

THE UNIVERSITY OF CALGARY

PERCEPTIONS OF HEALTH STATUS AND HEALTH
BEHAVIOURS OF ADULTS WITH
CONGENITAL HEART DISEASE

BY

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A THESIS

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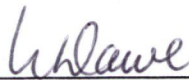
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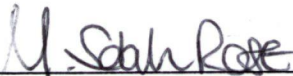
The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Perceptions of Health Status and Health Behaviours of Adults with Congenital Heart Disease" submitted by Barbara S. Sibbald in partial fulfilment of the requirements for the degree of Master of Science.



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ABSTRACT

Congenital heart defects (CHDs) are relatively common congenital disorders however little is known about adults with such disorders. This study described the health perceptions and behaviours of adults with CHDs who attended a specialised outpatient clinic at a large teaching hospital. A 71% response rate was achieved (n = 161) to a mailed, self-administered questionnaire which was comprised of the SF-36 Health Survey, the Nottingham Health Profile, and selected items from Canada's Health Promotion Survey: 1990. Reported health behaviours were compared to the general Alberta population and health perceptions were compared to standardised population norms. Overall, health perceptions and health behaviours of adults with CHDs did not differ substantially from the general population. Health perceptions and behaviours were influenced somewhat by disease severity. Understanding health perceptions and behaviours of a select group of individuals can assist providers of health services in planning health care delivery for that group.

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DEDICATION

This thesis is dedicated to my husband Don, and my son Christopher without whose patience and understanding this project would not have been completed.

TABLE OF CONTENTS

	Page
Approval Page.....	ii
Abstract.....	iii
Acknowledgements.....	iv
Dedication.....	v
Table of Contents.....	vi
List of Tables.....	ix
List of Figures.....	x
CHAPTER ONE: THE RESEARCH PROBLEM	
I. Introduction and Rationale.....	1
II. Conceptual Framework.....	3
III. Literature Review.....	6
IV. Research Questions.....	12
V. Rationale for the Final Study Design.....	12
CHAPTER TWO: METHODS	
I. Study Design.....	17
II. Definition of Congenital Heart Disease.....	17
III. Subject Selection.....	18
IV. Measurement.....	19
V. Study Procedures.....	23
VI. Ethics.....	24
VII. Analysis Approach.....	25
VIII. Data Management.....	29

CHAPTER THREE: RESULTS

I. Response Rate.....	30
II. Description of the Sample.....	31
A. Non-respondents.....	31
B. Study Respondents.....	33
III. Health Perceptions.....	40
A. General Perceptions of Health.....	40
B. SF-36 Health Survey.....	42
C. Nottingham Health Profile.....	68
IV. Health Behaviours.....	75

CHAPTER FOUR: DISCUSSION

I. Socio-demographic Characteristics.....	89
II. Health Perceptions and Behaviours.....	92
A. Perceptions.....	92
B. Health Behaviours.....	96
C. Summary of Health Perceptions and Behaviours.....	100
III. Measurement Tools.....	102
IV. Strengths and Limitations of the Study.....	105
V. Suggestions for Future Research.....	107
VI. Implications for Care.....	109
VII. Conclusions.....	110
References.....	111
Appendix A.....	121
Appendix B.....	122
Appendix C.....	123
Appendix D.....	125
Appendix E.....	129

Appendix F.....	130
Appendix G.....	131
Appendix H.....	132
Appendix I.....	133
Appendix J.....	134

LIST OF TABLES

Table	Page
1.1 Number of Cases of CHD Ascertained Through Review of Charts: Years of Birth 1966 - 1969.....	16
3.1 Severity of Disorder Among Non-respondents.....	33
3.2 Severity of Disorder of Respondents.....	35
3.3 Income Adequacy.....	37
3.4 Family Life Cycle by Gender.....	39
3.5 Self Rated Health.....	41
3.6 Nottingham Health Profile and Gender.....	70
3.7 Nottingham Health Profile and NYHA - Males.....	71
3.8 Nottingham Health Profile and NYHA - Females.....	71
3.9 Nottingham Health Profile and FLC - Males.....	73
3.10 Nottingham Health Profile and FLC - Females.....	74
3.11 Cigarette Smoking by Gender and Age.....	76
3.12 Prevalence of Alcohol Use by Gender and Age.....	78
3.13 Frequency of Drinking by Gender.....	79
3.14 Frequency of Exercise by Gender.....	82

LIST OF FIGURES

Figure		Page
1	Age Distribution of Non-respondents	32
2	Age Distribution of Respondents.....	34
3	Physical Functioning Score by Gender.....	43
4	Physical Functioning Score by NYHA Category.....	45
5	Physical Functioning Score by FLC Category.....	46
6	Role-Physical Score by Gender.....	47
7	Role-Physical Score by NYHA Category.....	48
8	Role-Physical Score by FLC Category.....	49
9	Bodily Pain Score by Gender.....	50
10	Bodily Pain Score by NYHA Category.....	51
11	Bodily Pain Score by FLC Category.....	52
12	General Health Score by Gender.....	53
13	General Health Score by NYHA Category.....	54
14	General Health Score by FLC Category.....	55
15	Vitality Score by Gender.....	56
16	Vitality Score by NYHA Category.....	57
17	Vitality Score by FLC Category.....	58
18	Social Functioning Score by Gender.....	59
19	Social Functioning Score by NYHA Category.....	60
20	Social Functioning Score by FLC Category.....	61

21	Role-Emotional Score by Gender.....	62
22	Role-Emotional Score by NYHA Category.....	63
23	Role-Emotional Score by FLC Category.....	64
24	Mental Health Score by Gender.....	65
25	Mental Health Score by NYHA Category.....	66
26	Mental Health Score by FLC Category.....	66

CHAPTER 1

THE RESEARCH PROBLEM

I. Introduction and Rationale

Congenital heart disease (CHD) is a broad classification of diseases including ventricular septal defect (VSD), atrial septal defect (ASD), tetralogy of Fallot and coarctation of the aorta¹. As is inherent in the name, these conditions are present from birth.

Little is known about the population affected by these disorders. Who are they? How do they cope? How do they adapt to their condition both psychologically and socially? How do they manage their lives on a daily basis? How do they view their health? In what types of health behaviours do they engage? These questions have not been adequately addressed or answered by past research in the area of adult congenital heart disease.

Among all congenital anomalies, CHDs are relatively common disorders. The most often quoted estimate of the birth prevalence in industrialised societies is approximately 8 per 1000 total births (Jones & Blackwood, 1992) although rates as low as 2.8 per 1000 total births have also been mentioned in the literature (Pradat, 1992). The livebirth rate has also been cited as ranging from 3 to 10 per thousand (Grabitz, Joffres & Collins-Nakai, 1988; Hoffman, 1990). However, Grabitz et al. (1988) quote the livebirth

¹ See Appendix A for a list of disorders included in the category.

rate in northern and central Alberta between the years 1981 and 1984 as 5.54 per 1000 live births when non invasive diagnostic techniques are employed (clinical examination and echocardiography with or without invasive techniques such as cardiac catheterisation, surgery or autopsy). When invasive techniques alone are employed for purposes of case definition, the rate drops to 3.36 per 1000 live births. However, these authors also contend that the rates seem to be rising in Alberta. The rates reported by Grabitz et al. (1988) will be adopted for the purpose of this study since it is the best data available for Alberta with respect to live births although one might have to allow for possible differences between the northern and southern regions of the province.

With current total births in Calgary at approximately 12,000 per year (Lowry & Anderson-Redick, 1992) we could realistically expect 67 live births per year of infants with CHD in the city alone using the 5.54/1000 livebirth rate. This number could be as high as 120 births per year if the entire region of southern Alberta is considered. (Lowry & Anderson-Redick, 1992).

Given that 85% of newborns with CHDs are expected to survive into adulthood (Garson, 1992), adults with CHDs will constitute an increasingly greater proportion of the patients among cardiac and general medical caseloads since many of these individuals will require ongoing care and monitoring by health care professionals. It is not difficult to imagine that the proportion could increase further as medical and surgical treatment techniques improve, as perinatal care improves, and as morbidity and mortality from other causes of illness amenable to intervention or prevention decrease.

Due to the anticipated increase in the numbers of adults with CHD who will require health care services, and in response to questions posed by the clinicians practising in the field, the purpose of the study is to describe such individuals with respect to their perceptions of their health status and their health behaviours. The perceptions and behaviours of adults with CHDs are compared with the general

population. Comparisons are also made within the group of adults with CHDs according to differing levels of disease severity.

Given the nature of CHDs, it might be expected that adults with these disorders would be vigilant regarding their health due to the ongoing awareness of the presence of a heart defect. Understanding perceptions of health and health related behaviours can be of value for enhancing communication between health care providers and patients, for targeting health promotion strategies to this unique group of individuals, and for formulating hypotheses about the determinants of health behaviours in future analytic studies.

II. Conceptual Framework

Health, according to the document Achieving Health for All (Epp, 1986), is defined as a resource "which gives people the ability to manage and even change their surroundings . . . [and as] a state which individuals and communities alike strive to achieve, maintain or regain, and not something that comes about merely as a result of treating and curing illnesses and injuries" (p. 2). By extension therefore, health behaviours could be considered indicators of individuals' perceptions towards health, health promotion and illness prevention.

Many authors refer to Kasl and Cobbs' classic definition that states preventive health behaviour is "any activity undertaken by an individual who *believes himself to be healthy*, for the purpose of preventing or detecting illness in an asymptomatic state" (Glanz, Lewis & Rimer, 1990, p. 10). However, because this study deals with individuals who are not necessarily in good health and may or may not believe themselves to be healthy, Kasl and Cobbs' definition seems somewhat inappropriate in this context. Therefore, in this study the definition proposed by Gochman (1988) has been adopted. He states that health behaviours are "those personal attributes such as beliefs,

expectations, motives, values, perceptions, and other cognitive elements; personality characteristics, including affective and emotional states and traits; and overt behaviour patterns, actions and habits that relate to health maintenance, to health restoration, and to health improvement "(p. 3).

For the purpose of this study, the Health Belief Model (HBM) is used to guide the examination of perceptions of health status and health behaviours (see Appendix B). The model states that individuals will undertake preventive health behaviours when they perceive they are susceptible to adverse health outcomes, when these outcomes are perceived to be serious, and when the perceived benefits to preventive actions outweigh the barriers to undertaking such actions . The model further specifies that perceptions are modified by psycho social and demographic variables and by the presence of appropriate cues from external sources to spur action (Janz & Becker, 1984; Kirscht, 1988; Rosenstock, 1990).

The Health Belief model is not used to predict behaviour in this study. Nor is it intended that the model be proved or disproved. Rather, it is used to provide a framework to assist in formulating the research questions, and to guide the analysis and interpretation of the data. The model may ultimately be of use for assisting health care providers to better understand the health behaviours undertaken by a group of individuals with congenital heart defects.

In this study, the focus is on the "Individual Perception" component of the model, particularly as it relates to the subjective assessment of health status. The focus is also on "Modifying Factors" which, according to the model, influence individual perceptions and behaviours. Health behaviour is represented in the model by the component "Preventive Health Action". This aspect is taken to mean those behaviours undertaken by the individuals to protect their health or to prevent illness.

It is understood that many conceptual models which attempt to explain health behaviours are flawed to some degree in their predictive abilities. Health behaviours, it is generally agreed, result from a multitude of interrelated factors. The HBM itself specifies the interdependence of many dimensions or variables. Health perceptions are of particular interest in this study thus the HBM is adopted because it, more than other models, addresses individual perceptions as they affect health behaviours.

The family life cycle might also influence individual perceptions of health and ultimately health behaviours. The concept fits rather neatly into the psycho-social sub-component of the HBM. Although it is not addressed specifically in the Model, it is possible to place this construct in the category of "Modifying Factors" (see Appendix B).

It is possible that the perceptions of health status and, in particular, health behaviours might vary depending upon the individual's phase in the life cycle of the family. According to Carter and McGoldrick (1989), there are six such stages in the family life cycle: leaving home (the single young adult); the joining of families through marriage (the new couple); families with young children; families with adolescents; launching children and moving on; and families in later life. According to the authors, each phase has its own specific developmental tasks and psycho-social implications. Unlike developmental stages of the individual which are organised according to successive ages such as Havighurst's developmental stages of infancy and early childhood, middle childhood, adolescence, early adulthood, middle age, and later maturity (Havighurst, 1972), the family life cycle focuses on family systems and the relationships and responsibilities which accompany the various phases. The family life cycle is also not as dependent on fixed ages within which developmental tasks should be accomplished, as is evident in the individual life stage models. Because the theory of the family life cycle emphasises interpersonal relationships, it would be reasonable to expect that commitments to others and responsibilities for oneself and others might affect or

influence health behaviours. This is particularly evident if one considers the single adult (emotionally committed and responsible for him- or herself), the married adult (emotionally committed and responsible for one other) or the adult who has made the decision to have children (emotionally committed to and responsible for more than one other individual).

In summary, the Health Belief Model and family life cycle are two frameworks used to understand adults with CHD. The HBM focuses on health perceptions and health behaviours, whereas the family life cycle stresses the responsibilities and commitments specific to each developmental phase of the family, and the social rather than individual perspective of development.

III. Literature Review

A large body of published literature on CHDs relates to the frequency of occurrence of CHDs in industrialised countries and has been estimated as ranging from approximately 3 per 1000 to 10 per 1000 live births (Ferencz et al., 1985; Grabitz et al., 1988; Hoffman, 1990; Mehta & Chidambaram, 1992; Mitchell, Korones, & Berendes, 1971; Wilson, Correa-Villaseñor, Loffredo, & Ferencz, 1993). Risk factors for developing the disorders such as a positive family history, and causal links or associations between certain factors and the development of a CHD have also been explored but no consistent causal factors have been identified (Bracken, 1990; Goldberg, Lebowitz, Graver, & Hicks, 1990; Rosenthal, Wilson, Permutt, Boughman, & Ferencz et al., 1991; Thompson, McInnes, & Willard, 1991; Tikkanen & Heinonen, 1991; Tikkanen & Heinonen, 1992). These studies have not included descriptions of affected adults' functioning and behaviour.

A second fairly large body of information relates to the outcomes of various medical and surgical treatments for CHDs. For example, a long term follow-up study of

individuals with coarctation repairs found that 72% were alive 30 years post-operatively (Cohen, Valentin, Steele, Driscoll, & McGoon, 1989). The study also found that surgery performed in early childhood was the best predictor of long-term survival. The study examined only physical and physiological outcomes. Health behaviours and health perceptions of patients who had undergone treatment procedures or who lived with heart defects were not addressed.

A. Paediatrics

Some of the paediatric literature on CHDs relates to children and adolescents with respect to their emotional status (anxiety and depression), coping, and family dynamics (DeMaso, Beardslee, Silbert, & Fyler, 1990; DeMaso et al., 1991; Linde, 1982; Linde, Rasof, Dunn, & Rabb, 1966; Linde, Adams, & Rozansky 1971; Myers-Vando, Steward, Folkins, & Hines, 1978; Spurkland, Bjørnstad, Lindberg, & Seem, 1993). These studies found that parental anxiety, expressed as overprotectiveness, led to anxiety and coping difficulties among the children with CHDs. Of interest, the degree of anxiety and degree of coping difficulty experienced by the children did not correlate highly with the severity of the disorder. These studies did not provide information about the health behaviours of the children or adolescents, or their perceptions of their own health status. These studies focused on psychological or psychiatric variables rather than on behavioural variables.

B. Chronic Diseases

The chronic diseases literature does not adequately reflect the uniqueness of a CHD population. Most of the literature on chronic disease deals with coping strategies related to adult onset disorders such as hypertension, diabetes and arthritis, that lead to the loss or perceived loss of some function or ability that individuals once had. Pollock (1986) for example, studied groups of individuals with the above conditions attempting to

identify factors that promote adaptation to chronic illness. In particular, the study attempted to test the hypothesis that "hardiness", defined as a personality structure predisposing to adaptive behaviour, explains why some individuals with chronic disease cope better with their illness than others. Although the study acknowledges that more research is needed in the field, "hardiness" did seem to play a role in adaptation to chronic illness. Bombardier, D'Amico, and Jordan (1990), also conducted a study to explore the relationship of appraisal and coping to the adjustment to chronic illness. The subjects were adults who had a variety of chronic disorders such as low back pain and headache, cardiovascular disease, gastroenterologic problems and a variety of psychiatric disorders. Again, the disorders were all adult onset. The authors concluded that emotion-focused coping (self blame, wishful thinking and avoidance) was correlated with poor psycho-social adjustment and depression.

All of the conditions mentioned above are different from congenital heart disease. Adults with CHDs are functionally disadvantaged at birth and thus have not undergone the same experiences as those who develop disease later in life, such as the loss or perceived loss, of some function or ability. If any loss has been felt by adults with CHD it may well be the loss of what might have been had the heart defect not been present. The very nature of the group of congenital heart disorders is that a defect has been present since birth. The affected individuals, therefore, know no other way of living.

C. Adults

The small amount of research that has been undertaken on adults with CHD focuses on the psycho-social aspects of living with these disorders with findings similar to the paediatric studies described earlier.

An early investigation by Garson, Williams and Reckless (1974), studied a group of young adults (mean age of 19 ± 0.4 years) with Tetralogy of Fallot in order to assess

the psychological implications of having a CHD. The adults were all patients who had been seen as children at the Duke Medical Centre. The authors concluded that these young people were significantly more neurotic than expected by chance, and that they were "self-indulgent, dependent, overprotected, less well informed, lacking ambition, and operated more on the basis of feelings than thought" (p. 429). The severity of the psychological symptoms did not correlate highly with the severity of the disorder which was similar to the findings in the paediatric studies (DeMaso, et al., 1991; Myers-Vando, et al., 1979). Garson's study did not include descriptions of the health perceptions or health behaviours of this group of patients. One must interpret the results of the study with caution as it focused on a single disorder in a selected group of patients therefore the results cannot be generalised to whole adult populations with CHD.

Manning (1983) and Perloff (1991) acknowledge that there might be psychosocial adjustment problems among adults with CHDs including anxiety, poor self-esteem and neuroses. However, from their experience and clinical judgement, most of these individuals cope quite well in their daily lives. It is unclear whether these observations are research based rather than simply anecdotal reports. As with Garson's study, one must interpret the statements with caution as Perloff in particular studied individuals seen at the UCLA School of Medicine. This sample might not be representative of the total population of adults with CHDs. Again, health behaviours were not addressed.

Brandhagen, Feldt and Williams published a study in 1991 which examined the long term psychological implications of congenital heart disease among patients who were referred to the Mayo Clinic. It was found that these patients showed evidence of psychological stress beyond levels which were expected based on estimates from normative data. Anxiety and depression were significantly higher in the clinic attendees and these symptoms seemed unrelated to the severity of the disorder. The authors pointed out that while their study results cannot be translated into a typical personality

profile for a particular patient in the group, the results do give a general impression of the group as a whole. The extent to which the findings can be used even as a general description of CHD individuals is limited due to the selected nature of the sample used. Not unlike the Duke Medical Centre and UCLA, the Mayo Clinic is a large referral centre in the United States, and many of the individuals included in the study may be more ill or vary in some systematic way from other CHD patients. Again, the study did not include information about perceived health status or health behaviours.

Kokkonen and Paavilainen (1992) explored the issue of social adaptation of young adults with CHDs. The study included all patients with confirmed CHD born between the years 1963 and 1968. These individuals were at least 19 years of age at the time of the study and had been seen at the Oulu University Central Hospital in Finland. A randomly selected, age matched control group drawn from the general population was used. The authors concluded that the CHD individuals were psycho-socially immature when compared to the age matched controls, in that they had developed a more dependent life-style, "living with their parents without a marital or quasi-marital relationship" (p. 23). The study also concluded that a cyanotic heart defect was one of the factors predisposing to poor success at school and a dependent lifestyle. As with the previous studies, health behaviours and perceptions of health status were not examined. Also, although a control group was selected, the subjects were still drawn from an institution and therefore the results may not be generaliseable to the general population of young adults with CHDs.

The most recent study carried out by Gersony et al. (1993) assessed the quality of life of adult patients with aortic stenosis (AS), pulmonary stenosis (PS) and ventricular septal defects (VSDs). This was a sub-study of the Second Natural History Study of Congenital Heart Defects, the first having been reported in 1979. The first study was a large collaborative investigation which studied 2,401 patients with the foregoing

diagnoses. The second study was a follow-up of the same cohort approximately 15 years later. A number of parameters were examined including physical responses to treatment. Survival, recurrence risks in offspring, and quality of life were also assessed. Quality of life issues included employment status, education level, insurability, marital status, and family history. A single question was asked of the respondents with respect to their perceived health status: "How would you describe your present health?" which was to be rated excellent, good, fair or poor. The majority of respondents (91.9%) described themselves as having excellent or good health. Furthermore, the CHD group was not different from the general U.S. population with respect to perceived health status. However, an extensive examination of perceived health status was not undertaken. A single question does not appear sufficient to appreciate the perceptions of the subjects studied. There was also no investigation into the health behaviours of this group. The authors concluded that patients diagnosed with the disorders included in the study did not differ from the general U.S. population in terms of the quality of life. One might dispute that the variables used in the study to measure quality of life were inadequate. They seem more appropriately categorised as socio-demographic variables which, it can be argued, do play a role in quality of life. However, this is perhaps too narrow a perspective. Inclusion of individuals' perceptions of their health and their lives within psychological and social domains likely would be better measures of the complex issue of quality of life.

D. Summary

As can be seen from the literature review, the health behaviours of individuals with CHDs have not been described adequately, nor has any systematic exploration of their perceptions of their own health status and behaviours been undertaken. Of the few published studies, most focus on psycho-social adaptation with findings that some adults

with CHD are less well adapted, more immature and more dependent than unaffected peers. Coping has been assessed with equivocal results. Socio-demographic aspects of the population have been described. Although the published information is valuable in gaining some insight into the psychological and sociological nature of these individuals, an understanding of the health behaviours and self perceptions of health might provide some indication of the extent to which individuals with CHDs perceive their impairment to be a disability or handicap. In turn, this understanding might assist health care providers to plan health and education strategies specific to the needs of this unique group of individuals.

VI. Research Questions

Based upon the literature review and the conceptual framework, the following research questions were developed.

1. Do perceptions of health status and health behaviours of adults with CHD differ from the general population?
2. Do perceptions of health status and health behaviours differ between individuals according to disease severity?
3. Do perceptions of health status and health behaviours differ between individuals according to family life cycle stage?

V. Rationale for the Final Study Design

In preparing to conduct the research study, an attempt was made to determine the feasibility of a population based study. An assessment was done with the understanding that one paediatric cardiologist saw most children born with CHDs in Calgary and perhaps southern Alberta in the late 1960's and 1970's. It is also known that cardiac catheterisation was the diagnostic standard of practice at that time (before the advent of

the widespread use of the echocardiogram), and that these procedures were performed at the Holy Cross Hospital in Calgary. The microfilmed records at the Holy Cross Hospital of all individuals who were born in the years 1966 to 1971 and diagnosed with a CHD were reviewed. The Adult Congenital Heart Disease Clinic at the Calgary General Hospital was also approached seeking support for the study, as the physicians at that institution took over the care of many of the patients of the now retired paediatric cardiologist. The population of interest was those individuals born in the above stated years who currently constitute a group of young adults with CHDs. The year 1966 was determined to be the starting point as this was the approximate date that the paediatric cardiologist commenced practising in Calgary.

Because echocardiography was not in use at the time, confirmed diagnoses of CHD were made by invasive techniques such as cardiac catheterisation, surgery and autopsy. Using the prevalence rate of 3.36 per 1000 live births based on invasive diagnostic methods quoted earlier by Grabitz et al. (1988), it was expected that the number of affected liveborn individuals would be approximately 45 per year. This estimate is based on the estimated livebirth rate in southern Alberta in those years (Statistics Canada, 1976 & 1977). The record search at the Holy Cross Hospital for individuals born in the years 1966 through 1969 with a diagnosis of CHD (confirmed by cardiac catheterisation, surgery or autopsy) yielded far fewer cases than the expected numbers. The review of patient records yielded a range of 11 to 20 per year over the four year interval. If one adds in the numbers diagnosed clinically or those cases that were questioned but not confirmed, then the numbers increase slightly (range 13 - 27 per year).

There are a number of reasons for this apparent underascertainment including:

- a) not all cases were seen at the Holy Cross Hospital possibly due to:
 - i) the opening of another institution in Calgary which provided similar paediatric services (Foothills Provincial Hospital);

- ii) children being seen at hospitals elsewhere;
- b) not all cases had cardiac catheterisations i.e. less severe defects;
- c) incorrect diagnosis ;
- d) a missed diagnosis of CHD, particularly the milder forms;
- e) no autopsy in cases where death occurred before a diagnosis could be made.

This may not be an exhaustive list, however the reasons seem to be the most likely explanations to account for the discrepancy between the observed and expected number of infants with CHDs.

The foregoing possible errors in ascertainment could be a source of research bias particularly in the form of misclassification and selection biases. The bias would be in favour of the more severe defects and therefore the more ill patients. There is no way of knowing how representative this group of individuals is of the total population of individuals born with CHDs in the years 1966 - 1969. A number of other sources of data would need to be employed in order to achieve more complete ascertainment. This could conceivably entail contacting all physicians (family practitioners, cardiologists and internal medicine specialists) and hospitals in southern Alberta (and perhaps farther afield). The accomplishment of such a task with limited resources and time was considered unfeasible within the scope of this study.

Given the preceding discussion, the study focused on a clinic population served by an ambulatory clinic at the Calgary General Hospital. One must acknowledge that when conducting an institutionally based study, similar limitations will be imposed as mentioned above namely that the results may not be representative of the population of adults with CHDs. In fact the study may be skewed to the more severe spectrum of disease since those individuals may be more likely to seek medical care at a large teaching hospital. However if one recognises the limitations and is careful about making

generalisations, such a study can still provide useful information about this specific group of individuals and perhaps generate hypotheses for future analytic studies.

A. Description of Chart Reviews

Although a population based study was not undertaken, a brief description of the individuals ascertained through the chart reviews is provided in Table 1.1. Tables for the individual years 1966 through 1969 can be found in Appendix C.

