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Do they want to know? Analysis of the decision for presymptomatic testing

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Iowa State University, 1991

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Do they want to know? Analysis of the decision for presymptomatic testing

by

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ABSTRACT

This study examined the decision-making process involved when individuals consider being tested presymptomatically for two different diseases, Huntington's disease and HIV infection (including the Acquired Immunodeficiency Syndrome). Each disease has a long latency period between contracting the disease and developing obvious symptoms. Both illnesses follow a debilitating, catastrophic path often involving neurological and cognitive deterioration. No successful cure currently exists for either disease. Recent advances in medical diagnostic technology have presented patients with the opportunity to know if they will develop these illnesses. Positive test results may be devastating while no successful cure for the diagnosed disease is currently available. The circumstances under which an individual will choose to be tested for such an illness is examined in this study. Policy capturing techniques (PCT) were used to determine the contribution of the independent variables by covarying the five dichotomous variables to create 32 hypothetical diagnostic testing situations to assess the individual decision processes of 217 undergraduate subjects. These five independent variables were: transmission mechanism, health status of the subject, partner/parent carrier status, physician test recommendation, and reproductive plans. Results indicate significant main

effects for each of the five factors for the whole group. The five variables combined to account for more than 65% of the variance in the diagnostic decisional choices from the hypothetical scenarios. Cluster analysis was performed on the individual patterns of beta weights to determine if there were groups of subjects with similar decisions strategies. Seven clusters were found to represent different decisional patterns. Subject variables were of some use in describing the membership of each cluster. History of previous serious illness, plans for diagnostic testing, native language, and income were found to predict cluster membership and hence decision strategy. The implications of inadequate descriptors for the clusters and possible limitations in PCT are discussed.

INTRODUCTION

"What profits wisdom when there is nothing to be done."

Sophocles in Oedipus Rex

A number of recent medical breakthroughs have provided society with a new set of complex issues to consider. Advances in the diagnosis of a variety of medical conditions and illnesses have allowed medical practitioners the opportunity to offer currently healthy persons a look into their futures. Technological advances now allow a person to be tested for illnesses for which no symptoms have yet been detected or that may not develop for many years. Among these medical conditions are illnesses for which no current treatment or method of prevention is successful. The advent of these new medical services permits people to ask questions and to receive information about what their own medical future holds for them and to face the prospect that they may find that it holds a debilitating, degenerative terminal illness. How individuals will face the availability of such information is the purpose of this investigation.

The focus of the present study will be to explore how individuals go about deciding whether to be tested for late-onset, catastrophic diseases. The study

[1]This study was conducted under the guidelines and with the approval of the Iowa State University Human Subjects Committee.

will use a policy capturing technique (PCT) to explore how certain aspects of the decision situation affect whether or not one will choose to be tested and whether there are groups of individuals who go about the decision process in similar ways. The present study investigated five factors considered important in the testing decision: transmission mechanism, health status of the subject, partner/parent carrier status, physician test recommendation, and reproductive plans.

The emotional consequences of a disease and the emotional demands of coping with the physical, social, and medical aspects of that disease present tremendous difficulties to the patient. Chronic disease presents particularly potent challenges to a person's ability to cope. Chronic diseases typically are slow in onset, have a slower progression, and have a longer if not permanent duration. Many chronic illnesses result in a permanent health decline ending in death. On the other hand, acute disease often has a shorter more intensive presentation that quickly abates when the body's immune defenses are activated or when appropriate medical intervention is performed. Both acute and chronic illnesses involve such a major threat to personal resources that considerable effort has been put forth to identify the disease process at the earliest possible time.

People are often called upon to make decisions in their lives. Quite often these decisions are performed with little effort and have little lifelong

importance. What to eat today, when to go to the dentist, whether to lose a few pounds, or to exercise more are decisions that most of us give little thought. Some decisions are of more importance. Making long-term choices about diet and lifestyle are potent for people with heart disease. Likewise, individuals with severe medical conditions have to make difficult decisions about risky treatments or surgery. These decisions often involve high risk and great uncertainty.

In many situations, decision making by the patient is surrendered to the physician or other health care professional. For example, many persons surrender authority for making decisions about clinical tests to their physician. In fact, many diagnostic tests such as blood testing and x-rays are ordered by the physician without input at all from the patient.

To a great extent, public health officials play an important role in health decision making. In some sense, public health efforts to recommend blood cholesterol screening or breast mammography are efforts to persuade patients to seek testing for conditions that they do not know they have. These efforts are made not only to promote requests for testing by the patient but also to persuade health care professionals to offer routine testing to patients who may not initiate testing themselves. Generally, these efforts are aimed to promote greater insight into one's own health status and to promote health behavior changes to improve health or treat illness. Most testing decisions are relatively

easily made with little emotional impact, even when the patient is actively involved in deciding to be tested.

In some situations, however, the results of health testing have dramatic repercussions. Diagnostic procedures can reveal severe illness. They may reveal disease or illness that threatens permanent health problems or even death. A mammogram may reveal breast cancer or a blood test may reveal diabetes. In such cases, testing involves risks that are not routine and should involve greater informed participation by the patient. This greater need for informed participation has led to testing guidelines that include pre-test counseling to help the patient to make more informed decisions and prepare emotionally for the results.

Individuals at risk for certain genetic diseases now have the opportunity to be tested to determine if they will become ill. This testing can be performed for some conditions before symptoms develop. When testing is performed for some diseases that cannot be avoided, successfully treated, or cured, the results from such tests can be devastating for the patient and consequently demand greater patient participation in the decision about testing.

While progress has been made in explicating the variables related to some health behaviors, little has been done to study decisions related to asymptomatic diagnosis. Asymptomatic diagnostic testing differs from the traditional medical model where interventions are limited to persons who are ill.

Given the urgency of the AIDS epidemic and the diagnostic breakthroughs brought about by recombinant DNA research, the current study will begin to identify some of the important variables of the decision process of being tested for incurable conditions before one becomes ill.

The study will explore the health decision process of healthy young individuals by having them rate their willingness to be tested for two late-onset terminal illnesses in 32 hypothetical diagnostic testing situations. Multiple regression will reveal the salient situational factors related to the decision process of each subject. Analysis will determine the decisional strategy for the overall sample and for subgroups of the sample. Membership in the derived clusters of subjects with similar decisional strategies will be described through relationships with subject variables.

LITERATURE REVIEW

Choice is essential in life. Life offers many different opportunities for various alternatives in lifestyle. Important decisions are involved in choice of childbearing, occupation, and home. Individuals also make decisions regarding how they maintain their health and utilize medical services. Psychology has played an important role in the effort to assist individuals in making best use of various health services.

Many of these efforts involve attempts to examine how people make decisions to change risky health behavior or to begin health promoting behaviors. Examples of the former are studies of smoking and drinking behavior. Efforts have been made not only to examine early life events that predispose one to participate in such risky behavior as smoking and abusive use of drugs and alcohol but also of ways to prevent or change such behaviors. Examples of the latter include studies of participation in preventive dental care, medical checkups, and vaccination programs.

Research on the personal determinants of health actions can be represented by those that focus on either cognitive processes or personal characteristics and lifestyle. Cognition can be interpreted as the personal thought processes which serve as a frame of reference for integrating experiences and choices. Cognition is composed in part of beliefs, attitudes,

expectations, values, and perceptions. Cognitive approaches to understanding health behavior have focused on the individual experience of health events, such as variations in coping based on individual beliefs and values. Major theoretical approaches to understanding health actions include the health belief model, the health locus of control model, and the behavioral intention model. I will examine each of these models and then examine their application for several illustrative health behaviors. Further, I will review studies of personal and lifestyle characteristics related to certain health behaviors.

Perspectives of Health Behavior

Health Belief Model

The health belief model (HBM) has been the major frame of reference for health behavior since the 1950's (Gochman, 1988). The health belief model is essentially a rational model of decision making that developed from health education efforts. An early reported use of the model was an attempt by Rosenstock, Derryberry, and Carriger (1959) to predict the effective use of a tuberculosis screening procedure. In its simplest form the model posits that the likelihood that individuals will participate in a particular preventive health action is a function of his/her perceived susceptibility, the perceived seriousness of the condition, and the perceived availability of actions that will treat or prevent the negative outcome. Persons are more likely to initiate a particular health behavior if they believe they are at risk, the condition is serious, and specific

actions are likely to be beneficial above and beyond any costs or barriers to the behavior.

The HBM has been widely used to study a number of diseases and other health situations. It has been used to study many categories of behavior including prevention, screening, and sickness behavior in adults, adolescents, and children. Several excellent reviews of the HBM trace the development of the model and its refinements (Kirscht, 1988, Becker, 1974, Becker et al. 1977, and Janz & Becker, 1984) . Given the dynamic nature of the model, several versions have been developed, some of very complex design. Its most basic components are explored further here.

Susceptibility is a personal assessment of risk for a specific disease or health outcome. Susceptibility is a probabilistic assessment of the likelihood of a negative health outcome in the absence of a specific action to change or avoid it. It seems a sufficient but not necessary condition of action that one believe that a health threat exists before one would take action to affect it. Kirscht (1988) states that susceptibility has been regarded as meaningful across a number of conditions but in and of itself is not an adequate predictor of changes in health behavior. Work by Perloff (1983) and Weinstein (1984), among others, explored inaccurate assessments of personal susceptibility, so called "perceived invulnerability," and its effects on subsequent beliefs and health actions. Major findings include the widely supported observation that

people who have not been victimized by negative life events tend to view themselves as "uniquely invulnerable" and that this perception is related to perceived controllability of the condition and lack of previous experience. Interventions that provide specific risk information about peers reduced the degree of inaccuracy of risk assessment.

The severity of the illness is assumed to be a rational assessment of all the disutilities or costs associated with the health threat. In some sense, severity is the value an individual places on the medical, social, moral, and financial costs of the disease or other health threat. Consequently, a disabling knee injury might be valued as more severe by an athlete than by a sedentary person even though the injury was the same. In most manifestations of the HBM this assessment is assumed to be primarily a rational rather than emotional process. Eckert and Goldstein (1983) have asserted that severity seems to serve as a cue or trigger to initiate the decision process in the face of a threat judged to be significant.

Belief that an action is available that can reduce the risk or minimize the negative effects of the threat provides the options for possible choices. One is more likely to engage in a health promoting action if he or she believes in the efficacy of the action than if the action is unlikely to help or will not help significantly. Such beliefs have been measured most frequently in terms of the perceived strength of effectiveness or benefit (Weinstein, 1984).

Just as the benefit of the relevant health action is important in the decision process, the costs of adopting the behavior and barriers to adopting the behavior must also be considered. The costs of the behavior include pain, discomfort, and financial outlay as well as social and environmental access barriers to the action or service. The HBM posits that a change in behavior is made after an individual decides that the benefits of adopting an effective health promoting action outweigh the costs in the presence of a meaningful health threat. Janz and Becker (1984) judged that "perceived barriers" was the best predictor of behavioral change, followed by "perceived benefits" and "perceived susceptibility," in HBM studies conducted from 1974-1984. The importance of the "cost-benefit ratio" in the HBM is a direct outgrowth of its roots in subjective expected utility (SEU) decision models (Kirscht, 1988).

Health Locus of Control Model

Rotter's (1966) concept of locus of control has also been applied to health behavior. This model predicts that behavior is a function of the expectancy that a certain action will lead to a particular outcome that has its own reinforcement value. In this context, health locus of control is the degree to which an individual believes that his or her health is controlled by his or her own behavior (internal locus of control) rather than being controlled by others or by chance (external locus of control). Though results have been contradictory, there is some support for the position that those with an internal locus of control

are more likely to engage in preventive health actions than those who are more "external" (Seeman & Seeman, 1983). Several authors (Wallston, Wallston, Kaplan, & Maides, 1976; Lau & Ware, 1981) have developed their own psychometric instruments to measure health locus of control. Breast self-examination (BSE) is an example of a health action that has been found to be related to health locus of control. Lau (1988) reports correlations as high as .21 between internal control and BSE use among women who value health highly. When corrected for attenuation due to measurement error, the correlation rises to .36, still accounting for only 13% of the variance in BSE. Reviewers now conclude that locus of control is multidimensional and that early conceptualizations of a generalized personality dimension may have been too simplistic (Lau, 1988).

Excellent reviews of this model by Wallston and Wallston (1978) and Lau (1988) conclude that specific health locus of control studies have not been particularly successful in supporting the theory. Wallston and Wallston point out that health locus of control beliefs have generally not been related to health information seeking, with the exception of hypertension, nor to preventive health behaviors like exercise and weight loss, except for smoking cessation. Lau (1988) concurs that locus of control has not been shown to singly predict many health behaviors but points to positive outcomes in several public health programs that considered locus of control. This suggests that designing media

messages aimed at specific populations of internals and externals may be most beneficial. For example, BSE advertisements that match a woman's attribution of health control are more likely to be read, considered, and adopted than if they match for only a fraction of the population.

Behavioral Intention Model

Beginning in the 1970's, several attempts were made to propose social psychological models to understand and predict health behavior, especially reproductive behavior. Fishbein (1972) developed a general model based on behavioral intentions. The model was refined and adapted in later work with other colleagues (Ajzen & Fishbein, 1980; Fishbein & Jaccard, 1973). The model hypothesizes that a person's attitude toward some specific act, moral beliefs about the act, and perceptions of social norms relevant to the act determine a person's intention for the action. Such intention mediates and predicts eventual behavior. This behavioral intention is hypothesized to be influenced by a rational interaction of one's attitude toward performing the behavior, normative beliefs about what s/he should do, and motivation to comply with others. Other variables, such as personality or personal "psychological variables," are unrelated to differences in attitude or normative beliefs and can affect intention only indirectly. In effect, these more general attitudes and beliefs are less important than attitudes and beliefs about the specific health behavior and affect intention only indirectly if at all.

More recent modifications of the model by Byrne and his colleagues (Byrne & Fisher, 1983) hypothesize that psychological factors influence the process of decision making in important fashion. They propose that general personality characteristics and more generalized attitudes affect health behavior independent of the intention. Several of these factors have been studied and seem to support the idea that general emotional orientation toward sexuality is strong enough to affect knowledge about contraception and to interfere with thoughtful, logical decision making about reproductive behavior. Gerrard (1987) points out that personality factors like sex guilt and erotophobia are strongly associated with contraceptive risk taking and contraceptive failure despite contraceptive intention. Such findings suggest that strong negative emotional reactions inhibit effective decision making by disrupting rational cognitive processes or limiting access to accurate information.

Other models

As can be seen in the description of the above models, each was based on assumptions of cost-benefit analysis and rational decision making. Each attempted to describe and predict health behavior accurately and became more complex in its attempts to do so. Other approaches have also been used to describe health behavior. Efforts to "prescribe" rather than "describe" behavior have also been applied to health behavior.

Public health education efforts have made use of a number of prescriptive decision models. Prescriptive models describe how decisions should be made rather than how the are actually made. Chell (1989) points out that while theorists are busy devising comprehensive decision making models, people are busy using their own "sometimes inefficient" methods. Some decision models evolved from early efforts to describe economic behavior. Such efforts usually are based on the concepts of probability and utility and focus on maximizing outcome while limiting cost. Given that most human choices involve personal judgment about relative gains and losses, classical models have been used for theoretical rather than practical efforts.

Several models of decision making have been adapted from the field of career counseling. Such efforts tend to focus on educating individuals about effective ways to approach important decisions, collect information, select and evaluate alternative, and then to make meaningful and satisfactory choices. Krumboltz and several colleagues (Mitchell & Krumboltz, 1984; Krumboltz, Mitchell, & Jones, 1976) propose that genetic and environmental influences, learning experiences, and task approach skills contribute to generalizations of self concept. They also lead to a personal decisional methodology based on cognitive and emotional abilities. Finally, these factors determine the available repertoire of behaviors. Based on this conceptualization, Krumboltz and Hamel (1977) developed a seven stage decision procedure. The "DECIDES" model

requires the decision maker to define the problem, establish a plan of action, clarify personal values, identify alternatives, discover probable outcomes, eliminate alternatives systematically, and start action. The model is generic and has been applied in a number of decision making situations.

Janis and Mann's (1977) conflict model also serves to describe effective decision making. The conflict model developed out of their observations on the effects of stress. They describe five distinctive patterns of coping with stressful decisional conflicts. The five coping patterns are vigilance, unconflicted inertia, unconflicted change to a new course of action, defensive avoidance, and hypervigilance. Vigilance is the most effective coping strategy and results in thorough information search, unbiased assimilation of new information, and effective decision making. The other four coping mechanism are occasionally effective for simple or routine decision but tend to produce defective results for consequential choices.

The sequential steps involved in vigilant decision making have been extracted and offered as a guideline for making better decisions. Under the conflict model, an "ideal" decision is most likely to be reached if the decision maker:

1) thoroughly canvasses a wide range of alternative courses of action;

2) surveys the full range of objectives to be fulfilled and the values

implicated by the choice;

3) carefully weighs whatever he knows to be fulfilled and the values implicated by the choice;

4) intensively searches for new information relevant to further evaluation of the alternatives;

5) correctly assimilates and takes account of any new information or expert judgment to which he is exposed, even when the information or judgment does not support the course of action he initially prefers;

6) reexamines the positive and negative consequences of all known alternatives, including those originally regarded as unacceptable, before making a final choice;

7) makes detailed provisions for implementing or executing the chosen course of action, with special attention to contingency plans that might be required if various known risks were to materialize. (Janis & Mann, 1977, p. 11)

Research on Health Decision Making

Breast Examination

Typical of public health efforts to reduce the effects of serious and life-threatening illnesses is the movement to encourage self examination for breast cancer. The American Cancer Society recommends regular monthly breast self-

examination (BSE) for all women over the age of 20 (Lalor & Hailey, 1989). A Gallup poll (1974), however, found only 18% of women did monthly exams. A number of studies have explored factors related to compliance with this particular public health recommendation (Kelly, 1979; Lalor & Hailey, 1989). Kelly (1979) found the most frequent reason cited for not doing self-exams was women did not feel susceptible to developing breast cancer. This perceived invulnerability was also found by Hailey (1987), who reported that 61.5% of those surveyed denied their susceptibility with reasons such as "my health is generally good."

Redd and Jacobsen (1987) reviewed a wide range of psychological factors related to cancer. They concluded that compliance with recommendations of self-examination for breast cancer as a form of presymptomatic testing has been very difficult to elicit. Grady (1984) and Turnbull (1978) identified several factors contributing to the lack of compliance. Chief among them was the necessity of teaching a new behavior, a behavior that is not externally reinforced, and that may be punished by finding out that the individual is diseased. In fact, mass media campaigns, modeling techniques, and peer support have proven only marginally effective promoting self-examinations (McKusker & Morrow, 1980; Meyerowitz & Chaiken, 1987).

Lalor and Hailey (1989) tested the effects of pamphlets on self-examination intention. Pamphlets focusing on negative consequences of not

doing BSE and on positive consequences of doing BSE produced increases in perceived susceptibility to breast cancer. Such pamphlets can be seen to increase the reader's belief in the severity of the health threat and to improve the perceived efficacy and potential benefits of BSE.

In one of the earliest studies of factors related to patient delay in seeking diagnosis, Goldsen, Gerhardt, & Handy (1957) analyzed data from 727 patients who presented to New York hospitals for diagnosis of symptoms that might be caused by cancer. They sought to determine which personal factors accounted for observed delays in seeking diagnosis for their medical symptoms. Those patients who put off seeking a medical examination to determine the cause of their symptoms for three or more months (delayers) were compared to those who responded to the emergence of their symptoms by seeking medical attention relatively quickly (nondelayers). Nearly one-third of patients examined were classified as delayers. In fact, 19% of the most extreme delayers, who delayed seeking a diagnosis for over one year, failed to consider their own search for diagnosis delayed. Goldsen et al.'s (1957) major finding was that the delay in seeking a diagnosis for cancer was not idiosyncratic to cancer itself, but was an example of a more general long-lasting "general and customary orientation towards medical problems" (p. 6). It seems that delayers in seeking diagnosis for this specific disease were very likely to typically respond to previous medical problems with similar delays in seeking medical attention.

It seems reasonable to assume that one must first suspect that a symptom might be related to a serious illness before being motivated to seek medical attention for diagnosis. Goldsen et al. (1957) examined whether delayers were less accurate in properly identifying symptoms that might be related to cancer and in failing to respond to serious symptoms with appropriate timeliness. Findings suggest that recognizing a serious symptom of cancer actually increased the delay among some patients. They found that when individuals believed that the serious symptom was related to "something that cannot be cured," they were more likely to delay diagnosis only if they had a previous generalized anxiety about cancer. Hence, it seems a person will be more likely to respond to warning symptoms by promptly seeking care when anxiety about the illness is low and the possibility of a cure exists.

Huntington's Disease

Genetic diseases and birth defects are another area where public health efforts have been made to elicit participation in presymptomatic testing. One of the very earliest breakthroughs in the exploding area of molecular genetic research was the discovery by James Gusella et al. (1983) at Massachusetts General Hospital of a genetic marker closely linked with Huntington's Disease (HD). Recombinant DNA technology uses easily identified protein sequences called markers to determine the location of specific unidentified genes.

Gusella's group discovered a restriction fragment length polymorphism (RFLP) called G8 on human chromosome 4 that is in close proximity to the dysfunctional gene that causes HD. An RFLP is an easily identified segment of DNA that serves as a standard marker on a specific chromosome. The degree of proximity allows researchers to determine the probability that an individual who carries a particular marker also carries the defective gene. The very close proximity of the G8 sequence to the purported HD gene allows for determining with a 95% accuracy whether the person is a carrier of the defective HD gene. The accuracy of carrier status prediction has improved to 99% with the identification of additional markers since Gusella et al.'s initial discovery.

