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M.Ed. in School Counselling

"Knowledge of and attitudes towards genetic disorders amongst certain Canadian and South African high school students."

February 1988.

DECLARATION

I declare that this research report is my own work. It is being submitted for the Degree of Master of Education (School Counselling) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in any other University.

SIGNED : _____

Abstract

Human reproduction usually works well normally yielding a healthy child. However, there are certain genetic factors which may alter the course of this development. Many young people are unaware of the existence of certain genetic disorders and unfortunately may only learn about them when faced with the problem personally.

In order to motivate for the education of the school population, a study of the knowledge and attitudes towards genetic disorders was undertaken in a South African school and compared cross-culturally with a Canadian sample. For the purposes of this study, only Down's Syndrome, Spina Bifida and Tay Sachs Disease were addressed. Twenty five matriculants in a Johannesburg Jewish Day School were tested. Using a questionnaire, the procedure involved the administration of a pre-talk test followed by a talk by a gynaecologist about genetic disorders. A post-talk test was then administered. The same procedure was followed in Canada.

It was found that Canadian students on the average scored significantly higher than the South African students in terms of their knowledge of genetic disorders. Post-test scores revealed evidence of greater improvement in the South African students' knowledge. In examining attitudes, there was no evidence after the talk that attitudes towards genetic disorders had changed. It was shown that South African males fared poorer than the other

groups in terms of their knowledge about genetic disorders. Since it was found that knowledge about genetics was lacking in both samples, it was felt that the introduction of a genetic counselling course would benefit students whilst a captive audience at school. Such a course would stress the dangers and long-term ill effects genetic disorders may have upon the family physically, psychologically, socially and financially. Ongoing and continuing genetic education in the general population must be emphasised if a preventive programme of this nature is to become fully effective.

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Chapter I

1.1 Scope of the study

This study examines the knowledge of and attitudes towards genetics and genetic counselling in a specific high school population in Johannesburg, South Africa, as compared with that of a high school student population in Toronto, Canada; pre-test and post-test knowledge is examined as well as attitudes. Screening procedures are looked at including the role of the physician in detecting genetic disorders; the role of the school counsellor in the organisation of genetic information workshops is emphasised.

1.2 Review of the literature

The process of human reproduction works so well that the result is usually a healthy baby. However there are certain factors, some of which can be controlled, that can affect the outcome of any pregnancy. These factors include family background, the parent's health and the care the mother receives during the pregnancy. Much has been learned about prenatal and genetic influences on the development of the unborn baby.

1.2.1 **Genes**

Every person inherits the same number of genes from each parent. Genes are chemical units, present in every cell, that direct the expression of thousands of human traits. All of the genes in each cell are arranged into structures called chromosomes.

Abnormal genes that a child inherits from the parents result in a genetic disorder. Inherited disorders range in severity from minor abnormalities such as the extra presence of a finger or toe, to life threatening conditions such as Tay Sachs disease. A genetic condition may be evident in a child at birth, or it may not be noticeable until later in life. For the purposes of this study, only Down's Syndrome, Spina Bifida and Tay Sachs Disease will be discussed.

1.2.2 **Down's Syndrome**

According to the South Africa Inherited Disorders Association (1), Downs Syndrome, is a condition characterised by physical and mental abnormalities. All populations have an overall risk of producing one child with Down's Syndrome in every thousand births. A child with Down's Syndrome may have eyes that slant a little more than normal, and may have short hands, feet and

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1.2.2 Down's Syndrome

According to the South Africa Inherited Disorders Association (1), Downs Syndrome, is a condition characterised by physical and mental abnormalities. All populations have an overall risk of producing one child with Down's Syndrome in every thousand births. A child with Down's Syndrome may have eyes that slant a little more than normal, and may have short hands, feet and

trunk, and sometimes a straight crease in the palm of the hand. The child may be slow to turn over, sit up, crawl and walk. Affected babies tend to have more heart defects as well as more colds and infections than normal babies. The diagnosis is made at or soon after birth, and is confirmed by analysis of the child's chromosomes by means of a blood test. The most serious problem is that of mental retardation. Intelligence develops very slowly in most cases, but in a few it develops to a fair degree. However, most of them function at a very low level of intelligence and are usually not capable of complicated mental performance. The I.Q. of people with Down's Syndrome is usually about 50 (with a range of 30-70). It must be appreciated that the mentally retarded child has a limited level of development and that the ultimate goals to be aimed at should be set at realistic and attainable levels. There are 3 R's important to the training of the retarded child:-repetition, relaxed attitude, and routine.

Gross motor control is affected. The Down's Syndrome child is usually not able to walk until the age of two years or later, usually followed by other forms of activity such as climbing.

Social acceptability on the part of the Down's Syndrome child involves a simple appreciation and disapproval of his behaviour on the part of others. The ultimate goal in fine motor control and dexterity is to be able to handle

every day objects with reasonable proficiency. In sensory and perceptual development the aim is to develop the child's ability to identify everyday stimuli for the sake of personal safety and a better understanding of the environment.

Furthermore there is no cure at present. Children who remain in a nurtured home environment may progress further than those institutionalised.

There are three different types of Down's Syndrome:-

(1) Trisomy 21 : This is caused by faulty cell division during the formation of either the sperm or the egg. The risk of this increases with the age of the mother as shown in the following table: (This causes about 95% of Down's Syndrome children).

Age (years)	Risk
under 30	1 in 1500
30 - 34	1 in 750
35 - 39	1 in 300
40 - 44	1 in 100
over 44	1 in 40

(2) Transloction:

This occurs in about 4% of cases. It may be hereditary and may take several forms. Children with translocation type of Down's Syndrome have part of an extra chromosome 21 which becomes attached to another chromosome. Some may carry a translocation without showing any signs of disease because they possess the correct amount of genetic material. The normal child receives one chromosome of pair 21 from each parent. The parent with a translocation has a very high risk of producing a child with Down's Syndrome and it is important that such a parent be identified.

(3) Mosaicism:

This occurs when a person has cells with different chromosome counts and is extremely rare. These babies may have only some of the features of the syndrome because only some of their cells have the abnormal number of chromosomes.

Those most at risk of having a child with Down's Syndrome are:

i) Women over 35

ii) A couple with a child who has Down's Syndrome

iii) A couple with a child who has a genetic defect

iv) A woman who has had difficulty in falling pregnant or has had several miscarriages.

An amniocentesis may be suggested in the 15th or 16th week of a pregnancy. Fluid is drawn out of the uterus and tested to see whether the foetus has the genetic defect associated with Down's Syndrome or not. If the foetus is affected, a termination of the pregnancy can be considered.

According to the Department of Health, Welfare and Pensions (2), reactions of parents to the birth of a baby with Down's Syndrome seem to go through various stages, namely:-

i. Shock and disbelief, in which the parents attempt to deny the facts and insulate themselves against the shock or reality.

ii. A developing awareness of the loss, marked by the painful effects of sadness, guilt, helplessness, bewilderment and mourning. At times psychosomatic symptoms may occur.

iii. Recovery and acceptance, during which the mourning takes its course, the trauma and loss are overcome and a state of health and well-being re-established.

Mothers often report that once they have recovered from the first shock and sense of loss at learning that their child is mentally retarded, they feel they want more detailed information and practical guidance. They want to

know more about the causes of Down's Syndrome and the possibility of a recurrence. They want to know what to expect of their child and what the future holds for him or her.

At this time, they contend, genetic counselling is required. It is the writer's contention that genetic counselling should begin long before this stage.

1.2.3 **Spina Bifida**

The Department of Health, Welfare and Pensions (2) defines Spina Bifida as a congenital malformation of the spinal cord and of the backbone by which it is normally enclosed and protected. This malformation results in a swelling in the midline of the back, which is usually covered only by a thin membrane and not by the skin. The swelling contains varying amounts of clear fluid, known as "cerebrospinal fluid".

There are 2 types of spina bifida:-

i. The Meningocete type:- Here the swelling consists only of fluid and covering membranes, and is less serious than the other type.

ii. The Myelomeningocele form:- which is more common and much more serious. The swelling contains the imperfectly formed spinal cord, which reaches the surface in the centre of the swelling. Here it is

exposed to drying out, injury, as well as to infection.

In South Africa, approximately one baby in every thousand born suffers from this malformation. It is as common in boys as it is in girls, and occurs more frequently in homes of economic depression and war. Genes from both parents, together with the unknown factors in the environment, work to produce a baby with such a defect. Generally, there is a resultant loss of use of the legs, malfunctions of the rectum and the bladder, as well as sexual dysfunction. Hydrocephalus occurs in about 80% of children with spina bifida. It is due to an abnormality which prevents free circulation of the cerebrospinal fluid which normally courses through channels in and around the brain. The fluid then accumulates and causes the head to enlarge excessively during the early months of life. This may result in mental retardation. Most children with hydrocephalus are mildly retarded and difficult to educate. Some may be bright, and it is preferable to mainstream them whilst others, unfortunately, require admission to special centres. Hydrocephalus may also cause squinting in some children due to pressure on the nerves of the eyes. The effect on the family is profound. The initial reaction to news of this kind may be shock or guilt. Pertinent questions relating to future children are

raised. Furthermore, if the baby survives, how would the family cope with the child at home? Socially there may be many difficulties for the affected child. Will the child be able to attend an ordinary school which is a preferable alternative to a school for the handicapped, obviously depending on the child's capabilities? Adolescence, normally a difficult life task to negotiate for most children, may become a traumatic event in their lives. Special schools, rehabilitation courses and alternative accommodation must be looked at.

1.2.4 Tay Sachs Disease

Tay Sachs Disease is a fatal genetic disorder in children that causes the progressive destruction of the central nervous system. It is caused by the absence of a vital enzyme called Hexosaminidase A (hex-A). Without hex-A, body substance or liquid, called EM_2, ganglioside builds up abnormally in the cells, especially in the nerve cells of the brain. This destructive process begins in the foetus early in pregnancy, although the disease is not clinically apparent until the child is several months old. By the time a child with Tay Sachs Disease is 4 or 5 years old the nervous system is so badly affected that life itself cannot be supported. Even with the best of care, Tay Sachs Disease children die by the age 5.

Tay Sachs Disease is one of a group of disorders called storage diseases. Among the storage diseases, the lipidases include Tay Sachs, Niemann - Pick and Gaucher diseases.

In South Africa at present, there is a carrier rate of one in every twenty five Jews, and in Canada one in twenty, whilst one in two hundred and twenty five in the general population, is a carrier. The incidence of high risk Jewish couples in South Africa is one in six hundred and twenty five and in Canada one in four hundred.

Symptoms:-

The Tay Sachs baby appears normal at birth and seems to develop normally until about six months of age.

Thereafter development slows down; there is a loss of peripheral vision and the child exhibits an abnormal startle response. By one year of age, most children suffer recurrent convulsions with diminishing ability of the brain to function. The stricken infant begins to regress and loses skills one by one - the ability to turn over, to sit, reach out or to crawl.

There is an increasing loss of co-ordination, seizures, a progressive inability to swallow and inefficient pulmonary functions. By approximately age 3, the child is blind, mentally retarded, paralysed and totally out of contact with the outside world.

Populations with high risk :

Recessive genetic diseases, like Tay Sachs, often occur more frequently though not exclusively in a defined population. A person's chances of being a Tay Sachs Disease carrier are greatest if he/she is of Eastern European (Ashkenazi) Jewish descent. Approximately 85% of the children affected with Tay Sachs Disease are Jewish. Tay Sachs can and does occur in Jews of Sephardic origin and in the non-Jewish community. There is a noticeable incidence of Tay Sachs Disease in Italian Catholics and in a group of non-Jewish Canadians (Newfoundland).

Tay Sachs most often appears in families with no prior history of the disease. The Tay Sachs Disease gene can be carried without being expressed through many generations. Both parents must be carriers of the recessive Tay Sachs Disease gene in order to produce a Tay Sachs baby. Carrier status does not affect the mother and father physically in any way. High risk couples have a 25% chance with each pregnancy of producing a child with Tay Sachs Disease.

1.2.5 **Testing Procedure**

Amniocentesis has been used for a number of years as the standard method of diagnosing Down's Syndrome and other genetic disorders during pregnancy. Chorionic Villi

Sampling (CVS)(3) is a new method of prenatal diagnosis currently being studied by doctors. When amniocentesis is performed, amniotic fluid cells that come from the foetus are studied to determine whether the foetus is normal. When CVS is performed, cells from the placenta (afterbirth) are studied to determine whether the foetus is normal. Because cells in the foetus and cells in the placenta come from the same original cell, formed when the egg and sperm join at fertilization, it is believed that by studying cells of the placenta the same amount of information about the foetus can be obtained as by studying cells from the foetus itself.

Comparison between Amniocentesis and CVS(4)

Procedure

Amniocentesis	CVS
A thin needle is inserted into the mother's abdomen to remove a small amount of fluid from the sac surrounding the developing foetus.	A small tube is inserted through the mother's vagina and cervix to collect tissue from the placenta.

Timing

Amniocentesis is performed about sixteen weeks after the mother's last menstrual period.	CVS is usually done eight weeks after the mother's last menstrual period.

Results

In most cases, the results are known three to four weeks after amnioscentesis.	In most cases, the results are known one week after C V S.

Grebner, Wapner, Barr and Jackson (5) report that "chorionic villus tissue may be useful for the first trimester of prenatal diagnosis of genetic disease. Chorionic villi derived from the trophoblast layer of the early placenta can be examined directly for chromosomal or metabolic abnormalities in much the same way as cultured amnion cells are. The sampling technique is safe within the limited experience so far available."

Based on personal communication with Dr. Eugene Grebner, Ph.D, Director of the Tay Sachs Laboratory (Jefferson Memorial Hospital, Philadelphia), at the National Tay Sachs Conference held in Washington in May 1986, it can be reported that CVS is medically simpler than the better known amniocentesis and carries another plus for anxious parents-to-be. Instead of waiting until the 16th week of pregnancy to have an amniocentesis, carrier couples can have the tests and their results well within the first trimester of pregnancy. Emotionally and medically this makes a huge difference.

Dr. Laird G. Jackson, Director of the Division of Medical Genetics at Jefferson; and Dr. Ronald G. Wapner, Director of the Division of Fetal - Maternal medicine at the same hospital, brought the CVS technique to the U.S. from Europe. They were the first to use it to detect Tay Sachs

Disease. In South Africa, the CVS will eventually replace amniocentesis as the first line of genetic diagnosis. The CVS procedure was developed in China in the early 1970's. Dr Denny Fairweather, MD, Chairman of the Department of Gynaecology at University College in London brought the CVS procedure to the Western World by observing chorion being grown in a laboratory when on a visit to China. He and his colleagues then developed a catheter to obtain a snippet of chorionic tissue to be sucked out for testing. Ultrasound was used to assist the insertion of the catheter.

1.2.6 Moral & Ethical Considerations

Since this study concentrates on knowledge and attitudes towards genetic disorders in a Jewish community, Tay-Sachs is of particular relevance. Studies are therefore quoted particularly for Tay Sachs Disease and not Down's Syndrome or Spina Bifida.

According to Clarke (6) the bulk of published information on physicians' attitudes towards genetic screening in general, and screening for Tay Sachs Disease in particular, suggests that failure to refer patients for testing is probably more often due to ignorance or lack of understanding of the problem than to hesitancy on moral grounds. Lowden's findings (7) would seem to support this as does a Community Health Project (8) in which it was

found that less than half of the general practitioners surveyed in the study informed their patients about the existence of Tay Sachs Disease. They recommend that the teaching of biology in high schools should be modified to include the relaying of knowledge about genetic disorders, and that a more accessible screening program be made available for high school and university students. However, according to Clarke(6), resistance to testing has centered around "social, psychological and ethical issues", such as the stigmatisation of persons identified as carriers of Tay Sachs Disease, or the fact that prevention really amounts to feticide, which some doctors find repugnant under any circumstances. Some physicians may discourage unmarried people from being tested because of the possible social and psychological problems that carrier identification may create. A study undertaken by Beck, Blauchman, Scriver and Clow (9) reveals the need for improved knowledge of genetics amongst clients and advocates to improve health perceptions and the benefits of genetic screening.

What then are the social and psychological problems created by the information that one is a carrier of a fatal genetic disease?

Firstly, from a social point of view, there are a number of considerations :-

Should a known carrier refuse to marry a mate who has not been tested?

Should two carriers break up an engagement or marriage if they learn they are both carriers as a result of a screening programme? This often brings to mind the issue of abortion as an alternative to having an affected child.

