

**PEER-TO-PEER COUNSELING FOR INDIVIDUALS RECENTLY TESTED POSITIVE
FOR HUNTINGTON'S DISEASE**

by

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University of Pittsburgh, 2013

Huntington's disease (HD) is a hereditary condition that affects the brain and nervous system. The gene associated with HD was identified in 1993 and was one of the first conditions for which presymptomatic testing became available, allowing individuals to know that they will develop this disease in the future. Genetic counselors provide information about HD to individuals along with the necessary support to cope with this knowledge. Peer-to-peer programs have been widely successful in helping individuals cope with various medical conditions, but have not been applied to the HD community. The public health significance of this project was identifying that presymptomatic individuals within the HD community following their positive test result need additional support and offered peer-to-peer counseling as a solution to this health issue. Common associated problems among these individuals are increased stress, depression, and feelings of isolation. A peer-to-peer counseling program for those who undergo genetic testing should be successful and a service genetic centers could easily incorporate into existing clinical practice to improve the overall health within the presymptomatic HD community. The purpose of this study was to develop, implement, and evaluate a peer-to-peer training program for individuals who have tested positive for the HD gene mutation. Twenty participants were recruited on a voluntary basis from the HD community in Pittsburgh, PA who had previously tested positive at least one year prior, and two participated in the training to prepare the mentors with the necessary skill set and knowledge for counseling and providing

support to their peers. After the training, a survey evaluated the usefulness, content, and presentation of the material, allowing the researchers to identify areas in need of change in the training manual. The findings of the surveys revealed that the content of the training was well received and helped better prepare the mentors for their role in peer-to-peer counseling. Volunteers reported being well prepared for the peer support role. In the future, mentors will be paired with a peer who has recently tested positive and surveys will evaluate their satisfaction with a peer-to-peer program.

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PREFACE

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1.0 INTRODUCTION

Huntington's disease (HD) is a fatal progressive, neurodegenerative genetic disorder with symptoms that include characteristic changes in movement, personality changes, and cognitive decline. HD affects both men and women and is inherited in an autosomal dominant pattern, which means that individuals with an affected parent have a 50% chance of inheriting the disorder and are said to be at-risk for HD. Genetic testing for HD became available in the early 1990's. Individuals found to be mutation carriers will develop the disease in their lifetime, usually between the third and fourth decades of life.

At-risk individuals who test positive for the Huntington's disease gene mutation are unique in the medical field in that few tests can predict our future medical health; however, testing for Huntington's disease has allowed individuals with a family history of HD to undergo presymptomatic predictive testing. A considerable amount of research has been conducted on presymptomatic predictive testing for Huntington's disease; with a substantial focus on the psychological effects this knowledge has on the individual. Much concern was expressed regarding the potential risks associated with presymptomatic testing for HD. This resulted in thorough monitoring conducted early in the history of the testing process to ensure that individuals would not commit suicide following a positive result disclosure. To many researchers' surprise, few individuals committed or attempted suicide after disclosure of their results. In fact, data suggest that people who receive positive genetic test results cope well with

the information with no severe depression. [2, 25, 34] Research does suggest however, that asymptomatic individuals already show evidence of psychological vulnerability and will therefore need considerable support. Research has recognized that presymptomatic testing can be done safely in a supportive setting. [2] However, additional research indicates that levels of hopelessness in individuals who tested positive can increase over time. The conclusion from this research study found that testing for fatal inherited diseases has the potential to create a long-term, lifelong stress. [11]

The current methods for supporting individuals who test positive for HD in Pittsburgh, PA include: online support groups, face-to-face support groups led by professionals, online chatrooms, the HD helpline, the Special Needs Clinic at UPMC, and informational materials distributed online and by the Huntington's Disease Society of America (HDSA). Research has looked into the usefulness of online support groups and identified that the two primary areas of exchange were informational and emotional support. Informational support predominantly focused on understanding the genetics, heredity, risk, and lack of gender specificity of the disorder. Emotional support was often provided by acknowledging the feelings of others and validating them by reiterating their own similar views and experiences. [4] The support group of the local HDSA chapter is very active within the city of Pittsburgh and is open to individuals touched by HD in some way. However, presymptomatic individuals testing positive often do not utilize the support group. Many have expressed the reason for this as being overwhelming to witness affected individuals in the support group as though they are looking into a mirror of their future. Given the need for support for presymptomatic individuals and the lack of uptake of the current support group resources, our project sought to fulfill the needs of this specific facet of the HD community.

The benefits of volunteer peer support are clearly different from those of professional support. Peer support offers a more cost effective method to offer emotional support and guidance to reliable sources of relevant information from the perspective of shared personal HD experiences. Peer support can provide reassurance and hope, increase knowledge about the HD experience, provide self-help strategies, and decrease feelings of isolation. Peer support is often touted as getting information from someone “in the know.” It can be empowering to both the peer and the mentor. Peers often serve as a positive role model for behavior that in the case of HD can involve coping skills.

This research study proposed to develop and implement a peer-to-peer training program for individuals who had tested positive for the Huntington’s disease gene mutation. We developed a comprehensive training manual and trained a small group of mentors who had tested positive at least one year prior. The training of the mentors involved a one-day training program at the University of Pittsburgh to prepare the mentors with the necessary skill set and knowledge for counseling and providing support to their peer. The training content of the peer-to-peer counseling program was developed for this study with the goals of providing emotional and informational support in mind. The training involved the use of potential scenarios and role plays as the primary tools for teaching boundaries, communication skills training, methods for sharing their story, information on regarding when to refer, and resources available to individuals with Huntington’s disease. The purpose of this project was to establish and document the development of a peer-to-peer counseling training program for Huntington’s disease among individuals who have tested positive for the HD gene mutation and pilot test a preliminary evaluation tool of the study. In the future, the investigators of this study will match newly

testing positive asymptomatic individuals with the trained mentors. The next section explores and presents the background and rationale for the format of this project.

2.0 BACKGROUND AND SIGNIFICANCE

A peer-to-peer program to assist gene positive individuals for Huntington's disease has never been conducted. Peer-to-peer programs have been successful in assisting individuals in coping with various medical conditions, but have not been applied to genetic conditions for which presymptomatic testing is available. [18] Our project utilized two pilot studies that were previously conducted to establish a groundwork for this program. The first pilot study was conducted at the Huntsman Cancer Center at the University of Utah for individuals who had been diagnosed with breast cancer. This research group developed a peer-led genetics module to increase the knowledge of genetics among women diagnosed with breast cancer. Their results found that peer-led genetics modules can increase knowledge about genetics. [32] The other pilot study conducted at the US Army Medical Research and Material Command at Fort Detrick, Maryland in 2004 created a peer-staffed hotline for individuals at high risk of developing hereditary breast cancer by family history or positive genetic testing for BRCA1 or BRCA2. The results from this project identified a positive reaction to the hotline and a desire for continued availability. However, no such programs have been used within the Huntington's disease community, nor have they been routinely used outside of the studies cited. Peer-to-peer programs are widely successful for a variety of conditions and for a variety of age groups. Application to genetic testing should be equally successful and might be a service genetic centers could easily incorporate into existing clinical services.

The foundation of this project is built on two primary topics: Huntington's disease and peer-to-peer counseling. To lay the groundwork for this project it is important to understand general information about Huntington's disease, the psychosocial effects of this condition, and genetic testing. It is also relevant to explore methods of peer support and the rationale for selecting peer-to-peer counseling as the most appropriate approach for this project. To do this, the following sections will discuss the background information about Huntington's disease and peer support approaches.

2.1 HUNTINGTON'S DISEASE

Huntington's disease is a hereditary neurodegenerative disorder caused by an expansion in the huntingtin gene on chromosome 4. Most people with HD begin to develop symptoms between 35 and 44 years of age. A rare form of HD, called juvenile HD, has onset of symptoms at a much earlier age, around 20 and affects approximately 5-10% of the HD population. [33] As the disease progresses, individuals with HD are unable to care for themselves.

A triad of symptoms characterizes Huntington's disease: motor, cognitive, and psychiatric disturbances, that progress over years. The average survival after the onset of symptoms is 15 to 20 years. Chorea, involuntary movement, and impairment of voluntary movements, characterize the movement disorder. Individuals with HD often experience reduced manual dexterity, slurred speech, swallowing difficulties, problems with balance, and falls. The cognitive symptoms initially include a loss of speed and flexibility especially in the completion of complex tasks. More impairment that is global develops later as the disease progresses. The psychiatric symptoms vary, but the most common symptom is depression. Patients can suffer

from mania, obsessive-compulsive disorder, irritability, anxiety, agitation, impulsivity, apathy, social withdrawal, and obsessiveness. [33] The symptoms experienced by individuals with Huntington's disease vary from individual to individual but often follow a specific pattern of progression. The next section discusses how the disease progresses and the stages of progression.

2.1.1 Progression

HD progresses in three stages: early, middle, and advanced. During the early stage, symptoms can include minor involuntary movements, subtle loss of coordination, difficulty thinking through complex problems, and may be accompanied by a depressed or irritable mood. Symptoms during the middle stage progress to an extent that most individuals are no longer able to work or drive and perform tasks such as managing finances and household chores. At this stage, chorea may be quite prominent and individuals will have increasing difficulty with voluntary motor tasks, issues with balance, falls, and weight loss. Patients often struggle with problem solving skills involving sequence, organization, and prioritization. In the advanced stage, patients require assistance in all activities of daily living. Patients are often nonverbal and bedridden. At this stage, chorea is often replaced by rigidity.

2.1.2 Disease Characteristics

Characteristics of the disease can be divided into three categories: movement, cognition, and psychiatric disturbances.

2.1.2.1 Movement

Huntington's disease is characterized by both disturbances in voluntary as well as involuntary movement. Chorea is the characteristic involuntary movement disturbance that occurs with individuals affected with HD. Chorea consists of nonrepetitive jerking of the limbs, face, or body. Approximately 90% of individuals affected will develop this feature of the disease and will increase during the first ten years of onset of the disorder. The movements themselves are continuously present during waking hours and are often worsened by stress, anxiety, or depression.

Medications will not alter the progression of the underlying illness, however, they can assist in reducing chorea to improve gross motor control and quality of life. Three main classes of medications are commonly used to suppress chorea in HD: neuroleptics, benzodiazepines, and dopamine depleting agents. Each class has its advantages and disadvantages. Individuals with HD are often very sensitive to medications and therefore should be started at low doses to avoid over medicating.

As the disease progresses other involuntary movements may develop. Among these are bradykinesia, slowness in the execution of movement; rigidity, an increase in muscle tone causing resistance to externally imposed movement; spasticity, stiffness or rigid muscles; myoclonus, sudden brief jerks involving groups of muscles; tics, brief, intermittent stereotyped movements such as blinking, nose twitching, head jerking, or abnormal postures; epilepsy, and dystonia, sustained muscle contractions that cause twisting and repetitive movements or abnormal posture. Myoclonus is more common in the juvenile form of the disease. Epilepsy is rare in adults but can occur in about 30% of individuals with juvenile onset disease. Dystonia can affect many aspects of movement such as the deterioration of handwriting, the tendency of

one foot to pull up or drag while walking, uncontrollable blinking, tremor, and speech difficulties. [25]

Impairment of voluntary motor function is an early sign of HD. Affected individuals can mistakenly be labeled as clumsy. Motor speed, fine motor control, and gait are all affected. Oculomotor disturbances such as difficulty initiating eye movement, slow and overshooting eye movements, and problems in gaze fixation affect as many as 75% of affected individuals, occurring early and worsening over time. Dysarthria, the slowing and slurring of speech; dysphagia, difficulty swallowing; and hyperreflexia, exaggerated reflexes are also common symptoms that individuals with HD develop over time. Dysphagia results from impaired voluntary control of the mouth and tongue and impaired respiratory control due to gulps of liquid. [25]

Weight loss is a common problem with individuals affected with HD. Due to diminished food intake and chorea, HD patients require a large caloric intake to maintain their body weight. The two primary strategies employed to achieve this are increasing the number of meals per day or increasing the calorie content of the food. [25, 33]

2.1.2.2 Cognition

A global and progressive decline in cognitive capabilities occurs in all individuals with HD. Symptoms can include forgetfulness, slowness of thought processes, impaired ability to analyze and understand space with relation to mental imaging, navigation, distance and depth perception, as well as an impaired ability to manipulate acquired knowledge. Initial changes in cognition affect memory, the ability to plan and organize events or activities in a sequential way, and attention and concentration.

Difficulties in planning, organization, sequencing, and prioritizing can affect responsibilities at home and at work. Many individuals start to complain of problems with organization in the early stages of disease. Divided attention is often compromised with HD, limiting individual's ability to multitask. Having a structured schedule can be a means of compensating for this symptom. Initiation, starting an activity, is often compromised in individuals with HD. Perseveration, being fixed on a specific thought or action, can also occur. Some individuals experience issues with impulse control that manifest as irritability, temper outbursts, sexual promiscuity, and acting without thinking.

HD can also cause deficits in spatial perception. Individuals' ability to manipulate objects in their mind is impaired, so for instance, the distance between their body and a doorway may be misjudged.

Individuals with HD often suffer from a lack of insight or self-awareness that is thought to be the result of a disruption in the pathways between the frontal regions of the brain and the basal ganglia. This symptom can explain otherwise irrational behavior in individuals with HD.

Speech is another major area affected with HD. The most common language difficulties in individuals with HD are speaking clearly, starting conversation, and organizing their thoughts. [25, 33]

2.1.2.3 Psychiatric Disturbances

Individuals with HD develop significant personality changes. Unlike the other features of the disorder, psychiatric disturbances tend not to progress over time. Common symptoms of psychiatric disturbances include explosiveness, apathy, aggression, alcohol abuse, sexual dysfunction and deviations, delusions, paranoia, and increased appetite.

The incidence of depression in both pre-symptomatic and symptomatic individuals is more than twice in the general population. It has not been determined if the depression is caused by the disease, or the psychological effects of having the disease. Suicide and suicidal ideation are common in individuals with HD, but the incidence rate depends on the disease course and predictive testing results. The most critical periods for suicide risk were found to be just prior to receiving a diagnosis and when affected individuals loose independence.

While depression is the most common psychiatric problem in HD, a smaller number of individuals experience mania, displaying elevated or irritable mood, over activity, decreased need for sleep, impulsiveness, and grandiosity. HD patients often display an obsessive preoccupation with particular ideas. [25]

2.2 GENETICS OF HD

The huntingtin (*HTT*) gene encodes the huntingtin protein. The normal function of the protein is not known. The *HTT* gene contains a repeating sequence of three base pairs, CAG, called a trinucleotide repeat. An excess number of CAG repeats in the gene results in a protein containing an excess number of units of the amino acid glutamine. The excess of CAGs causes the abnormal huntingtin protein to be processed differently in the body and accumulate in the nucleus of neuron cells of the brain. The number of CAG repeats indicates whether or not an individual will develop HD. (See Table 2-1) [33]

Table 2-1. CAG repeats

Number of CAG Repeats		Phenotype
Normal	≤ 26	Normal
Intermediate	27-35	Not at risk of developing HD, may be at risk of having a child with HD
HD-causing	36-39	Reduced penetrance HD- causing
	≥ 40	Full penetrance HD-causing

2.2.1 Genetic Counseling for HD

Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. [24] Components included in a genetic counseling session often include gathering information, establishing or verifying a diagnosis, risk assessment, information giving, and psychological counseling and support. [29] Topics such as insurance, employment, social and family issues may be discussed to better assist individuals who are considering genetic testing or coping with test results.

Huntington's disease is inherited in an autosomal dominant manner. Autosomal dominant inheritance means that both men and women can be affected with HD, and each child of an affected individual has a 50% chance of inheriting the abnormal *HTT* gene, and developing the disease, and a 50% chance of inheriting the normal *HTT* gene. Inheriting one abnormal *HTT* gene is sufficient to develop the disease.

Although most individuals diagnosed with HD have an affected parent, the family history may be negative, unknown, or the parent may be uninterested in testing. Family history can appear negative for a number of reasons: the failure to recognize the disorder in family members,

early death of the parent before the onset of symptoms, the presence of a repeat in the intermediate range or reduced penetrance range in an asymptomatic parent, or late onset of the disease in the affected parent. If a parent is in the reduced penetrance range, the risk for the allele to expand is about 5%.

The number of CAG repeats remains stable in the somatic cells of an individual throughout their lifetime. Genes with expanded CAG repeat sizes are prone to expand when they are passed from one generation to the next. This is particularly true in the case of paternal transmission. Children who have inherited the abnormal gene can have a larger repeat number than the affected parent and could consequently develop symptoms at a younger age. The earlier onset of symptoms in a child compared with a parent is called anticipation.

2.2.2 Diagnosis of HD

The diagnosis of HD is suspected in the presence of the characteristic symptoms: progressive motor disability featuring chorea, mental disturbances that include cognitive decline, changes in personality, and/or depression, and a family history consistent with autosomal dominant inheritance. Genetic testing can be used to determine the risk status of the individual, however, the diagnosis of the disease is still often made by a clinical examination.