Huntington's Disease is a currently incurable hereditary disorder of the central nervous system characterized by progressive motor deterioration, behavioral changes, and cognitive decline. HD is an autosomal dominant disorder with complete penetrance, meaning that each of the offspring of an individual with the disease has a 50% chance of inheriting the defective gene and that every person who inherits the gene will eventually develop the disorder if they do not die of other causes. Age of onset of its symptoms varies widely with HD, though symptoms most commonly appear between the ages of 30 and 40 years. Individuals in affected families can never be entirely certain that they have escaped the disease even at age fifty or sixty. In the 10 to 20

years following onset, the progression of symptoms is relentless, eventually resulting in incapacitation and death.

The pattern of symptoms of HD most notably includes a distinctive chorioform movement disorder marked by facial contortions and flailing of the arms and legs. This movement disorder progresses to a complete inability to control the muscles of the limbs and face. The symptoms of Huntington's disease result from premature death of neuronal cells in the brain, most notably in the basal ganglia. Many persons with HD become invalids and must rely on family and the medical community to help meet even their most basic daily living needs.

After their initial success with HD, Gusella et al. (1983) observed, "It is likely that Huntington's disease is only the first of many hereditary autosomal diseases for which a DNA marker will provide the initial indication of chromosomal location of the gene defect" (p. 238). In fact, just such progress has been made. Among the other genetic diseases to which recombinant DNA technology has been applied are Alzheimer's disease, hypercholesterolemia, retinoblastoma, Duchene muscular dystrophy, adult polycystic kidney disease, hemophilia A, cystic fibrosis, neurofibromatosis, and manic depression, among others (Rothstein, 1988). Further, DNA probes can be used to test for about 30 genetic diseases during the first trimester of pregnancy.

Genetic researchers have embarked on one of the most ambitious scientific projects in history, the Human Genome Project, prompted by these early successes. Under the guidance of James Watson, researchers throughout the world have coordinated efforts to map and sequence the entire human genome. The genome is the entire complement of human chromosomes and the genes that build them. By mapping the entire genome, researchers will be greatly assisted in finding genes involved with known genetic diseases and in discovering heretofore unproven genetic ties to a variety of diseases. In fact, Nobel laureate Walter Gilbert has referred to the human genome as the "Rosetta stone of biological information" (Rothstein, 1988).

More than 4,000 genetic diseases are known to date (Rothstein, 1988). With the ability to detect these genetic diseases before they are symptomatic, individuals will be faced with more frequent and more important testing decisions. Society and its individuals need to determine how it will treat persons who are asymptomatic but will probably become ill in the future.

Among the extraordinarily complicated issues related to predictive testing is the situation with late-onset diseases. Prenatal testing for birth defects has been available for decades and used by women who could then choose to abort an imperfect fetus. Rates of abortion are nearly 100 percent for conditions such as muscular dystrophy, cystic fibrosis, and thalassemia which affect the

infant very early in life (Rothstein, 1988). In the case of late-onset diseases, women and men will be faced with the tremendous burden of evaluating what kind of a life is worth living. Even more troubling will be diseases for which a predisposition leads to a strong but not inevitable likelihood of developing the condition.

Another thorny question arises when testing and diagnosis are available long before a cure or treatment exists. Such situations will involve the availability of information about future illness while still asymptomatic and for which little can be done. This is not a new situation in medicine where successful treatment often lags behind the ability to diagnosis a problem. For most genetic conditions, a successful treatment may not be available for decades, if ever. Given such conditions, choosing to be diagnosed will not carry its greatest benefit, namely proper identification of a health threat in order to avoid or cure it.

Huntington's disease provides an excellent point to study the questions arising from the availability to predict late onset, catastrophic diseases for which no successful treatment currently exists. It is well suited to study for several reasons. There is very good information about the cause and course of the disease. It has a rich history of research and rational consideration. Medical researchers have considered for some time the impact of presymptomatic diagnosis both on those at risk and on the prevalence of the disease in the

greater population. HD has a strong international research and support society which includes extensive pedigrees of affected families and tissue banks. Finally, the hereditary pattern of the disease produces very stable probabilities of risk and very serious, inevitable consequences.

Three years before the successful development of the HD predictive test by Gusella et al., Emery (1980) wrote regarding at risk individuals, "Some might be reassured by a predictive test, but unless the test were highly sensitive and detected all preclinical cases, some might not be convinced by the results. The main problem lies with those who would have to be informed that instead of living with the hope that they might have escaped the disease, they now have to accept the near certainty of developing the disease at some time in their lives" (p. 345). Such views pointedly deal with the perceived accuracy of the procedure as well as the lack of meaningful benefit from being diagnosed. Emery goes on to comment on the choice between certainty and uncertainty. He notes that "Having discussed this matter with many at-risk individuals, most would prefer to live in the hope of being unaffected rather than risk being told that there is a certainty of becoming affected" (p. 346). He concluded that research on predictive testing should be pursued only after an effective treatment has been found.

Flinn and Bazzell (1983) reviewed the neuropsychiatric complications of a variety of abnormal movement disorders, including Huntington's disease.

They documented a number of potential difficulties including conduct disorders, affective disorders including higher risk for suicide, deterioration of cognitive functioning including memory, schizophreniform disorder, personality disorders, increased rates of separation and divorce, sexual aberrations, and criminal behavior. Folstein et al. (1983) studied the rate of conduct disorder in a sample of 112 offspring of 34 Huntington's Disease patients. They reported an increased incidence in disrupted families, and that affective disorder may be an early manifestation of the HD gene. Clearly, HD has significant psychiatric and cognitive aspects which may affect decision making even before more classic symptoms are evident.

The attitudes of a number of British at-risk individuals towards diagnosis were examined by Barrette and Marsden (1979). They found a large number of cases where physicians had delayed notifying young women of their at-risk status until they were married and had had children. Only 7% of at-risk respondents said they preferred not to know the hereditary consequences of the disease. Less than half (43%) would state what they would do to notify their own children. Most (61%) said they were prepared to tell their offspring not to procreate to prevent the transmission of the disease to another generation.

Tyler and Harper (1983) studied the attitudes of 92 affected individuals (carriers) and 91 at-risk persons from Wales and their relatives. Twelve percent (12%) of carriers had professional advice before completing their families

compared with 68% of at-risks. They estimated that 82% of those affected and 60% of at-risks might have restricted the size of their families if they had known in time. The majority of both groups found genetic counseling useful but few felt it changed their plans. Tyler and Harper concluded that the burden of telling children the risks is too great for most parents and that professional help is needed to assist in such communications. Although 56% overall wished to take a predictive test, only 40% of parents wished to know if they were at risk of passing the gene on to their children. It seems that many individuals have ambivalent feelings not only about their own condition but also their role in passing the gene to their children.

Schoenfeld et al. (1984) explored the possible impact of presymptomatic testing for Huntington's Disease in a group of 55 at-risk U.S. individuals. Structured interviews found that fully 73% of respondents said they would take such a test. Further, more than 67% of those agreeing to testing would not have children should the test be positive. They found no association between any demographic or social variables and intention to be tested.

Nancy Wexler (1985), a member of Gusella's original research team and at risk for HD herself, reported that the reason most often given by individuals who want to be tested is the desire to end the uncertainty of living without knowing if they would develop Huntington's disease. Some consider the ambiguity of one's health status to be the most stressful aspect of being at risk

for the disease. These individuals often must make decisions about career, marriage, and childbearing prior to knowing whether they will ever develop the disease. Self-monitoring of possible symptoms, such as forgetfulness or clumsiness, is common as individuals dread the onset of the disease that led to the deterioration and death of a parent.

Given the serious potential outcomes of predictive testing, several authors have begun to offer ethical guidelines for any testing program. Crauford and Harris (1986) explored a number of ethical considerations in predictive testing. They identified 3 areas of concern: the accuracy of predictions, the burden of knowledge and risk of suicide, and possible misuse of test results. They disagree with those who assume that uncertainty is preferable to near certain knowledge that one will develop HD in due course. They argue that early diagnosis would give carriers of the gene time to prepare emotionally and financially, thereby reducing the impact of the onset of symptoms when they do occur.

Crauford and Harris argue that those respondents who have indicated a desire for predictive testing presumably believed that the advantages of knowing would outweigh the disadvantages, in responding to the view that in the absence of a specific treatment the risks attached to predictive testing outweigh the benefits. They point out that it has been suggested that patients with multiple sclerosis benefit from being able to come to terms as soon as

possible with their illness. Additionally, studies of surgical patients suggest that the amount of information sought preoperatively varies and that satisfactory psychological adjustment depends on disclosure of information that is tailored to individual personality characteristics.

Several attempts have been made to assess interest in presymptomatic testing since it has become available. Evers, Cassiman, and van den Berghe (1987) surveyed the attitudes of 49 at-risk persons from Belgium and 27 of their spouse/partners. They found that nearly equal percentages (57% and 60%, respectively) of potential carriers and their spouse/partners were willing to be tested. The persons at risk were more likely to be unsure about when they would be tested (39%) but their spouse/partners were more (55%) likely to prefer testing as soon as it was widely available. The most frequently cited reasons for being tested cited by the potential carriers were to have certainty of their carrier status (29%), to make decisions about childbearing (21%), to make decisions about marriage (18%), to inform their children of their risk (18%), to make career plans (11%), to look for assistance for a positive test result (11%), to start treatment if tested positive (11%), and for financial reasons (7%). No one cited reducing the frequency of HD in the population as a reason and nearly one third (32%) could give no reason for being tested. The reasons given for deciding not to be tested were that a positive result would be too

emotionally loaded (56%), that no treatment was available (44%), and belief that they did not carry the gene (11%).

Similarly, Kessler et al. (1987) surveyed the attitudes of 69 Americans at-risk for Huntington's disease after the development of the presymptomatic test procedure. In that sample, four out of five subjects (79%) said they would use a presymptomatic predictive test if it were available. This compares to 63% willing to be tested in a similar sample surveyed by Markel et al. (1987). Further, nearly 2/3 of subjects would use the test for prenatal diagnosis, and of these 71% would terminate a pregnancy if the fetus was found to carry the HD gene. In contrast, in the Markel et al. sample only 49% would use a prenatal test and only 43% of those would abort a fetus that carried the HD gene. The issue of childbearing was the most commonly identified area of concern related to testing. These results are consistent with those of Schoenfeld et al. (1984) and Markel et al. (1987) in demonstrating that testing positive for the HD gene would likely result in a marked reduction in intended number of children in at-risk persons.

A survey by Mastromauro et al. (1987) of 131 individuals at 50% risk of inheriting HD found that 66% intended to avail themselves of the test when it is available. Individuals who were single, separated, or divorced were more likely to be interested in testing than those who were married. Among the reasons offered for desiring testing were: the desire to end the uncertainty of their status

(40%); the wish to know if one's children were at risk (30%); to be able to make financial plans (21%), and to be able to make childbearing plans (10%). Eight percent wanted to be tested to confirm their belief that they carried the gene; 6% wanted to confirm their belief that they did not. Nearly 53% of those not intending to be tested said they preferred to live with the hope that they had not inherited the HD gene and hence would not develop the disease.

A logistic regression to test the predictive power of factors associated with a desire to be tested revealed that marital status ($p<.01$) and anticipation of relief ($p<.05$) or depression ($p<.05$) in response to a positive test result were found to be the most powerful predictors of test use ($\chi^2 = 28.07$, $p<.0001$). Intentions for prenatal testing varied between 41% to 89% among subjects of varied religious affiliation.

The majority of subjects indicated that they would experience feelings of depression, anxiety, or sadness to a positive test result. Respondents indicated that they would likely experience guilt (20%) or a diminished sense of self-worth (20%) as a result of a positive test result. Twenty percent (20%) of the respondents reported that they would feel a sense of relief as a result of a positive result. However, twenty-nine percent (29%) of respondents expected to have suicidal thoughts after receiving a positive result. In fact, more than twenty-one percent (21%) of those interviewed felt at risk for committing suicide if they found out they would develop Huntington's disease, most frequently at the point

when the disease became disabling. Those who felt at risk for suicide were less likely to desire testing than those not considering suicide (χ^2 = 10.22, p<.05).

Logistic regression procedures applied to factors related to prediction of intention toward presymptomatic testing revealed that single, separated, and divorced respondents who expected to feel relief regardless of test results were most likely to desire testing, while married individuals who expect to react to a positive result with feelings of depression were least likely to agree to presymptomatic testing. Reproductive plans were generally only a minor factor in the decision to be tested.

Phone interviews with 56 at-risk individuals from Kansas conducted by Meissen and Berchek (1987) surveyed attitudes, beliefs, and behavioral intentions related to presymptomatic testing for Huntington's disease. They found that 65% of the sample intended to use the test themselves when available, that 42% would use a prenatal test, and that 35% would test at-risk minors. Nearly 83% of those who plan to have children in the future would take the test themselves while only half would use a prenatal test. Intentions toward testing were positively related to attitudes about presymptomatic testing ($t(50)$ = 2.93, p<.01). They found that all those who expect their anxiety level to be reduced by testing would accept testing while 80% of those who believe that the availability of the test had increased their anxiety level did not intend to be

tested. Reasons given for testing by those intending to test include: general planning for future (58%); eliminate doubt and worry (42%); and family planning (17%). Reasons given for not testing include fear of adverse emotional reactions and fear of a positive test result. Respondents in this sample had little information about the test and its procedures.

Quaid et al. (1987) invited at-risk individuals from the Baltimore area to participate in a testing program. Letters were returned from 387 potential subjects and 349 were contacted. Only 44 (12.6%) had requested testing during the 4 month interim period. An additional 3 at-risk individuals were added later. She proposed that the low turnout may be related to several factors, including the less than certain 95% accuracy of the test, the genetic linkage procedures requiring samples from family members, the demanding research protocol, and the gap between intention and behavior. Previous surveys had higher rates of intention (Schoenfeld et al., 1984; 73%) (Stern & Eldridge, 1975; 77%) (Tyler & Harper, 1983; 56%; only population based survey of at-risks.)

Swavely, Silverman, and Falek (1987) investigated the effect of being informed of the new diagnostic test for HD upon individuals at risk. Their findings indicated the at-risk population did not show levels of anxiety different from a normative population or from at-risk individuals unfamiliar with the

procedure. Hence, it appears that knowledge of the availability of the presymptomatic diagnostic test does not affect anxiety level about HD.

Meissen et al. (Meissen, Myers, Mastromauro, Koroshetz, Klinger, Farrer, Watkins, Gusella, Bird, & Martin, 1988) studied 47 persons at risk for Huntington's disease who requested a presymptomatic or prenatal genetic-linkage test. Nineteen persons later dropped out. Fifteen presymptomatic and one prenatal test were completed. Four of fifteen (25%) yielded positive results; seven (44%) were negative; and five (31%) were uninformative. Seven additional people awaited results at time of publication. Among the most frequently cited reasons for requesting testing were a need to know or desire to end the ambiguity of being at-risk (55%), general planning (51%), clarify risk status of children (32%), to reduce uncertainty (19%), to know before telling children about HD (13%), family planning (13%), as a factor in possible marriage or relationship (13). The study was done at Massachusetts General Hospital and involved 5 visits and follow-up with counseling and psychological testing. Only 20 percent of people at risk who inquired about the test attended the first appointment. Recent surveys of persons at 50% risk for Huntington's disease report that about 2/3 intend to request predictive testing (Meissen et al., 1988; Kessler et al., 1987; Mastromauro et al., 1987; Meissen & Berchek, 1987; Markel et al., 1987)

Proper testing for Huntington's Disease involves collecting blood samples from related family members for proper determination of the proper gene type. Current needs vary from 1 to 10 family members depending on pedigree. All testing programs in the initial pilot project screened out individuals with identifiable early Huntington's symptoms. Of about 75 individuals tested to date at Johns Hopkins about 25% were carriers (Codori, personal communication, January, 1991).

According to Phillip Cohen (personal communication, January, 1991) of the Huntington's Disease Society of America, about 150 individuals have completed testing to date out of more than 125,000 people thought to be at risk in this country. Testing became available on a research basis in 1983 and became available on a clinical basis in 1990. Around 20 centers across the country are currently conducting the genetic testing, with nearly all testing now done for clinical rather than research purposes. The cost of testing at these clinics typically varies from $3000 to $5000. While the lack of local testing facilities, the high cost, and only recent availability of clinical testing have limited the number of at-risk persons tested, clearly other more personal factors must be affecting people's decision making about using the presymptomatic test. Certainly 150 persons from a potential pool of 125,000 (.1 %) is much less than the two-thirds figure (66%) usually cited for intention to be tested.

AIDS and HIV Infection

Another important public health effort has been directed at controlling the spread of the Human Immunodeficiency Virus (HIV). HIV is the virus implicated in the development of AIDS. AIDS has been described as the most serious infectious disease epidemic of our time. The catastrophic, lethal course of the disease along with the rapid rate at which the disease has spread has mobilized massive efforts to study the natural history of the disease as well as social and psychological factors related to the prevention, spread, course, treatment, and repercussions of the disease.

Acquired Immunodeficiency Syndrome (AIDS) was first detected in 1981 in a small group of American homosexual males. The syndrome is marked by deterioration of immune system functioning and the development of opportunistic diseases that had previously been rare and usually benign. In 1981, reports to the Centers for Disease Control (CDC) of five cases of a rare type of pneumonia (pneumocystis carinii) and 26 cases of a rare cancer (Kaposi's sarcoma) in young gay men triggered the creation of a research team to monitor and study this new epidemic (Heyward & Curran, 1988). Each of the conditions was almost unknown except among patients with severely compromised immune systems. Within three years of the detection of AIDS, researchers had determined that the epidemic of opportunistic diseases was tied to an underlying viral infection that damaged the immune system, identified

a retrovirus that was shown to cause the disease, determined the cellular target of the virus, and developed a diagnostic blood test (Gallo & Montagnier, 1988).

Since first detected in 1981 in young gay men in New York and California, epidemiological studies have followed the AIDS epidemic as it progressed. Reviews of these studies (Heyward & Curran, 1988; Mann, Chin, Piot, & Quinn, 1988), trace the effects of the epidemic as it spread throughout the U.S. and the world. Early on, researchers became convinced that the disease that caused AIDS had a considerable latency period between initial infection and the onset of illness. Hence, it became necessary to track not only the reported number of fully developed cases of AIDS but also the larger number of people infected but who do not show symptoms of the disease.

Nearly one million persons in the United States are currently infected with the HIV virus (CDC, 1990). Projections are that there will be 52,000 to 57,000 new cases of AIDS diagnosed in 1990, another 56,000 to 71,000 in 1991, and 58,000 to 85,000 in 1992. Overall, only about 10% of those infected with HIV have been diagnosed as having AIDS. This projection shows a flattening of the growth curve of new AIDS cases but still sizable increase in the incidence of HIV disease.

While the most recent summary from the CDC (1990) reports that about one million people in the U.S. are currently infected with the HIV virus, as many as ten million people world-wide are believed to be infected (Rothstein, 1990).

HIV seroprevalence, the percentage of individuals in a population who test positive for HIV, varies considerably by risk group, gender, race, age, and geographic area. Median seroprevalence is estimated to be 0.7% for Caucasian Americans and Hispanics and 1.0 for African Americans (CDC, 1990).

Given that about one-fifth of AIDS cases are among persons aged 20-29, and the incubation period of the disease may be up to five years or more, many individuals must have contracted the virus in their high school or college years. Consequently it is critical that research on this at-risk group proceed (Healy & Coleman, 1989).

The CDC, in collaboration with the American College Health Association (1990), conducted unlinked HIV-serovalence surveys of 19 colleges and universities. Blood samples drawn for routine clinical blood tests were tested for HIV antibodies. Results from 1988 to 1989 indicate that 30 seropositive students were identified from 16,861 blood samples. The median seroprevalence rate for 19 campuses was 0% and ranged from 0% to 0.9%. At least one seropositive student was found at 9 of the 19 universities. Twenty-eight of the 30 HIV positive students were male even though two-thirds of those sampled were female. Given the much higher rates of other sexually transmitted diseases, it is expected that seropositivity rates will quickly rise when a breakthrough occurs in this population. MacDonald et al (1990) found

that over 5 % of a sample of Canadian college students reported at least one previous sexually transmitted disease (STD). The rate of previous STD went up to 11% for men and 24% for women with 10 or more sexual partners.

Acquired Immunodeficiency Syndrome (AIDS) is the final manifestation of a progressive immune system disorder. The HIV virus is transmitted when a healthy person is exposed to the infected blood or semen from someone who carries the HIV virus. AIDS is an infectious disease. It is contagious but cannot be spread by everyday casual contact. It is transmitted in the same way that venereal diseases are spread. People are usually exposed through sexual intercourse with someone who has the virus, through sharing needles or syringes with an infected person, through an infected mother's blood during pregnancy or delivery, or through accidental contact with contaminated blood or blood products.

A person who has been exposed to the virus may or may not become infected. The HIV virus is considered difficult "to catch" as evidenced by the great difficulty scientists had in cultivating the virus outside the human body in the lab. If newly infected, a person may feel fine, look healthy, and be unaware of any symptoms of illness. After being infected, individuals usually, but not always, experience mild, flu-like symptoms that last from 5 to 15 days as the body tries to fight the disease. These symptoms clear up quickly and the individual returns to apparent health. This period of relative health may last for

weeks or years. Usually within 6 to 8 weeks from the day of infection the body's immune system begins to produce significant levels of antibodies to the HIV virus. This process is called seroconversion and is the first time when routine testing can reveal the presence of the HIV in the newly infected person's blood. An individual is considered seropositive when his or her body has begun to produce sufficient amounts of antibodies to be detected by testing. A negative test result indicating a seronegative status does not mean that one has not been infected but may reflect an infection so recent that seroconversion has not occurred.

