Retest	15	1
Pre-counseling	15	1
Disclosure	15	1
Bring someone	14	2
Help	13	0
Answered	16	7

Table 41: Testing - Inactive

Inactive	Yes	No
Decision	12	1
Trust	13	0
Retest	12	1
Pre-counseling	12	1
Disclosure	11	2
Bring someone	9	3
Help	9	0
Answered	13	6

Table 42: Decision - Act vs. Inact

Decision	Yes	No
Active	16	0
Inactive	12	1

p-value: 0.448

Table 43: Trust Result - Act vs. Inact

Trust	Yes	No
Active	16	0
Inactive	13	0

Table 44: Retest - Act vs. Inact

Retest	Yes	No
Active	15	1
Inactive	12	1

p-value: 0.704

Table 45: Pre-counseling Session - Act vs. Inact

Pre-counseling	Yes	No
Active	15	1
Inactive	12	1

p-value: 0.704

Table 46: Disclosure - Act vs. Inact

Disclosure	Yes	No
Active	15	1
Inactive	11	2

p-value: 0.420

Table 47: Bring Someone - Act vs. Inact

Bring Someone	Yes	No
Active	14	2
Inactive	9	3

p-value: 0.357

Table 48: Questions Answered - Act vs. Inact

Answered	Yes	No
Active	16	7
Inactive	13	6

p-value: 0.599

D.3 ATTEND SUPPORT GROUP VS. NOT ATTENDING SUPPORT GROUP

Table 49: Attend Support Group - Logistics

Support Group	Yes	No
Appt	9	0
Park	8	1
Desk	9	0
Answered	9	3

Table 50: Did Not Attend Support Group - Logistics

No SG	Yes	No
Appt	20	0
Park	17	3
Desk	19	1
Answered	20	7

Table 51: Appointment - ASG vs. NASG

Appointment	Yes	No
ASG	9	0
NASG	20	0

Table 52: Parking - ASG vs. NASG

Parking	Yes	No
ASG	8	1
NASG	17	3

p-value: 0.636

Table 53: Front Desk - ASG vs. NASG

Front Desk	Yes	No
ASG	9	0
NASG	19	1

p-value: 0.690

Table 54: Questions Answered - ASG vs. NASG

Answered	Yes	No
ASG	9	3
NASG	20	7

Table 55: Support Group - Medical Staff

SG	Yes	No
Moore	11	0
Gettig	11	0
SW	11	0
Answered	11	1

Table 56: Does Not Attend Support Group - Medical Staff

No SG	Yes	No
Moore	3	3
Gettig	14	0
SW	14	0
Answered	14	13

Table 57: Dr. Moore - ASG vs. NASG

Dr. Moore	Yes	No
ASG	11	0
NASG	3	3

p-value: 0.029

Table 58: Ms. Gettig - asg vs. nasg

Ms. Gettig	Yes	No
ASG	11	0
NASG	14	0

Table 59: Social Workers - asg vs. nasg

Social Workers	Yes	No
ASG	11	0
NASG	14	0

Table 60: Questions answered - asg vs. nasg

Answers	Yes	No
ASG	11	1
NASG	14	13

p-value: 0.017

Table 61: ASG - Testing

SG	Yes	No
Decision	8	0
Trust	8	0
Retest	7	1
Pre-counseling	8	0
Disclosure	8	0
Bring someone	8	0
Help	8	0
Answered	8	4

Table 62: NASG - Testing

No SG	Yes	No
Decision	20	1
Trust	21	0
Retest	20	1
Pre-counseling	20	1
Disclosure	18	3
Bring someone	16	5
Help	14	
Answered	21	7

