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Psychological Well-Being in Adults with
Congenital Heart Defects

by

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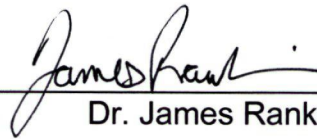
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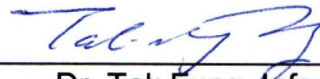
The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Psychological Well-Being in Adults with Congenital Heart Defects" submitted by Yvonne Balon in partial fulfillment of the requirements for the degree of Master of Nursing.



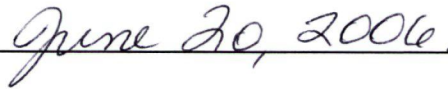
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ABSTRACT

The purpose of this cross-sectional survey was to measure whether the structural complexity of the congenital heart defect (CHD) impacts psychological well-being (PWB) in adults with CHD. A total of 163 patients participated in the study (85 with simple and 78 with complex CHD).

Study instruments consisted of a demographic questionnaire and a scale of PWB which measures six dimensions (autonomy, environmental mastery, personal growth, purpose in life, positive relations, and self-acceptance). Statistical analysis was done using SPSS 13.0 and included descriptive statistics, independent t-tests, and two-way analysis of variance (ANOVA). There was no statistically significant difference found in mean scores of each of the six dimensions of PWB between those patients with simple and those patients with complex CHD. Statistically significant differences were found when variables such as age, gender, marital status, employment, education, and spirituality were introduced.

The knowledge gained through this research will inform nursing practice in the biopsychosocial care of adults with CHD and supports the development of multidiscipline programs of care for adults with CHD.

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To my parents, John and Leona, who taught me that anything is possible if you work hard enough. I know my father is looking down very proudly and saying, "well done". Bev and Tom, you have always been there to listen and give honest feedback, thank you. To my running pals and Q-group, thank you for listening. My appreciation also goes out to my supervisor, Dr. Karen Then, and my committee members, Dr. Jim Rankin and Dr. Tak Fung for seeing me through this project and encouraging me to think philosophically about my practice. Dr. Then, thank you for all your editing and helping me to articulate my thoughts.

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DEDICATION

To my children, Tara, Paul and Jill, and to my best friend-you
are my joy, my inspiration, my life, and my love, forever,
always.

LIST OF ABBREVIATIONS

ACC	American College of Cardiology
ASD	Atrial Septal Defect
ACHD	Adult Congenital Heart Disease
ACHC	Adult Congenital Heart Clinic
AISH	Assured Income for the Severely Handicapped
APN	Advanced Practice Nurse
AU	Autonomy
CAS	Child Assessment Schedule
CBCL	Child Behaviour Checklist
CFD	Chronic Family Difficulties
CGAS	Children's Global Assessment Scale
CHD	Congenital Heart Defect
CHREB	Conjoint Health Research Ethics Board
CI	Confidence Interval
CID	Paykel's Clinical Interview for Depression
DSM III	Statistical Manual of Mental Disorders
DSM-III-R	Statistical Manual of Mental Disorders Revised
EM	Environmental Mastery
GHQ30	General Health Questionnaire 30
GBB	Geissener Complaint Questionnaire
GTS	Geissen Test Score

HADS	Hospital Anxiety and Depression Scale
HAQ	Health Assessment Questionnaire
NYHA	New York Heart Association
PR	Positive Relations with Others
PL	Purpose in Life
PG	Personal Growth
PWB	Psychological Well-Being
QOL	Quality of Life
RA	Rheumatoid Arthritis
RADAI	Rheumatoid Arthritis Disease Activity Scale
SA	Self-Acceptance
SCL-90-R	Symptom Checklist 90-Revised
SD	Standard Deviation
SF-36	Short Form 36
SFI	Support for Financial Independence
SOC	Sense of Coherence
SOZU-k22	Social Support Questionnaire
SQ	Kellner Symptom Management Questionnaire
VAS	Visual Analog Scale
WHOQOL-Bref	World Health Organization Quality of Life-Brief
YASR	Young Adult Self-Report

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CHAPTER 1

INTRODUCTION

The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (1948, p 28). The mandate of WHO is to develop the science of primary prevention and primary health care. Yet the western world uses the presence or absence of disease or illness or the biophysical state as the marker of health and well-being.

Well-being is not only a biophysical concept but it is a philosophical concept as well. It concerns the mind and the body and their interconnectedness. Well-being is a dynamic process that changes over time. It is about an individual and how that individual engages in living-physically, intellectually, socially, psychologically, and spiritually. If health is to be defined as more than the absence of disease or infirmity, then psychological, social, and spiritual well-being must be also be included in the indices of health.

The Adult Congenital Heart Clinic (ACHC) at the Peter Lougheed Centre in Calgary follows adult congenital heart patients in southern Alberta, southwestern British Columbia, and south-eastern Saskatchewan. In this patient population, positive human health is about finding and maintaining well-being while living with the constant uncertainty of a chronic disease superimposed on the issues of everyday life. Patients ask whether they will have complications after reparative or palliative surgery, whether they will have to have repeat surgery, and whether their surgical result will last three years or ten years. These are questions no one can answer. Then there are questions about adult life issues such as whether they can have children, what will happen if they decide to become pregnant, what are the risks of pregnancy, what are the chances of having a baby with a heart defect, and will they live a normal life span. They ask how they will be able to support their family if they get sick and

require time off work for repeat surgery. If adults with a congenital heart defect (CHD) are to live full and productive lives, all patient concerns must be addressed whether they fall in the biophysical, psychological, social, or spiritual realm.

With the focus on primary prevention in health care (WHO, 1948) effort has been made to move beyond the biophysical concept to look at the multidimensional response to and illness. Historically, in CHD, the presence or absence of psychological well-being (PWB) has been viewed as inversely proportional to psychological dysfunction such as depression, anxiety, behavioral problems, poor psychosocial functioning. (Horner, Liberthson, & Jellinek, 2000; Popelová, Slavik, Škovránek, 2001; Spurkland, Bjornstad, Lindberg, & Seem, 1993; Utens, Versluis-Den Bieman, Verhulst, Meijboom, Erdman, & Hess, 1998). There is an abundance of instruments available to measure psychological dysfunction but no instruments to specifically measure psychological well-being. With the development of a PWB instrument (Ryff, 1989), there is now an opportunity to view PWB by looking at the presence of positives rather than the absence of the negatives.

The mandate of the ACHD clinic team at the Peter Lougheed Hospital in Calgary is to assess and intervene on biophysical, psychological, social, or spiritual complications of CHD in order to promote well-being. The team consists of three cardiologists, one full-time nurse, one part-time nurse and a social worker with formal links to specific resources within the Calgary Health Region. The CHD research that has been completed thus far emphasizes patients' self-reported problems or complaints across multiple domains (physical, cognitive, psychological, social, and economic). Patients' self-reported strengths have not been examined. Understanding patients' strengths will provide a more complete

picture of their overall functioning and enable the ACHD team to support those strengths that support PWB.

Purpose of the Study

The purpose of this research is to examine the relationship between two levels of complexity in adults with CHD and psychological well-being.

Objectives of the Study

The objectives of the study are to:

1. Measure the relationship among the six dimensions of psychological well-being in two groups of adults with congenital heart defects using a scale of psychological well-being (Ryff, 1989).
2. Identify whether there is a difference in psychological well-being between adults with simple structural heart defects and adults with complex structural heart defects.

CHAPTER 2

LITERATURE REVIEW

The majority of children born with complex heart defects (CHD) did not survive to adulthood before the advent of cardiopulmonary bypass in 1958 (Sparacino, 1994). These children would enter the adult world of cardiology in the 1980's. It was then that the need to establish specialty clinics for adults with congenital heart defects became apparent. The first adult clinic in Canada was established in Toronto in 1990 and a clinic in Calgary was established a year later. As a result, research on adults with complex CHD, prior to the last two decades is sparse and not surprisingly is limited to natural history studies and case reports. A thorough search of ACADEMIC SEARCH PREMIER, CINAHL, EMBASE, MEDLINE, HealthSTAR, PsychINFO over the past 15 years was conducted using the keywords of well-being, psychological well-being, quality of life, coping, resilience, self-efficacy, stress, inner strength, positive affect and adult CHD, young adult CHD, chronic illness, and mental health. The recent research that was found in the CHD literature focuses on outcomes and includes both psychological and social outcomes. Given that adult clinics have only been established in the last 15 years, most of the research found on psychological outcomes has been conducted in children and adolescents.

The following literature review will focus on the psychological and social outcome research that has been conducted over the last 15 years. Research conducted in children and adolescents with CHD will be discussed first with research conducted in adults with CHD to follow. Following this, there will be a review of relevant research on psychological well-being conducted in the chronic illness and mental health literature.

Congenital Heart Disease

In the early CHD literature, well-being is expressed as an absence of psychopathology. Psychologists have conducted the research on psychological

outcomes in CHD using depression and anxiety scales, behavioral checklists, or structured clinical interviews. Some research studies included measures of self-esteem and coping. Social outcomes have been measured by various means including level of education attained, employment, social relationships, marital status, and whether the individual has continued to reside at home with parents (this indicates the level of independence) (Brandhagen, Feldt, & Williams, 1991; Cox, Lewis, & Stuart, 2002; Gupta, Guiffre, Crawford, & Waters, 1998; Horner et al., 2000; Kokkonen, Paavilainen, 1992; Lane, Li & Millane, 2002; Popelova, Slavik, & Skovranek, 2001; Spurkland, Bjornstad, Lindberg, & Seem, 1993; Utens, Bieman, Verhulst, Meijboom, Erdman, & Hess, 1998).