Following initial infection and seroconversion, the HIV disease moves into the first stage, marked by a long, seemingly stable period where the person is said to HIV positive. During this stage the person appears outwardly healthy but may transmit the virus to others through sexual or blood contact. The great majority of people infected with HIV are in this long asymptomatic stage. Sixty to 70 percent of those in this asymptomatic HIV positive stage remain symptom-free for more than five years, some for as long as twelve years or more.

The second clinical stage of HIV infection was formerly considered to be AIDS Related Complex (ARC). ARC is a stage where the weakened immune system becomes progressively less able to protect the body form disease-causing organisms. The resulting pattern is alternating periods of illness and wellness. The illnesses are generally caused by viruses, parasites, and fungi

rather than by bacteria. Symptoms range from mild to serious and most often include swollen lymph glands, recurrent fever, weight loss, severe diarrhea, fatigue, and a general sense of discomfort. ARC is now considered to be a point along a continuum of the HIV disease rather than a discrete stage.

The third stage of HIV infection is AIDS and occurs when cumulative damage results in a failure of the body's immune system. As a result, opportunistic infections like pneumocystis carinii pneumonia (PCP), Kaposi's sarcoma (KS), cytomegalovirus (CMV), toxoplasmosis, progressive multifocal leukoencephalopathy (PML), cryptococcal meningitis, and tuberculosis are more likely. Additionally, digestive disturbances and anorexia frequently contribute to serious weight loss and wasting. A formal diagnosis of AIDS is made when a certain cluster of clinical conditions have been met. Current CDC guidelines for diagnosis of AIDS include: 2 of the following lasting longer than 3 months: fever, weight loss, lymphadenopathy, diarrhea, fatigue, and night sweats; 2 lab findings: low number of T-helper cells and a low ratio of T-helper to T-suppressor cells; and 1 of the following: low white blood cell count, low red blood cell count, low platelet count, or elevated levels of serum globulins (CDC, 1987).

Clinical AIDS represents a severe collapse of the immune system. There is a distinct possibility that 100% of those infected with HIV will suffer the consequences of their infection, including dealing with a chronic illness,

increased morbidity, and premature mortality (Institute of Medicine, 1988). Though it is believed that all people infected with HIV are likely to eventually develop AIDS, the picture is not complete. The length of time from initial infection to a diagnosis of AIDS has been as long as 12 years with a mean of 4.5 years (Rothstein, 1988). It remains to be seen whether all individuals infected with the virus will inevitably develop AIDS. AIDS is usually fatal within two years of diagnosis (Rothstein, 1988).

Recommendations about testing have been offered by the CDC (1987) and other groups (Koop, 1987). Early recommendations about testing focused on advising certain identified at-risk groups. Gay men, Haitians, and hemophiliacs were the focus of early warnings as the first U.S. AIDS cases were centered in these populations. More recent public health efforts have emphasized advocating testing for individuals who engage in certain high risk behaviors, rather than their group status. Current testing recommendations are directed to those who have unprotected sex with an infected partner, have unprotected sex with multiple partners or with a partner who has multiple partners, shared needles or syringes with others, who are the sexual partners of IV drug users, are considering pregnancy and have engaged in other risky behavior, or who have any reason to wonder if they might be infected.

Coates et al. (1988) examined issues related to HIV antibody testing and made recommendations for needed psychological research. Individuals facing

testing, they observe, must "(a) identify themselves at risk for exposure to a fatal and stigmatizing illness for which there is currently no cure; (b) undergo an uncomfortable and inconvenient medical testing procedure - including a relatively long waiting period for test results; (c) publicly admit (to a stranger, at least) that they are at risk for this disease by undergoing the testing process ; (d) weigh the societal risks of undergoing the testing process; (e) weigh whether they can psychologically navigate a positive test result; and (f) return for a second visit to the testing site to learn the results of their HIV test" (p. 859).

The need for research about individual decision processes for predictive testing is also recognized by others. The Institute of Medicine (1988) published wide-ranging recommendations in their report Confronting AIDS: Update 1988. Among their findings is that antibody testing and screening have advantages both public and individual. Screening helps assure the safety of donated blood and organs and is crucial in surveillance and planning for the epidemic. Individual benefits from testing include improved patient care due to timely medical treatment, fostering individual behavior change, and helping to identify contacts who are at risk. Consequently, the committee supported further studies of the behavioral impact of testing (1986; 1988). As Cates and Handsfield have noted "The benefit of testing depends primarily on the individual's knowledge of his or her test results, not on health authorities' creation of registries of infected persons" (1988, p. 1534).

Coates (in press) also bemoans the "dearth" of information on the effectiveness of behavioral change interventions. In his review of research on primary and secondary prevention of HIV infection, he details the need for continuing research into behavioral components to help prevent individuals from becoming infected in the first place (primary prevention) and in preventing the progression of the disease in those individuals already infected. To the extent that predictive HIV testing can prompt individuals at risk but as yet uninfected to extinguish or adapt risky behavior and can assist infected individuals to adopt healthy behaviors and initiate timely medical care, research into decision making can be valuable.

Lyter et al. (1987) surveyed 2047 gay and bisexual men involved in the Pittsburgh cohort of the Multicenter AIDS Cohort Study to assess their interest in being tested for the HIV virus. Sixty-one percent of the sample expressed interest in learning their results with only 54% (N=1,251) subsequently attending appointments to hear their results. Only 9% (N=188) declined to learn the results but fully 30% (N=608) failed to respond to survey. A comparison of those who failed to respond to the offer showed the group to be younger, nonwhite, and less educated. No significant differences were found in demographic, behavioral, or attitudinal variables between those who accepted or declined to be informed of their results. The four most frequently cited reasons for wanting to know their HIV status were to learn if they had been

infected (90%), to cope better with fear of AIDS (46%), to promote change in sexual behavior (40%), and to confirm a perceived negative status (40%). The four most frequently cited reasons for declining diagnostic results were because the test is not predictive of AIDS (48%), because a positive result would cause worry about developing AIDS (48%), because they would not be able to cope with a positive result (31%), and they would be afraid to have sex if testing positive (28%). Nearly three-quarters of the sample agreed with a statement about personal responsibility to prevent the spread of the virus to their sexual partners.

Carlson and McClellan (1987) offered voluntary HIV testing to 46 male IV drug abusers (IVDA's) in a V.A. medical center methadone treatment program. Eighty-five percent of this sample agreed to be tested. The remaining 15% declined testing because they stated that they had ceased IV drug use several years prior to the study and hence believed that they were not at-risk for the infection. Seven of the 39 subjects who agreed to be tested failed to be tested because of the deteriorated condition of their blood veins. Testing revealed that no one was seropositive for the HIV virus. The authors concluded that the high rate of agreement to participate in testing in an at-risk population widely believed to be dubious of testing reflects participation in a treatment program, a very trusting relationship with the clinical staff, and faith in the confidentiality of the results.

The importance in detecting important aspects of the testing decision is pointed out by a study of the relative seroprevalence rates among those who consent and refuse HIV testing. Hull et al. (1988) offered voluntary, anonymous HIV testing to all patients at a sexually transmitted disease (STD) clinic. Overall, four-fifths (82%) of the sample accepted testing. Analysis revealed that African American men were more likely to refuse testing than men from other ethnic groups. Acceptance rates did not vary by other demographic or sexual behavior variables. Blinded testing of those who refused the HIV test revealed an HIV prevalence rate 5.3 times higher than among those who accepted testing. The rate increased to 8.8 times among African American and Hispanic men and 7.3 times higher among male homosexuals compared to their counterparts who accepted testing. This strongly points out the need for interventions to increase the participation in testing programs of those individuals most likely to initially refuse diagnostic testing and to be most likely to test positive.

Aral et al. (1988) studied whether women who engage in HIV-related high risk behavior get tested for AIDS. Women who engaged in any high risk behavior were three times as likely (12%) as those who had not engaged in risky behavior (4%) to have been tested in the past for HIV. Even so, fully 85% of those with risky behavior in their past had never been tested for HIV. Women who had a partner positive for HIV were the most likely to have been tested but

even then, sixty percent (60%) still had not been tested themselves. Clearly, even though women at-risk were more likely to have been tested for the HIV virus, the great majority had not decided to be tested on their own at the time of the study.

The increased likelihood that at-risk women in a family planning clinic were more likely to have sought HIV testing was not matched in the male populatlon of a STD clinic. In the latter group, those men at advanced risk were least likely to consent to testing when offered. However, the difference may be related to the fact that the STD clinic sample was asked if they were interested in testing rather than if they had been tested previously. Further, the STD sample was a group seen for disease diagnosis rather than well treatment for pregnancy.

A blinded analysis by Evans et al. (1988) conducted on over 25,000 test results from an anonymous HIV testing clinic documented that women and heterosexuals were becoming larger proportions of clinic clients over time as the HIV epidemic spread from its initial homosexual/bisexual breakthrough. Further, they found that 20% of those tested were HIV positive, a result somewhat lower than when the clinic population was composed of predominantly homosexual and bisexual men.

Another issue was raised when Fehrsl et al. (1988) surveyed clients who requested HIV testing. They found that offering anonymous rather than

confidential testing produced a decreased mean latency period from the point of deciding to be tested to actually having the test performed. The latency dropped from 12 to 5 months amongst those at greatest risk. Clearly, for some individuals a period of time exists between when one considers being tested, decides to be tested, and then seeks testing.

Studies conducted in other nations suggest similarities across nationalities. Ohi et al. (1988) surveyed Japanese health care students about their willingness to be tested for HIV. Ninety (90%) percent expressed a willingness to be tested, with a preference for a testing clinic without carrier notification. Lebas et al. (1988) reported on the client demographics of an alternative testing site in France. In that sample, prostitutes composed the largest group of clients (47%), followed by homosexual/bisexual men (33%) and students (24%). When asked about their choice of testing site, most (65%) selected the alternative clinic because it was anonymous, with the remainder using the facility because it was free. Massari et al. (1988) examined trends in HIV testing among general practitioners in France. They found that men and women were about equally likely to be tested. Women were most likely to seek prenatal and prenuptial testing while men gave prenuptial testing, IV drug use, and presence of a STD as their reasons for testing. In a survey of all citizens who sought HIV testing in Sweden in late 1987, Olin et al. (1988) found that the sexes were equally represented, that 23% of the sample had been tested

previously, that women tended to overestimate their risk, and that homosexual men underestimated their risk based on HIV status.

Idiosyncratic properties of AIDS bear careful consideration. HIV and its sequelae are currently incurable. Consequently, at-risk individuals are asked to make life-long behavior changes and to be tested when there is little incentive for those who find out they are already seropositive. A positive test result does not lead to any treatment likely to cure the disease or even to forestall the eventual outcome. It is likely to elicit great personal distress. Potential rejection by family and significant others are very real outcomes. Positive outcomes of testing positive include reduction in fear of the unknown, opportunities to change behaviors to avoid spreading the disease to loved ones, and time to potentially prepare emotionally and financially for the consequences of the disease. Further, discrimination in employment, health care, and housing are not uncommon. These conditions closely resemble some aspects of the presymptomatic testing situation for Huntington's Disease covered earlier. Additionally, the mechanisms of transmission involve attention to the sensitive areas of sexual, reproductive, and addictive behaviors (Becker & Joseph, 1988).

Goldblum and Seymour (1987) have pointed out several advantages of HIV testing. First, testing may motivate those who participate in high risk behaviors to stop, reduce, or adapt their behavior. It may reduce the anxiety of

those unlikely to be infected but who nevertheless worry about their status. Testing may allow women considering childbearing to consider if they should become pregnant, if they should terminate a pregnancy, breast feed their infant, or have their infant vaccinated for other diseases with vaccines made from live viruses. Risks involved with testing include individual emotional problems, interpersonal problems, social ostracism, self-induced withdrawal, discrimination, preoccupation with illness, and suicidal ideation.

The CDC, in its most recent nationwide plan the CDC Plan for Preventing Human Immunodeficiency Virus (HIV) Infection: A Blueprint for the 1990's (1990), includes among its assumptions that an individual's knowledge of HIV status is important for both the individual's well-being and for prevention efforts. With such knowledge, seronegative individuals can take action to ensure they remain uninfected. Seropositive individuals can seek timely medical management and care that can delay or prevent the onset of illness and also take steps to prevent the transmission of the virus to others (Centers for Disease Control, August, 1990).

One of the clear advantages of HIV carrier status knowledge is the opportunity to help prevent the transmission of the disease to others. In fact, the scientific development with the greatest impact on the prevention of HIV has been the development of procedures to screen blood for the virus (Rothstein, 1988). This development allows for universal screening of all donated blood

used for transfusions and a variety of blood products. Additionally, testing has proven successful in promoting changes in risk behavior. Knowledge of risk status and undergoing the testing procedure has been shown to be related to reductions in risky sexual behavior in gay and bisexual men (Coates, Morin, & McKusick, 1987; Fox, Ostrow, Valdiserri, VanRaden, & Polk, 1987; McKusker et al., 1988; Farthing et al., 1987; Godfried et al., 1987; Willoughby et al., 1987). Coates et al (1987) followed for three years a group of gay and bisexual men who were tested for HIV antibodies. The reported rate of unprotected anal sex dropped from 48% to 5% among men who tested positive. The rate of decrease among men who were seronegative was much smaller, from 22% to 18%.

Similarly, Fox et al. (1987) surveyed a different group of gay men six months after testing. The men who tested positive had a history of greater numbers of sexual partners and greater rate of unprotected anal intercourse than those who tested negative. After six months, the survey revealed that seropositive men decreased unprotected anal sex to 42% of baseline while the rate for seronegatives dropped to 62% and to 5% for those tested who did not receive their results. These findings suggest that knowledge of antibody status separately adds to improvements in risk behaviors. Public health communications previously have been shown to decrease risky sexual behavior in some populations (Becker & Joseph, 1988; Stall, Coates, & Hoff, 1988).

Similar positive effects of antibody testing have been reported with other populations. Des Jarlais (1988) reported that a number of studies presented at scientific meetings have found that counseling and antibody testing for IV drug abusers were related to decreased risk behavior, with the greater risk reduction among seropositive individuals.

Recent advances have allowed health care providers the chance to offer infected individuals some treatments that may delay the onset of symptoms and prolong life. Recent research has shown that timely and early treatment with zidovudine (AZT) can slow progression of HIV infection to AIDS in asymptomatic individuals (NIAID, unpublished data). Development of new experimental treatments continues. Early diagnosis during this asymptomatic stage has been widely recommended (Centers for Disease Control, 1990) as it allows for timely medical treatment for opportunistic diseases, implementation of behavioral changes to increase overall health, and behavioral changes to prevent transmitting the infection to others.

Importance of the Present Study

There are several clear advantages of presymptomatic diagnostic status knowledge for planning for the future and several that are more ambiguous and personal. Knowledge of carrier status allows for timely planning regarding significant relationships and marriages, family and childbearing, employment and finances, health care, and spiritual issues. Knowledge of carrier status

generally would serve to decrease fear for those who test negative for HIV or the HD gene. It may also serve to reduce the fear of the unknown for persons who test positive but who have exaggerated or unfounded fears.

There may also be very serious personal costs involved with presymptomatic testing, especially when the disease is life threatening and cannot be cured. One faces the possibility of being overcome by anxiety or depression because of a positive test result. A positive outcome may trigger personal guilt about behavior that led to exposure to the disease or for possibly passing it on to others. One faces possible rejection from significant others and discrimination in personal, social, and economic spheres. Some people will experience a decrease in hopefulness as their hope of being free of the disease is dashed. A positive result may negatively affect a large number of previously made plans for the future. One may be confronted with tremendous medical problems and their accompanying financial costs.

Studies of early cohorts (Joseph et al., 1987; Ostrow et al., 1988) show increased rates of mental health consequences like depression and anxiety among gay men who tested positive for HIV. Studies of more recent cohorts (Coates, Morin, & McKusick, 1987; Coates et al., 1988) reveal that as the epidemic has matured, testing positive produces no greater long-term psychological symptoms than being in a risk group and testing negative or not undergoing testing at all.

On the other hand, Marzuk et al. (1988) documented that the suicide rate among a group of men diagnosed with AIDS was nearly 36 times greater than men in the general population. Many of the suicides examined were violent and obvious. More subtle suicides or suicides that were not properly reported suggest that the real rate was probably even higher (Coates et al., 1988), and calls for more accurate widely based studies have been made (Glass, 1988). As mentioned earlier, suicide rates for people with HD are also considerably higher than for the population at large.

Clearly, presymptomatic testing for these two illnesses, among others, has serious potential ramifications. The very strong emotions aroused and conflicting values involved cloud the issue. Great numbers of people at risk for either disease have decided not to seek presymptomatic testing. This study seeks to understand some of the important variables involved in the decision process. To date, analysis of the decision for presymptomatic testing has consisted of surveying high risk individuals for their reasons for testing. Such efforts have several serious shortcomings. First, individuals may or may not be able to explain their decision process. Second, individuals may be affected by subtle but potent variables of which they may be unaware. Some of the surveys have relied on choosing a reason from a previously constructed list of reasons. Further, the decision may be based on a combination or summation of reasons. Finally, most of the studies have looked at at-risk individuals for only one

particular disease. Such efforts lack generalizability given the rather unique characteristics and experiences of these individuals. Very few studies have been published utilizing healthy members of the general population, resulting in a patchwork of narrowly focused, atheoretical observations. No major study has been published that details how college students or other healthy young adults think about testing or about their own previous testing behavior.

The Present Study

The present study uses policy capturing technique (PCT) to begin the process of identifying important aspects of the presymptomatic testing decision. Rather than rely on previous models which were constructed to explain other types of health decisions or to prescribe certain rational decision making processes, the present study takes a more phenomenological approach. The study investigates how healthy young adults decide whether to be presymptomatically tested for late-onset terminal illnesses. Five independent variables, transmission mechanism, health status of the subject, partner/parent carrier status, physician test recommendation, and reproductive plans, will be systematically combined to study their effect in hypothetical test situations.

Policy capturing technique is a strategy that determines preferences, expressed interest, or desirability for a number of scenarios that are constructed by a factorial combination of the dimensions under study (Hammond, Rohrbaugh, Mumpower, & Adelman, 1977; Kluth & Muchinsky, 1984). The

factorial combination of the dimensions ensures the orthogonality, or statistical independence, of the different dimensions and permits investigation of the effects of each factor independently of the others (Heskith, Durant, & Pryor, 1990). Multiple regression analysis of the quantitative judgments of each subject are typically performed with the individual judgments as the criteria and the stimulus dimensions as the predictors. Individuals reveal their strategies by rating the strength of their preference for the unique combination of variables in the hypothetical situation. By analyzing these expressed preferences for the various combinations of variables, one is able to determine the relative importance of the variables for the decision and how the individual combines them.

A clear advantage of PCT is that it allows for great flexibility in selecting variables to be studied. A wide variety of personal and environmental variables can be used. Focusing on human judgment of options rather than using models of "correct" decision making, acknowledges the great amount of nonrational and idiosyncratic processes that mark human decision making (York, 1989). PCT has been used to study a number of human judgment situations including the decisions of arbitrators in wage cases (Bazerman, 1985), individual preferences of students for occupational environments (Kluth & Muchinsky, 1984), the evaluations of EEOC experts about possible sexual harassment (York, 1989),

investment strategies (Slovic, 1969), and the ethical reasoning of organizational consultants (Tannenbaum, Greene, & Glickman, 1989).

The present study investigates five factors considered important by the investigator in the testing decision: transmission mechanism, health status of the subject, partner/parent carrier status, physician test recommendation, and reproductive plans. The purpose of the study is to determine the extent of the influence of each of the variables on an individual's decisions to be tested for diseases through the use of regression procedures in a policy-capturing technique.

Analysis occurs at the level of the sample as a whole and for subsamples of subjects. Cluster analysis techniques are used to determine if there are subgroups of individuals who have similar decision making processes. Subject variable correlates to decision making are also examined.

Research Questions and Hypotheses

It is hypothesized that subjects will utilize information from the scenarios in deciding about diagnostic testing. Within-subject multiple regression produces a set of beta coefficients for each subject for each of the five independent variables under scrutiny. These individual sets of coefficients, or beta weights, serve to describe individual decision strategies and are used for subsequent analyses. While many models seek only to identify the common decision model that best describes the group as a whole, the present study will

examine both the decision strategy of the group as a whole and of discrete subgroups of subjects within the sample.

The first phase of analysis (Phase1) will be performed to identify those processes that describe the overall group. Descriptive and inferential statistics will be computed. Combined individual regression weights and ANOVA's will reveal the unique contribution of each of the five independent variables and overall predictiveness for the sample as a whole. Further analyses will elucidate the relationships between the independent variables and both categorical and continuous subject variables. The following specific relationships are predicted a priori:

1a. Individual perception of risk for contracting HIV will be positively related to willingness to be tested for HIV in the hypothetical scenarios. Individual perception of risk for HD will be positively related to willingness to be tested for HD. Likewise, the seriousness of HD and HIV disease, measured as personal concern about contracting the disease, will be related to willingness to be tested under the experimental conditions.

1b. Individuals who place great priority on having children, shown by present parental status and/or future childbearing plans, are predicted to place a significant weight on the childbearing variable in the scenario model.

The second phase of analysis (Phase 2) looks to discover the unique combination of independent variables each subject uses and then to find common strategies among subgroups within the sample. In this sense, this study is more exploratory than confirmatory. It is expected that different patterns of weighting scenario variable information will emerge and reflect clusters or subgroups of individuals with similar decision strategies. It is expected that the equation developed for each group will account for a significant amount of the variance in the decision task. A variety of demographic and personal data collected are expected to relate to cluster membership. While the effects of each of these subject variables is not known, certain factors are expected to predict cluster membership. Consequently, several specific predictions are offered:

2a. Knowledge of a significant other who has tested positive for HIV will be related to membership in clusters that positively weight testing for HIV. Similarly, knowledge of a significant other who has tested positive for HD will be related to membership in clusters which positively weight testing for HD.