Table 63: Decision - asg vs. nasg

Decision	Yes	No
ASG	8	0
NASG	20	1

p-value: 0.724

Table 64: Trust - asg vs. nasg

Trust	Yes	No
ASG	8	0
NASG	21	0

Table 65: Retest - asg vs. nasg

Retest	Yes	No
ASG	7	1
NASG	20	1

p-value: 0.483

Table 66: pre-counseling - asg vs. nasg

Pre-counseling	Yes	No
ASG	8	0
NASG	20	1

p-value: 0.724

Table 67: Disclosure - asg vs. nasg

Disclosure	Yes	No
ASG	8	0
NASG	18	3

p-value: 0.364

Table 68: Bring Someone - asg vs. nasg

Bring Someone	Yes	No
ASG	8	0
NASG	16	5

p-value: 0.171

Table 69: Answers - asg vs. nasg

Answers	Yes	No
ASG	8	4
NASG	21	7

p-value: 0.430

D.4 MARRIED VS OTHER

Table 70: Married - Logistics

Married	Yes	No
Appt	18	0
Park	14	4
Desk	18	0
Answered	18	6

Table 71: Single, Widowed, Divorced (Other) - Logistics

Other	Yes	No
Appt	12	0
Park	12	0
Desk	11	1
Answered	12	4

Table 72: Appointment - mar vs other

Appointment	Yes	No
Married	18	0
Other	12	0

Table 73: Parking - mar vs. other

Parking	Yes	No
Married	14	4
Other	12	0

p-value: 0.112

Table 74: Front Desk - mar vs. other

Front Desk	Yes	No
Married	18	0
Other	11	1

p-value: 0.400

Table 75: Answers - mar vs. other

Answers	Yes	No
Married	18	6
Other	12	4

p-value: 0.640

Table 76: Married - Med staff

Married	Yes	No
Moore	6	2
Gettig	14	0
SW	14	0
Answered	14	9

Table 77: Other - Med staff

Other	Yes	No
Moore	8	1
Gettig	10	0
SW	10	0
Answered	10	6

Table 78: Dr. Moore - mar vs. other

Dr. Moore	Yes	No
Married	6	2
Other	8	1

p-value: 0.453

Table 79: Ms. Gettig - mar vs. other

Ms. Gettig	Yes	No
Married	14	0
Other	10	0

Table 80: Social Workers - mar vs. other

Social Workers	Yes	No
Married	14	0
Other	10	0

Table 81: Answers - mar vs. other

Answers	Yes	No
Married	14	9
Other	10	6

p-value: 0.593

Table 82: Married - Testing

Married	Yes	No
Decision	20	0
Trust	20	0
Retest	19	1
Pre-counseling	19	1
Disclosure	18	2
Bring someone	18	2
Help	18	
Answered	20	4

Table 83: Other - Testing

Other	Yes	No
Decision	8	0
Trust	8	0
Retest	7	1
Pre-counseling	8	0
Disclosure	8	0
Bring someone	5	3
Help	6	
Answered	8	8

Table 84: Decision - mar vs. other

Decision	Yes	No
Married	20	0
Other	8	0

Table 85: Trust - mar vs. other

Trust	Yes	No
Married	20	0
Other	8	0

Table 86: Retest - mar vs. other

Retest	Yes	No
Married	19	1
Other	7	1

p-value: 0.497

Table 87: Pre-counseling - mar vs. other

Pre-counseling	Yes	No
Married	19	1
Other	8	0

p-value: 0.714

Table 88: Disclosure - mar vs. other

Disclosure	Yes	No
Married	18	2
Other	8	0

p-value: 0.503

Table 89: Bring Someone - mar vs. other

Bring Someone	Yes	No
Married	18	2
Other	5	3

p-value: 0.123

Table 90: Answered - mar vs. other

Answered	Yes	No
Married	20	4
Other	8	8

p-value: 0.029

D.5 OVER AGE 45 VS UNDER AGE 45

Table 91: Greater than 45 (older) - Logistics

>45	Yes	No
Appt	9	0
Park	8	1
Desk	8	1
Answered	9	7

Table 92: Less than 45 (younger) - logistics

<45	Yes	No
Appt	17	0
Park	14	3
Desk	17	0
Answered	17	3

Table 93: Appt - older vs. younger

Appointment	Yes	No
Older	9	0
Younger	17	0

Table 94: Parking - older vs. younger

Parking	Yes	No
Older	8	1
Younger	14	3

p-value: 0.569

Table 95: Front Desk - older vs. younger

Front Desk	Yes	No
Older	8	1
Younger	17	0

p-value: 0.346

Table 96: Answered - older vs. younger

Answered	Yes	No
Older	9	7
Younger	17	3

p-value: 0.062

Table 97: Older - Med.staff

>45	Yes	No
Moore	8	1
Gettig	10	0
SW	10	0
Answered	10	6

Table 98: Younger Med. Staff

<45	Yes	No
Moore	6	2
Gettig	12	0
SW	12	0
Answered	12	9

Table 99: Dr. Moore - older vs. younger

Dr. Moore	Yes	No
Older	8	1
Younger	6	2

p-value: 0.453

Table 100: Ms. Getting - older vs. younger

Ms. Gettig	Yes	No
Older	10	0
Younger	12	0

Table 101: Social Workers - older vs. younger

Social Workers	Yes	No
Older	10	0
Younger	12	0

Table 102: Answers - older vs. younger

Answers	Yes	No
Older	10	6
Younger	12	9

p-value: 0.505

Table 103: Older - Testing

>45	Yes	No
Decision	10	1
Trust	11	0
Retest	9	2
Pre-counseling	10	1
Disclosure	10	1
Bring someone	9	2
Help	9	
Answered	11	5