2.2.3 Genetic Testing for HD

Genetic testing for the HD gene mutation usually utilizes a blood sample, but can be performed on other tissue samples as well such as skin, amniocytes, chorionic villi, or autopsy material. Genetic testing is most often performed as a diagnostic test to confirm a clinical diagnosis, a

predictive test, or a prenatal test. The two major motivations for requesting predictive testing are certainty for the future and family planning. [7] A retrospective research study examined the uptake of genetic testing for Huntington's disease over a 19 year period from 1990 to 2009. The results of this study showed 212 individuals elected genetic testing, 43% tested positive. Of the individuals at-risk for Huntington's disease however, only about 14.7% of individuals sought testing. [22] These are the findings of one research group in the UK, however, these results are roughly comparable to other clinic populations, such as UPMC. Figure 1 below shows a flowchart of the average number of individuals that uptake testing upon attending HD clinic in a given year, the average number that come back either positive or negative, and the average of those tested positive that are either symptomatic or asymptomatic.

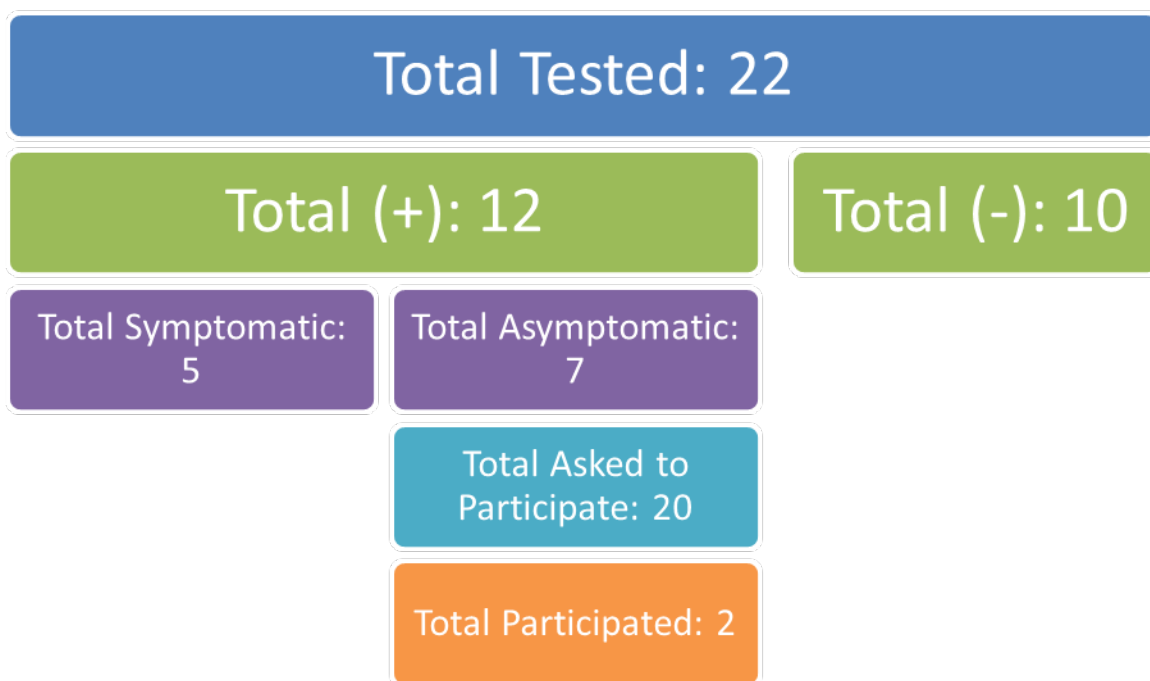


Figure 1 Average Number of Individuals Tested at UPMC

Diagnostic genetic testing is performed when a patient currently has symptoms that are suggestive of HD. Even with a positive genetic test result, the patient's symptoms may not be explained or caused by HD and ultimately still require a clinical examination and diagnosis.

Predictive testing is performed when an individual is at risk for inheriting and developing HD based on family history. Predictive testing protocols have been carefully established to protect individuals seeking testing and assist in resolution if difficulties arise. [13] At-risk individuals can have molecular genetic testing to determine if they have inherited this disorder. This testing has been available for over twenty years. Predictive testing can determine whether the genetic change is present but is not useful in accurately predicting age of onset, severity, type of symptoms, or the rate of progression of the disease. Prior to predictive testing, at-risk individuals could only wait for the inevitable development of symptoms, which could be emotionally taxing and involve key life decision-making in the presence of uncertainty. Predictive testing has alleviated the necessity to wait. [25]

At-risk asymptomatic individuals often seek testing in order to make personal decisions regarding reproduction, financial matters, or career planning. Others express the desire to elucidate the unknown. Genetic counseling is ideal before and after predictive testing has taken place. Genetic counselors meet with at-risk individuals and discuss their motivation for requesting testing, assess their knowledge about HD, and discuss the impact of possible test results. Usually at this appointment, a neurological exam is performed to ascertain the individual's current symptomatic or asymptomatic status.

The presence of the disease-causing allele should first be elucidated in the affected parent or an affected relative before prenatal testing is performed. A mother carrying a fetus at a 50% risk of inheriting HD is eligible for prenatal testing by chorionic villus sampling between 10 and

12 weeks of pregnancy or amniocentesis between 15 to 18 weeks of pregnancy. In addition, prenatal testing for pregnancies at 25% risk can be performed using linkage analysis in such a way that will not reveal the status of the at-risk parent.

Careful discussion is warranted in the case of prenatal testing to ensure the mother/couple understand the implications of testing and discuss what she/they would plan to do once the results are available. Prenatal testing can be used for the purpose of pregnancy termination or for early diagnosis. Genetic counseling is warranted to explain the rationale of why we generally do not test minors and how identifying these genetic results might change their child's future. Prenatal testing seems to be an acceptable and chosen option for a minority of couples at-risk for HD. [13]

Preimplantation genetic diagnosis (PGD) may also be available for families with a known mutation identified. PGD is a procedure used prior to implantation to help identify genetic defects within embryos created using in vitro fertilization. The process often involves taking one or two cells from the embryo after it has divided to the eight-cell stage, extracting DNA from the cell, and copying the DNA using the polymerase chain reaction (PCR). The huntingtin gene is then analyzed to determine the number of CAG repeats and embryos without the CAG expansion are implanted into the uterus. [1] The success rate of PGD for HD varies by center, but is generally around 20% per oocyte retrieval and 25% per embryo transfer which is within the average success rate of general IVF cycles. [9, 31]

2.3 PSYCHOSOCIAL ISSUES RELATED TO HD

The psychosocial issues related to HD can be vast and far-reaching. Moreover, the psychosocial concerns can be influenced by the stage of the disease. Individuals in the presymptomatic stage are often coping with the results and dealing with decisions about the future, such as family planning. Once the individual starts to show symptoms, new psychosocial issues may arise such as coping with the continual loss of skills and abilities, accepting the increasing need for support and care from others, and possibly struggling to cope with these changes due to symptoms of the disease itself. The families of individuals with HD also represent a group of individuals affected by the disease. They must cope with the results and are often planning alongside the affected individual for the future and may end up being the primary caregiver of their spouse, parent, or sibling. They may find themselves at risk as well, or worry about their children or other family members. The scope of psychosocial issues is quite broad but for the purposes of this paper, the focus is on the literature examining the psychosocial issues relating to a presymptomatic individual. This literature will be reviewed in the next section.

2.3.1 Coping with Results

Follow-up studies have been conducted to determine the psychological burden following a positive test result for HD. Studies show that about 10-15% of both carriers and non-carriers experienced some psychological problems, including psychological burden, a period of depression, hopelessness about the future, concern about their children, or guilt. Only 0.97% of individuals required psychiatric hospitalization, attempted suicide or committed suicide after testing. [7] Research in Vancouver revealed that symptoms of depression and anxiety were most

common in carriers in the first two months following testing, but that after one year, the depression levels had fallen back to the baseline level. Those found to struggle the most accepting and coping with their test results, were not those with simply a positive result, but rather those that expected a different result. [7] Individuals with a prior history of psychiatric problems or significant and prolonged adverse psychological reactions to other stressful events were also at an increased risk for maladjustment to the test results. Overall, predictive testing for HD reduced uncertainty and provided an opportunity for appropriate planning. [12]

Many individuals seeking testing may do so hoping that knowing their results will allow them to feel in more control of their future. Retrospective research has revealed this not to be the case with individuals in the HD community. Despite the feeling of lacking control, research has found, three years after receiving the result, most carriers had found a balance between facing reality and living as normal a life as possible.

Many individuals testing positive have intimate knowledge about and experience of the course of illness in other family members. This can often be an obstacle in the process of coping with their positive test result, because many individuals with a family history of HD carry the misconception that their disease will look like their family member's. Every individual's disease manifests differently, so no two individual's disease course are identical. This can be a relief for those who had severely affected relatives. However, these individuals understand the disease progression and the ultimate outcome.

The lack of effective treatments for HD is a significant source of potential burden. Many individuals hold hope for a cure or effective treatment for HD, if not in their lifetime, then in their children's.

There is no turning back after receiving a predictive test result. Genetic counselors often ask individuals again at the time of their results disclosure if they are sure they want their genetic test results. At any time individuals can choose to decline hearing the test results and wait until they are ready. Once individuals hear their test result, there is no going back. That is why the process of genetic counseling is especially important with this condition to explore the coping plan and support system for individuals seeking testing. The result of psychological pressures on individuals as the possible onset of symptoms draws nearer include anxiety, increased vigilance, and closer watch for symptoms. [27]

The potential for employment or insurance discrimination is less likely now with the passing of the Genetic Information Nondiscrimination Act (GINA) in 2009. This law prohibits discrimination in healthcare coverage and employment based on genetic information. GINA ensures that health insurers cannot request or require genetic information or use it for decisions regarding coverage, rates, or preexisting conditions. The law also prohibits most employers from using genetic information as the basis of employment decisions such as hiring, firing, or promotions. [23]

2.3.2 Family Planning

Follow-up data gathered one year after the communication of a positive test result revealed that the test result had an impact on reproductive decision-making. Many research studies found that carriers of the HD mutation with a desire for children were confronted with new dilemmas, such as having children or not, and making use of prenatal testing or not. [13]

2.4 PATIENT SUPPORT AND RESOURCES

Current resources and patient support available to individuals with HD include: online support groups, face-to-face support groups, online chatrooms, the HD helpline, the Special Needs Clinic at UPMC, and informational materials distributed online and by the Huntington's Disease Society of America (HDSA). The HDSA provides information about HD, and connects individuals with HD to resources such as the local HD chapter, the nearest HD social worker and HDSA center of excellence, as well as support groups and information on current research and clinical trials. The HDSA local chapter in Pittsburgh, PA is very active within the HD community.

2.5 PEER SUPPORT

Peer support is an overarching umbrella term that encompasses a number of different peer involvement approaches. Peer support is a created source of support, internal to a community that share similarities with the target population and possess knowledge that is derived from personal experience rather than formal training. [6] The primary peer support approaches focused on in this text are: peer counseling, peer education, and support groups. The most appropriate peer support approach is dictated by the goals of the project. The different types of peer support are described and the rationale for choosing peer counseling is explained in the next sections.

2.5.1 Peer Education

The history of peer education originates as far back as the ancient times of Aristotle. There have been many peer education initiatives throughout history. In the recent past, peer education has been utilized as a successful intervention with several medical disorders, particularly HIV testing, drug and alcohol abuse, heart disease, diabetes, and cancer. The primary goal of peer education is the diffusion of information and dissemination of skills. The model itself is built on the foundation that a leader within the community can serve as a role model for an ideal health behavior. Peer education can take many forms, such as support groups, telephone education, one-on-one education, Internet websites, and chat rooms. Peer educators represent an untapped resource that can provide services to deliver information regarding HD, testing, and coping with results at a relatively low cost. [32]

Peer education has been applied within a range of different settings. These have included schools, colleges, youth centers, community settings, and informal networks. Selection of the setting depends on the particular group. In groups for whom an obvious venue did not exist, some form of outreach contact was employed for peers to work in an informal network. [28] The use of peer education has been demonstrated as effective, regardless of the health behavior, the population, or the demographics of the individuals who are the target audience. [32]

The rationale for peer education includes a number of factors, some of which can be supported by the Social Learning Theory. [26] The Social Learning Theory states that to be a credible role model one needs to have high status within the peer group. All of the studies that have used popular opinion leaders within communities were successful peer education initiatives. The evidence suggests that their status within the community was a factor in their effectiveness.

Most central to the Social Learning Theory is the concept of role modeling. Many advocates of peer education argue that the role of the peer educator is to serve as a positive role model and to provide social information rather than merely providing facts.

Self-efficacy is a concept in the Social Learning Theory. [26] This concept relates to a person's confidence in performing a particular behavior and his/her expectations of success. People are more likely to practice socially learned behavior if they think it will be effective.

Peer education is beneficial to those involved in providing it. The need for a high level of self-efficacy among peer educators is crucial if they are to carry out interactions with their peers. Studies have shown that individuals volunteered to be peer educators because they believed they would be effective or had past experience of effectiveness in social situations.

2.5.2 Support Groups

Psychotherapeutic group interventions conducted by professional therapists have been shown to help facilitate adjustment to disease. Often, however, cost is a major barrier associated with formal psychotherapy. The use of support groups incorporates some of the elements of formal psychotherapy predominantly focusing on providing emotional support through peer discussion and information support through education. [16] Emotional support includes expressions of care, encouragement, attentive listening, reflection, and reassurance, in the absence of criticism. [6] Most interventions include components of both education and discussion resulting in positive effects on adjustment at a significantly lower cost. [16]

The primary goal of support groups is to offer social support and reduce feelings of isolation. Support groups are built on the foundation that shared common experiences are an important part of the therapeutic process. Support groups can take place in a variety of settings

but are often found in community buildings, hospitals, or churches. Support groups have been established for many topics including but not limited to, grief and loss, caregiver issues, support for individuals related to the patient, and specific genetic conditions. Support groups can offer reduction in the sense of isolation by exposing individuals to others who have experience with a condition, social support, sharing of information about the condition and treatments, understanding, and acceptance. [15] There is also evidence that offering support to other people can be beneficial for the mentor. Volunteering has been shown to result in improved physical health, increased feelings of self-worth, reduced symptoms of depression, improved communication skills, and positive changes in behavior. [6]

Support groups for genetic conditions are now organized under the Alliance of Genetic Support Groups. Genetic support groups have been established for a variety of conditions, such as Huntington's disease, hemophilia, neurofibromatosis, and Down syndrome. The focus of genetic groups often surrounds sharing of information, building a network, and better coping with the psychosocial issues associated with the specific disease. [15]

Research has looked into the usefulness of online support groups and identified that the two primary areas of exchange were informational and emotional support. Informational support predominantly focused on understanding the genetics, heredity, risk, and lack of gender specificity of the disorder. Emotional support was often provided by acknowledging the feelings of others and validating them by reiterating their own similar views and experiences. [4] The training content of this peer-to-peer counseling program was developed with these goals in mind.

2.5.3 Peer-to-Peer Counseling

There are a number of benefits with the use of peer counseling. Peer counseling is more cost-effective than the other methods discussed earlier. Peers have been noted as a credible source of information due to their shared and common personal experience with Huntington's disease, which can also be applied to information about HD. Peer counseling is empowering for those involved. Also, it has already been established as a means of sharing information and advice. Peers may be more successful than professionals in passing on information because people sometimes identify more with their peers. Peer counselors also act as positive role models. Peer counseling has also been shown to be beneficial to those involved in providing it. Peer counseling can serve to reinforce learning and support through ongoing contact.

The benefits of volunteer peer support are clearly different from professional support. [18] Peer support offers a more cost effective method to offer emotional support and guidance to source relevant information from the perspective of shared personal HD experiences. Peer support can provide reassurance and hope, increase knowledge about the HD experience, and provide self-help strategies and decrease feelings of isolation. Peer support is often touted as getting information from someone "in the know." Peers often serve as a positive role model for behavior that in the case of HD can be applied to coping skills.

There are also limitations to peer counseling that should be addressed and considered when selecting the appropriate peer support approach. Peer counseling is established under the assumption that mentors who have experienced HD can better understand and relate to individuals trying to deal with the same condition. Each individual experience will be different with HD. The perspective of an individual is shaped by various factors including family history, prior experience with the condition, age, relationship status, family composition, or life

circumstances. Each of these factors and many others will determine and mold an individual's experience. Their ability to relate to others is often not something that is known early in the peer counseling process.

Because peer counseling is not a professional service it can be difficult to establish accountability in the case of negative outcomes. There is also not a method to monitor discussions and content between peer and mentor. This creates the challenge of knowing whether or not a peer needs referral for professional counseling and is not being provided that opportunity or if misinformation is being shared.

Another major area of concern is that mentors may mix their personal problems with their own experience of HD with those of their peer. This can result in the mentor creating a problem in the mind of the peer that really does not exist for the peer. [3]

2.5.4 Comparing Peer Support Approaches

Each of the three peer support approaches explored above have advantages and strengths. To select the most appropriate method for this study the primary investigator and myself examined the strengths and differences of each approach. Figure 2 displays the differences and similarities between each of the peer involvement approaches considered for this project.

