MOTIVATIONAL DETERMINANTS IN VOLUNTARY
TAY SACHS SCREENING

A thesis submitted in partial satisfaction of the requirements for the degree of Master of Public Health in Community Health Education

by

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ABSTRACT

MOTIVATIONAL DETERMINANTS IN VOLUNTARY TAY SACHS SCREENING

by

Howard Jaye Horwitz

Master of Public Health in Community Health Education

This study explores some of the factors associated with participation in voluntary Tay Sachs Disease screening programs at three Southern California college campuses. The purpose of this study is to identify factors among participants and generalize characteristics that seem to suggest the likelihood they will participate.

A questionnaire was used to gather demographic and motivational information from those electing to be tested for the Tay Sachs trait. Participants at the screenings at California State University, Northridge, Los Angeles Pierce College, and Santa Ana Junior College had the opportunity to voluntarily complete a short questionnaire.
It is from their responses that the motivational generalizations were drawn.

This is an exploratory study, and as such, several assumptions were suggested thought to be closely associated with the results that would emerge. These assumptions do not lend support to qualitative support to the characteristics of the respondents.

Analysis of the data indicated that more often participants were women of the Jewish faith and in the 20 to 24 years age group. This woman is aware of Tay Sachs Disease, but she has not had any prior contact with it. She has seen a physician within the last six months and appraises her health as good to excellent. Although she does not see herself as being highly susceptible to carrier status, being found a carrier would have a profound impact.

Some practical implications of this study and recommendations for increasing utilization of voluntary screening programs are also included. Among these various recommendations are having all questionnaire questions and answers thoroughly pretested. This will help eliminate confusion and undesired responses.

Active support of prominent campus and community figures is desired to increase overall participation, particularly among men.
Repetition of this type of study and those similar to it are recommended to add clarity and continuity to the field of motivational research.
Chapter 1

INTRODUCTION

Tay Sachs Disease is the most common form of gangliosidosis, a condition where GM$_2$ ganglioside accumulates to dangerous proportions. There is usually a large accrual within the components of the central nervous system. Thousands of infants have died from this disease since its recognition in the late 1800's (1:107).

This genetic disease is recessively inherited and normal appearing carrier parents have a one in four chance of having an affected child. At birth, the child appears normal. Tay Sachs children have been described as "beautiful with long eyelashes, clear skin, and pink doll-like complexions (2:108)." Gradually, the central nervous system begins to deteriorate, owing to ganglioside build-up. By the time the child is eight months old, loss of physical and mental capabilities are apparent. The absence of a vital enzyme, Hexosaminidase A, or Hex A, is the cause of the disease. Hex A usually degrades the ganglioside.

As the disease progresses, medical management becomes more difficult. The child loses the ability to sit up, to eat, and to control elimination. Seizures and blindness follow. Eventually the infant loses all contact with the environment. There is no treatment and death
is certain between the age of three to six years.

Despite the grim reality of the disease, future occurrence is almost wholly preventable. The key to prevention is the early identification of carriers prior to their having more children.

In 1969, O'Brien and Okada discovered that children with Tay Sachs Disease were missing the Hex A enzyme (3:15). Further, they discovered that carriers of the recessive gene had only about half as much of this enzyme as did non-carriers.

Their findings stimulated the acute need to initiate mass screening programs for detecting carriers of Tay Sachs in the general population. Current screening procedures require a single blood test and over 180,000 people in North America have already been screened at community-based programs. Over 170 couples-at-risk have been identified (4). A couple-at-risk is one where both partners are carriers of the same recessive gene. In this situation, there is a one in four chance, with each pregnancy, that the child will be affected.

Statistics gathered prior to spring, 1974, indicate that one out of every 300 non-Jewish people in the general population is a carrier of Tay Sachs (5). However, the Ashkenazi Jewish population has a particularly high carrier rate of 1:30. There have been over 65,000 people tested
in California since 1974 (6). The unofficial carrier rate has been as high as 1:150 in the general population. This figure makes the initial estimated carrier rate about twice what was thought in 1974 (7). Personnel at the California Tay Sachs Disease Program think that the carrier rate is not necessarily increasing. Rather, as more and more non-Jews are tested, their carrier rate is not as low as what was originally thought.

Statement of the Problem

Until the early 1970's little research was done in regard to health behavior aimed at the reduction of genetic diseases. This was largely due to the relatively incurable nature and the absence of preventive measures. But, over the past decade screening procedures have made it possible to detect various genetic disorders. Among these were Sickle Cell Anemia, Thalassemia, and Tay Sachs. The most recent motivational research primarily investigated the "at-risk" population.

Little research has focused on the reasons why members of the "not at-risk" groups chose to be tested. Also, little has been done with regard to exploring the motivation of either group as to reasons for participation or lack of participation in genetic screenings. "Motivation" refers to any stimuli, either internal or external, that facilitates the individual to participate.
This Investigator has been unable to locate any current studies dealing with motivating factors of college age students that may be associated with voluntarily obtaining Tay Sachs tests. This population occupies a strategic and easily accessible segment. They also constitute a highly vulnerable target group.

Therefore, a critical need exists to identify those factors which may influence the likelihood that the college age student will initiate this preventive health action.

**Purpose of the Project**

The purpose of this exploratory study will be to identify primary motivational determinants which may be associated with stimulating the target population to avail themselves of preventive health screenings programs.

This project will attempt to study determinants within both the "at-risk" Jewish population and the "not at-risk" general population.

A secondary purpose of this study will be to identify particular factors to which participation may be attributed. This will involve an analysis of relationships between both populations to determine if persons who are less at risk for exhibiting carrier status choose to be tested for the same reasons as those who have a greater probability.
Rosenstock noted that there is generally a widespread failure of the general population to take part in screening programs for the early detection of asymptomatic diseases (8:1). This situation exists even when the services are provided free of charge. If the Investigator can identify important motivational aspects of participatory behavior in the Tay Sachs Program, this information could be useful in tailoring more effective public education programs. Also, specific information obtained in this study could be used to modify or augment current educational programs and literature of the Tay Sachs Program. It is suggested that information derived from this study, conducted within a genetic screening setting, might have application to a wide range of other preventive health programs.

Assumptions of the Study

Certain underlying assumptions are set forth owing to the exploratory nature of this study. While these assumptions do not lend themselves to rigorous quantitative testing, they do constitute primary focal points of the investigation, particularly as they might demonstrate support for qualitative characteristics of those who choose to participate in Tay Sachs screenings.

Major Assumption: It will be possible to identify some specific "motivational determinants" which may be
associated with participatory behavior in Tay Sachs screening programs.

This major assumption is based on empirical evidence of the Investigator who was involved with the Tay Sachs program and noticed that when free genetic testing is offered to a group of people, there are many who take advantage of the service, but there are also many more who do not. It is assumed that there are factors which encourage, if not directly bring about, this participatory behavior. This "ingredient," it is suggested, is missing from those who refrain. However, there may be a more powerful force that is causing the reluctance that leads to nonparticipation.