Hunter and Fletcher (10) maintain that the abortion issue is still one which divides many people. There are irreconcilable conflicts between highly charged principles and rights, that is, those relating to the mother and the foetus. The abortion issue represents an emotional rather than a logical conflict, and the opposing beliefs of the pro and anti abortionists rests equally on the belief that foetuses are or are not persons.

Jakobovits (11), Chief Rabbi of the British Commonwealth, in discussing the preventive programmes regarding Tay-Sachs disease, contends that, "It might be feared that by subjecting an entire community to these blood tests, not to mention the attendant publicity which is bound to focus public attention on the Jewish proclivity to the disease, one might induce a "communal neurosis' by creating a state of undue anxiety or notoriety, especially among the less sophisticated members of the community."

From a psychological point of view, Tendler (12) states that "mass screening programmes present a special "psychological problem". The information they provide can help avoid many tragedies, but this very knowledge may be injurious. The adolescent youth struggling with the psychological stress of his maturation process may be ill-equipped to accept with equanimity the knowledge that he is a carrier of a genetic flaw."

Schneiderman, Lowden and Rae-Grant (13) have observed Tay Sachs screening clinics and interviewed families approximately two years after the screening programme. Their findings indicate that people face the problem of anticipated loss and heightened anxiety while being tested; however, there were no long-term detrimental effects. Ninety eight percent of those families interviewed were in favour of the screening programme. All families indicated that the testing had in no way resulted in any long-term emotional ill effects on them. Anxiety was heightened whilst undergoing testing and awaiting the results. However, this was followed by relief from the unaffected families. The affected families either showed guarded optimism or realistically reappraised family planning. There was no long-term morbidity in any family interviewed.

Schneiderman, Lowden and Rae-Grant (14) in a subsequent article six years later and using case illustrations,

discuss family reactions due to the advent of carrier screening programmes and amnioscentesis. Where the diagnosis is positive, they state that the family is faced with the very real problems of facing the diagnosis, recurrent hospitalisations, and future family planning. In addition, and equally important, they are faced with the painful process of grief and mourning. For the health professional team which is dealing with families undergoing anticipated loss of a child, it is important to know the husband and wife's individual history, the family's coping style and capacity, the children's developmental history, and finally the kind of support systems available to them.

1.2.7 **Educational Perspectives**

"Screening for heterozygotes for detrimental mutations is becoming a feasible means to avoid the birth of children with severe and often lethal genetic disorders. Because this ability may be coupled with the potential for causing harm to those screened, careful evaluation of screening programmes and critical attention to their design is essential".(15)

In the same study above, in order to assess the feasibility of screening the single Jewish population for Tay Sachs Disease, a questionnaire examining the knowledge

of and attitudes towards genetics in general, and Tay Sachs Disease in particular, was sent to 348 Yale University Jewish undergraduates. It was found that 78% were able to answer general genetic questions correctly, whilst only 1.9% could answer specific Tay Sachs Disease questions correctly. Strong correlations were found between knowledge and attitudes, but no significant differences appeared between male and female respondents. No significant relationships were found between income and genetic knowledge although a negative relationship was found between income and Tay Sachs Disease knowledge. It was found that although a large proportion of the students had never learned about Tay Sachs Disease, the ne edia and the school were significant sources of information. A serious void in the role of the medical community in transmitting Tay Sachs Disease information was revealed through the small number of students who named their doctor as their source of knowledge.

In this regard, Lowden (16) has reported from Canada that "only 31% of physicians whose practices served a largely Jewish population advised Tay Sachs Disease screening, although 76% had beer asked questions about such screening."

Until this void in communication can be overcome, educational programmes, directed at the medical community as well as the general population, must be undertaken to

ensure positive attitudes towards genetic screening amongst those being screened and their peers.
The development then of health attitudes in general is "dependent upon factors including the level of anxiety, knowledge, and information and partially related to socio-economic backgrounds. When all of these factors are considered therefore, an effective and successful screening programme can be designed for most populations at risk".
Zeesman, Clow, Cartier and Scriver (17) in a seven year follow-up on carriers of the Tay Sachs gene detected by high school screening, found that carriers and non-carriers uniformly approve genetic screening for other mutant phenotypes (for themselves and for other persons); 95% of both carriers and non-carriers approve being screened in high school. These findings indicate that persons screened in high school :

(i) have positive attitudes towards genetic screening long after the experience;

(ii) intend to make appropriate use of the test result.

Clow and Scriver (18) found high school screening in the community preferable to reliance on physicians faced with increasing demands in medical genetics. They found a sound knowledge of pertinent issues and a positive attitude to genetic screening among high school students

in general, as well as satisfactory attitudes toward and knowledge about the Tay Sachs screening experience amongst those who have been screened. Most of those expressed the desire to use the information and to seek additional guidance from a genetic counsellor or physician if indicated in the future.

Interestingly, the teachers in the school were involved in the study. Kits on genetics were given to them in a three part in-service programme emphasising the opportunity to introduce genetics as a subject in biology classes as a means of improving knowledge about genetic disease. Controversy surrounds the issue of whether it is appropriate to screen the high school student. This study revealed that students have a favourable attitude towards the screening process itself and that the 75% participation rate is a voluntary expression of acceptance by individuals in a peer group. This study also emphasises that physicians cannot be relied upon for being practical advocates of genetic screening and that high school screening could be invaluable in this regard. They conclude that "the screening experience can be used to introduce real-life perspectives into the teaching of human biology in the high school."

Jenkins, Lane and Kromberg (19), in discussing Tay Sachs Disease screening and prevention in South Africa in 1977, surmise that the high educational and occupational

achievement as well as the high socio-economic position of the South African Jewish community would " lead one to suppose that the basic requirements for a successful programme directed towards the prevention of Tay Sachs Disease were already present." However, after lengthy discussions with pertinent and relevant people concerning the problem no demand for such a programme has been made. Further they state that "it is our impression that the attitude of society to disease is not as educated in South Africa as it is in the United States." The writer contends that in 1977 this may have been true, but the question now raised is whether the Americans are indeed currently better informed. Furthermore, the writer agrees with their comments that "South African society is relatively conservative, and in spite of its higher socio-economic, educational and occupational conditions within the society, the Jewish community does nevertheless reflect this conservatism. Also, in assigning priorities for public health projects, it is essential to remember that in South Africa the Jewish community constitutes only 0.5% of the country's total population. About 80% of the population is made up of black, khoisan and coloured peoples and the majority are poor, tuberculosis is rampant and malnutrition is common owing to economic circumstances which are undoubtedly worsened by ignorance". (p.95)

In metropolitan Toronto in 1974, Lowden et al (20) enlisted the help of the B'Nei Brith Women of Toronto in cooperation with the local federation of Jewish Women's Councils. Steering committees were set up to arrange clinics in the community centres, as well as volunteers. Discussion groups were arranged, the media was informed, and brochures and pamphlets were distributed. Seven thousand five hundred and sixty-five people were tested. In their discussion, the authors state "mass screening for Tay Sachs Disease in an informed population is feasible. Is it worthwhile and does it justify the cost ($2.00 per patient)? These questions are not answered simply. Carrier screening is worthwhile when it prevents a disease that cannot be treated." (p.230)

Beck, Blaichaman, Scriver and Clow (9) maintain that up to 30% of present day admissions to paediatric hospitals are those of simple mutations, chromosomal aberrations and multifactorial circumstances. With such a statistic it is reasonable to assume that genetic disease should be a matter of general interest to those involved in health care and its clients. They regard information giving and the screening of high school students as the most efficient approach to screening for the Tay Sachs gene.

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1.2.8 **Summary**

In reviewing the literature, a general study of genetics is presented followed by detailed descriptions of Down's Syndrome, Spina Bifida and Tay Sachs Disease.
Testing procedures are examined with specific reference to Chorionic Villus sampling as a new method of prenatal diagnosis.
It has been found their physicians' attitudes towards genetic screening suggests that failure to refer patients for testing is more due to ignorance of the problems than to hesitancy on moral grounds. Social and psychological difficulties arising from information that one is a carrier of a genetic disease are presented. The abortion issue remains an unresolved conflict. Families interviewed two years following a screening programme felt that the testing had not resulted in any long-term emotional ill effects on them. Controversy surrounds the issue of whether it is appropriate to screen the high school student. It was found that students have a favourable attitude towards the screening process. However, an improved knowledge of genetics amongst clients and advocates to improve health perceptions and the benefits of genetic screening is strongly suggested.

Chapter II

2.1 Rationale for the study

Many people tend to be unaware of what genetic defects are, and of the psychological, sociological, familial and financial implications when they do occur.

It is estimated that one in every fourteen babies has one or another birth defect. Some are evident at birth (Down's Syndrome, cleft palate, club-foot) whilst others are less obvious and manifest themselves later in life (diabetes, porphyria, Huntington chorea).

According to the Department of National Health and Population (22), there are many birth defects, ranging from minor abnormalities to serious, sometimes fatal, disorders. Some are conspicuous (dwarfism), whilst others are hidden (congenital heart defects).

Birth defects can be classified into three broad categories, namely : genetic, environmental and multifactorial.

At present, birth defects cannot be cured. However, in some of these disorders, much can be done to alleviate or prevent certain disabilities which may occur.

Knowledge about these defects may mean prevention. This is the rationale and motivating factor for this work.

There are known defects that can be prevented by means of

detection through amnioscentesis or chorionic villus sampling of the unborn baby, or by diagnosis and the commencement of treatment as soon as possible after birth. Genetic counselling could inform those at risk about the options available to them so that unexpected suffering for known carriers need not occur, as in Tay Sachs Disease. Tay Sachs Disease is a fatal disease. There is no known cure. A simple blood test can determine whether an individual is a carrier or not. However, there are many people who are unaware of their carrier status. Education and knowledge about diseases can make all the difference to an individual or couple who genetically may transmit these. Knowledge may therefore imply prevention. Doctors in South Africa do not screen their patients routinely. Time and cost factors may account for this. Clergymen and rabbis resist informing their congregants because of the abortion issue.

Recently, chorionic villi biopsy has been developed. This is a new gynaecological technique whereby a woman can be tested for an affected foetus between nine to twelve weeks of pregnancy instead of having to wait until sixteen weeks before an amniocentesis can be performed. Women and men need to become more informed about their carrier status and to be aware of the alternatives open to them. Mass screening, as undertaken by the National Tay Sachs and Allied Diseases Association in America is a free service

to individuals who wish to have blood taken to determine their carrier status. It is their contention that there is no longer any stigma attached to being a carrier. In view of the above, the evidence suggests that final year high school students must be informed about the existence of the disease whilst they are a captive audience to reduce the risk of another Tay Sachs baby being born. On leaving high school, they may never attend an informative lecture on Tay Sachs or allied disease or be tested.

2.2 Aims of the study

The specific aims of the study are:

i. To survey the knowledge of and attitudes towards genetic diseases in a Johannesburg Jewish Day School and

ii. to compare the sample cross culturally with the knowledge of and attitudes towards genetic diseases in a Toronto Jewish Day School.

iii. to pave the way for the introduction of genetic counselling as a service into the schools.

iv. On the basis of the findings of the study, make recommendations as to future areas of study.

2.3 Method

2.3.1 Subjects

Twenty five matriculants from a South African Jewish Day School and twenty five from a Canadian Jewish Day School are tested. The procedure is the administration of a pre-talk test followed by a talk about genetic disorders. A post-talk test is then administered. The age equivalent of matric in South Africa is grade 12 in Canada. The talk is given in South Africa by a gynaecologist and in Canada by a doctor currently employed by the Hospital for Sick Children, University Avenue, Toronto.

2.3.2 Measure

2.3.2.1 Design of the Questionnaire

After in-depth reading and research into the subject of Tay Sachs and Allied Diseases, as well as attendance at the National Tay Sachs and Allied Diseases Conference held in Washington D.C. in May 1986, pertinent questions were formulated so as to co-incide with the outlined aims of the study.

In the section "Identifying Information" it is considered important to pinpoint the subject's parents' place of origin as some of the disorders have their beginnings in certain parts of the world. For example, the origins of Tay Sachs Disease can be traced back to

Eastern Europe, and is a disorder more common to Ashkenazi Jews as opposed to Sephardic Jews.

2.3.2.2 **Structure and content of the Questionnaire**

The structure of the questionnaire is that of multiple choice with a three-part range of alternative choices. Where it was deemed necessary, an extra alternative was included (questions 21 and 22). Multiple choice answers are chosen because of the practicality of collating and quantifying the data. Because of the time constraint in administering the questionnaire twice within the allotted time of the session (one hour) due consideration is given to the length of it.

Twenty two questions are constructed, the first fifteen designed to test knowledge about genetics in general and some specific genetic disorders, and the last seven to assess the subjects attitudes towards these.

Questions 1 - 14 are designed to test the subjects' knowledge about genetics and genetic disorders. This includes, firstly, a general question about genetics and its' causes. Knowledge about the developing foetus and diseases that could harm it are then tested, followed by more specific questions on Down's Syndrome, Spina Bifida and Tay Sachs Disease.

Questions 15-22 are designed to test the attitudes of the sample in terms of being aware of an individual

with a genetic disorder, the importance of knowing about genetics, attitudes to testing anxiety levels, reactions, marriage plans, and the importance of including a genetic counselling course into a high school curriculum. (See Appendix C, page 49).

2.3.3 **Procedure**

Twenty five subjects are randomly drawn from the matriculant group of a Johannesburg Jewish Day School. A gynaecologist in private practice intimately acquainted with genetic disorders is invited to address the students. He is briefed by the writer as to the purpose of the talk and the specific subject areas to be covered. He is limited to a forty minute talk because of the constraints of time within a school. Before the talk the students are presented with a brief outline of the motivation behind the study. The same questionnaire is administered as the post-talk test one hour later.

The same procedure is followed in Canada with twenty five subjects from a Toronto Jewish Day School.

2.4 **Design**

i. The study uses a survey approach which incorporates a questionnaire. The questionnaire

serves to elicit data about knowledge of and attitudes to genetic disorders.

ii. The data is descriptive and the frequency of occurrence is expressed in percentages.

iii. Results for males and females are compared within the South African and Canadian samples as well as cross-culturally.

iv. Data is analysed using parametric statistics involving the t-test. Knowledge and attitudes are scored separately. Knowledge is compared for the South African sample on a pre-talk test and post-talk test. The test is applied to the Canadian sample, and finally cross-culturally these are compared. A similar strategy is adopted for that of attitudes except that the answers are assigned scores from 4-1 ranging from positive to negative as a way of quantifying these.

As would be expected "the parametric tests, with their more rigorous demands on the data, are somewhat more powerful on the whole than non-parametric tests; certain complex inferential problems can be solved only by parametric methods. For these reasons, parametric tests are preferred when the data to be analysed appear to meet the test requirements." (21).

Since both the South African and the Canadian students received different lectures by different doctors about genetics, and the fact that their emphasis differed, the conclusiveness of these results are somewhat limited.

Chapter III

3.1 Results

3.1.1 A comparison of knowledge of South African and Canadian students on the pre-talk and post-talk questionnaire

In order to assess the viability of introducing a genetics course into the schools, a need for this must first be established. If it can be shown that knowledge of genetics is lacking, this would provide motivation for the desired course. Testing of attitudes is considered important in order to assess possible acceptance of such a course by students.

Fifteen knowledge questions are included in the questionnaire and seven attitude questions follow.