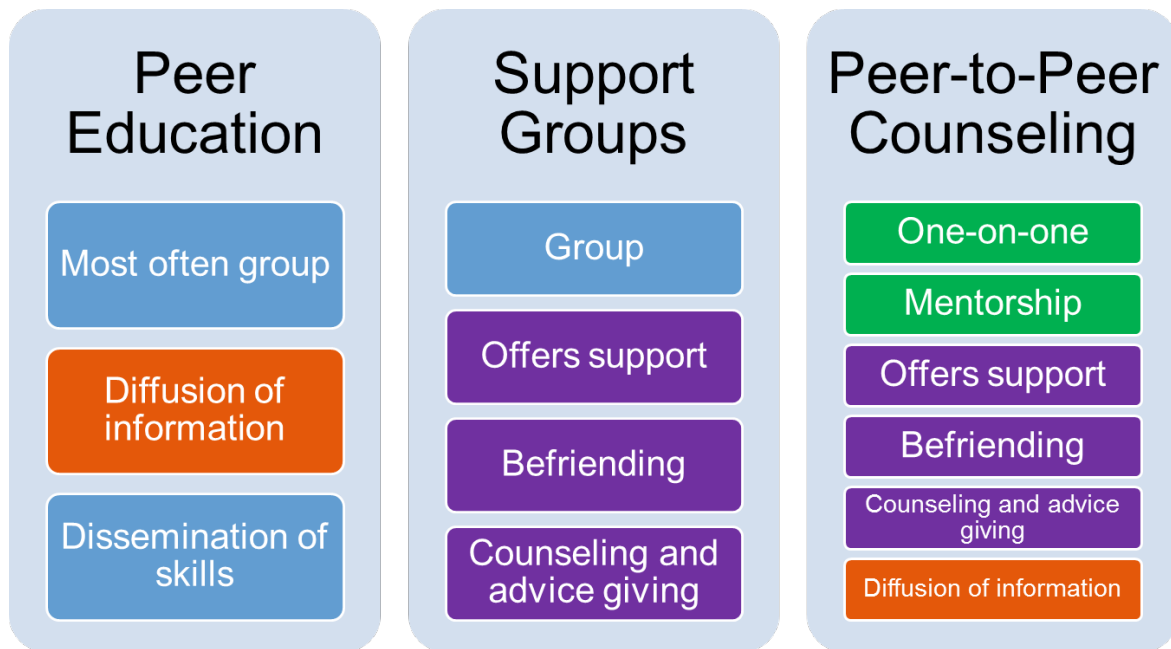


Figure 2. Differences and Similarities of Peer Involvement Approaches

Peer education most often takes place in a group setting and operates under the primary goals of diffusion of information and dissemination of skills. Support groups take place in a group setting and offer support, befriending, and counsel and advice giving. Peer-to-peer counseling occurs as one-on-one. Peers involved in this type of peer involvement offer support to their peers, befriending, and counsel and advice giving. In addition, peer-to-peer counseling allows for the diffusion of information as well as the aspect of mentorship.

The primary difference between peer education and peer counseling is the goal of peer education. Peer education seeks to teach and alter a behavior in the target population. Our study does not primarily seek to change a behavior and therefore is not the ideal peer support approach for our project. Peer education also often takes place with one peer working with a group, whereas peer counseling is more often one-on-one work between peers. Peer education involves outreach, diffusion of information and dissemination of skills, presentation of information, and

often is based in communities. Peer counseling in contrast, is built on principles of befriending, offering support, mediation to resolve disputes, advice giving, and mentorship. [14]

The primary difference between support groups and peer-to-peer counseling is that support groups operate in a group setting. Within the HD community, there is already a very active support group open to anyone touched by HD in some way, affected individuals, family members, presymptomatic individuals, etc. Our study sought to identify another approach of support to offer to individuals with HD and found that presymptomatic individuals are often not utilizing the support group. Peer-to-peer counseling encompasses many of the strengths of each of the approaches as well as unique characteristics that were appropriate in the HD community and this project, namely the aspect of mentorship and taking place one-on-one.

3.0 STUDY DESIGN AND METHODS

This research study is a descriptive study that utilized quantified data from an evaluation and satisfaction survey. This project proposed to establish and document development of a peer-to-peer training program for individuals who had tested positive for the Huntington's disease gene mutation and pilot test a preliminary evaluation tool of the study. We trained a small group of mentors (n=2) who had tested positive at least one year prior and will select asymptomatic newly tested individuals who had a positive test result as the peers in the future. The training involved a one-day training program at the University of Pittsburgh to prepare the mentors with the necessary skill set and knowledge for counseling and providing support to their peer. The training involved the use of potential scenarios and role plays as a primary tool for boundaries, communication skills training, methods for sharing their story, information on when to refer, and resources available to individuals with Huntington's disease. In the future, we will show the benefits of peer-to-peer counseling being useful to peers and assisting in the coping process of having the genetic mutation for HD. The primary tool utilized to assess the training was achieved through questionnaires with standard statistical analysis of the data.

3.1 IRB APPROVAL

This project received IRB approval to develop, implement, and evaluate a peer-to-peer training program for individuals who have tested positive for the Huntington's disease gene mutation. A total of up to 5 mentors who had tested positive at least one year prior were approved to be trained in a two-day training program. The training would be evaluated through the use of surveys and the peer-to-peer interaction would also be evaluated with surveys. The surveys and informed consent forms were approved by the IRB.

3.2 PARTICIPANTS

Twenty eligible participants were contacted and offered the opportunity to be trained as mentors. Two participants were ultimately trained, one male and one female. The age of the participants was over 18 years old. All participation was voluntary and did not affect their patient care.

There are multiple reasons for the total number of subjects enrolled in this research study. This was a pilot study intended to evaluate the helpfulness of a peer-to-peer program did not require a large number of participants, but rather to generate some interest and explore the utility of the developed training manual. A maximum of five pairs of subjects were originally selected and approved as this is a rare condition and testing is only selected by about 15% of at-risk individuals worldwide. The uptake rate was low within the HD community with individuals being incapable to participate in the study at this time for various reasons. Many presymptomatic individuals do not share their gene test results with their employers and

therefore the timing of this study posed a significant challenge to involve individuals in a training program that did not take place on a scheduled workday.

3.3 RECRUITMENT

The participants recruited for this study were contacted and selected by the advisory committee from the patient population of Dr. Valerie Suski, DO from the University of Pittsburgh Medical Center (UPMC) Special Needs Clinic in the Department of Neurology. Those testing positive for the HD gene return every six months and those testing positive are known to the primary investigator of this study. Mentors were individuals who had tested positive for the HD gene mutation at least one year ago. The primary investigator of this study, Elizabeth Gettig, MS, CGC, will disclose all HD testing results and will offer newly disclosed patients an opportunity to work with a mentor after the mentor training is complete. All participation was voluntary and did and will not affect patient care.

The eligibility criterion for participation in this study was a positive Huntington's disease gene test. The exclusionary criteria were children under 18 years of age, an individual with a negative or inconclusive Huntington's disease genetic test, and an individual with a known mental health condition such as depression or suicidal thoughts or actions. The advisory committee verified eligibility prior to contacting individuals for recruitment. Medical records include age, HD genetic test results, and prior health histories.

The anticipated risks to the participants in this project was the possible emotional discomfort from sharing sensitive personal information regarding their experience with Huntington's disease and the potential for breach of confidentiality. Both mentors and peers

were advised that their discussions should be treated as confidential. In addition, participants were not required to share information that may cause emotional discomfort. To ensure the participants' privacy is respected the mentor and peer will meet in a private room at the University of Pittsburgh or conduct conversations over the telephone in a private area.

Informed consent was obtained prior to the mentor training from each of the study participants and administered the first surveys after completion of the training. (Copies of the informed consent documents can be found in Appendix B.3.)

3.4 ASSESSMENTS

Surveys were used to assess the: 1) success of the mentor training, 2) the satisfaction of the mentor with the peer-to-peer relationship after six months, and 3) the satisfaction of the peer with the peer-to-peer relationship after six months. (See Appendix B.2 for copies of the surveys utilized in this study.)

The surveys were developed and modeled after a pilot study conducted at the Peter MacCallum Cancer Center in 2009. Kinnane et al. developed a peer support training program for volunteers in a hospital-based cancer information and support center. Volunteers assisted the Cancer Support Nurse by helping patients and families find information and provide face-to-face peer support. Pre-training questionnaires were used to rate existing skills and post-training questionnaires were used to evaluate the training. Kinnane et al. utilized pre-training questionnaires to determine the preparation for volunteering, the volunteers knowledge regarding the role and boundaries of volunteering, and the knowledge of communication skills. Each day of the three day training, the participants were asked to rate the training. One month following

the training, a post-training evaluation was administered. This was the same as the pre-training questionnaire. [17]

For the use of this study, only post-training evaluations were employed due to the determination that pre-training evaluations would not provide additional information regarding the participants than was already known. Unlike the Peter MacCallum study, this study involved the selecting of eligible participants from a clinic population known to the advisory committee. The knowledge of each of the participants would circumvent the necessity of a pre-training evaluation, and only serve to reinforce known information about the participants. Due to first-hand interaction with each participant prior to enrollment in this study, the advisory committee knew the understanding of HD and communication skills of each participant.

The questions for the evaluation of the training were selected with consideration of the goals of the study as well as the questionnaires from the Peter MacCallum study. The majority of the evaluation was developed as a quantitative assessment to aide in the interpretation of the results. The quantitative portion of the evaluation asked the participants to rate their prior and current knowledge of peer-to-peer counseling to assess how the training contributed to this knowledge. The evaluation also asked for the participant to rate their current: 1) confidence level, 2) understanding of effective communication skills, 3) knowledge of boundaries as a peer counselor, 4) strategies to talk with your peer, 5) confidence supporting a peer, 6) understanding for the rationale of peer counseling, 7) awareness of support services, 8) knowledge of community services, 9) knowledge about internet information, 10) comfort level with sharing your story, 11) knowledge of HD, and 12) comfort level with recognizing a peer that needs additional help. The participant was then asked to rate how much the training influenced each of the above characteristics. The remainder of the evaluation utilized qualitative questioning to

elicit additional feedback from the participants regarding areas of the training that were most and least beneficial, as well as areas for improvement of the training.

The assessment survey was administered to the participants at the completion of the training program, to rate on a five-point scale questions about the training and aspects of peer counseling. The survey consisted of 32 questions: 27 quantitative questions: 15 questions addressed personal characteristics and skills needed as a peer counselor, 12 questions were pertaining to the impact the training had on the above characteristics and skills, and 5 qualitative questions sought feedback regarding the most and least helpful aspects of the training. The quantitative questions utilizing the five-point scale asked the mentors to rate the training and personal factors with 1= excellent, 2= above average, 3= average, 4= below average, and 5= extremely poor. The quantitative questions regarding how much the training contributed used the following scale: 1= a great deal, 2= much, 3= somewhat, 4= seldom, and 5= none. Participants were also asked to indicate the most valuable and least valuable aspects of the peer-to-peer training and about specific training areas they would like included or might like to receive further information.

The questions for the evaluation of the peer-to-peer counseling were selected with consideration of the primary goal of developing a satisfaction survey to assess the utility of peer counseling, the satisfaction of the peer and mentor, and to determine areas for improvement. The majority of the evaluation was developed as a quantitative assessment to aide in the interpretation of the results. The quantitative portion of the evaluation asked the peers to rate their satisfaction with: 1) peer counseling, 2) their peer mentor, 3) their mentor's communications skills, 4) their mentor's listening skills, 5) their mentor's ability to make them feel respected and valued, and 6) their mentor helping them adjust to their positive test result.

The survey also asks the peer how likely he or she is to: 1) recommend peer counseling, 2) continue peer counseling, 3) become a peer counselor, and 4) use services and resources discussed with their mentor. The qualitative portion of the survey asks the peer to explain how peer counseling has helped, what aspects were most and least helpful, and areas for improvement. Similar questions were developed for the mentor with a few variations. The quantitative questions asked the mentor to rate satisfaction with: 1) peer counseling, 2) their peer, 3) their listening skills, 4) their communication skills, 5) their ability to make their peer feel respected and valued, and 6) helping their peer adjust to their test result. The survey also included questions to evaluate the likelihood that the peer would become a peer counselor or use the services discussed in counseling. The qualitative portion of the surveys were the same.

The results of the surveys assessing peer satisfaction are pending after the completion of pairing the mentors with their peers and meeting together for six months.

3.5 TRAINING MANUAL

Elizabeth Gettig, Dr. Robin Grubs, Dr. Valerie Suski, Rachael Monaghan, Peggy Polito, and Peggy Humbert developed the training materials for the mentor training program. The training manual was utilized throughout the training. The content of the training manual is listed in Table 3-1.

The training manual was developed utilizing the Peter MacCallum study and other peer-to-peer training manual resources. [17, 30] The advisory committee contacted both of the pilot study authors for training materials used in their studies. However, neither author was able to forward their resources or manuals. The topics determined to be most useful for inclusion in the

training and manual were: 1) an introduction and explanation of the project, 2) informed consent forms for participants to read and sign, 3) an overview of the training, 4) an agenda outlining the plan for the training day, 5) a summary of peer counseling, 6) guidelines of peer counseling, 7) communication and listening skills, 8) understanding boundaries, 9) role plays, 10) information about HD and support services, and 11) information to know when to refer a peer. These topics were then expanded and developed in Word and Powerpoint by members of the advisory committee (Rachael Monaghan, Christa Lorenychick, Alicia Martinez, and Elizabeth Gettig). Exercises, role plays, scenarios, and video links were also included into the training and training manual to facilitate teaching of concepts related to the project. The scenarios were created by common situations, experiences, or feelings affecting families and individuals with HD. The manuals were developed to allow the mentors to follow along with the training content but also the used as a reference after the training was completed.

Two versions of the training manual were constructed: one version was to be given to the mentors and the other version given to the advisory members in attendance at the training day. The same content was included in each of the manual versions; however, the reference materials of video links, exercises, and additional role plays were not included in the mentor manual. To easily distinguish one version from the other, the manuals were assembled in different color binders: the mentor binders were blue, and the trainer binders were black.

Table 3-1 Content of peer-to-peer training manual and day

<i>Training Manual</i>	<i>Participants were provided with the training manual. The manual was designed to be a reference both during and after the training.</i>
Training Day Content	Introduction and explanation of the project Consent to act as a subject in a research study Overview of the training Welcome exercise- HD crossword puzzle

Table 3-1 Continued

Additional Manual Content	<p>Peer counseling factsheet summarizing what it means to be a peer mentor</p> <p>Peer-to-peer counseling guidelines outlining the goals, expectations, roles, and responsibilities of participating in this program</p> <p>Who, what, where, and why of peer counseling</p> <p>Role play exercise 5 (discussion on theoretical attitudes of individuals who have newly tested positive)</p> <p>Communication and listening skills covering verbal and non-verbal communication, open and closed questions, empathy, reflection, and effective listening</p> <p>Establishing boundaries video (depicts how to resist giving out personal information)</p> <p>Counseling basics covering assessment, rapport, body language, paraphrasing, and open and closed questions</p> <p>HD review</p> <p>Telling your story</p> <p>Role play (tell us your story)</p> <p>HD support and services available for patients and families</p> <p>Assessing emotions and recognizing when a peer needs referred to a medical professional</p> <p>Difficult scenarios</p> <p>Summary of the training program</p> <p>Key components of peer counseling</p> <p>Additional exercises</p> <p>Additional videos</p> <p>Additional role plays</p> <p>Surveys</p>
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3.6 TRAINING

The participants (n=2) and the training coordinators (n=4, Elizabeth Gettig, Rachael Monaghan, Peggy Polito, and Peggy Humbert) attended the peer-to-peer training day. The investigators of the study, a genetic counselor and a genetic counseling intern and two individuals from the

advisory committee (See Appendix C), both trained as social workers, facilitated the training. The training was completed in one day. All of the facilitators are experienced and qualified in teaching and delivered aspects of the course content. The program was developed using the principles of adult learning and based on a previous pilot study and peer-to-peer training program manuals' content. [17] Combinations of didactic methods of teaching and group activities were employed to deliver the training content. Each of the training coordinators participated in teaching information for the training. The overall cost for the one day training was approximately \$100 per participant.

4.0 RESULTS

4.1.1 Evaluation of the Training

The results of the post-training survey are listed in Table 4-1. The participants reported that their knowledge about peer-to-peer counseling was different before the training and improved following the training. After attending the training program both participants rated their current knowledge of peer-to-peer counseling and confidence as a peer mentor ‘above average’ or ‘excellent’.

Attending the training program was reported as impacting self-ratings ‘a great deal’ to ‘much’ in all but six questions asked. For one participant, understanding of effective communication skills was influenced only ‘somewhat’ by attending the training program. For one participant, awareness of support services available to individuals with HD, knowledge about helping newly testing positive individuals find internet information that is reliable, sharing their story with HD, knowledge of HD, and recognizing an individual that needs additional help from a professional like a social worker or psychologist were influenced only ‘somewhat’ by attending the training program.

4.1.2 Evaluation of the Training Content

The advisory committee reviewed the training manual for subject matter, correctness, and relevance for the training. The training content was evaluated through the use of surveys following the training. The most helpful aspects of the program were learning about establishing boundaries with a peer and techniques to respond in a way that does not overemphasize their personal experiences with HD. Also reported as helpful was the feeling that resulted from the training of being able to ‘help out’. The least helpful aspects of the program reported were the HD facts. Participants indicated an area which needed improvement were the role plays. One participant felt the role plays could be more open-ended. They identified talking, listening, skills necessary to convey interest to their peer, and information on HD as areas for further information and training.