Assumption 1: There will be a difference among those who participate with regard to the degree they perceive susceptibility to transmit the disease and the seriousness it would have.

It is assumed that among all groups, there will be a low degree of perceived susceptibility and a moderate degree of perceived severity. Further, it is assumed that among those who indicate a higher degree of perceived susceptibility, more will identify themselves as being Jewish.

Owing to the relatively low carrier rate in the general population, 1:200-300, it is unlikely that any
given person sees himself at particularly high risk of being a carrier. Despite the low probability, the impact of being found a carrier may be significant. Initial Tay Sachs research indicates that the disease had its origin in a Eastern-European Jewish population. It seems reasonable that with either direct or indirect exposure to the Program, the descendants of this population will see themselves as having more vulnerability to carrier status.

Assumption 2: There will be specific demographic differences among those who participate in the Tay Sachs screening programs.

Rosenstock stated, based on countless studies on the patterns of utilization of preventive detection screening programs, "In general, services are used most by younger people . . . females . . . and those with better education (9:28)."

It is assumed by this Investigator that more of the participants will be women, and that more of them will be in the 20 to 24 years age group. Further, there will be more participants who are Jewish than any other religious group.

Assuming that test-takers are aware of their ancestry and know that the incidence of Tay Sachs is higher among Jews, these people should be more likely to take part in screenings.
Assumption 3: Women who participate in Tay Sachs screenings will indicate that they think about their health more often than do men. These women will also indicate that when they do see a physician, it is more often for a routine check-up.

Both parts of this assumption have their origin in past medical research. Studies have presented support for the notion that women tend to be more conscious of their health and are more apt to engage in routine preventive check-ups (10:28).

Limitations of the Study

The purpose of this study is exploratory in nature, and not absolute hypothesis testing. Thus, the study's outcome will generate support for these assumptions and provide insight into the motivation of this particular population.

Owing to the limited research on motivation, the state of the art of this discipline is in its infant stages. There is then limited generalizability that can be made from the data that will emerge, except to this population.

Despite these limitations, this study may yield insights into the field of motivational research and serve as a basis for future studies.

There were also some methodological limitations. Only persons who participated in the Tay Sachs testings in
May and June, 1978, in Southern California, were included in this study. Thousands of people had taken the blood test prior to this date. Perhaps these individuals who participated earlier were the ones with higher degrees of perceived susceptibility and severity. If this were true it would be difficult to draw conclusions from this group and generalize them to the whole Tay Sachs population. Also, the degree to which the earlier participants might have "sensitized" the participants in this study is not known.

The text of all material is limited to English. Despite this, several foreign students completed the questionnaires with the help of translators.

The sample was limited to the first 500 who chose to participate. Those who began the questionnaire and did not complete it were eliminated.

**Definition of Terms**

**Ashkenazi or Askenazi Jew:** The group of people with Jewish ancestry from Northeastern Europe (see Appendix A).

**Asymptomatic:** Without overt or visible signs of disease.

**Carrier:** A person who has been identified by means of a blood test as carrying a recessive gene in his genetic make-up.

**Couple-at-Risk:** A man and a woman, each of whom is a
a carrier of the same recessive gene, who are contem­
plating conceiving a child together.

Genotype: The kind and orientation of the genes in the
cells of an individual.

Motivational Determinant: Any internal or external factor
which causes an individual to act in a particular way
or elicit a particular response.

Phenotype: The overt, physical characteristic that a
person exhibits as a result of his genotype.

Perceived Severity: The degree of personal relevance that
being found a Tay Sachs carrier would have for the
individual.

Perceived Susceptibility: The extent to which a person
feels he is likely to be found a carrier of the
Tay Sachs gene.

Recessive: Not the dominant. A recessive will not appear
in the phenotype unless it is present in the genotype
in the double dose, "aa."

Recessively Inherited: Diseases, disorders, or traits
that are expressed in the offspring of parents, both
of whom are carriers of the same recessive trait.
There is a 1:4 probability that the condition will
be exhibited.
Chapter 2

REVIEW OF THE LITERATURE

Andie Knutson has said that the field of motivational research "... is often viewed as the panacea for those who seek to influence man's behavior. It excites the imagination with sophisticated techniques that seem to promise easy solutions to complex problems (11:197)."

Although much research has been conducted in this elusive field, the state of the art is still primitive. Man is not a predictable animal and often his behavior is irrational and inconsistent.

Despite the number of studies that have been published, the absolute predictability they produced is at best limited. "The public health official should be warned ... some of its (past research) spectacular successes have been offset with dismal failures (12:197)."

This literature review section will examine research of selected investigators who sought to explain health behavior.

A brief history of postulated explanations of human behavior will be examined first. Although these theories came from individuals in a wide range of academic
disciplines, each thought they had the answer to why man acts the way that he does.

The Health Belief Model illustrates the notion that a decision to participate in health programs is not unidimensional. It is the interplay of both internal and external factors whose sum total tries to predict the course of action. Both the strengths and weaknesses of this model will be later discussed.

The last section of the literature review focuses on the studies of other scientists who have attempted to understand and explain factors that influence health. A number of the studies dealt with past Tay Sachs research, while others focus on participation in other preventive health programs.

**Early Explanations of Human Behavior**

Sigmund Freud said that all behavior is motivated. Nothing happens by chance or coincidence, despite man's inability to give a rational explanation for his behavior (13:162). To Freud, man acted to serve his ego. Everything that was said or done was either for ego satisfaction or ego protection (14:1).

Pavlov is best known for his research with classical conditioning, whereby a neutral stimuli can be reinforced so as to elicit a response even after the reinforcement is removed (15:1507). Although this type
of conditioning was most used with animals, Pavlovian conditioning has been expanded to explain human behavior also.

Similar to classical conditioning is Operant Conditioning of B. F. Skinner (16). According to Skinner, any response can be the operant or trigger to reinforcement. Soon the rewarded response is performed in anticipation of reward.

By observing the actions of Graylag geese, Lorenz postulated his notion of imprinting (17:137). Early life experiences were thought to have a significant impact on the future behavior of the adult. "The general application toward human behavior is that man is not free from his past. His phylogenetic heritage gives rise to his own behavior (18:365)."

Kurt Lewin took a leadership position in research regarding man as part of his overall environment. His general approach was termed Field Theory (19:57). Lewin proposed that every individual sees himself as an entity within a highly charged field. Within this field, there are forces which to varying degrees influence man's behavior.

Lewin thought that man would be drawn toward positive forces and repelled from negative ones. Health and safety were positive, while disease and risk were
negative. According to Field Theory, behavior should always be toward the positive.

Maslow suggested that man's behavior is in response to the order and magnitude of certain physiological and psychological needs (20:82). These needs can be ordered in a hierarchy beginning with air, water, and food. These needs continue to include safety, love, self-esteem, and creativity. Only after early needs are satisfied can man move toward higher stages of self-actualization.