Children and Adolescents

Spurkland et al., (1993) used survey method and psychiatric assessment to compare adolescents with complex CHD ($n = 26$) consisting mostly of cyanotic defects to an age and sex matched group of adolescents with mild CHD consisting having had a repair of an atrial septal defect (ASD) ($n = 26$). Comparisons were made on somatic condition, psychopathology, psychosocial functioning, and chronic family difficulties. Included in the complex group were those with univentricular heart, tricuspid atresia, severe pulmonary stenosis or atresia with tetralogy of Fallot, double outlet right ventricle or transposition complexes, Ebstein's anomaly and severe left-sided valvular disease. Three instruments were used. The Child Assessment Schedule (CAS) measures subjective psychopathology by arriving at a total pathology score. It is derived by information given by the child. The Child Behavior Checklist (CBCL) is a report of behaviour and emotional symptoms observed by parents. The Children's Global Assessment Scale (CGAS) is a clinician evaluation of the child's psychological and sociological functioning.

Using the Child Assessment Schedule (CAS) and a semi-structured interview to provide psychiatric diagnoses according to the Statistical Manual of

Mental Disorders (DSM III), 11 adolescents in the complex group and seven in the ASD or simple group met criteria for DSM III diagnosis including anorexia, over-anxious disorder, separation anxiety, major depression, dysthymic disorder, attention deficit disorder, and conduct disorder. There was no significant difference between the groups.

In comparing the CAS scores, the researchers found a significant difference in between the two groups (complex group mean 44.0, SD 18.7; ASD group mean 27.6, SD 14.9, $p < 0.001$).

Only one-third of the complex group had CGAS scores which indicated normal psychosocial functioning compared to the ASD group. In the ASD group more than half had CGAS scores indicating normal psychosocial functioning (complex group mean 64.2, SD 17; ASD group mean 76.2, SD 12.7, $p < 0.02$). The scores on the CBCL showed no significant difference in behaviour/emotional problems and social competence between the adolescents with simple structural heart disease and those with severe CHD.

There was a significant positive correlation ($r = 0.46$, $p \leq 0.05$) in the complex group between CAS and functional ability as rated by New York Heart Association (NYHA), (American Heart Association, 1953). No significant correlation was found in the ASD group. There was also a significant negative correlation ($r = -0.40$, $p \leq 0.05$) between CGAS and NYHA in the complex group. No significant correlation was found in the ASD group. There was no significant correlation between CBCL and NYHA.

Chronic family difficulties (CFD) were assessed based on available information such as housing, employment, network support and possible marital or family discord as well as parents' and other family members' mental and somatic health. CFD were scored on an interval scale from zero to six where

zero is none and six implies severe strain. The inter-rater reliability for CFD was scored by an independent child psychiatrist and based on written material from the adolescent and parent interviews (0.87 and 0.54). Half of the families in both groups had no or only minor chronic family difficulties (complex group mean 2.8, SD 2.34; ASD group mean 2.5, SD 1.7; no significant differences between the two groups).

There was a significant positive correlation between CBCL and chronic family difficulties observed in both groups (complex group $r = 0.55$, $p \leq 0.001$; ASD group $r = 0.62$, $p \leq 0.0001$). There was also a highly significant negative correlation between CGAS and the degree of chronic family difficulties in both groups (complex group: $r = -0.55$, $p = \leq 0.0001$; ASD group: $r = -0.77$, $p \leq 0.0001$) (Spurkland et al., 1993). Additionally, there was an increased incidence of psychiatric problems in the complex group, and an association between psychosocial functioning and chronic family difficulties and psychosocial functioning and physical capacity. The findings suggest that good functional ability and the absence of chronic family issues may act as protective mechanisms for optimal psychosocial functioning in adolescents with congenital heart disease. This single study highlights the complexity in examining a multidimensional concept using multiple instruments.

Utens et al., (1994) conducted a descriptive exploratory follow-up study to assess the behavioral and emotional pathology in children and adolescents with CHD, nine years or more after post surgical correction that was conducted in infancy or childhood and compare them to a group of age-related Dutch peers. If the child was 10 - 15 years old at the time of the study the parents completed the CBCL. Children who were 11 - 17 years at the time of study completed the Young Adult Self-Report (YASR) which captures the occurrence of a broad range of psychological dysfunction. On the CBCL, CHD children and adolescents

obtained significantly higher problem scores than their age-related peers ($p < 0.001$ for both).

Utens et al., (1998), used the YASR to compare the mean problem scores of 19 - 25 year old young adults with CHD and a group of Dutch reference peers ($n = 166$). However, in this study, no differences were found between the mean problem scores of the two groups. Analysis of variance (ANOVA) were computed by cardiac diagnosis, sex and age as independent variables showed that cardiac diagnosis did not have an effect on psychopathology found in the YASR. In light of the results of the previous study, this study suggests that although CHD children may exhibit more problems than their age-related peers but by the time they reach young adulthood there is no difference between CHD adolescents and their age-related peers.

Gupta et al., (1998) examined behavioural/emotional pathology in children recruited ($n = 39$) at a paediatric cardiology clinic in Calgary but the results differed from those found by Utens et al., (1998). The survey by Gupta et al., (1998) compared anxiety, fears, depression, and behavioural problems in children with CHD to data from a normative sample group using a variety of instruments. The Fear Survey Schedule for Children assesses the level of fearfulness on five factor subscales. This schedule has been reported to be reliable and valid (Ollendick, 1983). The Revised Child Manifest Anxiety Scale is a self-report measure of 37 items to measure a total score of four factor subscales (physiological anxiety, worry/oversensitivity, social concerns, and a lie scale). It is reported to have both high internal consistency and high reliability (Reynolds & Paget, 1983). The Child Depression Inventory of 1992 is a 27-item self-rated and symptom-oriented measure which discriminates those with major depressive or dysthmic disorders and quantifies a range of depressive symptoms. It is been used in a number of studies to evaluate depression in

children and it has been shown to have acceptable internal consistency and reliability (Kovacks, 1992). The State-Trait Anxiety Inventory (1983) is a self-report completed by parents and collects information on how parents feel about their child right now and then how they normally feel. There is a children's version as well. The questionnaire is reported to have adequate validity and reliability (Butz & Alexander, 1993). The CBCL is a self-report completed by parents. Although this instrument has eight domains, the researchers chose to use only the factor on anxiety, the total t-score and the internalizing and externalizing t-scores. The CBCL has excellent reliability, inter-parent agreement, and validity (Achenback & Edelbrock, 1983). Children with CHD demonstrated significantly more fear of failure and criticism than the normative sample group (CHD children: mean 38.4, SD 8.00; normative sample: mean 29.54, SD 6.92, $p < 0.001$), fear of injury and small animals (CHD children: mean 36.33, SD 8.79; normative sample: mean 26.9, SD 6.80, $p < 0.001$), medical fears (CHD children: mean 9.59, SD 2.14; normative sample: mean 6.8, SD 2.10, $p < 0.001$), and internalising (CHD children: mean 57.22, SD 9.21; normative sample: mean 50.1, SD 9.80, $p < 0.001$). Children with CHD also demonstrated significantly more physiological anxiety (a factor subscale of the Revised Child Manifest Anxiety Scale) (CHD children: mean 5.21, SD 2.08; normative peers: mean 4.10, SD 2.45, $p < 0.01$) and psychological anxiety (CHD children: mean 57.05, SD 7.25; normative peers: mean 54.1, SD 5.90, $p < 0.01$).

In light of the numerous hospitalizations, procedures, and surgeries that CHD children have, it would be reasonable to anticipate these results. In comparing the cyanotic CHD children (complex) ($n = 24$) to the acyanotic CHD children (simple) ($n = 15$), the cyanotic CHD children demonstrated significantly more fear of the unknown (complex CHD: mean 30.1 SD 6.4; simple CHD: mean 25.9, SD 5.7, $p < 0.05$) and physiological anxiety (complex CHD: mean 10.8, SD 2.4; simple CHD: 9.1, SD 2.7, $p < 0.05$). State anxiety was significantly higher in cyanotic children than acyanotic children (complex CHD: mean 53.9,

SD 11.3; simple CHD: mean 45.5, SD 6.9, $p < 0.01$) and trait anxiety was significantly higher in cyanotic versus acyanotic children (complex CHD: mean 54.7, SD 12.4; simple CHD: mean 45.6, SD 6.7, $p < 0.01$). The researchers concluded that although children with CHD do not present with psychological adjustment problems, they are still at risk for covert physiological anxiety, medical fears, depression, and behavioural problems. Children with cyanotic disease are a subgroup that is at higher risk for these problems than acyanotic children with CHD.

Adults

As mentioned earlier, research on the care of the adult with CHD is in its infancy. Before cardiopulmonary bypass and the new surgical techniques that followed, many of the children born with complex congenital heart defects did not survive to adulthood. The psychosocial research completed on adults with CHD to date has focused on the presence or absence of psychopathology and quality of life.

Brandhagen et al., (1991) surveyed 463 consecutive patients (response rate 32%) who had one of nine diagnosis and who had attended their institution between July 1 and September 30, 1963. The number of patients from each of these nine diagnostic groups who completed questionnaires varied from 2 to 53. Patients were sent an eight-page questionnaire to evaluate current clinical status and demographics. The questionnaire also included the Dy scale which is a measure of assessment of independence and the Symptom Checklist Revised-90 (SCL-R-90) which is a self-report measure of nine dimensions of symptoms and three global indices of psychological distress. Both of these instruments have been standardized to a mean of 50 with use in a normal population. T-scores for each patient were paired with a mean t-score of 50 and the differences were analyzed by the signed rank test. The rank sum test was used for two-group comparisons within the study sample. Two-tailed p values were reported.

A comparison of results to the standardized normative data for the Symptom Checklist 90-Revised (SCL-90-R) revealed statistically significant differences in psychological dysfunction including obsessive-compulsive behavior, interpersonal sensitivity, depression, paranoid ideation, psychosis, general severity index, and symptom total ($p < 0.0001$). Correlation of psychological test scores and the severity of the cardiac defect failed to establish that the complexity of the structural heart defect was related to the presence or degree of psychological distress as measured by the SCL-90-R. According to the ACC classification (Webb & Williams, 2001), the only diagnosis in this study that is complex is transposition of the great arteries ($n = 2$). The majority of patients had simple CHD defects ($n = 106$). This may account for failure of this research to establish a correlation between the clinical severity of the defect and psychological distress.