As can be seen from Table 1.1, the number of cases actually identified fell far below the expected numbers for the respective years. The years 1970 and 1971 were not completed as it was obvious that full ascertainment was not going to be possible from the single data source. For a complete description of the types of CHD identified from the chart reviews and the syndromes and congenital anomalies associated with the CHDs refer to Appendix D.

Table 1.1
Number of Cases of CHD Ascertained Through
Review of Charts: Years of Birth 1966 - 1969

Diagnosis	1966 n	1967 n	1968 n	1969 n
Confirmed ^a	10	9	16	9
Clinical ^b	1	0	2	2
Possible ^c	2	1	5	0
Other anomalies ^d	2	2	4	9
Survival ^e (alive)	9	6	21	16
Survival ^e (dead)	6	6	6	4
Total Observed ^f	15	12	27	20
Total Expected ^g (Estimated)	45	44	45	45

^aNumber of cases confirmed by cardiac catheterisation, surgery or post mortem.

^bNumber of cases diagnosed by clinical evaluation alone and not corroborated by any diagnostic test. ^cCases where CHD was mentioned in the differential diagnosis with no

further information to substantiate or refute the diagnosis. ^dNumber of cases of CHD associated with other anomalies or syndromes. ^eSurvival status indicates whether the

individual was alive or dead at the time of the last entry on the medical record. ^fNumber of cases ascertained through chart reviews. ^gExpected number of cases based on the estimated prevalence of CHD and the estimated number of births for southern Alberta in the years 1966 through 1969.

CHAPTER 2

METHODS

I. Study Design

The study design consisted of a survey of adults with congenital heart diseases. The survey was completed using a mailed, self administered questionnaire with one follow up. The questionnaire was designed to elicit information regarding the health perceptions and health behaviours of individuals who have been diagnosed with a congenital heart defect.

II. Definition of Congenital Heart Disease

Congenital heart disease (CHD) was defined for the purpose of this study as a "gross structural abnormality of the heart or intrathoracic great vessels that is actually or potentially of functional significance" (Mitchell et al., 1971, p.324) and which is present from birth. Patent ductus arteriosus (PDA), which is often viewed as a normal physiological variant in the newborn and which, for the most part, closes spontaneously was included in the definition only if it persisted into adult life and was compromising an individuals' cardiac or respiratory status. Functional abnormalities such as congenital heart block were also included.

III. Subject Selection

The sampling frame consisted of 336 individuals registered with the Adult Congenital Heart Disease Clinic at the Calgary General Hospital for the period September, 1991 (establishment of the clinic) to April, 1994. The clinic is a hospital based ambulatory care clinic at a tertiary referral centre with the target population adults from southern Alberta who have been diagnosed with a CHD. Two cardiologists are associated with the clinic. One of the cardiologists who is the clinic director was consulted at the outset regarding the feasibility of the study and to seek permission to access the clinic records.

All patients diagnosed with a CHD and who had been seen at the Clinic at least once were eligible for selection. The final list of subjects was compiled by applying the following exclusion criteria:

- i) Individuals who did not have a confirmed diagnosis of a CHD by echocardiogram, cardiac catheterisation, or surgery.
- ii) Mental retardation (e.g. Down Syndrome).
- iii) Congenital anomalies other than heart defects.
- iv) Other chronic disorders that might confound the interpretation of health perceptions and behaviours of adults with CHDs.
- v) Age less than 20. Age 20 was chosen as it is lower limit of the age category 20-24 in Canada's Health Promotion Survey: 1990. (study results are compared to the results of the Survey).

The exclusion criteria having been applied, 174 individuals with confirmed CHD were deemed eligible to participate in the study. Of the initial 336 individuals identified, 162 were excluded, approximately half of whom were excluded for non health related reasons, the most common reasons being no congenital heart defect or age less than 20. Consultation was sought from the clinic director when classification as to eligibility

became problematic. See Appendix E for a detailed summary of how the final number of eligible subjects was established.

IV. Measurement

The study questionnaire consisted of three standardised measurement tools: Canada's Health Promotion Survey: 1990, The Nottingham Health Profile, and the SF-36 Health Survey, all of which are described below. For all of the tools, subjects were required to check the appropriate response category for all but seven questions which required the respondents to fill in a blank with a number or short phrase.

A. Health Behaviours

Health behaviours were assessed using selected questionnaire items adapted from Canada's Health Promotion Survey : 1990 (Stephens & Fowler Graham, 1993). The survey results provide recent age-specific data against which to compare the results obtained from the adult CHD sample in the current study. Categories used to elicit information about health behaviours included exercise, use of tobacco, alcohol and drugs, dental health, and blood pressure. Five questions were added to the standard questionnaire, one in each of the sections labelled physical health, exercise, drugs, workplace, and dental health. The added questions relate specifically to adults with CHDs.

With some modifications and additions, the 1985 Health Promotion Survey had been adapted for use in the 1990 Survey. The questionnaire was focus tested and pilot tested extensively before a final version was approved for use in the 1990 Survey. Dawn Fowler Graham, an editor of the technical report of the Survey, stated that although there was no official or systematic evaluation of the reliability and validity of the instrument, most of the questions have been used in many other surveys of this nature (personal

communication, February, 1994). Despite the unavailability of reliability and validity assessments, and because of the wide spread use of the survey items in many similar surveys, it was assumed for the purpose of this study that the questionnaire would in fact provide valid information about the study sample. A factor also considered in using the Survey was the availability of Alberta-specific data for some questionnaire items.

B) Health Perceptions

1. Nottingham Health Profile

Health perceptions were measured using the Nottingham Health Profile (NHP). The tool, developed in the United Kingdom, is a subjective measure of health status intended for use in community surveys and surveys of various patient populations. The instrument has been used extensively in a variety of settings (Jenkinson, Fitzpatrick, & Argyle, 1988; Hunt et al., 1980) including a recent quality of life study of adults with CHDs undertaken at The Toronto Hospital. The NHP is currently being used in an ongoing Canadian multicentre survey of Quality of Life among individuals who have had a defibrillator implanted.

The instrument measures an individual's perceptions of his/her health status and includes six domains: physical mobility, pain, sleep, social isolation, emotional reactions, and energy level. The NHP can be scored using a weighted scoring system or by a simple tally of affirmative responses. The latter approach is used most often (McDowell & Newell, 1987) and it is the approach used in this study.

Construct validity has been previously tested by comparing four groups of elderly people who differed in health status (Hunt, et al., 1980). The results suggest that the NHP discriminated well between the groups. Criterion validity was established on the premise that a decision to consult with a physician was indicative of a perceived health problem by a patient. A study was conducted in a large general practice setting to

compare the results of the NHP between those who consulted physicians with those who did not and it was found that the scores differed significantly between the two groups (Hunt, McKenna, McEwan, Williams, & Papp, 1981). Non-consulters were defined as those individuals who had not contacted their physician in the previous 6 months, whereas consulters were those who had 3 or more contacts with a physician in the same period. Both the consulters and non-consulters came from the same general practice. Face and content validity were addressed when the instrument was developed by using patients' statements about their experiences. The profile, therefore, is made understandable and relevant to the respondents (Hunt & McEwen, 1980). Reliability has been assessed by the test-retest method which indicates an acceptable degree of reliability (reliability coefficients ranging from .75 to .88) (Hunt, McEwan, & McKenna, 1985). Finally, the instrument measures only negative aspects of health, however in defense of the instrument, Hunt (1988) points out that reliable and valid measures of positive health status have yet to be developed.

2. SF-36 Health Survey

Perceptions of health status were also measured using the SF-36 Health Survey questionnaire, a short form of a longer instrument developed for use in the Medical Outcomes Study (MOS) during the mid 1980's in the United States (Ware & Sherbourne, 1992). The SF-36 is endorsed by the Medical Outcomes Trust, a non-profit organisation committed to developing and distributing high quality, standardised instruments to the health care community. The SF-36 is a brief, comprehensive standardised tool for measuring health status from the individual's point of view. Population based, age specific normative data is available to assist in the interpretation (Jenkinson, Coulter, & Wright, 1993). It is a relatively new tool, however most of the items have been adapted from instruments that have been used for many years (Ware & Sherbourne, 1992).

The instrument measures eight health concepts: physical functioning, role limitations due to physical problems, social functioning, bodily pain, general mental health, role limitations due to emotional problems, vitality, and general health perceptions. Scoring is accomplished by summing the responses as measured on a Likert scale. A higher score indicates a more positive perception of health status. The authors of the instrument contend that reasonable content validity exists as the items stem from concepts widely used in the literature when addressing perceptions of health status (Ware & Sherbourne, 1992).

McHorney, Ware, Rogers, Raczek, and Rachel (1992) tested for criterion validity by comparing the instrument with the long form of the MOS Health Status Scale, single item measures of health status and the Dartmouth COOP Charts which use a cartoon format to describe aspects of health. The SF-36 was found to compare well with the long form of the MOS Health Status Scale with an expected loss of precision in measurement because fewer questions or items were used to assess each concept. Precision was defined as "the usefulness of a measure in making clinical comparisons under the conditions of a given study" (McHorney, et al., 1992, p. MS257). It was acknowledged by the authors that the long form is cumbersome and time consuming and therefore not as well received by respondents. The SF-36 on the other hand was more precise than the single item measures or the poster charts, was well received and quickly completed by respondents. Although it may be less precise than the long form, the authors maintain it provides sufficient depth to assess subjective health status, particularly in community surveys or in busy physician practices.

Garratt, Ruta, Abdalla, Buckingham, and Russell (1993) assessed construct validity by factor analysis. Five relevant factors were identified: physical functioning; mental health and energy; social functioning, pain and role limitations attributable to physical problems; general health perception; and role limitations attributable to

emotional problems. No health scale covered more than one factor. They stated that "this precise correspondence between factors and scales is rare in factor analysis and thus particularly reassuring for the validity of the SF-36" (Garrett et al., 1993, p. 1442). Internal consistency has been reported with reliability coefficients ranging from .76 to .92 depending upon the concept being measured (Jenkinson et al., 1993; Garratt et al., 1993).

The authors of the tool acknowledge that further testing of the reliability and validity of the instrument would be beneficial especially since the tool is relatively new (McHorney et al., 1992). Nevertheless, the instrument's strengths are that it is standardised and normative age-specific population data is available for comparison.

V. Procedures

Each of the 174 individuals identified as being eligible to participate in the study was mailed a package which included the study questionnaire and a covering letter under the signature of the director of the Adult Congenital Heart Disease Clinic. The letter explained the nature and purpose of the study and emphasised that although a response would be valued and important, there was no obligation on the part of the subject to participate in the study. It also emphasised that anonymity would be maintained, so that no single individual would be identified in the study results. Included in the package was a stamped return envelope addressed to the the researcher at the Department of Community Health Sciences at the University of Calgary.

All questionnaires were coded by a number in order to determine who might need a follow-up contact. A second mailout consisting of the complete package was sent to non-respondents after approximately four weeks. Because the study sample is a relatively homogeneous group, a fairly high response rate was anticipated (Dillman, 1978). Although Dillman (1978) recommends three follow-up mailings, only a single follow-up was planned in this study to ensure that the subjects would not feel unduly harassed or

coerced. Restricting the follow-up to a single reminder may have adversely affected the response rate, but given the small clinic population from which the sample was drawn, and the potential for perceived coercion on the part of the subjects, the decision was made to deviate from Dillman's recommendation.

Non-response to the follow-up was taken as a subject's refusal to participate. A tear-off sheet on the back of the questionnaire was included so that those who were interested in the results of the survey could mail back the sheet under separate cover requesting a summary of the study results.

With their knowledge of the subjects, the two clinic cardiologists classified all of the eligible subjects according to the New York Heart Association (NYHA) functional classification scheme (Gersony et al., 1993). Refer to Appendix F for a description of the classification. The clinicians were blinded with respect to those who had or had not responded to the survey. Classification according to family life cycle was performed by the researcher once the questionnaires were returned. The classification was based on demographic information provided by the subjects.

VI. Ethics

Permission to gain access to the records of the clients of the Adult Congenital Heart Disease Clinic was obtained from the physicians under whose authority the clinic operates. Institutional approval was granted by the Calgary General Hospital Research and Development Committee.

All respondents were informed in writing of the purpose of the study and were assured that participation in the study was entirely voluntary. They were also assured of confidentiality of all information provided. The questionnaire did not identify subjects by name. One reminder letter was issued and non-response to the reminder was considered refusal to participate. Subjects were not contacted repeatedly for fear that this would be

construed as undue pressure. It was hoped that the subjects would take an interest in the study and respond to the questionnaire because of the possibility of the development of new or revised programme of care tailored to their needs. Thus it might have been perceived as a benefit to the respondents and to others in similar circumstances. Informed consent was assumed with the return of the questionnaire. The study results are reported in aggregate form so no single individual can be identified thereby protecting the anonymity of subjects. Ethical approval was granted by the Conjoint Medical Ethics Committee of the Faculty of Medicine, University of Calgary, before the study commenced.

VII. Analysis

The data were first analysed to obtain a description of the respondents with respect to age, gender, family status (based on the family life cycle) and severity of disorder (based on the NYHA functional classification). Tables and graphs are used to present and illustrate the data. The statistical software package SYSTAT was used for the analysis.

The analysis was guided by the research questions. The approach used was to first examine health perceptions, followed by an examination of health behaviours. For the convenience of the reader, the research questions are stated again:

Question 1: Do perceptions of health status and health behaviours of adults with CHD differ from the general population?

Question 2: Do perceptions of health status and health behaviours differ between individuals according to disease severity? The classification of severity is based on the NYHA functional classification of heart disease.

Question 3: Do perceptions of health status and health behaviours differ between individuals according to family life cycle stage?

A. Perceptions

1. SF-36 Health Survey

The SF-36 Health Survey was used to compare the perceptions of health status of the study sample against age and gender specific standardised norms based on the general US population. Canadian norms have since been published but were not available at the time of the study. Because of small numbers in the study sample, gender specific analyses of various age categories was not possible. Each subgroup would have been too small for meaningful interpretations. Males and females were examined separately as it is known from the epidemiological literature that gender often confounds the results of a study. There was also evidence from the norms provided by the SF-36 Health Survey that there were gender differences in the general population sample where females tended to score somewhat lower than the males.

Medians, quartiles and interquartile ranges were used in the analysis because the data were positively skewed. Box plots were used to graphically display the results.

Box plots enclose 50% of the data and extend to the lower and upper quartiles indicated by the "hinges" or the upper and lower limits of the box. The middle value of the ordered data set at which point 50% of the data lie above and 50% below, termed the median, is indicated by a straight line through the box. The quartiles represent the 25th and 75th percentiles of the data set. Skewness in the data is evident when the median lies close to one or other quartile. The "whiskers" or lines extending from each of the hinges terminate at the "inner fences" which indicate the values 1.5 times the interquartile range. The interquartile range, or the difference between the 75th and 25th percentile of the data, is an indicator of the dispersion of the data set. Values outside of the "inner fence" are

indicated by asterisks and values 3 times the interquartile range are indicated with circles. Both of these values are considered "outliers" or extreme values in the data. The box plots also indicate the 95% confidence limits of the median and are notched at the median. The boxes return to full width at the lower and upper confidence limits.

Confidence intervals can be interpreted within the repeated sampling paradigm where, if one were to sample a number of groups from an adult CHD population, 95 times out of 100 the median for each group would fall within the upper and lower confidence limits. If the confidence limits do not overlap between groups, one can be confident at the 95% level that the medians are different suggesting that the groups being compared are different.

As with the behaviours, the subjects were categorised according to the NYHA functional classification and by FLC and similar comparisons were made to determine whether differences existed between the groups.

Because multiple comparisons were used, and since p-values have not been adjusted, one must be aware of the increasing likelihood of finding significant results purely by chance. Also, it must be noted that the sample size is small therefore the results must be interpreted with caution.

2. Nottingham Health Profile

The affirmative responses to the Nottingham Health Profile were tabulated with a higher score indicating a perception of poorer health status. Because a weighted scoring system was not used, it was decided that statistical analyses could not be interpreted with any degree of certainty. Therefore, a descriptive approach to the analysis was undertaken and no statistical tests were done. Absolute counts are reported and subgroups explored.

B. Behaviours

Behaviours related to exercise, use of tobacco, drugs and alcohol, blood pressure monitoring and dental health were first described by gender and age (when sample size permitted) and were compared with the available age and gender specific Alberta data from Canada's Health Promotion Survey: 1990. Again, for reasons stated earlier, genders were examined separately. It was also evident that the results of Canada's Health Promotion Survey: 1990 suggested that males and females tended to differ with respect to their health behaviours. The results are reported as percentages with 95% confidence intervals when appropriate. The confidence intervals indicate that, within the repeated sampling paradigm, 95% of the time the true population value or percent lies between the upper and lower limits reported.

After comparing the study sample with the Alberta data, the subjects were divided into sub-groups based on the NYHA functional classification and by family life cycle (FLC). Because of the small sample size, categories were collapsed to make between group comparisons possible. The NYHA functional classification of disease severity was analysed based on two categories : a) "no limitation" in functional ability due to the heart condition (NYHA=1); and b) "some limitation" in functional ability (NYHA>1). The three FLC classes were collapsed into two categories, "others" and "self". The intent was to keep those who were living alone as a distinct group classified as "self", and to group together those who live with others (where 'others' could be partners or offspring) into the category labelled "others". Where sample size permitted, chi-square analyses were used to assess whether there were associations between the variables in question and the sub-groups in the study sample. As well, 95% confidence intervals were estimated for the proportions.

VIII. Data Management

All questionnaires were returned to the University of Calgary, Department of Community Health Sciences where they were collected and reviewed by the researcher. Questionnaires were directed to the University in order to ensure that confidentiality and anonymity could be maintained. The data from the questionnaires were entered directly into a computer data base by the researcher. To ensure accuracy of the data entry, each questionnaire was double entered. Very few errors were found. Once all of the responses had been entered, the data were examined for unusual entries. Any such entries were checked against the original questionnaire and corrected if necessary.

Once the data were cleaned and confirmed, the responses to the Nottingham Health Profile and the SF-36 Health Survey were reviewed separately. The number of positive responses in each of the 6 domains was tabulated for the Nottingham Health Profile to arrive at a score for each subject.

A lengthy process was necessary to deal with the SF-36 Health Survey. First it was necessary to recode a number of items according to the criteria outlined in the scoring manual (Medical Outcomes Trust, 1994). Seven items were reversed scored, therefore recoding was necessary to ensure a higher score indicated a perception of better health status on all items. Once the recoding was completed, scores within each health concept were calculated. The third stage involved transforming the raw scores of each health concept into standardised scores which could then be used to compare the results with the general population. This transformation procedure was done according to instructions in the Scoring Manual.

The scores for the Nottingham Health Profile, and the transformed scores for the eight health concepts of the SF-36 were the data upon which the health perception analyses of this study were based.

CHAPTER 3

RESULTS

This chapter provides the results of the analyses performed on the data according to the research questions asked. A brief summary of the response rate is presented first, followed by a description of the sample and the results of the analysis.

I. Response Rate

Of the 174 eligible subjects identified for the study, 161 individuals were located and received the mailed study questionnaire. Despite repeated attempts by the staff of the clinic to locate the remaining 13 patients to determine their current addresses, these individuals could not be located. Thus the denominator for the response rate was based on the revised number of 161 eligible subjects. Of the initial 174 survey questionnaires mailed, 72 (41%) responded. Eighty-nine follow-up questionnaires were subsequently mailed, of which 43 (48%) were returned. Therefore the overall response rate from the 161 eligible subjects was 71% (115 responses).

Three returned questionnaires were not used in the analysis. One was not used since it was obvious from comparing the birthdate on the questionnaire with that on the master list of subjects, that the individual for whom the questionnaire was intended had not filled out the form. Two questionnaires were received after the cut-off date of September 8, 1994 when much of the analysis had been completed. The gain in response

rate would have been approximately 1% but the yield of new information would be low, thus the decision was made not to include the two late responders in the final analysis.

II. Description of the Sample

The following section provides a description of the sample with respect to socio-demographic variables including gender, age, stage in the family life cycle, severity of the disorder (NYHA), education level and income level. A brief description of the non-respondents is also included. No differences were noted between the respondents and non-respondents on gender, age, and severity of the disorder (NYHA).

A. Non-respondents

1. Gender

Of the 161 eligible subjects who were mailed the survey 46 did not respond. Of the 46 non-respondents 25 (54%) were male (95% Confidence Interval (CI) = 40% to 68%). As will be seen later, there was insufficient evidence to indicate a gender difference between the respondents and non-respondents.

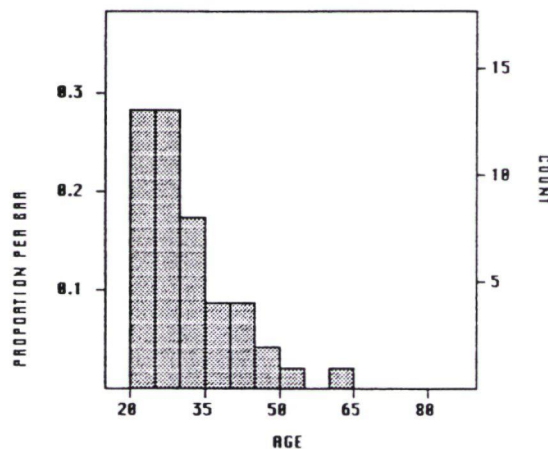
2. Age

The histogram shown in Figure 1 graphically illustrates the age distribution in the non-responder group. As shown, the age distribution is positively skewed, that is, there are proportionately more individuals in the younger age groups. Because the data are skewed, the results are presented using the median, first quartile (Q1), third quartile (Q3), and the interquartile range (IQR) as discussed earlier (see page 27).

The median age overall for the non-responders was 28 (Q1 24, Q3 35, IQR 11) . The minimum age was 20 which was pre-determined at the outset of the study through

the application of the inclusion criteria. The maximum age was 64. These data show that, when compared with the respondents, there was no difference between the two groups.

Figure 1. Age Distribution of Non-respondents



The gender specific age distribution among the non-responders is described as follows. The median age for the females was 28 years (Q1 26, Q3 34, IQR 8) whereas the median age for the males was 26 years (Q1 23, Q3 37, IQR 14) . The interquartile range for males is somewhat wider than that for females perhaps indicating a slightly wider distribution in age among the males. As well, there is a suggestion that the males are slightly younger than the females. However, overall the data do not suggest any great difference either among males or females. The gender specific age distribution is similar among the respondents.

3. Severity of Disorder (NYHA)

Table 3.1 describes the distribution of non-respondents within the 4 NYHA categories. Because there were so few subjects in categories 3 and 4, these were

collapsed for the purpose of illustration. Individuals with no functional limitations constitute the largest number (NYHA Category I). A progressive decrease in numbers is evident as the severity of the disorder increases. In the remainder of the results, the categories are collapsed further with those with no functional limitations classified as NYHA=1, and those with some limitations categorised as NYHA>1.

Table 3.1
Severity of Disorder Among Non-respondents

NYHA Category	Non-respondents				
	Female			Male	
	n	%	95% CI.	n	%
I	16	76	58% to 94%	16	64
II	3	14	0% to 29%	5	20
III & IV	2	10	0% to 23%	4	16
Total	21	100		25	100

Again, as will be seen later there is no difference between the responders and non-responders with respect to distribution within NYHA categories.

B. Study Respondents

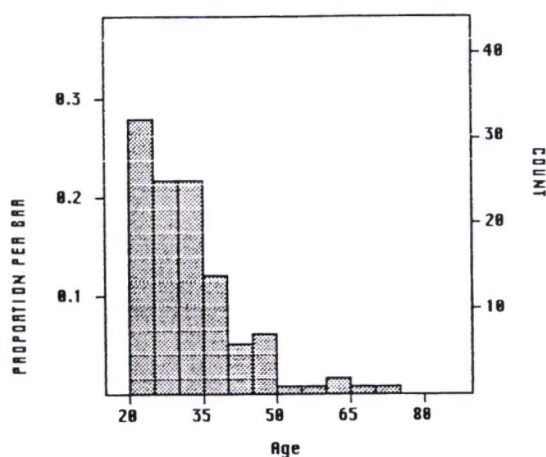
1. Gender

Of the 115 subjects who responded to the survey, 53 (46%) were male (95% CI = 37% to 55%).

2. Age

As with the non-responders, the age distribution is positively skewed. The histogram in Figure 2 illustrates the age distribution in the responding group. The minimum age was 20 the maximum age was 71 and the median age was 30 (Q1 24, Q3 35, IQR 11) among the responders. Referring back to the age distribution of the non-responders it can be seen that the two groups do not differ with respect to age.

Figure 2. Age Distribution of Respondents



The responding males and females were quite similar with respect to age. The median age for the females was 31 years (Q1 25, Q3 35, IQR 10) whereas the median age for males was 29 years (Q1 24, Q3 35, IQR 11).

Therefore, on the variables which can be used to compare the responders with the non-responders (age, gender and disease severity) there is no evidence of a significant difference between the two groups.

3. Severity of Disorder (NYHA)

Table 3.2 describes the distribution of the responders within the 4 NYHA categories. As with the non-responders, categories 3 and 4 were collapsed. A similar pattern emerges among the responders as was evident among the non-responders where, as the severity of the disorder increases, the number of individuals within that category decreases. NYHA I (no functional limitation) accounts for about two thirds of the study sample.

Table 3.2
Severity of Disorder of Responders

NYHA Category	Responders					
	Female			Male		
	n	%	95% CI.	n	%	95% CI.
I	42	68	56% to 80%	36	68	56% to 80%
II	14	22	12% to 32%	13	24	13% to 35%
III & IV	6	10	3% to 17%	4	8	1% to 15%
Total	62	100		53	100	

4. Education

Overall, 63% percent of the individuals in the sample had some form of post secondary education; 45% had completed community college or university. Eleven percent indicated that they had not completed secondary school. A small proportion (6%) of the respondents indicated they had some form of 'other' education however it was not possible to determine from the survey the level or type of education attained. It is interesting to note that only 28% of Canadians were reported in Canada's Health

Promotion Survey: 1990 as having completed post secondary education. However "age" may confound the interpretation of the results since the Canadian data includes individuals 15 to 19 years of age. As well, the Canadian data is more evenly distributed across the age groups (by study design) thereby proportionately weighting the older age groups where fewer individuals had attained secondary or post secondary education. It is not possible to determine from the Canadian survey results presented, the percentage of Canadians over the age of 20 who reported having some education at the post secondary level. Nevertheless the discrepancy is an unusual observation perhaps worthy of further exploration.