Table 104: Younger - Testing

<45	Yes	No
Decision	13	0
Trust	13	0
Retest	13	0
Pre-counseling	13	0
Disclosure	13	0
Bring someone	10	3
Help	10	
Answered	13	8

Table 105: Decision - older vs. younger

Decision	Yes	No
Older	10	1
Younger	13	0

p-value: 0.458

Table 106: Trust - older vs. younger

Trust	Yes	No
Older	11	0
Younger	13	0

Table 107: Retest - older vs. younger

Retest	Yes	No
Older	9	2
Younger	13	0

p-value: 0.199

Table 108: Pre-counseling - older vs. younger

Pre-counseling	Yes	No
Older	10	1
Younger	13	0

p-value: 0.458

Table 109: Disclosure - older vs. younger

Disclosure	Yes	No
Older	10	1
Younger	13	0

p-value: 0.458

Table 110: Bring Someone - older vs. younger

Bring Someone	Yes	No
Older	9	2
Younger	10	3

p-value: 0.585

Table 111: Answered - older vs. younger

Answered	Yes	No
Older	11	5
Younger	13	8

p-value: 0.468

D.6 MORE THAN FIVE YEARS BETWEEN TESTING AND FILLING OUT THE SURVEY VS. LESS THAN FIVE YEARS

Table 112: Greater than 5 years - Logistics

>=5	Yes	No
Appt	9	0
Park	8	1
Desk	9	0
Answered	9	6

Table 113: Less than 5 years - Logistics

<5	Yes	No
Appt	17	0
Park	14	3
Desk	16	1
Answered	17	4

Table 114: Appointment - more than 5 vs. less than 5

Appointment	Yes	No
More than 5	9	0
Less than 5	17	0

Table 115: Parking - more than 5 vs less than 5

Parking	Yes	No
More than 5	8	1
Less than 5	14	3

p-value: 0.569

Table 116: Front Desk - more than 5 vs. less than 5

Front Desk	Yes	No
More than 5	9	0
Less than 5	16	1

p-value: 0.654

Table 117: Answered - more than 5 vs. less than 5

Answered	Yes	No
More than 5	9	6
Less than 5	17	4

p-value: 0.157

Table 118: More than 5 - med. staff

>=5	Yes	No
Moore	1	1
Gettig	7	0
SW	7	0
Answered	7	8

Table 119: Less than 5 - Med. staff

<5	Yes	No
Moore	13	2
Gettig	15	0
SW	15	0
Answered	15	6

Table 120: Dr. Moore - more than 5 vs. less than 5

Dr. Moore	Yes	No
More than 5	1	1
Less than 5	13	2

p-value: 0.331

Table 121: Ms. Gettig - more than 5 vs. less than 5

Ms. Gettig	Yes	No
More than 5	7	0
Less than 5	15	0

Table 122: Social Workers - more than 5 vs. less than 5

Social Workers	Yes	No
More than 5	7	0
Less than 5	15	0

Table 123: Answered - more than 5 vs. less than 5

Answered	Yes	No
More than 5	7	8
Less than 5	15	6

p-value: 0.124

Table 124: Testing - greater than 5

>=5	Yes	No
Decision	9	0
Trust	9	0
Retest	8	1
Pre-counseling	9	0
Disclosure	9	0
Bring someone	8	1
Help	8	
Answered	9	5

Table 125: Testing - Less than 5

<5	Yes	No
Decision	14	0
Trust	14	0
Retest	13	1
Pre-counseling	14	0
Disclosure	14	0
Bring someone	11	3
Help	11	
Answered	14	7