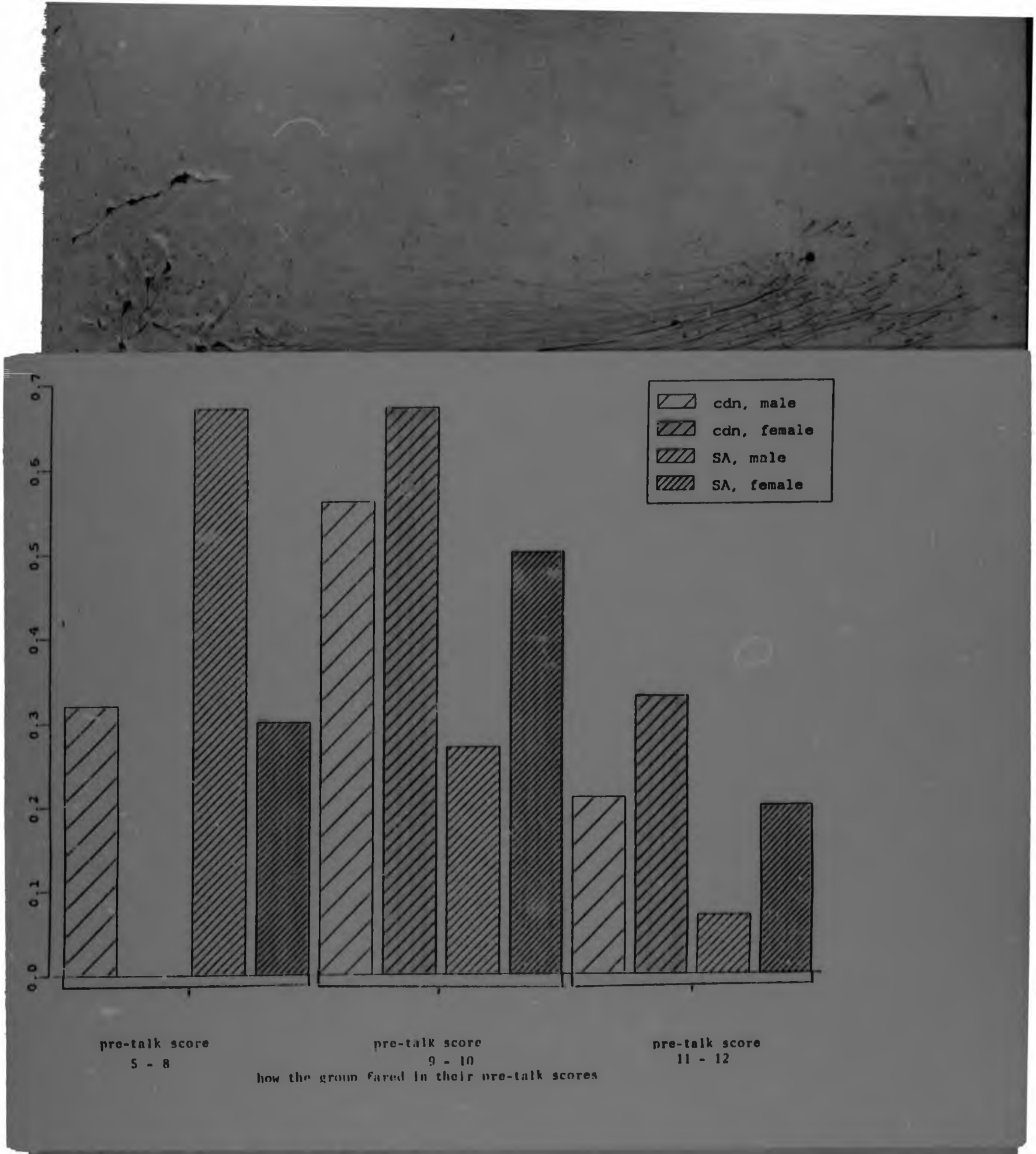
The first issue examined is whether there is evidence of a difference in knowledge when the pre-talk scores of the students from the two countries are compared. (Questions 1 - 15; Appendix C).

The statistical test used to examine this question is that of a "two sample t-test". For each group of students, the average score on the first part of the test is calculated as well as the standard deviation for each score so as to yield the amount of variability in the data.

Ho: Mean score for South African = Mean Score for Canadian; Canadian mean = 9.68; standard deviation =

1.1804; South African mean = 8.48; standard deviation = 1.6104; t = 3.00.

Under the null hypothosis, the probability of obtaining a t statistic as extreme or more extreme than 3.00 is 0.0043. The null hypothesis is therefore rejected. There is thus evidence that the Canadian students on the average scored significantly higher than the South African students (see Histogram on next page).



pre-talk score 5 - 8 | pre-talk score 9 - 10 | pre-talk score 11 - 12

how the group fared in their pre-talk scores

In comparing the post-talk scores, one way to examine this was to examine the raw differences. That is, post-talk scores minus pre-talk scores.

Canadian mean = 0.68; standard deviation = 1.464; South African mean = 2.16; standard deviation = 2.075; t = 2.91.

Under the null hypothesis of no difference, the probability of obtaining a t-statistic as extreme or more extreme is 0.0055. The null hypothesis is therefore rejected. This means there is evidence of greater improvement in the South African students. The South African sample's incremental knowledge specifically about Tay Sachs Disease is greater than the Canadian sample. (Appendix E).

However, instead of only raw differences, one could examine relative improvement. This would take into account the fact that students with high pre-talk scores cannot have large (positive) differences between their post-talk and pre-talk scores.

Therefore, rather than raw differences, one possibility is:- $\frac{\text{post - pre}}{\text{max - pre}}$

which is the improvement relative to a possible improvement. A difficulty here though was that one student scored the maximum of 12 on her pre-talk test,

making (max - pre) = 0. A different measure is thus devised :-

E = the maximum error on the pre-talk scores. Since the worst mark is 5, E = (12-5) = 7. The new measure is :-

$$\frac{\text{post - pre}}{\text{max + 2E - pre}}$$

This measure still has the following characteristics :

(i) it reflects the amount of information left to learn (that is, it gets small as pre gets big);

(ii) it cannot become zero.

(Canadian mean relative improvement = 0.0383; standard deviation = 0.0844; South African mean = 0.1157; standard deviation = .1111; spooled = 0.09867; p = 0.0124).

Under the null hypothesis of no difference between the two groups, the probability of obtaining a t-statistic as extreme as the one we observe is 0.0124.

Therefore, there is evidence of greater relative improvement in the South African group. This is perhaps more revealing than the test based on raw improvement. Since the Canadian students began with higher scores, one may have expected the South African group to show a greater improvement based on raw improvement. However, we can see that they also show a greater relative improvement. (See Appendix F and G).

An interesting dimension in the analysis of the students' knowledge, is their specific knowledge about Tay Sachs Disease. There are four questions on Tay Sachs in the first twelve. Therefore :-

$$\text{Tay Sachs} - \frac{\text{(pre-Tay Sachs)}}{2}$$

This yields a measure of how much the student knows specifically about Tay Sachs, corrected for the students' overall level of knowledge. (That is, the students' incremental knowledge about Tay Sachs).

This value is obtained in the following manner :- There are twelve questions, eight general and four specifically on Tay Sachs. If we know how many questions a student scored correctly (pre), and we know how many Tay Sachs questions the student scored correctly, then (pre - Tay Sachs) is the number of "general" questions the student scored correctly. (Tay Sachs - general) could be a measure of the difference between a student's particular knowledge of Tay Sachs and the student's general knowledge about hereditary diseases. Since there are as many general questions as there are Tay Sachs questions, we divide the "general" score by 2. Now we can determine if the incremental knowledge of the Canadians is equal to the incremental knowledge of the South Africans.

(Canadian mean = -0.16; standard deviation = 1.239;

South African mean = 0.8; standard deviation = 1.041; spooled = 1.14; p = 0.00469).

The null hypothesis of no difference between the two groups is rejected. It is the South African group which shows the higher incremental score.

3.1.2 A comparison of attitudes of South African and Canadian students on the pre-talk and post-talk tests

In analysing attitudes, it is evident from the results that the two groups both yield the same pre-talk scores (t = 0.420). There is no evidence in the post-talk that attitudes have changed which rejects the writer's assumption that improved knowledge would improve attitudes favourably. Reasons for this are suggested further

dian mean = 0.0302; South African mean = 0.0302).

elation between knowledge and attitudes is 0.18 is not statistically significant.

3.1.3 Sex differences

Sex effect in pre-talk scores

Score	Cdn. male	Cdn. female	S.A. male	S.A. female
5-8	.32	0	.67	.00
9-10	.56	.67	.27	.50
11-12	.21	.33	.07	.20

The pre-talk scores are divided more or less into equal groups : 5-8, 9-10, 11-12. For each group the proportion of each type of student who obtained that score is considered.

From the above table it can be seen that 67% of the South African males have pre-talk scores of 5-8; 27% have 9-10; and 7% have 11-12.

If we look at the other students, only 32% of the Canadian males and 0% Canadian females as well as 30% of the South African females have low scores.

It appears that the South African males score lower than the other groups. Suggestions for this are offered further.

In analysing responses to each individual question it must be noted that the first question "What is a birth defect?" is not quantified as the response varies so greatly in both the South African and Canadian samples. The same

difficulty applies to question 5 "Name 3 common birth defects". Here there are a multitude of answers extremely broad in both the samples. However, in the post-test, in both populations, the answers narrow and become more specific with medical names being used. The talks given by the doctors have obviously helped to improve subjects' specific knowledge about genetic dysfunctioning.
(The remaining results are presented in tables in the Appendix. An interpretation of them is offered in the Discussion).

3.1.4 Summary of Results

(i) Canadian students on the average score significantly higher than the South African students in terms of their knowledge about genetic disorders.

(ii) Post-talk scores reveal evidence of greater improvement in the South African students' knowledge.

(iii) In comparing attitudes, the two groups both yield the same pre-talk scores. There is no evidence in the post-talk that attitudes have changed.

(iv) South African males score lower than the other groups on the knowledge section about genetic disorders.

Chapter IV :

4.1 Discussion of Research Findings

More than a decade ago, students in Montreal, Canada were screened in high school for genetic disorders. What followed in Toronto was an increased awareness of the importance of such screening which lead to the B'Nei Brith organisation's first mass screening programme of the general population at about the same time. The fact that Canadian students in this study appear more knowledgable is not very surprising, considering the awareness in the city. The fact that the Canadian students take genetics as part of their biology course is in itself not sufficient in maintaining a sharp level of awareness of such disorders. The programme needs to be detailed about specific disorders and not disorders in general. Nonetheless, this still points to the fact that they are better informed and that a genetic programme for the South African sample would be beneficial to them.

4.1.1 Changes in knowledge

The South African students show a greater relative improvement in their scores perhaps because they never had the basic knowledge to start with, and perhaps also because of the difference in the guest speaker. The South African guest is a gynaecologist whilst the Canadian guest

is a paediatrician with a speciality in genetics. Their different speciality backgrounds must obviously impinge on their talks and the amount of specific knowledge they imparted. It is shown that the South African sample's incremental knowledge specifically about Tay Sachs Disease is greater than the Canadian sample. This may be due to the talk as well as the fact that the Canadian's knowledge about Tay Sachs Disease was already in place.

The South African sample improves in knowing what the developing child can be most harmed by; that women over 40 run more risk of having a Down's Syndrome baby; and that Tay Sachs Disease is always fatal. They seem to be particularly receptive to the talk. The Canadians improve significantly in terms of their knowledge about Spina Bifida.

4.1.2 Changes in Attitude

In examining attitudes it is shown that there is no statistical evidence of a positive change in the post-talk test which differs from Austein et al (15) who found that attitudes are directly correlated with improved knowledge. Perhaps this was so because the attitudes to start with did not appear that negative. After the talk however, all say they would seek genetic counselling; there appears to be a breakdown in their negative attitudes to genetic

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disorders as most indicate that they would marry a carrier after listening to the options available to them.

It is important to note that all of the students wish to see genetic education introduced as a unit in the school curriculum.

4.1.3 Sex Differences

After an examination of sex differences in the two samples, it is clear that the knowledge of South African males is weak, and that the Canadian females appear most knowledgeable as a group. This confirms findings in other studies (15) where women were found to be more interested and better informed than their male counterpart. One suggestion could be that because of the woman's biological identity plus the fact that she carries the child for nine months of pregnancy, she may be more prone to seek out knowledge which affects her very own body.

In analysing the responses on the questionnaire, the Canadian group is familiar with the following concepts :

- What is a birth defect;
- the developing child can be most harmed by;
- At which age is there most risk of bearing a baby with Down's Syndrome;
- Spina Bifida is a disorder characterised by;
- What does a Tay Sachs baby look like at birth;

The South African sample demonstrates good knowledge in the following areas :-

- Which disease that may be unnoticed in the pregnant woman, could harm her unborn baby;
- Spina Bifida is a disorder characterised by;
- What does a Tay Sachs baby look like at birth;
- Which is the best way to test for Tay Sachs Disease.

4.2 Limitations of the study

4.2.1 The two talks given are not controlled in any way which may distort the results. The talk given in South Africa is by a gynecologist. In Toronto, the talk is given by a doctor who has a PhD in genetics. The content emphasis of their speeches is different even though they are briefed by the writer beforehand on what topics to cover and in what length and detail.

4.2.2 Question 5 is eliminated due to the fact that the Tay Sachs carrier rate in Canada differs from that of South Africa.

4.2.3 Questions 1 and 3 are eliminated from the sample because of difficulties in quantifying these. Other questions could have been asked in their place. For example, socio-economic factors could have been correlated with knowledge about genetics, since in Canada their original backgrounds

vary so greatly (Polish, Russian, Israeli, Canadian and South African). (Appendix C; pg. 49)

4.3 Suggestions for applications of the findings

The prime objective of the study is to determine the amount of knowledge students in a high school in South Africa have about genetic disorders and their attitudes towards these. It is thought that in order to substantiate and broaden the study, a cross-cultural study of students in a Canadian high school would prove interesting and helpful. This proved to be so. As a more advanced Western democracy, the Canadian students' knowledge is higher than that of their South African counterparts. The introduction of a genetic counselling course would greatly benefit a prevention programme of the dangers and long-term ill-effects genetic disorders may have upon an individual and his family both physically and mentally. It is hoped that with this study the writer can emphasize to the local schools the importance of having such information whilst students are a captive audience still at school.

In Canada, the importance of ongoing and continuing genetic education must be stressed if a preventive programme of this nature is to be fully effective.

4.4 Suggestions for Further Research

The results of this study, in relation to its aims, demonstrate the following :-

(i) Canadian students scored higher than the South African students in terms of their knowledge of genetic disorders. However, it was stressed that in order to ensure some level of awareness about genetics, the Canadian programme in the schools must be ongoing and that a genetic awareness programme in South Africa to begin with is necessary and beneficial.

(ii) There was no evidence after the talk, that attitudes in relation to genetic disorders had at all changed. It was suggested that this may have been so since the attitudes to begin with did not appear that negative. All of the students expressed the wish to have genetic eduction introduced as a unit in the school curriculum.

(iii) South African males did poorer than the other groups on their knowledge about genetic disorders.

These findings could form a basis for the Tay Sachs Association of S.A. for their use in gaining entry into local schools, as well as to S.A.I.D.A. (S.A. Inherited Disorders Association). In Canada, hopefully the B'Nei Brith Organization, who run mass screening programmes in

the country, could benefit from the findings in terms of giving impetus to a job already well done. The fact that the study shows that Canadian students are not well informed about Tay Sachs disease could motivate them further to run such programmes. On an even broader scale, National Tay Sachs and Allied Diseases in the United States may benefit from it as their philosophy is not only to educate in the schools but mass screen people at a later stage in their lives.

As far as suggestions for further research is concerned, other population groups could be investigated such as those who are high risk for genetic disorders such as sickle cell anaemia.

It is important at this point to mention the role of the school counsellor in introducing genetic counselling services into the school as a preventitive programme. 'Prevention' is stressed as opposed to the curative aspects where obviously the matters rests with doctors and specialists in the field.

Genetic awareness could be offered as part of a biology unit either given in a group discussion or as a unit taught by a biology teacher. Outside speakers could be invited in. An outline of a course content is offered on the following page : (23)

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I. Introduction

II. Basic Principles of Genetics
Mitosis, Meiosis, Chromosome Technology, The Cell, Chromosomes and Genes, Protein Synthesis, Mutations, Metabolic Disorders

III. Recombinant DNA

IV. Genetic Handicaps
Nature and extent, Chromosomal disorders, Common chromosomal disorders, Spontaneous abortion, Infertility, Single gene disorders, Autosomal dominant inheritance, Autosomal recessive inheritance, Sex-linked inheritance, Mendelism, Multiple alleles, Multifactorial inheritance, Blood groups and blood group incompatibilities

V. Harmful Genes in Population Groups
Porphyria, Haemophilia, Thalassaemia, Tay-Sachs disease, Albinism, Cystic fibrosis, Hyperlipidaemia, Sclerosteosis, Progressive familial heart block, The Martin-Bell syndrome, Huntington chorea, Oudtshoorn skin, Pseudoxanthoma elasticum, Lipoid proteinosis, Polyposis of the colon, Summary

VI Chromosomes, Genes and Cancer

VII Ecogenetics

VIII. Prenatal Development

IX. Dysmorphologies in the Newborn

X. Teratogenic Agents
Principles of teratology, Teratogenic agents, The foetal alcohol syndrome

XI. Concepts of Handicaps and Congenital and Hereditary Disorders
Incidence of handicaps, Prevention of handicaps, Deafness, Blindness, Mental retardation, Schizophrenia

XII Prevention of Congenital and Hereditary Disorders
Methods of prevention, Prenatal diagnosis of neural tube defects, Comment on screening, Genetic counselling

XIII. Genetic Services in the RSA

XIV Knowledge and Attitudes of the Public with regard to Congenital and Hereditary Disorders

XV Psychosocial Aspects of Genetic Handicaps

XVI. The Economic Aspects of Genetic Handicaps

XVII Evaluation of Drugs for Porphyric Patients

XVIII. The Human Gene Map

The programme could be offered concurrently to parents and teachers so that they could be of assistance to students should anxieties arise.