Horner et al., (2000) undertook to establish a psychological profile of adults (mean age 38 years, range 26-56 years) with complex CHD by performing psychiatric evaluations based on the Statistical Manual of Mental Disorders Revised (DSM-III-R) by interview and questionnaire ($n = 29$) (American Psychiatric Association, 1987). They found that four patients met DSM-III-R diagnostic criteria for major depressive disorder, five had panic disorder, and 12 had clusters of symptoms of posttraumatic stress disorder. Additionally, 11 of the 29 also had dysthymia cluster symptoms (hopelessness, loss of sleep, decreased energy, concentration, and appetite, and poor self-esteem) and nine had adjustment disorder symptoms with depressed mood and/or anxious mood either currently or in the past. Although six patients met symptomatic criteria for psychiatric diagnosis, most functioned well in day-to-day life. Contrary to the study by Brandhagen et al., (1991), there is no comparison group or comments from the researchers as to how these findings differ from that of the normal population.

Popelová et al., (2001) did a prospective survey of 76 consecutive adults with cyanotic CHD (complex) attending a single tertiary referral centre between 1993 and 2000. Patients completed Zung's self-rating questionnaire on depression. The results showed that 11 of the 32 responders (34%) with complex CHD were depressed (mean score 66.9, SD 8.7, range 53-89, $p < 0.010$). The scores from the remaining 21 (66%) did not indicate depression (mean score 41.5, SD 5.5). The level of education was significantly higher in the group without depression ($p = 0.026$). The group without depression was significantly younger (33.6 years, SD 8.7) than the group with depression (40.5 years, SD 6.8, $p = 0.01$). Those with depression had a significantly worse functional scale (mean 2.95, SD 0.48, $p = 0.03$) than those who were not depressed (mean 2.48, SD 0.452). The group with depression had a significantly higher level of unemployment ($p < 0.000$). There was no significant difference between the group with depression and the group without depression as far as degree of cyanosis, level of hematocrit, oxygen saturation, or previous surgeries. The researchers conclude that the results show a high incidence of depression in cyanotic CHD. Although this research has been conducted in adults with CHD in the Czech Republic, the results of this study on cyanotic CHD are similar to the results of the study by Gupta et al., 1998, in Canada on children with cyanotic CHD.

A survey conducted by Cox et al., (2002) explored the prevalence of psychopathology in adults with CHD. A sample ($n = 101$) was recruited from attendees at an adult CHD clinic and compared to a control group of randomly selected attendees at an orthopaedic clinic ($n = 45$) at the same hospital in South Wales. The General Health Questionnaire (GHQ30) mean score was significantly lower for the CHD group (26.8) than the comparison orthopaedic group (33.9) with a mean difference of 7.1 (95% CI, 1.7, 12.4, $p = 0.01$).

The researchers did not provide information as to the acute or chronic nature of the orthopaedic problem. This information is important to the

interpretation of results. Due to the chronic nature of CHD, one might expect that patients would score lower on the GHQ30 than the orthopaedic patients which may expect full recovery. The mean Hospital Anxiety and Depression Scale (HADS) score for the CHD group was 9.1 as compared to 11.8 with a mean difference 2.7 (95% CI, 0.2, 5.2, $p = 0.04$). These findings contradict the findings on depression in the study by Popelová et al., (2001) but support the findings of the study by Utens et al., (1993). One may speculate that there could be many reasons for these studies to have different results. The first may be that Popelová et al., (2001) used clinical interviews and an instrument to screen for depression only, whereas the study by Utens et al., (1993) used a self-report instrument which measures a broad range of psychopathology, not just depression. Different instruments make it difficult to compare study findings.

The mean age of the patients in the study by Utens et al., (1993) was 21.7 years, mean age in the study by Cox et al., (2001) was 31.7 years, and mean age for the study by Popelová et al., (2001) was 36.5 years. This researcher's clinical experience has shown that adolescents and young adults use denial as a way of coping with a chronic illness in order that they can keep up with their peer group. A self-report instrument used in this age group may well yield different results.

An observational, cross-sectional survey on quality of life study using the Short Form Health Survey (SF-36) was conducted by Lane et al., (2002) in Birmingham, United Kingdom ($n = 276$, response rate 58.6%). The SF-36 is a generic self-report measure which uses a multiple item scale to assess eight health concepts: physical functioning, general health, mental health, role limitations caused by physical health problems, energy/vitality, role limitations caused by emotional problems, social functioning, and bodily pain (Jenkinson et al., 1996). Internal consistency found Cronbach alpha coefficients for the scales ranging from 0.73 to 0.96, with a median of 0.95 in a general population study conducted in the UK.

Reliability testing gave Pearson product moment correlation coefficients ranging from 0.60 to 0.81, with a median of 0.76.

Comparisons were made to the population normative data for people of the UK aged 30 to 34 years and between five treatment categories: surgically cured (curative cardiac surgery); surgically corrected (anatomical correction with potential for further operation); surgically palliated (palliation with/without potential for further operation); medical (no indication for cardiac surgery); and conditions deemed inoperable apart from transplant (inoperable group). The median age in each of the five treatment categories was similar. Comparisons were also made between those patients with cyanotic (complex) and acyanotic (simple) CHD. Cyanotic (complex) patients ($n = 18$) had significantly worse quality of life in seven of the eight health related concepts assessed by the SF-36 than age and sex matched acyanotic (simple) patients ($n = 54$) ($p < 0.01$). Patients deemed surgically cured had a significantly poorer quality of life than the general population in all domains except for pain ($p < 0.05$). This researcher's clinical experience with adults with CHD has shown that even though patients are surgically cured many have a perception of a poorer quality of life than the general population. However, this appears to be reserved to those patients who are diagnosed with CHD in midlife. For example, an atrial septal defect is a common CHD defect that is often not diagnosed until mid-life. This defect can be surgically cured with no risk of complications as a result of their heart defect. Yet this researcher has found that many patients who are diagnosed with CHD in adulthood and go on to have have a definitive surgical repair have more difficulty returning to life post surgery than some of the younger, complex CHD patients who have had two or three surgeries. This difficulty may be related to the age at diagnosis or the fact that complex patients anticipate they will have multiple surgeries.

Patients with inoperable or cyanotic conditions had significantly poorer physical functioning ($p < 0.01$) and overall general health perception ($p < 0.05$) than all other patients. The Spurkland et al., (1993) study as discussed above, found a significant correlation between psychopathology and physical functioning in adolescents with complex CHD and a significant difference between adolescents with complex CHD and simple CHD. However, their sample was small ($n = 26$) and difficult to generalize. The (complex) cyanotic group used for comparisons in Lane et al., (2002), is smaller ($n = 18$) and also difficult to generalize. The association between physical functioning and psychopathology may be directly due to the harmful effects of physical incapacity and the corresponding restrictions it places on the individual rather the defect per se.

Social functioning and energy/vitality scores for the cyanotic group were significantly lower than either those in the medical group ($p = 0.015$ and $p = 0.003$, respectively), or the surgically corrected group ($p = 0.049$ and $p = 0.006$ respectively) but, similar to the surgically cured group. These findings are not surprising given that cyanosis has a significant impact on the physical functioning of the patient and limits the day to day activities of the patient.

Recent neuropsychological testing on cyanotic CHD patients has found they suffer from organic cerebral dysfunction due to cyanosis or repeated open heart operations (Oates, Simpson, Turnbull, & Cartmill, 1996; Wernovsky, Stiles, Gauvreau, Gentles, duPlessis, Bellinger, Walsh, Burnett, Jonas, Mayer, & Newburger, 2000). The relationship between organic cerebral dysfunction and psychopathology in adults with CHD is yet to be examined.

Age and socioeconomic status can also play a role in limiting social functioning and energy/vitality scores despite the complexity of the CHD defect. The surgically cured group had poorer mental health than the surgically corrected group ($p = 0.027$). The surgically cured group had significantly poorer social function ($p = 0.038$) and mental health ($p = 0.003$) than the medical study group

which once again may be related to neuropsychological effects of prolonged cardiopulmonary bypass. The difference between surgically palliated patients and the medical patients was that the surgically palliated patients had significantly poorer scores in the category of physical functioning than medical patients ($p = 0.033$). Patients with inoperable conditions had a poorer quality of life in all areas than the other four treatment groups. This finding is not surprising.

Simko & McGinnis (2003), in a cross-sectional case-control designed study examined QOL in adults with CHD selected from an outpatient pediatric CHD clinic at a university affiliated teaching hospital in the northeast United States. The pediatric clinic follows approximately 500 adult CHD patients. The researchers used the Sickness Impact Profile (SIP) to measure health status in 124 of 484 eligible participants who responded (25.6% response rate). Of the 124 patients participating, 56 had (complex) cyanotic CHD and 68 had (simple) CHD. The primary diagnoses used for the cyanotic CHD group included tetralogy of Fallot, transposition of the great arteries, single ventricle, and tricuspid atresia. The primary diagnoses used for the acyanotic CHD group included ventricular septal defect, coarctation of the aorta, atrial septal defect, aortic stenosis, and pulmonary stenosis. The SIP is a self-rating instrument that measures health status by assessing the way sickness impacts daily behaviour and everyday activities. The SIP is composed of 36 items that describe activities associated with everyday living and is designed to assess the patient's perception of the performance of these activities. Reported reliability estimates range from 0.81 to 0.95 (Damiano, 1996). Content and criterion validity has been reported (Damiano, 1996; Visser, Fletcher, Parr, Simpson, & Bupitt, 1994). On the NYHA functional classification, 54.2% of all patients considered themselves Class I (37% cyanotic and 68.2% acyanotic patients), 35.8% considered themselves Class II (48.2% cyanotic and 25.8% acyanotic patients), 7.5% considered themselves Class III (7.5% of cyanotic and 13.0% acyanotic

patients), and 2.5% considered themselves Class IV (1.9% cyanotic and 3.0 acyanotic patients). The only significant difference in the mean SIP scores between all patients (mean 11.1), the acyanotic patients (mean 4.1), and the cyanotic patients (mean 19.8) was found in the category of work ($p < 0.001$).