Table 4-1 Post Training Survey and Results

Questions asked	Excellent or a great deal 1	Above average or much 2	Average or somewhat 3	Below average or seldom 4	Extremely poor or none 5
1. How would you rate your previous knowledge of peer-to-peer counseling before this training?	1/2	0/2	0/2	1/2	0/2
2. How would you rate your current knowledge of peer-to-peer counseling?	1/2	1/2	0/2	0/2	0/2
3. How would you rate the information you were given to be a peer mentor?	2/2	0/2	0/2	0/2	0/2
4. How would you rate your current confidence level as a peer mentor?	1/2	1/2	0/2	0/2	0/2

Table 4-1 Continued

4a. How much of this is the result of this training program?	2/2	0/2	0/2	0/2	0/2
5. How would you rate your current understanding of effective communication skills?	0/2	1/2	1/2	0/2	0/2
5a. How much of this is the result of this training program?	0/2	1/2	1/2	0/2	0/2
6. How would you rate your knowledge of your boundaries as a peer counselor?	1/2	1/2	0/2	0/2	0/2
6a. How much of this is the result of this training program?	2/2	0/2	0/2	0/2	0/2
7. How would you rate the strategies that currently help you talk to your peer mentees with a positive test result for HD?	2/2	0/2	0/2	0/2	0/2
7a. How much of this is the result of this training program?	2/2	0/2	0/2	0/2	0/2
8. How would you rate your current confidence in supporting someone with a positive test result for HD?	1/2	1/2	0/2	0/2	0/2
8a. How much of this is the result of this training program?	1/2	1/2	0/2	0/2	0/2
9. How would you rate your current understanding for the rationale for peer counseling?	2/2	0/2	0/2	0/2	0/2
9a. How much of this is the result of this training program?	2/2	0/2	0/2	0/2	0/2
10. How would you rate your current awareness of support services available to individuals with HD?	1/2	1/2	0/2	0/2	0/2
10a. How much of this is the result of this training	1/2	0/2	1/2	0/2	0/2

Table 4-1 Continued

program?					
11. How would you rate your current knowledge of community services available to individuals with HD?	1/2	1/2	0/2	0/2	0/2
11a. How much of this is the result of this training program?	1/2	1/2	0/2	0/2	0/2
12. How would you rate your current knowledge about helping newly testing positive individuals find internet information that is reliable?	1/2	1/2	0/2	0/2	0/2
12a. How much of this is the result of this training program?	1/2	0/2	1/2	0/2	0/2
13. How would you rate your current comfort level with sharing your story with HD?	1/2	1/2	0/2	0/2	0/2
13a. How much of this is the result of this training program?	1/2	0/2	1/2	0/2	0/2
14. How would you rate your current knowledge of HD?	2/2	0/2	0/2	0/2	0/2
14a. How much of this is the result of this training program?	1/2	0/2	1/2	0/2	0/2
15. How would you rate your current comfort level to recognize an individual that needs additional help from a professional like a social worker or psychologist?	1/2	0/2	1/2	0/2	0/2
15a. How much of this is the result of this training program?	1/2	0/2	1/2	0/2	0/2
16. Are there other areas of the training from which you think you would benefit in your role as a peer counselor? No Talking, listening, being able to convey interest					
17. What did you find most helpful about the peer-to-peer counseling program? I feel I can help out.					

Table 4-1 Continued

Learning about boundaries, responding in a way that doesn't overemphasize my experience. Ex: Just because my family is supportive doesn't mean theirs will be.	
18. What did you find the least helpful about the peer-to-peer counseling program?	Everything is fine. Huntington's facts, but we went through it pretty fast.
19. What needed improvement or should be included in the peer-to-peer counseling program?	Nothing. I like the idea of the role-playing, but maybe a little more open-ended.
20. Any other comments?	I would like to know more information on HD.

5.0 DISCUSSION

A review of the literature indicates that the use of peer self-help groups are both beneficial to the peer as well as the mentor. The benefits have been studied among individuals coping with various issues or conditions. Examples of issues and conditions utilizing peer support include: substance abuse and addiction, bereavement, cancer, caregiver burden, chronic illness, and diabetes, to name a few. The examples included are most relevant for comparison to our project due to overlapping commonalities between the issues affecting individuals in the given groups, such as depression, feelings of loss or guilt, isolation, anxiety, anger, stress, and feeling out of control. The use of peer support for each of the given topics resulted in common findings. In general, certain characteristics increased while others decreased amongst participants. Characteristics that increased in peer support participants included: self-esteem, psychological adjustment, positive moods, sense of control, happiness, freedom to express feelings, knowledge of the condition, friendships, sense of community and belonging, family life, coping with disease, following doctors' orders, support, positive outlook on life, satisfaction with medical care, motivation, and quality of life. Characteristics that decreased in peer support participants included: anxiety, physical symptoms, negative moods, depression, grief, guilt, anger, isolation, and stress. [18] Participation in peer-to-peer training increases feelings of self-esteem, freedom to express feelings, knowledge of the condition, a sense of community, and motivation.

Communication among individuals identified to have HD includes helping individuals cope with the emotional impact of a life-threatening illness; understanding and remembering complex information; and dealing with uncertainty while maintaining hope. Peer-to-peer counseling has the potential for providing individuals dealing with these complex issues surrounding HD the continued contact with trained volunteers who can serve as a confidant and equal who finds themselves in a similar position. The training and supervision of peers who provide support has been only minimally reported in the literature and is an area for further exploration and future research. [5]

The goal of this research study was to develop, implement, and evaluate a peer-to-peer training program for individuals who had tested positive for the Huntington's disease gene mutation. We trained a small group of mentors who had tested positive at least one year prior and will select newly testing positive asymptomatic individuals as their peers. The training of the mentors involved a one-day training program to establish and equip the mentors with the necessary skill set and knowledge for counseling and providing support to their peer.

Results from the evaluation of the training program by participants indicated that most aims of the program were achieved. Volunteers reported being well prepared for the peer support role.

Although well received, the training program was intensive and could have been distributed over two days instead of just one day. The role plays and information about HD seemed to suffer the most from this adjustment.

The role plays were an essential part of the training as indicated from previous research in the literature as well as feedback from the participants. One participant felt that the role plays could be more open-ended.

Both participants in the training program expressed further interest in information about HD. One participant in particular noted how quickly the material was reviewed for this particular topic. Possible solutions could include eliciting prior knowledge about HD before the training to ascertain the necessary level of detail of information provided regarding HD. Another solution would be to extend the training from one to two days, allowing for more time to be spent on question and answer and information giving on HD.

The second purpose of this project was to examine the benefits and helpfulness of peer-to-peer counseling for Huntington's disease among individuals who have tested positive for the HD gene mutation. Due to constraints of time, participant availability, and peers in need of support, the other proposed aspects of this project are yet to be completed. They include matching the mentors with a newly tested individual with positive results. The meeting is encouraged to be in person or by telephone if necessary. To evaluate the usefulness of the peer counseling aspect of this project, additional surveys will be administered to both the peer and mentor to determine if the counseling is mutually beneficial. This project will support the usefulness of peer-to-peer counseling for HD for both peers and mentors.

5.1 LIMITATIONS OF THE STUDY

This study is limited to a small study sample ($n=2$) with only one male participant and one female participant, making it difficult to generalize the study findings to gender and to larger participant groups. One of the participants had already been working with newly tested positive individuals on a voluntary basis with individuals seeking peer support from the local HDSA chapter.

For the majority of questions surveyed, the interpretation was straightforward. However, for some questions it was challenging to determine whether the participants' answer was the result of the training failing to meet its objectives or just a general area unaffected by the training. For example, one participant indicated that his/her understanding of effective communication skills was average and only somewhat the result of the training program. Another participant indicated that his/her comfort level to recognize an individual who needed additional help from a professional was average and only somewhat the result of the training program. These responses are difficult to attribute to problematic elements in the training. However, it would be reasonable to take the conservative approach and create additional learning modules for the topics of communication and referral.

There may be a need for additional support to presymptomatic newly tested positive individuals within the HD community and peer-to-peer counseling may well solve that need for additional support. Huntington's disease may not be the best genetic condition to start testing the utility of peer-to-peer counseling as a means of support for genetic conditions. Certain challenges may arise that make peer-to-peer counseling less effective within the HD community as a result of the symptoms associated with this condition. The fact that psychiatric disturbances are a characteristic part of the disease may complicate the evaluation of certain characteristics such as reducing feelings of depression and isolation. Altered mental processes may overrule any support or benefit peer-to-peer counseling may offer. Furthermore, individuals are often resistant because of the manifestation of symptoms to recognize they have become symptomatic and can be resistant to change. This may pose significant challenges in the process of removing mentors from the peer-to-peer counseling role. Therefore, the authors of this project recognize

that a less than successful result within the HD community will not necessarily predict the utility of peer-to-peer counseling in other presymptomatic genetic conditions.

5.2 FUTURE STUDIES

Evaluation of future programs could include alteration of the surveys to address some of the unforeseen challenges discussed above. Perhaps considering a pre-training survey to determine the baseline levels for each of the post-training questions, may make interpretation easier. In addition, a survey specifically asking about the helpfulness of each of the training topics may be informative.

To incorporate the feedback regarding the role plays into the future implementation of the training, a possible solution would be to have a few pre-rehearsed role plays as examples of role playing but also as a learning tool throughout the training. The remainder of the role plays could be done with trainer and mentor and mentor to mentor. This added level of participation may provide for a stronger sense of confidence in the mentor, as well as allowing the mentors to interact with and support each other. Another possible solution to this feedback could be to incorporate telling their story at the beginning of the training.

The feedback from the surveys also indicated that there was room for improvement on the section regarding information about HD. There are several ways to address this issue: 1) consider a pre-test about HD at the beginning of the training to assess the needed level of detail and areas to focus the information about HD section, 2) incorporate the information about HD into a fun exercise such as jeopardy or bingo.

Points to consider for the future implementation of this program or similar future programs are setting guidelines for determining when an individual should no longer serve as a mentor as well as determining the procedure for how these decisions will be made and by whom. A potential endpoint for serving as a mentor in the peer-to-peer program could be when the mentor becomes identified as clinically symptomatic. However, the potential impact this will have on the mentors as well as their peers has yet to be explored. Further consideration to the emotional and psychological impact on the peer may be warranted given that reducing isolation and providing hope are goals of this project and both aspects could be affected by losing a mentor.

It may also be important to consider implementing a method to evaluate the mentors' knowledge of HD, perhaps by questionnaire. This could ensure that the mentors are knowledgeable enough to accurately answer HD and informational questions with their peer. Another solution to this feedback could be to include a scenario as an icebreaker at the beginning of the training to assess the baseline understanding and skill level of the mentors.

Another area that could utilize a questionnaire may be to evaluate baseline coping skills of peers to determine the adequate amount of time spent in a peer-to-peer relationship for the maximum results as well the most ideal candidates for inclusion in future research studies. It may also be worthwhile to consider determining the most effective matching process to assign mentors to peers. For the purpose of our project, the advisory committee is heavily involved within the HD community and was capable and qualified to determine matching mentors with peers, but may warrant exploration for the application to other communities worldwide.

It may also be warranted when considering completing this study to use comparison groups to evaluate the utility of a peer-to-peer support program for presymptomatic individuals.

The comparison groups would include those that utilize and attend the local HDSA support group, those that refuse any outside support, and those that utilize professional therapeutic support services. It may be additionally informative in this process to include baseline and post evaluations to assess psychological well-being. This comparison would be the most informative to determine if peer-to-peer support is the most beneficial form of support for presymptomatic individuals with HD.

6.0 CONCLUSIONS

Despite the limitations, this study represents a preliminary analysis of the helpfulness of a training program for a peer-to-peer counseling group among individuals tested positive for the HD gene mutation. By identifying topics of greater interest and areas for improvement, the results of the study can inform the further development of the most effective training program for peer-to-peer counseling. Training, matching, and regular communication will contribute to an ongoing group of trained volunteers. Although peer-to-peer counseling will not eliminate or treat feelings of hopelessness, our hope would be that individuals would feel more comfort knowing they are not alone in how they feel and that someone else has been where they are now, reducing their level of hopelessness and isolation. Areas for future study include: determining the usefulness of peer-to-peer counseling for mentors and peers, assessing the emotional and psychological impact of losing a mentor, and determining a matching process to assign mentors to peers.

APPENDIX A

TRAINING MANUAL CONTENT

A.1 INTRODUCTION AND EXPLANATION OF PROJECT

INTRODUCTION AND EXPLANATION OF PROJECT

PEER-TO-PEER TRAINING FOR THOSE WHO HAVE TESTED POSITIVE FOR THE HUNTINGTON'S DISEASE GENE

Primary Investigator:

Elizabeth Gettig

Co-Investigators:

Rachael Monaghan

Robin Grubs

BACKGROUND:

This project proposes to develop, implement, and evaluate a peer-to-peer training program for individuals who have tested positive for the Huntington's Disease gene. We will train a small group of mentors who have tested positive for the gene at least one year prior and select newly diagnosed individuals as the mentees. Training of the mentors will involve a two day training protocol to prepare the mentors with the necessary skill set and knowledge for counseling and providing support to their mentee. The training will involve the use of potential scenarios and role-play as a primary tool for counseling preparation, a clear definition of role expectations and boundaries, communication skills training, methods for sharing their story, information on when to refer, and resources available to individuals with Huntington's Disease. We will show that sharing personal experiences between peer mentor and mentee is useful to the mentees' process of coping with having the gene for HD. Assessment of the training and peer to peer counseling will be achieved through questionnaires.

PURPOSE:

The purpose of this research study is to establish the effectiveness of peer-to-peer counseling for Huntington's Disease among individuals who have tested positive for the Huntington's Disease Gene.

GOALS:

The study hypothesis is that peer to peer counseling in Huntington's Disease patients will assist recently diagnosed individuals in coping with their gene test result.

RELEVANCE:

A peer-to-peer program to assist gene positive individuals with HD has never been conducted. Peer-to-peer programs have been successful in helping individuals cope with various medical conditions. A pilot study was conducted for those who have tested positive for the breast cancer genes previously (conducted at the Huntsman Cancer Center at the University of Utah), but such programs have not been used with the HD community nor have they been routinely used outside of the one study cited. Peer-to-peer programs are widely successful for a variety of conditions and for a variety of age groups. Application of the strategy to gene testing should be equally successful and be a service that genetic centers could easily incorporate into existing clinical services.

A.2 PEER COUNSELING FACTSHEET

PEER COUNSELING FACTSHEET

WHAT IS PEER COUNSELING?

- Peer counseling involves sharing your story about your HD testing experience and the impact it had on you, your family, and your life planning.

WHAT IS A PEER COUNSELOR?

- A peer counselor/mentor is a person who had an experience that can be shared with someone in a similar situation.

WHERE DOES PEER COUNSELING TAKE PLACE?

- Peer counseling may take place in small groups or in a one-on-one setting. A peer counselor may meet face-to-face or by telephone with their peer.

WHY DO PEER COUNSELING?

- Peer counseling is an effective way to provide support to individuals who have just received an HD gene positive test result. You may recall the adjustment to receiving this news yourself and this information may be helpful to your peer.
- Peer counseling is successful because you have shared the experience of testing positive for the HD gene personally. Your credibility with your peer is established by this similar experience.
- People who take part in peer-to-peer programs often report a helpful and useful experience because their peer shares similar background and interests.
- Peer counseling is often compared to receiving advice from a friend "in the know," rather than from an authority figure.
- People get a great deal of information from their peers on issues that are especially sensitive. Sensitive issues concerning the test result will impact important relationships.
- Peer counseling is a way to empower people by providing a safe environment for peers to share their feelings with you, an individual who has shared a similar life experience.
- Peer counseling can be a means of communicating information to people to give them the opportunity to participate in activities that affect them and to access the information and services they need to protect their health.

A.3 PEER COUNSELING GUIDELINES

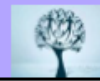
Peer-to-Peer Training



A Program from the Western PA Chapter of the Huntington Disease Society of America and the Genetic Counseling Program of the University of Pittsburgh School of Public Health

Advisory Group

- Elizabeth Gettig
- Peggy Polito
- Peggy Humbert
- Valerie Suski
- Robin Grubs
- Rachael Monaghan
- Christa Lorenychick
- Alicia Martinez



HD Peer-to-Peer Counseling Guidelines

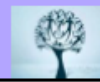
Our goal is to make everyone comfortable by creating a supportive environment where feelings and thoughts may be expressed freely.



HD Peer-to-Peer Counseling Guidelines

Information shared during peer counseling is kept confidential.

You cannot talk about any conversation or information without the individual's permission.



HD Peer-to-Peer Counseling Guidelines

Your feelings and experiences are important to your peers, but try to keep your comments brief so that you are both contributing to the discussion.



HD Peer-to-Peer Counseling Guidelines

An important aspect of peer counseling is to learn from your experiences and be supportive of the peer assigned to you.

You are encouraged to share and learn from each other.



HD Peer-to-Peer Counseling Guidelines

It is essential not to judge the beliefs of others because we need to support one another.



HD Peer-to-Peer Counseling Guidelines

We want everyone to feel comfortable in the peer-to-peer program.



HD Peer-to-Peer Counseling Guidelines

Thank you for your time and willingness to be a mentor.



A.4 PEER WHO, WHAT, WHERE, AND WHY

The Who, What, Where, and Why of Peer Counseling



Mentor

- A mentor is a person who had an experience that can be shared with someone in a similar situation.



Where Does Peer Counseling Take Place?

- Peer counseling may take place in small groups or in a one-on-one setting.
- A mentor may meet face to face or by telephone with their peer.



Peer Counseling

- Peer counseling involves sharing your story about your HD testing experience and the impact it had on you, your family, and your life planning.



Why Peer Counseling?

- Peer counseling is an effective way to provide support to individuals who have just received an HD gene positive test result.
- You may recall the adjustment to receiving this news yourself and this information may be helpful to your peer.



Why Peer Counseling?