The early behavioral researchers attempted to explain human behavior in terms of unidimensional factors. They may have presumed that adult behavior is the result of a specific early experience, reinforced behavior, or a body need. This investigator suspects that man's behavior is more complex. Perhaps it is the interaction of a number of these factors, and possibly more, that motivate behavior.

The Health Belief Model

To better understand the motivational determinants present in the Tay Sachs experience, established predictive models should be examined. Although not without limitations, it is useful to examine the Health Belief Model of Hochbaum, Kegeles, Leventhal and Rosenstock (20:2).

In the mid-1950's these four social scientists were
commissioned by the United States Public Health Service to develop a working model for predicting the health behavior of the American people. At this time, the main focus was on prevention of future disease rather than on treatment of existing ones.

Hochbaum et al. postulated that in order for any action to occur the individual first must recognize a degree of personal susceptibility. This can be thought of as the subjective perception of the risk of acquiring the disease.

Perceived severity, the second contributing factor, they hypothesized varies from individual to individual. According to Robbins, "Severity can be judged by the degree of emotional arousal created by the thought of the disease as well as the types of difficulties the individual thinks that the health condition will create for him (21:91).

Both susceptibility and severity have large cognitive components and are based on the individual's knowledge of and beliefs about the disease.

Once these two factors are internalized, the "Benefits to Barriers" ratio is examined. The individual will weigh the good that can be derived from the health action against any possible ill effect.

The final component is the cue to action. It may be internal or external and the intensity of this cue is
inversely proportional to the degree of perceived susceptibility and severity. The higher this level the milder the cue need be.

To illustrate the relationship between the Health Belief Model and Tay Sachs screenings, Becker et al. studied a group in the Washington, D.C. area (22:57).

Becker's target population consisted of adults of child-bearing years. Their cue to action was a saturated media campaign of television, radio, newspapers, personal letters and appeals from physicians and community leaders.

Perceived severity was interpreted as the individual's view of the impact of being found a carrier. Susceptibility included the person's belief that he could be a carrier. Benefits were measured in terms of potential good that may come as a result of participation. Barriers were not noted in the study.

Analysis of the data showed that those who participated were younger and had fewer children; over 80 percent desired more children. Perceived susceptibility was highly correlated with participation, while high perceived severity was a negative factor.

The findings of Becker et al. are impressive and seem to indicate that high perceived susceptibility and the desire for more children may also be primary motivators in Tay Sachs participation. However, the Becker study was based on an almost entirely Jewish
population. It was also one of the first such screenings to be offered. Since the earlier study, hundreds of thousands of people have had the opportunity to be tested. The California Tay Sachs Program is now testing more and more non-Jews. Perhaps there are other reasons for participating in voluntary screenings besides perceived susceptibility based on religion and the desire for more children. This study intends to explore those motives.

Perhaps the strongest shortcoming of the Health Belief Model is that the majority of the research that supports it is retrospective. These projects have gathered information about the beliefs and behavior of people at the same time. Their beliefs are assumed to have existed long before the behavior was exhibited.

One of the other problems was the failure by most of the studies to show supportive data and still have a reliable sample size. In some cases, difficulties in categorizing responses or obtaining responses to every item have reduced sample size to dangerously low proportions (23:33).

Kegeles studied the members of a pre-paid dental group for their utilization of the services for preventive check-ups (24:90). While his findings tend to support the Health Belief Model, it must be mentioned that the original sampling was 430 people. The final pool of acceptable responses was only 77.
Health beliefs also change with time and experience. Upon the public hearing that Betty Ford and Happy Rockefeller both had breast cancer, there was increased interest in breast self-examination procedures and early cancer diagnosis. After a few months, the interest diminished to previous levels (25).

The role of perceived severity, a major component of the model, can never clearly be established. When a relationship has existed, it was very complex, and generally linked to sick role behavior. Only when a moderate degree of severity was recognized did a positive health behavior ensue. A low or a high degree tended to result in maladaptive behavior (26:98).

One of the precepts of the model is that it would predict health behavior in the absence of symptoms. These conditions are not often met. Usually, it is the appearance of a symptom that prompts medical treatment.

Patterns of all behavior are developed in early life and usually not as the result of any rational health motive. Children brush their teeth, eat balanced meals, or are immunized at their parents' insistence. Soon these behaviors are ingrained in the child. The Health Belief Model cannot explain these preventive health actions.
Recent Motivational Research

Dichter points out that all health-related services and products live in a more competitive environment than the public realizes. Vitamins, reducing aids, exercise equipment and fluoridated toothpastes are not only competing against other similar products, but with more pleasure-producing products. Dichter suggests that health may be boring and that health products are actually addressing a variety of public fears (27:112).

Many health problems are associated with aging. The fear of old age may be a motivator not to seek medical help. It was reasoned that the young do not have to worry about hypertension, heart disease or cancer. Acknowledging these conditions is to admit growing old.

If mental blocks can be removed change is possible. Everyone has some preconceived notions, superstitions, and fears which may hinder their acceptance of a disease state or their willingness to seek treatment.

Nathanson collected data to lend support to the idea that men are more often involved in risk-taking activities while women tend to avoid risks and take more preventive measures (28:142).

She defines risk-taking in terms of cigarette smoking, alcohol consumption, use of narcotics and driving behavior. For all classes of risk, with the exception of use of prescription drugs, men engage in them more often
than do women. For every three cigarettes that a woman smokes, a man will smoke four, for every one heavy drinker who is a woman, four are men, and for every two miles a woman drives, a man will drive four (29:237, 30:64, 31:350).

Nathanson contends that if risk-taking is one end of a spectrum then preventive health action is the other. Williams found that cigarette smoking is negatively associated with the use of seat belts, obtaining dental check-ups and tooth brushing activity (32:374).

The positive orientation that women possess toward the medical regime may be responsible for the only class of risk-taking in which they predominate. Women are more frequently the users and abusers of prescription drugs. This is the substance that may be obtained by entering the medical system.

If this study would substantiate the findings of Nathanson, there should be more women participants than men. Further, these women should see their doctors more often, have more regular check-ups and think about their health more often.

Studying motivation in a cancer detection clinic, Stromberg and Bourque-Nord attempted to determine the participant's primary reasons for attending the clinic (33:10).

As to why people did choose to participate in the
screening, the most common answer was strong belief in the efficacy of preventive testing. Actual prior contact with the disease, either personally or a family member, was the least common response.

Many of the choices of the motivational questionnaire used by Stromberg and Bourque-Nord were used by this Investigator. However, their subjects were to choose their top three reasons, whereas in this study only one will be allowed. The Investigator feels that the forced choice may yield truer and nonconfounded data.

Zalkind and Schactman developed a well-illustrated decision-making tree to describe health behavior in a flu vaccination program (34:52).