The NYHA classification was self-rated by the patients. Only 10% of patients ($n = 12$) perceived their heart defect to NYHA Class III and IV (complex). While the NYHA classification is commonly used by cardiologists to assess function in congestive heart failure patients, its reliability when used for CHD patients and for self-report has not been established. Perloff & Child, (1998) recommend the use of the UCLA Congenital Heart Disease Functional Classification rather than the NYHA Functional Classification for classification of the congenital heart population.

Using the same 124 patients with CHD from the above study, Simko & McGinnis, (2005) compared these patients to 124 healthy controls obtained from a random community sample by "word of mouth", advertising in churches, on bulletin boards, and the local newspaper. These healthy controls were matched by age, gender, race, and socioeconomic status. Simko & McGinnis, (2005) found a significant difference in the total mean SIP scores (CHD group: mean 4.71, healthy control group: mean 1.02, $p < 0.001$). There was also a significant difference in the physical scores (CHD group: mean 1.90, healthy control group: mean 0.16, $p < 0.001$) and the psychosocial scores (CHD group: mean 6.33, health control group: mean 1.50, $p < 0.001$). In addition, all the category scores were significantly higher for patients with CHD than for healthy controls ($p < 0.05$). The areas that adults with CHD reported as lacking in QOL involved the SIP categories of work, sleep, and rest,

Rose, Köhler, Sawitzky, Fliege, & Burghard, (2005) undertook to examine the relative significance of biological factors compared to psychological and social factors, for various quality of life dimensions in adults with CHD and compare them to a representative sample selected from four representative

samples of the German population. The representative samples were collected by different established German opinion research centers. On average, the investigated sample was 10 years younger than the average of the German population sample. Patients had different degrees of cardiac dysfunction ($n = 111$). A total of 11 patients in this study are complex by the ACC classification (Webb & Williams, 2001). The remainder fall into the ACC classification (Webb & Williams, 2001) of simple heart defects ($n = 79$) and moderately complex heart defects ($n = 21$). CHD patients were examined and those with no contraindications were given a cardiopulmonary study ($n = 95$). All participants were asked to complete questionnaires concerning QOL (WHOQOL-Bref, Cronbach $\alpha = 0.70 - 0.80$), their cardiac complaints (Giessener Complaint Questionnaire GBB, Cronbach $\alpha = 0.87$), their personality traits (Giessen Test GTS, Cronbach $\alpha = 0.74$), and the social support they experience (Social Support Questionnaire SOZU-k22, Cronbach $\alpha = 0.88$).

The descriptive comparisons between the study sample and the comparison groups were analyzed using t-tests for independent group samples. In all aspects but the social domain, the health related QOL of CHD patients was significantly diminished compared to the normal population ($p < 0.001$). A structural equation model (SEM) was used to illustrate the interacting connections between the variables within the group of patients with CHD. The SEM proposed was valid showing good indices of fit ($\chi^2 = 1.18$, $p = 0.55$; ACFI = 0.92). The objective test of cardiopulmonary function was most significant for the reporting the variances in cardiac complaints ($\beta = -0.28$) and for the physical component of the health related quality of life ($\beta = 0.32$). Cardiopulmonary function had little relevance for the other quality of life dimensions. Depressive personality disposition contributed the greatest towards the explanation of variance in the psychological domain ($\beta = -0.26$) but also to cardiac complaints ($\beta = -0.20$). The level of social support contributed significantly to the variance in the psychological and social quality of life dimensions ($\beta = 0.51$ for both).

The researchers recommended that rather than a traditional medicine focus on improving somatic function, programs for these patients need also to include a focus on psychosocial therapy.

Comparing the impact of CHD on social outcomes Kokkonen & Paavilainen, (1992), compared the social adaptation of 71 young CHD adults from Oulu University Central Hospital in Oulu, Finland to 211 age-matched randomly selected controls from the population registry of the area. Nine were cyanotic, 62 were acyanotic. A pediatric cardiologist performed a clinical assessment which included an echocardiogram, electrocardiography, x-ray, and submaximal exercise testing. The social outcomes were determined through collecting information on education, vocational training, present and previous employment, separation from home and social integration to the society. Significant relative risk ratios for poor social maturation in young adults with CHD included disability (95% CI 1.3, 4.1, $p < 0.01$), poor success at school (95% CI 1.3, 3.6, $p < 0.01$), and male sex (95% CI 1.0, 2.2, $p < 0.05$). The findings suggest that even when treated, growing up with CHD can significantly impact adult life and therefore the treatment plan should consider the developmental processes of adolescence and young adulthood in order to avoid psychosocial issues later in life.

There are a number of concerns that have been found in the CHD literature review. First, there are few studies that have addressed the psychosocial impact of CHD in adults. Most of the psychosocial research has been done on children and adolescents. Before 1958 and the advent of cardiopulmonary bypass many children born with complex structural CHD did not survive to adulthood (Sparacino, 1994). New technology has made survival possible for 85% of children born with complex CHD (Sparacino, 1994). There are now subspecialty clinics across Canada, the US and Europe dedicated to meeting the multidisciplinary needs of adults with CHD. Those needs include psychosocial functioning. Psychosocial research that has been conducted on

children and adolescents should not be generalized to adults because of developmental variations that occur throughout the life span.

Secondly, there is a considerable amount of cross study variation in the kinds of psychosocial outcomes that have been measured. Different studies have examined different outcomes, using different methods, at different ages, over different time spans. Some use longitudinal cohorts (Brandhagen et al., 1991) and others have measured outcomes in childhood and adolescence (Gupta et al., 1998, Utens et al., 1998). Some use clinic or hospital population based cross-sectional surveys to compare other patient populations to CHD patients (Cox et al., 2002) or to population norms (Kokkonen & Paavilainen, 1992; Lane et al., 2002; Rose et al., 2005; Simko & McGinnis, 2003). Many times when the most complex patients are being studied the sample size is small. This will affect the reliability and validity of the study. At other times, CHD patients are treated as one homogeneous group and no delineation is made between those with a simple, moderately complex, or complex structural heart defects.

Thirdly, in looking at psychological dysfunction, a variety of instruments have been used (Table 2.1) Each instrument varies in the psychopathology that is being measured and also in the age group to which it is targeted. Some are self-report instruments and as discussed earlier, results may vary depending on the age group to which it is administered. This causes inconsistency in research reporting.

Table 2.1 Summary of Instruments

Instrument	Who completes?	What it measures?
SF-36	Adult patient self-report	Quality of Life
SCL-90-R	Adult patient self-report	Psychiatric symptoms
CBCL	Parent assessment of child	Behavioral/emotional problems in children
YASR	Adolescent self-report	Psychopathology
HADS	Adult patient self-report	Anxiety and depression
CAS	Psychiatrist	Psychological dysfunction
CGAS	Clinician assessment of child	Psychological and social function
DSM-III-R	Psychiatrist	Psychiatric dysfunction
Giessen Test GTS	Adult patient self-report	Personality traits
WHOQOL-Bref	Adult patient self-report	Quality of Life
Social Support Questionnaire	Adult patient self-report	Social support

Fourth, other variables need to be considered that may affect research results such as socioeconomic status and family support, the effect of chronic hypoxia on the brain, the neuropsychological impact of multiple surgeries on cardiopulmonary bypass, (Wray & Sensky, 2001; Forbess, Visconti, Hancock-Friesen, Camille, Howe, Bellinger, & Jonas, 2002), and family support. All of these factors not only make it difficult to compare or replicate research results but also make results appear contradictory (Utens et al., 1998; Cox et al., 2002). Although all of these studies relate to individual concepts of PWB, none of them are all-inclusive and therefore it is difficult to extrapolate an understanding of PWB from the work that has been done thus far in CHD. In order to truly understand the impact of CHD on PWB it must be measured using a PWB instrument.

Finally, the CHD literature that has been reviewed focuses on psychological outcomes only. The research that has been done does not look at

the process that affects these outcomes. Without understanding the process, it is not possible to develop interventions to moderate or ameliorate psychological dysfunction. Process focused research attempts to understand the mechanisms that act to modify the impact of chronic illness on life and the ways in which patients adapt to a chronic illness to maintain PWB. It is necessary to assess both the internal and external risk factors that intensify the reaction to adversity and the internal and external protective factors that ameliorate a patient's response to adversity. It is in this area of protective factors that there is a paucity in the pediatric and adult CHD literature and therefore the literature review was broadened to include chronic illness and mental health literature. It is here where research on protective mechanisms can be found (Büchi, Sensky, Allard, Stoll, Schnyder, & Klaghofer, 1998; Mangelli, Gribbin, Büchi, Allard, & Sensky, 2002).

Chronic Illness

In 1995, Ryff and Keyes proposed a study to test a multidimensional model of PWB that includes six dimensions— positive relations with others (PR), autonomy (AU), environmental mastery (EM), personal growth (PG), purpose in life (PL), and self-acceptance (SA). This multidimensional model of PWB was developed through the convergence of theoretical frameworks taken from developmental and clinical psychology with some preliminary work on positive health taken from the mental health literature. Developmental psychology included Erickson's (1959) psychosocial stages, Buhler's (1935) basic life tendencies, and Neugarten's (1973) personality changes that continue through the life cycle. Further descriptions of well-being were taken from Maslow's (1968) conception of self-actualization, Allport's (1961) formulation of maturity, Roger's (1961) depiction of the fully functioning person, and Jung's (1933) account of individuation. From the mental health literature, the contributions of Birren and Renner, (1980) and Jahoda, (1958) on positive health were also included. The breadth of the theoretical framework adds considerable strength to multidimensional model of PWB.