- Peer counseling is successful because you have shared the experience of testing positive for the HD gene personally.
- Your credibility with your peer is established by this similar experience.



Why Peer Counseling?

- People who take part in peer-to-peer programs often report a helpful and useful experience because their peer shares a like background and interests.



Why Peer Counseling?

- Peer counseling is often compared to receiving advice from a friend "in the know," rather than from an authority figure.



Why Peer Counseling?

- People get a great deal of information from their peers on issues that are especially sensitive.



Why Peer Counseling?

- Sensitive issues concerning the test result will impact important relationships. Test results impact your relationship with your:
 - Spouse or Significant Other
 - Children
 - Extended Family
 - Employer
 - Other relationships



Why Peer Counseling?

- Peer counseling is a way to empower people by providing a safe environment for peers to share their feelings with you, an individual who has shared a similar life experience.



Why Peer Counseling?

- Peer counseling can be a means of communicating information to people to give them the opportunity to participate in activities that affect them and to access the information and services they need to protect their health.



A.5 PEER KEY COMPONENTS

Key Components

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Key Components

Key Components of Peer-to-Peer Training

- Exploration of the rationale for peer counseling, including its benefits and barriers.



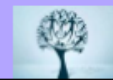
Key Components of Peer-to-Peer Training

- Building background knowledge of skills-based health education and behavior change interventions.



Key Components of Peer-to-Peer Training

- Building basic knowledge of the program's content and the health issues it addresses.



Key Components of Peer-to-Peer Training

- Exploration of personal values around the health issues being addressed, including attitudes towards gender-based norms and biases.



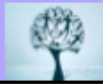
Key Components of Peer-to-Peer Training

- Training in the methodologies for skills building and the use of role play to develop the skills necessary for peer counseling.



Key Components of Peer-to-Peer Training

- Training in communication and group-work skills.



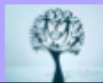
Key Components of Peer-to-Peer Training

- Basic guidelines for planning, implementing, monitoring, and evaluating peer counseling programs.



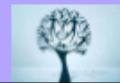
Key Components of Peer-to-Peer Training

- Exploration of strategies for outreach to vulnerable individuals.



Key Components of Peer-to-Peer Training

- Referral to peer counseling resources:
 - Peer counseling guides
 - Textbooks on peer education and behavior change
 - Resources on content areas of peer counseling



Key Components of Peer-to-Peer Training

- Referral to health services that exist in the area:
 - Clinics
 - Information sources
 - Pharmacies
 - Supportive services, etc.



A.6 PEER COMMUNICATION AND LISTENING

Skills Needed to Work Effectively with Your Peer



Communication Skills

Types of Communication

- Verbal
- Non-verbal
- Empathy



Types of Communication

Verbal Communication

- Definition:
 - What we say and how we say it
- Keys:
 - Using open ended questions
 - Clear and concise
 - Proper word choice

Non-verbal Communication

- Definition:
 - What we do and how we do it
- Keys:
 - Body language
 - Eye contact
 - Facial expression
 - Tone of voice
 - Non-verbal cues

Open-Ended Questions

- Information is required to answer open-ended questions.
- Benefits:
 - They reveal deeper and more personal issues
 - Allow for more peer centered support
- Example:
 - Closed: Did you get tested for HD?
 - Open: What issues did you think about when you were deciding to get tested for HD?



Empathy

- Empathy is expressed both verbally and non-verbally.
- Empathy is the ability to understand another person's experience as if it were your own AND to communicate this understanding to the other person.



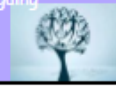
Expressing Empathy

- Empathy can be expressed in many ways.
- Perspective taking:
 - Put yourself in the shoes of your peer and ask yourself how you might think and feel. This may be easy because you may share common experiences.
- Relate one of your own personal experiences.
- Listen to what your peer is saying to you.



Expressing Empathy

- Be aware of your peer's nonverbal behaviors.
- Structure your responses with statements like:
 - Is it possible that...
 - Maybe you are feeling...
 - Perhaps you feel...
 - So it sounds as though you might be feeling...
- Communicate acceptance by not arguing with or pushing aside your peer's feelings.



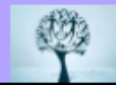
Expressing Empathy

- Allow time for your peer to respond to you. Sometimes silence is a good tool.
- Recognize:
 - Body language
 - Facial expressions
 - Non-verbal cues
 - Cultural differences
 - Tone of voice



Expressing Empathy

- Reflection:
 - Restating what your peer has just expressed to you, either explicitly in words or implied, concisely in your own words.
 - This allows your peer to hear possibly for the first time his/her own feelings out loud as well as building a more trusting counselor-to-peer relationship.



Steps for Reflection

- Seek to understand what your peer is saying to you and what she is not saying to you.
- Offer this idea back to your peer in your own words.
- Clarify the topic.
- Ask questions.
- Paraphrase and summarize what you hear your peer saying to you.



Common Empathy Mistakes

- Over identifying
 - Feeling too much for your peer. Remember you are here to help your peer.
- Making assumptions
 - When you make assumptions about what your peer may not explicitly be saying to you, you must be careful that you are not wrong as you may offend or upset your peer.
- Being afraid of your peer's feelings
 - Many peers will display a range of emotions. You need to remember that people feel what they feel.



Common Empathy Mistakes

- Using clichés
 - Avoid using clichés like, "Time heals all wounds," as it will make you sound less genuine.
- Pretending to understand
 - Your peer will know if you are only pretending to understand her. The foundation of a good peer-to-peer relationship is trust. If you do not understand, ask your peer to explain. You will seem genuinely interested.



Common Empathy Mistakes

- Parroting
 - If you use reflection as a way to express empathy, be careful to not repeat verbatim what your peer just said to you.
- Talking too much
 - Peer counseling is about allowing your peer the opportunity to express her thoughts and feelings with someone like herself. Make sure to give her the opportunity to do that.



Listening Skills

Effective Listening

- Incorporates the best aspects of empathy and listening.
- Key points:
 - Listening
 - Fully understanding feelings and needs
 - Gathering and checking facts
 - Helping the other person with her needs



Effective Listening

- The key point that distinguishes effective listening from other types of listening, is the desire to be helpful to the other person.



Effective Listening

- Listen to your peer's words, tone of voice, and other verbal aspects such as pace, volume, and style.
- Gather facts from what you hear your peer saying to you.
- Observe her body language and facial expressions.
- Express empathy.



Effective Listening

- Give feedback to your peer.
- Weigh the consequences of her behavior when your peer cannot.
- Be attentive to your peer by maintaining eye contact, keeping open body language, and leaning forward showing interest in your peer.



A.7 PEER VIDEOS

3 VIDEOS TO SHOW PEER COUNSELOR TRAINEES:

ESTABLISHING BOUNDARIES USING ACTIVE LISTENING

This video serves as a prime example on how to tactfully resist giving out personal information as well as offering other ways to communicate. One good technique would be to keep a journal when the peer has the urge to talk to his/her peer counselor and upon their next meeting, they can address whatever the peer wrote down.

<http://talkingitthrough.educationnorthwest.org/content/mentoring-video-player>

FEELING DEPRESSED

Because people with HD often experience depression this video could be very useful. The peer counselor can ask what would make the peer happy and tell them to act on that (as long as it is appropriate and healthy). The peer counselor may encourage their peer to express their feelings if they are isolating themselves. The counselor may also refer peers to professionals; however, the peer counselor should never pressure the peer to seek professional help.

<http://talkingitthrough.educationnorthwest.org/content/mentoring-video-player>

RUNNING AWAY FROM HOME

This video could be applicable for individuals with HD if they wish to desert their family. This video shows an obvious example because the girl states that she wants to run away, but real life situations may not be that clear cut. Once this video is shown, the trainers should state that the peer counselors need to be observant and watch for subtle signs from their peers. Peer counselors should enforce that running away both literally and figuratively is not their only

option. They may ask the peer why they want to leave their spouse, family, etc. The counselor should think about ways to improve the situation. For example, ask the peer, “Have you talked to them about this?” Ask them to envision what it would be like if they left their spouse, family, etc. Always remain supportive because the peer counselor is supposed to be there for their peer and always ask if the peer is comfortable with what you (the peer counselor) are suggesting. Finally, if the peer counselor needs assistance, ask the director or another trainer for help as soon as possible.

<http://talkingitthrough.educationnorthwest.org/content/mentoring-video-player>

A.8 PEER COUNSELING BASICS

Counseling Basics

Assessment of Counseling

- Rapport
- Open-Ended Questions
- Feelings/Issues
- Body Language
- Focus
- Summarizing/Paraphrasing
- Referrals (If Used)



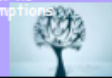
Rapport

- Rapport means making people comfortable.
- In peer-to-peer counseling, you want to show warmth and caring concern
- You want to be non-judgmental - there will be times your peer might make different choices and that is OK.
- Most of all you want your peer to feel important and feel her have someone to talk to



Open Ended Questions

- Open ended questions are ones where the answer is not yes or no but ones where people have to say something back to you.
- Examples are, "Tell me more," or "Tell me about that," "How did that work out?"
- You want to establish good timing, a natural flow in your conversation and not appear to be "interviewing" your peer.
- Minimal interruptions and avoiding yes-no questions are good counseling techniques
- Sometimes you just have to ask a yes or no question and that is ok, but avoid assumptions and leading questions.



Closed vs. Open Ended Questions

□ Examples:

Closed-Ended Question	Open-Ended Question
Do you get on well with your boss?	Tell me about your relationship with your boss.
Who will you vote for this election?	What do you think about the two candidates in this election?
What color shirt are you wearing?	That's an interesting colored shirt you're wearing.



Open Ended Questions

- Ones you might use:
- What does HB mean to you?
- What prompted you to get tested?
- What do you think will happen next now that you know your test result?
- How do you think you will go about solving that problem?
- How did you make that choice?
- What information do you have about that?
- What would you do differently?
- Why do you feel that way?



Feelings/Issues

- ❑ In talking to your peer, one counseling technique you might use is to reflect back on what was just said. You can rephrase it or just repeat it. Sometimes people see information differently just because someone else said it.
- ❑ You want to acknowledge and support your peer and you can do that by nodding your head or saying that happened to you too. (But be honest, only agree when you did have that exact thing happen to you.)



Feelings/Issues

- ❑ Early in your conversation with your peer you need to give her permission to say most anything to you and you will keep that information confidential.
- ❑ As a mentor, you should be able to pick up on cues and pursue feelings and sensitive issues
- ❑ You do not want to deny or skirt feelings/issues



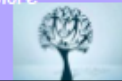
Body Language

- ❑ You as the mentor need to watch your peer's body language and you need to be aware of your OWN body language.
- ❑ You will use listening skills such as:
 - Head nodding or leaning forward in your chair to show you are really listening.
- ❑ Avoid body language that may indicate you are disinterested, such as looking at your watch or hair twisting.
- ❑ Silence and pauses are good things in a peer-to-peer situation. Let time pass while your peer is thinking about what she just said.
- ❑ Avoid interrupting
- ❑ Use a comfortable tone of voice - no yelling, no high pitched responses!



Focus

- ❑ Stay focused on your peer.
- ❑ Your story is important too but this time it is not all about YOU.
- ❑ If you feel in over your head, after meeting with your peer give your support people a call. (Your supports are the Peggies or Betsy.)
- ❑ Your support people can help explore alternatives with you.



Summarizing/Paraphrasing

- ❑ We mentioned this before, but we say it again and will role play this technique with you.
- ❑ Rephrasing or reflecting what the peer just said means your understanding of their situation is accurate.
- ❑ It clarifies what is going on
- ❑ And when you want to wrap up your peer conversation, these reflections are an easy way to summarize what you accomplished during this time together.



A.9 HD REVIEW

HD Review

HD Review

Facts About Huntington's Disease

- ▣ Estimated to affect as many as 1/10,000-1/20,000 Americans.
- ▣ 150,000 Americans are at risk for inheriting this condition.
- ▣ Most people begin developing symptoms in their forties and fifties, although changes may occur earlier or later in a person's life.



HD Affects Everyone

- ▣ HD impacts relationships with the spouse, children, and extended family.
- ▣ Career decisions, financial planning, and insurance issues not only impact the person affected, but their family members as well.



The Epidemiology

- ▣ HD has been reported in nearly all countries.
- ▣ HD affects all races but the gene occurs more frequently in Caucasians.
- ▣ Both sexes are affected equally.
- ▣ Prevalence of HD is between 30-70 individuals per million in the population.



Living at Risk

- ▣ What causes HD?
 - ▣ An abnormal copy of the huntingtin gene is passed from parent to child.
 - ▣ Every person who carries the abnormal copy of the gene will eventually develop symptoms.
 - ▣ Males and females have the same chance of inheriting the abnormal gene.
- ▣ A direct gene test allows a person to find out if he carries the abnormal HD gene.
 - ▣ However, it cannot determine when symptoms will begin or what the severity will be.



The Genetics

- ▣ Gene - determined to be located on the short arm of chromosome 4 in 1983. Ten years later the gene and variation were identified.
- ▣ Variation - An expanded trinucleotide repeat in which cytosine-adenine-guanine, or CAG, is repeated over and over again.
- ▣ Protein- "huntingtin" collects in the nucleus of a cell disrupting the function of neurons.



Genetic Testing

- Genetic Testing for HD
 - The decision to test is intensely personal.
 - There is no "right" answer.
 - Test results take several weeks and generally include a session devoted to each of the following:
 - Genetic counseling
 - Neurological exam
 - Psychological interview
 - Discussion of results
 - Follow-up



Genetic Testing

- Genetic Testing for HD
 - Testing for children is generally prohibited before age 18.
 - Children under the age of 18 may be tested to confirm a diagnosis of juvenile onset HD.



CAG Trinucleotide Repeat

Gene description	Repeat #	Phenotype
Normal allele	< 26	Normal
Mutable normal allele	27-35	Normal
HD allele (reduced penetrance)	36-39	
Normal/HD		
HD allele	> 40	HD



The Epidemiology

- The function of the gene is still unknown.
- Research has been conducted to show the huntingtin gene is necessary for life.



Autosomal Dominance

- HD is inherited in an Autosomal Dominant pattern.
 - Autosomal refers to the location of the disease causing gene on any chromosome 1-22, that is not a sex chromosome.
 - Dominant refers to how the gene is inherited. Dominant conditions require only one non-working copy of a gene for an individual to be affected.

Autosomal Dominant Inheritance

- Multiple generations are affected.
- Males and females are equally likely to be affected.



Autosomal Dominance

Autosomal Dominant Inheritance Cont.

- Male to male transmission occurs.
- Each offspring of an affected parent has a 50% chance of being affected and a 50% chance of being unaffected.



Clinical Aspects

- ▢ The age of onset is typically between 35 and 45 years of age.
- ▢ There is a juvenile form of HD that is characterized by symptom onset <20 years.
- ▢ Most individuals live an average of 15 years after symptoms first appear.



Clinical Aspects

- ▢ The symptoms of HD can be thought of as a triad of emotional, cognitive, and motor disturbances.



Emotional Aspects

- ▢ Depressed or irritable mood
- ▢ Loss of interest or pleasure in activities
- ▢ Change in appetite or weight
- ▢ Fatigue or loss of energy
- ▢ Thoughts of death
- ▢ Poor concentration
- ▢ Psychomotor agitation or delay
- ▢ Insomnia or hypersomnia
- ▢ Feelings of worthlessness or excessive guilt



Emotional Disturbances

- ▢ Depression
- ▢ Irritability, Aggression, and Impulsivity
- ▢ Lack of interest
- ▢ Anxiety
- ▢ Schizophrenia-like symptoms
- ▢ Obsessions
- ▢ Abnormal sexual behavior



Cognitive Disturbances

- ▢ Dementia
- ▢ Lack of initiation
- ▢ Difficulty with divided attention
- ▢ Speech impairment



Motor Disturbances

- ▢ Chorea is often the most noticeable feature
 - ▢ Abnormal involuntary and voluntary movements
- ▢ Swallowing difficulties
- ▢ Difficulty with speech production
- ▢ Morbidity



Treatment

- ▢ Symptoms we can treat:
 - ▢ Behavior
 - ▢ Movement
- ▢ Interventions:
 - ▢ Diet
 - ▢ Exercise
- ▢ There is no treatment for dementia.



Other Issues

- ▢ Driving privileges may cease due to progression of the disease.
- ▢ Smoking by patients may become dangerous due to choreic movements.
- ▢ Disability benefits are available to HD patients when they no longer are able to perform at work.
- ▢ Living wills must be considered so terminal care wishes may be expressed.



Testing on Minors

- ▢ Minors should not be tested unless there is a medically compelling reason for doing so, i.e., an at-risk child is believed to be showing symptoms.
- ▢ Some professionals feel that no circumstances justify testing a minor, as the genetic test does not confirm that the symptoms are Huntington's disease.



Prenatal Testing

- ▢ Includes testing of a fetus at risk for carrying the abnormal gene for HD.
- ▢ This can be done through:
 - ▢ Direct genetic testing
 - ▢ "Nondisclosing" variation of the test which approximates the risk of the fetus without disclosing the genetic status of the at-risk parent



Prenatal Testing

- ▢ Prenatal Testing using:
 - ▢ CVS or Amniocentesis
 - ▢ Identifies fetuses that carry the mutated gene for possible termination, adoption, or preparation.