2b. A previous pattern of avoiding diagnosis as evidenced by previous delays in seeking either diagnosis or treatment for a serious illness will be negatively related to membership in clusters that heavily weight individual subject symptom carrier status.

2c. Knowledge of a significant other who has tested positive for either HD or HIV will be related to membership in clusters that positively weight testing when the partner or parent of the subject has tested positive for the respective disease.

2d. Childbearing status and childbearing plans are predicted to be directly related to membership in clusters with the highest beta weight on the childbearing plans independent variable.

The effects of sex, ethnicity, language, religion, age, education, and income on sample variable weightings or cluster membership are not explicitly predicted a priori. Exploratory analyses will examine the relationship of other subject variables with decisional strategy as operationalized by sample mean beta weights in Phase 1 and cluster membership in Phase 2. Various subject variables will be used to help characterize the members in each cluster based on the use of ANOVA, correlational, and chi-square techniques. These relationships, except as specified above, are not explicitly predicted a priori.

METHODS

Subjects

A sample of 232 students was recruited from the undergraduate volunteer pool at Iowa State University. All subjects were enrolled in undergraduate psychology courses and obtained extra credit for their participation. Fifteen subjects were dropped from the study after preliminary analyses because the independent variables under study accounted for less than forty percent of the variance in their responses, suggesting lack of attention to the task. The forty percent crtieria was chosen arbitrarily. Of 217 subjects who were studied, 48 percent were male and 52 percent were female. Demographic information for the sample is presented in Table 1.

Procedure

All subjects attended a large-group testing session. During the session, all subjects completed the Consent Form, the Personal Data Sheet (PDS) to obtain demographic and sociological information, and the 32 hypothetical health decision scenarios of the Health Decisions Questionnaire (HDQ).

Measures

Subject Variables

After reading a brief description of Huntington's Disease and of HIV infection (and AIDS) (see Appendix B), subjects completed the PDS (see Appendix C) to obtain demographic information and to assess whether they had

Table 1. Descriptive statistics for the sample

Variable	N	%
Education		
Freshman	106	52
Sophomore	53	26
Junior	28	14
Senior	17	8
Language		
English	195	90
NonEnglish	22	10
Religion		
Catholic	79	36
Protestant	66	30
Other Christian	37	17
Moslem or Muslim	3	1
Other	13	6
None	19	9
Income		
< $15,000	7	3
$15-30,000	48	22
$30-45,000	51	24
$45-60,000	51	24
>$60,000	60	28
Ethnic		
African American	12	6
Asian American	9	4
Caucasian American	172	79
Hispanic American	3	1
International Student	17	8
Native American	1	1
Other	3	1
Marital		
Single, dating	143	66
Single, not dating	46	21
Engaged	10	5
Married	4	2
Monogamous Nonmarital	14	7
Children		
Parent	4	2
Nonparent	213	98

been previously tested for either Huntington's disease or the HIV virus, their current intentions about being tested, current carrier status (if known), personal experience with anyone with either disease, sexual orientation, reproductive plans, previous delays seeking any medical diagnosis, and previous delays seeking medical treatment. Additional subject variables were assessed using a continuous measure (seven-point Likert scale) for personal concern about each disease, perceived level of risk for each disease, confidence in the diagnostic procedures, and perceived ability to cope with positive and negative test findings.

Dependent and Independent Variables

The dependent variable in this study is derived from the HDQ (see Appendix D) which was developed specifically for this investigation. Subjects were asked to rate on a seven-point Likert scale the likelihood of their being tested, with 1 indicating "extremely unlikely" and 7 indicating "extremely likely," to get a continuous measure of preference to be tested under the hypothesized circumstances. Hence, the dependent variable was the likelihood of being tested under that unique combination of circumstances. Each subject generated one testing likelihood rating for each of the 32 hypothetical scenarios.

The HDQ consists of 32 hypothetical situations in which the subjects are asked to imagine themselves. Each situation varies five important aspects of

the decision-maker's condition (the five independent variables) in a completely randomized within-subject factorial design (CRF-2x2x2x2x2). In this policy capturing design, all subjects completed the same 32 completely crossed combinations of the 5 dichotomous independent variables. The order of the scenarios was counterbalanced to control for order effects. The five independent variables under scrutiny are as follows:

A) Transmission mechanism (Hereditary vs Infectious);

B) Health status (Asymptomatic vs Symptomatic);

C) Partner /Parent carrier status (Clear risk in partner or parent vs Uncertain risk);

D) Physician test recommendation (Recommended by physician vs No recommendation by physician);

E) Reproductive plans (Plan to have children vs Plan not to have children).

Statistical Analysis

Policy Capturing Analysis

Following policy capturing technique (e.g. Bazerman, 1985; Heskith, Durant, & Pryor, 1990; Kluth & Muchinsky, 1984), the importance of each decisional aspect was determined using multiple regression analysis. Policy capturing techniques emphasize performing analyses of the preferences or decisional behavior of the individual subject. The "policy" of each subject is the

derived weights given to each of the factors under study and is based on how personally likely he or she rated his or her willingness to be tested under each of the 32 possible combinations comprising the hypothetical situations. The policy is "captured" by multiple regression analysis to reflect each subject's overall preferences for various aspects of the decisional situation.

The testing preference ratings were regressed against the independent variables to produce one multiple regression equation for each subject. The derived standardized beta weights indicated directly the relative importance attached to each of the five variables by each subject. This procedure allowed for the capture of the policy of each subject toward diagnostic testing.

The variance (R^2) in the preference ratings accounted for by the weightings of the five aspects of the decisional scenarios in the HDQ was also computed.

Inferential Analyses

Analyses of the individual regression coefficients generated for each subject were performed at two different levels. During Phase 1, analyses were performed to compute inferential statistics for the sample as a whole. ANOVA's were performed to determine the main effects of the five independent variables on the decisional preference ratings of the HDQ. The relationships of subject variables to the decision strategy of the sample as a whole were examined through use of ANOVA, correlational, and chi-square procedures.

The second line of analysis (Phase 2) was to detect subgroups of subjects with similar decision weighting patterns and then to find subject variables which described membership in the subgroups. Ward's clustering techniques (Borgen & Barnett, 1987; SAS, 1990; Ward, 1963) were applied to the individual standardized beta weightings to determine if assigning individuals to subgroups best described different patterns of decisional preferences. Again, ANOVA, correlational, and chi-square analyses were used to determine the relationships of subject variables to cluster membership.

Phase 1 Analyses

Individual beta weights were standardized within subject and then combined to create sample mean beta weights. These within-subject multiple regression coefficients were combined to assist in determining the effect of the independent variables in predicting decisional choice for the whole sample.

ANOVA and general linear modeling was performed to determine the effects of the categorical independent variables on the dependent variable of decisional choice for the sample as a whole. Chi-square analyses were performed to determine the effects of the continuous subject variables.

Phase 2: Subgroup Analyses

Cluster analysis was performed on the beta weight pattern of each individual to determine if there were groups of people with similar decisional styles. Appropriate ANOVA, chi-square, and Pearson correlation coefficients

were computed to assist in describing the members of each decisional style cluster.

The null hypothesis for all analyses was rejected at alpha level = .05.

RESULTS

Individual multiple regressions were computed for each subject, resulting in a standardized beta weight for each of the five independent variables and a value of the amount of variance accounted for by the regression model, R^2, for each individual subject. Beta weights were standardized within individual with a mean of zero, a standard deviation of one, and an intercept of zero. Standardization served to emphasize the relative importance of each independent variable and their overall pattern while it controlled for the absolute level of prediction of the testing decision.

Phase 1: Sample-wide Analysis

Table 2 gives the descriptive statistics for each of the five independent variables for the sample as a whole. Overall sample mean standardized beta weights were computed for each of the five independent variables and are graphed in Figure 1. The mean amount of variance accounted for by the combination of all five variables (R^2) was 65.9%.

Analysis of variance was performed to determine the effects of the independent variables on the testing decision. Main effects F-values are reported in Table 3. The partner/parent carrier status variable had the greatest

Table 2. Sample mean standardized beta weights of independent variables and $\underline{R}^2$

Variable	Mean	Standard Deviation	Minimum	Maximum
A. Transmission mechanism	0.228	0.186	-0.248	0.766
B. Health status	0.275	0.151	-0.203	0.734
C. Partner/Parent carrier status	0.555	0.173	-0.145	0.925
D. Physician test recommendation	0.185	0.159	-0.265	0.643
E. Reproductive plans	0.189	0.203	-0.203	0.774
$\underline{R}^2$	0.659	0.114	0.396	0.929

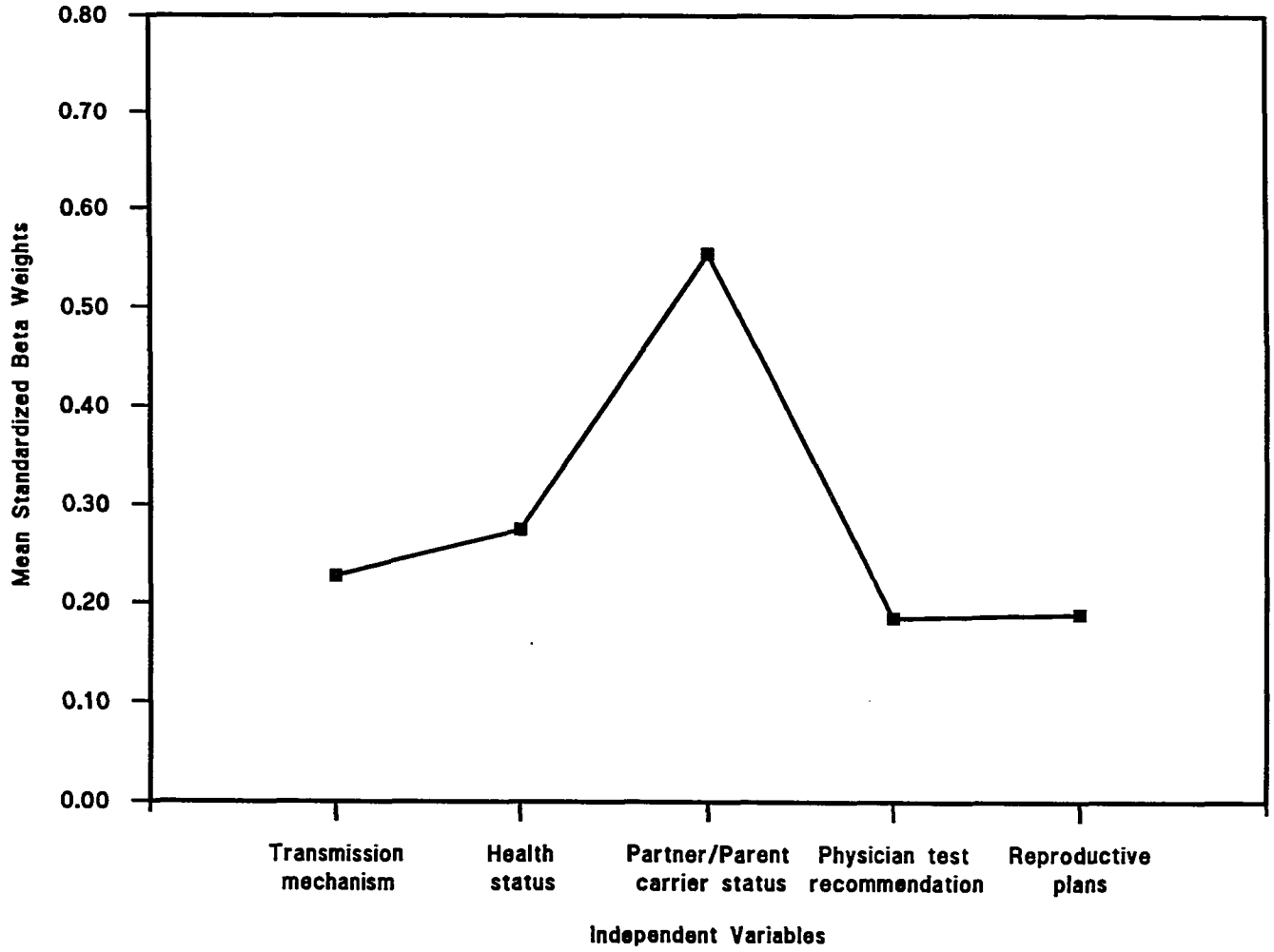

Figure 1. Decision profile composed of mean standardized beta weights for the whole sample

Table 3. F-values of main effects for the independent variables

Source	SS	F	Probability	Eta^2
A. Transmission mechanism	1036.65	283.61	0.0001***	.04
B. Health status	1499.64	602.63	0.0001***	.06
C. Partner/Parent carrier status	6255.94	1103.91	0.0001***	.26
D. Physician test recommendation	621.25	298.67	0.0001***	.03
E. Reproductive plans	665.06	168.10	0.0001***	.03
Corrected total	23949.69			

N = 217.

impact overall on the testing decision in the hypothetical situations and its main effect accounted for 26% of the variance alone.

Categorical Subject Variable Relationships

Analysis of variance procedures were performed to determine the effects of the categorical subject variables on each of the five independent variables, operationalized as individual standardized beta weights. Results are summarized in Table 4.

Sex

Gender strongly related to use of the reproductive plans independent variable (F [1, 206] = 6.86, $p<.01$), with female students utilizing the factor more strongly than males. Sex did not relate to use of the other four independent variables.

Ethnicity

Ethnicity did not significantly relate to any of the five independent variables.

Native Language

Native language significantly related to only one of the independent variables. Native English-speaking subjects were more likely to utilize information on reproductive plans when deciding to be tested (F [1, 215] = 5.20, $p<.05$). There were no differences in use of the other four independent variables on the basis of native language.

Table 4. F- values for ANOVAs of categorical subject variables and standardized beta weights

Subject variables	A. Transmission mechanism	B. Health status	C. Partner/Parent carrier status	D. Physician test recommendation	E. Reproductive plans
1. Sex	0.03	0.54	0.50	0.02	6.86**
2. Ethnicity	1.82	2.09	1.90	1.53	0.78
3. Native language	2.68	1.59	2.69	0.09	5.20*
4. Religious preference	0.61	1.61	0.90	3.23**	1.45
5. Income	1.30	0.75	0.16	0.10	0.37
6. Marital status	1.45	0.33	1.37	1.09	0.37
7. Childbearing status	0.16	1.29	4.32*	1.80	1.58

8. Childbearing plans	0.28	0.31	1.02	1.69	2.36
9. Sexual orientation	3.93*	0.10	0.21	0.59	1.61
10. Previous serious illness	0.32	4.27*	2.81	1.41	8.50**
11. Previous delay in seeking diagnosis	0.18	0.06	0.52	3.41	0.19
12. Previous delay in seeking treatment	0.06	0.23	0.40	3.02	0.05
13. Previous HIV Test	2.45	0.36	4.14*	0.24	0.25
14. HIV status	0.06	3.79	12.53***	0.12	0.02
15. Previous HD Test	-	-	-	-	-
16. HD Status	-	-	-	-	-
17. Future HIV Test Plans	1.17	0.21	0.38	1.79	1.92

Table 4. F-values for ANOVAs of categorical subject variables and standardized beta weights (cont.)

Subject variables	A. Transmission mechanism	B. Health status	C. Partner/Parent carrier status	D. Physician test recommendation	E. Reproductive plans
18. Future HD Test Plans	0.18	1.80	0.32	0.91	1.62
19. Knowledge of other with HIV	0.22	0.13	1.37	0.23	3.78*
20. Relationship with HIV-positive other	3.24	0.28	0.54	4.38	2.14
21. Knowledge of other with HD	2.39	0.02	0.11	0.02	0.66
22. Relationship with HD-positive other	17.06**	0.27	10.15*	1.77	7.43*

*** $p < .0001$ ** $p < .01$ * $p < .05$ $n = 217$

Religious Preference

Religious preference significantly related to use of the physician test recommendation variable. Follow-up Tukey's HSD tests failed to identify which of the religious affiliations produced the significant difference detected in the overall ANOVA.

Income

Income level of family of origin did not significantly relate to any of the five independent variables.

Marital Status

Marital status did not relate significantly to any of the five independent variables.

Childbearing Status

Childbearing status related to partner/parent carrier status (F [1, 215] = 4.32, p<.05) but not to the reproductive plans variable (F [1, 215] = 1.58, p<.21). Childbearing status did not relate to the other independent variables.

Childbearing Plans

Childbearing plans did not relate to any of the five independent variables.

Sexual Orientation

Only one on the 217 subjects studied identified herself as bisexual. No one identified herself or himself as gay or lesbian. Consequently, no separate

analyses were performed on the basis of sexual orientation. This low rate of self-reported bisexual and gay sexual orientation is likely an underreport but is consistent with previous studies with undergraduate students from the same university (M. Gerrard, personal communication, August 24, 1991).

Previous Disease

Twelve of the subjects (6%) reported a serious illness at some time during their life. The remaining subjects (94%) reported no history of major medical problems. Twenty-four subjects (12%) reported having delayed seeking a diagnosis for a potentially serious medical condition. Further, twenty subjects (10%) indicated that they have delayed seeking medical treatment at least once.

Previous serious illness significantly related to two independent variables: subjects with a history of a serious previous illness were more likely to heavily weight health status (F [1, 215] = 4.27, $p<.05$) and more likely to heavily weight reproductive plans (F [1, 215] = 8.50, $p<.01$).

A history of previous delays in seeking diagnosis or in seeking treatment for a potentially serious illness did not significantly relate to any of the five independent variables.

HIV Test

Twenty-eight of the subjects (13%) had tested for HIV at some time in their life. chi-square analyses revealed no significant pattern difference on the

basis of age, ethnicity, or native language. The effect of gender did approach significance (X^2 [1, N = 208] = 3.40, p<.07), with males being more likely to have sought testing.

Subjects who had been previously tested for HIV weighted the partner/parent risk status variable more heavily than did those who had not been tested (F [1, 215] = 4.14, p<.05). No other independent variable was significantly related to past HIV testing.

HIV Status

Only one of the 28 subjects (4%) who had been tested was positive for HIV. The subject was male and heterosexual. His current health status was listed as HIV positive with no symptoms of AIDS. Analyses performed on the basis of HIV status were not performed due to the small size of the subsample.

HIV Testing Plans

Three subjects expect to be tested soon, another 64 (28%) plan to be tested at some point in the future. Thirty-nine percent of the sample (N = 90) have no plans to be tested for HIV. Thirty-one percent were uncertain about their testing plans.

Future plans for HIV testing did not significantly relate to any of the five independent variables.

HIV Experiences

Only seven persons in this sample (3%) have had personal acquaintance with anyone who was HIV positive or had AIDS. Females were more likely than males to know someone with HIV. Four of the seven subjects knew someone only at the level of a casual acquaintance.

Knowledge of others with HIV significantly related to weighting of the reproductive plans variable (F [1, 215] = 3.78, $p<.05$), with those who know someone who is HIV-positive more heavily weighting the factor. None of the other independent variables significantly related. The type of relationship with an HIV-positive other was also unrelated to the independent variables.

Huntington's Disease

No one in this sample had previously tested for HD, but sixteen (8%) expressed interest in being tested in the future. Seven of the subjects knew someone with HD, none of whom were affected family members or close friends. The sample was generally not concerned about developing HD (M = 2.2, SD = 1.5). They believed that it was unlikely that they would develop the disease (M = 1.7, SD = 1.1). The subjects had a high level of confidence in the diagnostic test (M = 5.1, SD = 1.4). Perceived support from significant others and family if the subject were to have the disease was widely perceived to be very high (M = 6.4, SD = 1.1). As expected, subjects consistently reported that it

would be easier to cope with a negative test finding than a positive result indicating the presence of the condition (t [216] =27.54, p<.0001).

Future plans for HD testing did not relate to any of the five independent variables. Though knowledge of another who has HD did not relate to any of the five variables, the type of relationship with the HD-positive other was related to weightings on transmission mechanism (F [1, 5] = 17.06, p<.01), partner/parent carrier status (F [1, 5] =10.15, p<.05), and reproductive plans (F [1, 5] = 7.43, p<.05). Subjects who listed the known HD-positive person as a casual acquaintance had a higher mean weighting on transmission status than did those who listed the HD-positive person in the category of other (p<.01). Subjects who listed the known HD-positive person in the other category had higher beta weights on partner/parent carrier status (p<.05) and reproductive plans (p<.05). The meaning of the difference in the relationship categories casual acquaintance and other is not known.

Continuous Subject Variable Correlates

The effects of the continuous subject variables were assessed by computing Pearson correlation coefficients between subject variables and individual standardized beta weights on each of the five independent variables and are summarized in Table 5.

Table 5. Correlation matrix of continuous subject variables and standardized beta weights

Subject variables	A. Transmission mechanism	B. Health status	C. Partner/Parent carrier status	D. Physician test recommendation	E. Reproductive plans
1. Personal concern about contracting HIV	.10	-.01	-.04	-.08	-.05
2. Perceived risk of HIV infection	.04	-.03	.09	.05	-.02
3. Personal concern about developing HD	-.07	-.09	-.08	-.02	.07
4. Perceived risk for HD	.02	-.03	-.03	-.01	.07
5. Confidence in HIV test	.11	-.20***	.03	.01	.05

6. Confidence in HD test	.09	-.15*	.01	.03	.10
7. Ability to cope with a positive HIV test	.10	.02	-.02	.01	-.05
8. Ability to cope with a negative HIV test	-.04	.17*	.22***	-.06	-.03
9. Ability to cope with a positive HD test	.09	-.00	.01	-.08	.05
10. Ability to cope with a negative HD test	.03	.04	.17*	-.03	.08
11. Support from significant others if HIV positive	.06	.06	-.01	.12	-.18**
12. Support from significant others if HD positive	.00	-.04	.03	.03	-.01

*** $p < .0001$ ** $p < .01$ * $p < .05$ $n = 217$

HIV Beliefs

Thirty-one percent of the sample (N = 66) expressed some degree of personal concern about HIV in their lives (M =3.4, SD = 1.9). Overall, subjects felt at fairly low personal risk for contracting HIV (M =2.0, SD = 1.0). Only 4 subjects reported that they were likely to contract HIV in their lifetimes. As expected, individuals perceive that they would be better able to cope with a negative test finding than with a positive test finding indicating infection with the HIV virus (t [216] =29.60, p<.0001). Subjects tended to believe that they would have difficulty coping with a positive HIV test with males having more confidence in their coping ability than women (t [166] = 2.12, p<.01).