As always though, the school counsellor needs to have an open door policy whereby students feel free to approach the counsellor to discuss their personal feelings. By informing his/her students of his/her own knowledge and comfort in discussing these matters, the counsellor can free the students to question, search and ultimately find the answers they are looking for so that preventable tragedies may never occur.

APPENDIX

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C. QUESTIONNAIRE

NAME: ----------

AGE: ----------

SEX: ----------

DATE: ----------

PARENTS COUNTRY OF ORIGIN: --- ----------

Please place a tick ( ) in the box corresponding to the appropriate response.

1. What is a birth defect?

---

2. Birth defects are caused by:

Heredity	☐
environment	☐
both	☐

3. The developing child can be most harmed by:

x-rays	☐
amnioscentesis	☐
ultra-sound	☐

4. Which disease that may be unnoticed in the pregnant woman, could harm her unborn baby?

German Measles ☐

Chicken pox ☐

Mumps ☐

5. Name 3 common birth defects.

i) German Measles ☐

ii) Chicken Pox ☐

iii) Mumps ☐

6. Genetic counselling could mean expert advice on one of the following:

Marriage guidance ☐

Counselling what to do when your baby is born ☐

Expert medical advice about avoiding birth defects in your future children ☐

7. Down's Syndrome is characterised by

Physical abnormalities ☐

Mental abnormalities ☐

Both ☐

None of the above ☐

8. At which age is there most risk of bearing a baby with Down's Syndrome?

25 - 30 years ☐

30 - 35 years ☐

over 40 years ☐

9. Spina bifida is a disorder characterised by:

- Split spine ☐
- Curvature of the spine ☐
- Mental illness ☐

10. Tay Sachs Disease is an inherited genetic disorder which is always fatal within 5 years in:

- 50 % of cases ☐
- 75 % of cases ☐
- Always fatal ☐

11. The proportion of Jews who are carriers of Tay Sachs is:

- 1 in 10 ☐
- 1 in 25 ☐
- 1 in 50 ☐

12. Did you know that your carrier status of Tay Sachs Disease is detectable by:

- A simple blood test ☐
- A physical check-up ☐
- x-ray ☐

13. What does a Tay sachs baby look like at birth?

- Normal ☐
- Paralysed ☐
- Retarded ☐

14. At approximately age 6 months, the baby with Tay Sachs Disease:

- May begin to sit ☐
- Will sit ☐
- Will sit but deteriorate ☐

15. Are you aware of anyone with a genetic disorder?

- Yes ☐
- No ☐
- Uncertain ☐

16. How important do you consider it to be to know about genetic disease?

- Very important ☐
- Important ☐
- Not very important ☐
- Not at all ☐

17. When do you think is the right age for people to be tested for genetic disorders?

- High School ☐
- When engaged to be married ☐
- When married ☐
- When pregnant ☐

18. How anxious do you become on hearing about genetic disorders?

- Very anxious ☐
- Fairly anxious ☐
- Not at all anxious ☐

19. If you discovered you are a carrier of a genetic disorder, would you:

- Remain silent about it ☐
- Discuss it with a friend ☐
- Seek genetic counselling ☐
- Other ☐

20. Would you marry a carrier of the gene for Tay Sachs Disease?

- Like to ☐
- Definitely would ☐
- Seek genetic counselling ☐
- Other ☐

21. Do you think that it is important that genetic information and counselling should included in the regular school curriculum?

- Extremely important ☐
- Fairly important ☐
- Fairly unimportant ☐
- Extremely unimportant ☐

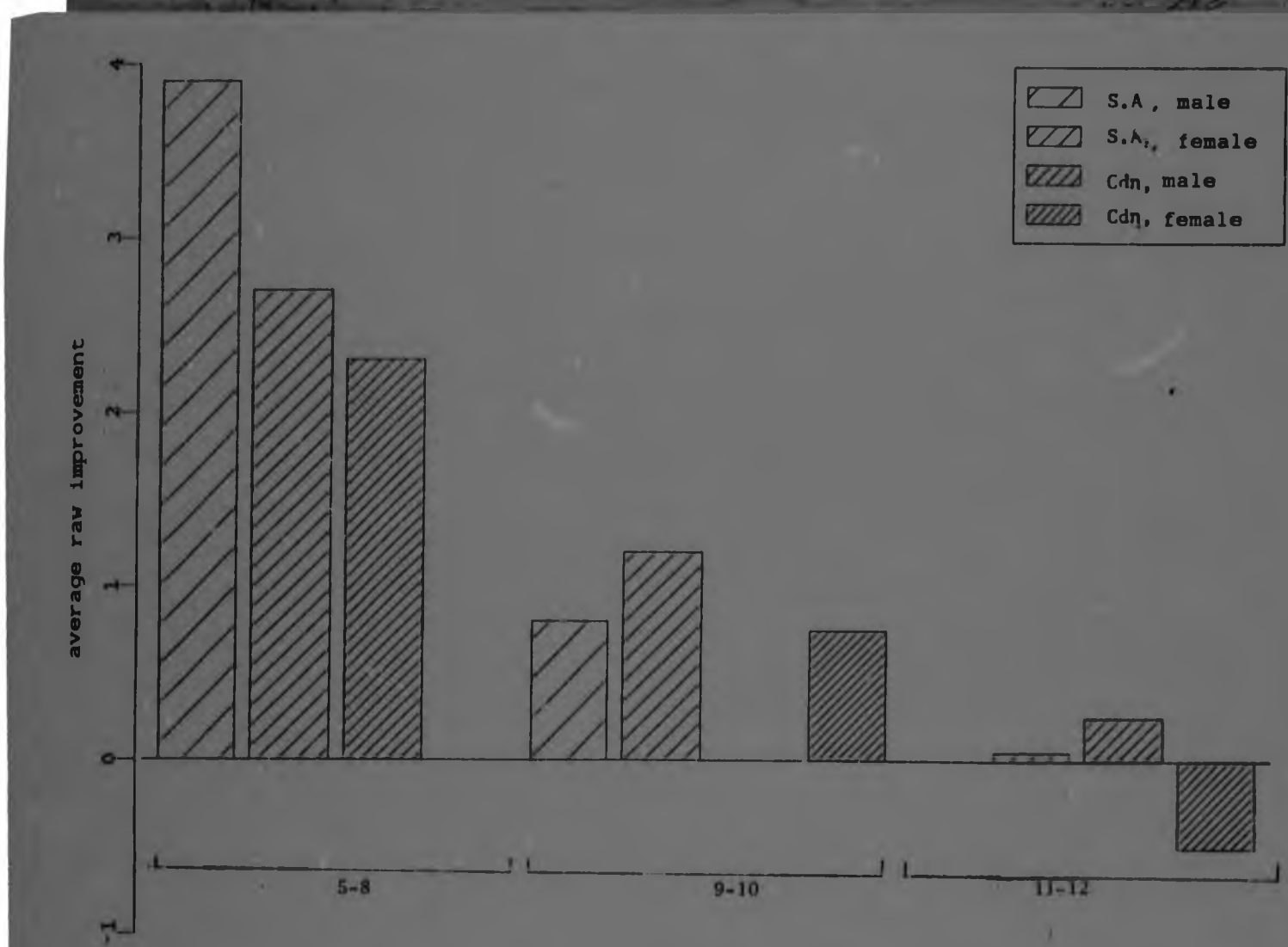
22. How imperative would you consider it to be for a pregnant woman to be screened for a genetic disorder?

- Extremely important ☐
- Fairly important ☐
- Fairly unimportant ☐
- Extremely unimportant ☐

Thank you for your co-operation.

D. HISTOGRAMS

D. HISTOGRAMS


S.A , male
S.A., female
Cdn, male
Cdn, female
average raw improvement
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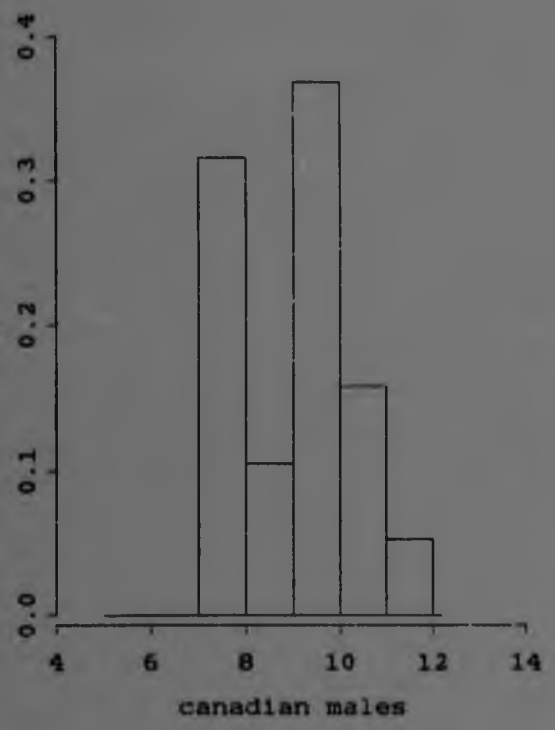
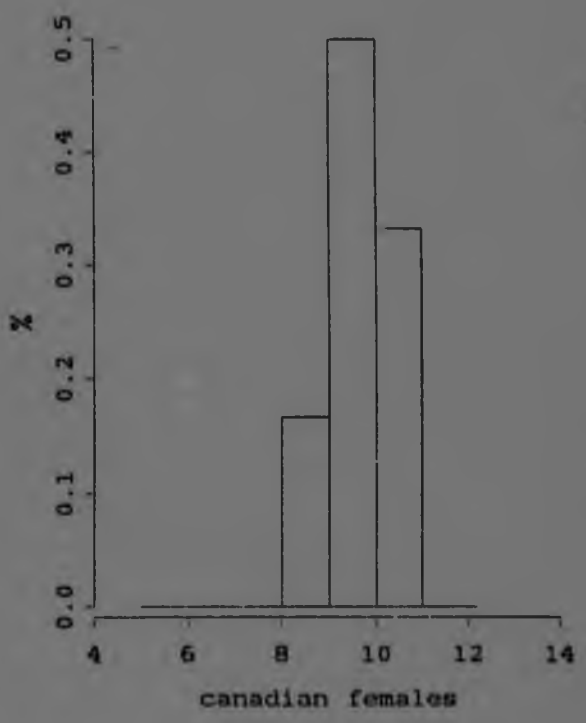
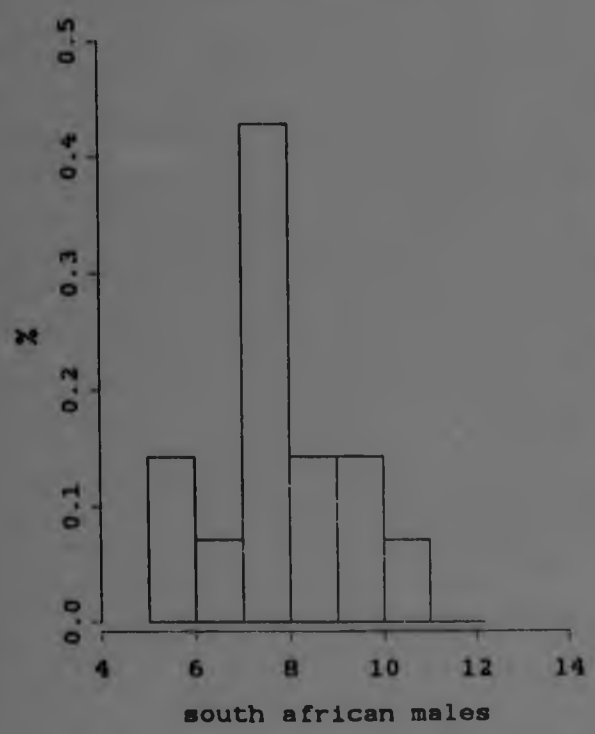
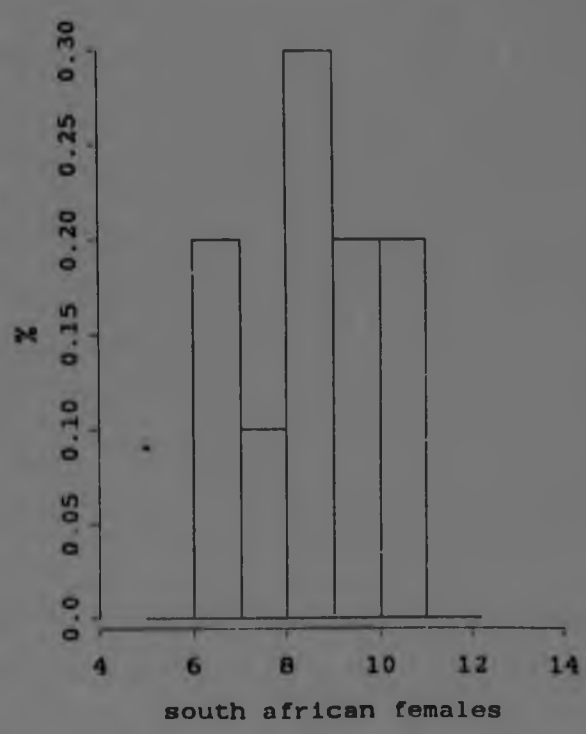
0
-1
5-8
9-10
11-12
pre-talk test score group