5. Income

It was expected that there would be some missing data with respect to the question of income as some individuals may be reluctant to report their income levels. Overall 7 individuals (6%) failed to answer the question (4 male, 3 female) and 13 (11%) claimed not to know the total household income for the reference year (7 male, 6 female). Twenty individuals (17%) did not provide income data (versus 14% in the Canadian health promotion survey).

One measure of socio-economic status is that of "income adequacy" as defined in Canada's Health Promotion Survey :1990 (1993, p.7). This measure is based not only on total household income, but also on the number of individuals living in the household. Table 3.2 illustrates the percentages of individuals within the categories given in the Health Promotion Survey. For the present study, the Survey's categories of "Other Poor" and "Lower Middle" have been combined. Table 3.3 indicates that, for the most part, the estimates for the study sample do not appear to differ from the estimates from the general Canadian population but for one possible exception. It appears that there might be a disproportionately higher number of individuals in the study group who fall into the

category "Very Poor" than in the Canadian population overall. It should be noted however, that the Canadian data are reported in percent only. No raw data were available so confidence intervals could not be calculated for the general population. It is therefore difficult to form any firm conclusions. It should also be noted that this is the case for all of the study variables which are compared with data from Canada's Health Promotion Survey: 1990.

Table 3.3
Income Adequacy

Income Category	Sample			Canada
	n	%	95% CI	%
Very Poor	15	13	7% to 19%	4
Other Poor/ Lower Middle	29	25	17% to 33%	31
Upper Middle	35	31	22% to 38%	36
Rich	16	14	8% to 20%	15
Not reported/ Unknown	20	17	11% to 24%	14
Total	115	100		100

6. Employment

For the study sample as a whole, 63% reported working at a job or business (60% of females; 66% of males) as their main activity during the past year, while 12% reported that they were students (8% of females; 17% of males). Of the 6% who reported looking for work, 4% were female and 2% were male. Of those who reported working during the past year, 56% worked 30 hours or more per week (55% of females; 55% of males). Overall, 75% were either employed or were students. Canada's Health Promotion Survey: 1990 (p.20) reports that 70% of those surveyed were likewise

engaged. Without raw data from Canada or Alberta and because of the small size of the study sample, it is not possible to say whether the differences are statistically significant. However it does not appear that the study sample differs from the Canadian population to a great degree with respect to employment status.

7. Family Life Cycle

Table 3.4 indicates the proportions of males and females according to their stage in the family life cycle (FLC). The "living alone" category includes those who have never been married as well as those who are separated or divorced and who have no children living in the household. The category "living as married", includes those who are legally married as well as those who are living common-law and who have no children living in the household. The third category, "living with children" includes any individual who has one or more children living in the household, regardless of marital status. The categories are mutually exclusive.

As shown in Table 3.4, 68% of females were married and/or have children perhaps indicating a commitment to or at least responsibility for more than oneself whereas 44% of males fell into the same category.

Because the study sample size was relatively small, the Family Life Cycle categories were again collapsed for further analyses. The "living alone" category was left as originally defined and labelled "self". However, the "living as married" and "living with children" categories were combined into a new category "living with others" and labelled as "others". The collapsing of categories allowed adequate numbers for developing between group comparisons.

Table 3.4
Family Life Cycle by Gender

FLC Category	Females			Males		
	n	%	95% CI	n	%	95% CI
Living Alone	20	32	20% to 44%	30	56	43% to 69%
Living as Married	21	34	22% to 46%	11	21	10% to 32%
Living with Children	21	34	22% to 46%	12	23	12% to 34%
Total	62	100		53	100	

There is a suggestion that more males than females in the study sample live alone, where more women than men live with another person. However, because the sample size is small and the confidence intervals are very wide, precise conclusions are not possible.

In summary, with respect to the socio-demographic variables measured, an interesting question arises with respect to the education level of the study respondents. There is no conclusive evidence that the study sample is more highly educated than the general Canadian population, however further exploration is warranted. Income adequacy also raises the question of whether the study sample does in fact have a greater proportion of individuals in the 'very poor' category. There is a suggestion that this is true however the study sample size is not large enough to draw any firm conclusions. Regarding employment status, the study sample seems similar to the general population. When the family life cycle data were examined, the genders were similar across categories except that there appeared to be more males than females who lived alone.

III. Health Perceptions

This section will first address some general perceptions of health and then explore the results as they relate to the SF-36 questionnaire and the Nottingham Health Profile. As well, Alberta data from Canada's Health Promotion Survey: 1990 are used to compare general health perceptions. The SF-36 Health Survey provides gender specific population based normative data against which to compare the study sample. Age specific data is also provided, however the study sample was too small for such comparisons. The Nottingham Health Profile is used to compare between NYHA functional classes and Family Life Cycle categories only.

A. General Perceptions of Health

Table 3.5 illustrates the respondents' self rated health status compared to the Alberta population. It appears that overall there is not much difference between the study sample and the general Alberta population except for the "excellent" health status category. The data show that fewer individuals in the CHD sample consider themselves to be in excellent health compared to the general Alberta population. It must be noted however, that the numbers of subjects per health category is very small, and the confidence intervals are very wide. It is therefore difficult to form any firm conclusions based on such small numbers.

Table 3.5
Self Rated Health

Health Rating	Study Sample						Alberta	
	Female			Male			Female	Male
	n	%	95% CI.	n	%	95% CI.	%	%
Excellent	6	10	2% to 18%	4	7	1% to 15%	25	23
Very Good	19	31	19% to 43%	18	34	21% to 47%	38	40
Good	19	31	19% to 43%	19	36	23% to 49%	26	28
Fair	10	16	7% to 25%	10	19	8% to 30%	9	8
Poor	7	12	4% to 20%	2	4	0% to 9%	3	2
Total	61*	100		53	100		100	100

* 1 missing value

In order to compare within groups, the self rated health categories were collapsed into two groups. Those who responded "excellent", "very good", or "good" were placed in a single category labelled "good", while those who rated themselves as being in "fair" or "poor" health were placed in a second category labelled "poor". When the data were analysed according to NYHA functional class (NYHA=1 or NYHA>1), there was an association evident between self-rated health and NYHA category among males (Fisher's Exact Test (FET), $p = .001$). Fifty-three percent of males with some functional limitation (95% CI = 34% to 72%) rated themselves as being in "fair" or "poor" health whereas 8% of males with no functional limitation (95% CI = 0% to 17%) rated themselves similarly. There was no evidence for a similar association among females (FET, $p = .360$). There

was also no evidence for an association between self-rated health and FLC (FET, $p = .283$).

B. SF-36 Health Survey

The SF-36 Health Survey questionnaire measures 8 health concepts: physical functioning; role-physical; bodily pain; general health; vitality; social functioning; role-emotional; and mental health. Each of the concepts is described more fully below as the data are presented.

Because the data were skewed, with subjects generally reporting higher scores, the data are presented using box plots which show the median, the first and third quartiles, and the range of responses. A higher score indicates a perception of better health status. The possible range of scores for each category is 0 - 100. The box plots are compared to the normative data provided in the SF-36 Health Survey: Manual & Interpretation Guide (Ware, J.E. et al, 1993). These comparative data are shown as a vertical line drawn next to the box plots. The line extends from the first to third quartile of the population data with a horizontal line bisecting the vertical at the population median.

The box plots are notched at the median and return to full width at the upper and lower limits of the 95% confidence limits for the median. If the intervals around two medians overlap one can be confident that, 95 times out of 100, the two medians are not different.

As mentioned earlier, the 'hinges' represent the first and third quartiles of the data, the 'whiskers' extend to the most extreme non-outlying values (1.5 times the inter quartile range (IQR)), the asterisks represent outlying values greater than 1.5 times the IQR, and the open circles represent extreme outliers or those values greater than 3 times the IQR. Confidence intervals for the median of the normative data are not available.

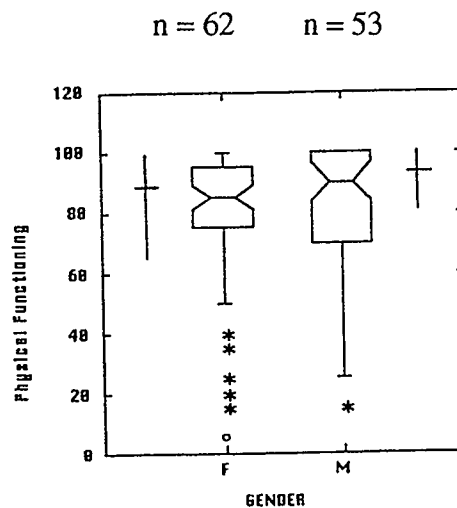
The box plots are presented first to compare the study sample with the normative data and are followed by the 'between' group comparisons based on the NYHA functional classification of disease and FLC categories.

The actual numerical data, including the minimum and maximum scores, the median, and the first and third quartiles are presented in tabular form in Appendices G (study sample versus the sample from the general population), H (NYHA and gender), and I (FLC and gender).

1. Physical Functioning

Physical functioning refers to limitations in performing physical activities due to health concerns. A low score indicates limitations in performing physical activities, whereas a high score indicates no limitations in performing any type of physical activities. The box plots in Figure 3 illustrate the range of responses from both males and females.

Figure 3. Physical Functioning Score by Gender.



The confidence intervals for the medians in the above box plots overlap suggesting no difference between males and females with respect to physical functioning. However, the interquartile range is somewhat larger for the males indicating relatively more dispersion in the results between the first and third quartiles. On the other hand, among females there appear to be more outlying or extreme values.

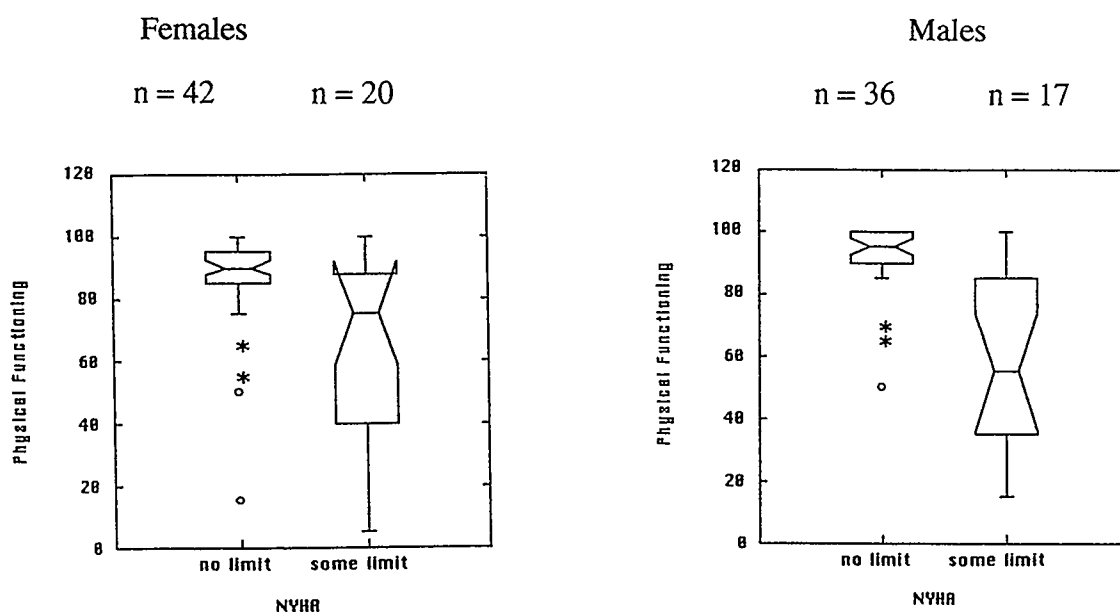
When compared with the normative data, the males in the study sample do not differ substantially from the general population of males (medians 90 and 95 respectively). However, the interquartile range (IQR) is somewhat narrower in the general population (study sample $Q1=70$, $Q3=100$, $IQR=30$; population $Q1=80$, $Q3=100$, $IQR=20$) suggesting more lower scores in the study sample data.

The females in the study sample are also fairly similar to the general population of females (medians 85 and 90 respectively), however in this case the IQR for the general population is somewhat larger than that of the study sample (study sample $Q1=75$, $Q3=95$, $IQR=20$; population $Q1=65$, $Q3=100$, $IQR=35$). As can be seen from the box plots there are also a number of outlying or extreme low values in the study sample but if one looks at the range of scores there is little difference between females in the study sample and those in the general population. (See Appendix G for presentation of the data.)

When the study subjects were sub-divided into NYHA functional class ("some limitation" and "no limitation") it appears that among males there is a difference between individuals in the "no limitation" class and those in the "some limitation" class. The data in Figure 4 suggest that those with "some limitation" perceive that they are more limited than those in the "no limitation" class in relation to their abilities to perform physical activities. The scores are generally lower and there is also a much wider spread in the IQR.

Among females a slightly different picture appears. The confidence intervals for the medians overlap suggesting insufficient evidence to support a difference between the medians in the NYHA functional classes. However it is quite apparent that overall, the scores are considerably lower with a greater spread in the data in the "some limitation" category than in the "no limitation" category. However, because the study sample was so small there were really insufficient numbers to form firm conclusions. (See Appendix H for the data.)

Figure 4. Physical Functioning Score by NYHA Category.

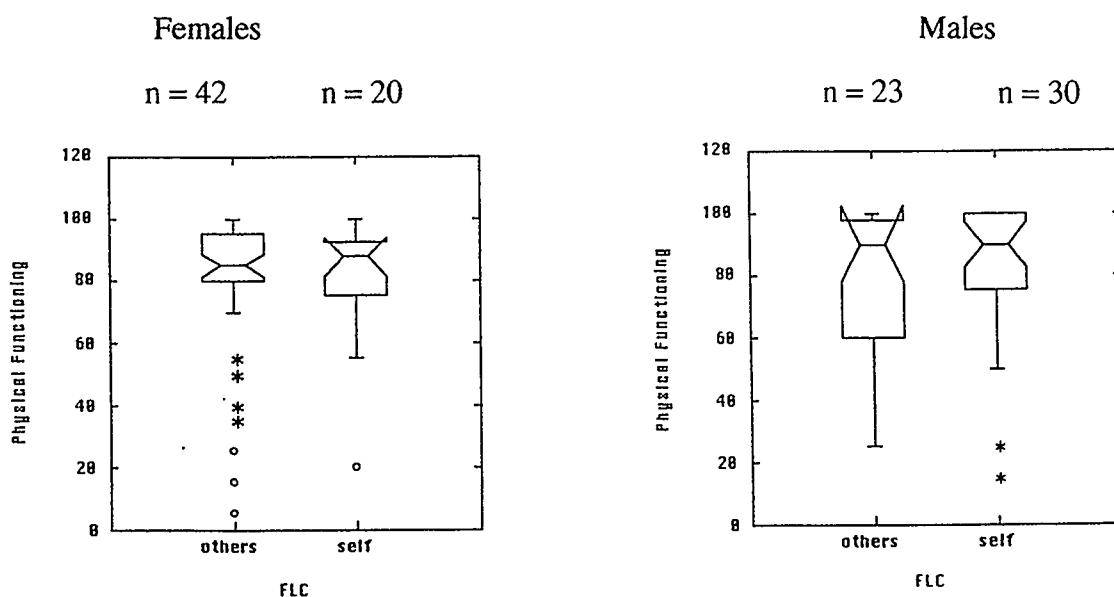


When the subjects were divided into the FLC categories of living alone ("self") and living with others ("others") (Figure 5), the confidence intervals for the medians overlap between the categories for both the males and females indicating no significant difference in physical functioning between FLC categories. (See Appendix I for the data.)

Among males there is somewhat greater dispersion in the data among those in the "others" category than those in the "self" category, however overall, it appears that the differences are not great.

Among females there are many more extreme outlying values in the "others" category than in the "self" category however the spread between the first and third quartiles is similar between categories.

Figure 5. Physical Functioning Score by FLC Category.



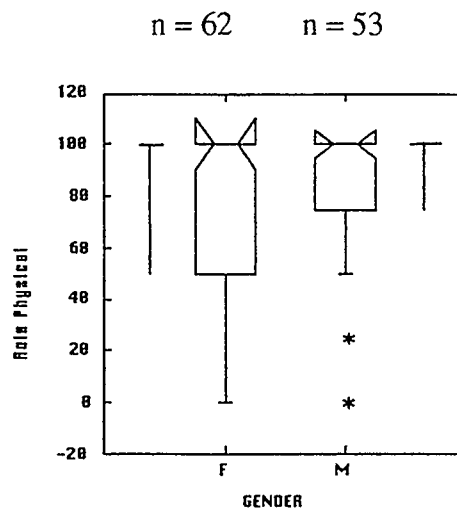
In summary, with respect to physical functioning, the study sample does not appear to differ markedly from the general population (Figure 3). However when one looks at NYHA functional class, the data show that those subjects (male and female) with some limitations in functional ability reported lower scores in physical functioning than those with no limitations in functional ability (Figure 4). When the box plots were examined by categories in the FLC, females appeared similar between categories. Males on the other hand demonstrate a greater spread of responses in the category labelled

"others" than in the category labelled "self"(Figure 5). But, as mentioned earlier, there is no significant difference between the medians among the males in the FLC categories.

2. Role-Physical

Role-physical refers to limitations in performing usual daily activities including work, due to physical health problems in the previous four weeks. Again a low score indicates difficulties fulfilling role obligations, whereas a high score indicates no limitations in this domain. The box plots in Figure 6 suggest that males and females do not differ significantly in this area as the confidence intervals for the medians overlap. However, there appears to be more dispersion in the female scores than in the male.

Figure 6. Role-Physical Score by Gender.



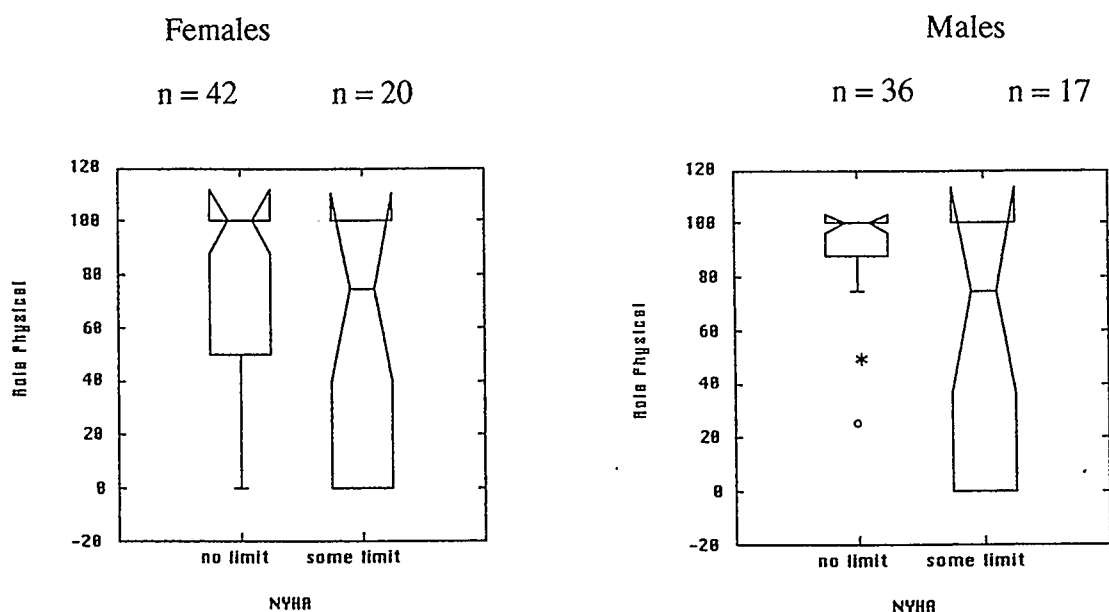
When compared to the normative data, males and females did not differ from the general population at all. The medians, quartiles and range of scores are identical between the study sample and the general population normative data.

When the data were analysed by NYHA functional class, the males with "some limitation" showed considerably more spread in their responses with many more lower

scores than males with "no limitation". However, the confidence intervals for the medians overlap suggesting no significant difference in the median scores between classes.

The data for the females indicates more dispersion in the scores for those in the "some limitation" category, however it is less marked than in the males. The confidence limits for the females also overlap suggesting no significant difference between the medians.

Figure 7. Role-Physical Score by NYHA Category.

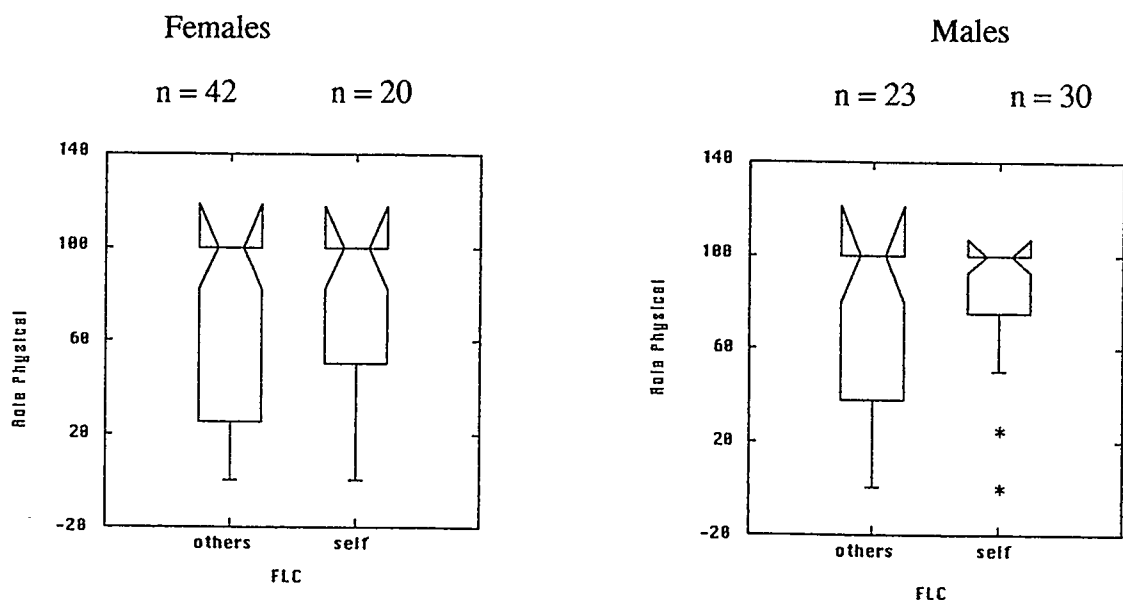


The Family Life Cycle (FLC) data in Figure 8 showed that the female subjects did not seem to differ substantially between categories except there is a suggestion of more dispersion in the data with the first quartile in the "other" category being slightly lower than in the category labelled "self"

The data describing males, on the other hand, show slight differences between categories. The confidence intervals for the medians overlap suggesting no real

difference between them however there appears to be a greater spread in the data in the "others" category than in the category "self".

Figure 8. Role-Physical Score by FLC Category.



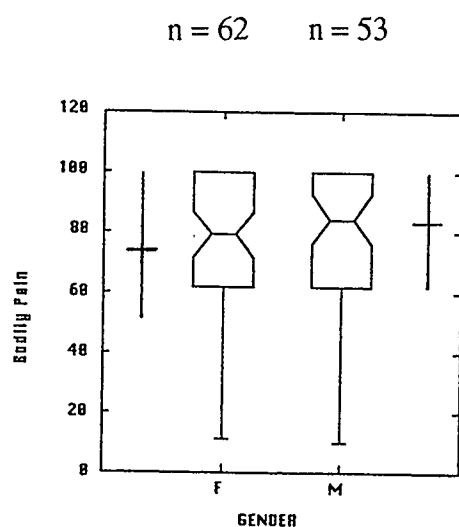
In summary, the study sample did not differ from the general population with respect to the Role-Physical health concept (Figure 6). There was a suggestion that for the FLC both males and females in the "others" categories had somewhat lower scores than those in the "self" category (Figure 8). This raises the question whether those who live with others feel more limitations in performing their usual daily activities than those who live alone. NYHA functional class appeared to be a factor in the subjects' perceptions of their limitations in performing usual daily activities. Those who have some functional limitation feel less able to perform such activities than those who have no functional limitation (Figure 7).

3. Bodily Pain

The concept of bodily pain refers to limitations in activities due to pain or discomfort. A low score indicates severe limiting pain whereas a high score indicates no pain or no limitations due to pain in the previous four weeks. The box plots for both the males and females in the study sample look essentially the same (Figure 9). In fact, the

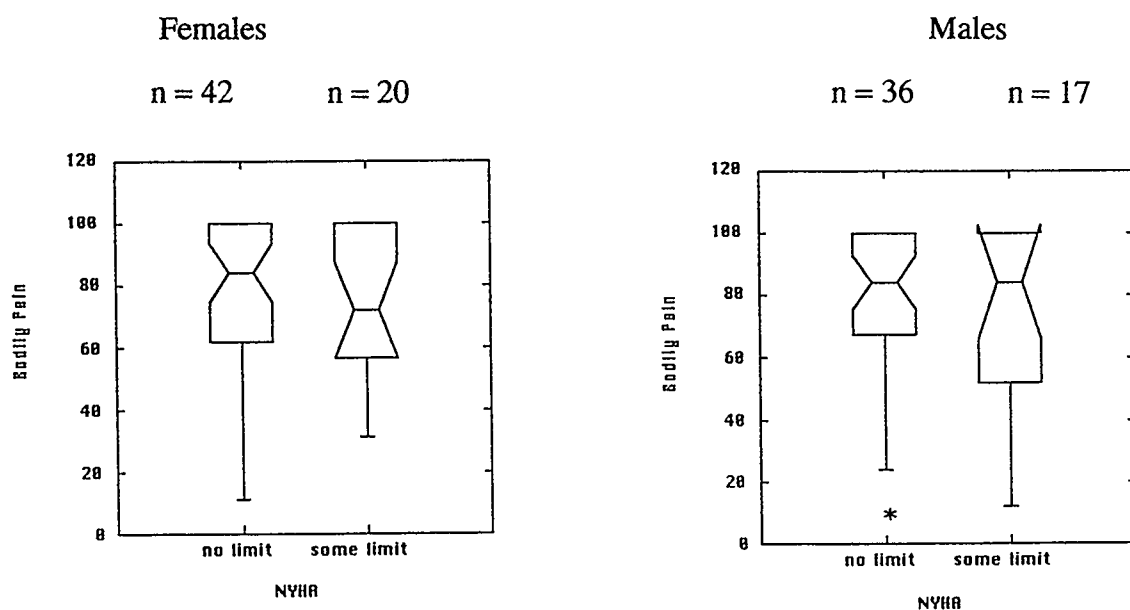
responses for both the males and females in the study sample are very like the responses for the general population (refer to Appendix G).