Using a national representative sample ($n = 1108$, 654 females, 454 males) of non-institutionalized, English speaking adults from across the U.S. and whose households had one telephone, the purpose of the study was to examine the replicative consistency of age and sex differences on various indicators of well-being and compare the relationships between theory based dimensions of PWB and three prominent indicators of well-being used in prior research (happiness, life satisfaction, depression). Participants were asked to complete a 14-item scale. The original scale that was developed contained 20-items and had high internal consistency and test-retest reliability, as well as convergent and discriminate validity with other measures (Ryff, 1989). Three of the original 20 items were chosen from each dimension to make a shortened version of the scale to accommodate time and cost restrictions of a national survey. The shortened scale correlated from 0.70 to 0.89 with the 20-item parent scales. Answers were marked on a 6-point continuum from one to six (strongly agree to strongly disagree). Thirty-minute telephone interviews of randomly selected adults from across 48 states were conducted. Nominal and interval data were collected and analysed using Chi square and correlation coefficients. Factor analysis of the data supported the proposed multidimensional model of well being. Comparison of theory based indicators of well-being and other frequently used measures of well-being (happiness, life satisfaction, and depression) indicated moderate to strong associations between two scales-- self-acceptance and environmental mastery (happiness and SA, $r = 0.36$, happiness and EM, $r = 0.40$; life satisfaction and SA, $r = 0.42$, life satisfaction and EM, $r = 0.39$; depression and SA, $r = -0.45$, depression and EM, $r = -0.50$; $p = 0.05$ for all). The remaining four dimensions of PWB, PR, AU, PL, and PG showed mixed or weak relationships with these prior indicators. This could indicate either that the prior indicators of well-being (happiness, life satisfaction, and depression) do not capture these four dimensions of PWB or that the four dimensions of PWB do not capture the prior indicators.

Büchi et al., (1998) conducted a cross-sectional study on rheumatoid arthritis (RA) outpatients to determine if a high sense of coherence (SOC) would protect patients against depression. SOC is the confidence that is seen in an individual who faces challenge. This individual is able to make sense of the challenge both cognitively and emotionally and sees the challenge as structured and predictable. They then draw from their resources to rise above and meet the demands of that challenge. Relationships between socio-demographic factors, disease activity (Rheumatoid Arthritis Disease Activity Index (RADAI), functional impairment (Health Assessment Questionnaire (HAQ), pain (Visual Analog Scale (VAS)), depression (The Hospital Anxiety and Depression Scale (HADS), and SOC was assessed in 89 outpatients with RA of which 73 were female. Thirty-one percent were rated as depressed according to HADS scores. No significant correlation was found between any socio-demographic variables and HADS depression ratings. However, depression ratings correlated significantly ($p < 0.001$) with scores of functional impairment (HAQ), pain (VAS), and disease activity (RADAI) ($r = 0.483$, $r = 0.485$, and $r = 0.487$ respectively). Therefore, if RA interfered in mobility or if pain was poorly controlled, there was an increased likelihood of depression. There was a significant ($p < 0.001$) negative correlation between SOC and depression ($r = -0.548$). An increased prevalence of depression was associated with low SOC and high self-rated pain levels, but not with other factors assessed. High SOC appeared to protect patients from depression despite decreased mobility and poor pain control.

Mangelli et al., (2002) used the scale of PWB (Ryff, 1989) to study the relationship between PWB and 'disease' variables including socio-economic factors, disease activity (RADAI), functional ability (HAQ), and depression and anxiety (HADS). The authors proposed two hypotheses: (1) PWB would be influenced by age and gender as it was in the general population and (2) PWB would protect the RA patient from affective disturbances. This cross-sectional study recruited consecutive patients ($n = 89$, 77 females, 12 males) attending a

London outpatient rheumatology clinic. Gender differences that were reported in the original validation study (Ryff & Keyes, 1995) were not found. This may be due to the fact that living with a chronic disease such as RA affects autonomy and environmental mastery despite age or gender. If this hypothesis is correct, it may be true for others living with chronic disease such as CHD patients. There was a significant correlation between pain, disease activity, and functional ability and depression and anxiety (correlation coefficients ranged from 0.39 to 0.55, all $p < 0.001$). As can be expected in those who suffer from depression and anxiety, there was a significant inverse correlation between each of the PWB dimensions and depression and anxiety (depression and AU correlation coefficients $r_s = -0.26$, $p < 0.01$; EM, $r_s = -0.64$, $p < 0.01$; PG, $r_s = -0.33$, $p = 0.01$; PL, $r_s = -0.48$, $p < 0.01$; SA, $r_s = -0.48$, $p < 0.01$). In other words, the higher the HADS score, the lower the score in all dimensions of PWB.

A cross-sectional survey was conducted by Rafanelli, Park, Ruini, Ottolini, Cazzaro, and Fava, (2000) to evaluate differential characteristics of instruments assessing well-being and distress in 20 patients with affective (mood and anxiety) disorders before and after psychotherapy. The control group consisted of 20 healthy subjects recruited by advertisement. A clinical psychologist administered the rating scales to both the 20 patients and the control group. Paykel's Clinical Interview for Depression (CID), Van Praag's Scale for Personality Disturbances, and Kellner's Symptom Management Questionnaire (SQ) measured psychological distress. The scale of PWB was used as the well-being measure (Ryff, 1989). The 20 patients were then treated by either cognitive behavioural therapy or by well-being psychotherapy. The 20 patients were then assessed at the end of the intervention by the same clinical psychologist using the same methods except for the Van Praag's Scale for Personality Disturbances which is a trait instrument.

The researchers reported that PWB scales were more sensitive to changes to treatment than SQ which had been found to be most sensitive in

other studies, Kellner, (1987). Assessments of affective disorders such as anxiety and depression tend to be concerned with symptomatic ratings such as anorexia, insomnia, feelings of hopelessness, and unhappiness and ignore the dimensions of PWB which are major components in quality of life (Fava, 1997). This statement is also reflective of what is found in the CHD literature. Much of the research has been conducted using instruments that screen for symptoms of affective disorders. The absence of affective disorders is then equated with PWB. PWB is a multidimensional concept. It should be measured by an instrument that measures PWB.

The PWB scales have also been widely used by investigators in other psychosocial disciplines to study well-being outcomes in response to various life challenges such as health and aging in Canadian seniors (Clarke, Marshall, Ryff, & Rosenthal, 2000), marital status change (Marks & Lambert, 1998), personal projects (McGregor & Little, 1998), caregiving (Li, Seltzer, & Greenberg, 1999), and recovery from depression (Fava, Rafanelli, Grandi, Conti, & Belluardo, 1998).

Mental Health

In the mental health literature the importance of recognizing both the negative factors and the positive factors that promote or prevent psychopathology as central to understanding of the human condition was evidenced as early as 1901. When William James (1901) delivered the Gifford Lectures on Natural Religion at the University of Edinburgh, Scotland, he described "health-mindedness" and "the sick soul" (James, 1999). More recently, the focus has been on the concept of "resilience" (Antonovsky, 1979; Coutu, 2002; Dyer & McGuinness, 1996; Wolff, 1995). Resilience has been defined as a process highly influenced by protective factors that mediate a patient's response to adversity and protects from negative outcomes (psychological, social, and emotional pathology). Luthar, (1991) completed a cross-sectional survey on inner city adolescents (n = 144) from a city public

school in Connecticut. Students were drawn from 10 ninth-grade classrooms. A total of 83% participated. The mean age was 15.3 years, $SD = .78$, range 14.0 to 17.2 years. The mean socioeconomic status of the families was 52.4 as rated by the Two-Factor Index of Social Position (Hollingshead & Redlich, 1958). This falls in the second lowest of the five Hollingshead categories. Seventy-seven percent of the students belonged to minority groups. Measures of negative life events were assessed using The Life Events Checklist (Johnson & McCutcheon, 1980) which asks about the positive and negative life events and the extent to which the events have affected the respondent over the past year. Acceptable levels of test-retest reliability and validity have been reported for this instrument among adolescent samples (Brand & Johnson, 1982). A self-report questionnaire was used to obtain information on family size, household composition, and ethnicity. Parental education and occupation were obtained through verbal communication with the parents. Measures of competence included teachers' ratings using the Teacher-Child Rating Scale (Hightower, Work, Cowen, Lotyczewski, Spinell, Guare, & Rohrbeck, 1986). This assesses behaviors within two domains, problems (acting out, shy-anxious, and learning) and adjustment (frustration tolerance, assertive social skills, and task orientation). Psychometric properties have been reported (Hightower et al., 1986). Peer ratings were measured by The Revised Class Play questionnaire (Masten, Morison, & Pellegrini, 1985). The items of The Revised Class Play questionnaire measure three behaviors: aggressive-disruptive, sensitive-isolated, and sociability-leadership. School grades were assessed by school records. Moderator variables were assessed using The Ravens' Standard Progress Matrices which measures intelligence. Psychometric properties have been established (Raven et al., 1977). The Social Skills Inventory (Riggio & Throckmorton, 1986) measures several dimensions including emotional expressivity, emotional sensitivity, and emotional control. Acceptable coefficients of test-retest reliability and internal consistency and validity have been

established (Riggio, 1986) Locus of control was measured by The Nowicki-Strickland Locus of Control Scale (Nowicki & Strickland, 1973). High reliability and validity have been reported (Nowicki & Strickland, 1973). Ego development was measured using the abbreviated version of the Sentence Completion Test, Form 81 (Loevinger, 1985). Acceptable internal consistency, test-retest reliability, and validity have been found (Hauser, 1976; Loevinger, 1979, 1985). The Children's Depression Inventory (Kovacs, 1982) assessed depression. Acceptable levels of internal consistency and validity have been reported (Kovacs, 1985; Saylor, Finch, Spirito, & Bennett, 1984). Anxiety was measured using the total anxiety score from the Revised Children's Manifest Anxiety Scale (Reynolds & Richmond, 1985). Acceptable reliability and validity coefficients have been reported (Reynolds & Richmond, 1985). Depressive tendencies were measured by The Depressive Experiences Questionnaire (Blatt, D'Affiti, & Quinlan, 1979). Adequate psychometric properties have been demonstrated (Blatt, Quinlan, Chevron, McDonald, & Zuroff, 1982; Zuroff, Moskowitz, Wielgus, Powers, & Franko, 1983).