Intercorrelations between various subject variables related to HIV were computed and are reported in Table 6. Perceived risk of contracting HIV significantly correlated with personal concern about contracting HIV (r = .36, p<.0001). Concern about contracting HIV negatively related to perceived ability to cope with a positive test result (r = -.20, p<.01), but not with a negative test result. As would be expected, perceived ability to cope with a positive test finding positively correlated with perceived support from others if one were HIV positive (r = .26, p<.01).

HD Beliefs

Intercorrelations between various subject variables related to HD were computed and are reported in Table 7. Though perceived risk of contracting HD

Table 6. Intercorrelation matrix of selected HIV subject variables

Subject variables	2	3	4	5	6
1. Concern about contracting HIV	.36***	.10	-.20**	-.13	.00
2. Perceived risk of contracting HIV	-	.12	-.17*	-.02	.02
3. Confidence in HIV diagnostic test		-	-.00	.14*	.15*
4. Perceived ability to cope if HIV positive			-	.10	.26**
5. Perceived ability to cope if HIV negative				-	.03
6. Perceived support if HIV positive					-

*** p<.0001.

** p<.01.

* p<.05.

N = 188.

Table 7. Correlation matrix of selected HD subject variables

Subject variables	2	3	4	5	6
1. Concern about contracting HD	.37***	.05	-.10	-.16*	-.07
2. Perceived risk of contracting HD	-	-.12	-.14	-.07	-.19**
3. Confidence in HD diagnostic test		-	.07	.24**	.16*
4. Perceived ability to cope if HD positive			-	.05	.08
5. Perceived ability to cope if HD negative				-	.20**
6. Perceived support if HD positive					-

*** p<.0001.

** p<.01.

* p<.05.

N = 188.

significantly correlated with personal concern about contracting HD (r = .37, p<.0001), neither perceived risk nor personal concern related to any of the five independent variables.

Confidence in the HD diagnostic test significantly related to health status (r = -.15, p<.05) but not to any of the other independent variables. Confidence in the HD diagnostic procedure significantly related to one's perceived ability to cope with a negative test result (r = .24, p<.01), but not to perceived ability to cope with a positive result. None of the five independent variables was related to the perceived ability to cope with either a positive or negative HD test.

The intercorrelations between the standardized beta weights for each of the five independent variables are reported in Table 8. As shown in the table, the strongest relationship was between partner/parent carrier status and reproductive plans (r = -.44, p<.0001). Further, transmission mechanism significantly related to health status (r = -.28, p<.0001) and partner/parent carrier status (r = -.31, p<.0001). While other variables were statistically related, the magnitude of the relationship does not suggest a practically significant effect.

Phase 1 Hypotheses

Hypothesis 1a was not supported by the results of the study. Personal concern about contracting HIV and HD were not significantly correlated with use of the transmission mechanism independent variable (Table 5; r = .10 and r = -.07, respectively). Perception of personal risk was also not significantly

Table 8. Correlation matrix of mean standardized beta weights

Scenario variables	B	C	D	E
A. Transmission mechanism	-.19**	-.28***	-.31***	.07
B. Health status	-	-.02	-.08	-.19**
C. Partner/Parent carrier status		-	-.00	-.44***
D. Test recommendation			-	-.17**
E. Reproductive plans				-

*** p<.0001.

** p<.01.

* p<.05.

N = 217.

correlated with use of the transmission mechanism variable (r = .04 and r = .02, respectively).

Childbearing status and childbearing plans both failed to be significantly related to use of the reproductive plans independent variable (F [1, 215] = 1.58, p=.21 and F [1, 215] = 2.36, p=.07, respectively).

Phase 2: Subgroup Analysis

The individual standardized beta weights were entered as data for a cluster analysis using the method developed by Ward (Ward, 1963). Clusters were created using individual standardized beta weight coefficients only. The derived clusters are groups of individuals with similar beta weightings on the five variables. The aggregate decision profile for each cluster is composed of the mean standardized beta weights for the members of the cluster.

On the basis of the Ward's cluster analysis performed on the 217 individually computed profiles of standardized beta weights, a seven cluster solution was generated. The seven cluster solution was determined solely on the basis of scree plot examination.

Statistics for each group will be discussed individually. Figure 2 shows the weighting of the independent variables for each of the seven clusters. Table 9 presents the means and standard deviations of the beta weights by cluster. The mean beta weights for each of the variables were in the positive direction for each cluster. The amount of variance in decisional choice ($R2$) accounted

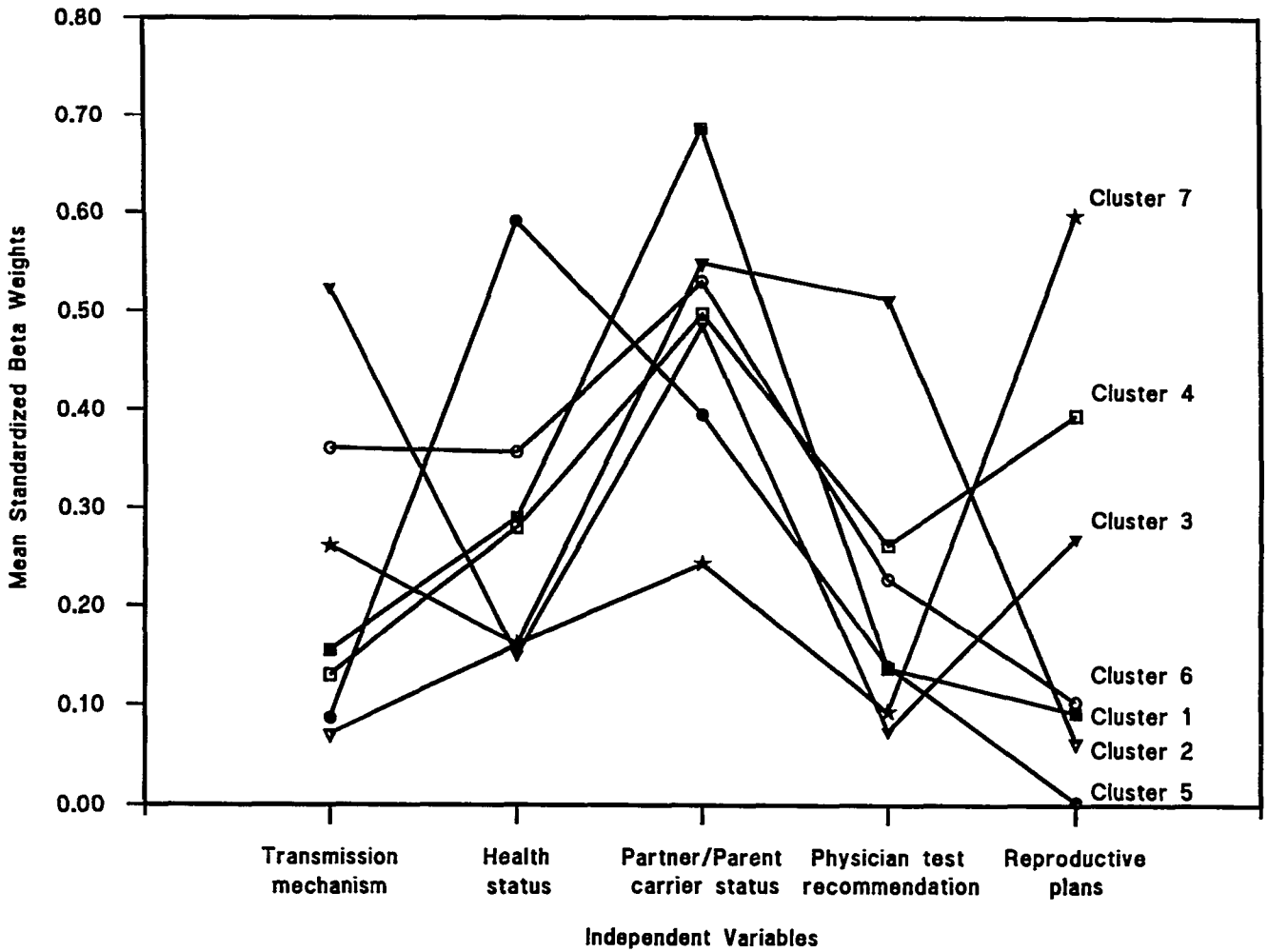

Figure 2. Decision profile composed of mean standardized beta weights for each of the seven clusters

for the five independent variables for each cluster of subjects are also presented in Table 9. As can be seen, the R^2's for the various clusters are high and are very similar to each other, ranging from .620 to .694. It is uncertain whether the consistency of the R^2's for each of the clusters is an artifact of standardizing the beta weights to control for level effects.

Post hoc Tukey's HSD test results are reported as subscripts in Table 9. Subscripts reflect significant differences between clusters on each of the independent variables. For example, for the independent variable of health status, Cluster 5 differs from all other clusters and is subscripted "a". Clusters 1, 4, and 6 do not significantly differ from each other (subscript "b") but do differ from all the other clusters. Likewise, Clusters 2, 3, and 7 (subscript "c") do not significantly differ from each other but do differ from the other clusters.

Table 10 presents the chi-square analyses performed to determine the effects of each of the categorical subject variables on membership in each of the seven clusters.

Cluster 1

The first cluster generated by the cluster analysis was composed of 85 subjects (39%). Table 9 presents the mean standardized beta coefficients for this and the other clusters. A clear risk of disease transmission from a carrier partner/parent was the most important aspect of the scenarios in predicting that

Table 9. Mean standardized beta weights for each cluster[1]

Variable	Cluster 1	2	3	4	5	6	7
A. Transmission mechanism							
Mean	.155$_{cd}$	.071$_{d}$	.524$_{a}$	.130$_{d}$	.087$_{d}$	.361$_{b}$	.261$_{bc}$
SD	.115	.085	.142	.094	.128	.108	.210
B. Health status							
Mean	.290$_{b}$	.160$_{c}$	.150$_{c}$	.280$_{b}$	.591$_{a}$	.357$_{b}$	.161$_{c}$
SD	.124	.086	.127	.084	.074	.116	.168
C. Partner/Parent carrier status							
Mean	.686$_{a}$	.549$_{b}$	.485$_{bc}$	.497$_{bc}$	.395$_{c}$	.530$_{b}$	.243$_{d}$
SD	.103	.118	.141	.110	.228	.115	.105
D. Physician test recommendation							
Mean	.137$_{cd}$	.512$_{a}$	.074$_{d}$	.262$_{b}$	.139$_{cd}$	.227$_{bc}$	.093$_{d}$
SD	.096	.064	.108	.122	.196	.149	.119
E. Reproductive plans							
Mean	.092$_{d}$	.063$_{d}$	.269$_{c}$	.394$_{b}$	.003$_{d}$	.103$_{d}$	.596$_{a}$
SD	.130	.110	.138	.116	.083	.100	.133
R^2							
Mean	.670	.640	.694	.620	.639	.670	.625
SD	.118	.098	.106	.108	.117	.112	.111

Note. Mean standardized betas and standard deviations.

[1] Means within rows that do not share common subscripts differ at $p<.05$ according to Tukey's HSD test.

Table 10. Chi-square analysis of categorical subject variables and subgroup clusters

Subject variables	Cluster1	Cluster2	Cluster3	Cluster4	Cluster5	Cluster6	Cluster7
1. Sex	1.70	0.92	0.06	4.59	0.21	0.97	0.42
2. Ethnicity	0.02	0.71	0.51	2.44	3.21	0.00	0.19
3. Native language	0.81	0.11	0.25	1.77	21.26***	0.08	0.29
4. Religious preference	-	-	-	-	-	-	-
5. Income	0.02	2.14	0.24	1.09	0.17	4.06*	0.38
6. Marital status	0.34	1.85	0.58	0.65	0.18	0.28	0.85
7. Childbearing status	-	-	-	-	-	-	-

8. Childbearing plans	0.00	0.00	0.18	0.50	0.52	0.45	1.16
9. Sexual orientation	-	-	-	-	-	-	-
10. Previous serious illness	1.50	2.36	4.26*	0.03	0.60	2.57	5.00*
11. Previous delay in seeking diagnosis	1.45	2.35	0.24	0.93	0.01	0.00	0.00
12. Previous delay in seeking treatment	0.03	0.29	0.03	1.77	0.01	0.73	1.41
13. Previous HIV Test	1.89	0.43	2.09	1.35	0.64	0.06	0.43
14. HIV status	-	-	-	-	-	-	-
15. Previous HD Test	-	-	-	-	-	-	-
16. HD Status	-	-	-	-	-	-	-
17. Future HIV Test Plans	0.27	1.41	2.46	0.74	0.00	0.82	2.60

Table 10. Chi-square analysis of categorical subject variables and subgroup clusters (cont.)

Subject variables	Cluster1	Cluster2	Cluster3	Cluster4	Cluster5	Cluster6	Cluster7
18. Future HD Test Plans	5.90*	0.12	2.99	0.15	1.19	5.99**	0.12
19. Knowledge of other with HIV	0.34	0.51	0.02	0.00	0.31	0.01	0.51
20. Relationship with HIV-positive other	-	-	-	-	-	-	-
21. Knowledge of other with HD	0.04	0.58	0.02	0.00	0.32	0.99	0.58
22. Relationship with HD-positive other	-	-	-	-	-	-	-

*** $p < .0001$ ** $p < .01$ * $p < .05$ $n = 217$

a member of this cluster would decide to be tested (Figure 3). Willingness to be tested increased when the partner or parent of the subject had been positively diagnosed with the disease. The second most important variable was the health status of the subject. The subject was more likely to decide to be tested if they themselves were beginning to show symptoms of the disease in question. Other variables were of less significance in adding to the overall predictiveness of the model (R^2 = .67). The pattern of group mean beta weights is shown in Figure 3.

ANOVA and chi-square tests revealed that subjects who planned not to be tested for HD in the future were overrepresented in this cluster (X^2 [1, N = 217] = 5.90, p=.02). All other subject variables were not related to membership in this cluster (Table 10).

Cluster 2

The second cluster is distinguished by relatively equal weighting of the two most important variables (Figure 4). Mean standard beta weights presented in Table 9 show that both a clear risk from a carrier and a specific recommendation from a physician for diagnostic testing were the most significant predictors of willingness to be tested. The overall model generated an R^2 of .64 for this cluster. Sixteen subjects (7%) were assigned to this cluster.

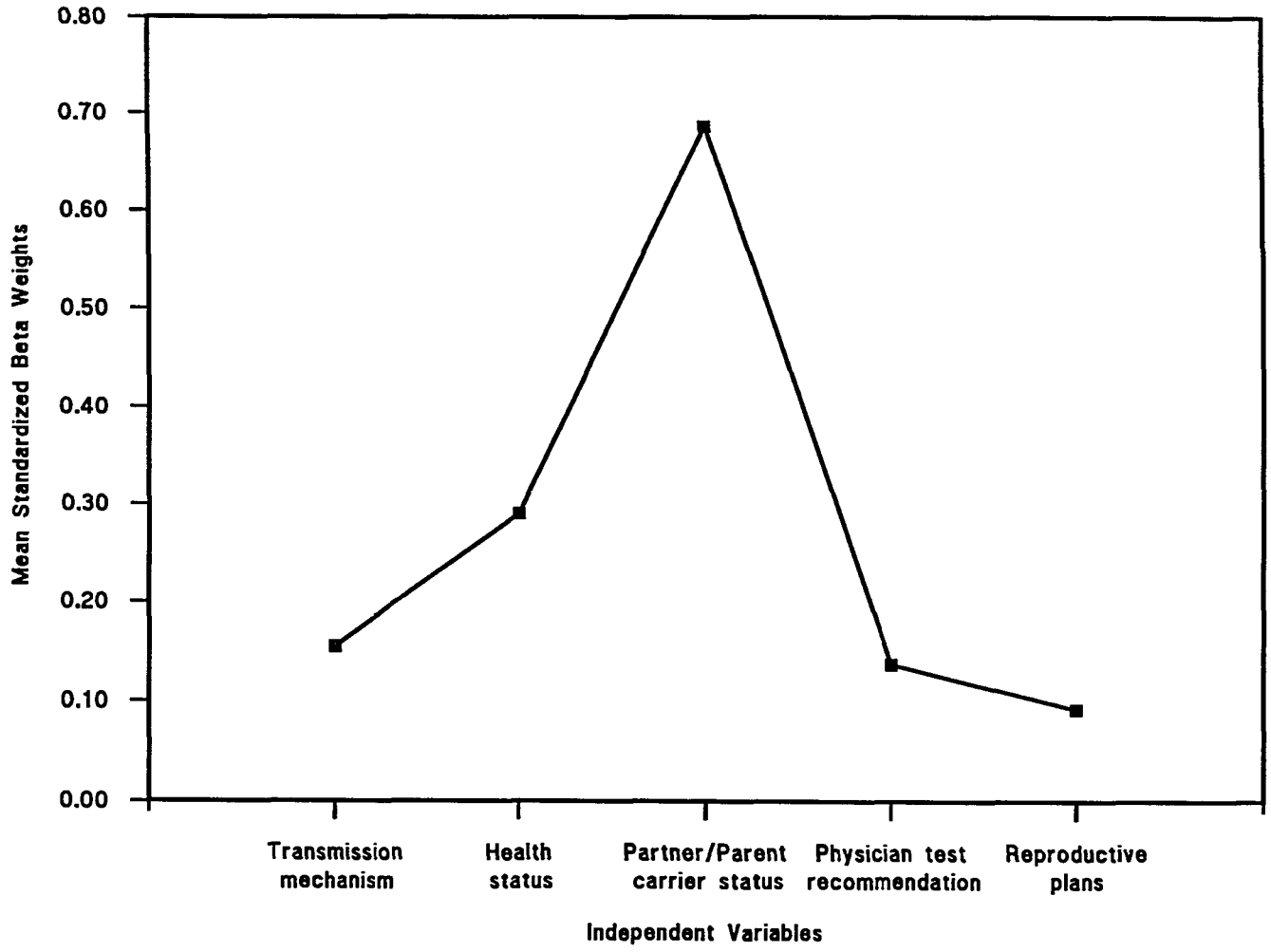

Figure 3. Decision profile composed of mean standardized beta weights for Cluster 1

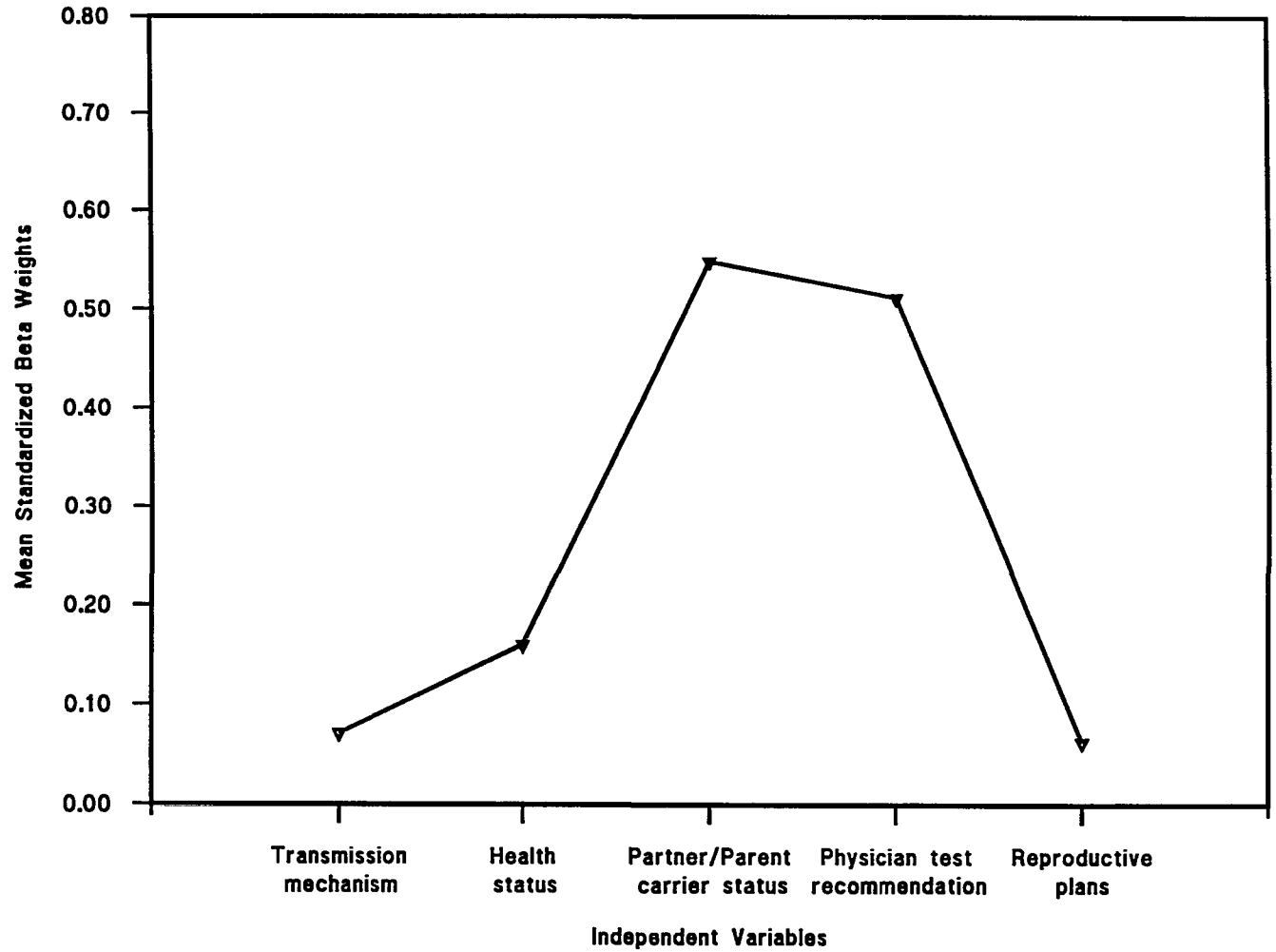

Figure 4. Decision profile composed of mean standardized beta weights for Cluster 2

None of the subject variables assessed differentiated membership in this group (Table 10).