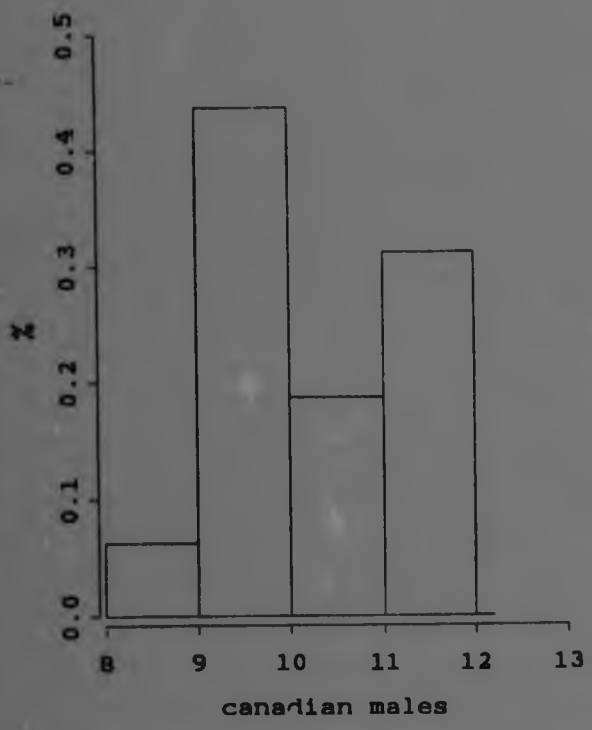


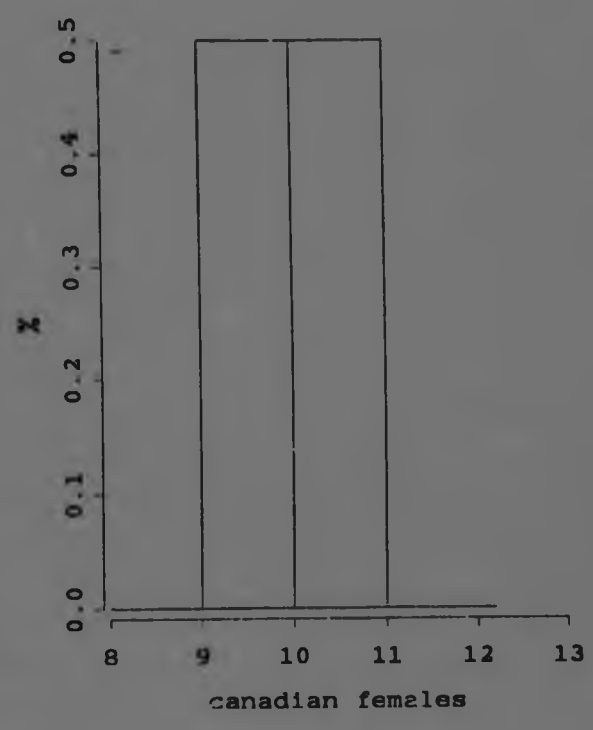


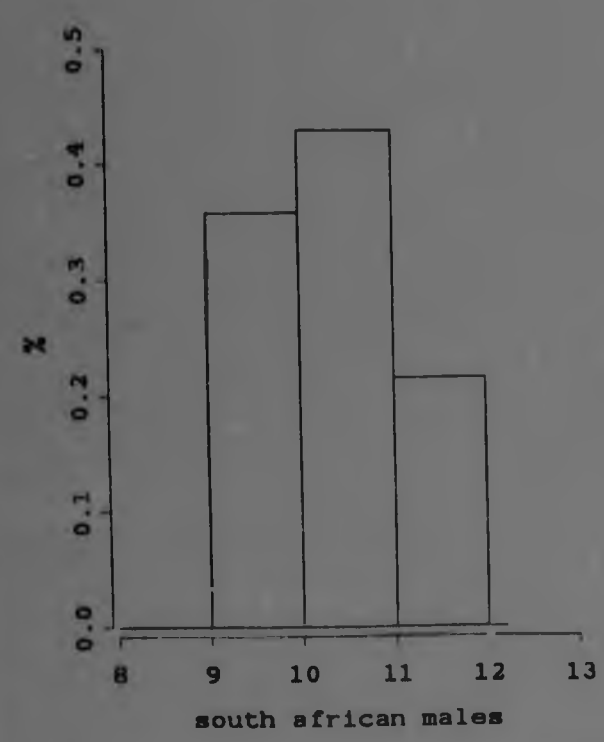


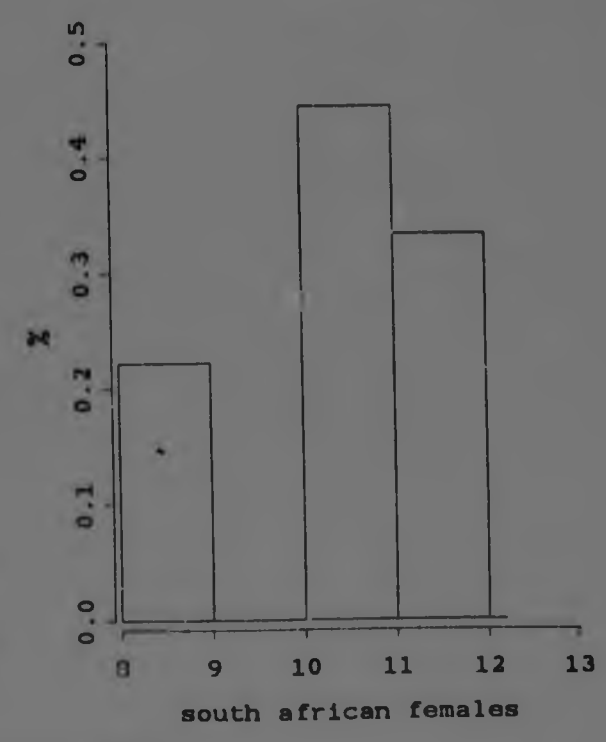


pre-talk knowledge

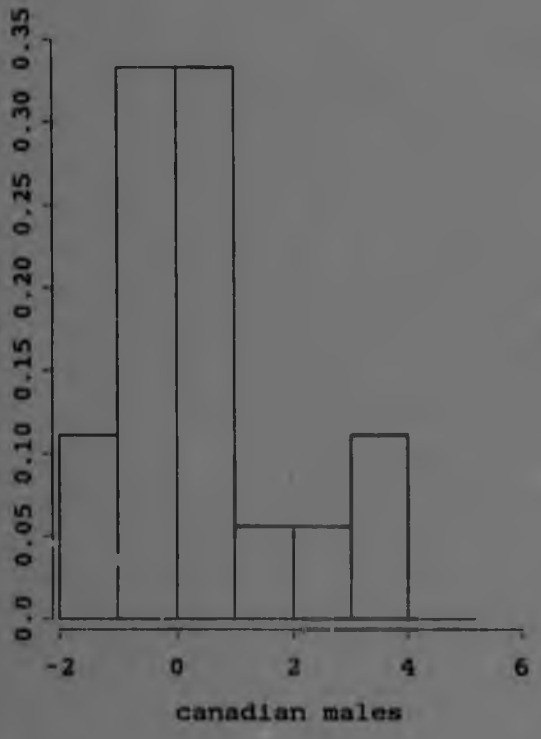


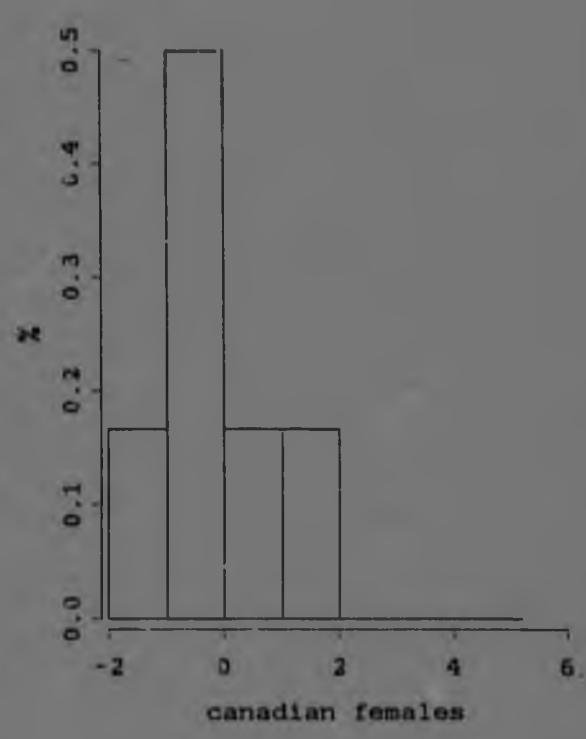


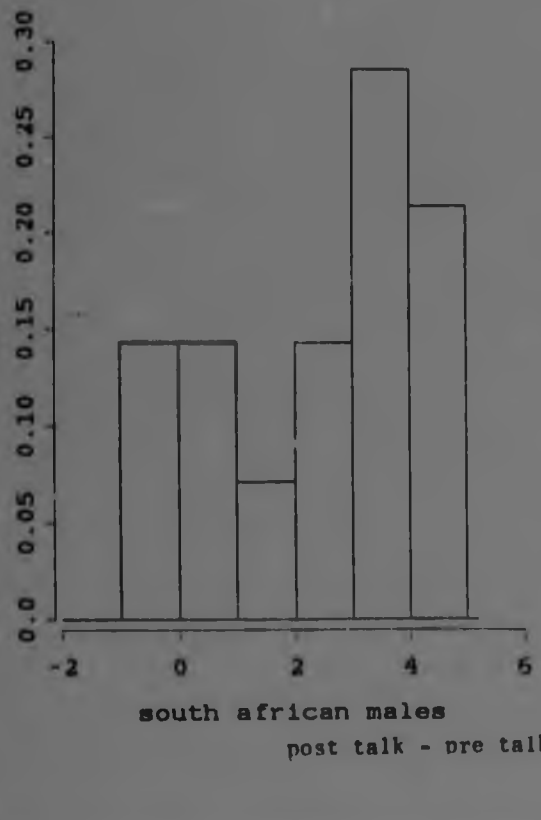


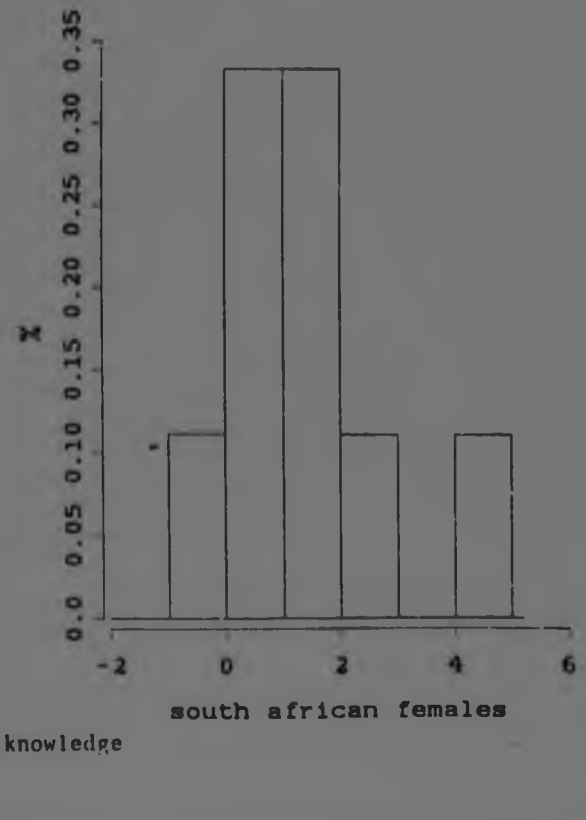


post talk knowledge

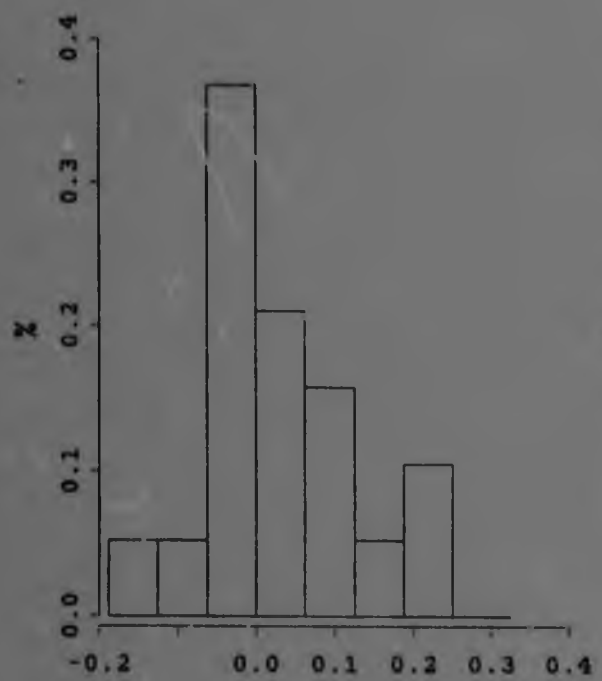




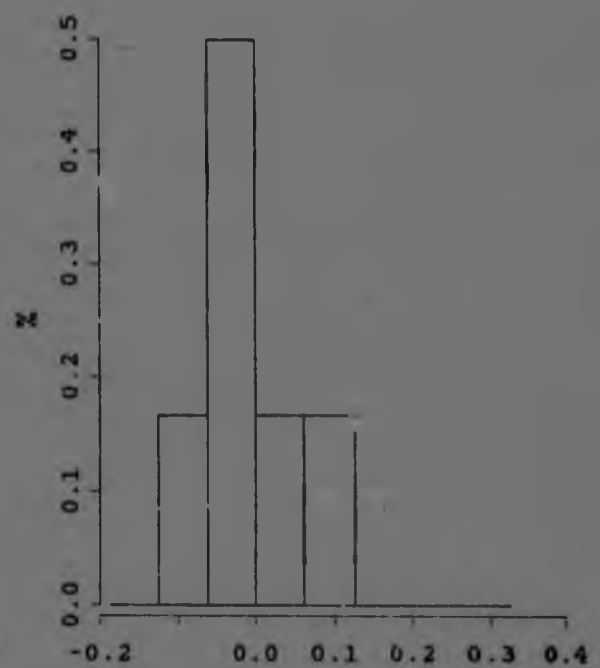




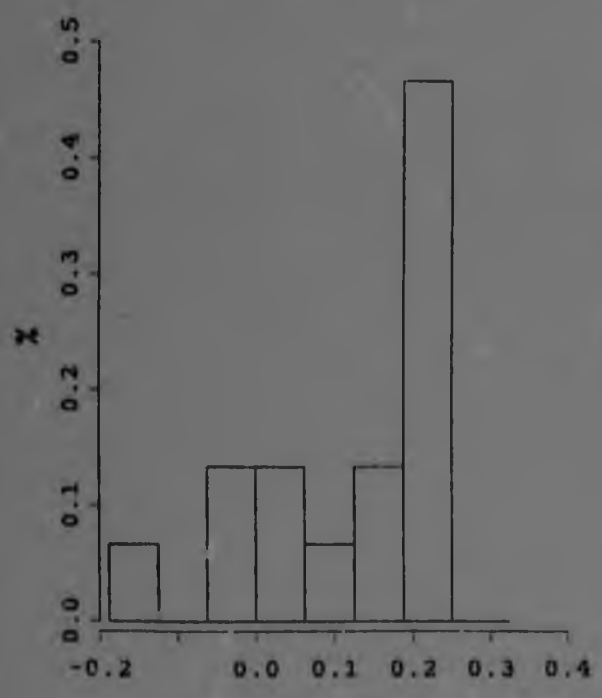
post talk - pre talk knowledge



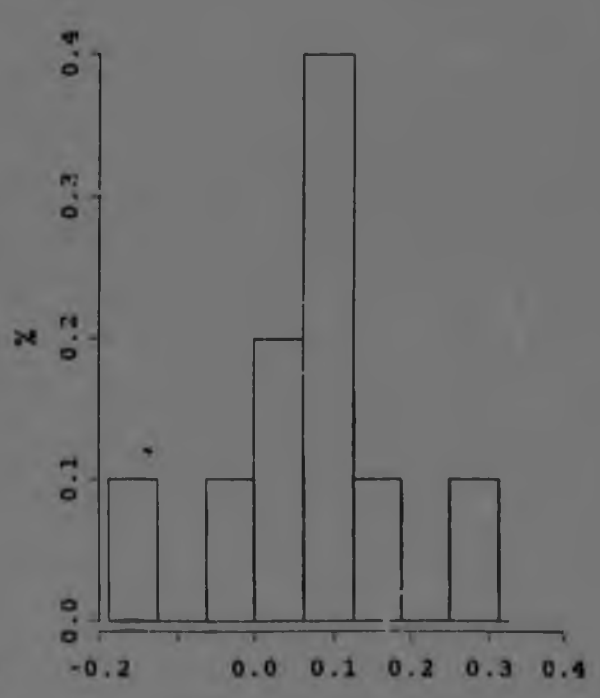
canadian males



canadian females

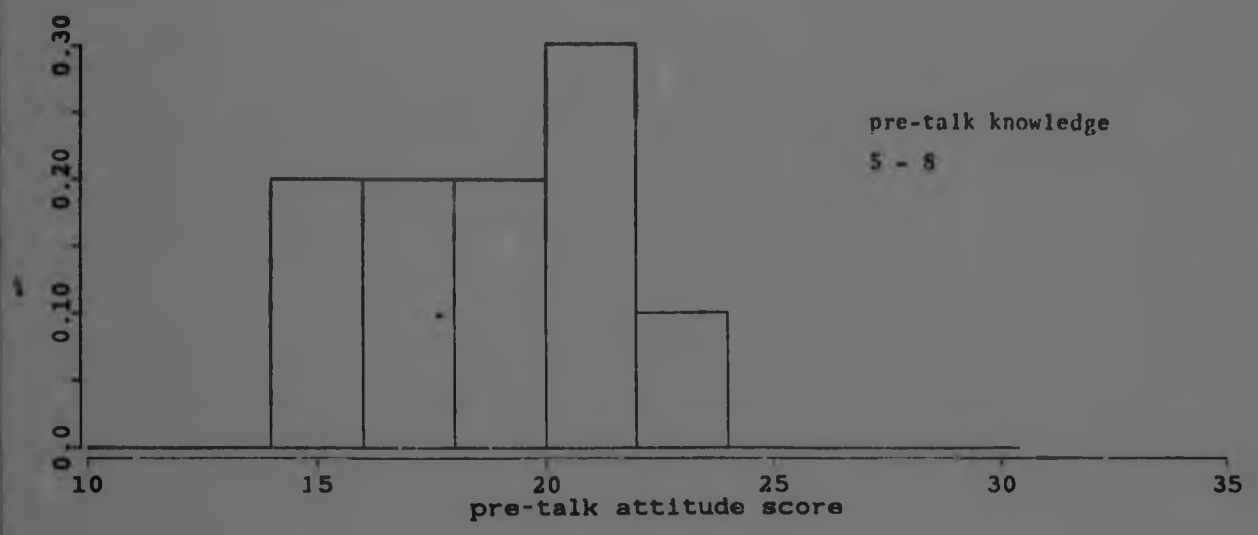