Their decision tree diagrammed advantages and health hazards to taking the vaccinations (with relative probability of occurrence). Health hazard variables included reaction to the vaccine, chance of contracting the flu after taking the vaccine, effectiveness and mortality rates.

The inclusion of information on Guillain-Barre Syndrome—a form of paralysis which has been linked to the swine flu vaccine, did not alter the decision to take or reject the injection for most people.

The Investigator supposes that prospective Tay Sachs participants conduct similar decision trees in their minds. The wide reaching media campaign prior to the screening
provides the statistical information. Although there is no danger to the individual effect on future children may be great.

"Recommendation for prevention and treatment of chronic diseases emphasizes long-term modification of patient health activities. Thus far the public has accepted these recommendations only moderately," states Lund (35:678).

Seventh grade children in Lund's study were given the opportunity of participating in a fluoride treatment program. They were arbitrarily put into one of three introductory sessions prior to the start of the three-part treatment. The three sessions were information only, information and discussion, and information and a small reward.

The information with reward seemed to have the strongest impact in having the children complete all three fluoride applications. This study seemed to imply that even if the person understands and believes in the program, the addition of a tangible reward seems to increase compliance.

Haefer and Kirscht studied various components of the Health Belief Model in their article, "Motivation and Behavioral Effect of Modifying Health Beliefs (36:478)."

Haefer and Kirscht showed the subjects films dealing with cancer, heart disease and tuberculosis.
The participant's likelihood to participate in programs to lessen the impact of these diseases was noted both before and after the showing of the films.

Results indicated that it was possible to change some beliefs with the presentations. These changes were thought to account for an increased likelihood to take preventive action. However, personal practices such as smoking and eating habits were not markedly changed, despite changes in beliefs from the films.

Haefer and Kirsch concluded that altering one's beliefs about health would be sufficient to change actions that are motivated by pure health matters. This will generally be insufficient, however, to change behaviors that fulfill a variety of motives.

The majority of previously cited articles deal with participation in preventive screening programs. This study by Weintraub et al. examines patient nonparticipation (37:59).

Their investigation dealt with school-age children and free fluoride treatment as a means of reducing tooth decay.

Of the 294 families who did not allow their children to take part, 43 percent indicated that they were already receiving the treatment elsewhere. Another 15 percent could not participate as they were wearing orthodontic appliances which preclude topical treatment.
The findings are interesting in that non-participation was not out of fear or inaccessibility. Rather, it was because their preventive needs were already being met. This Investigator expects a very high nonparticipation rate in Tay Sachs testings. Because the program has offered the service for a number of years, many may have already been tested.

A strong statement against the Health Belief Model was voiced by Weisenberg et al. in their study dealing with children's dental programs (38:59). Seventh grade students were asked about their beliefs about health and participation in preventive programs.

Results seemed to indicate that few of the variables of the Health Belief Model were related to participation in fluoride treatment. If a relationship did exist, it tended to be the opposite of what the model would have predicted.

In their conclusion they stated, "These data, combined with other health beliefs, suggest the possible absence of any causal relationships between health belief and health behavior." They continued, "... these two phenomena might well be parallel systems that develop from the same experiences, but serve the individual in different ways."

The literature review seems to support an earlier contention that the state of art of motivational research
is in its infancy. The literature seems to be divided. Some of the studies indicate a strong relationship between beliefs and behavior; others say none exists. There is much work being done in the field, yet there is not much agreement.

The exploratory assumptions have their roots in these past research studies. The outcome of this project may lend some qualitative support to these findings, or be another that failed to make an accurate prediction about the all-too-often irrational behavior of man.
Chapter 3

METHODOLOGY

This project seeks to identify motivational factors which are related to the likelihood that people will participate in voluntary health screening programs. This chapter will discuss the methodology by which these factors are identified, grouped, and interrelated.

The following methodological considerations will be presented:

Phase 1: Design and development of a survey instrument to assess demographic and preference choices of those who participate in Tay Sachs screenings.

Phase 2: Implementation of the survey instrument.

Phase 3: Analysis of the data.

Phase 1: Development of the Instrument

It was decided by the Investigator that the most expedient and least expensive way of gathering motivational data would be by means of a questionnaire.

The questionnaire had to be approved by the directors of the California Tay Sachs Program. Their main criteria, aside from its ability to collect meaningful data, were brevity, clarity, and that it must be completely voluntary.
Brevity was the most important consideration. The questionnaire was to be an addition to the normal Tay Sachs information packet. The directors did not want to overburden the respondent, feeling that too much paper work would cause antagonism toward the program, as well as slow down the screening process. It had to be voluntary since they did not want anyone to feel that failing to complete the form would have any bearing on their test results.

a. Format of the Instrument

The questionnaire is divided into two parts. The first is blank spaces for the transference of demographic information from another form. The second contains seven personal preference items.

Items 1 through 12 correspond to demographic variables that were previously answered on the Tay Sachs questionnaire (see Appendix B). This area is clearly set off and states "For Office Use Only" (see Appendix C).

Items 13 through 28 include seven personal preference items. The first six are fixed alternative, while the last is open-ended.

The fixed alternative limits the choices of the respondent. The advantage of this type of question is in allowing the Investigator the greatest degree of uniformity. Kerlinger points
out that the fixed alternative forces the individual to choose from predetermined answers and aids greatly in the coding of the answers (39:482).

The Investigator and three Tay Sachs staff members met to decide which answers would be most appropriate for each question. During the pre-testing additional responses were found.

Despite the advantages of the fixed alternative, there are some disadvantages. Sometimes the answers tend to be superficial, never reaching the true feelings of the individual. Many times he is forced to choose the answer that most closely approximates his feelings. The difference in perception of word meaning between individuals is also a shortcoming. Kerlinger adds that social pressure or ignorance regarding the question content can yield unreliable results (40:484).

The Investigator felt that the advantages of the fixed alternative outweighed any potential disadvantages. Given the age, educational background of the sample, and the nontechnical language of the questionnaire, it is felt that reliable results will be obtained.

The last item is the open-ended question. This type gives the respondent a frame of reference,
but limits the restraints put on the reply. An open-ended question was used at the end because none of the other questions asked for the specific motivation for participation. Parton said, "Fixed alternative formats, written judiciously, can be most useful when mixed with open-ended items (41:162)."

b. Pretesting the Instrument

The questionnaire was pretested for purposes of deleting and/or clarifying any aspect that was incorrect, ambiguous, or confusing. After employing an established pretesting format, several changes were made.

The Krishnamurty Methodology for Individual Tryout (42) was used as the pretest instrument (see Appendix D).

The instrument was pretested by members of the Tay Sachs Program, both professional and clerical, and students at California State University-Northridge. The students were both graduates and undergraduates from various academic areas. Such a diverse group was selected to approximate the subject pool that would be answering the questionnaire.