Cluster 3

Type of disease was the best predictor for Cluster 3 (N=27), with subjects more willing to be tested for HIV than for HD (Table 9). Clear risk from a carrier partner/parent was also a very important predictor for this group (Figure 5). Plans to have children also contributed to the overall predictiveness of the model (R^2 = .69).

Members of this group had a higher rate of previous serious disease (X^2 [1, N = 217] = 4.26, p=.04). No other subject variables were related to membership in the cluster (Table 10).

Cluster 4

The decision pattern for Cluster 4 is marked by the generally equal levels of predictiveness of four variables: the carrier status of the partner/parent, plans to have children, the health status of the subject, and physician recommendation for testing (Figure 6). Table 9 lists the mean standardized beta coefficients. This group consisted of 30 subjects and had the lowest overall predictiveness (R^2 = .62).

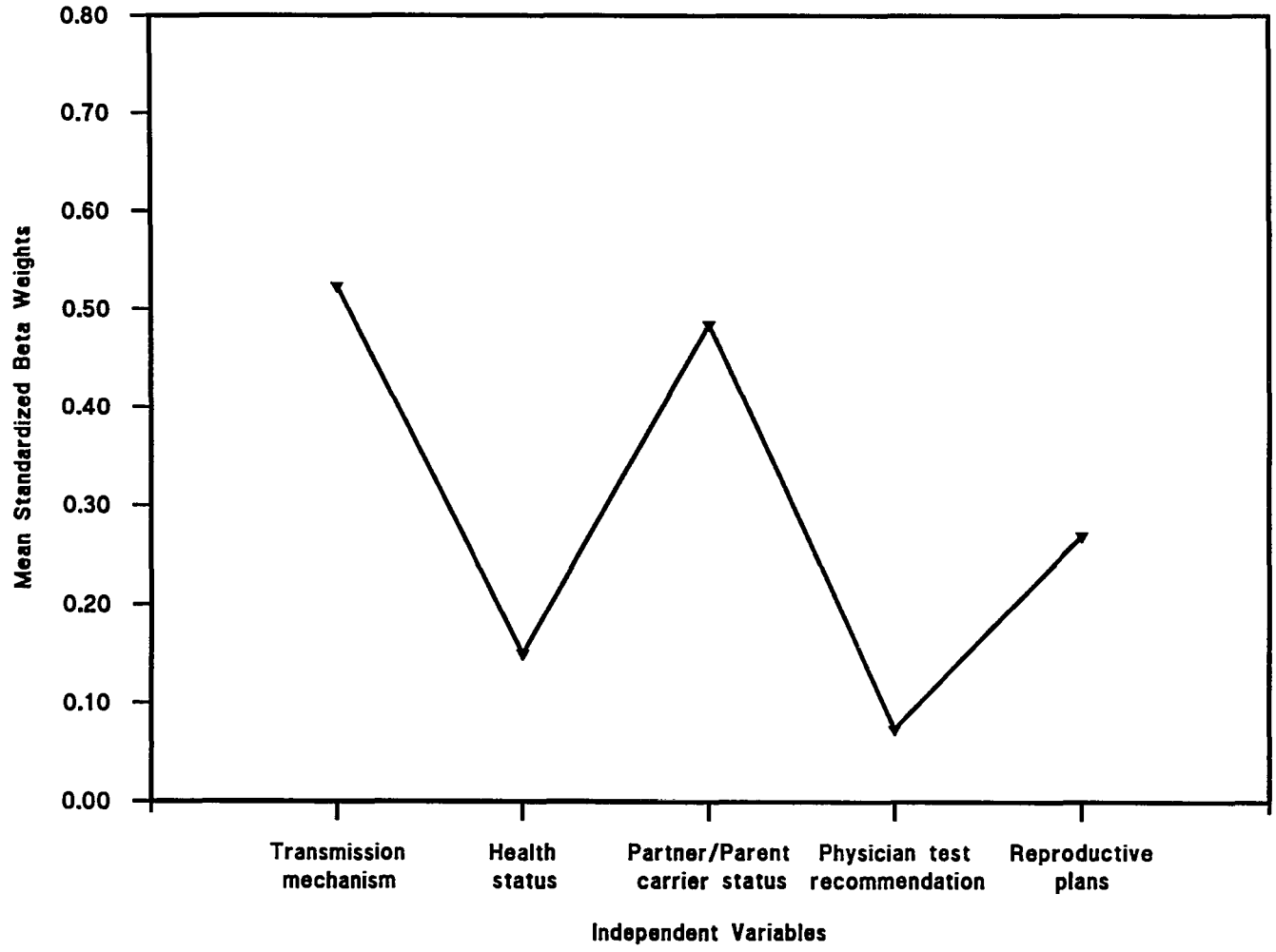

Figure 5. Decision profile composed of mean standardized beta weights for Cluster 3

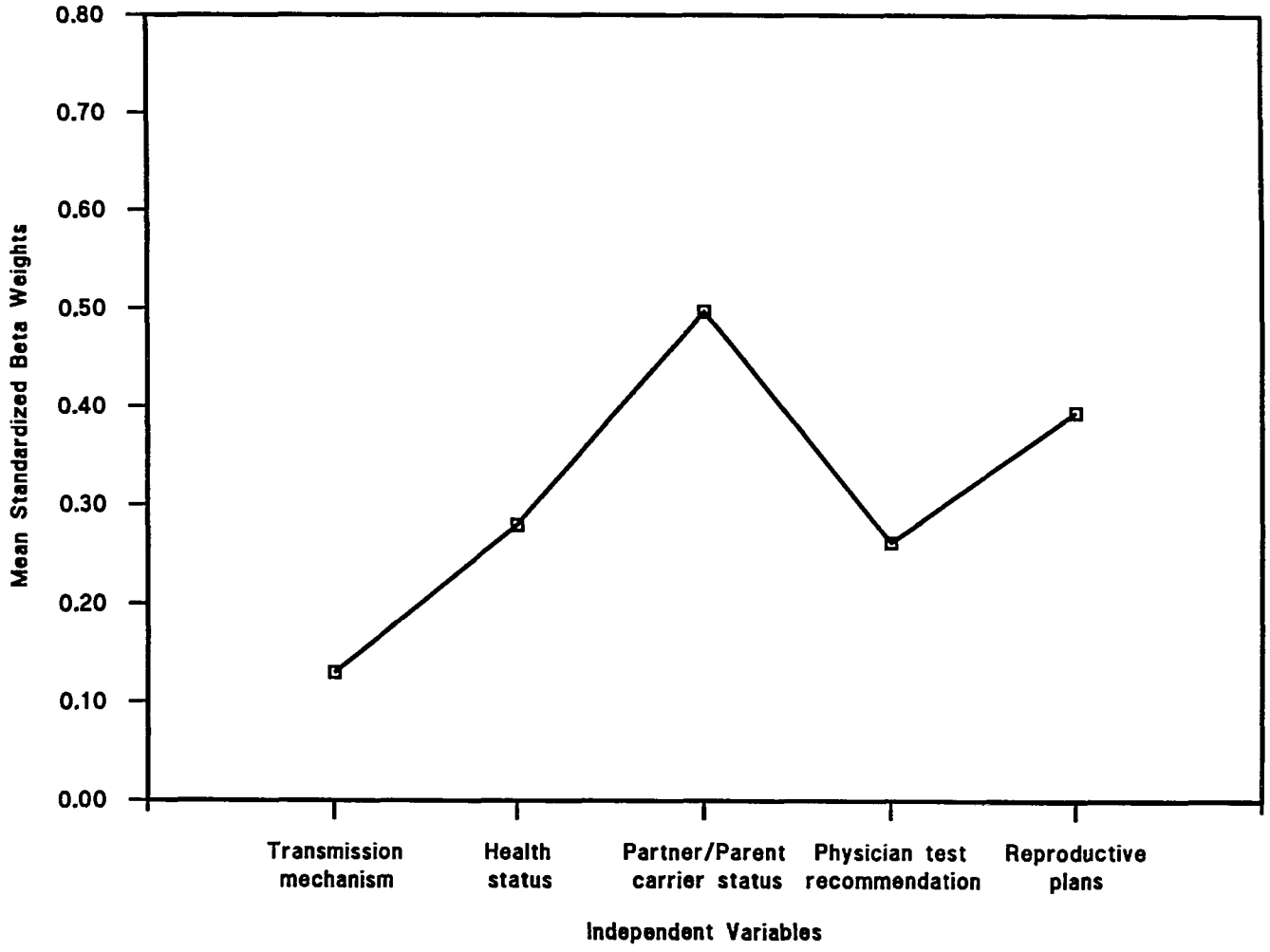

Figure 6. Decision profile composed of mean standardized beta weights for Cluster 4

This cluster is marked by an overrepresentation of female students (X^2 [1, N =217] = 4.59, p=.03). Membership was not related to any of the other subject variables (Table 10).

Cluster 5

The regression model for the fifth cluster reflects the high predictiveness of two variables; subject health status and carrier status of partner/parent (Figure 7). The overall combination of variables generated an R^2 of .64 (Table 9). This was the smallest cluster with only 9 members (4%).

This group is marked by an overrepresentation of non-English native language students (X^2 [1, N =217] = 21.26, p=.00). No other subject variables related to membership (Table 10).

Cluster 6

All of the variables of the model except childbearing plans contributed to a significant degree to willingness to be tested among members of this group, the second largest cluster with 34 members (Figure 8). The most important variable was the carrier status of the partner/parent (Table 9, R^2 = .67).

Students who plan to be tested for HD at some point in the future were overrepresented in this cluster (X^2 [1, N = 217] = 4.06, p=.01). No other subject variables related to membership in this cluster (Table 10).

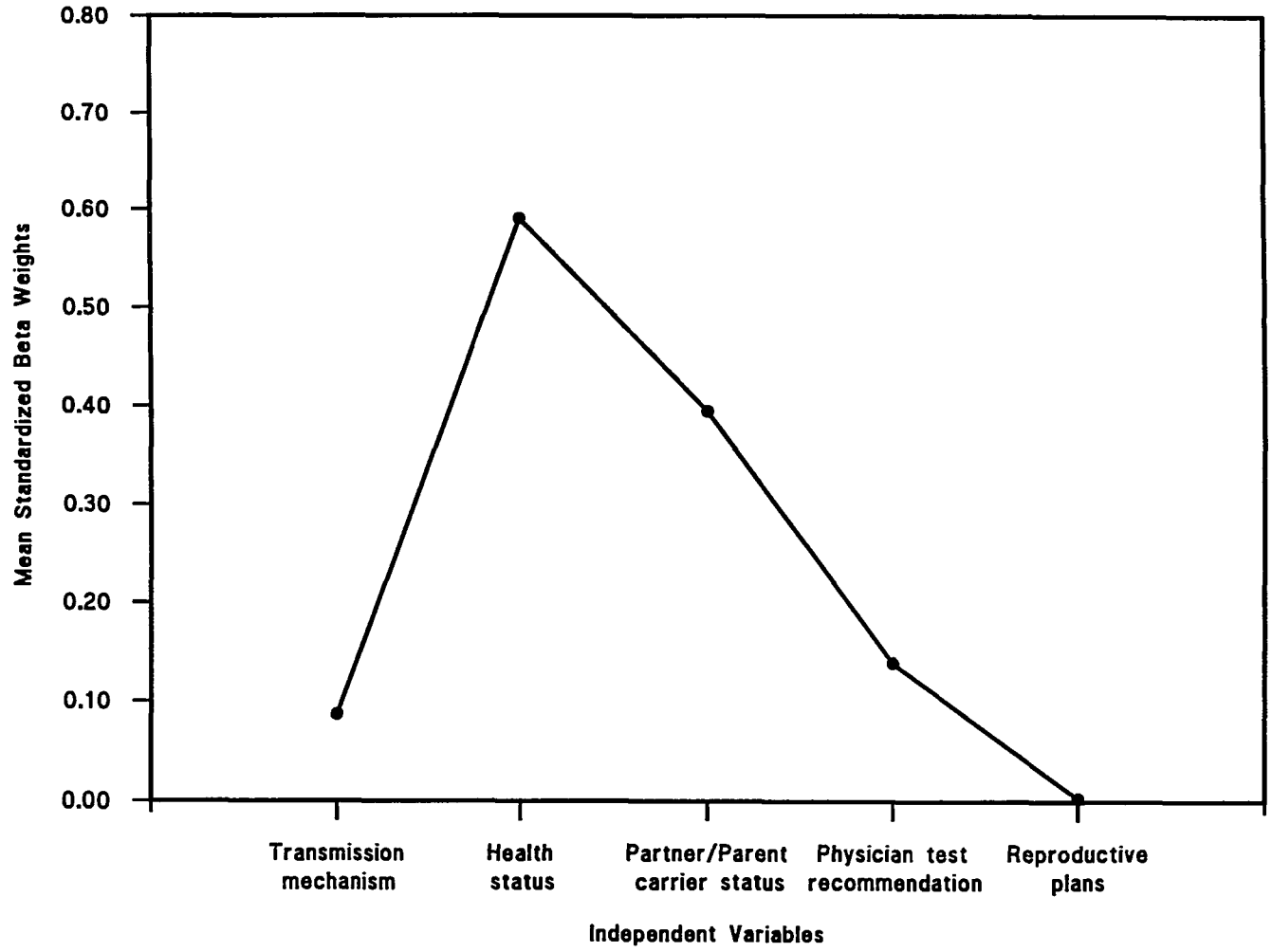

Figure 7. Decision profile composed of mean standardized beta weights for Cluster 5

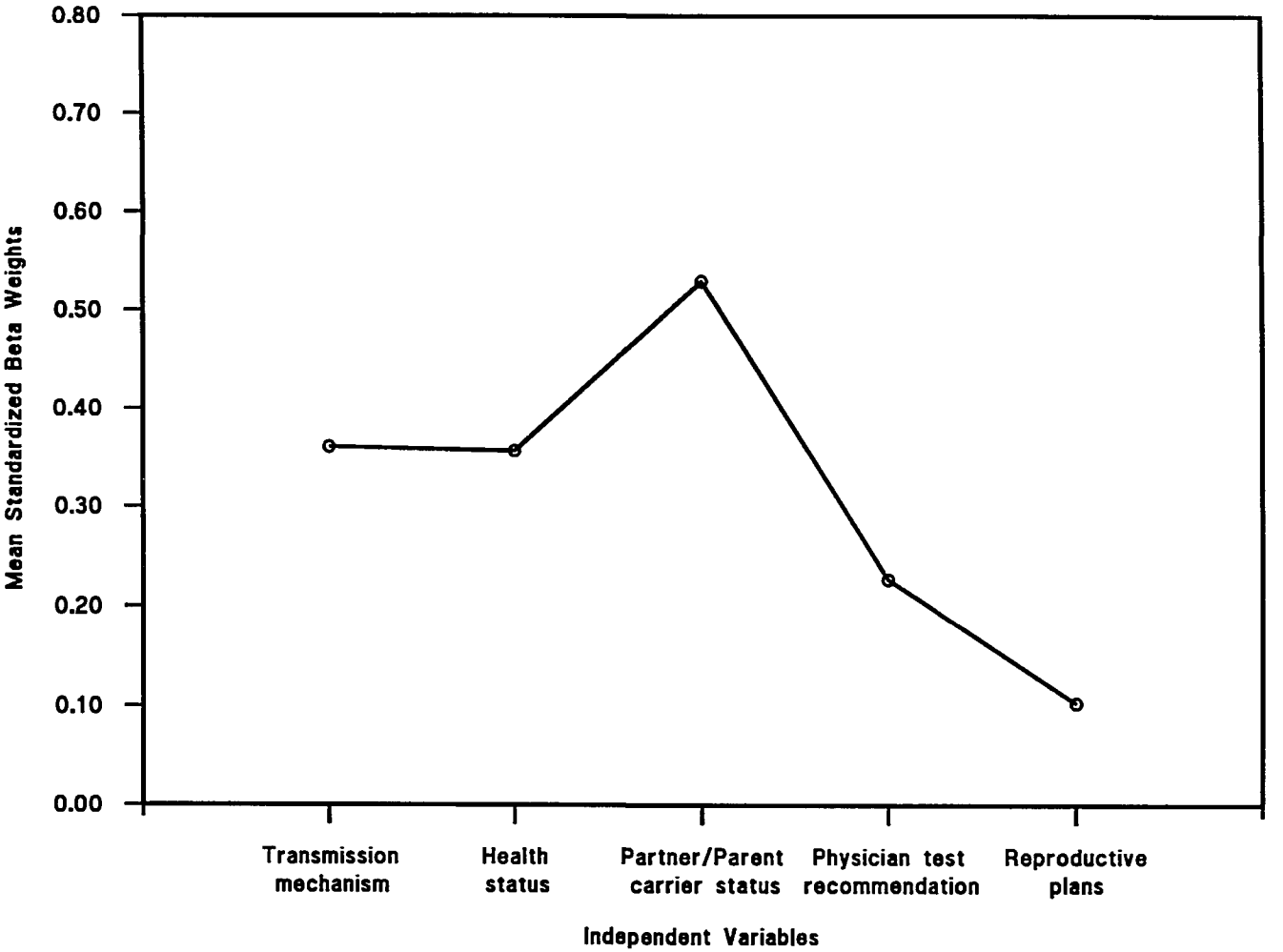

Figure 8. Decision profile composed of mean standardized beta weights for Cluster 6

Cluster 7

The final group of sixteen subjects was distinguished by the high weighting of childbearing plans and the relatively modest contributions of transmission mechanism and carrier status of the partner/parent (Figure 9). Table 9 lists the mean standardized beta weights and standard deviations for this cluster.

This group was marked by a higher incidence of previous serious disease (X^2 [1, N =217] = 5.00, p=.03). Other subject variables did not significantly relate to membership in this cluster (Table 10).

Phase 2 Hypotheses

Hypotheses 2a and 2c were not supported in the study. Knowledge of a significant other who carries the HIV virus was not related to cluster membership (all X^2 's < 0.51, p's>.48), nor was knowledge of a significant other who carried the HD gene (all X^2 's < 0.99, p's>.32).

Hypothesis 2b was not supported in the study. A history of previous avoidance of seeking diagnosis for a potentially serious disease was not related to cluster membership (all X^2 's < 2.35, p's>.13). A history of previous avoidance of seeking treatment for a potentially serious disease also was not related to cluster membership (all X^2 's < 1.77, p's>.18).

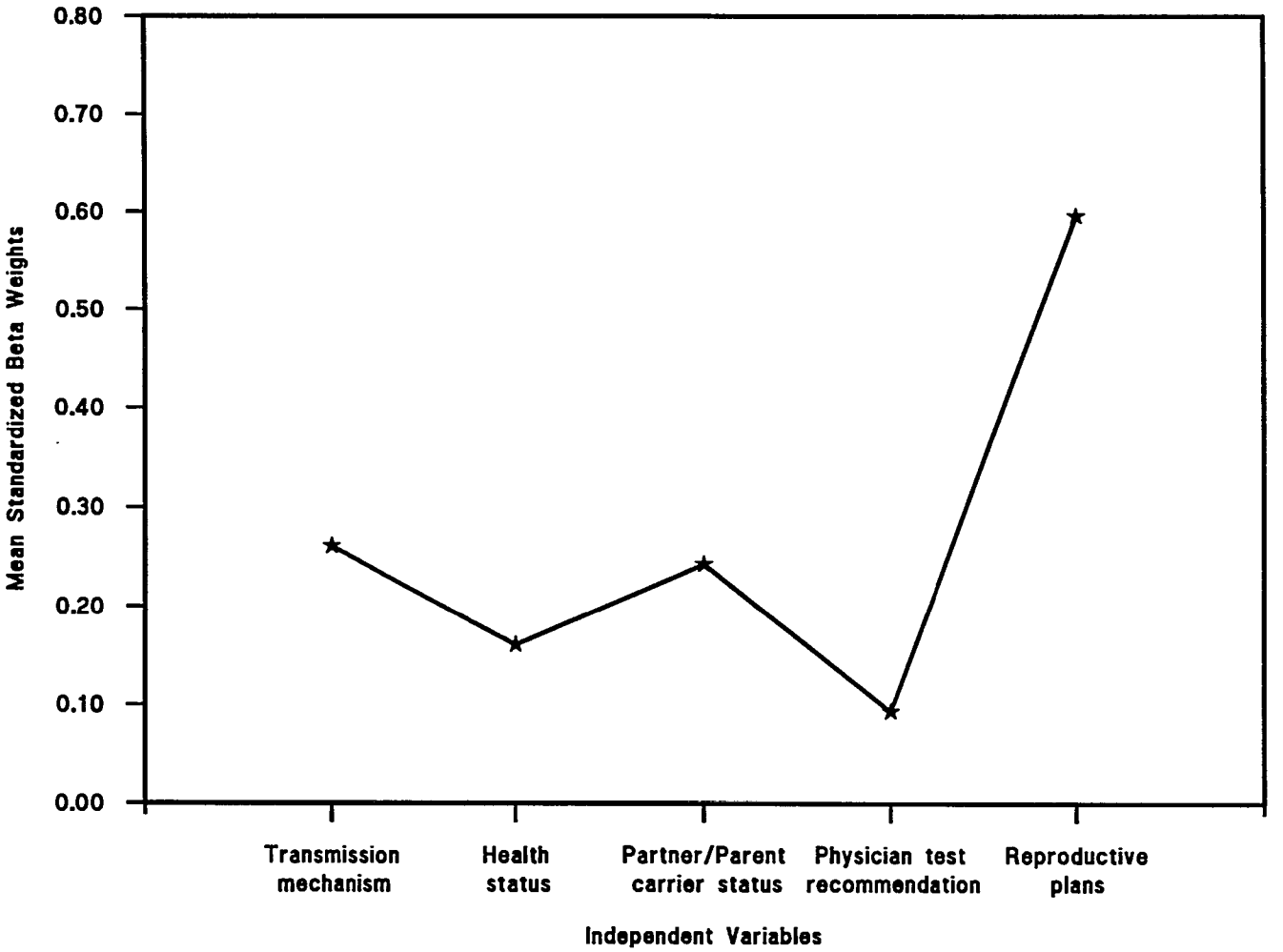

Figure 9. Decision profile composed of mean standardized beta weights for Cluster 7

Hypothesis 2d was not supported by the study. The relationship between cluster membership and current childbearing status could not be tested due to the small number of students who were currently parents (n = 4). Future childbearing plans was not significantly related to cluster membership (all χ^2's < 1.16, p's>.28).