Figure 9. Bodily Pain score by Gender.



When NYHA functional class data were examined (Figure 10), there was little difference noted between groups among females. There is a suggestion that the males in the "some limitation" category had somewhat lower scores than males in the "no limitation" category, however, the medians are very close between groups and the sample size is too small to draw any firm conclusions. The box plots in Figure 10 illustrate the spread of the data.

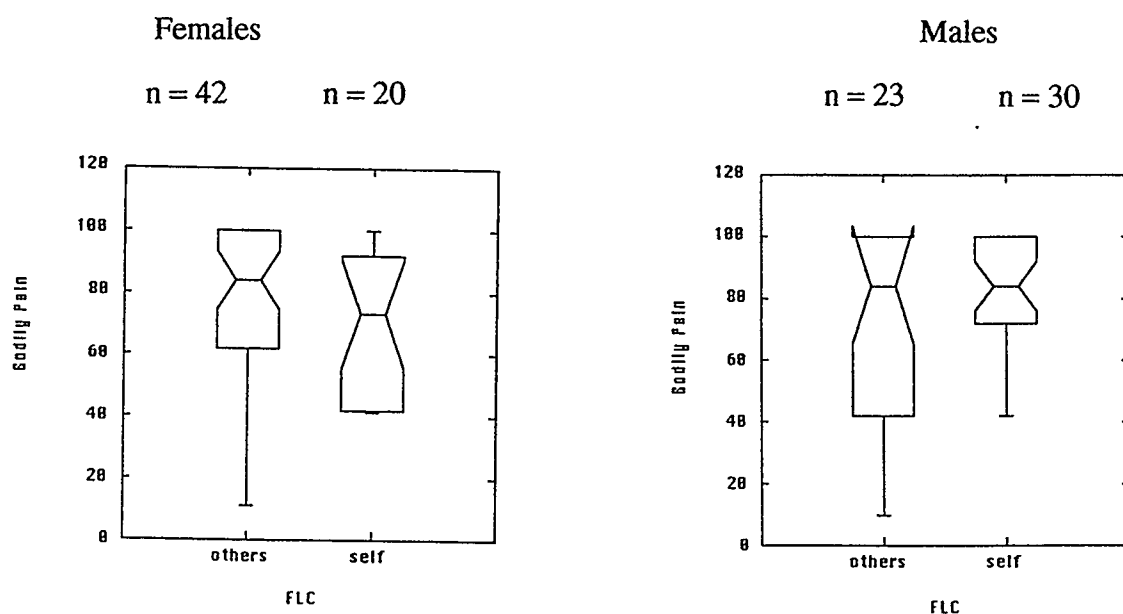
Figure 10. Bodily Pain Score by NYHA Category.



With respect to the FLC categories, it appears that females in the "self" category have somewhat lower scores, which seems to indicate a perception of more bodily pain among females who live alone than among women who live with others, notwithstanding the fact that the confidence intervals for the medians overlap (refer to Figure 11).

Conversely, males appear to have lower score in the "others" category indicating a perception of more bodily pain than males in the "self" category. In this case too, the confidence intervals for the medians overlap suggesting no significant difference between the groups.

Figure 11. Bodily Pain Score by FLC Category.



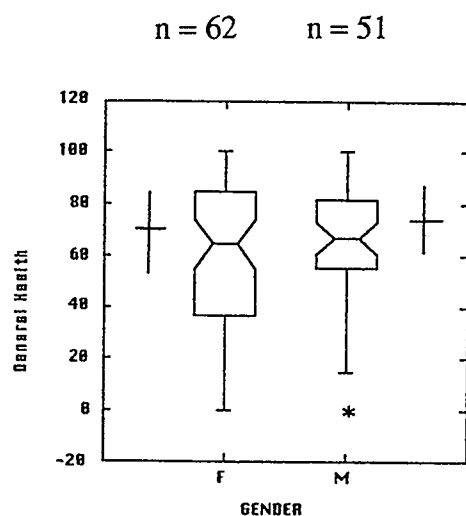
In summary, the study sample does not differ from the general population to any significant degree (Figure 9), nor do the NYHA classes (Figure 10) or FLC categories (Figure 11) differ significantly among males and females. Although in some cases the scores may appear lower in one category or another, the study sample is too small to make precise estimates.

4. General Health

General health refers to the subjects' general health perceptions. A high score indicates a perception of excellent health, whereas a low score indicates a perception of poor health. Although the medians for both males and females are not different, there appears to be a greater spread in the scores among females than among males (Figure 12). When compared to the general population, the males in the study sample do not differ markedly from the normative data. However, the females in the study sample differ somewhat from the general population in that they seem to have lower scores (study sample Q1=37, general population Q1=57). Refer to Appendix G for a full description of

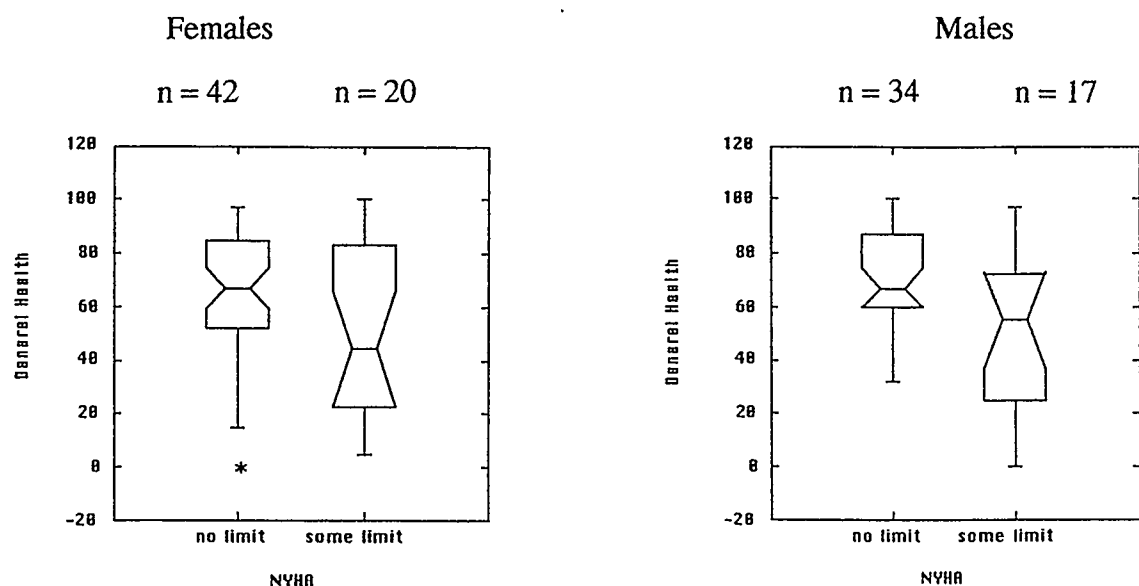
the data. It should be noted that for this health concept there were two missing values from the male subjects.

Figure 12. General Health Score by Gender.



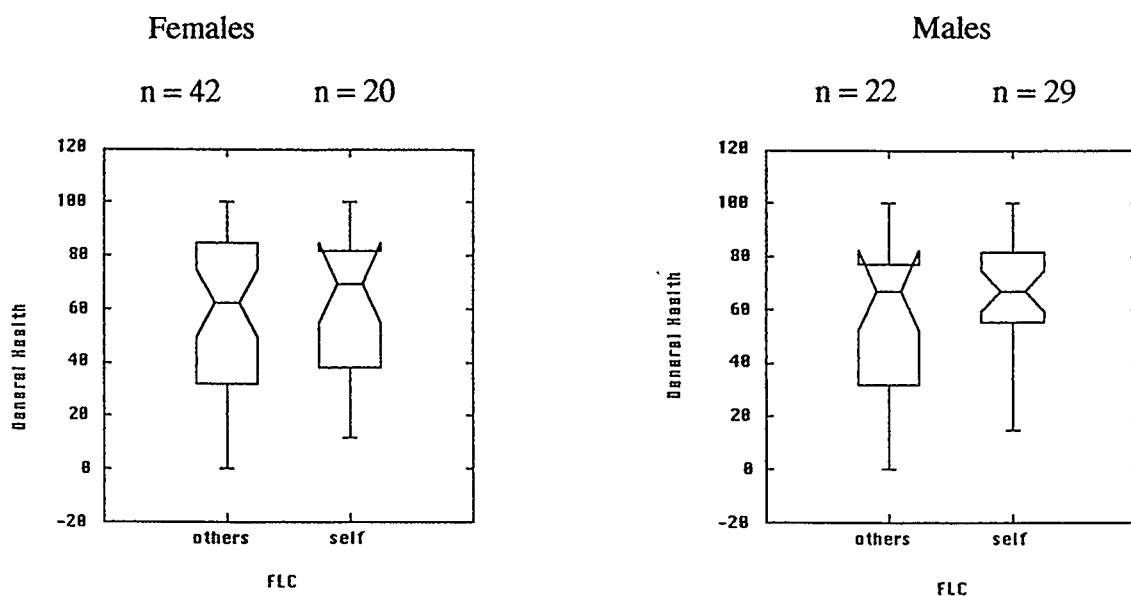
When the data were analysed according to NYHA functional class, it appeared that, for both males and females, there was greater spread in the scores in the "some limitation" category than in the "no limitation" category (Figure 13). The median scores also appeared lower in the "some limitation" category than in the "no limitation" category although the confidence intervals overlap indicating no significant difference between the NYHA functional class medians. The two missing values from the male subjects were from the "no limitation" category.

Figure 13. General Health Score by NYHA Category.



With respect to the family life cycle, the female study subjects do not differ between categories (Figure 14). The males in the study sample are also fairly similar between groups, however there is a suggestion that there is more dispersion in the data among subjects in the "others" category with perhaps a greater number of respondents reporting lower scores than in the "self" category. There was one missing value from each category of male subjects.

Figure 14. General Health Score by FLC Category.

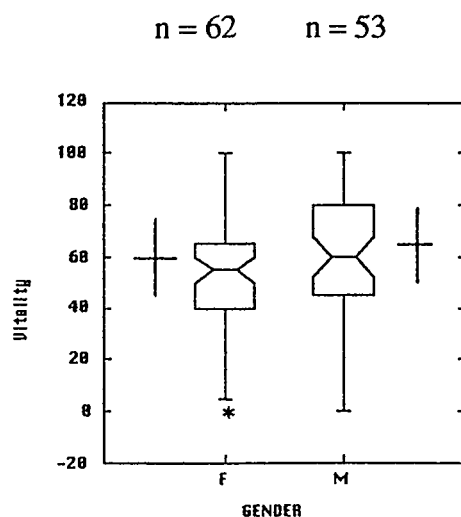


In summary, males in the study sample did not differ markedly from the general population with respect to their perceptions of their general health. Females, on the other hand differed slightly in that they seemed to have somewhat lower scores than the general population and somewhat lower scores than the males in the study group indicating possibly a poorer perception of general health status. It also appears that subjects, both male and female, who have some limitation in functional ability according to the NYHA functional classification of disease perceive their health to be poorer than those who have no limitation. There did not appear to be substantial differences between groups in the family life cycle except perhaps a hint that males who live alone tend to perceive their health as somewhat better than those who live with others.

5. Vitality

Vitality refers to the subjects' perceptions of their energy or fatigue levels. Low scores indicate that the subjects feel tired or fatigued all or most of the time, whereas high scores indicate feeling full of energy all or most of the time.

Figure 15. Vitality Score by Gender.

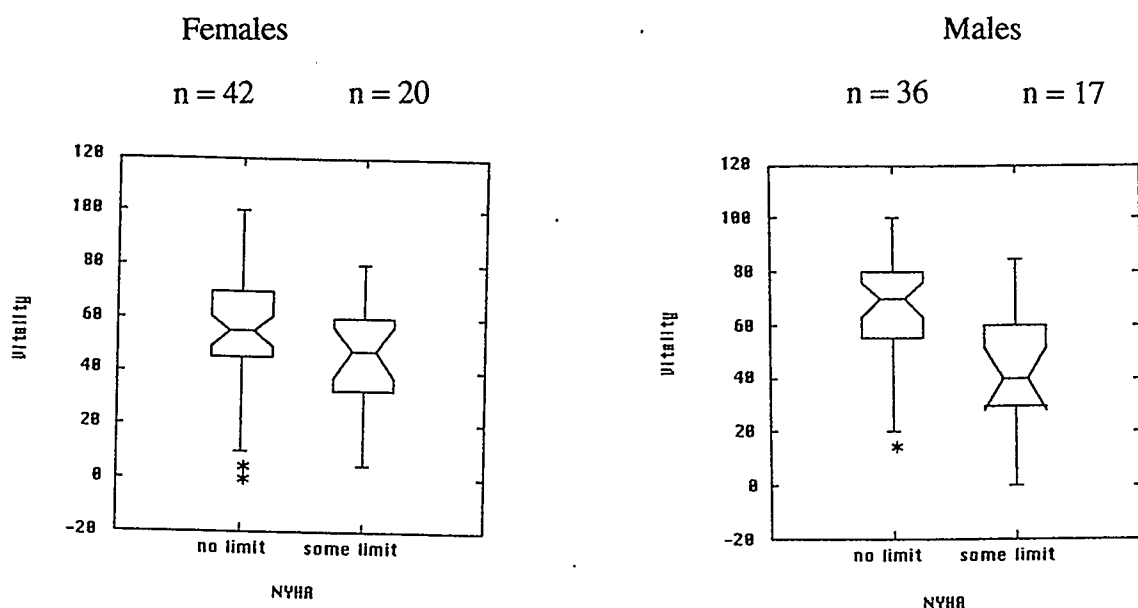


Neither males nor females differ from the general population with respect to this health concept however the box plots suggest that the males may score slightly higher overall than the females (Figure 15). The medians are not different and the confidence intervals for the medians overlap indicating no difference between the genders, however one could argue that the males did score slightly higher overall.

When NYHA functional class data were analysed, the female study subjects did not differ greatly between groups (Figure 16). There is a suggestion that females with some functional limitations scored slightly lower (indicating less energy) than females with no functional limitations, however the sample size is too small to make firm conclusions particularly since the confidence intervals for the medians overlap.

Males, on the other hand do seem to differ between NYHA functional class. The confidence intervals for the medians do not overlap suggesting a difference between groups in that males with some limitation in functional ability scored lower than those with no functional limitations. This suggests that males with some functional limitation may feel more fatigued than males with no limitations.

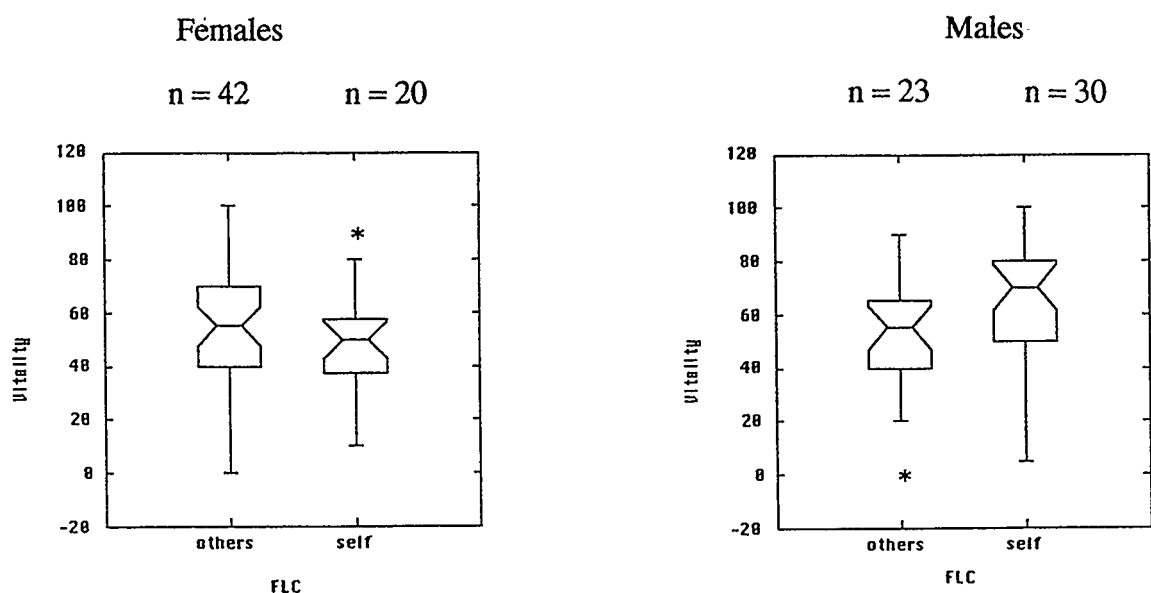
Figure 16. Vitality Score by NYHA Category.



With respect to the family life cycle, the box plots suggest that males in the category labelled "others" have somewhat lower scores than males in the category labelled "self" indicating a perception of decreased vitality among males who live with others than males who live alone (Figure 17). The confidence intervals for the medians overlap slightly which causes one to interpret the results with caution.

On the other hand, the box plots suggest somewhat higher score for females in the category labelled "others" suggesting a perception of increased vitality or energy among women who live with others than women who live alone. However the confidence intervals overlap markedly which indicates there may in fact be no difference between FLC categories among women.

Figure 17. Vitality Score by FLC Category.



In summary, the study subjects did not differ from the general population with respect to their perceptions of their vitality or energy (Figure 15). Males tended to score slightly higher than females in the study sample however this was also true among the males in the general population. Both males and, to a lesser degree, females who had some functional limitation based on NYHA functional class tended to score lower than their counterparts with no functional limitation (Figure 16). Males who lived with others tended to score lower than males who lived alone, however the reverse appeared to be the case among females (Figure 17). As with the earlier concepts, one must be wary of over-interpreting the data when dealing with a small sample size, however trends are apparent and could be followed up in future studies.

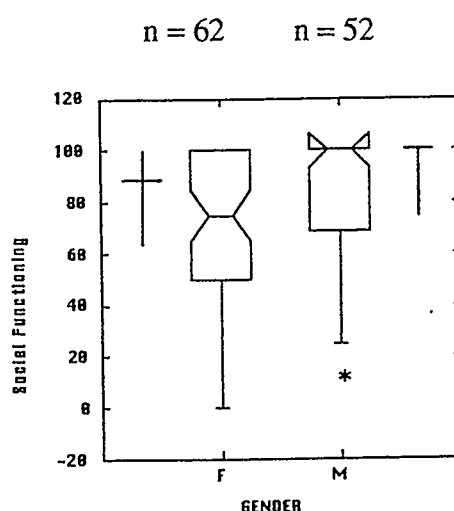
6. Social Functioning

Social functioning refers to the effects of physical or emotional problems on subjects' ability to participate in social activities. A low score indicates excessive

interference with social activities and a high score indicates no interference with usual social activities.

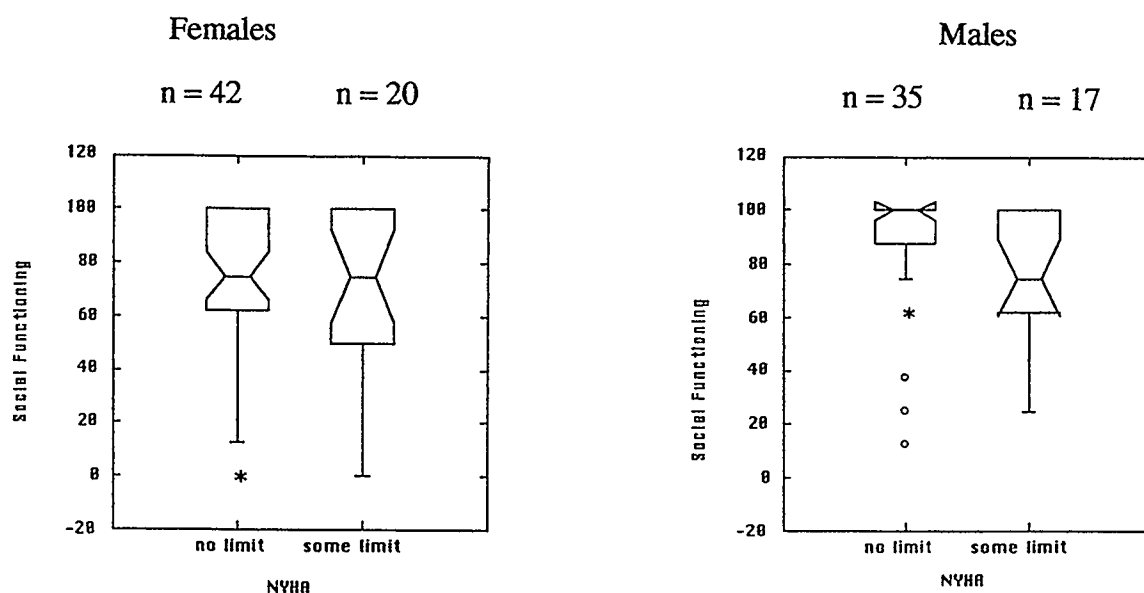
Gender differences were noted in this sample with respect to this variable. Male subjects scored higher overall than did the female subjects suggesting that the males felt less interference with social activities due to physical or emotional problems than did the females. Neither the males nor the females differed markedly from the normative data from the general population however the females did have a somewhat lower median score than the general population sample. There was one missing value from the male subjects.

Figure 18. Social Functioning Score by Gender.



When the data were analysed according to NYHA functional class, males subjects with some limitation had significantly lower scores than the males with no limitation. Female subjects on the other hand were similar between categories.

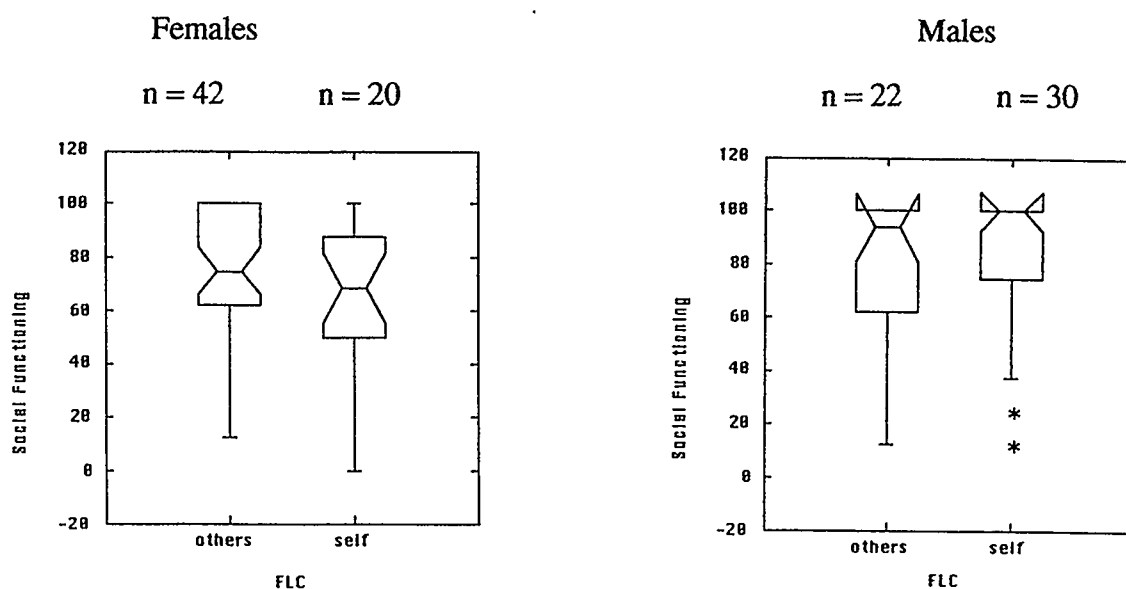
Figure 19. Social Functioning Score by NYHA Category.



There is a suggestion therefore, that males in the study sample who have some functional limitation, versus those with no functional limitation, perceive that their abilities to perform socially are impaired due to physical and emotional problems.

The box plots in Figure 20 indicate that there was no significant difference between FLC categories among males or females in the study sample. However, there is a suggestion that males living with others had slightly lower scores than males living alone. Females living alone on the other hand may have somewhat lower scores than females living with others. However, one cannot make too much of these differences both among males and females as the sample size is so small.

Figure 20. Social Functioning Score by FLC Category.



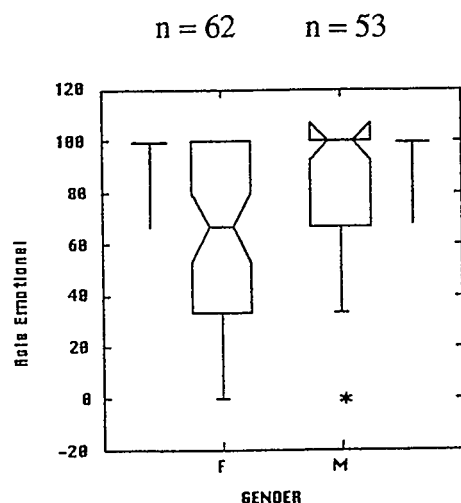
In summary, the study subjects did not differ from the general population according to their perceptions of their social functioning (Figure 18). As with the general population, males tended to score higher than females. With respect to NYHA categories, males with some functional limitation tended to score much lower than males with no functional limitation whereas among females there was no difference between categories (Figure 19). When FLC was explored, females did not differ between categories, however, males who lived with others scored lower than males who lived alone (Figure 20).

7. Role-Emotional

Role-Emotional refers to limitations or problems with daily activities, including work, due to emotional problems. A high score indicates no problems in this domain. The following box plots indicate that the females in the study sample scored lower than the males in the sample. The females in the sample also scored lower than the females in the general population (study sample Q1 33, median 67, Q3 100; population Q1 67,

median 100, Q3 100). Males in the study sample, on the other hand were no different from the general population of males. There is therefore a suggestion that the females in the sample experience more difficulties fulfilling role obligations as a result of emotional problems than both the males in the sample and the females in the general population.