south afr_can males



south african females

relative change in knowledge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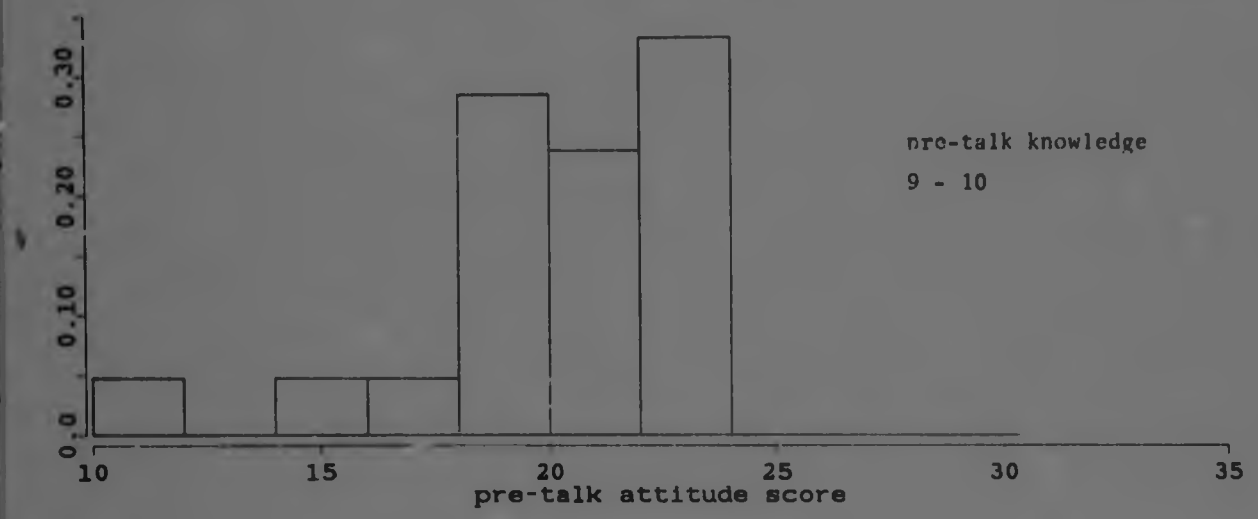
pre-talk attitude score
pre-talk knowledge
5 - 8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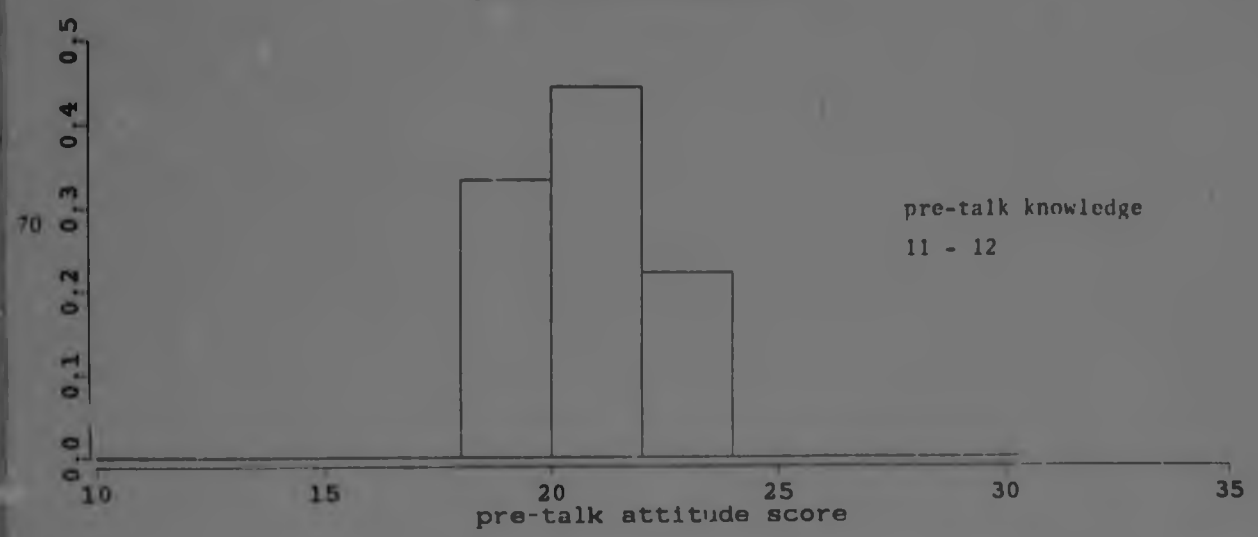
pre-talk attitude score
pre-talk knowledge
9 - 10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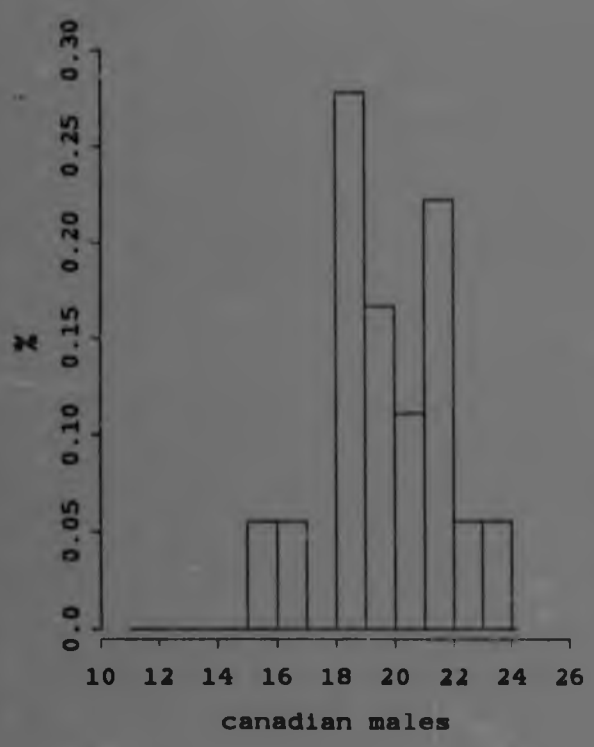
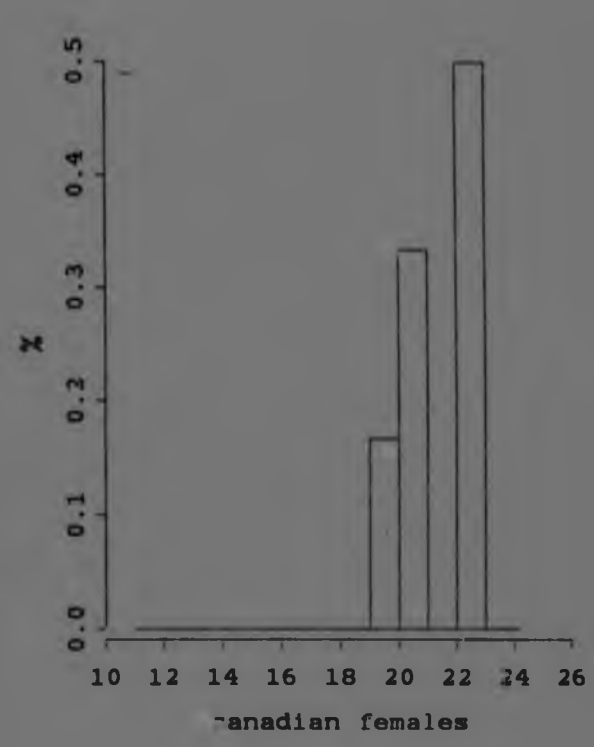
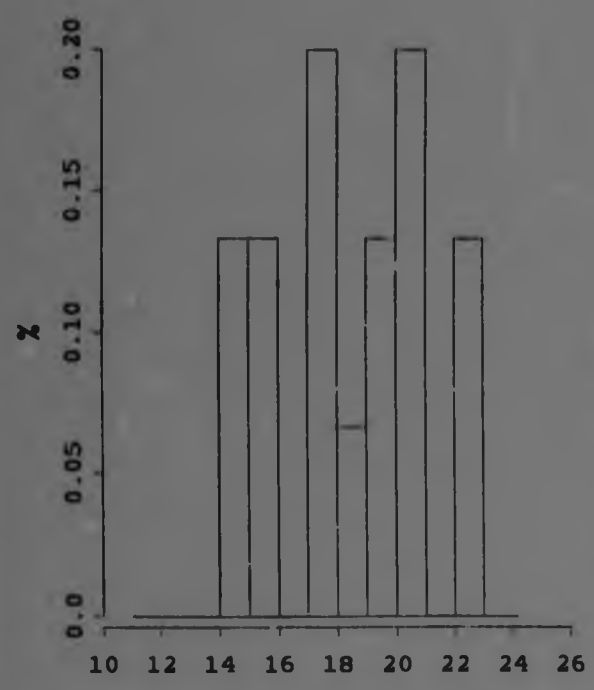
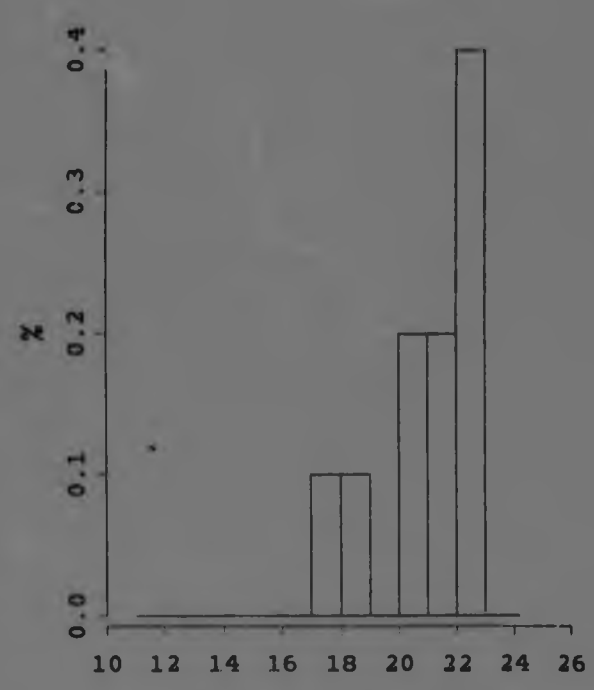
pre-talk attitude score
pre-talk knowledge
11 - 12