Each individual was told that it was the instrument that was being tested, and not themselves. They were told to report any criticisms of the form. The pretest group was also asked if they could think of any better
way of rephrasing either the questions or answers.

c. Revisions of the Instrument

After the pretesting was completed, the following changes in the original text were made:

Question 1 was changed to "Please rate your present general health," from the original "Please rate your health."

Question 4 was changed to "Would you say that you think about your health . . .," from the original text of "I think about my health . . ."

Question 7 was changed to "Why did you come in to be screened for Tay Sachs today?" from the original text, "Why did you come in to be tested?"

The remainder of the questionnaire is in its original text.

Phase 2: Implementation of the Instrument

a. Selection of the Population

The population in this study was comprised of participants of three Tay Sachs screenings in Southern California during May and June, 1978. Since the Tay Sachs testings were already scheduled at college campuses, it was assumed that the majority of participants would be of college age (17-25 years of age). Anyone taking the blood test could participate in this study.
A college-age population is desirable since motivation based on the desire to have additional children is a criterion under investigation.

b. Setting for the Administration of the Instrument

Participation in this study was voluntary. Anyone being tested could fill out the optional questionnaire. It was to be completed prior to the actual blood-drawing to eliminate the possibility that someone would answer the questions from recollection, rather than from immediate feelings.

c. Collection of the Data

Questionnaire analysis was initiated after the third Tay Sachs screening. Since the data were contained on two different forms, the Tay Sachs Information sheet and the behavioral questionnaire were stapled together at each test location and kept that way until analysis began.

Phase 3: Evaluation of the Data

Initially all the questionnaires were screened for completeness and for valid answers. Any that were found to be incomplete or with inappropriate "joke" answers were discarded. The remainder, 441 (88.2 percent), constituted the sample for this study.

The instrument was precoded, making the transfer of information fairly simple. To facilitate analysis, the
nine most popular answers to the open-ended question were tabulated and assigned code numbers. Any response that was not in the top nine was coded "9," meaning some other response. Once all the forms were coded the information was punched onto computer cards.

The data analysis was done utilizing the Statistical Package for the Social Sciences (SPSS) (43).

Initially a frequency distribution was ordered for each item to get a quantitative feeling for respondent preference.

A second run was conducted using cross-tabulations to study possible relationships that exist between variables. When a relationship seemed to exist, Chi-square tests were conducted to test for the statistical significance of the assumed relationship.

A discussion of the collected data and conclusions reached about the data will follow in the next chapter.
Chapter 4

RESULTS AND DISCUSSION

This chapter describes the characteristics of those who participated in the study. Tables have been generated to assist the reader in gathering demographic and preference data. Inferences are also drawn which will help to generalize about the health motives of this population.

Characteristics of the Sample

Of the 500 behavioral questionnaires that were printed, 484 (96.8 percent) were collected at the screenings at California State University-Northridge, Los Angeles Pierce College, and Santa Ana Junior College. Of these, 41 were rejected due to incompleteness, invalid responses, or illegibility. The remaining 441 (88.2 percent) constitute the final sample.
TABLE I

AGE OF THE RESPONDENTS

<table>
<thead>
<tr>
<th>Age</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 20 years</td>
<td>130</td>
<td>29.5</td>
</tr>
<tr>
<td>20 to 24 years</td>
<td>207</td>
<td>45.4</td>
</tr>
<tr>
<td>25 to 29 years</td>
<td>74</td>
<td>16.3</td>
</tr>
<tr>
<td>30 to 34 years</td>
<td>18</td>
<td>4.1</td>
</tr>
<tr>
<td>35 years or older</td>
<td>12</td>
<td>2.7</td>
</tr>
</tbody>
</table>

The average age of the test takers was 22 years with a range from 12 to 53 years. The modal age was 19 years. Of the sample 270 (61.5 percent) were female and 171 (38.5 percent) were male.

TABLE II

SEX OF THE RESPONDENTS

<table>
<thead>
<tr>
<th>Sex</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>170</td>
<td>38.5</td>
</tr>
<tr>
<td>Female</td>
<td>271</td>
<td>61.5</td>
</tr>
</tbody>
</table>
TABLE III

RELIGION OF THE RESPONDENTS

<table>
<thead>
<tr>
<th>Religion</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jewish</td>
<td>221</td>
<td>50.1</td>
</tr>
<tr>
<td>Catholic</td>
<td>92</td>
<td>20.9</td>
</tr>
<tr>
<td>Protestant</td>
<td>84</td>
<td>19.1</td>
</tr>
<tr>
<td>All Other Religions</td>
<td>44</td>
<td>10.0</td>
</tr>
</tbody>
</table>

On the religious preference question 50.1 percent (N=221) were Jewish, 20.9 percent (N=92) were Catholic, and 19.1 percent (N=84) were Protestant. The remaining 10.0 percent (N=44) identified with some other religious group.

Tables IV and V indicate that the appearance of Tay Sachs in the families is very rare. Only one person or 0.2 percent of the sample had a relative who had the disease. Three people (0.7 percent) knew of carriers.

TABLE IV

PRESENCE OF TAY SACHS DISEASE IN FAMILY OF RESPONDENT

<table>
<thead>
<tr>
<th>Presence of Tay Sachs in Respondent's Family</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>No</td>
<td>439</td>
<td>99.6</td>
</tr>
<tr>
<td>Not Sure</td>
<td>1</td>
<td>0.2</td>
</tr>
</tbody>
</table>
TABLE V

KNOWLEDGE OF TAY SACHS CARRIER IN THE FAMILY OF RESPONDENT

<table>
<thead>
<tr>
<th>Carrier in the Respondent's Family</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
<td>0.7</td>
</tr>
<tr>
<td>No</td>
<td>435</td>
<td>98.6</td>
</tr>
<tr>
<td>Not Sure</td>
<td>3</td>
<td>0.7</td>
</tr>
</tbody>
</table>

TABLE VI

RESPONDENT'S DESIRE TO HAVE ADDITIONAL CHILDREN

<table>
<thead>
<tr>
<th>Respondent desires more children</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>253</td>
<td>57.4</td>
</tr>
<tr>
<td>No</td>
<td>47</td>
<td>10.7</td>
</tr>
<tr>
<td>Not Sure</td>
<td>111</td>
<td>25.2</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>30</td>
<td>6.8</td>
</tr>
</tbody>
</table>

Two hundred and fifty-three participants (57.4 percent) indicated that they would like to have additional children in the future. Forty-seven (10.7 percent) did not want any more children.
TABLE VII
RESPONDENT'S APPRAISAL OF HEALTH

<table>
<thead>
<tr>
<th>Appraisal</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>209</td>
<td>47.4</td>
</tr>
<tr>
<td>Good</td>
<td>206</td>
<td>46.7</td>
</tr>
<tr>
<td>Fair</td>
<td>26</td>
<td>5.9</td>
</tr>
<tr>
<td>Poor</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Results indicated people had a favorable impression of their health, 94.1 percent (N=415) rating their health as good to excellent. Table VIII shows that 64.4 percent (N=285) had seen their physician within the last six months. When respondents did see their doctor, it was most often for a specific illness. (See Table IX.)