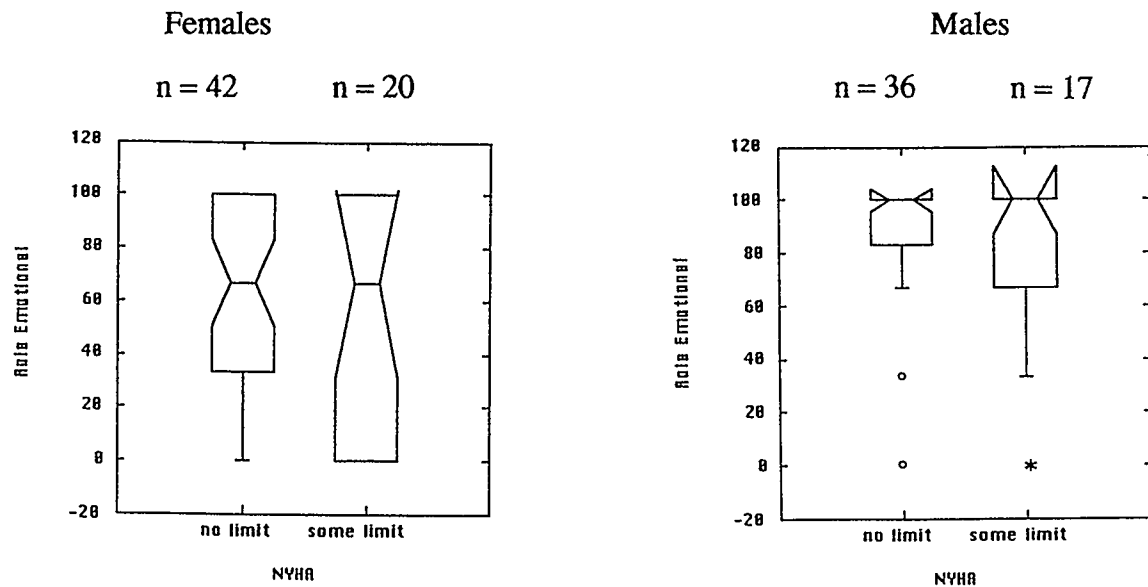
Figure 21. Role-Emotional Score by Gender.



When NYHA functional class was examined, both males and females with some functional limitation had lower scores overall than did those individuals with no limitation (first quartiles lower in "some limitation" category) although the medians between categories for both genders were the same (refer to Figure 22).

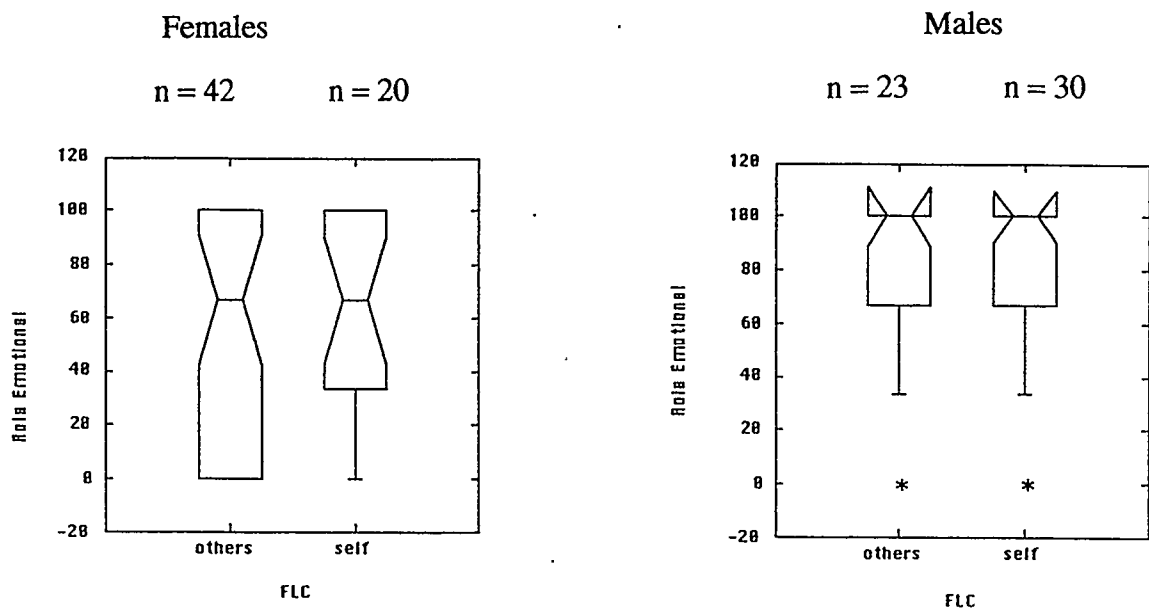
Again, the sample size is too small to draw any firm conclusions regarding this health domain and NYHA functional class..

Figure 22. Role-Emotional Score by NYHA Category.



The family life cycle data suggest that there is no difference between categories for males in the study sample. For females on the other hand, although the medians between categories are the same, the first quartile in the "others" category is lower than in the "self" category suggesting that women in the study sample who live with others may have more problems with daily activities due to emotional problems than women who live alone.

Figure 23. Role-Emotional Score by FLC Category.



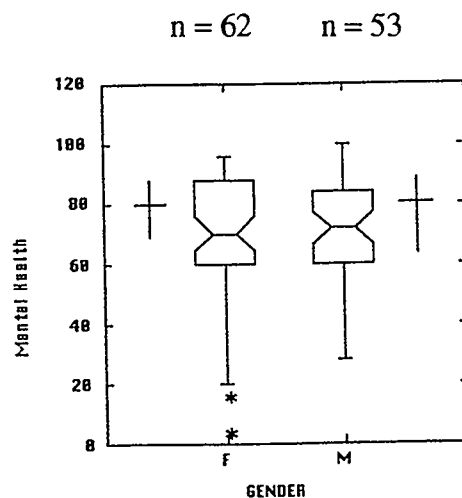
In summary, in the case of the ability to fulfil role obligations based on emotional status, there were differences noted between the study females and females in the general population where females in the study sample tended to score lower. Males in the study sample, on the other hand, were no different from the males in the general population (Figure 21). As with most of the previously discussed concepts there was a trend for both males and females who had some functional limitation based on NYHA functional class to score lower than their counterparts who experienced no functional limitation (Figure 22). There was no difference between FLC categories both among males and females, however there is a suggestion that females who live with others may have more difficulty fulfilling role obligations due to emotional problems than females who live alone (Figure 23).

8. Mental Health

The concept of "mental health" measures four dimensions including anxiety, depression, loss of behavioural/emotional control, and psychological well-being. A low

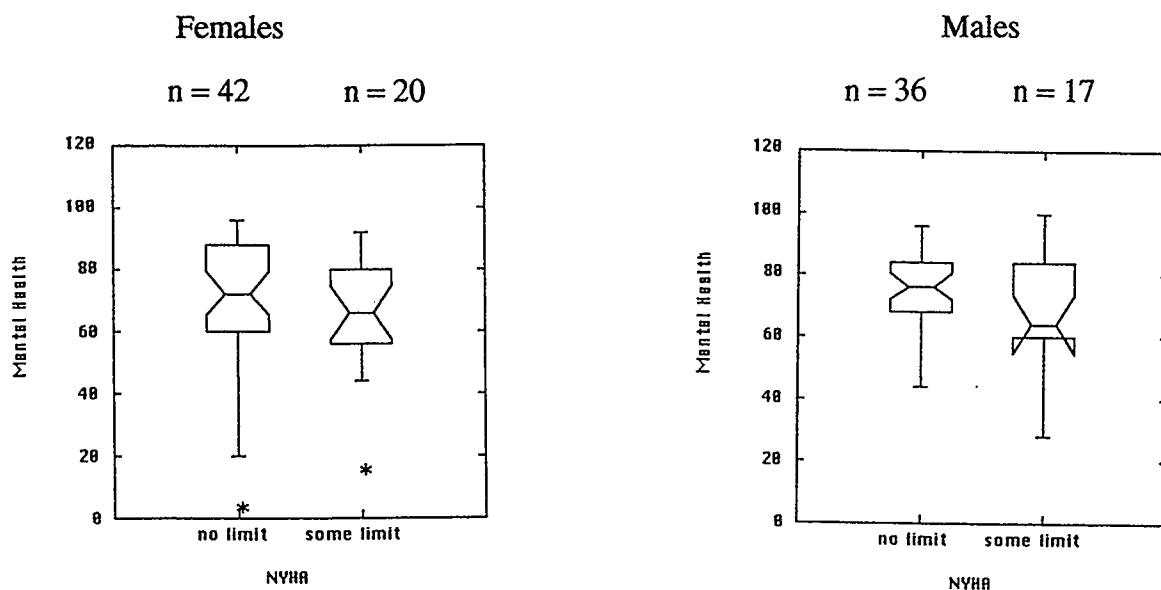
score indicates feelings of anxiety and depression all of the time whereas a high score indicates feeling of well-being all of the time. As shown in Figure 24, the genders were similar in the study sample. The study sample data for both males and females were also similar to the normative population data however one could argue that perhaps the study sample subjects scored somewhat lower overall than the normative population.

Figure 24. Mental Health Score by Gender.



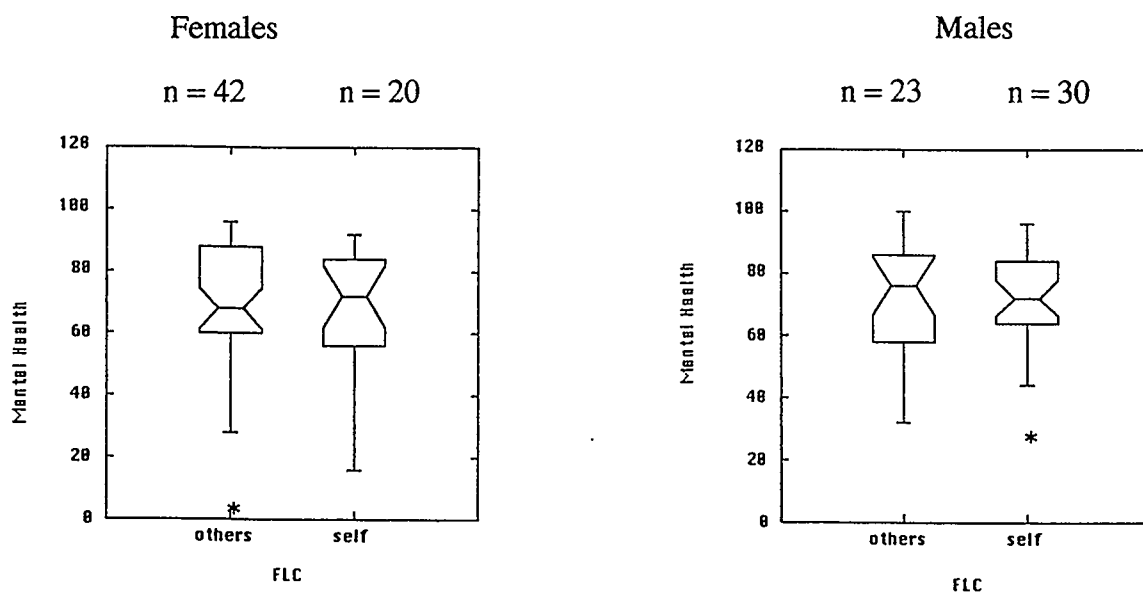
There were no major differences between NYHA functional classes in either the males or females from the study sample however here too it could be argued that respondents with some functional limitations scored somewhat lower than respondents with no functional limitations. This finding was more marked among the males.

Figure 25. Mental Health score by NYHA category.



The data also suggest there were no differences between categories in the family life cycle for either gender (see Figure 26).

Figure 26. Mental Health Score by FLC Category.



In summary, there is a suggestion that the study subjects scored slightly lower than the general population (Figure 24) however with a small sample size it is difficult to be certain. True to the general pattern or trend, subjects with some functional limitation according to the NYHA classification scheme tended to score somewhat lower than subjects with no functional limitation (Figure 25). There was also no difference between FLC categories among the males and females in the study sample (Figure 26).

9. Summary of SF-36 Health Survey

Overall, the study subjects did not differ from the general population in the eight health concepts of the SF-36 Health Profile. This appeared to be generally true for males and females, however there are suggestions that among females there is a poorer perception of health status in the domains of "General Health" and "Role-Emotional" (see Figures 12 and 21). The same did not appear to be true for males. In the "Mental Health" domain, it could be argued that the subjects, both male and female, scored lower than the general population (Figure 24), however, the differences are small, confidence intervals could not be estimated for the general population, and the sample size is small, making it difficult to draw firm conclusions. Generally, when there were differences between groups of NYHA functional class, the subjects with some limitations in functional ability reported lower scores than subjects with no functional limitations. However, in only three domains was there evidence of statistically significant differences. In the areas of "Physical Functioning", "Vitality" and "Social Functioning", males who had some functional limitations scored significantly lower than males with no functional limitations. There were no significant differences noted between NYHA categories among females, however, there was still a trend for females with some functional limitation to score lower than those with no functional limitations.

For all of the health concepts, the confidence intervals for the medians overlapped suggesting insufficient evidence to support a difference between categories of the FLC. However, a trend was noted where males, who lived with others such as in the domains of "Physical Functioning", "Role-Physical", "Bodily Pain", "General Health", "Vitality", and "Social Functioning", scored slightly lower than the males who lived alone. In the domains of "Role-Emotional" and "Mental Health", there was no difference between FLC categories among males. Females who lived alone, on the other hand tended to score lower in the domains of "Bodily Pain", "Vitality", and "Social Functioning", than females who lived with others. There is a suggestion that females who lived with others scored slightly lower in the domains of "Role-Physical" and "Role-Emotional" than females who lived alone. In the domains of "Physical Functioning", "General Health", and "Mental Health", there was no difference between FLC categories among the females.

C. Nottingham Health Profile

The Nottingham Health Profile (NHP) measures six health concepts: energy level, pain, emotional reactions, sleep, social isolation and physical mobility. The instrument is scored by tallying the number of affirmative responses to the questions in each domain. Unlike the SF-36 Health Survey where a high score indicated perceptions of better health status, a high score in each domain of the NHP indicates a perception of poor health status or feelings of distress for the health concept measured. It was expected that most subjects would have few affirmative responses because the tool tends to measure extreme or severe problems. This was the intent of the tool's author in order to reduce the number of potential false positive results (Hunt et al., 1985). Thus, scoring other than zero in any domain on the tool, indicates more severe problems within the health concept.

The instrument is used in this study to compare groups within the sample only. No comparisons were made with the general population. The tables used to illustrate the data divide the respondents into two groups. The first group is comprised of subjects who answered "no" to all questions within the health concept, indicating no perceived impairment in that domain. The second group includes subjects who responded "yes" to one or more questions in the health concept, indicating a perception of some impairment in that domain. Genders were compared, followed by NYHA functional class and FLC subgroups.

1. Gender Comparisons

Table 3.6 illustrates the proportions of male and female subjects who responded affirmatively to the statements on the questionnaire. In the areas of "emotional reactions" and "sleep", a greater proportion of males indicated some impairment than no impairment. Females responded similarly to the males in the area of "emotional reactions", however the same pattern was not apparent in the "sleep" domain. If one were to try to compare the NHP with the SF-36, the domains most comparable would be that of Mental Health (SF-36) and Emotional Reactions (NHP). It is in these domains where the responses could be interpreted similarly. There is some evidence to suggest that the study respondents rated their mental health as being somewhat problematic (refer to Figure 24). Consistent with that finding were the results shown in Table 3.6 where more males and females reported some impairment (as opposed to no impairment) in the concept "Emotional Reactions". Again, the results should be interpreted with caution because of the sample size and the nature of the sampling frame from which the subjects were selected. However there is sufficient evidence to raise questions about the psychological status of this group of respondents.

Table 3.6
Nottingham Health Profile and Gender

Health Concept	Males n=52*				Females n=62			
	No Impairment		Some Impairment		No Impairment		Some Impairment	
	n	%	n	%	n	%	n	%
Energy Level	36	69	16	31	32	52	30	48
Pain	43	83	9	17	48	77	14	23
Emotional Reactions	24	46	28	54	28	45	34	55
Sleep	23	44	29	56	35	56	27	44
Social Isolation	31	60	21	40	40	65	22	35
Physical Mobility	37	71	15	29	39	63	23	37

*1 missing value

Although the SF-36 and the NHP categories cannot necessarily be directly compared in all domains, a similar trend is evident between the genders where females tend to rate their health as slightly poorer than do the males in the study sample.

2. NYHA Functional Class

Results of the Nottingham Health Profile were analysed separately for males and females in order to observe for differences between the NYHA functional classes. The data for both males and females are presented in Tables 3.7 and 3.8. The tables show the percentage of individuals within the NYHA sub-groups who responded that they had no or some impairment in the NHP categories.

Table 3.7
Nottingham Health Profile and NYHA
Males

Health Concept	NYHA = 1 (no limitation) n = 35*				NYHA >1 (some limitation) n = 17			
	No Impairment n %		Some Impairment n %		No Impairment n %		Some Impairment n %	
Energy Level	29	83	6	17	7	41	10	59
Pain	30	86	5	14	13	76	4	24
Emotional Reactions	18	51	17	49	6	35	11	65
Sleep	16	46	19	54	7	41	10	59
Social Isolation	22	63	13	37	9	53	8	47
Physical Mobility	29	83	6	17	8	47	9	53

* 1 missing value

Table 3.8
Nottingham Health Profile and NYHA
Females

Health Concept	NYHA = 1 (no limitation) n = 42				NYHA > 1 (some limitation) n = 20			
	No Impairment n %		Some Impairment n %		No Impairment n %		Some Impairment n %	
Energy Level	24	57	18	43	8	40	12	60
Pain	35	83	7	17	13	65	7	35
Emotional Reactions	19	45	23	55	9	45	11	55
Sleep	24	57	18	43	11	55	9	45
Social Isolation	29	69	13	31	11	55	9	45
Physical Mobility	31	74	11	26	8	40	12	60

A trend similar to the one seen in the SF-36 health survey emerged where respondents who had some functional limitation, based on the NYHA classification criteria, tended to have a perception of poorer health status than respondents with no functional limitations.

Among males there was a consistent trend across all domains for individuals with some functional limitation to feel somewhat impaired in the health concept measured. At first glance this may not seem true for the domains of "Pain" and "Physical Mobility" where a smaller proportion of respondents indicated they felt some impairment than those who indicated they felt no impairment. However, if one compares the NYHA categories, it is interesting to note that the percentage of respondents indicating some impairment in those domains increases from individuals with no functional limitation to those with some functional limitation. An interesting observation among males with no functional limitation is in the domains of "Emotional Reactions" and "Sleep" where there is an equal proportion of respondents in both impairment categories.

Among females, in the domains of "Emotional Reactions" and "Sleep", the responses were essentially the same in that the proportions of respondents indicating no or some impairment was the same between NYHA categories. In the areas of "Social Isolation" and "Physical Mobility" the proportion of women indicating some impairment increased in those respondents who had some functional limitation. The general trend still exists, as was evident among the males, that women who have some functional limitation experience some impairment in their perception of health status in the domains measured, the exceptions being "Emotional Reactions" and "Sleep". Perhaps these domains are influenced by much more than NYHA functional class alone.

As mentioned earlier, although the health domains cannot be compared directly between the NHP and SF-36, it is interesting to note that similar trends were noted with both health survey tools measuring perceived health status.

3. Family Life Cycle

In most of the NHP health domains, males who lived with others tended to indicate a perception of poorer health status. In all but the domains of "Social Isolation" and "Physical Mobility", a greater proportion of males who lived with others than who lived alone indicated some impairment in the health concept measured. This was a similar finding with the SF-36 health survey as well.

Table 3.9
Nottingham Health Profile and FLC
Males

Health Concept	FLC (self/alone) n = 30				FLC (others) n = 22*			
	No Impairment		Some Impairment		No Impairment		Some Impairment	
	n	%	n	%	n	%	n	%
Energy Level	23	77	7	23	13	59	9	41
Pain	27	90	3	10	16	73	6	27
Emotional Reactions	14	47	16	53	10	45	12	55
Sleep	14	47	16	53	9	41	13	59
Social Isolation	17	57	13	43	14	64	8	36
Physical Mobility	21	70	9	30	16	73	6	27

* 1 missing value

The female study subjects responded somewhat differently from the males. The data suggest that women who live alone tend to rate their health more poorly than do women who live with others. This trend was evident with varying degrees in all domains but two: "Energy level" and "Emotional Reactions". Again one must interpret the results

with caution especially because of the small sample size, however the reverse trends among males and females are interesting findings.

Table 3.10
Nottingham Health Profile and FLC
Females

Health Concept	FLC (self/alone) n = 20				FLC (others) n = 42			
	No Impairment		Some Impairment		No Impairment		Some Impairment	
	n	%	n	%	n	%	n	%
Energy Level	11	55	9	45	21	50	21	50
Pain	14	70	6	30	34	81	8	19
Emotional Reactions	9	45	11	55	19	45	23	55
Sleep	9	45	11	55	26	62	16	38
Social Isolation	11	55	9	45	29	69	13	31
Physical Mobility	12	60	8	40	27	64	15	36

4. Summary of the Nottingham Health Profile

At the outset it should be noted that the study sample is small therefore precise conclusions cannot be formulated. However there are some trends which may be interesting to pursue with a larger sample.

Overall, when the genders were compared, without dividing the sample into sub-groups, very few differences were noted. Both males and females responded fairly similarly in the six health concepts measured. However, if one were to describe a trend, perhaps it could be noted that females tended to rate their health somewhat poorer than the males in the study sample. It is certainly not a strong trend, however in the domains

of "Energy Level", "Pain", and "Physical Mobility", a greater proportion of women indicated some impairment in the health domain than did the males. Within the domain of "Emotional Reactions" the genders responded the same. This general trend was evident with the SF-36 Health Survey as well. Interestingly, a reverse trend was noted in the domain of "Sleep" in which a greater proportion of males indicated some impairment than females.

When the subjects were divided into sub-groups based on NYHA functional class a trend similar to that noted with the SF-36 became apparent. Generally the responses to the NHP questionnaire items indicated a perception of poorer health status among the respondents who were classified as having some functional limitation than among subjects classified as having no functional limitations as outlined earlier. This trend was evident both among the female and male study subjects.

Within the FLC categories, a curious phenomenon became evident where overall, males who lived with others perceived their health to be poorer than males who lived alone and females who lived alone perceived their health to be poorer than females who lived with others. The evidence is not strong to support these conclusions however there is a suggestion that this paradox was evident with the SF-36 as well.

IV. Health Behaviours

In this section selected health behaviours of adults with CHDs as a whole, and broken down into the subgroups described earlier, are explored. Comparisons are made within groups and with the health behaviours of the general population. The results of Canada's Health Promotion Survey: 1990 provided the data against which the sample was compared.

A. Cigarette Smoking

Table 3.11 describes those who answered "Yes" to the question "At the present time, do you smoke cigarettes?". Raw data is not available for the Alberta population so direct comparisons are not possible. However, confidence intervals were estimated for the study sample.

Table 3.11
Prevalence of Cigarette Smoking by Gender and Age
CHD Sample and Alberta

Age Group	Study Sample						Alberta	
	Female			Male			Female	Male
	n	%	95% CI.	n	%	95% CI.	%	%
20 - 29	9	30	14% to 46%	7	26	9% to 42%	35	37
30 - 39	5	22	5% to 38%	3	19	0% to 40%	30	35

A single individual of the 19 subjects over 40 years of age reported being a current smoker therefore no comparison was made with the Alberta data as it would not provide meaningful information. As can be seen in Table 3.11, it appears the study subjects are less likely to smoke compared to the Alberta population. However, the significance of the differences is questionable given the wide confidence intervals and the lack of comparative data for Alberta from which confidence intervals could be estimated.

The total number of smokers in the study sample is fairly small overall as can be seen in the above table therefore comparisons with the Alberta data must be viewed with caution. Only 25 of the 115 (22%) respondents reported smoking in the last 12 months (11 males; 14 females).

Because of the small numbers of smokers in the study sample, it was necessary to collapse the categories of functional ability to "no limitation" (NYHA=1) and "some limitation" (NYHA>1) in order to make the interpretation more meaningful. Smoking status was categorised as "current smoker", "former smoker" and "never smoked". When looking at gender separately, there appears to be evidence for an association between functional class and smoking status among women (FET, $p = .011$). However, among men there does not seem to be any evidence for such an association (FET, $p = .49$). The data showed that 62% of females with no functional limitation (95% CI = 47% to 77%) reported never having smoked whereas 30% of females with some limitation (95% CI = 10% to 50%) reported the same. The data also indicated that 50% of females with some functional limitation (95% CI = 28% to 72%) reported having quit smoking, whereas only 14% of females with no limitation (95% CI = 4% to 24%) reported having quit. The proportion of women who still smoke is essentially the same for both NYHA groups. A similar association is not evident for males. However, for both groups, the numbers of subjects is too small to make firm conclusions.

There was no evidence for an association between categories in the family life cycle (FLC) and smoking status ($\chi^2=.74$, $df=2$, $p = .69$). Again, because of the small numbers it was necessary to collapse the FLC categories. Two categories were created based on whether the individual was single, or whether he or she had some affiliation either with a significant other or with offspring ("self" or "others").

B. Alcohol Consumption

Of the 115 total respondents to the survey, 100 (87%) answered "Yes" to the question "In the past 12 months have you taken a drink?" (53/62 females; 47/53 males). A drink was defined in the survey as: one bottle of beer or glass of draft; one small glass of wine; or one shot or mixed drink with hard liquor. Table 3.12 illustrates the responses

by age group for those who responded "yes" to the above question. Table 3.13 illustrates the frequency of drinking by gender. Both of the tables also provide the Alberta percentages for each category.

As can be seen from Table 3.12, the study subjects do not appear to differ from the general Alberta population in that almost everyone reported having taken a drink in the last 12 months. However the number of individuals in the study sample was small as is evident from the raw data and very wide confidence intervals. As mentioned earlier, the Alberta data is reported in percentages only. No raw data were available against which to compare the study sample.

Table 3.13 indicates that 15 (13%) individuals (6 males, 9 females) claimed to have abstained from drinking in the previous 12 months, 7 of whom (4 males, 3 females) claimed to be lifetime abstainers.