All of the participants in Luthar (1991) study were at high-risk in terms of negative life events and socio-demographic variables. The purpose of the study was to determine why some inner-city youth with high risk profiles were able to maintain socially competent behavior. Intelligence, internal locus of control, social skills, ego development, and positive life events were investigated. Ego development was found to be a protective factor directly related to competence, whereas locus of control and social skills were interactive, moderating factors. One curious finding in this study was that those labeled as resilient were significantly more anxious and depressed than those low-risk youth.

Robins, John, Caspi, Moffitt, and Stouthamer-Loeber, (1996) conducted a cross-sectional study of adolescent boys (4th grade) from mixed ethnic backgrounds with three personality profiles: resilient (n = 194), overcontrollers (n = 40), undercontrollers (n = 58). Personality types had been previously

determined during the first phase of the larger research study, the Pittsburgh Youth Study, by using the California Child Q-Set which is an instrument intended for use by lay observers and has been widely used in personality, developmental, and clinical psychology. (Block & Gjerde, 1986; Ozer, 1993; Renken, Egeland, Marvinney, Mangelsdorf, & Sroufe, 1989; Shoude, Mischel, & Peake, 1990; van Lieshout & Haselauger, 1994; Waters, Noise, Vaughn, & Ricks, 1985). Participants for the larger study consisted of 868 boys randomly selected from public schools in Pittsburgh, Pennsylvania. Using multiple informants (caregiver, child, and teacher) and multiple data-types (self-report, observer-report, and objective tests (the short form Wechsler Intelligence Scale for Children-Revised (Weschler, 1974), the Self-Report Delinquency Interview (Elliott, Huizinga, & Ageton, 1985), and the CBCL. Those with resilient personalities were described as verbally expressive, energetic, personal, dependable, open-minded, smart, and self-confident. Those with resilient personality profiles were found to be successful in school, unlikely to be delinquents, and relatively free of psychopathology.

In other studies (Garmezy, Masten, & Tellegen, 1984; O'Dougherty, Wright, Garmezy, Lowewenson, & Torres, 1983) manifestations of competence despite exposure to stressful events is defined as "stress resistance". In 1991, Garmezy summarized the findings of a program of research undertaken with colleagues Ann Masten and Auke Tellegen entitled "The Project Competence Studies of Stress Resistance in Children". In this article Garmezy suggests that "it is critical to identify those "protective" factors that seemingly enable individuals to circumvent life stressors" (1991, p 20) In 1995, Werner described protective factors that are within the individual, within the family, and within the community. In 1999, Masten described parenting quality, intellectual functioning, and self-efficacy as protective factors.

As evidenced from the above, the focus appears to be changing. More interest is being given to the positive aftermath of a life crisis such as

bereavement, illness, captivity, major accidents, chronic disability, and abuse. Although subjects have come from diverse age groups, the central theme of this research is that of articulating the positive outcomes of traumatic experience. Tedeschi and Calhoun, (1995) and Tedeschi, Park and Calhoun, (1998) found that growth after suffering can include such outcomes as new self-perception, an appreciation of one's own vulnerability, change in relationships with others, and a change in life philosophy.

The research in posttraumatic stress disorder describes cognitive and emotional life changes that may occur following significant suffering. This path of inquiry draws on existential philosophy (Frankl, 1992) and applies perspectives to numerous contexts e.g. chronic illness, bereavement, cancer, HIV, heart attack, sexual abuse. Researchers see growth as a result of posttraumatic stress related to constructs of resilience, SOC, and hardiness. The emphasis is on defining the types of growth that can follow crisis.

Personality researchers have studied the idea of growth through trauma. Aldwin and Sutton, (1998) describe life stress in adulthood as a way of increasing coping skills, self-esteem, self-confidence, and self-knowledge. Emmons, Colby, and Kaiser, (1998) found that goal change does not necessarily follow trauma but rather that it is the lack of goal change (the ability to carry on with life plans) that was associated with recovery. Tennen and Affleck, (1998) described additional personality characteristics that contribute to flourishing such as dispositional optimism, in other words, the outlook one has on life. Park, (1998) noted that some people describe a traumatic event as the best thing that could have happened to them. He suggested that optimism and hope, spirituality and religiousness, extraversion, and the appraisal and coping processes are personal characteristics relevant to the understanding of growth through adversity. Similarly, Saakvitne, Tennen, and Affleck, (1998) suggest that trauma can be transformative and leads to reconstruction of the meaning of life, a renewal of

faith, trust, hope, connection to others and the community, and a redefinition of self.

In the child/adolescent literature and in the adult literature on resilience and stress resistance, the focus of research has been on the challenges that individuals confront as they travel throughout life. In childhood and adolescence, however, the dependent variable is growing up in high-risk environments such as low socioeconomic status or having parents with alcoholism or psychopathology. In the adult literature it is an acute event or unexpected trauma. CHD in adulthood, for the majority of cases, is not an acute event or unexpected trauma.

In both the child/adolescent literature and the adult literature researchers have suggested there are protective mechanisms that promote resilience or stress resistance but little research has been done to further define what these may be.

In 2000, in a special issue of the *American Psychologist*, Seligman and Csikszentmihalyi acknowledged the importance of the positive psychology movement. They expressed concerns about the negative focus of clinical psychology and the inattention to the positive or what makes a good life. Following this, in 2002, Snyder and Lopez edited the *"Handbook of Positive Psychology"* adding momentum to the positive psychology movement. Three chapters in the handbook condemn the illness or disease focus of clinical psychology. The authors believe the DSM has institutionalized this negative focus and they call for a broader focus, one that includes human strengths and resources.

Folkman and Moskowitz, (2000), in their review of the research on coping comment that discussions of negative affect and other adverse outcomes have dominated the research on coping. Positive affect is an outcome that can co-occur with negative affect during chronic stress. It is their belief that "psychologists need to gain a better understanding of the significance of positive

affect in the midst of stress and how people generate and sustain positive affect under these conditions." (p. 652)

A Canadian study to examine eight measures of mental health and to look for associations with nine potential demographic and psychosocial determinants was conducted by Stephens, Dulberg and Joubert (2000). The research was a secondary analysis of the public use data file of the 1994/95 National Population Health Survey (NPHS). The NPHS provides an authoritative picture of the Canadian population living in the 10 provinces. Data was collected by computer-assisted personal interview with both a household representative and selected individuals. The maximum sample available for analysis was 17,626 persons, 12 years of age and over but for most analysis the average sample was 14,500. Seven indicators of mental health were measured: SOC using Antonovsky's scale (1987); self-esteem using the Rosenberg scale (1965); sense of mastery measured by seven questions (Pearlin, Lieberman, Menaghan, & Mullan, 1981); happiness and interest in life measured by a single item on the Health Utility Index (Torrance, Furlong, Feeny, & Boyle, 1992); depression measured by a set of 27 questions on symptoms taken from the Composite International Diagnostic Interview (Kessler, McGonagle, Zhao, 1994); distress measured by a six-item checklist with a score of 5 or greater indicating high distress; cognitive impairment measured by two items which are part of the Health Utility Index (Torrance et al., 1992). The psychosocial and demographic factors associated with mental health problems were inversely associated with the indicators of well-being. The researchers comment that there has been no systematic examination of the factors associated with positive and negative mental health and they suggest that mental health promotion should emphasize conditions that foster resilience and support.

Yeo and Sawyer, (2003), conducted a literature search using Medline 1980 to 2002, to explore the emotional well-being of the young person with

chronic illness and strategies that promote better health outcomes. They concluded that traditional health care is focused on disease outcomes. They believe that, to improve health outcomes in young people with chronic illness, health professionals need to strengthen the relationships within the family, school, and peer group and with the health care team.

Psychosocial research in adults with CHD has only recently begun to appear in the literature. This research has focused on the presence or absence of psychopathology and quality of life to measure psychological well-being. This psychosocial research has not used a specific instrument to measure PWB. The chronic illness research has used instruments to measure PWB and has found that high scores in the six dimensions of PWB may reduce the incidence of psychological dysfunction in chronic illness. This research may provide further insight into the protective factors that promote psychological well-being.

Despite the challenge of chronic disease superimposed on life transitions, many CHD patients with a complex structural heart defect, by self-report to this researcher, feel they do extremely well. This study will use Ryff's instrument to compare adults with simple structural heart defects to adults with complex structural heart defects on the six dimensions of PWB to determine whether the complexity of the structural heart defect determines those who will do well, psychologically, and those who will not.

Chapter 3

Theoretical and Conceptual Framework

The subspecialty of adult CHD in cardiology has developed rapidly over the past 15 years. There are a limited number of advanced practice nurses practicing in this subspecialty. No formal conceptual framework for the advanced practice nurse (APN) in the care of adults with CHD has been developed. This chapter will describe the theoretical and conceptual framework for APN practice in the care of the adult with CHD. This conceptual framework forms the foundation for this researcher's clinical practice and this research thesis.

Over the past twelve years of clinical practice, what this researcher saw in clinical practice was not what was found in the psychosocial research in adults with CHD. Adults with CHD at the clinic in Calgary, by self-report, indicated that their lives were, for the most part, good. This incongruity between clinical practice and research led to reflection and the subsequent development of a APN conceptual framework for practice

A number of nursing theories have informed the development of a conceptual framework for APN practice in the care of the adult with CHD. These include Neuman's Systems Model (Neuman, 1989), Meleis's Life Transition Theory (Meleis, Sawyer, Im, Messias, & Schmacher, 2000), Mishel's Uncertainty-in-Illness Theory (Mishel, 1990), and Oberle and Davies Supportive Care Model (Oberle & Davies, 1992). Neuman's Systems Model (Riehl & Roy, 1980) and Ryff's Theory of Psychological Well-Being (Ryff & Keyes, 1995) are central to the conceptual framework; however, strands of the other nursing theories add to the matrix to form a total person approach that includes the biophysical, the cognitive, the psychological, social, and spiritual dimensions of each individual.