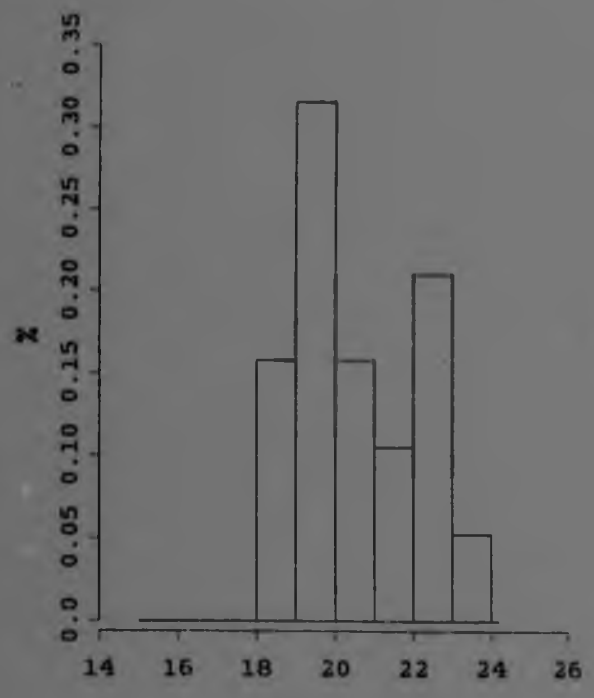


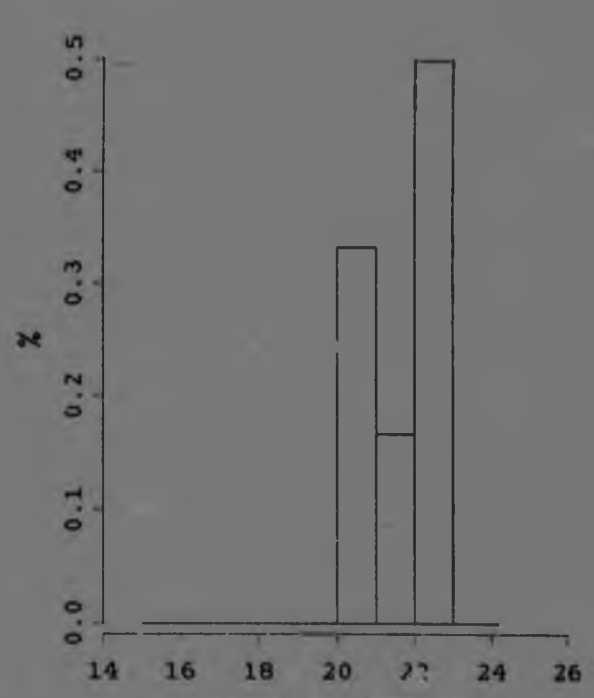


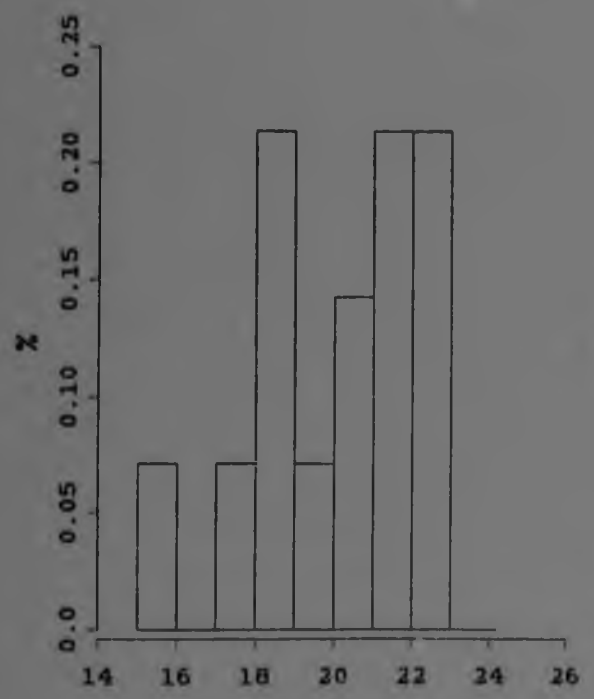


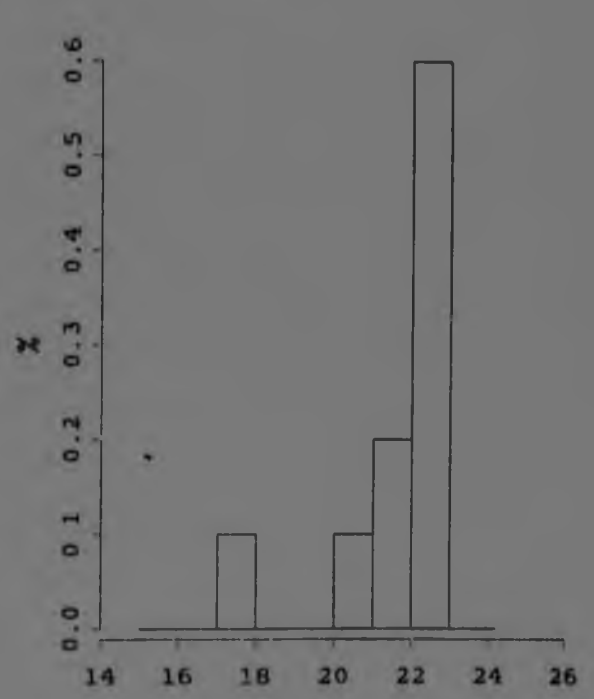


pre talk attitude scores

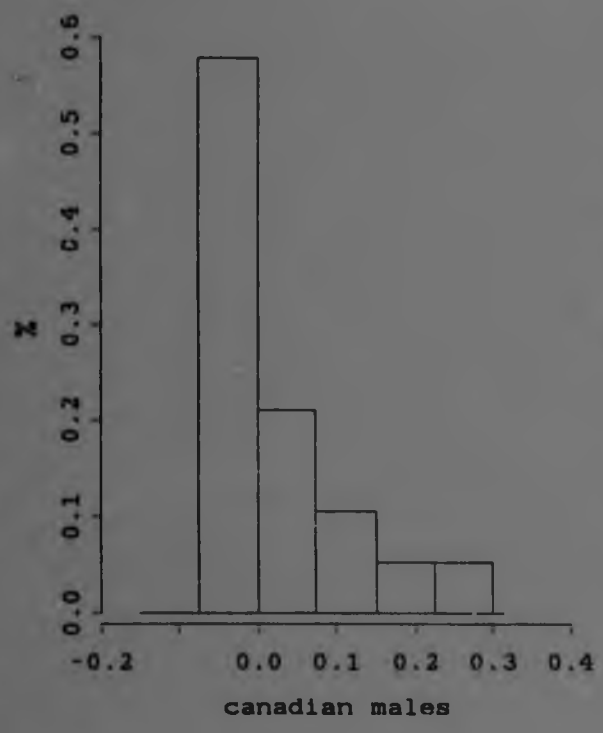


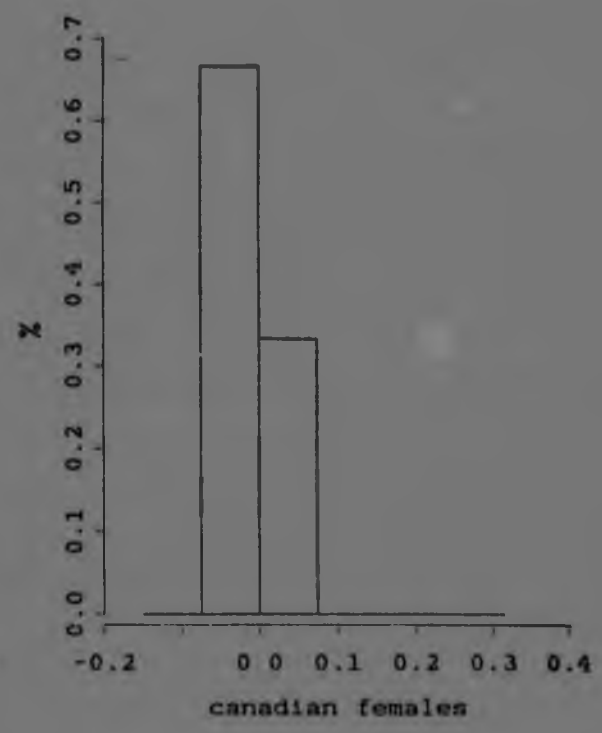


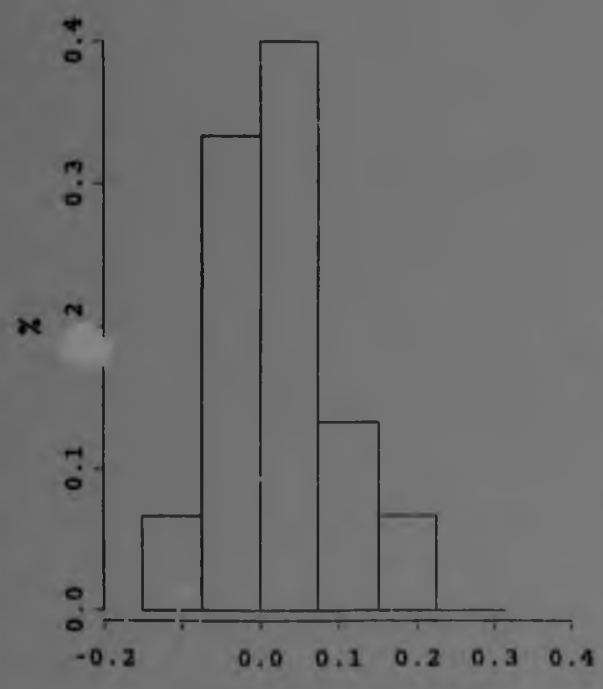


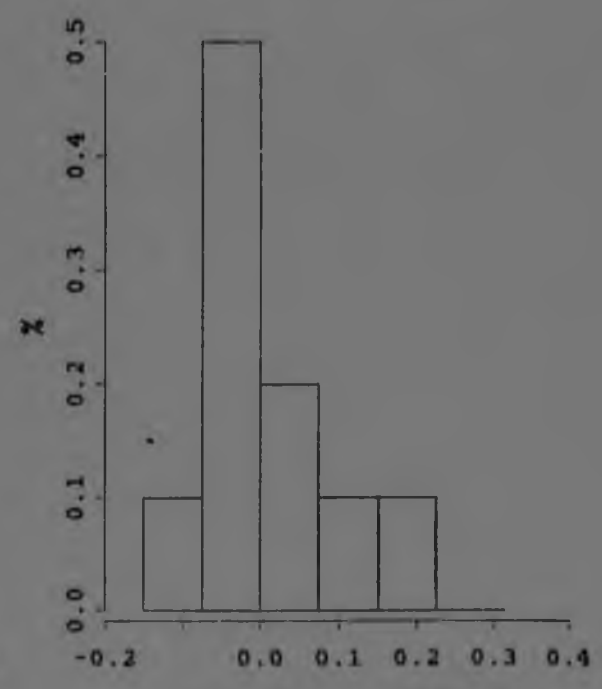


post talk attitude scores

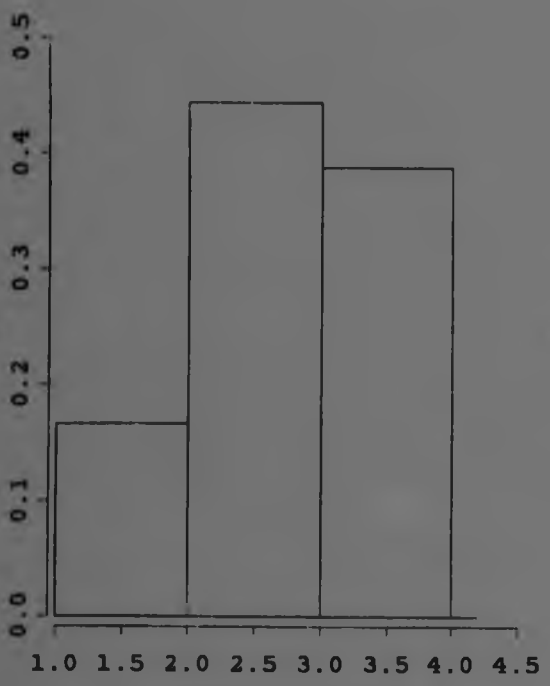




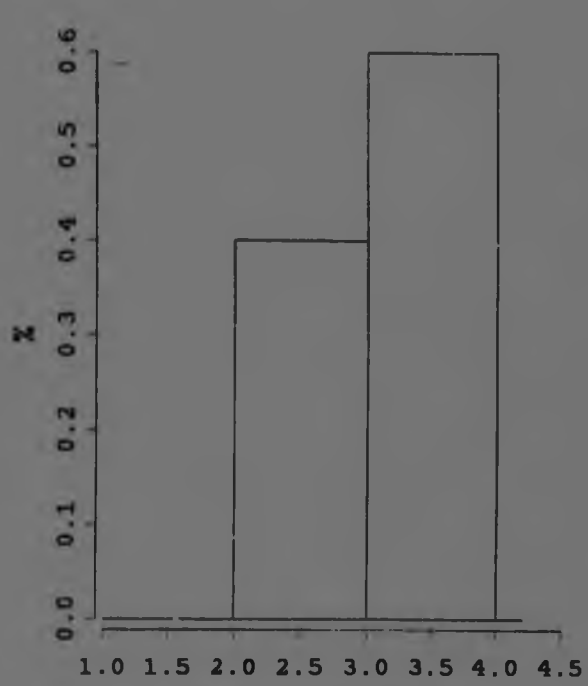




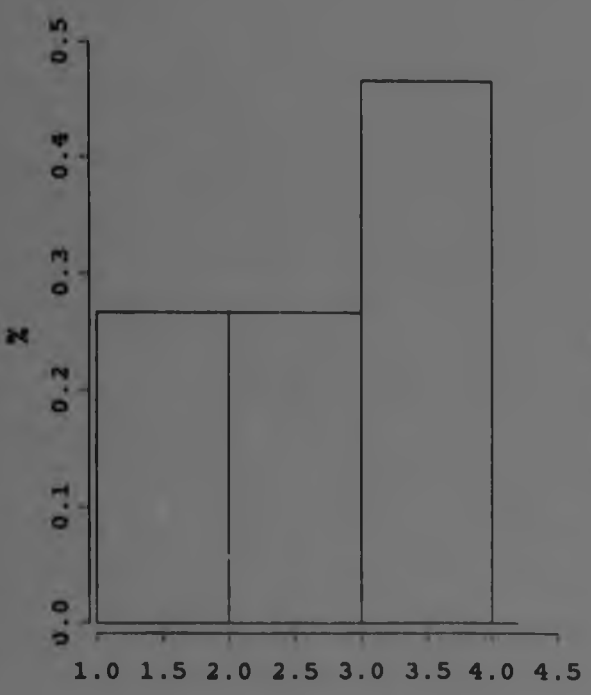
relative change in attitude



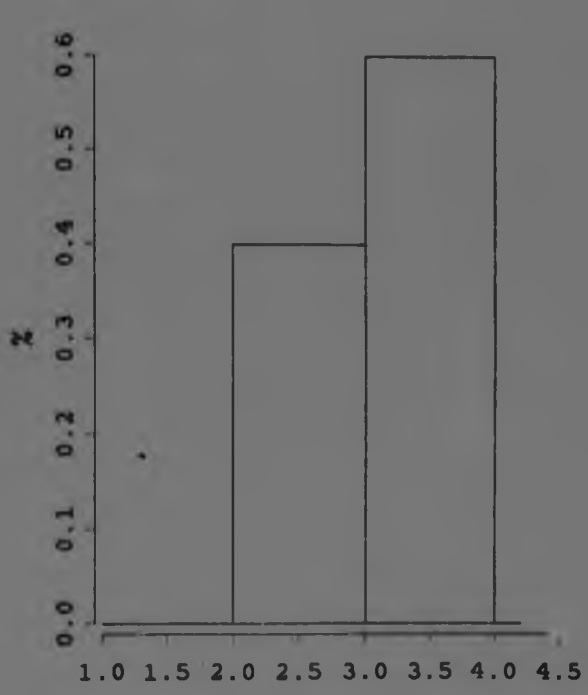
canadian males



adian females

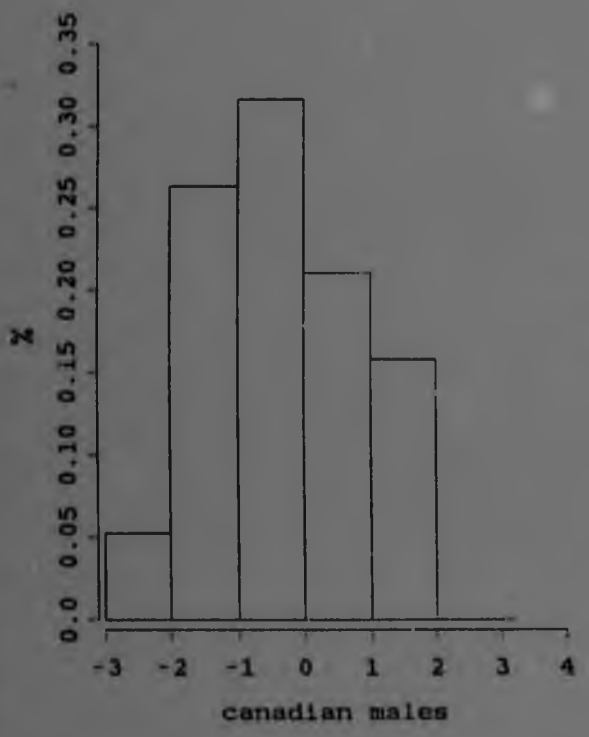


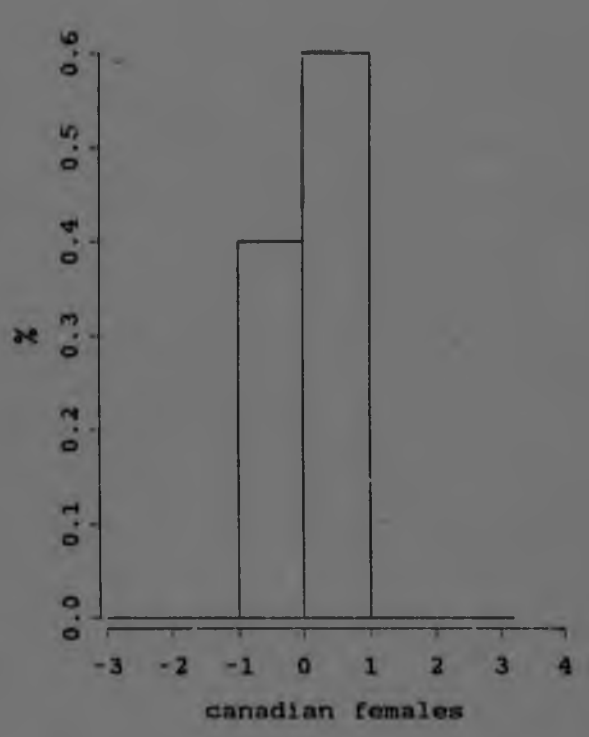
south african males

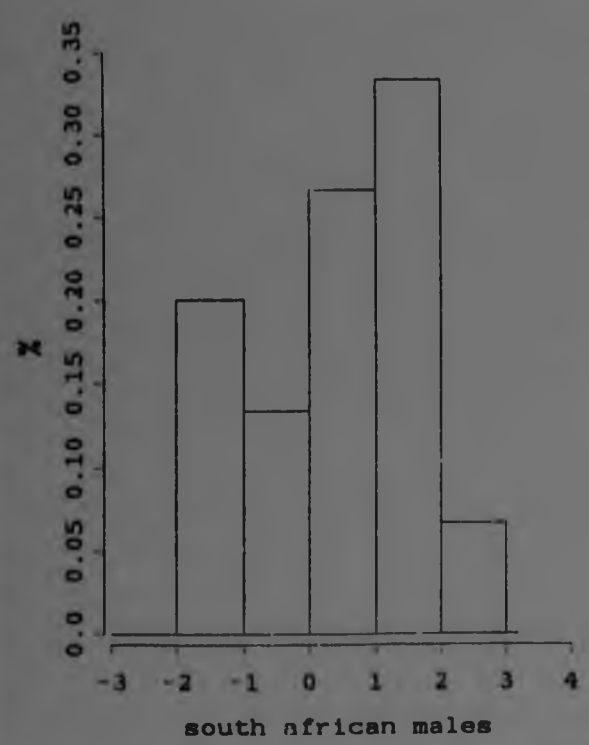


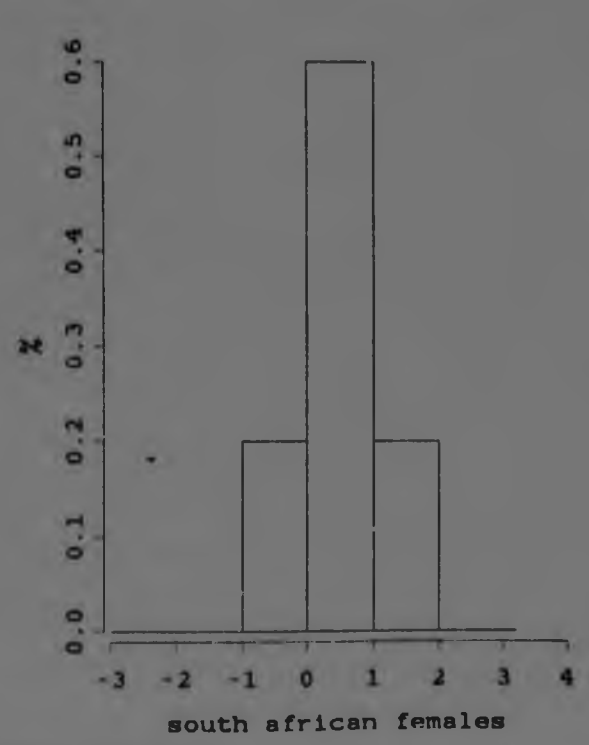
south african females

Tay Sachs scores

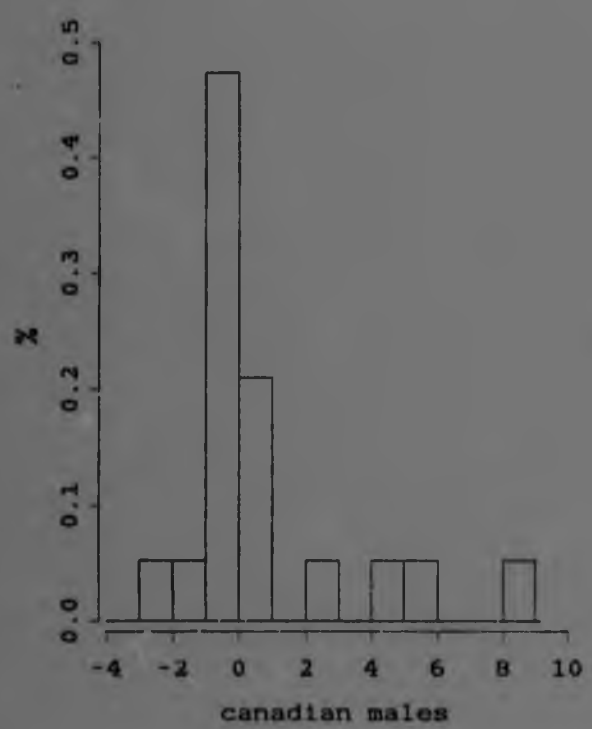








incremental knowledge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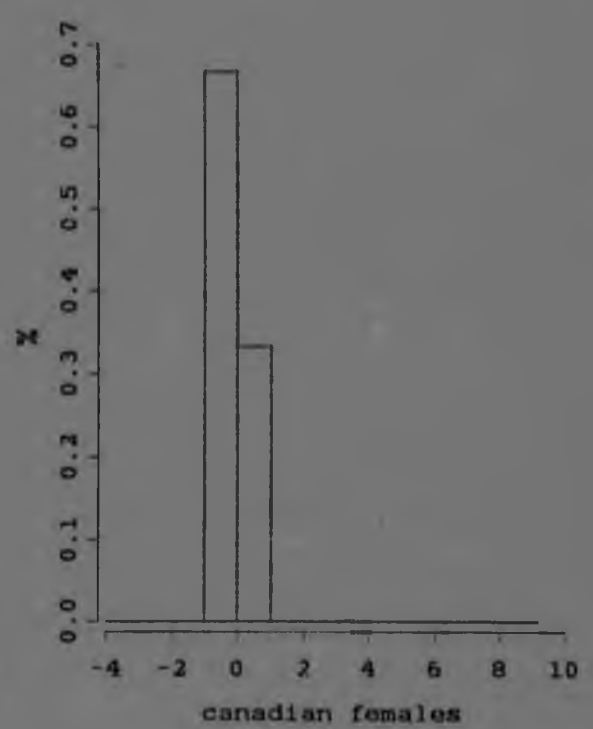
canadian males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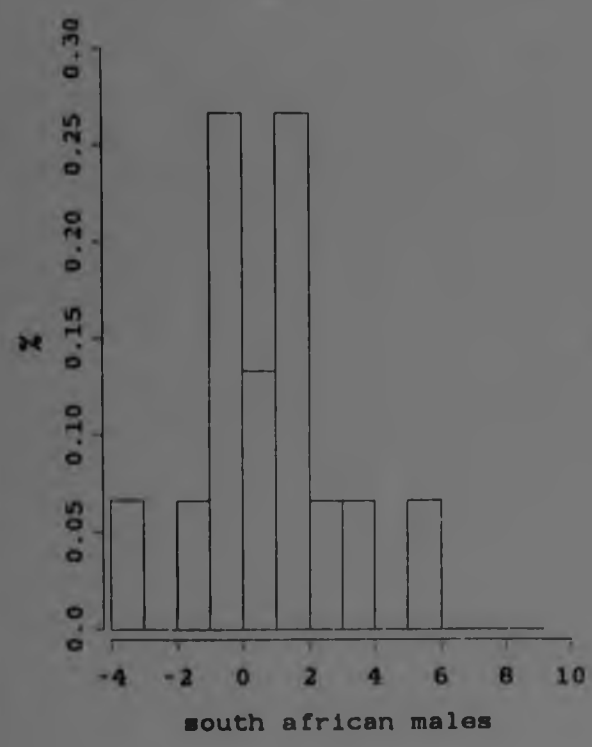
canadian females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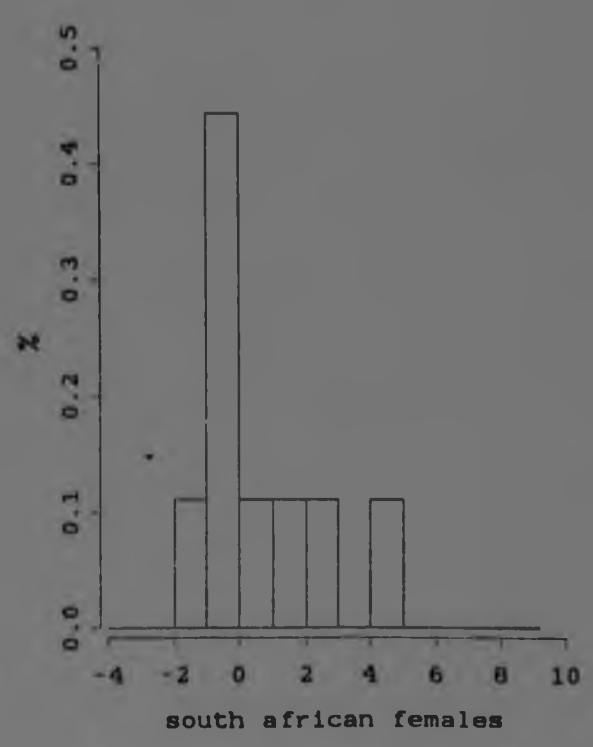
south african males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south african females

E. TABLES OF RESULTS

Tables 1 + 5 are not missing.
Those were never quantified
This was explained in the
thesis (Appendix C, 1 + 5)

"What is a birth defect?" + "Name 3 common birth defects" were left as descriptive data. The numbers of the tables were not changed so as to maintain consistency.

" "

Table 2: Birth defects are caused by:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Heredity	6	(24)	6	(24)	8	(32)	8	(32)
Environment	0	(0)	0	(0)	0	(0)	0	(0)
Both	19	(76)	19	(76)	17	(68)	17	(68)
Total	25		25		25		25	

Table 3: The developing child can most be harmed by:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
X-Rays	16	(64)	25	(100)	24	(96)	24	(96)
Amnioscentesis	4	(16)	0	(0)	0	(0)	0	(0)
Ultra Sound	5	(20)	0	(0)	1	(4)	1	(4)
Total	25		25		25		25	

Table 4: Which diseases that may be unnoticed in the pregnant woman, could harm her unborn baby:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
German Measles	21	(84)	15	(60)	25	(100)	10	(40)
Chicken Pox	0	(0)	2	(8)	0	(0)	2	(8)
Mumps	4	(16)	8	(32)	0	(0)	13	(52)
Total	25		25		25		25	

Table 6· Genetic counselling could mean expert advice on one of the following:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Marriage Guidance	0	(0)	3	(12)	1	(4)	2	(8)
Counselling what to do when your baby is born	0	(0)	1	(4)	5	(20)	2	(8)
Medical advice about avoiding birth defects to your future children	19	(76)	21	(84)	19	(76)	16	(64)
Total	19*	(76)	25		25		20*	(80)

Table 7: Down's Syndrome is characterized by:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Physical Abnormalities	0	(C)	1	(4)	0	(0)	1	(4)
Mental Abnormalities	0	(0)	1	(4)	1	(4)	0	(0)
Both	23	(92)	23	(92)	22	(88)	24	(96)
None of the Above	0	(0)	0	(0)	0	(0)	0	(0)
Total	23*	(92)	25		23*	(92)	25	

Table 8: At which age is there most risk of bearing a baby with Down's Syndrome?:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
25-30	0	(0)	0	(0)	0	(0)	0	(0)
30-35	3	(12)	0	(0)	0	(0)	0	(0)
Over 40 (100)	22	(88)	25	(100)	25	(100)	25	
Total	25		25		25		25	

Table 9: Spina Bifida is a disorder characterized by:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Split Spine	19	(76)	7	(28)	20	(80)	15	(60)
Curvature of the Spine	5	(20)	18	(72)	2	(8)	10	(40)
Mental Illness	1	(4)	0	(0)	3	(12)	0	(0)
Total	25		25		25		25	

Table 10: Tay Sachs is an inherited genetic disorder which is always fatal within 5 years in:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
50% of the cases	5	(20)	1	(4)	1	(4)	0	(0)
75% of the cases	4	(16)	8	(32)	0	(0)	3	(12)
Always Fatal (88)	16	(64)	16	(64)	24	(96)	22	
Total	25		25		25		25	

Table 11: The proportion of Jews who are carriers of Tay Sachs disease cannot be tabulated as the answer differs statistically in each country.

Table 12: Did you know what your carrier status of Tay Sachs Disease is detectable by:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
A simple blood test	25	(100)	24	(96)	25	(100)	24	(96)
A physical check-up	0	(0)	0	(0)	0	(0)	0	(0)
X-Ray	0	(0)	1	(4)	0	(0)	1	(4)
Total	25		25		25		25	

Table 13: What does a Tay Sachs baby look like at birth?:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Normal	21	(84)	22	(88)	24	(96)	24	(96)
Paralysed	2	(8)	1	(4)	1	(4)	0	(0)
Retarded	2	(8)	2	(8)	0	(0)	1	(4)
Total	25		25		25		25	

Table 14: At approximately 6 months of age, the baby with Tay Sachs:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
May begin to stand	1	(4)	5	(20)	10	(40)	4	(16)
Will stand	5	(20)	1	(4)	2	(8)	0	(0)
Will stand but deteriorate	19	(76)	19	(76)	13	(52)	21	(84)