Table 3.12
Prevalence of Alcohol use by Gender and Age

Age Groups	Study Sample						Alberta	
	Female			Male			Female	Male
	n	%	95% CI.	n	%	95% CI.	%	%
20-29	27	90	79% to 100%	24	89	77% to 100%	87	92
30-39	18	78	62% to 95%	14	88	71% to 100%	88	90
40-59	6	100		8	89	68% to 100%	78	88
60+	2	67		1	100		65	81

As can be seen from Table 3.13, the number of individuals per category is small resulting in very wide confidence intervals. Nevertheless there is no evidence to suggest that the frequency of drinking among individuals in the study sample is different from the general Alberta population.

Table 3.13
Frequency of Drinking by Gender

Frequency of Drinking	Study Sample						Alberta	
	Female			Male			Female	Male
	n	%	95% CI	n	%	95% CI	%	%
every day	1	2	0% to 5%	2	4	0% to 9%	1	5
2-3 times per Week	5	8	2% to 14%	11	21	10% to 32%	8	22
Once per Week	7	11	3% to 19%	11	21	10% to 32%	13	18
1-2 Times per Month	13	21	11% to 31%	14	26	14% to 38%	23	22
< Once per Month	27	44	31% to 57%	9	17	7% to 27%	32	14
Non- drinker	9	15	6% to 24%	6	11	3% to 19%	20	12
Total	62	100		53	100		100	100

As with cigarette smoking, the data were explored with respect to drinking status and drinking frequency according to NYHA functional class and stage in the Family Life Cycle.

Drinking status was categorised into "former drinker", "current drinker" and "never drinker". However when the data were analysed, the individual cells had very small numbers especially when broken down by gender. The categories were therefore modified to "drinker" and "non-drinker" but the non-drinking categories still had few individuals. Nevertheless there was evidence of an association between NYHA classification and drinking status among males (FET, $p = .01$). Ninety-seven per cent of males with no functional limitation (95% CI = 92% to 102%) were drinkers whereas 71% of males with some functional limitation (95% CI = 50% to 92%) reported being drinkers. The analysis failed to demonstrate a similar association among females (FET, $p = .45$).

To examine the association between drinking frequency and NYHA classification, the drinking frequency categories were collapsed into "rare or non-drinker" and "regular drinker". A rare drinker was defined as one who drank less than once per month. A regular drinker was defined as one who drank at least 1-2 times per month. The NYHA classification was collapsed as described earlier. There was insufficient evidence to indicate an association between NYHA functional class and drinking frequency (FET, $p = .074$). There was also insufficient evidence to support an association between FLC and drinking frequency (FET, $p = .707$).

There was no evidence for an association between drinking status and FLC (FET, $p = 1.00$). Drinking status was categorised as "drinker" and "non-drinker" as was done for the NYHA analysis.

C. Exercise and Activity

Table 3.14 illustrates the frequency of exercise among the CHD sample versus the Alberta population. These results reflect responses to the question "How many times per week, on average, do you exercise?"

Overall, there was insufficient evidence to suggest a difference between the study sample and the Alberta population. There is a suggestion that fewer individuals in the study sample (both male and female) exercised at least once per week, than in the Alberta population. There is also a suggestion that a smaller proportion of females in the study sample than in the Alberta population exercised 3-4 times per week. There may also be a suspicion that a greater proportion of males in the Alberta population than in the study sample reported never exercising. Again, because the sample size per category is so small, interpretation of the data must be made with caution. Overall, however, there does not appear to be an important difference between the study sample and the Alberta population regarding exercise frequency.

Regular exercise was defined by Canada's Health Promotion Survey: 1990 as exercise at least 3 times per week. Forty-six percent of males (95% confidence interval = 34% to 58%) in the CHD sample responded that they took part in regular exercise whereas 28% of females (95% confidence interval = 17% to 39%) responded likewise. The Alberta data indicate that 56% of both males and females exercised regularly. The data suggest that the females in this sample differ somewhat from the general Alberta population in that they appear less likely to exercise regularly however, again because of the small sample size generalisations cannot be made with confidence. It also appears that females in the study sample are less likely to exercise regularly than males.

The sample size was too small to examine the data by age categories.

Table 3.14
Frequency of Exercise by Gender

Frequency of Exercise	Study Sample						Alberta	
	Female			Male			Female	Male
	n	%	95% CI.	n	%	95% CI.	%	%
Daily	7	11	2% to 20%	10	19	8% to 30%	20	25
5-6 Times per Week	2	3	0% to 17%	3	6	0% to 26%	10	10
3-4 Times per Week	9	14	6% to 24%	11	21	10% to 32%	26	21
1-2 Times per Week	14	23	12% to 34%	13	25	13% to 37%	20	22
< Once a Week	13	21	10% to 32%	7	13	4% to 22%	3	2
Never	14	23	12% to 34%	5	10	1% to 17%	21	20
Don't know	3	5		3	6		n.a.	n.a.
Total	62	100		52*	100		100	100

* 1 missing value

For the purpose of between group comparisons, the exercise frequency categories were collapsed due to small numbers per cell. Exercising at least 1-2 times per week was classified as regular exercise, and exercising less than once a week or never exercising were classified as sporadic/never. There is evidence to suggest that there is an association between NYHA functional classification and exercise frequency among males (FET, $p = .020$). Eighty-two per cent of men with no functional limitation indicated they exercised regularly (95% CI = 69% to 95%) whereas 47% of men with some functional limitation (95% CI = 23% to 71%) claimed to exercise regularly. There was no similar association for females (FET, $p = 1.00$).

There was no evidence for an association between exercise frequency and FLC (FET, $p = .179$).

In response to the question "Does your heart condition influence your decisions about how often or what type of exercise you might do?", about one-half of the respondents answered "Yes" (47% of males, 52% of females). When the responses were analysed according to NYHA functional class, 82% of males who had some functional limitation responded "Yes" (95% CI = 64% to 100%) whereas 31% of males with no limitations responded "Yes" (95% CI = 16% to 46%). The difference was statistically significant (FET, $p = .001$). Seventy-four percent of females who had some functional limitations responded "Yes" to the question (95% CI = 54% to 94%) whereas 42% of females with no limitations responded "Yes". (95% CI = 27% to 57%) Like the males, there was evidence to suggest a relationship between responding "Yes" to the question and NYHA classification (FET, $p = .031$). Both women and men with some functional limitation were more likely to report that their heart condition influenced their decisions about the frequency and type of exercise in which they engaged. It is important to note that again the confidence intervals are very wide therefore it is difficult to make any firm conclusions based on such a small sample size.

There was no evidence of a relationship between responding "Yes" to the above question and the FLC classification (FET, $p = .26$).

When asked the question whether they believed themselves to be limited in the kind or amount of activity they could do because of their heart condition, 43% of the respondents answered "Yes". There was evidence for an association between NYHA functional class and perceived activity limitation in the males (FET, $p = .001$). Seventy-six per cent of males with some functional limitation (95% CI = 56% to 96%) indicated that their heart condition limited the kind or amount of activity they believed they could do whereas 28% of males with no functional limitation (95% CI = 13% to 43%) responded likewise. There was also evidence for an association between NYHA functional class and activity limitation among females (FET, $p = .030$). Sixty-five

percent of females in the study sample with some limitation (95% CI = 44% to 86%) responded that their heart condition limited the kind or amount of activity they could do whereas 34% of female with no functional limitation (95% CI = 20% to 48%) responded the same. The data suggest that, as expected, subjects in the "some limitation" category were more likely to respond "yes" to the question than those in the "no limitation" category. There was no evidence to support such an association between FLC and activity limitation (FET, $p = .342$).

D. Medicines

When asked the questions about having taken medications in the past year, males and females responded similarly and were also very similar to their Alberta counterparts. Subjects reported taking tranquilizers (8% of males, 7% of females), antidepressants (8% of males, 3% of females), codeine, Demerol or morphine (males and females 21%), sleeping pills (6% of males, 7% of females), and ASA (77% of males, 80% of females). Forty-three percent of males and 23% of females indicated they took medications specifically for their heart condition.

The numbers were too few to examine the individual medications by NYHA and FLC except for the medications specifically for the heart condition. There appeared to be evidence for an association between taking medications specifically for the heart condition and the NYHA classification among males (FET, $p = .001$) and among females (FET, $p = .008$). Seventy-six percent of males with some limitation (95% CI = 66% to 86%) indicated they took medication specifically for their heart condition whereas 28% of males with no functional limitation (95% CI = 13% to 43%) responded the same. Among females, 45% with some functional limitation (95% CI = 23% to 67%) indicated they took medication specifically for their heart condition whereas 12% with no functional limitations (95% CI = 2% to 22%) responded likewise. The data indicate that

subjects with some functional limitation were more likely to take such medications. There was no evidence for an association between FLC category and the taking of heart medications (FET, $p = .841$).

E. Illicit Drug Use

When asked whether street drugs had ever been used, the percentages were generally very small. As with the previous section dealing with medications, males and females responded similarly and were, in general, not too different from the Alberta percentages. Illicit drug use included marijuana or hashish (32% of males, 31% of females), cocaine or crack (8% of males, 5% of females), LSD (4% of males, 8% of females), amphetamines (4% of males, 8% of females) and heroin (0 for both males and females). The only possible difference which could be commented upon is the slight discrepancy between females in the CHD sample and those in the Alberta population with respect to marijuana or hashish use. Thirty-one percent of females in the study sample reported having used these drugs (95% CI 20% to 42%), whereas 17% of females reported likewise from Alberta. Because the sample size is so small, this difference may not in fact be noteworthy.

There were too few individuals who reported illicit drug use to do analyses on the NYHA and FLC subgroups.

F. Blood Pressure

As expected, most of the study subjects had had their blood pressures checked within the past year (94% of males (95% CI 88% to 100%) and 88% of females (95% CI 80% to 96%)). This compares to the Alberta data which reports that 71% of males and 87% of females in the general population did likewise. It appears from the data that the males in the study sample were more likely to have their blood pressure checked in the

past year than males in the general population. The females in the study sample, were no different from the females in the general population. The frequency of blood pressure checking did not vary with the FLC or NYHA subgroups. The sample size was too small to make any meaningful comparisons based on age categories.

G. Dental Health

Dental health behaviours were explored because of the increased risk among individuals with CHDs of contracting subacute bacterial endocarditis (SBE). One major portal of entry for bacterial contamination is from the oral cavity. Good dental hygiene minimises the risk as does SBE antibiotic prophylaxis before dental procedures which might cause lacerations in the oral cavity.

Of the 115 respondents, 4 reported they did not have their own teeth (2 male and 2 female) and one individual (male) did not respond to the dental health questions. Therefore there were 110 responses to the survey questions. Most of the respondents (96%) reported brushing their teeth at least once per day which compares to the Alberta population where 94% reported the same. The Alberta data does not provide comparable data for each gender, however in the study sample, 100% of the females and 92% of males reported brushing at least once per day. Seventy-six percent of the study sample reported having seen a dentist in the past year compared to 71% of Albertans. Thus there is no evidence to suggest that the study sample differs from the Alberta population.

The majority of respondents (89%) had SBE prophylaxis recommended by their physician all of whom reported following the recommendations. There was no evidence for an association between SBE prophylaxis and NYHA classification (FET, $p = .545$), nor was there evidence for an association with FLC (FET, $p = 1.00$).

H. Summary of Health Behaviours

In summary, with respect to the foregoing descriptions of health behaviours it appears that overall the study subjects do not differ markedly from the general population. However, the data must be interpreted with caution because the sample size is very small particularly when subdivided into NYHA and FLC categories.

When the data were examined by NYHA functional class, there were a few observations worth noting as follows. There did not seem to be an association between smoking status and NYHA functional class among males, yet there was evidence for an association among females in that women with some functional limitation were more likely to have quit smoking than those with no limitations. As well, women with no functional limitations were more likely to have never smoked than women with some functional limitations.

There was no evidence for an association between drinking status and NYHA functional classification among females, however, males with some functional limitations were less likely to drink than males with no limitation. There was no association between drinking frequency and NYHA functional class among either males or females.

Males in the study sample who had some limitations in NYHA functional ability were less likely to exercise regularly (at least 1 to 2 times per week) than males who had no limitations in functional ability. There was no similar association detected among females although proportionately fewer women exercised regularly compared with men. When asked whether their heart condition influenced the frequency and type of exercise undertaken, not surprisingly, males and females who had some limitations in functional ability were more likely to respond in the affirmative than males and females who had no limitations. Similar results were apparent for subjects who had some limitation in functional ability when asked whether they felt they were limited in the kind or amount of activity that they do because of their heart conditions.

Both males and females who had some limitation in functional ability were more likely to have taken medication specifically for their hearts than subjects who had no limitations in functional ability.

CHAPTER 4

DISCUSSION

This chapter will discuss more fully the results reported in Chapter 3 including the socio-demographic variables of the study sample and in particular, the health behaviours and perceptions of health status of a sample of adults with congenital heart disease. A discussion of the usefulness of the instruments used, the strengths and limitations of the study, and suggestions for future research are presented.

At this point it must be clarified that the study examined only individuals with isolated CHDs. Individuals with other disorders or diseases were excluded from the study due to the nature of their mental or physical health. It is possible that the study sample is a relatively healthy subset of the clinic population which may affect the interpretation of the results. The results may not pertain to the excluded group.

I. Socio-demographic Characteristics

For the most part, the study sample did not differ markedly from the Canadian population (as reflected in the Canadian Health Promotion Survey) with respect to employment. However, some interesting differences emerged when education level and income adequacy, were explored in conjunction with employment status. When one first examines the data, the study sample as a whole is more highly educated (a greater proportion having completed post secondary studies), is equivalently employed, and has a

greater proportion of very poor individuals compared with the Canadian population. In order to explain the apparent discrepancy, one must first explore each variable in isolation. With respect to education level, it is clear that the sample size was too small to create subgroups based on age. If this had been feasible, it might have been possible to control for the potential confounding effects of age. Canada's Health Promotion Survey: 1990 (1993) included not only individuals between the ages of 15 and 19 years but also included a large proportion of individuals over the age of 40 years. The study sample, on the other hand, did not include any individuals between 15 and 19 years of age and had relatively little representation from the over 40 age group. This is an important distinction since most individuals between the ages of 15 and 19 years would not have completed post secondary studies, and, as was evident from the Canadian study, the maximum level of education attained decreased as the age of the respondents increased. Very few respondents over the age of 65 years had completed any post secondary education. The inclusion of these age groups in the Canadian survey potentially dilutes the overall response to the question of the maximum education level attained. The Canadian data suggest that approximately 38% of individuals between the ages of 25 and 44 years have completed post secondary studies (as opposed to the 28% reported overall) whereas, 45% of the total study sample indicated having completed community college or university. The differences do not now seem as great as one might have originally thought. In fact, because of the small study sample size (resulting in the decreased precision of the point estimate), because the raw data for the Canadian survey were not reported (resulting in the inability to estimate confidence limits), and because of the confounding effects of age, it is entirely possible that there was no difference between the study sample and the general population regarding education level.

Employment status seems to be equivalent between the Canadian population and the study sample. However, this study did not analyse the nature of the employment

whether it be managerial/professional, other white collar, blue collar (as did the Canadian survey), or full time or part time. Therefore, it is not possible to say with any degree of certainty whether there is or is not a difference between the two groups.

According to the study data, a greater proportion of the study sample than the Canadian population was classified as "very poor" with respect to income adequacy. Again, the concerns outlined earlier regarding small sample size, wide confidence limits, and no raw population data may well explain the observed difference. It is possible that a greater proportion of study subjects might be classified as "very poor". This could be explained by potentially more part time work among the study subjects, a higher rate of underemployment, or a different economic climate in 1994 (year of the current study) than in 1990 (year of the Canadian health promotion survey).

Despite the above noted concerns regarding the interpretation of the results, Gersony et al. (1993) reported similar results regarding educational attainment in their study of adults over the age of 25 years with one of three congenital heart defects (aortic stenosis(AS), pulmonary stenosis(PS), and ventriculoseptal defects(VSDs)). However, the current study and Gersony et al. (1993) are not necessarily comparable. The current study included all CHDs (subject to the exclusion criteria) and included individuals 20 to 25 years of age. It is also possible that the definitions of the education categories differ between the two groups. Nevertheless, it is worth noting that the two CHD studies did not appear, on the surface, to differ markedly with respect to education.

Gersony's study did not address income adequacy, however, employment status was explored. The categories differed from the current study so direct comparisons are not possible. However, 73% of Gersony's sample were employed or self employed compared to 63% for the current study sample who responded that they were 'working at a job'. The current study included categories not included in Gersony's study therefore it is difficult to comment on the apparent difference.

Like previously reported studies (Otterstadt et al., 1986, and Gersony et al., 1993), 90% of the respondents in the current study sample were classified as having no or slight functional limitation based on the NYHA classification of disease.

Gersony et al. (1993) reported that almost 90% of their sample was classified as having no functional limitation which was somewhat higher than in the current sample (68%). One might infer from this discrepancy that the study sample drawn from the patients attending the Adult Congenital Heart Clinic at the Calgary General Hospital is 'sicker' on the whole than Gersony's population or that there were differences in the physicians' approaches to classifying the subjects. The former explanation is plausible as the current study sample was not limited to the diagnoses of AS, PS, or VSD. Suffice it to say, the greatest proportion of adults with CHDs reported in the literature and in the current study have little or no functional limitations. This makes intuitive sense as those individuals more severely affected are more likely to develop complications and perhaps succumb to their disease.

In conclusion, with respect to the variables explored, the study sample did not differ markedly from the Canadian population nor did it appear to differ to any great extent (as far as comparisons can be made) from similar samples in previous studies reported in the literature.

II. Health Perceptions and Behaviours

1. Perceptions

In general the study subjects rated their health the same as the Alberta respondents to Canada's Health Promotion Survey: 1990 (1993). The one notable exception is that the study sample respondents, both male and female, were less likely to rate their health as 'excellent' compared to the general Alberta population. Given the nature of the conditions with which the study subjects are affected, this might be viewed as an

expected result. Of interest, Gersony et al. (1993) asked a similar question of their respondents. Unfortunately the categories in their study differed somewhat from the current study, most notably the exclusion of the category "very good". It is therefore not possible to compare the two studies precisely. However, it appears that more subjects in the current study rated their health as "fair" or "poor" (males, 23%; females, 28%) than did the respondents to Gersony's study (10.5%). If the categories are comparable, this again may reflect the possibility that the respondents to the current study are somewhat 'sicker' than the individuals in Gersony's study. Interestingly, Gersony et al. (1993) did comment that the distribution of responses varied with the diagnosis, where patients with VSDs were more likely to rate their health as "fair" or "poor" and less likely to rate their health as "excellent" than patients with AS or PS. Possible explanations for the differences were not provided by the authors. It was not possible in the current study to examine self-rated health by diagnosis, however this might prove to be an interesting area for future research.

One difficulty in interpreting broad categories of self-rated health when analysing data from a specific diagnostic group of subjects is that the health rating may or may not in fact be related to the disease or diagnosis of interest. It is not possible to determine whether an individual feels in poor health because of a heart condition or because of some other illness experienced at the time of responding to the questionnaire. However, a general picture of the group overall compared with the general population can be obtained as well as a general picture of the subgroups within the study sample.

When the 8 health concepts of the SF-36 were analysed no marked differences were noted between the study sample data and the normative population data. However some questions do arise when one examines the categories "General Health", "Social Functioning" and "Role-Emotional". It appears that females tend to score slightly lower than the general population. However, due to the limitations of the sample size, the

sample estimates are not precise therefore interpretation of the results must be made with caution. Nevertheless, in the domain of "General Health" for example, males and females in the general population did not differ markedly from each other. However, in the study sample, the females tended to score slightly lower than the general population of females and somewhat lower than the study sample males. This was somewhat different from the overall self-rating of health where women were as likely or perhaps more likely than men to rate their health as excellent. This may well reflect the difference in validity between single item measures of health status and multiple item measures. The SF-36 used five items to measure the concept whereas Canada's Health Promotion Survey: 1990 used only one item. Gender is explored by Verbrugge (1985) who suggests in her review article addressing gender issues and health that women may be more attentive to "body discomforts [which in turn] increases their felt symptom experience and their evaluation of symptoms as illness" (p. 172). This hypothesis coupled with a known cardiac defect may explain the slightly lower scores among the study sample women. A similar trend was evident from the data within the domains of "Social Functioning" (effects of physical or emotional problems on the ability to participate in social activities) and "Role-Emotional" (limitations or problems with daily activities due to emotional problems).

It is not possible to compare each domain separately between the SF-36 and the NHP, however, overall there is a suggestion of a trend toward poorer health perceptions among women than among men in the study sample.

Not surprisingly, where differences were noted in health perceptions when NYHA functional class was considered, the respondents who were categorised as having some functional limitations tended to have a perception of poorer health status than the respondents who had no functional limitations. This seemed true both among males and females although in some cases the differences were slight. Nevertheless, a consistent trend emerged from both the NHP and the SF-36.

There was one curious exception noted in the trend of poorer health perceptions among the more seriously affected respondents. Within the "Emotional Reactions" domain of the NHP (measured by questionnaire items such as, "Things are getting me down" and "I'm feeling on edge"), the data suggest that there is no difference between functional class and the perception of health status among females. Statistical tests were not performed, however the proportions of women who responded that they had "no impairment" or "some impairment" in this domain were identical in both NYHA categories. This raises the question of why do women who have no functional limitation see themselves as having the same level of impairment in this domain as women with some functional limitation? This may just be a chance observation in this data set or it may again relate to Verbrugge's (1985) article in which she contends that women are more aware and attentive to bodily symptoms. Because these women have a congenital heart defect, no matter how minor, it may be possible that a heightened awareness coupled with the heart defect increases women's anxieties and emotional reactions. If this is true, however, one must wonder why a similar pattern did not emerge among the other domains.

Overall, the category of Family Life Cycle (FLC) did not appear to have much influence on the perceptions of health status. A pattern or trend did not emerge within the FLC subgroups as was evident among NYHA categories. Overall, if differences were noted, they tended to indicate perceptions of poorer health status among respondents who live with others (particularly males), but even this was an inconsistent finding. Other issues may affect these perceptions besides the congenital heart defect such as the added strains of providing for and caring for others in the family. Financial concerns and concerns about the economy and employment could well influence responses. As well, whether there are children in the household, as well as the number and ages of the

children might also affect perceptions of health status. These issues would be interesting to pursue in future studies.

In conclusion, health perceptions overall, do not differ substantially from the general Alberta population or from the normative data. There is a suggestion that the study sample subjects might rate their health less highly than the general population which is consistent with previous literature. There is also a suggestion that females might perceive their health to be poorer than males in certain domains. A consistent and expected finding was the evidence that health perceptions varied with NYHA functional class in that subjects who were classified as having some functional limitation according to the NYHA classification system perceived their health to be poorer than the respondents who had no functional limitations. Family life cycle did not appear to be a major factor in affecting perceived health status. However, given the limitation of the study it is not possible to say with confidence that any differences noted in this sample can be generalised to other adults with CHDs. We can only say that the results apply to a subset of the Adult Congenital Heart Disease Clinic at the Calgary General Hospital due to the exclusion of clinic registrants with other anomalies or disorders. However, a number of areas which could be explored in future studies have been identified.

2. Health Behaviours

Overall, it appears that the study sample did not differ from the general population regarding the health behaviours studied. However, when comparing NYHA functional class categories, some interesting results emerged.

For example, with respect to smoking, the degree of severity of the functional limitation ($\text{NYHA} = 1$; $\text{NYHA} > 1$) did not seem to be associated with smoking status among males, that is whether the respondent had quit smoking, was currently smoking or had never smoked. One might expect that individuals who are more severely affected

would be less likely to smoke at all, however this did not appear to be the case among the male respondents. Among females, a rather different picture emerges. The data suggest that a greater proportion of women with some functional limitation have quit smoking than women with no limitation. This implies that more women with some limitation have taken up smoking at some point in their lives than women with no functional limitation. In fact the data indicate that 70% of women with some functional limitation are either current or former smokers whereas 38% of women with no functional limitation smoke or have quit smoking. This is a curious observation for two reasons: first, why was this trend apparent only among the female respondents? and second, why would females who are more severely affected by their heart disease based on NYHA functional class, take up smoking in the first place? It has been acknowledged throughout this report that the study sample is too small to make precise estimates based on the data and to form firm conclusions relying on those estimates. It is also difficult to know how representative the study sample is of the general population of adults with isolated CHDs. However, the seeming paradox is worth exploring. Because of the limitations of sample size, it was not possible to stratify the data based on age which might have been a factor influencing smoking status. According to Waldron (1988), young women "have been as likely or more likely than males to be smokers ... in recent years" (p.195), and perhaps age is a factor in this instance. However this does not explain the appearance that the more severely affected women have taken up smoking at some time in their lives. Verbrugge (1985) and Waldron (1988) suggest that men generally tend to partake in riskier behaviours than do women however in this study, it did not seem to be the case. A number of other factors could influence smoking behaviour including culture (Waldron, 1988), family of origin (Rossow & Rise, 1994; Sallis & Nader, 1988), and peers (Sallis & Nader, 1988). Rossow and Rise (1994) suggest that "parents provide models for their adolescent offspring in a range of health behaviours ... and in addition this modelling

influence persisted *at least* until the age of 20" (p.1305). Their study explored parental and adolescent health behaviours and although the study focused on adolescents the authors suggest that the behaviours learned in childhood and adolescence may persist well into adult life. The chronic disease literature also provides some possible explanations for the apparent paradox of seemingly 'sicker' individuals engaging in somewhat poorer health behaviours such as smoking. Arluke (1988) suggests that the chronically ill may not wish to be singled out as somehow different, or may wish to avoid being stigmatised therefore they "feel an imperative to cover up their conditions and keep up their routines so their relationships generally remain normal" (p.173). There may also be control factors at play. It is possible that patients with CHDs feel they have no control over their heart condition and therefore try to take control of other aspects of their lives. This may include behaviours which could prove detrimental to their health nevertheless, the behaviours are within their control. Miller (1983) maintains that powerlessness and fear of lack of control are common psychological reactions to chronic medical illness. The study of the determinants of health behaviours is a very complex issue particularly when coupled with the complexities of gender influences and chronic disease issues, so that no one explanation seems to suffice in explaining a particular health behaviour. Perhaps future studies may provide some explanations not yet hypothesised.