<http://www.hdsa.org/living-with-huntingtons/family-care/living-at-risk/index.html>



Pre-Implantation Genetic Diagnostic Testing (PGD)

- ▢ Pre-implantation genetic diagnostic testing (PGD)
 - ▢ Eggs that have been fertilized outside the body are tested for the abnormal HD gene
 - ▢ Only unaffected embryos are implanted into the uterus



Impact of HD

- A person may become extremely anxious and hypervigilant for symptoms.
- Some individuals have attempted suicide after learning their HD status.
- Some individuals withdraw from relationships with family members and loved ones.
- There becomes a possibility of discrimination by insurance companies and employers.
- Support systems can be formed.



Principles of Treatment

- Treatment must be tailored to the individual patient.
- Treatment must be directed at specific emotional, cognitive, and motor symptoms.
- Medication should be initially administered at low dose.



Principles of Treatment

- Medications effective at one stage of the disease may not be effective at another.
- A patient should have his/her medication regimen checked routinely.
- Non-pharmacologic interventions are also important.



High-Definition Fiber Tractography (HDFT)

- New imaging technology for studying the brain connections of patients with HD.
- This will:
 - further our understanding of HD
 - be used to evaluate new treatment methods



High-Definition Fiber Tractography (HDFT)

- This technology has allowed us to see:
 - The brains of patients with HD while they are still living
 - Monitor changes in the brain
 - Map connections in the brain
 - Watch the progression of 10 individuals' brains with HD



High-Definition Fiber Tractography (HDFT)

- Case studies have shown brain connection differences between patients with HD and unaffected controls.



Potential Applications of HDFT in Huntington's Disease

- ❑ Qualitative and quantitative assessment of the brain connections
- ❑ Comparison with normal subjects
- ❑ Comparison with HD patients in different stages of the disease
- ❑ Progression of the disease
- ❑ Evaluation of response to treatment



Current Research

- ❑ There are 135 research studies currently enrolling for HD
- ❑ Current research trials include:
 - ❑ Coenzyme Q10: drug study
 - ❑ CIT-HD: studying the effects of citalopram on HD
 - ❑ AFQ056: drug study
 - ❑ CREST-E: creatine monohydrate drug study



Additional Resources

- ❑ Huntington Disease Society of America
<http://www.hdsa.org/>
- ❑ International Huntington Association
<http://www.huntington-assoc.com>
- ❑ HD Lighthouse. Huntington's Disease: information and community
<http://hdlighthouse.org/index.shtml>
- ❑ Clinical Trials
<http://www.clinicaltrials.gov>



Additional Resources

- ❑ Questions? Call the HD Helpline
 - ❑ 1-888-779-HDSA (1-888-779-4372)

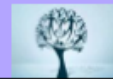


A.10 TELLING YOUR STORY

Telling Your Story

Telling Your Story

- What do you want to say?
- Have one or two specific messages in mind before beginning.



Telling Your Story

- When telling your story, your goal is to present in such a way that your peer hears it, understands it, knows it is important, and ultimately, uses the information from your story as a support.



Telling Your Story

- Emphasis is Important
 - Always keep your goals in mind.
 - Repeat important points so they stand out.
 - Use phrases such as, "I think it is very important to remember..."



Telling Your Story

- Before Telling Your Story:
 - Select a focus that you would like to talk about with your peer.
 - Give an example that illustrates your story.



Telling Your Story

- Tips for Telling Your Story:
 1. Be prepared.
 2. Select your focus.
 3. Select examples to use when telling your story that illustrate your focus.
 4. Emphasize your main points.



Telling Your Story

- Tips for Telling Your Story cont.:
- 5. Anticipate key questions and think about your answers before telling your story.
- 6. Be concise in your answers - avoid jargon and big words.
- 7. Treat peer to peer counseling like having a conversation in your living room with a friend.




Telling Your Story

- Tips for Telling Your Story cont.:
- 8. Always, always, always tell the truth.
- 9. Slow down and know when to be silent. Be short and speak clearly.
- 10. Make sure you are understood.
- 11. Keep eye contact with your peer.




Telling Your Story

- Tips for Telling Your Story cont.:
- 12. Don't let your wardrobe overshadow your words.
- 13. Watch for nonverbal signals.



Telling Your Story

- If you remember nothing else:
- Keep your message short and simple.
- Be honest.
- And remember, this is your story, so it should be personal.



Telling Your Story

- For some examples of how to tell your story, visit the Huntington's Disease Society of America website:

<http://www.hdsa.org/about/faces-of-hd/index.html>

Jenny and Nicole



A.11 TELLING YOUR STORY- ONLINE EXAMPLES

JENNY

As someone dealing with this devastating disease for many years, I have a passion to help fight for a cure. My family and I have been battling with HD since I was about six years old as my mother began to show signs of chorea and other neurological symptoms. My mother committed suicide when I was fifteen due to the affects of HD. Many times I often question why things happen in life. I think about having children someday but considering that HD is hereditary, I knew that I had a 50% chance of being a carrier so I decided to get tested in order to plan my future. The HD gene showed up positive on my test results and the reality is that one day I must deal with the cognitive, motor, and behavioral deficits that will continue to increase as I get older. This affects my decisions about having children and the possibility of passing on the disease runs through my mind constantly. I am extremely motivated to help find a cure for the next generation and put an end to this disease. If my mother were still alive and well she would be doing anything in her power to help find a cure. As her daughter, I decided to fight this battle for her. For this reason, I currently am leading the HDSA Las Vegas Affiliate to plan fundraisers and initiate support systems in my local community. With the help of my affiliate members, we are raising awareness and instilling hope to the families affected around us. When I begin to get scared about the future, I realize that by trusting the support from my HDSA family I am more hopeful for the future.

NICOLE

I am a 39 year old wife, mother, and high school counselor. I found out I was gene positive on December 5th, 2008. It is a day I will never forget because it answered the question I had been asking myself daily for several years, wondering which way my 50/50 chance would fall. Despite the news I received that day, I actually found much relief in the power of knowing.

My parents knew HD was in the family but thought my paternal grandfather was not affected. Eventually when my father was in his 50's he started showing obvious signs and did test positive. I still remember the day I went with my mother and father to receive the news. I find comfort in knowledge and knew I would want to find out.

I have two sisters who needed to process this news. My one sister and I participated in genetic testing at the same facility, accompanying each other to our visits, even finding out the results on the same day. Fortunately her news was better than mine, she is gene negative. My other sister has chosen not to pursue that yet.

I am so grateful I know what lies ahead. Everyone will get something and I have the power to prepare. I feel that through the genetic testing, my family has gained acceptance for the disease. I am not afraid to share my story with others because I want people to know about HD. I speak to our high school AP Biology classes, I organize casual days at my school to raise money for HDSA, my husband and I participate in clinical trials at a Center for Excellence, and we have raised money for local Team Hope walks. We will continue our fight.

A.12 ROLE PLAYS

Role Play #1 (for Scenario 1):

In this role play two people will be needed to portray this scenario. They will sit down in chairs facing each other. In this scene, the peer counselor and peer have just met. The peer counselor has introduced themselves and now their peer is doing the same.

The peer says, “Now that I know I have HD, I have a stronger opinion about certain aspects of the disease. For instance, I am completely against experimental drugs that are not approved by the FDA. I saw what happened to my aunt/uncle when professionals administered these types of drugs to them. They only lived for a couple months once they started taking them. Their health declined too rapidly and I don’t want this to happen to me.”

The peer counselor may or may not be an advocate of experimental drugs but they need to remember it is acceptable to have different viewpoints. The peer counselor should respond in an understanding way.

For example, they can say, “I know that all drugs have side affects and the ones not approved by the FDA have more risks, but they are tested on animals prior to humans. The drugs that are produced now are a better quality and truly assist people in maintaining their daily routines. Try to keep an open mind about experimental drugs.”

In the discussion following this role play emphasize keeping an open mind and make sure the peer counselor acknowledges/addresses the peer’s viewpoint before they make a suggestion that differs from that viewpoint.

Role Play #2 (for Scenario 4):

In this role play two people will be needed to portray this scenario. They will sit down in chairs facing each other. In this scene, the peer is a married woman who has no children. She wishes to have a family with her husband. She is very distraught and asks the peer counselor how she can have a safe pregnancy so the baby won’t get HD. She mentions that her sister’s baby was tested and found positive for HD which makes her concerns much stronger.

The peer counselor must remember that besides adoption, egg donation, or pre-implantation genetic diagnosis there isn’t anything this woman can do to make sure her baby doesn’t get HD. They must also realize they are not the most qualified person to address this woman’s fears.

The counselor must show sincere empathy toward the peer and then gently say, “My knowledge about reproductive options is limited, but we have genetic counselors available that can explain it

much better than I can. Would you like to talk to one of them? I'm sure they can help you and answer any questions you have."

In the discussion following this role play emphasize that the best person to talk to the peer about reproductive options is the genetic counselor. Make sure that the peer counselor knows they should refer the peer to a genetic counselor.

Role Play #3 (for Scenario 5):

In this role play two people will be needed to portray this scenario. They will sit down in chairs facing each other. In this scene, a single man reveals to his peer counselor that he wishes to have a baby with his girlfriend even though he has HD. He wants to have a family and doesn't think this disease should stop him. He admits he told his family about his plans and they were not supportive. They don't think he is making the right decision and have tried to pressure him not to have any children. They remind him in the end his girlfriend will ultimately be raising the child without him. This conversation with his family is brought up constantly and he doesn't think he can handle it anymore. He states, "I don't appreciate my family giving me a hard time."

The peer counselor must be sympathetic to this man. He should say something similar to this: "it must be difficult to endure that pressure." The peer counselor should say that family is important, but they cannot make the decision whether to have children for you. Finally, the peer counselor should refer their peer to a genetic counselor. They can say, "Would you be comfortable speaking to one of our genetic counselors? They can discuss all of your options with you."

In the discussion following this role play emphasize showing empathy because this is what the peer needs most.

Role Play #4 (for Scenario 10):

In this role play two people will be needed to portray this scenario. They will sit down in chairs facing each other. In this scene, a woman tells her peer counselor that she is worried when she tells her fiancé that she has HD, he will leave her. She is stricken with anxiety and borderline despairing. She says, "I don't know what to do. I'm not sure if I can bring myself to tell him."

The peer counselor must refer this peer to a social worker or a genetic counselor. They may say, "I understand you're very upset right now. This is a difficult time. Would you be willing to speak with a social worker or one of our genetic counselors?" Maybe suggest that your peer and her fiancé see a counselor together.

In the discussion following this role play emphasize that it is NOT definite that he will leave you and that professional counseling is the best solution in this situation. The peer counselor should not take it upon themselves to counsel the peer.

Role Play #5 (for Scenario 16):

In this role play two people will be needed to portray this scenario. They will sit down in chairs facing each other. In this scene, a man in his thirties begins to tell his peer counselor that his mother has HD. He says, “I am afraid that if it gets too bad, I won’t be able to handle it. What if she shakes all the time? What if I can’t understand her anymore? How am I supposed to know what she wants? I don’t know if I’m strong enough.”

The peer counselor needs to be understanding. He should not give too much advice because they will be referring this person to a professional. The counselor should say, “I’m sure you love your mother very much and it would mean a lot to her if you cared for her. But if you really can’t do it, she won’t be disappointed. She’ll understand. And there is help out there for you if this does happen. Would you like to talk more about this with one of our genetic counselors? They can answer your questions even better than I can.”

In the discussion following the role play focus on the role of the peer counselor in this situation. They should make them aware of resources and then refer them to a social worker or a genetic counselor.

Role Play #6 (for Scenario 19):

In this role play two people will be needed to portray this scenario. They will sit down in chairs facing each other. In this scene, the peer appears to be in a panic. She is afraid of the unknown. She expresses to her peer counselor she doesn’t know what is going to happen to her. The peer says, “I’m scared of how fast this is going to happen. What if I can’t communicate with my family anymore? I’m afraid of being trapped in my own body.”

The peer counselor should tell the peer that HD is different for everyone and we cannot predict how it will be for them. Every story is unique. The peer counselor should say something like this: “I know this is an overwhelming time for you right now, but please don’t be afraid to reach out to your family. Friends and HD resources can help too. Try to relax and if you do, you can lead a more fulfilling life. I think talking to a social worker or a genetic counselor would really help you. Is that something you would want to do?”

During the discussion make sure to focus that HD is unpredictable, but that doesn’t mean it has to be scary. Make sure the peer counselors know who to suggest to go to for help and that they refer their peer to a professional.

Role Play #7 (for Scenario 20):

In this role play two people will be needed to portray this scenario. They will sit down in chairs facing each other. In this scene, the peer is very upset. They tell the peer counselor they are afraid that their sons and daughters will test positive for HD just like them. They say, “My mother had HD and three of her children including me got it. I saw what that did to her as well as my brother and sister. I don’t want to do that to my children. They don’t deserve that.”

The peer counselor should remain sympathetic and say something like this: “I know this is an overwhelming time for you right now but please don’t be afraid to reach out to your family. Friends and HD resources can help too. I think talking to a social worker or a genetic counselor would really help you. Is that something you would want to do?”

In the discussion, focus on the peer counselor knowing when to refer the peer to a social worker or a genetic counselor.

Role Play #8 (for Scenario 21):

In this role play two people will be needed to portray this scenario. They will sit down in chairs facing each other. In this scene, the peer has major anxiety about telling their family they have HD.

They say, “I’m not sure if my family will be accepting of me once I tell them. I’m a little afraid to actually. I know other people in my family have it, but they have better relationships than I do. Sometimes I feel like an outsider. Other times I think they just won’t be able to handle one more person in our family having HD.”

The peer counselor should remain sympathetic and say something like this: “I know this is an overwhelming time for you right now but please don’t be afraid to reach out to your family. Friends and HD resources can help too.” The peer counselor in this scene had a positive experience when they told their family so they can share their experience with their peer.

Afterward, they say: “I think talking to a social worker or a genetic counselor would really help you. Is that something you would want to do?”

In the discussion, focus on the peer counselor knowing when to refer the peer to a social worker or a genetic counselor.

Role Play #9 (for Scenario 23):

For this role play, two people will be required to act this scenario out. They will sit in chairs facing each other. In this scene, the peer is asked to explain how they felt once they received the positive test result. The peer answers, “Well, at first I couldn’t believe it. I mean I was in shock.

Then I became very angry. How dare this happen to me! I don't deserve this, you know? I couldn't really think straight I was so mad."

The peer counselor must be understanding and tell the peer that their feelings of anger are normal. The counselor may say something like, "I understand why you're angry. I had trouble accepting it myself at first. But it isn't healthy to stay mad. You know there are people and resources available that can help you through this emotional time. Would you be comfortable speaking to a social worker or genetic counselor? They helped me a lot when I was angry and trying to come to terms with my test result."

In the discussion following the role play focus on explaining to the trainees when it is appropriate to refer their peer to a professional. Emphasize that the peer counselor should be sympathetic and understanding.

Role Play #10 (for Scenario 28):

For this role play, two people will be required to act this scenario out. They will sit in chairs facing each other. In this scene, the peer is asked to describe what it is like living with HD. "Well, I just found out that I have HD but I had a feeling I did a long time ago. I really feel helpless...almost depressed. I truly feel that I have lost control of my life."

The peer counselor should remain sympathetic and understanding. They could say, "It is okay to feel helpless, but we want to get past this. What makes you happy in your life? You should try and surround yourself with those things. Also, now is the time to take control and you can by gathering information and taking the best possible care of yourself. If you do this, you can lead a more fulfilling and extended life. This will help you overcome your feeling of helplessness."

In the discussion following the role play focus on the counselor being positive. Emphasize that the peer counselor should ask the peer what makes them happy and maybe list a couple things that do. The counselor could even ask the mentee to write them down if they wish.

Role Play #11 (for Scenario 29):

For this role play, two people will be required to act this scenario out. They will sit in chairs facing each other. In this scene, the peer expresses concern over losing insurance after testing positive. The peer might say, "I heard a rumor that one of my coworkers was diagnosed a couple months ago with a terminal illness and they lost their insurance immediately. It was all hush-hush but the workers found out about it. I'm afraid this is going to happen to me."

The peer counselor should be familiar with the health care reform and comfortable discussing it with their peer. They may say something like, "Well I understand your fear. No one wants to lose their coverage. But did you know that in 2014 it will be illegal to deny anyone on the basis of

health status? Maybe talking to a social worker or a genetic counselor would be helpful. Would you like to speak to one of them?"

In the discussion following the role play make sure to discuss health care reform with all the peer counselors. You want to make sure they are familiar with this material before they speak with their peer.

Role Play #12 (for Scenario 33):

For this role play, two people will be required to act this scenario out. They will sit in chairs facing each other. In this scene, the peer is describing an experience at work where he/she was about to tell their coworker they had HD. They would say, "We were standing around in the break room and I had made the decision to tell my coworker. Just as I was getting ready to tell them, I choked. I couldn't say anything because I was afraid they would think of me differently."

The peer counselor should remember that it is the person's choice whether to share this information with their coworker. They could say something like, "I understand why you were afraid but it is your decision whether you tell them. It is okay if you want to and it is okay if you don't. Maybe you could tell someone you trust? Unfortunately, not everyone will be supportive and I just want to make you aware of that before you tell people."

In the discussion following the role play focus on the peer counselor telling the peer that it is their decision whether they tell people. Some people may judge them, but not everyone will and the peer needs to be aware of this.