TABLE VIII
TIME ELAPSED SINCE RESPONDENT'S LAST PHYSICIAN VISIT

<table>
<thead>
<tr>
<th>Time since last visit</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 Month Ago</td>
<td>119</td>
<td>27.0</td>
</tr>
<tr>
<td>1 to 6 Months Ago</td>
<td>165</td>
<td>37.4</td>
</tr>
<tr>
<td>7 to 12 Months Ago</td>
<td>75</td>
<td>17.0</td>
</tr>
<tr>
<td>13 to 18 Months Ago</td>
<td>24</td>
<td>5.4</td>
</tr>
<tr>
<td>19 to 24 Months Ago</td>
<td>23</td>
<td>5.2</td>
</tr>
<tr>
<td>More than 24 Months Ago</td>
<td>35</td>
<td>7.9</td>
</tr>
</tbody>
</table>
### TABLE IX
RESPONDENT'S REASON FOR LAST PHYSICIAN VISIT

<table>
<thead>
<tr>
<th>Reason</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular Check-Up</td>
<td>160</td>
<td>36.6</td>
</tr>
<tr>
<td>Specific Illness</td>
<td>231</td>
<td>52.4</td>
</tr>
<tr>
<td>Consultation</td>
<td>29</td>
<td>6.6</td>
</tr>
<tr>
<td>Other Health Reason</td>
<td>20</td>
<td>4.5</td>
</tr>
</tbody>
</table>

### TABLE X
FREQUENCY RESPONDENT THINKS ABOUT HIS HEALTH

<table>
<thead>
<tr>
<th>Frequency</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Often</td>
<td>141</td>
<td>32.0</td>
</tr>
<tr>
<td>Fairly Often</td>
<td>144</td>
<td>32.7</td>
</tr>
<tr>
<td>Once in a While</td>
<td>93</td>
<td>21.1</td>
</tr>
<tr>
<td>Seldom</td>
<td>23</td>
<td>5.2</td>
</tr>
<tr>
<td>Only when Sick</td>
<td>40</td>
<td>9.1</td>
</tr>
</tbody>
</table>
TABLE XI
RESPONDENT'S REASON FOR BEING TESTED FOR TAY SACHS

<table>
<thead>
<tr>
<th>Reason</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>To See if I have It (Tay Sachs)</td>
<td>36</td>
<td>8.2</td>
</tr>
<tr>
<td>To See if I am a Carrier</td>
<td>135</td>
<td>30.6</td>
</tr>
<tr>
<td>To Protect my Children</td>
<td>90</td>
<td>20.4</td>
</tr>
<tr>
<td>For Total Health Reasons</td>
<td>37</td>
<td>8.4</td>
</tr>
<tr>
<td>Persuaded by Media</td>
<td>34</td>
<td>7.7</td>
</tr>
<tr>
<td>Curiosity</td>
<td>32</td>
<td>7.3</td>
</tr>
<tr>
<td>It was Easily Accessible</td>
<td>24</td>
<td>5.4</td>
</tr>
<tr>
<td>Persuaded by Friend/Family</td>
<td>19</td>
<td>4.3</td>
</tr>
<tr>
<td>All Other Reasons</td>
<td>34</td>
<td>7.7</td>
</tr>
</tbody>
</table>

The most common response to the open-ended question "Why did you come in to be screened for Tay Sachs today?" was "To see if I am a carrier." It was given by 31 percent (N=135) of those polled.

Validating the Assumptions

No strict hypothesis testing was done to statistically support the Investigator's assumptions, owing to their exploratory nature. However, some analysis may be useful which helps to lend support to them.
For non-random, independent variables, Chi-square evaluation is helpful. In each case an assumption of no difference is used. A calculated Chi-square greater than the appropriate tabled value negates the stance of no difference. In this case, the assumption has more validity.

In this section, the exploratory assumption will be restated as well as relevant data. Should the assumption call for statistical support, a Chi-square table will be generated. A subjective decision about each assumption will follow.

Assumption 1: There will be a difference among those who participate with regard to the degree they perceive their susceptibility to transmit Tay Sachs and the seriousness it would have.

This assumption inferred that there would be low perceived susceptibility and moderate perceived severity. Table XII discloses that the modal response indicated that it was very unlikely that a respondent will be a carrier of Tay Sachs. Hence, low perceived susceptibility.
TABLE XII
RESPONDENT'S APPRAISAL OF LIKELIHOOD OF BEING A CARRIER OF TAY SACHS

<table>
<thead>
<tr>
<th>Likelihood</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Unlikely</td>
<td>195</td>
<td>44.2</td>
</tr>
<tr>
<td>Somewhat Unlikely</td>
<td>177</td>
<td>40.1</td>
</tr>
<tr>
<td>Somewhat Likely</td>
<td>52</td>
<td>11.8</td>
</tr>
<tr>
<td>Very Likely</td>
<td>15</td>
<td>3.4</td>
</tr>
</tbody>
</table>

TABLE XIII
RESPONDENT'S APPRAISAL OF THE IMPACT OF BEING FOUND A CARRIER

<table>
<thead>
<tr>
<th>Degree of Impact</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Great Deal</td>
<td>249</td>
<td>56.5</td>
</tr>
<tr>
<td>A Moderate Amount</td>
<td>141</td>
<td>31.9</td>
</tr>
<tr>
<td>Only a Little</td>
<td>36</td>
<td>8.2</td>
</tr>
<tr>
<td>None</td>
<td>12</td>
<td>2.7</td>
</tr>
</tbody>
</table>

Table XIII illustrates the respondent's perception of the impact of being found a carrier (perceived severity). The data indicate that being found a carrier would have a profound impact.
The last part of Assumption 1 indicates that among those who show a higher degree of perceived susceptibility, more will be Jewish. To test this assumption, a Chi-square table is presented to see if a relationship exists between religion and perceived susceptibility (perceived likelihood of being found a carrier).

**TABLE XIV**

**CROSS-TABULATION OF RELIGION AND LIKELIHOOD OF BEING A CARRIER**

<table>
<thead>
<tr>
<th>Religion</th>
<th>Very Unlikely</th>
<th>Somewhat Unlikely</th>
<th>Somewhat Likely</th>
<th>Very Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jewish</td>
<td>66 (96)</td>
<td>106 (88)</td>
<td>40 (26)</td>
<td>6 (8)</td>
</tr>
<tr>
<td>Catholic</td>
<td>51 (39)</td>
<td>27 (36)</td>
<td>5 (11)</td>
<td>8 (3)</td>
</tr>
<tr>
<td>Protestant</td>
<td>54 (37)</td>
<td>28 (34)</td>
<td>3 (10)</td>
<td>0 (1)</td>
</tr>
<tr>
<td>All Other Religions</td>
<td>21 (19)</td>
<td>16 (18)</td>
<td>5 (5)</td>
<td>1 (2)</td>
</tr>
</tbody>
</table>

**Numbers indicate Observed Frequencies**

**Numbers in parentheses indicate Expected Frequencies.**

\[
X^2 = \frac{\text{Sum of } O^2}{E} - N
\]

\[O - \text{Observed Frequency}\]
\[E - \text{Expected Frequency}\]
\[N - \text{Number in Sample}\]

\[
X^2 = 469.03 - 437 = 57.03
\]

\[
x^2 \text{ tabled d.f.} = 9 \quad \text{Alpha} = 0.05 \quad x^2 = 14.696
\]
When the calculated value exceeds the tabled value the hypothesis of no difference is rejected. Thus, 57.03 is greater than 14.684. This suggests strength for this section of the Assumption 1.