Alcohol consumption was also investigated and overall the study sample did not differ from the Alberta population regarding the prevalence of alcohol use or the frequency of drinking. Generally the study males tended to drink more frequently than the study females which is consistent with the previous literature (Waldron, 1988). Again, NYHA functional class was explored and in this case fewer males with some functional limitation responded that they were drinkers than those with no limitation. This makes intuitive sense but for females no such trend was observed. This may be related to the fact that women tend not to drink as much as men in the first place, but it is

interesting to note that a trend to fewer drinkers among the more severely affected women was not evident. However, it is difficult to interpret the data as very few individuals were classified as non-drinkers for both males and females. As mentioned earlier, it is likely that many factors govern the prevalence and frequency of drinking among groups of individuals such as culture, and health behaviours of the family of origin. Such aspects could be addressed in future studies.

Frequency of exercise was also explored. Overall this variable did not differ much from the Alberta population, however there is a suggestion that the study sample might exercise less frequently than the general Alberta population. This may reflect the population from which the study sample was drawn, but again, factors such as age, culture, and family of origin health habits may apply. A majority of both males and females in the study sample with some functional limitation indicated that their heart condition influenced their decisions about how often and what type of exercise they might undertake. This general response was reflected in the responses to the question about the frequency of exercise. Males with some functional limitation were less likely to exercise regularly than males with no functional limitation. Again, the genders responded differently in that this observation was not evident among females. This may perhaps be related to the suggestion from the data that the women tended to exercise less than the men overall and this is supported by the results from Canada's Health Promotion Survey: 1990, in which it states that "there is a significant tendency for men to be more active than women" (1993) particularly in the ages 15 to 24 and it is not until the ages of 45 to 64 that women become more active than men. Given the relatively young age of the study sample it is thus not surprising that a similar finding was revealed. However a number of different factors may also be at play such as role responsibilities, socialisation, and family of origin health behaviour expectations.

The results regarding health behaviours are inconsistent. One might intuitively think that adults with CHDs would behave somewhat differently from the general population and that the degree of severity associated with the CHD would influence health behaviours. However, the study results show that the adult CHD sample obtained from the Adult Congenital Heart Disease Clinic at the Calgary General Hospital appear to behave no differently from the Alberta population. Due to the limits of the sample size, generalisations cannot be made to the general population of adults with CHDs.

There was an inconsistent finding with respect to the effects of the severity of the heart disorder on behaviour. In some cases an expected result was observed. For example, men with more severe disorders were less likely to drink than men whose disorders were less severe. On the other hand, in some cases the result was unexpected. For example more women with some functional limitation were or had been smokers than women with no functional limitations. Factors influencing health behaviours are difficult to identify and many interrelated factors may be at play such as age, roles, gender, culture, societal expectations, peers, and family of origin to name a few. Perceptions of health status may or may not play a role and will be discussed further in the following section.

The Family Life Cycle did not appear to be a factor associated with health behaviours in this study. Perhaps if one were to explore family issues in future studies, a more fruitful approach might be to assess roles and responsibilities within a family structure. Perceptions of health status may well be dependent upon the degree to which family responsibilities are shouldered by individuals within the family unit coupled with the added stress of the diagnosis of a CHD.

3. Summary of Health Perceptions and Health Behaviours

Although the study was not designed to determine whether perceptions of health status influence, affect, or predict health behaviours, it is appropriate at this time to look

back to the Health Belief Model (HBM) which provided the conceptual framework for this study. As mentioned earlier in the paper, the HBM states that individuals will undertake preventive health behaviours when they perceive they are susceptible to adverse health outcomes, when the outcomes are perceived to be serious and when the perceived benefits to preventive actions outweigh the barriers to undertaking such actions. The model was chosen because of an interest in health perceptions and behaviours of a group of adults with CHDs. If these individuals perceive themselves to be ill or to be at risk of becoming ill, one might expect them to be more aware of the potential health risks of particular unhealthy behaviours and the health benefits of yet other behaviours, and modify their behaviours accordingly. One might expect that they would be more vigilant and cautious regarding their health. As was evident in the section dealing with health perceptions, overall there do not appear to be differences between the health perceptions of the study sample and the general population. As a total group, they do not appear to perceive themselves to be ill. The behaviours of the group, compared to the Alberta population, seem to reflect their perception of not being ill in that the behaviours of the study sample are remarkably similar to the Alberta population overall. However when one explores NYHA functional class, a fairly consistent finding emerged in that the subjects with some functional limitations were more likely to perceive their health to be poorer than the subjects with no functional limitation. However, this perception did not consistently translate into the behavioural realm. Genders responded differently where in some cases females with some functional limitations engaged in riskier behaviours such as smoking and in other cases males with some functional limitations modified their behaviours such as drinking.

It is clear from the literature that many factors influence or are associated with health behaviours. Norman (1986) in his review of the literature on the nature and correlates of health behaviours suggests that socio-economic status, age gender, family

social networks and personality characteristics all play a role to varying degrees, though no single factor in isolation seems to correlate strongly with health behaviours. The literature is somewhat ambiguous regarding the extent or degree to which perceptions or beliefs about health status influence behaviour. Although Rosenstock (1990) in his review of the HBM suggests that studies have indicated that 'perceived susceptibility' was an important factor overall in predicting the use of preventive health behaviours, he also states that the "belief-behaviour relationship has never been uniformly established ... [and it has] ... rarely, if ever been argued that beliefs are in themselves sufficient conditions for action" (p. 48).

The areas of health behaviours and health perceptions is very complex with apparently many factors implicated in determining health behaviours. Perceptions of health status may well play a role but not necessarily alone. Perhaps perceptions are important in determining or influencing health behaviours but only when in concert with other factors such as age, gender, ethnicity, socio-economic status to name but a few as suggested by the Health Belief Model (see Appendix B).

III. Measurement Tools

Three tools were used in the current study: the Nottingham Health Profile, the SF-36 Health Survey, and selected items from Canada's Health Promotion Survey: 1990. All three tools were useful as general measures of either perceived health status or health behaviours. Normative population data were available for the SF-36 Health Survey and recent Canadian or Alberta data were available against which to compare the selected health behaviours. A general picture of the study sample was therefore obtained by the use of these tools. However, due to the nature of the study design and of the questions asked of the respondents, no cause and effect relationships could be established. Also, because the tools were not created specifically for a group of adults with CHDs, it is

difficult to determine whether the responses reflected health perceptions and behaviours due to the presence of the heart defects, or due to some other illness or circumstance experienced by the subjects at the time of responding to the questionnaire. There was an attempt at the outset of the study to exclude individuals with obvious chronic diseases such as diabetes or schizophrenia from the sample to attempt to control for the confounding effects of such disorders as much as possible. However it is quite possible that other illnesses, not evident from the initial chart reviews, could well have been present thereby influencing the responses to the questionnaire. It is also possible that economic or financial circumstances could have influenced perceptions of health status.

The year 1994 was a difficult one for Calgary with the restructuring of many industries, corporations and institutions resulting in job losses or uncertainty about future employment prospects. One might expect that such an economic climate would have an impact on the general population as well as the study sample. The data against which the study sample was compared was collected in 1990, and although economic uncertainty might well have been a factor in that year as well, there has been in the intervening years, considerable upheaval in the financial and political world both across Canada and in particular Alberta. It would have been useful to have had a control group from the general population selected at the same time as the study sample.

The tools were more useful when comparing sub groups in the study sample. Again, because of the factors mentioned earlier, the responses may not necessarily have been the result of the presence of the CHDs. However, a consistent pattern emerged for the NYHA categories from both the NHP and the SF-36 with respect to health perceptions. It appeared from the data that the subjects who had some functional limitation tended to perceive their health status to be somewhat poorer than subjects with no functional limitation. Because the trend was consistent, and notwithstanding other

factors which could also affect responses, it is possible that the CHDs had some influence on the manner in which the subjects responded to the questionnaire.

There are some drawbacks when using mailed questionnaires such as this, particularly when a study focuses on a select group of individuals from a clinic population. It is possible that, even though confidentiality of responses and anonymity in reporting the results were stressed at the outset, there was some attempt on the part of the respondents to answer the questions in a manner reflecting what they thought the cardiologists or researcher might wish to hear particularly with respect to health behaviours (i.e. social desirability (Dooley, 1990; Fowler, 1984)). The respondents might have been concerned that some form of reprisal would ensue should the answers not be viewed favourably by the individual reviewing the questionnaire.

The SF-36 and the NHP were similar yet distinct tools. Neither could be compared exactly with the other, however overall the subjects responded similarly on both questionnaires. When subjects indicated a trend to perceptions of poorer health status on the SF-36 a similar result was shown on the NHP. In future studies however, it would be preferable to use the weighted scores for the NHP rather than a simple tally of affirmative responses. Because some domains had three items and others had eight or nine items, an affirmative response would not necessarily carry the same weight in each domain. The use of proportions of no affirmative responses versus some affirmative responses is not ideal and does not provide as accurate or complete a picture as might be obtained by using the weighted scoring system. In that case it might also be possible to compare the tools more closely. The NHP was also intended to measure more extreme health problems than was the SF-36 thus comparability again might not be precise. It is possible that a score of zero on the NHP, indicating no perceived health concerns could show on the SF-36 as a perception of somewhat poorer health status (Brazier, et al., 1992).

Because the NHP and the SF-36 measure health perceptions, albeit somewhat differently, they serve to complement each other and are also useful in confirming trends seen in the data.

As mentioned earlier, the SF-36 and the NHP are broad measures of perceptions of health status. It may be necessary to use finer measures to elucidate more fully the psycho-social impact of the diagnosis of congenital heart disease. However, determining areas to explore further from broad measures such as these, is a valuable step in understanding this group of individuals.

IV. Strengths and Limitations of the Study

A. Strengths

This study was intended to describe a group of individuals diagnosed with congenital heart disease who attended the Adult Congenital Heart Disease outpatient clinic at the Calgary General Hospital. The survey provided a broad picture of the group as a whole and provided some insight particularly into their perceptions of health status. Although it is a broad overview of such a group, it is somewhat reassuring to note that overall the subjects did not perceive their health to be too much worse than the general population, and behaved rather similarly to the general population as well. This counteracts anecdotal reports that individuals with CHDs are somewhat more focused on their health and believe they are much sicker than in fact they are.

This type of study is also valuable in raising questions or generating hypotheses to be answered or tested in future studies. Because few, if any, studies have addressed the health perceptions and behaviours of adults with CHDs, this type of investigation provides a valuable starting point from which to enter into further research projects.

B. Limitations

There are a number of limitations associated with a survey such as this. Because it is cross sectional and observational, it is not predictive in that cause and effect relationships cannot be established. Therefore, by design, it is not possible to determine whether health perceptions are predictive of behaviour. There is also a problem with generalising the results to a larger population of adults with CHDs. This study was based on a clinic population which was a select group of individuals who attend an outpatient clinic at a city hospital and did not have any other problems known to the researcher. It was not a sample randomly selected from the general population of adults with CHDs. There is inherent selection bias in this type of sample in that it is a convenience sample and may not be representative of all adults with CHDs. However, it could be argued that if the Adult Congenital Heart Disease Clinic has a clear mandate to provide service to the population of adults with CHDs in Calgary and perhaps southern Alberta, and not just to provide service to those individuals diagnosed and treated at the Calgary General Hospital, the sample may well be more representative than first supposed. But, one cannot be sure that full ascertainment has been obtained or that the sample indeed represents all adults with isolated CHDs. It is possible that this study sample obtained through a hospital out patient clinic is sicker than the general population of adults with CHDs. It is possible that a large number of affected adults do not attend such a clinic and may not seek specialised care for their disorder. It might be possible to say, however, that since the study sample was not very different from the Alberta population, it is unlikely that the rest of the adults with isolated CHDs (no other known health problems) who do not attend the clinic and are presumably less ill, would be in turn much different themselves.

One problem with respect to Alberta's results of Canada's Health Promotion Survey: 1990, was the lack of raw data. The results were published as percentages only.

It was therefore not possible to estimate confidence intervals for the data from the general population with which to make more meaningful comparisons with the study sample.

Another weakness of the study was the lack of a normal control population surveyed at the same time with the same questionnaire. Normative data and data from a previous health survey are helpful but it is not possible to control for factors such as the economic and political climate of the day, education level, socio-economic status, and age. Who can say that perceptions of poorer health status and risky health behaviours do not relate to a 'downturn' in the economy, job loss and employment insecurity?

In a survey of this type, with a fairly lengthy questionnaire with many variables to be explored and analysed, one runs the risk of finding statistically significant results purely by chance. It behoves the reader to take this into account when assessing the results from a study such as this and the writer to interpret the results with caution.

Sample size was also a factor which limited the study. Age and gender are known confounders (Hennekens & Buring, 1987) and the current study was not large enough to do reliable age and gender specific analyses. Nor was it possible to adequately explore the NYHA functional classes and FLC categories because it was necessary to collapse sub-groups in order to get sufficient numbers for analyses. For example, it is quite possible that individuals in NYHA category IV (unable to carry out any physical activity without discomfort) would respond very differently from individuals in NYHA category II (slight limitation in functional ability) on any or all of the variables examined.

However, given these limitations this type of study can certainly be important in laying the groundwork for further analytical research endeavours.

V. Suggestions for Future Research

Ideally, a population based study should be attempted in order to obviate the biases inherent in using a select group such as a hospital outpatient clinic. A population

based study would allow the researcher to draw a random sample from which generalisations could be more comfortably made to the population of adults with CHDs. Should this not be a feasible approach, a larger sample size obtained from collaborating with many centres providing outpatient care to adults with CHDs, should be attempted. One still runs the risk of a biased sample in that a select group of patients may attend such clinics, however if one tries to draw not only from outpatient clinics but also from cardiologist and family practitioner practices, one might be able to obtain a larger and more representative sample of adults affected with CHDs. With larger numbers, more confidence could be placed in the results of the sub-group analyses. A questionnaire designed especially for adults with CHDs might be useful to try to minimise confounding factors such as the presence of other disease processes or socio-economic circumstances. If one were to continue with a mail survey approach used in this study, the response rate might be increased by following Dillman's (1978) protocol more closely and perhaps augmenting the approach with telephone follow-ups. One does run the risk of alienating or angering the respondents by 'pestering' them to respond however Dillman (1978) and Fowler (1984) claim that response rates do increase with repeated contacts with the subjects.

It is interesting that overall, the study sample did not differ from the general population with respect to health behaviours and perceptions. Granted, many adults with CHDs may not be ill, but for those who do have some functional limitation or potential for future limitation, should they not in fact be more careful about their health behaviours than the general population? One must wonder whether this is a positive or negative finding. There are a few questions which arise such as why do females tend to perceive their health to be somewhat poorer than males in some domains? This may not be related to women with CHDs and as mentioned earlier likely relates to the broader issue of gender differences in health as discussed by Verbrugge (1985). There is also the paradox

of why do females with some functional limitation (NYHA) appear to be engaging in riskier behaviours regarding their health than males and women with no functional limitations ?

The family life cycle did not seem to be associated with many of the variables explored and may not be a useful criterion for sub-dividing a group of subjects. Perhaps if one wished to pursue this line of questioning, looking more closely at roles within the family might be more productive.

VI. Implications for Care

The results from this study can be of assistance to health care providers who care for and counsel adults with CHD. Understanding the patients' perceptions of health status and health behaviours is a valuable tool in communicating with patients and in planning health care delivery. It may be interesting and perhaps enlightening to some health care providers that, on the whole, adults with CHDs and no other health problems do not perceive themselves to be ill and they behave generally the same with respect to their health behaviours as does the general population. However, the fact that adults in this study have similar health behaviours to the general population may or may not be a "good thing" from a health promotion standpoint. It is encouraging to know that the health perceptions and behaviours do not differ from the general population, but in fact should these individuals not be more vigilant with respect to their health behaviours considering the added risk factor of having a CHD which the general population does not have?

It is also useful for health care providers to understand that patients who have some functional limitation based on NYHA criteria do perceive themselves to be less well than individuals with no functional limitations. Perhaps programmes could be developed, or use made of the access to the many services available within a large

hospital setting, to target this sub-group to assist them to cope with and monitor their health more effectively.

VII. Conclusions

This study is potentially one of many to follow regarding adults with CHDs. As stated at the outset of the paper, many reported studies in the literature have focused on the prevalence of CHDs, outcomes from various medical and surgical interventions and attempts to determine causation for CHDs. Few, if any, have addressed health perceptions and behaviours. In this day and age when increasingly the onus is on the individual to be responsible for his or her own health, studies such as this can provide the beginnings of some insight into the functioning of a specific group and thus target specific interventions, whether they be educational or otherwise, to make it easier for individuals to live with their disorder and care for their health more conscientiously.

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Appendix A

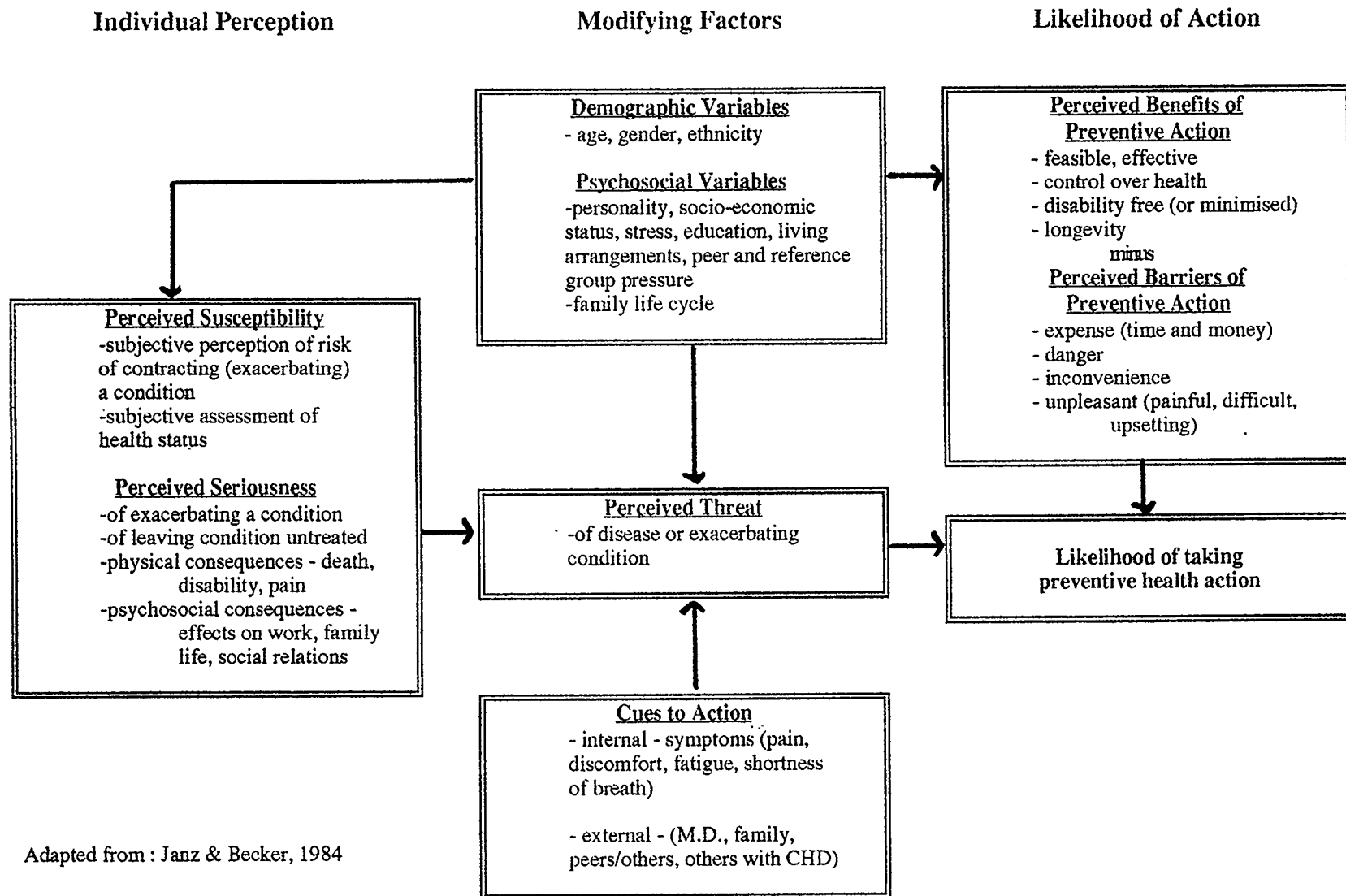
Examples of Congenital Heart Defects Encountered in Adults

Aortic Regurgitation
Aortic valve Disease (e.g.. bicuspid aortic valve)
Aortopulmonary Window
Atrial Septal Defects - ostium secundum, ostium primum, sinus venosus (ASD)
Coarctation of the Aorta
Common Atrium
Congenital Complete Heart Block
Congenital Mitral Regurgitation
Congenital Pulmonary Valve Regurgitation
Discrete Subaortic Stenosis
Ebstein's Anomaly of the Tricuspid Valve
Mitral Atresia
Partial Anomalous Pulmonary Venous Connection
Patent Ductus Arteriosus (PDA)
Pulmonary Artery Stenosis
Pulmonary Valve Stenosis
Supravalvular Aortic Stenosis
Tetralogy of Fallot (VSD with pulmonary stenosis)
Total Anomalous Pulmonary Venous Connection
Transposition of the Great Arteries (Vessels) (TGA or TGV)
Tricuspid Atresia
Truncus Arteriosus
Univentricular Heart
Vena caval-to-Left Atrial Communications
Ventricular Septal Defect (VSD)
Ventricular Septal Defect with Double Outlet Right Ventricle

Adapted from Perloff, J.K., & Child, J.S. (1991). Congenital Heart Disease in Adults. Philadelphia: W.B. Saunders Company (pp. 21-59)

Appendix B

Health Belief Model As it Applies to Adults with Congenital Heart Disease



Adapted from : Janz & Becker, 1984

Appendix C

Review of Cases Identified by Search of Records at the Holy Cross Hospital

1966

Number of Cases of CHD, Gender and Survival Status

1966	Survived		Deceased		Total
	Male n	Female n	Male n	Female n	
Confirmed	2	3	4	1	10
Clinical	0	1	0	0	1
Possible	1	1	0	0	2
Other Anomalies	0	1	1	0	2
Total	3	6	5	1	15

1967

Number of Cases of CHD, Gender and Survival Status

1967	Survived		Deceased		Total
	Male n	Female n	Male n	Female n	
Confirmed	3	2	2	2	9
Clinical	0	0	0	0	0
Possible	0	0	0	1	1
Other Anomalies	0	1	1	0	2
Total	3	3	3	3	12

.1968

Number of Cases of CHD, Gender and Survival Status

1968	Survived		Deceased		Total
	Male n	Female n	Male n	Female n	n
Confirmed	7	5	1	3	16
Clinical	1	1	0	0	2
Possible	3	1	1	0	5
Other Anomalies	0	3	0	1	4
Total	11	10	2	4	27

1969

Number of Cases of CHD, Gender and Survival Status

1969	Survived		Deceased		Total
	Male n	Female n	Male n	Female n	n
Confirmed	1	6	1	1	9
Clinical	1	1	0	0	2
Possible	0	0	0	0	0
Other Anomalies	2	5	2	0	9
Total	4	12	3	1	20

Appendix D

Types of Congenital Heart Disease Ascertained through Chart Review at the Holy Cross Hospital

Note: M = male
 F = female
 † = deceased
 number in brackets indicates number of cases of the disorder/defect

1966

Congenital Heart Disease with no other anomalies (confirmed cases only):

Aortic atresia († M)

Coarctation (M)

Hypoplastic left ventricle and aortic stenosis († M)

Mitral valve agenesis and coarctation († M)

Ostium primum with clefting of mitral valve (F)

Pulmonary branch aortic stenosis, right ventricular hypertrophy, massive PDA -
 Eisenmenger († F)

Tricuspid atresia, ASD, VSD, pulmonary stenosis, left ventricular hypertrophy and
 dilatation, right ventricular hypoplasia, overriding aorta, right sided aortic arch (†
 M)

VSD (F) (2)

VSD, infundibular stenosis (M)

Syndromes or anomalies with CHD or possible CHD:

Tracheo-oesophageal fistula with tetralogy of Fallot, pulmonary valve stenosis,
 overriding aorta and large VSD († M)

Trisomy 21 - VSD and ASD - AV Commune defect class III, tricuspid and mitral
 insufficiency (F)

1967Congenital Heart Disease with no other anomalies (confirmed cases only):

Aortic atresia, poorly developed right atrium and ventricle († F)

Coarctation, right ventricular hypertrophy and dilatation, persistent large ductus arteriosus and persistent PFO († F)

Complete anomalous drainage of pulmonary vessels († M)

Mantled septum secundum with small left atrium, ventricular chamber a common chamber without interventricular septum with one vessel arising from the base of the heart of truncus type († M)

Pulmonary atresia with ASD (M)

Tetralogy of Fallot (M)

Transposition of the great vessels (F)

VSD (F)

VSD and coarctation (M)

Syndromes or anomalies with CHD or possible CHD:

? Syndrome with VSD and pulmonary valve stenosis (F)

Hydrocephalus and ptosis Left kidney - persistent truncus arteriosus, VSD († M)

1968Congenital Heart Disease with no other anomalies (confirmed cases only):

Aortic incompetence - severe, with high VSD (M)

ASD secundum (M) (F) (2)

Complete atresia of the aortic valve with functional 2 chambered heart, diminutive left ventricle and rudimentary mitral valve (†F)

Pulmonary artery branch stenosis, anomalous left coronary artery, mitral valve insufficiency (F)

Pulmonary stenosis - mild to moderate (F)

Pulmonary valve stenosis (F) (M) (2)

Tetralogy and pulmonary atresia (†F)

Tetralogy of Fallot (M)

TGV (M) (†M) (2)

Tricuspid atresia, TGV, PDA, PFO (†F)

VSD (F) (M) (2)

VSD, aorta and pulmonary artery arising from right ventricle (double outlet), pulmonary artery stenosis and PDA (M)

Syndromes or anomalies with CHD or possible CHD:

Horseshoe kidney, bifid ureter, aortic valve stenosis, right ventricular hypertrophy, PDA (†F)

Multiple congenital anomalies - strabismus, bilateral foot deformities, functional megacolon, chest deformity (concave left hemithorax, unusually prominent right hemithorax), persistent urachus, VSD, PDA (F)

Trisomy 21 - AV Commune defect - Eisenmenger's, endocardial cushion defect (F)

Trisomy 21 - VSD and pulmonary stenosis (F)

1969

Congenital Heart Disease with no other anomalies (confirmed cases only):

Pulmonary valve stenosis (M)

TGV (F)

TGV with pulmonary stenosis, VSD (F)

TGV, and VSD (F)

TGV, hypoplastic left ventricle, VSD, PDA, PFO, mitral valve originating from right ventricle, hypertrophy and dilation of right ventricle and pulmonary artery (marked) (†F)

Tricuspid atresia with transposition and pulmonary stenosis (F)

VSD (F) (2)

VSD, right ventricular hypertrophy, large PDA, PFO (†M)

Syndromes or anomalies with CHD or possible CHD:

?Hallerman-Streiff Syndrome, small VSD (F)

?Turner's Syndrome - ASD (F)

Cleft lip and ? cleft palate, CHD 'not yet defined' (F)

Cleft lip and palate, low set ears, tetralogy of Fallot with absence of pulmonary valve,
hypoplastic left pulmonary artery (F)

Ivenmark's syndrome (splenic agenesis), absence of lower atrial septum, VSD,
deformities of tricuspid and mitral valves, common large trunk arising from
ventricular chambers in position of aorta (†M)

Obstructive uropathy of right kidney, moderate to large VSD (M)

Polydactyly, VSD (M)

Trisomy 21 - AV Commune defect (†M)

William's Syndrome - pulmonary artery branch stenosis with PDA (F)

Appendix E

Method to determine final eligible subject list

The total number of patients gleaned from clinic lists from September, 1991 through March, 1994 was 336.