Table 126: Decision - more than 5 vs. less than 5

Decision	Yes	No
More than 5	9	0
Less than 5	14	0

Table 127: Trust - more than 5 vs. less than 5

Trust	Yes	No
More than 5	9	0
Less than 5	14	0

Table 128: Retest - more than 5 vs. less than 5

Retest	Yes	No
More than 5	8	1
Less than 5	13	1

p-value: 0.640

Table 129: Pre-counseling - more than 5 vs less than 5

Pre-counseling	Yes	No
More than 5	9	0
Less than 5	14	0

Table 130: Disclosure - more than 5 vs. less than 5

Disclosure	Yes	No
More than 5	9	0
Less than 5	14	0

Table 131: Bring Someone - more than 5 vs. less than 5

Bring Someone	Yes	No
More than 5	8	1
Less than 5	11	3

p-value: 0.483

Table 132: Answered - more than 5 vs. less than 5

Answered	Yes	No
More than 5	9	5
Less than 5	14	7

p-value: 0.583

D.7 AFFECTED/UNAFFECTED VS. ACTIVE/INACTIVE

Table 133: Appointment - aff/unaff vs. act/inact

Appt – yes	Aff	Unaff
Active	6	14
Inactive	4	11

p-value: 0.567

Table 134: Parking - aff/unaff vs. act/inact

Parking - yes	Aff	Unaff
Active	3	11
Inactive	3	10

p-value: 0.638

Table 135: Parking - No - aff/unaff vs. act/inact

Parking - no	Aff	Unaff
Active	1	2
Inactive	0	1

p-value: 0.500

Table 136: Front Desk - yes - aff/unaff vs. act/inact

Front desk - yes	Aff	Unaff
Active	5	14
Inactive	4	9

p-value: 0.545

Table 137: Front Desk - No - aff/unaff vs. act/inact

Front desk - no	Aff	Unaff
Active	0	0
Inactive	0	1

Table 138: Moore - yes - aff/unaff vs act/inact

Moore - yes	Aff	Unaff
Active	3	11
Inactive	2	6

p-value: 0.620

Table 139: Moore - No - aff/unaff vs. act/inact

Moore - no	Aff	Unaff
Active	1	2
Inactive	0	2

p-value: 0.600

Table 140: Gettig - yes - aff/unaff vs. act/inact

Getting - yes	Aff	Unaff
Active	6	13
Inactive	5	10

Table 141: Social Workers - Yes - aff/unaff vs. act/inact

Social workers - yes	Aff	Unaff
Active	6	13
Inactive	5	9

Table 142: Test Decision - yes - aff/unaff vs. act/inact

Test decision - yes	Aff	Unaff
Active	7	12
Inactive	4	12

p-value: 0.352

Table 143: Test Decision - no - aff/unaff vs. act/inact

Test decision - no	Aff	Unaff
Active	0	0
Inactive	1	0

p-value: 0.352

Table 144: Trust - yes - aff/unaff vs. act/inact

Trust - yes	Aff	Unaff
Active	7	10
Inactive	5	11

p-value: 0.410

Table 145: Trust - no - aff/unaff vs. act/inact

Trust - no	Aff	Unaff
Active	0	0
Inactive	0	1

Table 146: Retest - Yes - aff/unaff vs. act/inact

Retest - yes	Aff	Unaff
Active	7	10
Inactive	5	10

p-value: 0.464

Table 147: Retest - No - aff/unaff vs. act/inact

Retest - no	Aff	Unaff
Active	0	1
Inactive	0	1

Table 148: Pretesting - yes - aff/unaff vs. act/inact

Pretesting - yes	Aff	Unaff
Active	6	9
Inactive	3	9

p-value: 0.343

Table 149: Pretesting - no - aff/unaff vs. act/inact

Pretesting - no	Aff	Unaff
Active	1	0
Inactive	1	0

Table 150: Disclosure - Yes - aff/unaff vs. act/inact

Disclosure- yes	Aff	Unaff
Active	6	10
Inactive	3	8

p-value: 0.449

Table 151: Disclosure - No - aff/unaff vs. act/inact

Disclosure - no	Aff	Unaff
Active	1	0
Inactive	1	1

p-value: 0.667

Table 152: Bring Someone - yes - aff/unaff vs. act/inact

Bring someone - yes	Aff	Unaff
Active	6	9
Inactive	2	8

p-value: 0.274

Table 153: Bring Someone - No - aff/unaff vs. act/inact

Bring someone - no	Aff	Unaff
Active	1	1
Inactive	2	2

p-value: 0.800

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