Role Play #13 (for Scenario 35):

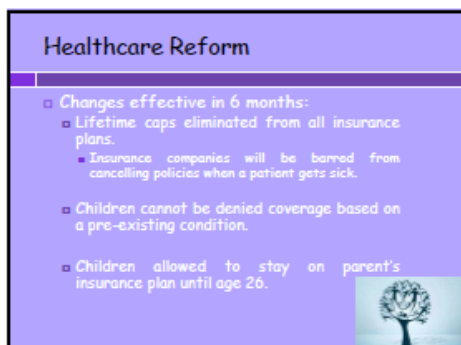
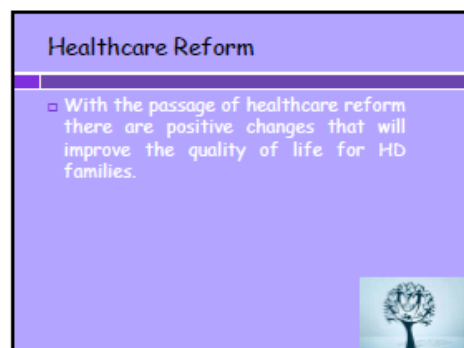
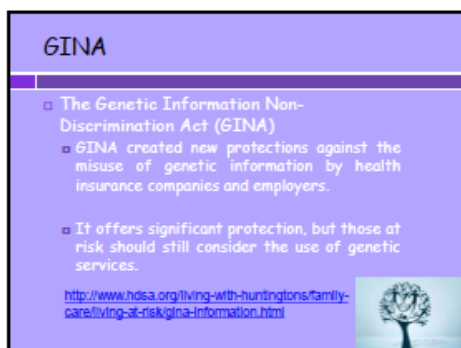
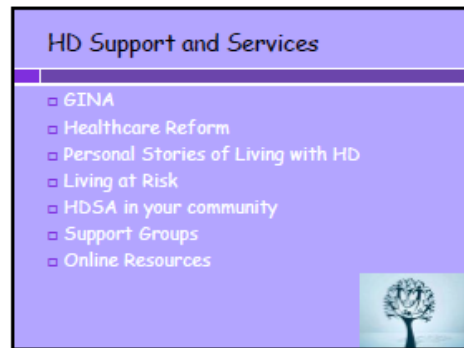
For this role play, two people will be required to act this scenario out. They will sit in chairs facing each other. In this scene, the peer is talking to their peer counselor about HD. The peer is saying, "...I'll never forget the look on my Mom's face when I told her I had HD..." The peer counselor notices that when the peer began talking about this experience, they became teary-eyed. They also note that the peer is beginning to tremble as they talk more about it.

The peer counselor leans forward and is attentive to the peer. They may briefly rest a hand on the peer. They may say, "Please tell me how you're feeling. I know this is difficult to talk about but I'm listening." Then if the peer responds or not the peer counselor should then say, "Would you be comfortable talking to a social worker or genetic counselor? I think they will help you more than I can and they're really easy to talk to."

In the discussion following the role play emphasize the importance of sincerity. Try to create an environment where the peer is comfortable talking with the peer counselor. Go over with the

peer counselors when it is appropriate to refer their peer to a social worker or a genetic counselor.

A.13 SUPPORT



Social Security Income

- Must be disabled to qualify for SSI
- Amount you receive is based on your income/financial need
- Pays benefits based on financial need/disability



Personal Stories of Living with HD

- For some example stories please visit:

<http://www.hdsa.org/living-with-huntingtons/faces/past-faces/index.html>



HDSA in your community

- Find your local HDSA Chapter, affiliate, or regional office:
- In Pennsylvania:
 - Eastern Pennsylvania Chapter: Caryn Freas
 - Western Pennsylvania Chapter
- Other Locations found at:

<http://www.hdsa.org/about/chapters-and-affiliates/index.html>



Support Groups

- In Pennsylvania:
 - Greensburg Area Family and Friends Meeting
 - Hershey, PA
 - Plymouth Meeting
 - Western PA- Meeting in Pittsburgh
 - Erie, PA
 - Other locations can be found at:

<http://www.hdsa.org/living-with-huntingtons/family-care/support-groups/index.html>



Online Resources

- For more information please visit:

<http://www.hdsa.org/living-with-huntingtons/family-care/other-med-resources/1177.html>

<http://www.hdsa.org/>



Additional Resources

- Questions? Call the HD Helpline
 - 1-888-779-HDSA (1-888-779-4372)



A.14 ASSESSING EMOTIONS

Assessing Emotions

3/3/2013

Assessing Emotions

Personal Risk Information

- When talking with your peer at the first meeting, you are making an assessment of how she is doing.



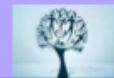
Concerns

- You may learn of current/past psychiatric disorders
 - Such as mood disorders, psychotic disorders, alcohol/substance abuse, ADHD, TBI, PTSD, Cluster B personality disorders, conduct disorders (antisocial behavior, aggression, etc.)



Concerns

- When adjusting to a positive HD test result, we are always worried about how the individual will adjust to the information and the possibility of suicide.
- Some of these behaviors are normal in response to a positive test result, but we expect these behaviors to resolve in about 2-6 months. If they persist, you should seek professional help.



Concerns

- If symptoms such as those below are seen, you should call the HD SA Helpline.
 - Change in eating and sleeping habits
 - Withdrawal from friends, family, and regular activities
 - Violent actions or behavior
 - Drug and alcohol use
 - Unusual neglect of personal appearance
 - Marked personality change
 - Persistent boredom, difficulty concentrating, or a decline in the quality of work
 - Frequent complaints about physical symptoms, often related to exertion, such as dizziness, headaches, fatigue, etc.
 - Loss of interest in pleasurable activities
 - Not tolerating praise



Concerns

- Be aware of and ask your peer about situations that cause excessive stress for your peer such as:
 - Triggering events leading to humiliation, shame, or despair; ongoing medical illness especially central nervous system disorders and pain; intoxication; family turmoil/chaos; social isolation.



Additional Resources

- Questions? Call the HD Helpline
- 1-888-779-HDSA (1-888-779-4372)



A.15 DIFFICULT SCENARIOS

Difficult Scenarios

Difficult Scenarios

- Scenario 1:
 - A peer expresses feelings you do not agree with.
- Possible solution:
 - Realize it is acceptable to have different viewpoints.
 - Be willing to listen to and support another person's feelings.



Difficult Scenarios

- Scenario 2:
 - A peer expresses feelings that her positive test result was determined by fate or a higher power seeking to punish them.
- Possible solution:
 - Inheriting the HD gene was 50/50, which was known prior to testing. We do not choose which genes we pass on to our children. Rather than being a matter of fate the gene test was 50/50 that the gene test was positive and there was no punishment being transmitted to your peer. As a peer counselor we want you to encourage faith and hope and higher power relationships.



Difficult Scenarios

- Scenario 3:
 - A peer expresses a reproductive opinion you do not agree with, e.g., choosing not to have children or terminating a pregnancy if a prenatal diagnosis is positive.
- Possible Solution:
 - As a peer counselor you should refer couples to discuss reproductive options further.
 - Peers need to be understanding and demonstrate support, but not offer their opinion about reproductive issues.



Difficult Scenarios

- Scenario 4:
 - A peer wants to know what reproductive options are available to reduce the risk that a future child will have HD.
- Possible solution:
 - A referral should be made to a genetic counselor.




Difficult Scenarios

- Scenario 5:
 - A peer shares that she has been pressured by her family not to have any children.
- Possible solution:
 - State that although family is important, the decision ultimately lies with them whether to have children. Refer them to discuss all of their options.




Difficult Scenarios

- Scenario 6:
 - Your peer makes statements which you believe are hints he may wish to hurt himself or others.
- Possible solution:
 - Make a referral immediately to either the social workers in the HD chapter or genetic counselor.




Difficult Scenarios

- Scenario 7:
 - A peer expresses a desire to make drastic or irrational life changes/decisions.
- Possible solution:
 - Respond by saying, "Tell me more about your plans."
 - Ask the peer to explain why she is considering these choices.




Difficult Scenarios

- Scenario 8:
 - A peer expresses concern about how her significant other or children reacted to the news of her test result.
- Possible solution:
 - Adjustment to the result is a difficult process for all family members especially the spouse. Encourage your peer to have discussions with their spouse and children about their feelings.




Difficult Scenarios

- Scenario 9:
 - A peer shares that his spouse wants a divorce.
- Possible solution:
 - Refer the peer to either the social workers or genetic counselor or suggest that the entire family see a family counselor.




Difficult Scenarios

- Scenario 10:
 - A peer expresses concern that her significant other will leave her.
- Possible solution:
 - Refer the peer to either the social workers or genetic counselor or suggest that the entire family see a family counselor.



Difficult Scenarios

- Scenario 11:
 - A peer expresses anxiety over whether or not to tell her friends she has tested positive.
- Possible solution:
 - Telling friends and family about a test result is difficult. Share with your peer how you went about this.
 - Referral to social workers and genetic counselor is available as well.



Difficult Scenarios

- Scenario 12:
 - A peer asks how his disease will look in the future/develop.
- Possible solution:
 - There is no clear path the disease will take because the symptoms and severity is different for every individual even within families. Tell him to remain calm.



Difficult Scenarios

- Scenario 13:
 - A peer expresses guilt/shame because she feels she has put her children at risk.
- Possible solution:
 - Tell her the guilt/shame she feels is natural, but unnecessary. Relate an experience that may have been similar that you felt after receiving your test results. Refer your peer to a social worker or genetic counselor.



Difficult Scenarios

- Scenario 14:
 - A peer expresses guilt or shame because he no longer wants to have children, but had previously planned with his significant other to have a family.
- Possible solution:
 - Refer your peer to a social worker or genetic counselor to discuss all reproductive options. Suggest talking to their significant other about his feelings perhaps in the presence of a family counselor or social worker.



Difficult Scenarios

- Scenario 15:
 - A peer expresses guilt/shame because she does not want to care for their affected family members because the remainder of her future is too hard to bear.
- Possible solution:
 - Explain if she truly cannot care for her family member(s), there is help available, and it does not mean they are selfish. Remind them that the disease presentation of their family members will not necessarily reflect what their disease will look like in the future.



Difficult Scenarios

- Scenario 16:
 - A peer expresses guilt/shame because he is concerned he will not be able to care for their family member(s) depending on when and how HD manifests itself.
- Possible solution:
 - Explain if he truly cannot care for his family member(s), there is help out there, and it does not mean they should feel guilty. Refer to a social worker or genetic counselor.



Difficult Scenarios

- Scenario 17:
 - A peer expresses guilt/shame because she wants her significant other to be her caregiver for her when necessary.
- Possible solution:
 - Tell her the feeling is natural to want someone to care about and for her. Remind her that her significant other will need to come to terms with the results the same way she is. Give him time to figure out how he feels; do not pressure him. There is still a long time before symptoms start. Refer to a social worker or genetic counselor.



Difficult Scenarios

- Scenario 18:
 - A peer expresses guilt/shame because he feels he is defective.
- Possible solution:
 - Many people with HD lead long fulfilling lives. It was not in his control that he inherited the disease and he is certainly not defective. Remind him to focus on the positive things in their life. If your peer shows signs of depression, refer him to a social worker or genetic counselor.



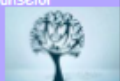
Difficult Scenarios

- Scenario 19:
 - A peer expresses fear of the unknown progression, timing, and extent of her disease.
- Possible solution:
 - Tell her it can be an overwhelming time, but do not hesitate to reach out to family, friends, and HD resources for support. There is no way to know how the disease will progress, worrying will only create more potential for anxiety. Remind your peer that the disease is different for everyone. Try to remain positive. Refer to a social worker or genetic counselor.



Difficult Scenarios

- Scenario 20:
 - A peer expresses fear that his children will also test positive.
- Possible solution:
 - Tell him it can be an overwhelming time, but do not hesitate to reach out to family, friends, and HD resources for support. Refer to a social worker or genetic counselor to discuss their fears.



Difficult Scenarios

- Scenario 21:
 - A peer expresses fear of telling her family members.
- Possible solution:
 - Tell her this can be an overwhelming time, and it can be helpful to reach out to family, friends, and HD resources for support. If your family was supportive, share your experience with your peer. Refer to a social worker or genetic counselor to discuss their fears.



Difficult Scenarios

- Scenario 22:
 - A peer expresses fear of upsetting his significant other or children.
- Possible solution:
 - Each person deals with difficult information differently. It may take time for his family members to come to terms with his test result. Having an honest and understanding environment is important for both parties. Refer to a social worker or genetic counselor to discuss their fears.



Difficult Scenarios

- Scenario 23:
 - A peer expresses anger about her positive test result.
- Possible solution:
 - These feelings are normal, but it is not healthy to remain angry. Resources are available to help her through this emotional time. Refer to a social worker or genetic counselor.



Difficult Scenarios

- Scenario 24:
 - A peer expresses anger directed toward his parent for "giving" him the gene.
- Possible solutions:
 - His parent could not control this outcome, so anger should not be directed towards him/her. Refer to a social worker or genetic counselor.



Difficult Scenarios

- Scenario 25:
 - A peer shows symptoms of or expresses depression and hopelessness.
- Possible solution:
 - Immediately refer her to a social worker or genetic counselor for additional help and support.



Difficult Scenarios

- Scenario 26:
 - A peer seems resistant to trust you and unsure of the situation.
- Possible solution:
 - Remain genuine, attentive, and share something of yourself such as giving him your story. Refer to a social worker or genetic counselor if trust cannot be built.



Difficult Scenarios

- Scenario 27:
 - A peer expresses she feels that she has lost control of her life.
- Possible solution:
 - A feeling of helplessness is common after first learning of her test results. Now is the time to gather information and work on taking the best possible care of herself in order to live a fulfilling and extended life. Gaining information and being prepared will empower them to overcome their feelings of helplessness.



Difficult Scenarios

- Scenario 28:
 - A peer expresses concern over losing insurance after testing positive.
- Possible solution:
 - Discuss health care reform with the individual and how in 2014, denying coverage on the basis of health status will be illegal. Refer to a social worker or genetic counselor.




Difficult Scenarios

- Scenario 29:
 - A peer expresses concern over his children losing insurance or having higher premiums if they test positive.
- Possible solution:
 - Discuss health care reform and how children cannot be denied coverage based on a pre-existing condition. Refer to a social worker or genetic counselor for more information.




Difficult Scenarios

- Scenario 30:
 - A peer expresses concern that she will lose her job if her employer finds out she has tested positive for HD.
- Possible solution:
 - Share with your peer that she does not need to disclose her test results to her employer. Discuss health care reform and state that employers cannot discriminate.




Difficult Scenarios

- Scenario 31:
 - A peer expresses concern that when he starts showing symptoms, he will lose his job.
- Possible solution:
 - Discuss health care reform with the individual and explain he cannot lose his job based on a health condition. Help him to recognize depending on the severity of their symptoms it may be the best choice to leave their work.




Difficult Scenarios

- Scenario 32:
 - A peer expresses anxiety over whether or not to tell her employer or coworkers that they have tested positive.
- Possible solution:
 - Empower her to recognize the choice to share this information is theirs alone. Make sure she is aware that some individuals will judge them and not be supportive.




Difficult Scenarios

- Scenario 33:
 - A peer engages in joking and laughter when discussing issues surrounding her positive test result.
- Possible solution:
 - Still discuss the support that is available and that they do not need to hide behind joking and laughter and are permitted to express their true feelings. Try using communication techniques to discover the root emotion being masked.




Difficult Scenarios

- Scenario 34:
 - During your discussion, your peer seems to be sweating, trembling, or becoming teary-eyed.
- Possible solution:
 - Remain supportive. Try not to cry in front of your peer, but be sympathetic and sincere. Ask your peer what he is feeling or what it is that seems to be upsetting him. Refer to a social worker or genetic counselor.



Additional Resources

- Questions? Call the HD Helpline
 - 1-888-779-HDSA (1-888-779-4372)



A.16 EXERCISES

EXERCISE 1: TRADITIONAL EGG DROP

OBJECTIVE: To help peer counselors work together and build teamwork

MATERIALS: Paper plate, Popsicle sticks, newspaper, scotch tape, straw, paperclip, carton of eggs

PROCESS: The participants should be divided into small groups, each approximately with the same number of participants. The following materials should be given to each group: paper plate, Popsicle sticks, newspaper, scotch tape, straw, paperclip, and an egg. Ten to fifteen minutes should be given for the participants to work together to create an egg package designed to successfully save an egg from breaking upon being dropped from a certain height (can be determined according to where the training is being held). A winner (if desired) can be determined by judging the participants on the creativity of the egg package and its successfulness in protecting the egg from breaking.

CLOSURE: Once the groups have completed the egg drop have all the participants come together to discuss the values of teamwork. Invite participants to discuss certain individuals' roles in creating a successful (or unsuccessful, but creative!) egg package. Emphasize the importance of teamwork.

EXERCISE 2: HD SCRABBLE

OBJECTIVE: Using teamwork to construct HD related words from randomized letters

MATERIALS: Index cards or small pieces of paper with letters on them, paper bags

PROCESS: The participants should be divided into small groups, and each group should be given its own bag full of letters. Once in their small groups, participants should be instructed to share something interesting about themselves to the group. The activity should be conducted like a normal scrabble game. Every individual should pull out seven letters from the bag, and HD related words should be constructed from the letters. Individuals may help each other if necessary. The words should be built off each other. New letters should be pulled out after every turn. Once every letter in the bag has been used, the game is over. Each group should then write a list of all the words they came up with during the game. The groups are then encouraged to discuss with each other their lists of words.

CLOSURE: Have the groups of participants come together and ask them to openly share their feelings regarding the game. Ask whether or not the participants learned any new words regarding HD that they may have never heard before. Answer any questions the participants may have about HD.