The notion of low perceived susceptibility for the entire group and higher perceived susceptibility for Jews in the population seems to have support from the data. The data do not support the assumption that being found a carrier would only have a moderate effect. Being found a carrier seems to have a greater impact than what was assumed.

Assumption 2: There will be specific demographic differences among those who participate in Tay Sachs screening programs.

It was postulated that more participants would be women, more participants would be in the 20 to 24 years age group, and that more participants would be Jewish.

Table II disclosed the sex of the respondents and clearly more women than men took part in the study--271 to 170.

Two hundred and seven (45.4 percent) were in the 20 to 24 years age group. This is more than in any other age group, and nearly as many as all the other groups combined.

Table III presented the religion of the
participants in this study. Over 50 percent (N=221) of the respondents were Jewish.

The data seem to lend support to Assumption 2. The majority of participants were women and most were in the 20 to 24 years age group and over half were Jewish. These results were expected since past research noted that participants in preventive health programs are more often women and younger adults (44:143). Jews, realizing that Tay Sachs is more common in people of Jewish ancestry, were expected to take part in greater numbers than were members of other religious groups.

Assumption 3: Women who participate in this study will indicate that they think about their health more often than do men. These women will also indicate that when they do see a physician, it is more often for a routine check-up.

Two Chi-square tables must be constructed in order to examine this assumption, the first to study the relationship between the sex of the respondent and how often health is considered; the second to study the relationship between sex of the respondent and the reason a physician is seen.
### TABLE XV

**CROSS-TABULATION OF SEX OF RESPONDENT AND THE FREQUENCY RESPONDENT THINKS ABOUT HIS HEALTH**

<table>
<thead>
<tr>
<th>Sex</th>
<th>Very Often</th>
<th>Fairly Often</th>
<th>Once in a While</th>
<th>Seldom</th>
<th>Only when Sick</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>55 (54)</td>
<td>59 (56)</td>
<td>27 (35)</td>
<td>11 (9)</td>
<td>23 (16)</td>
</tr>
<tr>
<td>Female</td>
<td>86 (87)</td>
<td>86 (89)</td>
<td>64 (56)</td>
<td>12 (14)</td>
<td>18 (25)</td>
</tr>
</tbody>
</table>

The numbers indicate the observed frequencies.

The numbers in parentheses indicate the expected frequencies.

\[
x^2 = \frac{\text{The Sum of } O^2}{E^2} - N
\]

where:
- \(O\) - Observed Frequency
- \(E\) - Expected Frequency
- \(N\) - Number in the Sample

\[
x^2 = 449.8 - 441 = 8.8
\]

The tabled value of Chi-square is larger than the calculated value. The null hypothesis of no difference remains. The first part of Assumption 3 is not substantiated.
### TABLE XVI
CROSS-TABULATION OF THE SEX OF THE RESPONDENT AND REASON FOR LAST PHYSICIAN VISIT

<table>
<thead>
<tr>
<th>Sex</th>
<th>Reason for Last Physician Visit</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Check-up</td>
<td>Specific Illness</td>
<td>Consultation</td>
<td>Other Reason</td>
</tr>
<tr>
<td>Male</td>
<td>47 (62)</td>
<td>106 (89)</td>
<td>6 (11)</td>
<td>11 (8)</td>
</tr>
<tr>
<td>Female</td>
<td>103 (98)</td>
<td>126 (142)</td>
<td>22 (17)</td>
<td>10 (13)</td>
</tr>
</tbody>
</table>

Numbers indicate observed frequencies.

Numbers in parentheses indicate expected frequencies.

\[
x^2 = \frac{\text{Sum of } O^2}{E^2} - N = 458.5 - 441 = 17.5
\]

The calculated value of Chi-square is greater than the tabled value. The hypothesis of no difference is rejected.

Looking at Assumption 3, there is no support for the first contention, women think about their health more often than do men, in this study. However, there is statistical support for the validity of the second part of the assumption. It appears that when women do see a physician it is more often for a check-up.
DISCUSSION

It appears that nearly half of the assumptions were strengthened by the data, while the other half were weakened. In both cases the ease of data collection offered by the fixed alternative format aided in this determination. However, the freedom that the open-ended question was supposed to give the respondent yielded some definite drawbacks for the Investigator. The biggest problem was in trying to categorize 441 responses. Another was the difficulty in trying to fit a given response into a set category without bias. Many times a respondent would give more than one answer, or his words seemed to indicate one answer and the context of the phrase indicated another.

The open-ended question, "Why did you come in to be screened for Tay Sachs today?" produced "To see if I am a carrier" as the modal response. The Investigator thought this was an obvious answer and wanted to avoid this type of response. Much effort was put into the question's wording and pre-test evaluation in order to discourage this type of answer. What were the motives that cause the individual to find out their carrier status is the curx of the study. However, in the desire to put as few restrictions on the replies of the participants, this end was not reached.
There seemed to be support for the assumption that sex is related to perceived severity. Women indicated that being found a carrier would have a more profound impact than did men. This may be explained by the maternal instinct to have and protect children. Since it is the woman who bears the child, it is possible that the knowledge that her child could be diseased is more distressing.

A relationship was discovered between how often a person thinks about his health and the reason he last saw a physician. The relationship is not between those who think about their health often and those who have routine check-ups. Rather, it is between those who rarely think about their health and those who have check-ups. Upon consideration, it may be that those who have regular check-ups need not worry about their health.
Chapter 5

SUMMARY AND RECOMMENDATIONS

Chapter 5 presents a summary of the data that was gathered in this study. A profile of the modal Tay Sachs participant will be portrayed, based on demographic and preference data the 441 subjects provided. Recommendations for future research will also be discussed.

Summary

The assessment of motivational determinants in this study is limited to a superficial examination. Much more intensive study is necessary before the true role of motivation with regard to health behavior is determined. Despite these limitations, the results of this study are interesting, and, in many instances, consistent with past research.

This study attempted to determine primary factors that operate to motivate participation in a voluntary genetic screening program. Data were collected from both demographic and personal preference variables. These data were intercorrelated in an attempt to establish a profile of the typical participant.