Total	25		25		25		25	

ATTITUDES

Table 15: Are you aware of anyone with a genetic disorder?:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Yes	6	(24)	11	(44)	8	(32)	10	(40)
No	10	(40)	10	(40)	11	(44)	10	(40)
Uncertain	9	(36)	4	(16)	6	(24)	5	(20)
Total	25		25		25		25	

ATTITUDES

Table 15: Are you aware of anyone with a genetic disorder?:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Yes	6	(24)	11	(44)	8	(32)	10	(40)
No	10	(40)	10	(40)	11	(44)	10	(40)
Uncertain.	9	(36)	4	(16)	6	(24)	5	(20)
Total	25		25		25		25	

Table 16: How important do you consider it to be to know about genetic disorders?:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Very Important	17	(68)	15	(60)	19	(76)	17	(68)
Important	7	(28)	10	(40)	6	(24)	8	(32)
Not Very Important	1	(4)	0	(0)	0	(0)	0	(0)
Not at all	0	(0)	0	(0)	0	(0)	0	(0)
Total	25		25		25		25	

Table 17: When do you think is the right age for people to be tested for genetic disorders?:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
High School	15	(60)	15	(60)	19	(76)	17	(68)
When engaged to be married	9	(36)	9	(36)	6	(24)	7	(28)
When married	0	(0)	1	(4)	0	(0)	1	(4)
When pregnant	1	(4)	0	(0)	0	(0)	0	(0)
Total	25		25		25		25	

Table 18: How anxious do you become on hearing about genetic disorders?

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Very anxious	7	(28)	7	(28)	8	(32)	7	(28)
Fairly anxious	13	(52)	13	(52)	17	(68)	14	(56)
Little anxious	5	(20)	5	(20)	0	(0)	4	(16)
Not at all anxious	0	(0)	0	(0)	0	(0)	0	(0)
Total	25		25		25		25	

Table 19: If you discovered you were a carrier of a genetic disorder would you:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Remain silent about it	1	(4)	1	(4)	0	(0)	0	(0)
Discuss it with a friend	1	(4)	1	(4)	1	(4)	1	(4)
Seek genetic counselling	21	(84)	22	(88)	24	(96)	24	(96)
Other	2	(8)	1	(4)	0	(0)	1	(4)
Total	25		25		25		25	

Table 20: Would you marry a carrier of the gene for Tay Sachs Disease?:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Likely to	5	(20)	10	(40)	13	(52)	12	(48)
Definately would	2	(8)	4	(16)	4	(16)	4	(16)
Unlikely to	15	(60)	10	(40)	5	(20)	8	(32)
Definately would not	1	(4)	1	(4)	1	(4)	1	(4)
Total	23*	(92)	25		23*	(92)	25	

Table 21: Do you think it is important that genetic information and counselling should be included in the regular school curriculum?:

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Extremely Important	13	(52)	11	(44)	17	(68)	13	(52)
Fairly Important	12	(48)	14	(56)	8	(32)	12	(48)
Fairly Unimportant	0	(0)	0	(0)	0	(0)	0	(0)
Extremely Unimportant	0	(0)	0	(0)	0	(0)	0	(0)
Total	25		25		25		25	

Table 22: How imperative would you consider it to be for a pregnant woman to be screened for a genetic disorder?

	Pre-test				Post-test			
Item	S.A.		Canada		S.A.		Canada	
	No	%	No	%	No	%	No	%
Extremely Important	23	(92)	23	(92)	15	(60)	22	(88)
Fairly Important	2	(8)	1	(4)	2	(8)	3	(12)
Fairly Unimportant	0	(0)	0	(0)	0	(0)	0	(0)
Extremely Unimportant	0	(0)	1	(4)	0	(0)	0	(0)
Total	25		25		17*	(68)	25	

F. TABLE OF RAW DATA

Table of Raw Data

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[2,]	0	0	10	10	11	20	3	-0.5
[3,]	0	0	9	8	16	21	4	1.5
[4,]	0	0	8	11	20	20	1	-2.5
[5,]	0	0	10	10	17	23	3	-0.5
[6,]	0	0	11	12	20	23	3	-1.0
[7,]	0	0	10	11	22	23	4	1.0
[8,]	0	0	8	12	21	21	2	-1.0
[9,]	0	0	11	12	22	22	3	-1.0
[10,]	0	0	8	12	19	19	4	2.0
[11,]	0	0	11	10	19	20	4	0.5
[12,]	0	0	9	10	24	23	2	-1.5
[13,]	0	0	10	10	23	24	4	1.0
[14,]	0	0	8	9	19	19	2	-1.0
[15,]	0	0	12	12	21	21	4	0.0
[16,]	0	0	10	8	19	20	3	-0.5
[17,]	0	0	8	10	22	22	4	2.0
[18,]	0	0	8	8	22	20	3	0.5
[19,]	0	0	10	11	19	19	3	-0.5
[20,]	0	1	9	11	21	21	1	-3.0
[21,]	0	1	10	10	23	23	3	-0.5
[22,]	0	1	10	10	23	23	4	1.0
[23,]	0	1	11	11	23	23	4	0.5
[24,]	0	1	11	10	21	22	4	0.5
[25,]	0	1	10	11	20	21	3	-0.5
[26,]	1	0	9	10	21	22	4	1.5
[27,]	1	0	8	12	15	19	2	-1.0
[28,]	1	0	5	10	23	23	3	2.0
[29,]	1	0	6	11	16	22	2	0.0
[30,]	1	0	8	11	18	19	2	-1.0
[31,]	1	0	7	11	15	15	3	1.0
[32,]	1	0	6	11	20	22	4	3.0
[33,]	1	0	8	12	23	23	4	2.0
[34,]	1	0	8	11	16	16	2	-1.0
[35,]	1	0	8	12	18	21	4	2.0
[36,]	1	0	9	10	21	23	4	1.5
[37,]	1	0	11	11	21	18	4	0.5
[38,]	1	0	10	10	19	21	4	1.0
[39,]	1	0	10	8	20	19	3	-0.5
[40,]	1	0	8	10	18	20	3	0.5
[41,]	1	1	10	8	22	18	4	1.0
[42,]	1	1	9	12	23	22	3	0.0
[43,]	1	1	9	11	23	23	4	1.5
[44,]	1	1	11	12	23	23	4	0.5
[45,]	1	1	11	11	19	22	4	0.5
[46,]	1	1	9	11	22	23	3	0.0
[47,]	1	1	8	9	18	23	4	2.0
[48,]	1	1	10	11	23	23	4	1.0
[49,]	1	1	7	9	21	21	3	1.0
[50,]	1	1	7	12	21	23	3	1.0

G. KEY TO TABLE OF RAW DATA

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[1] 0 = Canadian
1 = South African

[2] 0 = Female
1 = Male

[3] Pre-talk test score (knowledge)

[4] Post-talk test score (knowledge)

[5] Pre-talk test score (attitudes)

[6] Post-talk test score (attitudes)

[7] Pre-talk test score (Tay Sachs knowledge)

[8] Incremental knowledge of Tay Sachs

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