DISCUSSION

The availability of new testing technologies has created a watershed in access to information about our future personal health. The extent to which individuals have interest in using these new diagnostic tests has not been well examined previously. The present study explored the relative importance of aspects of the testing situation to subjects who were asked to imagine that they were considering using a diagnostic test. The study involved two diseases, HIV and Huntington's Disease, for which the testing decision is likely to be fraught with ambivalence. Such late-onset, terminal illnesses provide a unique opportunity to explore how people balance the personally relevant benefits and costs involved in diagnostic testing when no direct action can be made to halt the course of the illness.

The present study applied policy capturing techniques to determine how each of the subjects utilized five factors in deciding whether or not to be tested for illnesses for which they have no present symptoms and for which there is no present cure. Additionally, the illnesses are terminal with a catastrophic , debilitating course. The decision becomes one involving seeking information that may be very negative and for which direct action is unlikely to change the course of the illness. Hence, the costs of the decision increase with a potential decrease in the direct personal benefit of the decision for those who test positive.

The five variables combined to account for more than 65% of the variance in the diagnostic decisional choices from the hypothetical scenarios. Individuals in this study were found to utilize the hypothesized variables in varied combinations. It was hypothesized that groups of people would use similar decisional strategies and that these clusters of people with similar decisional styles could be described on the basis of health beliefs and previous health behavior.

Each of the five variables under investigation significantly influenced these people in deciding whether to be tested. The clear presence of risk from a carrier is a very potent signal of potential threat in many circumstances. Partner/parent carrier status was the most potent predictor for the sample as a whole. Further, it was the most potent predictor of decisional choice for four of the seven clusters.

Carrier Status of Partner or Parent

When individuals consider their own susceptibility to a risk, one of the most potent factors is the risk to persons like themselves. Both parent and partner, whether spouse or sexual partner, are quite often seen as such a similar other. In this study, partners and parents also serve as indicators of risk status as carriers of the diseases used in the scenarios. Huntington's Disease can only be inherited form an affected parent. Similarly, the most likely source of infection with the HIV virus is from an affected sexual partner. The presence

of a positive carrier status in parent (in the case of Huntington's Disease) or partner (in the case of HIV) serve as sufficient if not necessary cues to risk of both diseases.

Given the small amount of contact that these subjects have had with affected individuals in their own personal sphere, one may infer that there is lessened personal attribution and identification. For example, only one individual in the sample of 217 was self-identified as bisexual, none as homosexual male--two of the more widely identified risk groups for HIV infection. Further, only seven of the subjects knew anyone infected with HIV. No one had ever known a family member affected by HD. However, 30% of the sample plan to be tested for HIV in the future, and 8% plan to be tested for HD. While these rates may reflect a compliance with the idea of being tested generated by this experiment, it does seem consistent with cognitive models of health decision making that emphasize information-seeking (Kirscht, 1988). In contrast, the rates may reflect a value that one "ought" to be tested to meet some perception of a social norm relevant to the act of being tested (Fishbein & Ajzen, 1975). Such a view would be consistent with the Behavioral Intention Model (Ajzen & Fishbein, 1980).

That these subjects should express interest in HIV testing is not surprising given levels of risky sexual behavior in this population. As has been noted previously by Gerrard (1987), most college students are sexually active.

Most have more than one sexual partner and few use condoms on a consistent and effective basis. The presence of risky sexual behavior is borne out by high rates of sexually transmitted diseases which are spread by the same mechanisms involved in HIV infection (McDonald et al., 1990). It is hardly surprising that many college students might consider their own risk for HIV infection and indeed 13 percent (N=28) of this sample have already been tested to determine their HIV status. Though college students may not represent one of the highest risk groups for this disease, clearly they are involved in risky behavior (Gerrard, 1987) and in many cases perceive themselves at some risk as evidenced by the fact that 13% of this sample had been tested for HIV.

The low rate of reported homosexual or bisexual sexual orientation is consistent with other surveys of students from this university (M. Gerrard, personal communication, August 24, 1991). Similarly, a survey of Canadian community and university students (MacDonald et al, 1990) found that only 1% of the sample identified their sexual orientation as homosexual and another 1% as bisexual.

Symptom Status of the Subject

As might be expected, the symptom status of the subject was consistently related to intention to be tested under the conditions of the hypothetical situation. This finding has been well documented in other studies indicating the importance of positive symptomology as a salient clue that serves to initiate the

decision process (Becker, 1974; Janz & Becker, 1984; Kirscht, 1988). In fact, it is quite reasonable to expect that someone who is symptom-free is likely to perceive themselves at lessened risk of being ill and to dismiss warnings or recommendations on the supposition that they are personally irrelevant (Perloff, 1983). The presence of symptomology is often the clearest indicator of risk status (Croyle & Jemmott, 1991).

Carrier status of partner or parent and symptom status of subject are both indicators of personal risk. The potency of these two variables and their intercorrelation suggest that as indicators of personal risk increase and become less ambiguous, individuals perceive themselves at greater risk and increasingly intend to seek new information about their risk status. The effectiveness of the PCT technique is reflected in the importance of these two variables in accounting for differences in decisions about testing in the hypothetical testing situations despite no relationship between cluster membership and the subject's own testing history or perceived personal risk.

The importance of such personal risk perceptions is recognized by existing models of health behavior including the Health Belief Model (Kirscht, 1988) and the Behavioral Intention Model (Fishbein, 1972). While the current study did not seek to test these or any other specific models, the results do partially support the models.

Transmission Mechanism

The transmission mechanism of the disease, hereditary or infectious, may also have played some role in the decision process. While HIV and HD are not frequently associated together, they do have important similarities. Both are diseases with delayed onset, a catastrophic course, and no present cure. New diagnostic procedures are available to detect each years before the presence of obvious symptomology. Neurological and cognitive deterioration are among the earliest manifestations of each disease. Each often involves losses in important aspects of career, lifestyle, social life, and even cognitive abilities. Both are often marked by social isolation and dependence on others for even basic care.

Given these similarities, the subjects were more likely to be willing to be tested for HIV than for HD. This finding might be explained in terms of perceived greater risk from a disease with an infectious transmission mode. This is likely even more salient given public education efforts to point out that common intimate behaviors have risk for transmitting HIV. Any sexual partner who has had sexual contact with someone other than the subject, places the subject at some level of risk for the disease.

Huntington's, on the other hand, has a clear hereditary path of transmission. Additionally, HD is a dominant trait with complete penetrance. This means that one can only develop the disease by direct inheritance from an

affected parent. Hence, an individual can directly assess the presence or lack of risk if they know the HD status of their biological parents. Only when the carrier status of the biological parent is unknown or mistaken does the absolute risk status of an individual become ambiguous. Given that no one in this sample was aware of any family members with HD, Huntington's may seem like a remote, even impossible risk.

An alternative explanation may be related to different perceptions about the efficacy of potential medical interventions for HIV infection and HD. While no current cure or vaccination exists for HIV, recent medical advances do suggest that early aggressive medical management of the disease does increase longevity (Centers for Disease Control, August, 1990). On the other hand, no such palliative treatment exists for HD. Subjects in this study may be aware of this dissimilarity between these diseases separate from their transmission status.

Another interpretation might be greater familiarity with HIV and the AIDS pandemic. Certainly, great effort has been made to familiarize the public with HIV and AIDS than with HD. Such an interpretation would lend support to a decision style marked by greater attention being given to familiar health threats.

An alternative testing approach might utilize hypothetical or unidentified diseases to increase the equivalence of the studied diseases apart from their transmission mechanism. Such an approach suffers from potential decline in

the "reality" of the decision question. Make-believe diseases may not elicit the same level of attention or concern due to their abstract nature.

Childbearing Plans

Childbearing plans was salient to one of the groups. This suggests that personal values related to parenting bear directly on the health intentions of some people. One explanation may be the desire to spare one's child from the terrible burden imposed by these diseases. Such a desire would have to overcome the negative aspects of exposing oneself to the risk of detecting one's own terminal illness to have a significant effect on the variance in this task. The willingness to adopt the testing decision for indirect gains for others in the presence of risk to oneself seems to best be explained by a perceived social norm that one "ought" to protect one's children despite possible harm to oneself. Such a belief would be predicted for some individuals according to the Behavioral Intention Model (Fishbein, 1972). Direct measures of such perceived beliefs should be included in future studies.

The willingness to assume potential costs or threats to protect one's child is reflected in a number of common health behaviors. Many women willingly change their drinking, smoking, and eating habits during pregnancy to reduce prenatal risks (Gosselink, 1987). Likewise, changes in behavior to provide greater security to one's child, such as purchasing life insurance or giving up a risky hobby, are not uncommon. Other parents, however, may continue to

engage in risky behaviors like cigarette smoking despite evidence of the effects of second-hand smoke on children in the home. Clearly not all individuals have the same decisional priorities.

Physician Test Recommendation

In many circumstances, the decision to be tested is initiated by one's physician. Though one maintains the right to agree with or to refuse a physician's recommendation, in common practice, many individuals comply with little contemplation. In fact, diagnostic testing is often done with little input from the patient. A physician recommendation for diagnostic testing was a positive predictor of deciding to undergo testing. Several factors likely underlie this finding. Many individuals clearly surrender some decisional prerogative to their chosen health care provider. Such a choice likely involves trust in the professional to act in one's best interest and to perform only such procedures which are relevant and safe. Additionally, physicians are often seen as having greater knowledge and wisdom not only about the disease in question but about its best course for management. Under such circumstances, one may conclude that following the doctor's direction makes the most medical sense. Finally, our health care system has nurtured a pattern were physician recommendations are generally followed without question and where patients may not have experience or comfort in declining a physician's direction.

Sample-wide Hypotheses

Perceptions of personal risk for either specific disease were not found to be related to weightings on the transmission mechanism independent variable. Personal concern about the diseases also was not significantly related to use of the transmission mechanism information. This suggests that the testing situation did not elicit strong connections between personal perceptions of risk or seriousness for a specific disease and willingness to be tested specifically for the same disease. This lack of significant relationship may be understood as a manifestation of a high level of stated willingness among these subjects to be tested for both diseases. Indeed, sixteen subjects reported personal plans for being tested for HD despite the fact that no one in the sample had an affected family member. Such findings would be consistent with a generalized compliance with subject perceptions that the experiment endorses personal testing.

Describing Cluster Membership

Cluster analysis performed on the individual beta weights (determined by within-subject multiple regression) revealed a seven cluster solution. This suggests that seven different internally-homogeneous decisional styles seem to best represent this sample. Within each group, individuals have a common way of weighting the various aspects studied and their decisions can be predicted on the basis of knowledge of the level of each aspect.

Attempts to identify and predict decisional strategy cluster membership were generally unsuccessful. Gender seemed to have a significant effect on the value of childbearing planning in the testing decision but not on cluster membership itself. Likewise, other variables studied were related to the predictiveness of separate independent variables but not to cluster membership. The generation of specific measures of additional health values, such as personal comfort with medical uncertainty and importance of general health, in future studies will likely improve understanding of this decision process.

Specific Hypotheses

The hypothesis that knowledge of a significant other who carries the HIV virus was not supported. It was believed that a close relationship with a person who was either seropositive or who actually had AIDS would be related to decisional style. That it was not raises questions about the validity of the PCT to tap into subtle differences in testing preferences. It seems reasonable to suspect that as familiarity with someone with HIV becomes more intimate, that personal perceptions of risk and seriousness would increase and that such concerns would be related to how one decides about being tested. However, neither personal concern about the disease nor perceived risk for the disease were related to either cluster membership or to any of the independent variables. This supports the view that either the hypothetical situations lack

environmental validity for this young healthy sample or that the measures of perceived risk lack sensitivity.

Similarly, the hypothesis about the relationship between cluster membership and HD familiarity was not supported. Obviously, familiarity with individual with either disease exhibited no consistent effect upon the hypothetical testing situations. One reason might include that familiarity with affected others is markedly at a casual level. Such casual acquaintance may not have been potent enough to elicit detectable influences on decisional style. Further, the sample is likely more emotionally detached from the testing decision in this analog study than they would be in a more realistic testing situation. Hence, their testing decisions in this study probably do not reflect the full impact of heightned emotionality upon the testing process.

Previous history of avoidance in seeking diagnosis or treatment did not serve to identify cluster membership. While it was not expected that large numbers of these undergraduate students would have personal experiences with serious illness, it was believed that the experience would affect health decision making for those subjects who had had concerns about a personal serious illness. The lack of such a relationship is consistent with the above concerns about the ecological validity of the testing scenarios. The scenarios may not have been realistic enough to elicit sufficient anxiety to trigger an avoidant decisional style.

Personal childbearing plans were found to be consistent with membership in the cluster that most heavily weighted knowledge about childbearing plans in the hypothetical situations. Subjects who personally plan to have children at some time in their life weighted childbearing as the most potent predictor in cluster 7. Obviously, these subjects relate their own health decision making in these cases to reproductive planning. Such a relationship would be consistent with a high value for protecting one's children from serious disease.

Conclusion

As Croyle and Jemmott (1991) point out, "we know surprisingly little about the psychological impact of these tests" (p. 85) despite the major efforts under way to develop additional screening procedures for risk testing and the proliferation of risk factor testing programs. The importance of knowledge about diagnostic decision-making expands with the number of conditions for which asymptomatic testing is developed. As mentioned earlier, the Human Genome Project promises to generate great insights into the nature of disease and large numbers of potential diagnostic and risk-factor screening procedures. An understanding of how people will choose whether and how to utilize such screening tests is critical to maximizing their utility to both individuals and society (Wexler, 1985).

In conclusion, the present study found differences in how individuals use information when deciding whether to have diagnostic testing for late-onset, terminal illnesses. There are clearly some circumstances where individuals are more likely to be tested than in others. The independent variables examined were potent in helping people make their choices. Subject variables, however, proved to be of marginal use in distinguishing the membership of one group from another. Further examination of personal experiences, values, and expectations will be needed to further clarify the situation.

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APPENDIX A. SUBJECT CONSENT FORM

Consent to be a Research Subject
Iowa State University

This research project explores how persons go about making certain medical decisions. You will be asked to read a number of short descriptions of individuals facing a medical decision. You are to put yourself in the place of the person in the story and to report what you would do in the same situation. Additionally, you will complete a questionnaire about yourself and your health. All materials you complete will be anonymous.

In agreeing to participate in this experiment, I understand that:

1) As a participant, I will be asked to complete several questionnaires relating to my health.
2) I will be asked to read a number of hypothetical situations and to make medical decisions related to the stories.
3) All information I give during this experiment will be kept in strict confidence and will not contain my name or any other identifying information; there is no way for the investigators to identify which questionnaire is mine. Only the research investigator will have access to these anonymous data. My responses will be tabulated and recorded in terms of group information, not on an individual basis. In addition, electronic or paper files will be monitored in appropriately secure electronic or traditional files with access limited to the research investigators.
4) I understand that I may ask questions at any time.
5) I understand the benefits and risks involved in participating in this research and, if I need to, I will talk with someone who can help me sort through any reactions I may have.
6) Participation in this research progress is voluntary. I understand that I have the right to refuse to participate and the right to withdraw at any time without any penalty and that I will receive credit for the time spent on the project.

By signing below I agree to participate in this experiment.

_____
Printed Name

_____ _____
Signature Date

APPENDIX B. DESCRIPTIONS OF HUNTINGTON'S DISEASE AND HIV INFECTION

Description of Huntington's Disease

Huntington's Disease is an hereditary disorder of the central nervous system characterized by progressive motor abnormalities, typically involuntary twisting movements called chorea, and intellectual deterioration. Psychiatric disturbances often accompany this disease. Although the age of onset varies widely, symptoms most commonly appear in persons between the ages of 35 and 45 years. Once the disease has begun, it progresses relentlessly for a period of 10 to 20 years. During this time uncontrolled movements increase in severity, and the affected individual gradually becomes incapacitated. Speech becomes incomprehensible and finally ceases altogether. Facial expressions become distorted and grotesque. Mental functions deteriorate, and eventually the ability to reason disappears. Ultimately, the victim is totally disabled and unable to communicate. Death in these individuals is most often due to aspiration pneumonia or heart disease. Currently, there is no effective therapy to treat the symptoms or slow the progression of this disease.

Huntington's disease is an autosomal dominant disorder with complete penetrance. Males and females are at equal risk to inherit the disease, each child of an affected parent has a 50-50 chance of receiving the gene, and the presence of the gene, determined at the moment of conception, will invariably result in the disease. Approximately 1 in 10,000 people in the U.S. have Huntington's disease. In the United States, approximately 25,000 people are known to have the disease, while another 125,000 are at risk for carrying the gene and developing the disease.

Recent advances in medical technology have made it possible to test for Huntington's Disease, even before symptoms begin. These tests involve a blood test to obtain DNA which is then compared with afflicted family members' defective chromosome. The test is 99% accurate under the best circumstances. The test is available at more than 20 testing centers across the country.

Some controversy has developed about whether people would want to be tested for Huntington's Disease. Some individuals have decided not to be tested, given that the disease cannot be currently treated or cured. Others have decided to be tested to find out if they have the gene so that they can know what their future holds and can make plans. This study will ask you to consider if you would be tested and under what circumstances.

Description of HIV Infection and AIDS

Human Immunodeficiency Virus (HIV) is the virus that causes AIDS. HIV infection is a currently incurable infectious disease of the immune system. The infection is characterized by a general decline in the body's ability to fight off disease. Though the HIV virus itself does make some people sick, its biggest effect is that it allows diseases to infect the body. Over a period of years, an infected individual finds himself or herself getting sick more often, with more serious diseases, and has a harder time recovering. For nearly all infected people, they eventually lose the ability to fight off these opportunistic diseases and eventually die.

Mild flu-like symptoms at the time of initial infection with HIV are followed by apparent recovery and good health. During a period of several months or even years, the virus lays dormant in the body, slowly multiplying and decreasing the body's ability to fight off infection. During this period, called the seropositive stage, the body does produce some ineffective antibodies to fight the virus. These antibodies can be detected through a blood test that identifies that the person has been exposed to the virus. While this stage varies in length up to 10 years or more, the effects of the virus on the body add up. People feel fatigued, lose weight, and have night sweats, frequent fungal infections, and swollen glands. Finally, the damage to the immune system becomes so great that the body becomes unable to fight off more serious illness. Some people develop life-threatening pneumonia or skin cancer. Others develop neurological symptoms including loss of ability to walk, numbness, and possibly even loss of the ability to think clearly.

Not everyone who is exposed to the virus becomes infected. Further, it is not clear that everyone who is infected will eventually develop AIDS. Some researchers believe that it is a distinct possibility that nearly all people with HIV infection will eventually have to deal with serious chronic illness, if not full-blown AIDS.

As you probably have heard, HIV is an infectious disease that is spread through contact with certain body fluids from an infected person. HIV is infectious in the way that venereal diseases are. HIV is spread through unprotected anal, vaginal, or oral sex. It is spread through sharing infected needles or contact with infected blood. It is also sometimes spread from an infected mother to her children during birth. More than one million people in the U.S. carry the HIV virus, nearly 100,000 cases of AIDS have occurred in the U.S.

Currently used tests are more than 99% accurate. The test involves a blood test and can be obtained through most physicians, student health services, and medical centers. Many people have chosen to be tested for the

HIV virus. Many others have decided not to be tested. HIV infection is not currently curable, nor does any vaccine exist to prevent infection with the virus. Some treatments have been developed that improve quality of life and appear to slow the progression of the disease. No current treatment is believed to be able to cure the disease or prevent the eventual development of AIDS. This study will ask you to consider if you would be tested and under what circumstances.