336	
<u>-5</u>	Duplicates i.e. names changed and both names on the list
331	
<u>-2</u>	No other record of ever having been seen (no chart, no documentation etc.)
329	
<u>-29</u>	Age <20 years as of May 31, 1994
300	
<u>-3</u>	Deaths
297	
<u>-42</u>	Not CHD - assessed by cardiologist and determined not to be affected
255	
<u>-18</u>	Potential confounders (e.g.. diabetes, seizures, Crohns Disease, mental handicap)
237	
<u>-5</u>	Unable to locate (e.g.. out of country)
232	
<u>-14</u>	Syndrome or possible syndrome (eg. Ehlers-Danlos Syndrome, Turner's Syndrome , William's Syndrome, Noonan Syndrome)
218	
<u>-20</u>	Trisomy 21
198	
<u>-15</u>	Marfan or query Marfan syndrome
183	
<u>-9</u>	Not seen (no show, declined)
174	

Therefore 174 subjects were identified as being eligible to participate in the study

Appendix F

New York Heart Association Functional Class

<u>Class I</u>	no limitation
<u>Class II</u>	slight limitations
<u>Class III</u>	marked limitations
<u>Class IV</u>	unable to carry out any physical activity without discomfort

From: Gersony et. al., 1993, p. I-55

Appendix G
SF 36 Survey Results
Study Sample and General Population

Health Concept	Descriptive Statistics	Males		Females	
		Study Sample	Population	Study Sample	Population
Physical Functioning	Median	90	95	85	90
	Q1 Q3	70 100	80 100	75 95	65 100
	Min/Max†	15 100	0 100	5 100	0 100
Role-Physical	Median	100	100	100	100
	Q1 Q3	75 100	75 100	50 100	50 100
	Min/Max	0 100	0 100	0 100	0 100
Bodily Pain	Median	84	84	79	74
	Q1 Q3	62 100	62 100	62 100	52 100
	Min/Max	10 100	0 100	11 100	0 100
*General Health	Median	67	75	65	72
	Q1 Q3	55 82	62 87	37 85	57 85
	Min/Max	0 100	5 100	0 100	5 100
Vitality	Median	60	65	55	60
	Q1 Q3	45 80	50 80	40 65	45 75
	Min/Max	0 100	0 100	0 100	0 100
**Social Functioning	Median	100	100	75	87.5
	Q1 Q3	69 100	75 100	50 100	62.5 100
	Min/Max	13 100	0 100	0 100	0 100
Role Emotional	Median	100	100	67	100
	Q1 Q3	67 100	67 100	33 100	67 100
	Range	0 100	0 100	0 100	0 100
Mental Health	Median	72	80	70	80
	Q1 Q3	60 84	68 88	60 88	64 88
	Min/Max	28 100	12 100	4 96	0 100

* males 2 missing values (n=51) ** males 1 missing value (n=52) † minimum/maximum

Appendix H
SF-36 by NYHA
and Gender

Health Concept	Descriptive Statistics	Males				Females			
		NYHA=1		NYHA>1		NYHA=1		NYHA>1	
Physical Functioning	Median	95		55		90		75	
	Q1 Q3	90	100	35	85	85	95	40	88
	Min/Max	50	100	15	100	15	100	5	100
Role Physical	Median	100		75		100		75	
	Q1 Q3	88	100	0	100	50	100	0	100
	Min/Max	25	100	0	100	0	100	0	100
Bodily Pain	Median	84		84		84		72	
	Q1 Q3	67	100	52	100	62	100	57	100
	Min/Max	10	100	12	100	11	100	31	100
General Health	Median	67		55		67		45	
	Q1 Q3	60	87	25	72	52	85	23	84
	Min/Max	32	100	0	97	0	97	5	100
Vitality	Median	70		40		55		48	
	Q1 Q3	55	80	30	60	45	70	33	60
	Min/Max	15	100	0	85	0	100	5	80
Social Functioning	Median	100		75		75		75	
	Q1 Q3	88	100	63	100	63	100	50	100
	Min/Max	13	100	25	100	0	100	0	100
Role Emotional	Median	100		100		67		67	
	Q1 Q3	83	100	67	100	33	100	0	100
	Min/Max	0	100	0	100	0	100	0	100
Mental Health	Median	76		64		72		66	
	Q1 Q3	68	84	60	84	60	88	56	80
	Min/Max	44	96	28	100	4	96	16	92

Appendix I
SF-36 by FLC
and Gender

Health Concept	Descriptive Statistics	Males		Females	
		Self	Others	Self	Others
Physical Functioning	Median	90	90	88	85
	Q1 Q3	75 100	60 98	75 93	80 95
	Min/Max	15 100	25 100	20 100	5 100
Role Physical	Median	100	100	100	100
	Q1 Q3	75 100	38 100	50 100	25 100
	Min/Max	0 100	0 100	0 100	0 100
Bodily Pain	Median	84	84	73	84
	Q1 Q3	72 100	42 100	42 92	62 100
	Min/Max	42 100	10 100	41 100	11 100
General Health	Median	67	67	70	62
	Q1 Q3	55 82	32 77	39 82	32 85
	Min/Max	15 100	0 100	12 100	0 100
Vitality	Median	70	55	50	55
	Q1 Q3	50 80	40 65	38 58	40 70
	Min/Max	5 100	0 90	10 90	0 100
Social Functioning	Median	100	94	69	75
	Q1 Q3	75 100	63 100	50 88	63 100
	Min/Max	13 100	13 100	0 100	13 100
Role Emotional	Median	100	100	67	67
	Q1 Q3	67 100	67 100	33 100	0 100
	Min/Max	0 100	0 100	0 100	0 100
Mental Health	Median	72	76	72	68
	Q1 Q3	64 84	58 86	56 84	60 88
	Min/Max	28 96	32 100	16 92	4 96

Appendix J

2~

3~

4~

Dear

In collaboration with Ms. Barbara Sibbald, a registered nurse and a graduate student in the Department of Community Health Sciences at the University of Calgary, we at the Adult Congenital Heart Disease Clinic are conducting a survey to attempt to determine the health needs of adults with congenital heart disease. You belong to a special population about whom we know very little, especially about how you feel about your own health and what you do to maintain your health. Knowing this would provide valuable information to us as we try to plan for health services for your specific needs. The information gained from the survey will help us to plan health education and health promotion activities tailored to your specific needs.

Your response to the enclosed questionnaire is important to the success of the study. The questionnaire should take approximately 20 - 30 minutes to complete. You do not need to identify yourself on the questionnaire. All of the information you provide will be held strictly confidential. No one at the Clinic will have knowledge about your information or who responded so you have no need to be concerned that you will be treated somehow differently if you do not respond. In order to ensure your privacy, all questionnaires will be received by Ms. Sibbald at the University. No one else will see your questionnaire. Information will be shared with others only once questionnaire information from all participants is combined and summarised.

You are under no obligation to answer the questionnaire, but as I stated earlier each added bit of information will help us get a more complete picture of adults who have congenital heart disease. This could ultimately benefit you because of the possibility of developing programs better suited to your needs and may also benefit others who have similar health concerns.

Your responses will be kept completely secure. The questionnaires will be kept in a locked cabinet to ensure privacy, and the responses will be entered into a computer without any identifiers. The results of the survey will be reported in group form therefore no individual will be singled out.

If you wish a summary of the results of the survey, please detach the last page of the questionnaire and send it to the clinic in a separate envelope from the questionnaire.

If you have any questions or concerns about the survey or the questionnaire, please contact myself, Dr. N. Alvarez at 268-9190, or Ms. Barb Sibbald, at 268-9190 or 220-4268. We would be happy to answer any questions you might have.

The usefulness of the survey depends on you, so please take the time to complete and return the questionnaire in the enclosed stamped, self addressed envelope as soon as possible.

Thank you for your assistance,

N. Alvarez, M.D.
Director,
Adult Congenital Heart Disease Clinic
Calgary General Hospital

Barb Sibbald, R.N., B.A., B.N.
Survey Co-ordinator,
MSc Candidate,
Department of Community Health
Sciences,
University of Calgary

**Adult Congenital Heart Disease Clinic
Calgary General Hospital**

**SURVEY QUESTIONNAIRE ABOUT
YOUR HEALTH BELIEFS
AND PRACTICES**

May, 1994

**Most of the questions in this survey can be answered by
simply checking (✓) or circling the statement that most
closely describes your response**

Section A Perceptions of Health

This part of the survey asks for views about your health. This information relates to how you feel and how well you are able to do your usual activities. If you are unsure about how to answer a question, please give the best answer you can.

A1. In general, compared to other people your age, would you say your health is

Excellent [] Very good [] Good [] Fair [] Poor []

A2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago []

Somewhat better now than one year ago []

About the same as one year ago []

Somewhat worse now than one year ago []

Much worse now than one year ago []

A3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

<u>ACTIVITIES</u>	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	[]	[]	[]
b. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	[]	[]	[]
c. Lifting or carrying groceries	[]	[]	[]
d. Climbing several flights of stairs	[]	[]	[]
e. Climbing one flight of stairs	[]	[]	[]
f. Bending, kneeling, or stooping	[]	[]	[]
g. Walking more than a mile	[]	[]	[]

- | | | | |
|----------------------------------|-----|-----|-----|
| h. Walking several blocks | [] | [] | [] |
| i. Walking one block | [] | [] | [] |
| j. Bathing or dressing yourself | [] | [] | [] |

A4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- | | YES | NO |
|--|-----|-----|
| a. Cut down on the amount of time you spent on work or other activities | [] | [] |
| b. Accomplished less than you would like | [] | [] |
| c. Were limited in the kind of work or other activities | [] | [] |
| d. Had difficulty performing the work or other activities (for example, it took extra effort) | [] | [] |

A5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- | | YES | NO |
|--|-----|-----|
| a. Cut down on the amount of time you spent on work or other activities | [] | [] |
| b. Accomplished less than you would like | [] | [] |
| c. Didn't do work or other activities as carefully as usual | [] | [] |

A6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

- | | | |
|-----------------|---------------|----------------|
| Not at all [] | Slightly [] | Moderately [] |
| Quite a bit [] | Extremely [] | |

A7. How much **bodily** pain have you had during the past 4 weeks?

None [] Very mild [] Mild []
 Moderate [] Severe [] Very severe []

A8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all [] A little bit [] Moderately []
 Quite a bit [] Extremely []

A9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of pep?	[]	[]	[]	[]	[]	[]
b. Have you been a very nervous person?	[]	[]	[]	[]	[]	[]
c. Have you felt so down in the dumps that nothing could cheer you up?	[]	[]	[]	[]	[]	[]
d. Have you felt calm and peaceful?	[]	[]	[]	[]	[]	[]
e. Did you have a lot of energy?	[]	[]	[]	[]	[]	[]
f. Have you felt downhearted and blue?	[]	[]	[]	[]	[]	[]
g. Did you feel worn out?	[]	[]	[]	[]	[]	[]
h. Have you been a happy person?	[]	[]	[]	[]	[]	[]
i. Did you feel tired?	[]	[]	[]	[]	[]	[]

A10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time [] Most of the time [] Some of the time []
 A little of the time [] None of the time []

A11. How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	[]	[]	[]	[]	[]
b. I am as healthy as anybody I know	[]	[]	[]	[]	[]
c. I expect my health to get worse	[]	[]	[]	[]	[]
d. My health is excellent	[]	[]	[]	[]	[]

A12. Would you describe your life as . . .

Very stressful? []	Somewhat stressful? []	Not very stressful? []	Not at all stressful? []
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Section B

Nottingham Health Profile

Listed below are some problems people may have in their daily life.

Look down the list and put a check in the box [] under YES for any problem you have at the moment.

Check the box under NO for any problems you do not have.

Please answer every question. If you are not sure whether to say YES or NO, check whichever answer you think is MORE TRUE at the moment

	YES	NO
I'm tired all the time	[]	[]
I have pain at night	[]	[]
Things are getting me down	[]	[]

	YES	NO
I have unbearable pain	[]	[]
I take tablets to help me sleep	[]	[]
I've forgotten what it's like to enjoy myself	[]	[]
	YES	NO
I'm feeling on edge	[]	[]
I find it painful to change position	[]	[]
I feel lonely	[]	[]
	YES	NO
I can walk about only indoors	[]	[]
I find it hard to bend	[]	[]
Everything is an effort	[]	[]
	YES	NO
I'm waking up in the early hours of the morning	[]	[]
I'm unable to walk	[]	[]
I'm finding it hard to make contact with people	[]	[]
	YES	NO
The days seem to drag	[]	[]
I have trouble getting up and down stairs or steps	[]	[]
I find it hard to reach for things	[]	[]

REMEMBER, IF YOU ARE NOT SURE WHETHER TO ANSWER **YES** OR **NO** TO A PROBLEM, **CHECK** WHICHEVER ANSWER YOU THINK IS MORE TRUE AT THE MOMENT

	YES	NO
I'm in pain when I walk	[]	[]
I lose my temper easily these days	[]	[]
I feel there is nobody I am close to	[]	[]
	YES	NO
I lie awake for most of the night	[]	[]
I feel as if I'm losing control	[]	[]
I'm in pain when I'm standing	[]	[]
	YES	NO
I find it hard to dress myself	[]	[]
I soon run out of energy	[]	[]
I find it hard to stand for long (e.g. at the kitchen sink, waiting for a bus)	[]	[]
	YES	NO
I'm in constant pain	[]	[]
It takes me a long time to get to sleep	[]	[]
I feel I'm a burden to people	[]	[]
	YES	NO
Worry is keeping me awake at night	[]	[]
I feel that life is not worth living	[]	[]
I sleep badly at night	[]	[]
	YES	NO
I'm finding it hard to get on with people	[]	[]
I need help to walk about outside (e.g. a walking aid or someone to support me)	[]	[]
I'm in pain when going up and down stairs or steps	[]	[]

	YES	NO
I wake up feeling depressed	[]	[]
I'm in pain when I'm sitting	[]	[]

Section C**Physical Health**

The next questions are about your current physical condition.

C1. How tall are you without shoes?

____feet ____inches or ____centimetres

C2. How much do you weigh?

____pounds or ____kilograms

C3. Are you limited in the kind or amount of activity you can do because of your heart condition?

Yes [] No [] ----->> Go to question D1

C4 Are your activities limited . . .

	Yes	No	Don't Know	Not Applicable
a) At home?	[]	[]	[]	[]
b) At work or school?	[]	[]	[]	[]
c) In other activities (such as leisure time pursuits or trans- portation to or from work)?	[]	[]	[]	[]

C5 How well do you feel you are coping with this limitation? Would you say . . .

Very successful [] Somewhat successful [] Not very successful []
 Not at all successful [] Don't know []

C6 How important is each of the following in coping with your limitation? Is it "Very", "Somewhat " or "Not at all " important?

		Very	Some- what	Not at all	Don't Know	Not applicable
a)	Medical treatment you received?	[]	[]	[]	[]	[]
b)	Your family or friends?	[]	[]	[]	[]	[]
c)	Your general state of health?	[]	[]	[]	[]	[]
d)	Your own determination?	[]	[]	[]	[]	[]
e)	Prayer or spiritual help?	[]	[]	[]	[]	[]

Section D

Improving Health

D1. Do you believe any of the following would help you to improve your health and well-being?

		Yes	No	Don't Know	Not Applicable
a)	A more secure income?	[]	[]	[]	[]
b)	Moving to another neighbourhood or community?	[]	[]	[]	[]
c)	A change in job or business?	[]	[]	[]	[]
d)	Spending more time with family or close friends?	[]	[]	[]	[]
e)	Exercising more or being more physically active?	[]	[]	[]	[]
f)	Losing weight?	[]	[]	[]	[]
g)	Stop smoking?	[]	[]	[]	[]

- E5.** The following are sentences describing daily routines or activities. Check off the one that best describes your usual situation.
(MARK ONLY ONE)

- ☐ You sit during the day and do not walk about very much.
- ☐ You stand or walk about quite a lot during the day, but do not have to carry or lift things very often.
- ☐ You lift or carry light loads, or you have to climb stairs or hills often.
- ☐ You do heavy work or carry very heavy loads.

Section F

Smoking

The next few questions are about smoking.

- F1.** Have you ever smoked cigarettes?

Yes ☐ No ☐ ----->>Go to Question F6

- F2.** At the present time, do you smoke cigarettes?

Yes ☐ No ☐ ----->>Go to Question F6

- F3.** Do you usually smoke cigarettes everyday?

Yes ☐ ----->> How many per day? ☐ cigarettes

No ☐

- F4.** In your day to day activities, do you find restrictions placed on where or when you can smoke?

Yes ☐ No ☐ ----->> Go to Question F6

- F5.** Have these restrictions affected how much you smoke each day?

Yes ☐ No about the same ☐ Don't know ☐

If Yes, how so? Less each day ☐ More each day ☐ Tried to quit ☐

F6. How many of the people living in your household, including yourself, smoke cigarettes daily?

[] people (If none, enter 0)

F7. Do you ever feel unpleasant effects from the cigarette smoke of others?

Yes []

No []

Section G

Alcohol

Now I would like to ask some questions about alcohol consumption.

In the next questions, when I use the word drink, it means:

- One bottle of beer or glass of draft
- One small glass of wine
- One shot or mixed drink with hard liquor

G1. Have you ever taken a drink? (beer, wine, liquor or other alcoholic beverage)

Yes []

No [] ----->>Go to Question H1

G2. In the past 12 months have you taken a drink? (beer, wine, liquor or other alcoholic beverage)

Yes []

No [] ----->> Go to Question H1

G3. In the past 12 months, how often on average did you drink alcohol? Was it . . .

Every day []

4-6 times a week []

2-3 times a week []

Once a week []

Once or twice a month []

Less often than once a month []

G4 Thinking back over the last 7 days, starting with yesterday, how many drinks did you have on each day?

Did not have any drinks in past 7 days [] ----->>Go to Question H1

How many drinks did you have on . . .

Monday	[]	Friday	[]
Tuesday	[]	Saturday	[]
Wednesday	[]	Sunday	[]
Thursday	[]		

Section H

Drugs

This section will ask you about your use of medicines, pills and other drugs.

H1. In the past 12 months have you used . . .

	Yes	No
a) Tranquilizers such as valium?	[]	[]
b) Diet pills or stimulants?	[]	[]
c) Anti-depressants?	[]	[]
d) Codeine, demerol or morphine?	[]	[]
e) Sleeping pills?	[]	[]
f) ASA (Aspirin) or other pain reliever?	[]	[]
g) Medication specifically for your heart condition?	[]	[]

H2. Have you ever used . . .

	No	Yes	If Yes, have you used it in the past 12 months	
			Yes	No
a) Marijuana or hashish?	[]	[]	[]	[]
b) Cocaine or crack?	[]	[]	[]	[]

- c) LSD (acid)? ☐ ☐ ☐ ☐
- d) Amphetamines
(speed)? ☐ ☐ ☐ ☐
- e) Heroin? ☐ ☐ ☐ ☐

Section I**Workplace**

The next few questions are about your employment status.

- 11.** Which of the following best describes your main activity during the last 12 months? Were you mainly . . .

Working at a job or business ☐ ----->> **Go to Question I3**

Looking for work ☐ ----->> **Go to Question I2**

A student ☐

Retired ☐

Keeping house ☐

Other ☐ Specify _____

- 12.** Did you have a job or business at any time during the past 12 months?

Yes ☐

No ☐ ----->> **Go to Question J1**

- 13.** How many weeks did you work at a job or business during the last 12 months? (Include vacation, illness, strikes, lockouts, and maternity/paternity leave)

☐ ☐ weeks

- 14.** In the last year, how many days were you away from work or school because you were sick, injured, or disabled?

☐ ☐ days

☐ ☐ Don't know

- 15** Of the days you were away from work or school last year, how many were because of your heart condition?

☐ ☐ days

☐ ☐ Don't know

Section J**Dental Health**

Now I would like to ask you some questions about your teeth.

J1. Do you have one or more of your natural teeth?

Yes []

No [] ----->> Go to Question K1

J2. Have you seen a dentist in the past 12 months?

Yes []

No [] or Don't Know [] ----->>Go to Question J4

J3. During this time, did you see a dentist for . . .

	Yes	No
a) A dental checkup or cleaning?	[]	[]
b) A filling or extraction? (non-emergency)	[]	[]
c) Any periodontal treatment? (gum treatment)	[]	[]
d) Orthodontic treatment? (braces)	[]	[]
e) Crown or bridge work?	[]	[]
f) A dental emergency?	[]	[]

J4. How often do you usually brush your teeth?

Twice or more a day / after every meal []

Once a day []

A few times a week []

Once a week []

A few times a month []

Once a month []

Rarely / Never []

Don't know []

J5. Are you covered by dental insurance?

Yes []

No []

Don't know []

J6. Do you take precautionary antibiotics before any dental work is done?

Yes []

No []

Not Recommended []
or Prescribed

Section K

Blood Pressure and Cholesterol

K1. When did you last have your blood pressure checked?

Within the last 6 months []

7-12 months []

13 - 24 months []

More than 2 years []

Don't know []

Never [] ----->> Go to Question K5

K2. Have you ever been told by a doctor, nurse or other health professional that you have high blood pressure? (for women except when you were pregnant)

Yes []

No [] or Don't know [] ----->> Go to Question K5

K3. Are you doing anything to control your blood pressure?

Yes []

No [] ----->> Go to Question K5

K4. What are you doing?

Losing weight or maintaining weight loss []

Medication/pills []

Quit smoking []

Exercise regularly []

Reduce salt intake []

Other diet changes []

Relaxation []

Reduce alcohol use []

Other []

Don't know []

K5. Were you ever told by a doctor, nurse or other health professional that your blood cholesterol was high? (this would require a blood sample)

Yes [☐]

No [☐] or Don't know / Can't remember [☐] ----->> Go to Question L1

K6. Are you doing anything to control your cholesterol?

Yes [☐]

No [☐] ----->> Go to Question L1

K7. What are you doing?

Losing weight or maintaining weight loss [☐]

Reduce cholesterol in diet [☐] Eat less fatty food [☐] Other changes in diet [☐]

Exercise regularly [☐] Control stress and fatigue [☐]

Take prescribed medication [☐] Other [☐]

Section L

General Questions

Finally, I would like to ask some general questions about you.

L1 What your date of birth?

_____ Year

_____ Month

_____ Day

L2. What is your current marital status?

Single (never married) [☐]

Married (living with spouse) [☐]

Living common law [☐]

Separated [☐]

Divorced [☐]

Widowed [☐]

L3. For Women: Have you ever given birth?

Yes []

No []

If Yes, when were your children born?(year of birth) _____

L4 Are there any children under 15 years old living in your household?

Yes []

If so, how many are . . .

5 years old or less []

6 to 11 years old []

12 to 14 years old []

No []

L5. What is the highest grade or level of education you have ever attended or ever completed? (MARK ONE ONLY)

No schooling

[]

Some

Completed

Elementary

[]

[]

Secondary

[]

[]

Community College,
technical college,
CEGEP, or nurse's
training

[]

[]

University (e.g.. B.A.,
M.A., Ph.D.) or
teacher's college

[]

[]

Other education or training

[]

L6 If you were employed or worked in the past year, what was the nature of the work or employment? Please be as specific as possible.

L7 What is your best estimate of the total income of all household members from all sources in 1993 before taxes and deductions? Was the total household income . . .
(CHECK ONE)

Less than \$10,000 []	\$10,000-\$19,999 []	\$20,000-\$29,999 []
\$30,000-\$39,999 []	\$40,000-\$49,999 []	\$50,000-\$59,999 []
\$70,000-\$79,999 []	\$80,000 or greater []	No income []
Don't know []		

This questionnaire includes the **SF-36 Health Survey**, item numbers A1 to A11, reproduced with permission of the Medical Outcomes Trust, Copyright © 1992.

**PLEASE ANSWER THE FOLLOWING QUESTIONS AND MAIL THIS FORM
BACK TO THE ADULT CONGENITAL HEART DISEASE CLINIC SEPARATE
FROM THE QUESTIONNAIRE**

1. Are you interested in a summary of the results
of the survey?
(It is anticipated that the results will be available
in the spring of 1995). Yes [] No []
2. Would you be willing to be contacted at some
time in the future for further studies? Yes [] No []

**IF YOU ANSWERED 'YES' TO EITHER QUESTION, PLEASE PROVIDE THE FOLLOWING
INFORMATION:**

Name:

Address:

City:

Postal Code:

Telephone:

Please return this form to:

Ms. Barb Sibbald

Adult Congenital Heart Disease Clinic

The Calgary General Hospital

841 Centre Avenue East

Calgary, Alberta T2E 0A1