EXERCISE 3: PEER EDUCATION PASSWORD

OBJECTIVE: To learn and share information in a way that is fun and appealing.

TIME: 20 to 40 minutes

MATERIALS: Large index cards with selected words on them, one word per card. Two rows of chairs for participants.

PROCESS: Place two rows of chairs so that they face each other and ask the participants to sit on them. Have a stack of index cards with words ready to use, but do not let the participants see the words on the cards yet.

Stand behind one line and tell everyone to look straight ahead. Show the password to the people in the line facing you. The participants who have seen the password have to get those sitting opposite them to guess it, by giving them one-word clues. One person at the beginning of the line gives a clue, and the person sitting directly opposite him or her tries to guess the password. If he or she is wrong, the next person gives a clue, and the participant sitting opposite tries to find the password. This continues until someone guesses the word. Some suggested passwords are: repeat, muscle spasm, DNA, hereditary, caregiver, gene, family, etc.

Explain to the group that the idea of the information game they are playing is to give each other clues, so they can try to guess the correct answer. You can give them some guidelines for giving clues: although the clues themselves can only contain one word, the answers may have more than one word; the clue should not contain part of the actual answer in it. Rhyming clues are also discouraged.

CLOSURE: Once you have spent enough time (approximately 15 to 20 minutes) playing the game, sit with the group and ask the participants, one at a time, to tell the group whatever they can about the word they are holding. Then, invite others to add any information that they think may be relevant. As the facilitator, you can then correct any misinformation and add any relevant information you think necessary.

EXERCISE 4: INFORMING PARTICIPANTS ABOUT HD

OBJECTIVE: The overall objective of the proposed peer education session is to create awareness of HD and to build positive attitudes towards those affected by HD.

QUESTIONNAIRE: Questionnaires can be handed out as the participants walk into the room. Ask each person to fill it out. They are given about ten minutes to complete them and afterwards are collected. If at all possible, they should be scanned through quickly to see what the participants already know about the subject, which will help determine what information needs focused on and emphasized. The same questionnaire may be used at the end of the session, in order to help evaluate whether it was successful.

INTRODUCTION: It is important to start off with an introduction to the peer education session, to introduce the participants and to remind them of why they are here. An example of an introduction exercise is to have all of the peer educators stand in a line, say their names, and say why they are at the presentation, why they are teaching others about HD, and how HD impacts them. After this is completed, the peer educator could say: *“What we are trying to say is that we all, each and every one of us in this room, have to deal with the reality that HD exists in this world, and has an impact, directly or indirectly, on our lives.”*

ICEBREAKER: Have the participants restate their name and also state a fun fact about themselves that not many people know about.

ROLE PLAY: This is the focus of the exercise. Several scenarios should be selected beforehand by the peer educators. The scenarios should be presented to the participants and the participants should choose which of the scenarios they would like to see in the role play.

FINAL QUESTIONS: At the end of the session, the audience is invited to share their reactions to what they have experienced during the session. They may have responses to the role plays or questions that they felt were unanswered during the presentation. This is their chance to ask any questions they still have after participating in the whole session. The peer educators also have the opportunity to review issues that may have arisen out of the role plays; for example, some of the choices made by characters portrayed might merit discussion.

WRAP UP: In a wrap-up session, all participants and support staff are thanked for their contribution. Participants complete the post-workshop questionnaire that could be the same questionnaire used previously.

EXERCISE 5: ROLE PLAY BASED ON THE SPECTRUM OF ATTITUDES

OBJECTIVE: To practice some of the theoretical attitudes towards building skills around partnership.

TIME: 45 min

MATERIALS: Index cards

PROCESS: On one side of the index cards, write the word 'adult'. On the other side of the cards, write the following statements, one on each adult card:

You want to control everything.

You are a committed leader who cares about this and wants it to be a success.

You are passive.

You are outgoing and you do not take things seriously.

You are negative about everything that is suggested.

You are bored and do not want to be here.

Make sure you have three to four sets of these cards, depending on the size of your total group.

Introduce this session by referring to the spectrum of the attitudes theory, and to how many adults get stuck in attitudes that inhibit their efforts to work together. Ask the participants to experiment a little by role playing in different attitudes. Explain that you will ask them to form small groups (depending on the size of the whole group). Once they have formed their groups, hand out the cards to random individuals. The participants read the directions, and then tape the card to their chest so that the adult side is showing and ask them to begin their role play.

Explain that the group has to plan a big campaign event that involves peer education activities. Give them ten minutes to come up with a plan, and remind them that they must all agree with the plan they propose. Also, tell them to prepare a short presentation of their plan to give to the entire group.

After ten minutes, ask each group what plan they have come up with (even though, obviously, they will not have had enough time to finalize a plan). Ask them to share the plan, but be sure to ask if all members of the group agree with it.

CLOSURE: Once they have finished, ask them to share their roles with everyone in their small group. Keep participants seated in their groups and ask several people from each group to describe the process that they went through. Following each group reflection, ask the entire group the following questions:

- Who was the hardest person to work with?
- What did people do to reach out to this person?
- How did it feel to play your role?

- What were the most effective strategies for working together to come up with a new plan?

EXERCISE 6: STORYTELLING

For this exercise, the peer counselor trainees will be told to brainstorm ideas about their own story. It will be mandatory for the trainees to share their story with the group. Once they have been given time to think, everyone will move their chairs into a circle. There will be one or two circles depending on the size of the group. Each peer counselor will share their story and after they have finished, all members will be allowed to speak, provide input, be silent, etc. The leader of this circle will provide structure if needed.

EXERCISE 7: RESPECTING PRIVACY

Create a worksheet for a group discussion. There will be three situations. Situation one: The mentee asks the peer counselor for her phone number or other inappropriate information. Situation two: The peer counselor is pushy. Example: The counselor attempts to thrust his/her views on the mentee. Situation three: The mentee asks the peer counselor if they could meet outside of the session for some additional time. There will one or two questions at the end of each situation such as, “what could so-and-so have done differently?” Have all participants write down their responses. Then verbally discuss their responses with the group, and finally, share the best or most correct solutions with the group.

EXERCISE 8: KNOWING WHEN TO REFER FOR ADDITIONAL HELP

For this exercise, a role play will be conducted. Four people (all peer educators) will participate. Two peer educators will act the scenarios out and the other two educators will facilitate (narrate) the situation. A total of four scenarios will be acted out. Scenario 1: A mentee says to a peer counselor, “I think it would be better if I was dead.” Scenario 2: After the peer counselor tries to talk about the mentee’s future in a positive light, the mentee resists discussing that topic. Scenario 3: The mentee says to the peer counselor that she is worried her family isn’t paying attention to her and she feels isolated. Scenario 4: The peer counselor notices the mentee no longer wears bright colors, is no longer optimistic, and there are noticeable injuries on her body. At the end of these scenarios, a Q and A session will take place to address any concerns. The narrators (facilitators) at some point will address how to determine the severity of the situation.

APPENDIX B

IRB APPROVED DOCUMENTS

B.1 IRB APPROVAL LETTER



University of Pittsburgh *Institutional Review Board*

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
<http://www.irb.pitt.edu>

Memorandum

To: Elizabeth Gettig, MS, CGC

From: Christopher Ryan, PhD, Vice Chair

Date: 7/9/2012

IRB#: [PRO11100757](#)

Subject: Peer to Peer Training for Those Who Have Tested Positive for the Huntington Disease Gene

The University of Pittsburgh Institutional Review Board reviewed and approved the above referenced study by the expedited review procedure authorized under 45 CFR 46.110. Your research study was approved under 45 CFR 46.110 (7).

The IRB has determined the level of risk to be minimal.

Approval Date: 7/7/2012

Expiration Date: 7/6/2013

For studies being conducted in UPMC facilities, no clinical activities can be undertaken by investigators until they have received approval from the UPMC Fiscal Review Office.

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5)]. Refer to the IRB Policy and Procedure Manual regarding the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

B.2 SURVEYS

[Letterhead]

Survey post mentor training (Survey 1)

Question	Excellent or a great deal 1	Above Average or much 2	Average or somewhat 3	Below Average or Seldom 4	Extremely Poor or None 5
1. How would you rate your previous knowledge of peer to peer counseling before this training?					
2. How would you rate your current knowledge of peer to peer counseling?					
3. How would you rate the information you were given to be a peer mentor?					
4. How would you rate your current confidence level as a peer mentor?					

4a. How much of this is the result of this training program?					
5. How would you rate your current understanding of effective communication skills?					
5a. How much of this is the result of this training program?					
6. How would you rate your knowledge of your boundaries as a peer counselor?					
6a. How much of this is the result of this training program?					
7. How would you rate the strategies that currently help you talk to your peer mentees with a positive test result for HD?					
7a. How much of this is the result of this training program?					
8. How would you rate your current confidence in supporting someone with a positive test result for HD?					
8a. How much of this is the result of this training program?					
9. How would you rate your current understanding for the rationale for peer counseling?					
9a. How much of this is the result of this training program?					
10. How would you rate your current awareness of support services available to individuals with HD?					
10a. How much of this is the result of this training program?					
11. How would you rate your current					

knowledge of community services available to individuals with HD?					
11a. How much of this is the result of this training program?					
12. How would you rate your current knowledge about helping newly testing positive individuals find internet information that is reliable?					
12a. How much of this is the result of this training program?					
13. How would you rate your current comfort level with sharing your story with HD?					
13a. How much of this is the result of this training program?					
14. How would you rate your current knowledge of Huntington Disease?					
14a. How much of this is the result of this training program?					
15. How would you rate your current comfort level to recognize an individual that needs additional help from a professional like a social worker or psychologist?					
15a. How much of this is the result of this training program?					

16. Are there other areas of the training from which you think you would benefit in your role as a peer counselor?

17. What did you find most helpful about the peer to peer counseling program?

18. What did you find the least helpful about the peer to peer counseling program?

19. What needed improvement or should be included in the peer to peer counseling program?

20. Any other comments?

[letterhead]

Survey for mentor administered at 6 months with peer (Survey 2)

Question	Extremely satisfied 1	Somewhat satisfied 2	Neither Satisfied or dissatisfied 3	Somewhat dissatisfied 4	Extremely dissatisfied 5
1. How would you rate your overall satisfaction with your peer to peer counseling experience?					
2. How would you rate your satisfaction with your peer?					
3. How would you rate your satisfaction with your skills in being:					
3a. a good listener					
3b. communicating well					
3c. making your peer feel respected and valued					
4. How would you rate your peer's in adjustment to their HD test result?					

Question	Definitely 1	Very probable 2	Possibly 3	Probably not 4	Very probably not 5
5. How likely are you to recommend peer counseling to another person?					
6. How likely are you to continue peer to peer counseling in the future?					
7. How likely do you think your peer is to become a peer counselor in the future?					

8. How do you feel the peer to peer counseling program has helped you?

9. What did you find most helpful about the peer to peer counseling program?

10. What did you find the least helpful about the peer to peer counseling program?

11. What needed improvement or should be included in the peer to peer counseling program?

12. Any other comments?

[letterhead]

Survey for mentees administered at 6 months with peer (Survey 3)

Question	Extremely satisfied 1	Somewhat satisfied 2	Neither Satisfied or dissatisfied 3	Somewhat dissatisfied 4	Extremely dissatisfied 5
1. How would you rate your overall satisfaction with your peer to peer counseling experience?					
2. How would you rate your satisfaction with your peer counselor?					
3. How would you rate your satisfaction with your peer counselor's skills in being:					
3a. a good listener					
3b. communicating well					
3c. making you feel respected and valued					
4. How would you rate your satisfaction with your peer in adjusting to your HD test result?					

Question	Definitely 1	Very probable 2	Possibly 3	Probably not 4	Very probably not 5
5. How likely are you to recommend peer counseling to another person?					
6. How likely are you to continue peer to peer counseling in the future?					
7. How likely are you to become a peer counselor yourself in the future?					
8. How likely are you to use services and resources your peer counselor shared with you?					

9. How do you feel the peer to peer counseling program has helped you?

10. What did you find most helpful about the peer to peer counseling program?
11. What did you find the least helpful about the peer to peer counseling program?
12. What needed improvement or should be included in the peer to peer counseling program?
13. Any other comments?

B.3 CONSENT



University of Pittsburgh

Department of Human Genetics

Elizabeth A. Gettig, M.S., C.G.C.
Associate Professor
Co-Director, Genetic Counseling Program

Graduate School of Public Health
A306 Crabtree Hall
130 DeSoto Street
Pittsburgh, Pennsylvania 15261
Email: bgettig@pitt.edu
Tel: 412-624-3018
Fax: 412-624-3020

CONSENT TO ACT AS A SUBJECT IN A RESEARCH STUDY

TITLE: Peer to Peer Training for Those Who Have Tested Positive for the Huntington Disease Gene

PRINCIPAL INVESTIGATOR: Elizabeth Gettig, MS, CGC, Associate Professor of Human Genetics
130 DeSoto Street, Pittsburgh, PA 15213
Phone: 412.624.3066
e-mail: bgettig@pitt.edu

The purpose of this study is to develop, implement, and evaluate a peer to peer training program for individuals who have tested positive for the Huntington Disease (HD) gene. Approximately 5 people (mentors) who have tested positive for the gene over a year ago and 5 people (peers) who have recently tested positive, at least 18 years of age or older, will be invited to participate in this research study. If you agree to participate, **mentors will complete a training program and will be paired with a peer.** Mentors will complete a questionnaire after the training and both mentors and peers will complete a questionnaire about their experience with the peer to peer program six months after being paired. Completing the questionnaires will **take you less than 30 minutes.** For the purpose of this study, mentors and peers will meet or

have conversations over a six month period to provide support to the peer recently informed of their gene status. The relationship may continue longer but will not be part of the study.

There is little risk involved in this study. No invasive procedures or medications are included. **The major potential risk is a breach of confidentiality**, but we will do everything possible to protect your privacy. Another potential risk associated with your participation is the **discomfort** some people experience when discussing HD. This is not unusual, and if you like, we will discuss your feelings and concerns with you.

There are **no costs** to you for participating in this study, and you will receive **no direct benefit** from participating in this study.

All records pertaining to your involvement in this study are kept **strictly confidential** and any data that includes your identity will be stored in locked files, and will be retained by us for a minimum of five years. Your identity will not be revealed in any description or publications of this research. Results will not be shared with your instructors or University administrators, and will have no effect on your standing at this University. It is possible that authorized representatives from the University of Pittsburgh Research Conduct and Compliance Office (including the University of Pittsburgh IRB) may review your data for the purpose of monitoring the conduct of this study.

Your participation in this study is completely voluntary. You may refuse to take part in it, or you may stop participating at any time, even after signing this form. Your decision will not affect your relationship with the University of Pittsburgh.

If you have questions about this research study, you may contact the investigators listed at the beginning of this consent form. If you have questions about your rights as a research subject, please contact the Human Subjects Protection Advocate at the University of Pittsburgh IRB Office, 1.866.212.2668.

SUBJECT'S CERTIFICATION

- I have read the consent form for this study and any questions I had, including explanation of all terminology, have been answered to my satisfaction. A copy of this consent form will be provided to me.
- I understand that I am encouraged to ask questions about any aspect of this research study during the course of this study, and that those questions will be answered by the researchers listed on the first page of this form.
- I understand that my participation in this study is voluntary and that I am free to refuse to participate or to withdraw my consent and discontinue my participation in this study at any time without affecting my future relationship with this institution.
- I agree to participate in this study.
- Check and initial one of the roles below:
 - I agree to be a **Mentor** ☐ _____ (initials)

- I agree to be a **Peer** ☐ _____(initials)

Subject's Signature

Date

CERTIFICATION OF INFORMED CONSENT

I certify that I have explained the nature and purpose of this research study to the above-named individual, and I have discussed the potential benefits and possible risks of study participation. Any questions the individual has about this study have been answered, and we will always be available to address future questions as they arise.

Printed Name of Person Obtaining Consent

Role in Research Study

Signature of Person Obtaining Consent

Date

APPENDIX C

ADVISORY COMMITTEE

Thesis Director: Elizabeth A. Gettig, M.S., CGC, Associate Professor, Department of Human Genetics, Graduate School of Public Health, University of Pittsburgh

Thesis Committee Member: Robin E. Grubs, Ph.D., CGC, Assistant Professor, Department of Human Genetics, Graduate School of Public Health, University of Pittsburgh

Thesis Committee Member: Martha Ann Terry, Ph.D., Assistant Professor, Department of Behavioral/Community Health Science, Graduate School of Public Health, University of Pittsburgh

Thesis Committee Member: Jeanette M. Trauth, PhD, Associate Professor, Department of Behavioral/Community Health Science, Graduate School of Public Health, University of Pittsburgh

Advisory Committee Member: Peggy Polito, LSW, Family Services Coordinator, Western Pennsylvania Chapter, Huntington's Disease Society of America

Advisory Committee Member: Peggy Humbert, MSW, Family Services Assistant, Western Pennsylvania Chapter, Huntington's Disease Society of America

Advisory Committee Member: Valerie R. Suski, DO, Assistant Professor of Neurology, Department of Neurology, School of Medicine, University of Pittsburgh

Advisory Committee Member: Christa Lorenychick, BS, Genetic Counseling Student, Graduate School of Public Health, Human Genetics Department, University of Pittsburgh

Advisory Committee Member: Alicia Martinez, Volunteer, Graduate School of Public Health, Human Genetics Department, University of Pittsburgh

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