Appendix A provides a graphic representation of the conceptual framework used in this study. The concepts of coaching, advocacy, autonomy, valuing, and finding meaning are used by the APN to support the patient and family along their journey through life; a journey through life which has the health-

illness trajectory superimposed upon it. The circular broken lines indicate the vulnerability in the patient's line of defense in any of these areas.

Betty Neuman's Health Care Systems Model

The aim of Betty Neuman's Systems Model or total person approach is to understand man and his environment and provide a focused approach for a variety of nursing issues. The model is based on the individual's response to stress and factor reconstitution, which is a dynamic process. Theoretically, the model suggests that "each of us is surrounded by a perceptual field that is a dynamic equilibrium" (Riehl & Callista, 1980). In other words, an individual's world view varies according to their perception of this ever changing world.

Stressors can disrupt the dynamic equilibrium and it is the individual's perception of and reaction to the stressors that can result in equilibrium or disequilibrium. The individual's response is simultaneously affected by the physiologic, psychologic, sociocultural, and developmental variables.

Central to the framework of the CHD APN model is a "total person approach to care". The model assumes that each individual is unique and is a composite of known characteristics from five realms: biophysical, cognitive, psychological, social, and spiritual. This composite of characteristics comprises the individual and none of the parts can be viewed in isolation. In Neuman's model, the individual is an open system model that reacts to stress produced by the interfaces with his/her environment. Stressors, the reaction to stress and reconstitution, can be viewed on three different levels: intrapersonal (forces within the individual), interpersonal (forces between one or more individuals), and extrapersonal (forces occurring outside the individual). Any one stressor is capable of incapacitating an individual and reducing the effectiveness of his ability to cope. However, what constitutes a stressor for one person, may not constitute a stressor for another.

Using this conceptual framework, the patient must be assessed in each of the five realms on each of the three levels. The APN must be conscious of her

own perceptions and how this influences her assessment of the stressor while helping the patient find the meaning that a stressor has to the patient. The patient must validate this meaning. Once assessment is completed, intervention can begin at the level of primary, secondary, or tertiary prevention.

Meleis's Life Transition Theory

The APN must attend to changes and demands that transitions bring to the daily lives of CHD patients and their families. Life transitions (Meleis et al., 2000) and the vulnerability that accompanies these are experienced by everyone but these are particularly important for the patient who lives with chronic illness. Transitions are of four types: health-illness transition, developmental transition, situational transition, and organizational transitions.

Health-illness transition includes symptom management, procedure planning, surgical planning, rehabilitation, recovery, and healthy life style choices. Young adults with complex CHD often have residua/sequelae from previous interventions that may require further intervention. Risk reduction, intimacy/relationships, sexuality, genetics, family planning, pregnancy, childbirth, parenthood, menopause, aging, and death are developmental transitions.

Situational transition includes career planning, job loss due to health issues, migration, insurance/financial planning. Young adults with CHD were often left with the perception post-operatively that their heart was "fixed". No further thought was given to their heart condition and therefore no planning was done to define an appropriate career path based on future interventions or deterioration in functional ability. Over the course of history, we now know that many will develop complications later in life. Therefore, career planning, in order to continue to be a productive member of society despite a chronic illness becomes an issue. CHD patients often seek direction as to financial planning and life insurance. Life insurance is often not an option for a patient with a structural heart defect or if it is available, the premiums are prohibitive.

Organizational transition involves policy or operational changes within the health care system. Changes in programs or in staff can positively or negatively affect patients with chronic illness. They experience the cyclical patterns in health care delivery and know what has worked and not worked. Yet, they feel they are the last to have input into the way programs are delivered. As regular consumers, CHD patients are often reluctant to tell their story one more time or become the "guinea pig" one more time to train new staff.

The APN must be cognizant of the interrelated properties of transition—awareness (engagement, change and difference, time span, and critical points and events) in order to understand the patient's perception of transition. Awareness is reflected in the level of congruency between what constitutes a usual response in a similar situation. A patient must have some awareness of the changes that are occurring. Change and difference are essential properties of transition. Transitions are the result of change and transitions result in change. The patient must engage in the processes inherent in transition. The level of awareness the patient has with respect to this process will influence the level of engagement.

Personal conditions such as the meaning attributable to the transition, cultural and religious beliefs and attitudes, socioeconomic status, preparation and knowledge, and the community and societal conditions can either facilitate or inhibit successful outcomes during transition. These personal conditions are the same variables that are included in Neuman's Systems Model (Riehl & Callista, 1980).

Transition can be characterized as the depolarization and repolarization of the heart beat of life. It begins with a change or a critical event, followed by a period of instability, through to stabilization and culminates in mastery and identity reformation. Transition may also have a discrete ending as in death. In the conceptual framework for APN in CHD, the health-illness trajectory is the primary focus and as such, is seen as the foreground superimposed on life

transitions. The CHD patient welcomes life transitions, however, a sudden, unexpected, health-illness transition is often larger than life in that it may become life-limiting.

The role of the APN then is to guide the patient and family along health/illness, developmental, situational, and organizational transitions through a collaborative and holistic interpersonal process that is mediated by the APN-patient relationship and the APN's self-reflective skills.

Mishel's Uncertainty Theory

Will I have complications following reparative or palliative surgery? Will I have to have repeat surgery? Will my conduit last three years or ten years? When will I have repeat surgery? Can I have children? What are the risks to me? What are the risks to my child? Will I have a normal life span? What other health problems will I encounter? How will I support my family or myself if I get sick or require time off for repeat surgery? These are questions the APN frequently encounters.

According to Antonovsky (1987), for life to appear coherent, the events that comprise life must be structured, ordered, and predictable. When those events that surround a health crisis, its treatment, and recovery are vague, ambiguous, or unpredictable, a sense of coherence (SOC) is lost. The instability that results from the loss of coherence can disrupt the existing cognitive structures that enable the patient to cope with their congenital heart problem within the context of everyday life. At the peak of instability, formation of a new orientation toward life occurs. This new orientation toward life that is formed by this health crisis provides the foundation on which the new sense of order is constructed.

This experience is not foreign to the parents of the young adult. The birth of a child with CHD and the uncertainty surrounding this experience provides the foundation on which their new orientation to life is formed. It is a new experience for the young adult with CHD who is assuming responsibility for his or her own

health. It is at these times when the young adult might return to their parents for support and decision making. The focus for the APN during these times is to help the young adult and family negotiate the adult health care system. The APN coaches the young adult and family through the health crisis, helping them find that SOC through valuing, educating, becoming a patient advocate, and promoting autonomy.

Oberle and Davies Supportive Care Model

In designing a conceptual framework for APN in CHD, some of the concepts proposed by Oberle & Davies (1992) in the Supportive Care Model have to be included. "Valuing" in the conceptual framework for APN in CHD provides the context for all the APN's activities. Global valuing is about respecting the patient within the context of their family and their community. Particular valuing is about the individual patient and their unique characteristics and abilities. Connecting is about engaging with the patient and family, entering into their experience and their life in order to be the expert advocate and resource throughout the course of their life right through to end of life.

Although the term used in the Supportive Care Model is "empowering", autonomy is more appropriate for this framework. Autonomy is about enabling young adults and it is done by facilitating, mediating, mending, encouraging, and educating.

"Finding meaning" focuses on helping the young adult make sense of their illness when they are hit by a crisis. At end of life it is about facilitating reflections, fulfilling wishes, and meeting spiritual needs. It is about giving an opportunity to talk of dying and have their last wishes fulfilled.

"Doing for" in the context of CHD becomes the APN helping the young adult and family negotiate the health-illness trajectory superimposed on life. It is about team collaboration.

Although not included in the diagrammatic representation of the conceptual framework, "preserving own integrity" is inherent. In the supportive care model, by Oberle & Davies (1992) description, it is about the nurse's ability to maintain self worth and self-esteem as well as energy. While this is appropriate, the proposed conceptual framework for APN in CHD focuses more on the patient and family. In this researcher's view, preserving integrity would be part of promoting autonomy in the young adult with CHD.

Ryff's Theory of Psychological Well-Being

With all the challenges that the health-illness trajectory superimposed on life adds to the CHD patient, the question remains as to why some patients remain psychologically well and live life to the fullest, while others do not?

Over the past 30 years the psychological research has been dominated by contextual frameworks that look at how people cope and do well within specific stressful situations. The evidence produced by this research suggests the following facts:

- 1) that coping has multiple functions (including managing distress but also the problems causing the distress) (Parker & Endler, 1996);
- 2) that coping is influenced by appraisal and perception of control (Baum, Fleming, & Singer, 1983; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986);
- 3) that coping is influenced by personality dispositions (Carver & Scheier, 1999); and
- 4) social resources influence coping (Holahan, Moos, & Schaefer, 1996; Pierce, Sarason, & Sarason, 1996).

Despite growing evidence that PWB has a favorable impact on disease course and the biochemical and neurophysiological response of the individual, PWB has been underrepresented in this research. It has only been within the last two decades, as a result of the work of Ryff (1989), that there now exists a contextual framework of PWB through which this question can be studied.

Ryff (1989) developed the concept of PWB on theoretical grounds, based on existing philosophical and ethical accounts of the good life. Factors that promote psychological well-being include: leading a life with purpose, quality connections to others, self-acceptance, autonomy, environmental mastery, and personal growth. These form the "bedrock of criterial goods of life". (Ryff, 1998, p 3). Ryff's theory proposes it is the connection between this bedrock of criterial goods and the lens or outlook one brings to life that combine to form the individual differences in response to life challenges.