The typical participant was a Jewish woman in her early twenties. She did want to have additional children.
but at a later time. She was aware of Tay Sachs Disease but did not know of any relative who had the disease or was a carrier of it. She appraised her health as good to excellent and saw a physician within the last six months. The visit was for a specific complaint. Despite the fact that she does not see herself highly susceptible to the disease, being found a carrier would matter a great deal.

Although the prospective Tay Sachs participant need not possess all of these traits, the study suggests that the more traits a person has, the greater the likelihood of participation.

Recommendations

As a result of this study, the Investigator makes the following recommendations for future motivational research:

In addition to pretesting the questionnaire for clarity, sample answers should also be collected from the pretest population. The limitation of experience of the Investigator and those who helped develop answers may cause appropriate answers to be overlooked. Also, some of the given responses may not be acceptable, as in this study. When this happens, the question should be reworded to eliminate this situation. Perhaps the best way is by using all fixed alternative responses.

Careful consideration must be given prior to using
open-ended questions. Although this investigator thought the advantages would outweigh the disadvantages, sometimes the outcome is the reverse.

Another study, using a more diverse population (education, age, socio-economic background) would be beneficial.

For future screenings the Tay Sachs program should actively solicit the overt support of prominent physicians, faculty members, and student leaders to generate more participation from the not at-risk population.

Future educational programs for the Tay Sachs program, as well as any other preventive screening program, should emphasize for what purpose the individual is being tested and what the results mean. It is very important that all participants know how to interpret the outcome of the procedure. The results of this study showed that if people think that they are being tested to see if they have Tay Sachs Disease, they do not understand the purpose of the screening.

This study gathered some data to begin to predict participation based on some demographic and personal preference data. Further research is needed of the differences between groups; men and women, married and single, Jews and non-Jews, etc., to more clearly establish and solidify these determinants.
It will be through replication of this type of study and replication with expansion that the area of motivational research will become based less on random assumption and more on replicable scientific study. When this happens, preventive health screening programs can better serve those groups that can benefit from their services.
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APPENDIX B.

CALIFORNIA TAY-SACHS DISEASE PREVENTION PROGRAM - CONFIDENTIAL QUESTIONNAIRE

1. Date: __________________________ Testing Location: __________________________

2. Name: __________________________ Telephone No.: __________________________

3. Address: ________________________ (street) ________________________ (city) (zip)

4. Spouse's Name: __________________ Telephone No.: __________________________

5. What is your age? (PLEASE CIRCLE EACH APPROPRIATE NUMBER)

6. Are you... female 1
    male 2

7. Your marital status: married 1
    single 2
    single-marrying soon 3
    other 4

8. Number of living children: __________________________

9. Number of miscarriages/abortions: __________________________

10. Number of pregnancies: __________________________

11. Number of adoptions (if any): __________________________

12. Your religion (by birth): Jewish 1
    Protestant 2
    Catholic 3
    other 4

13. Country of origin of ancestors (parents or grandparents) other than U.S.: (Circle as many as apply)
    Poland 1
    Russia 1
    Germany 1
    other 4

14. Has Tay-Sachs disease ever occurred in a blood relative? Yes 1
    No 2

   If yes, give relationship and location:

15. Has any blood relative been identified as a Tay-Sachs carrier? Yes 1
    No 2

   If yes, give relationship and location:

--- Continued on other side ---

FOR OFFICE USE ONLY

Total Hex Activity 1

INITIAL Result: NC 1

Re test (date) 1

FINAL Diagnosis: NC 1
16. Do you have any current illness(es)?

   Yes  |  No
   1    |  2

   If yes, what illness(es)?

17. (FOR FEMALES) Do you take birth control pills?

   Yes  |  No
   1    |  2

18. Have you taken any medication in the past seven days? (Circle as many as apply)

   Vitamins  |  Aspirin  |  Diet pills  |  Sleeping pills  |  Tranquilizers  |  Thyroid medication  |  Antibiotics  |  Insulin  |  Other
   today  |  2-7 days ago
   Yes  |  No  |  1  |  2  |  1  |  2  |  1  |  2  |  1  |  2  |  1  |  2  |  3  |  2

   (if other, which?)

19. Are you/(spouse) pregnant now?

   Yes  |  No
   1    |  2

20. If yes, how many weeks?

   # weeks

21. Do you plan to have any (additional) children?

   Yes  |  No  |  Don't know
   1    |  2  |  3

22. Please note what you believe to be the correct answer. (Circle numerals as appropriate)

   A. Symptoms of Tay-Sachs disease are evident at birth.
      Yes  |  No  |  Don't know
      1    |  2  |  3

   B. Tay-Sachs disease is always fatal.
      Yes  |  No  |  Don't know
      1    |  2  |  3

   C. For a couple's children to be at risk for Tay-Sachs disease, only one parent must be a carrier of the Tay-Sachs gene.
      Yes  |  No  |  Don't know
      1    |  2  |  3

   D. What is the chance that a Jewish person of central-eastern European ancestry is a carrier of the Tay-Sachs gene?
      1 in 3600  |  1 in 900  |  1 in 30  |  1 in 10
      1    |  2  |  3  |  4

I consent to have a blood sample taken from me to determine if I carry the gene for Tay-Sachs disease. I understand that all of the information which I have provided, as well as the results of my test, will be handled confidentially and that the information may be used for statistical purposes only.

SIGNATURE: ____________________________
APPENDIX C.

For Office Use Only

| 1-5 | 6-7 | 8 | 9 | 10 | 11 | 12 |

This is an optional questionnaire to be used for a behavioral study. However, your cooperation in filling it out will be greatly appreciated. Thank you.

1. Please rate your present general health:  
   1. Excellent  2. Good  3. Fair  4. Poor

2. Approximately how many months ago did you last see a doctor?  
   1. Less than 1 month  2. 1 to 5  3. 6 to 12  4. 13 to 24  5. 25 to 36  6. more than 24 months

3. The last time you saw the doctor was it for:  
   1. A regular check-up  2. A specific illness or injury  3. Consultation  4. Other (please specify)

4. Would you say that you think about your health:  
   1. Very often  2. Fairly often  3. Once in a while  4. Hardly at all  5. Only when you feel sick

5. How likely do you think it is that you may be a carrier of Tay Sachs Disease?  

6. If you were found to be a carrier of Tay Sachs Disease, how much to you think it would matter to you?  

7. Why did you come in to be screened for Tay Sachs today?

Thank you for your cooperation!!
APPENDIX D.

KRISHNAMURTY'S METHODOLOGY
for INDIVIDUAL TRY-OUT

Start Here

Try the Item on One
Person at a Time

Revise Items that
Do Not Communicate

NO

Does Each Item -YES->
Communicate with the Person

NO

Revise the Part(s)
that Does Not
Communicate

YES

Does the Total
Program Communicate
with Two Consecutive
People

YES

Proceed for
Group Validation