APPENDIX C. PERSONAL DATA SHEET

Personal Data Sheet

1. Which of the following best describes your ethnic background?
   1. African American
   2. Asian American
   3. Caucasian American
   4. Hispanic American
   5. International Student
   6. Native American Indian
   7. Other

2. What is your native language?
   1. English
   2. Other language (not English)

3. Please list your religious preference, if any.
   1. Catholic
   2. Protestant
   3. Other Christian
   4. Jewish
   5. Moslem or Muslim
   6. Other
   7. None

4. Which of the following best describes the current annual income of the family you were raised in? (choose one)
   1. less than $15,000
   2. $15,000 to $30,000
   3. $30,000 to $45,000
   4. $45,000 to $60,000
   5. over $60,000

5. Which of the following best describes your situation?
   1. Single and dating.
   2. Single and not dating.
   3. Engaged to be married.
   4. Married.
   5. Divorced (or separated) and dating.
   6. Divorced (or separated) and not dating.
   7. Involved in a long-term monogamous relationship other than marriage.

6. Which of the following best describe your present situation?
   1. I have children.
   2. I am pregnant (or an expectant father).
   3. I have no children.

7. Which of the following best describe your plan for the future?
   1. Plan to have no children.
   2. Plan to have children in the future but not now.
   3. Plan to adopt a child or children.
   4. Undecided about plans for children.

8. Which of the following best describe your sexual or affectional orientation?
   1. Heterosexual.
   2. Gay or Lesbian.
   3. Bisexual.

9. Have you ever had a life threatening illness?
   1. No.
   2. Yes.

10. Have you ever suspected that you had a serious illness and delayed in seeking a diagnosis?
   1. No.
   2. Yes.

11. Have you ever suspected that you had a serious illness and delayed in seeking medical treatment?
   1. No.
   2. Yes.

12. Have you ever been tested for AIDS or the HIV virus?
   1. No
   2. Yes

13. If yes, what were the results?
   1. Positive for the HIV virus but do not have AIDS.
   2. Positive for the HIV virus and have AIDS.
   3. Negative for the HIV virus.

14. Have you ever been tested for Huntington's disease?
   1. Yes
   2. No

15. If yes, what were the results?
    1. Positive for carrying the Huntington's Disease gene but have no symptoms.
    2. Positive for carrying the Huntington's Disease gene and have begun to have symptoms.

16. Which of the following best describe your plans for being tested for the AIDS virus in the future?
    1. Plan to be tested soon.
    2. Plan to be tested at some point in the future.
    3. Do not plan to be tested.
    4. Uncertain about being tested.

17. Which of the following best describe your plans for being tested for the Huntington's Disease gene in the future?
    1. Plan to be tested soon.
    2. Plan to be tested at some point in the future.
    3. Do not plan to be tested.
    4. Uncertain about being tested.

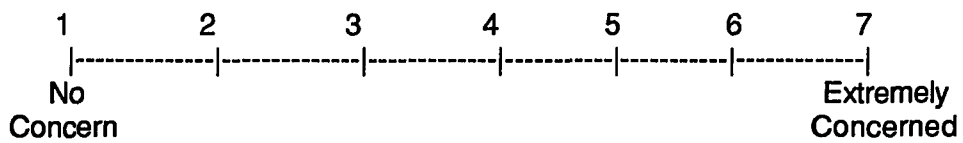
18. Have you ever known anybody who had AIDS or carried the HIV virus?
    1. No.
    2. Yes

19. If yes, what was their relationship to you? (If no, leave this question blank.)
    1. Parent
    2. Grandparent
    3. Aunt or uncle
    4. Spouse
    5. Brother or sister
    6. Own child
    7. Girlfriend or boyfriend
    8. Close friend
    9. Casual acquaintance
    10. Other

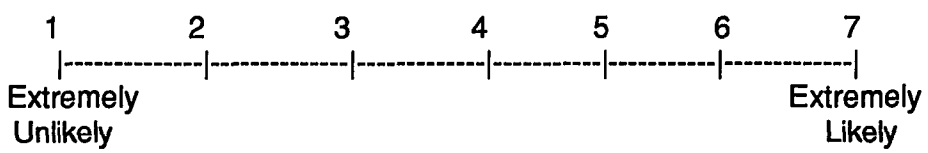
20. Have you ever known anybody who had Huntington's Disease or who carried the gene?
    1. No.
    2. Yes.

21. If yes, what was their relationship to you? (If no, leave this question blank.)
    1. Parent
    2. Grandparent
    3. Aunt or uncle
    4. Spouse
    5. Brother or sister
    6. Own child
    7. Girlfriend or boyfriend
    8. Close friend
    9. Casual acquaintance
    10. Other

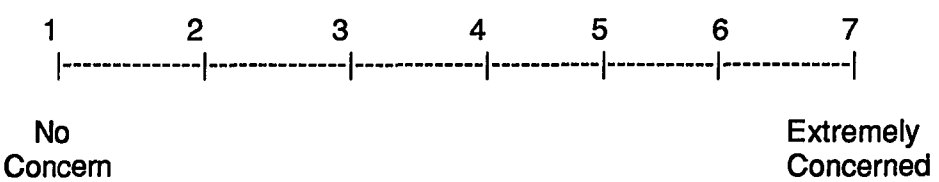
22. How much personal concern do you have about contracting the AIDS virus?



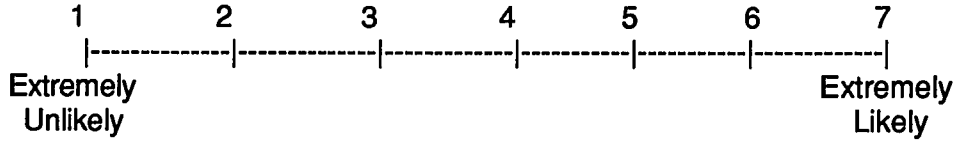
23. How likely is it that you will be infected by the AIDS virus during your lifetime?



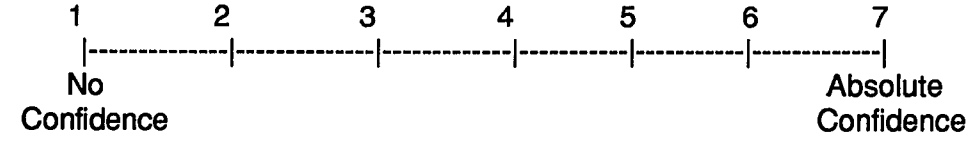
24. How much personal concern do you have about developing Huntington's Disease?



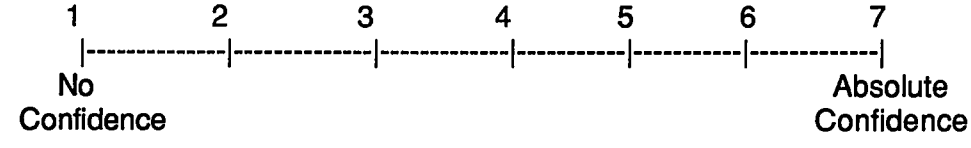
25. How likely is it that you will develop Huntington's Disease during your lifetime?



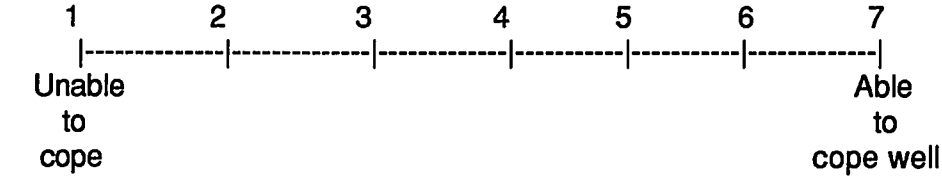
26. How confident are you in the ability of current diagnostic tests to detect the presence of the AIDS virus?



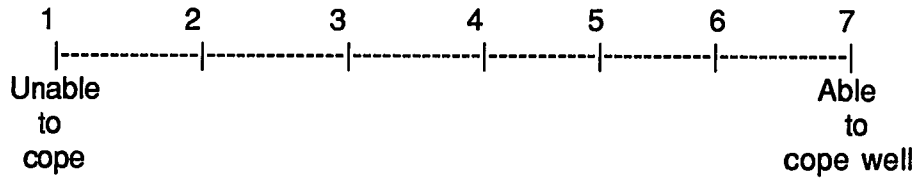
27. How confident are you in the ability of the described diagnostic test to detect Huntington's Disease?



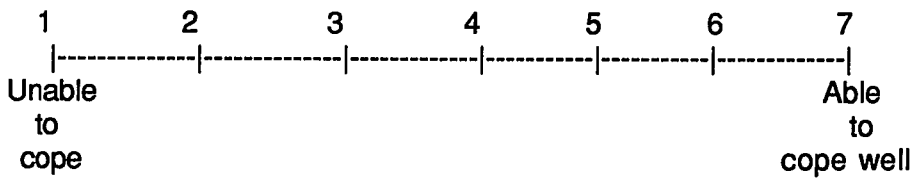
28. How well do you think you would cope if you were tested and found to carry the AIDS virus?



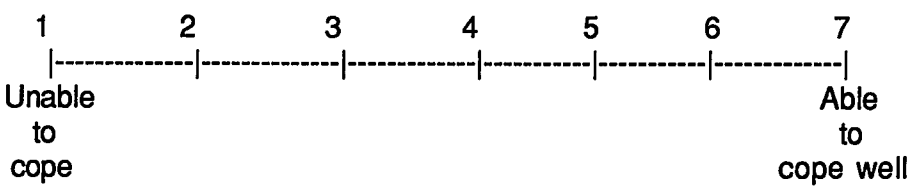
29. How well do you think you would cope if you were tested and found to carry the gene for Huntington's Disease?



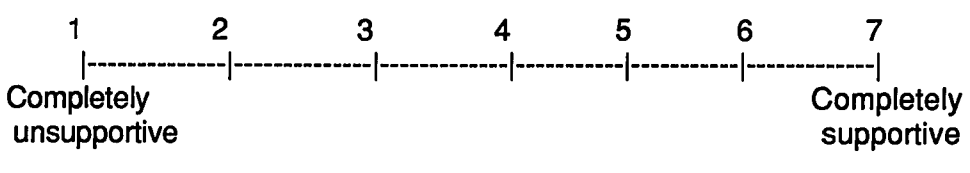
30. How well do you think you would cope if you were tested and were not found to carry the AIDS virus?



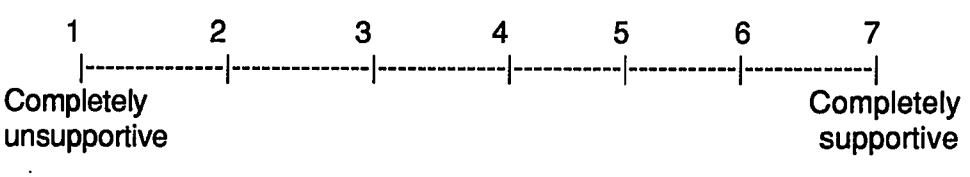
31. How well do you think you would cope if you were tested and were not found to carry the gene for Huntington's Disease?



32. How supportive do you think the important people in your life would be if you were tested and found to carry the AIDS virus?



33. How supportive do you think the important people in your life would be if you were tested and found to carry the gene for Huntington's Disease?



APPENDIX D. HEALTH DECISIONS QUESTIONNAIRE

Health Decisions Questionnaire

Directions. On the following pages are descriptions of a number of situations which you are to consider. Though some stories may seem alike, each scenario will vary a number of characteristics. After carefully reading and considering each description you will be asked to make a decision.

In each hypothetical scenario you are to imagine that you are the person involved and that the situation describes your own life. After considering the scene, you will be asked to answer a question about your decision to be tested for the disease in question.

Some of the situations may seem unlikely to you. On the other hand, some may very closely resemble your own life. In any case, please read each description carefully and consider them as if they do exist for you.

Scenario 1

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

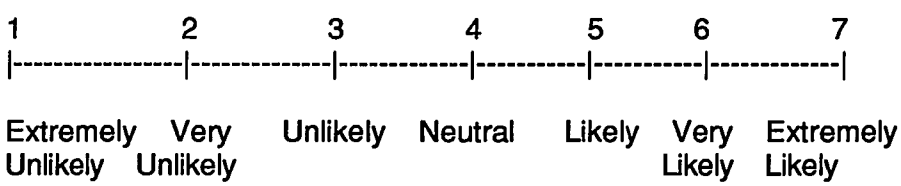
Lately your health has been good. You feel well and have no apparent symptoms of disease.

Your sexual partner has found out that s/he does carry the HIV virus. You have had sex with this partner and may have been infected with the virus.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?



Scenario 2

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

Your sexual partner has found out that s/he does carry the HIV virus. You have had sex with this partner and may have been infected with the virus.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 3

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

Your sexual partner has found out that s/he does carry the HIV virus. You have had sex with this partner and may have been infected with the virus.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 4

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

Your sexual partner has found out that s/he does carry the HIV virus. You have had sex with this partner and may have been infected with the virus.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 5

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

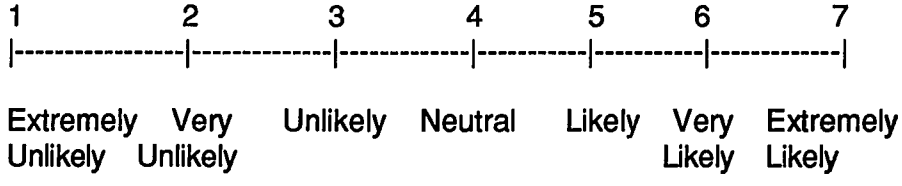
Lately your health has been good. You feel well and have no apparent symptoms of disease.

Your sexual partner has not been tested to determine if s/he does carry the HIV virus. You have had sex with this partner.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?



Scenario 6

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

Your sexual partner has not been tested to determine if s/he does carry the HIV virus. You have had sex with this partner.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 7

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

Your sexual partner has not been tested to determine if s/he does carry the HIV virus. You have had sex with this partner.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 8

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

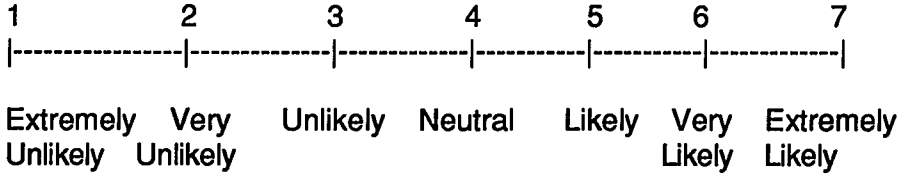
Lately your health has been good. You feel well and have no apparent symptoms of disease.

Your sexual partner has not been tested to determine if s/he does carry the HIV virus. You have had sex with this partner.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?



Scenario 9

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Your sexual partner has found out that s/he does carry the HIV virus. You have had sex with this partner and may have been infected with the virus.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 10

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Your sexual partner has found out that s/he does carry the HIV virus. You have had sex with this partner and may have been infected with the virus.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 11

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Your sexual partner has found out that s/he does carry the HIV virus. You have had sex with this partner and may have been infected with the virus.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 12

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

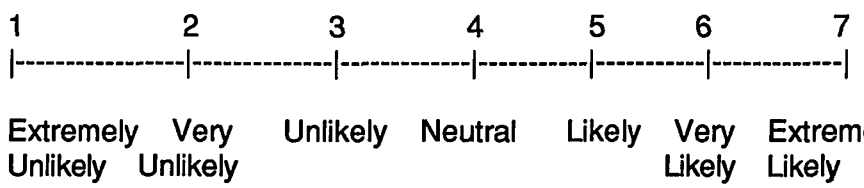
Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Your sexual partner has found out that s/he does carry the HIV virus. You have had sex with this partner and may have been infected with the virus.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?



Scenario 13

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Your sexual partner has not been tested to determine if s/he does carry the HIV virus. You have had sex with this partner.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 14

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Your sexual partner has not been tested to determine if s/he does carry the HIV virus. You have had sex with this partner.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 16

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Your sexual partner has not been tested to determine if s/he does carry the HIV virus. You have had sex with this partner.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 17

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having been infected with the HIV virus that causes AIDS. HIV is an infectious disease that is spread through sexual contact with an infected partner.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Your sexual partner has not been tested to determine if s/he does carry the HIV virus. You have had sex with this partner.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 17

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

One of your parents has had Huntington's Disease. You may have inherited the gene that causes the disease.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 18

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

One of your parents has had Huntington's Disease. You may have inherited the gene that causes the disease.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 19

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

One of your parents has had Huntington's Disease. You may have inherited the gene that causes the disease.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 20

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

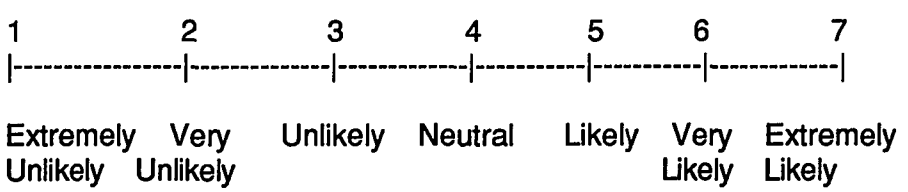
Lately your health has been good. You feel well and have no apparent symptoms of disease.

One of your parents has had Huntington's Disease. You may have inherited the gene that causes the disease.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?



Scenario 21

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

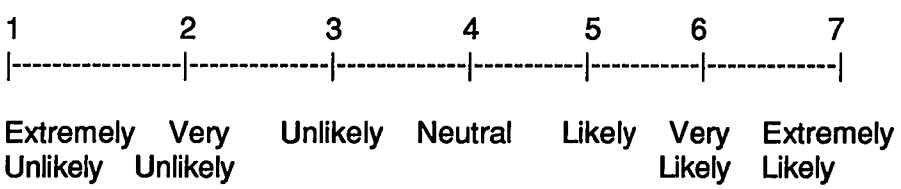
Lately your health has been good. You feel well and have no apparent symptoms of disease.

Neither of your parents has had Huntington's Disease up to this time.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?



Scenario 22

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

Neither of your parents has had Huntington's Disease up to this time.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 23

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has been good. You feel well and have no apparent symptoms of disease.

Neither of your parents has had Huntington's Disease up to this time.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 24

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

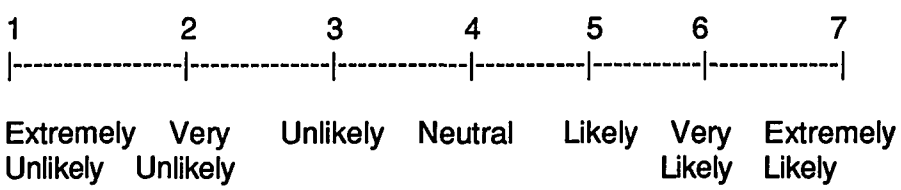
Lately your health has been good. You feel well and have no apparent symptoms of disease.

Neither of your parents has had Huntington's Disease up to this time.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?



Scenario 25

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

One of your parents has had Huntington's Disease. You may have inherited the gene that causes the disease.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 26

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

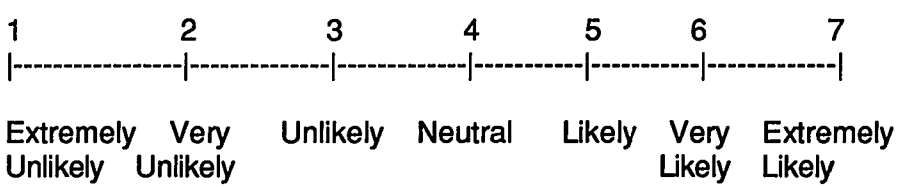
Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

One of your parents has had Huntington's Disease. You may have inherited the gene that causes the disease.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?



Scenario 27

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

One of your parents has had Huntington's Disease. You may have inherited the gene that causes the disease.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 28

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

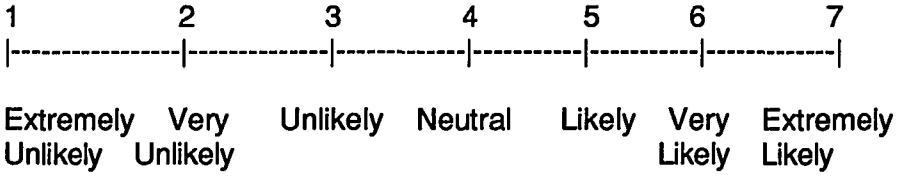
Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

One of your parents has had Huntington's Disease. You may have inherited the gene that causes the disease.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?



Scenario 29

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Neither of your parents has had Huntington's Disease up to this time.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 30

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Neither of your parents has had Huntington's Disease up to this time.

Your physician has recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 31

Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits your decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Neither of your parents has had Huntington's Disease up to this time.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would like to have a least one child and you plan to have a child at some point in the future.

How likely are you to be tested under these circumstances?

1	2	3	4	5	6	7
Extremely Unlikely	Very Unlikely	Unlikely	Neutral	Likely	Very Likely	Extremely Likely

Scenario 32

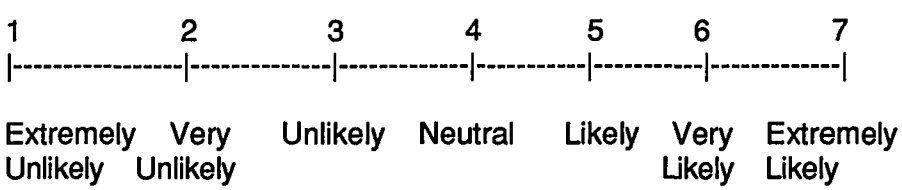
Directions. Please read the description below and imagine that you are the person. After reading the situation, answer the question at the bottom of this page. On the computer answer sheet, blacken the number of the choice that best fits *your* decision.

Imagine that you are considering your risk for having the gene that causes Huntington's Disease. Huntington's Disease is an hereditary disease that is passed from parent to child and anyone who inherits the gene will develop the illness.

Lately your health has not been good. You recently have been showing symptoms that are similar to this particular disease.

Neither of your parents has had Huntington's Disease up to this time.

Your physician has not recommended that you be tested to determine if you are a carrier of the disease and will develop the illness in the future.

After serious consideration, you have decided that you would not like to have any children.

How likely are you to be tested under these circumstances?