It is her belief that those who are securely grounded in quality living (purposeful life, quality relationships, self-acceptance, and environmental mastery) might well be expected to be optimistic and continue to do well psychologically when confronted with challenge. These individuals will transcend the passive view of the organism exhibited in the stress research, where the ultimate goal is adaptation and instead invoke a higher level, those that excel (Ryff, 1998).

The mandate of the CHD clinic team is to prevent the biophysical, psychological, social, and spiritual complications of CHD. That is, patients must be grounded in quality living in order that they may flourish in the face of their chronic disease process. This APN framework provides for assessment, intervention, and evaluation in the promotion of quality living for adults with CHD.

Despite what has been found in the literature, adults with CHD at the clinic in Calgary by self-report feel they do extremely well and live very happy and productive lives. This researcher's clinical experience contradicts what has been shown in the research. It may be that there are protective mechanisms that promote psychological well-being and that it is the presence or absence of these protective mechanisms, rather than the complexity of the defect which dictates those who do well, psychologically, and those who do not.

CHAPTER 4

METHODS

The purpose of this research is to examine the relationship between the complexity of the structural heart defect and psychological well-being in adults with CHD.

Research Hypothesis

The null hypothesis is that there is no difference in scores of psychological well-being between adults with simple structural CHD and adults with complex structural CHD.

Research Method

The survey method was used to examine the six dimensions of PWB in two groups of adults with CHD, those with simple structural CHD and those with complex structural CHD. Structural complexity was determined by using the ACC classification (Webb & Williams, 2001) which delineates three levels of structural complexity: simple, moderately complex, and complex heart disease.

Instruments

Part A consisted of 12 questions developed as a result of information obtained from the literature, discussion with other colleagues in ACHD, and the investigator's clinical experience and was included to gather information on socio-demographic and clinical factors. The supervisor and committee members reviewed Part A and revised it accordingly. A review of face and content validity was completed by two Faculty of Nursing members with expertise in questionnaire design. Part B of the questionnaire measured PWB using the 14-item scale which is the shortened form of the original 20-item scale developed by Ryff (1989) (Appendix C). Test-retest reliability coefficients for the 20-item scale were acceptable (SA, α .85, PR, α .83, AU, α .88, EM, α .81, PL, α .82, PG, α .81). Correlations with prior measures of positive functioning (e.g. life satisfaction, affect, self-esteem, internal control, morale) show positive and significant ($p < 0.001$) coefficients ranging from .25 to .73. Correlations with prior

measures of negative functioning show negative and significant ($p < 0.001$) coefficients ranging from α -.30 to α -.60. The scale comprises 84 items, equally divided among six dimensions measuring SA (α 0.91), PR (α 0.88), AU (α 0.83), EM (α 0.86), PL (α 0.88), and PG (α 0.85). Correlation of each of the dimensions with the 20-item original scale range from 0.97 to 0.99 (Ryff, 1989). Reliability and validity assessments of the 20-item parent scales have been detailed by Ryff (1989) and Ryff and Keyes, (1995). Responses to each item are made on a 6-point scale (1 = strongly disagree to 6 = strongly agree) with some items being reverse scored. Extensive theoretical literature was reviewed to develop the instrument including Maslow's (1968) conceptualization of self-actualization, Roger's (1961) view of the fully functioning person, Jung's (1933) formation of individuation, and Allport's (1961) conception of maturity, Erickson's (1959) psychosocial stages of development, Buhler's (1935) basic life tendencies that work toward fulfilment of life, Neugarten's (1973) description of personality change in adulthood, and Jahoda's (1958) positive criteria of mental health (Ryff, 1995). As a result of this review, many points of convergence of these multiple frameworks of positive human functioning were found. It was these points of convergence that were used to form the core dimensions of Ryff's multidimensional model of PWB (Ryff, 1995).

Operational Definitions

For the purposes of this study the following operational definitions were used.

Congenital Heart Defect (CHD)

A structural abnormality of the heart that results from abnormal cardiac development which impacts the physiological functioning of the heart.

Simple Structural Heart Defect

A structural abnormality of the heart that may or may not impact physiological functioning of the heart and may come to definitive repair as defined by the ACC classification (Webb & Williams, 2001).

Complex Structural Heart Defect

A structural abnormality of the heart that impacts the physiological functioning of the heart that is either inoperable or requires palliation or definitive repair of the defect in order to preserve heart function as defined by the ACC classification (Webb & Williams, 2001).

Psychological Well-Being (PWB)

An outlook or enduring attitude whereby life is seen as comprehensible, manageable, and meaningful. It includes six dimensions. It is often used interchangeably with Antonovsky's term, "sense of coherence" (Ryff & Singer, 1996; Antonovsky, 1987).

The Six Dimensions of PWB:

1. Positive Relations with Others (PR)

High scorer: an individual who has warm, satisfying, trusting relationships with others; someone who is concerned about the welfare of others and is capable of strong empathy, affection, and intimacy; someone who has an understanding of the give and take in human relationships.

Low scorer: has few close, trusting relationships with others; finds it difficult to be warm, open, and concerned about others; is isolated and frustrated in interpersonal relationships; not willing to make compromises to sustain important ties with others.

2. Autonomy (AU)

High scorer: an individual who is self-determined and independent; able to resist social pressures to think and act in a certain manner; regulates their behavior from within and evaluates self by personal standards.

Low scorer: is concerned about the expectations and important decisions; conforms to social pressures to think and act according to expectations of others; relies on judgements of others to make decisions in certain ways.

3. Environmental Mastery (EM)

High scorer: an individual who demonstrates competence in managing their environment, controls a complex array of external activities, makes effective use of available opportunities, and is able to choose or create contexts suitable to their personal needs and values.

Low scorer: has difficulty managing everyday affairs; feels unable to change or improve surrounding context; is unaware of surrounding opportunities; lacks sense of control over external world.

4. Purpose in Life (PL)

High scorer: this individual has goals and a sense of directness; they feel there is meaning to both present and past life; they hold beliefs that gives purpose to their life.

Low scorer: lacks a sense of meaning in life; has few goals or aims, lacks sense of direction; does not see purpose of past life; has no outlook or beliefs that give life meaning.

5. Personal Growth (PG)

High scorer: this individual has a feeling of continuing evolution and development and is open to new experiences; they sense their potential and change in ways that reflect insight and self-knowledge.

Low scorer: has a sense of personal stagnation; lacks sense of improvement or expansion over time; feels bored and uninterested with life; feels unable to develop new attitudes or behaviors.

6. Self-Acceptance (SA)

High scorer: an individual with a positive attitude toward the self; one who accepts both their good and bad qualities; one who feels positive about their life.

Low Scorer: feels dissatisfied with self; is disappointed with what has occurred in past life; is troubled about certain personal qualities; wishes to be different than one is.

Resilience

The capacity to prevail in the face of adversity.

Recruitment

Patients were recruited from the 1300 adults with documented CHD registered on the database of the ACHD clinic at the Peter Lougheed Hospital as of November 1, 2004. Historically, The Calgary Health Region Ethics Board (CHREB) gave ethical approval for patients to be entered on a clinic database in 1996 with their consent. Permission to approach this patient group and access the database was received from the directors of the ACHD Clinic.

In order to ensure the most variability between the two patient groups, those patients with simple structural heart defects and those patients with complex structural heart defects as defined by the ACC classification (Webb & Williams, 2001) were chosen to participate.

Sample Size and Data Collection

A thorough search of Academic Search Premier, CINAHL, EMBASE, Medline, HealthSTAR, PsychINFO yielded no prior study in the CHD literature that measured PWB in two patient groups upon which to base a sample size calculation. Therefore, all 180 patients with complex structural heart defects listed on the database as of November 1, 2004, that fit the ACC classification (Webb & Williams, 2001) were chosen. As November 1, 2004, the clinic followed 553 patients that fit the criteria for simple structural heart defects. In order to form the comparison patient group of 180 patients with simple structural CHD, the list of 553 patients with simple structural heart defects was scrambled by a cardiologist at the ACHD clinic who then generated a random list of patients with simple structural heart defects. From the scrambled list, 180 random patients were selected using the random number generator in EXCEL. Patients who

were developmentally challenged and unable to complete the questionnaire were excluded from the study.

A 60% response rate (108 patients in each group) was not achieved after the first mailing and so a reminder letter was mailed to all those who had not returned their questionnaire. The 60% response rate was not achieved after the reminder letter and so a second mail-out was sent to the new patients with complex structural heart defects who had registered at the clinic since the original list was generated in November 1, 2004. For the simple structural heart defect group, a new randomized list was constructed of the remaining 373 patients and any new patients with simple structural heart defects who had registered at the clinic since the November 1, 2004. From this new list, a random selection was made to generate 30 patients for the second mail-out.

Data Analysis

The data were coded, cleaned, and entered into SPSS 13.0 for analysis. Statistical analysis of the socio-demographic data included descriptive statistics of means, standard deviations, and ranges. Cross tabulations were done to compare variables of how they rate their health to the number of heart surgeries, to spirituality, and to employment. Independent t-tests were done to compare scores of PWB for both groups. One way analysis of Variance (ANOVA) was used for multiple comparisons of the scores of PWB in each of the six dimensions with level of education, rating of health, and employment. Pearson product moment correlation was used to look at the correlation between number of heart surgeries and scores in each of the six dimensions. Univariate analysis of Variance (UNIANOVA) was used to examine the impact of gender, marital status, level of education, employment status, rating of health and spirituality on the mean score of the six dimensions of PWB for each group. Wilk's Lambda was used as the test of significance.

Compliance with Ethical Standards

Confidentiality was maintained at every stage of the research. Only the researcher, the research assistant, and the supervisor had access to the completed questionnaires. The questionnaires for the patients with complex structural heart defects were assigned an identification number and sent out by the researcher. Those questionnaires that were sent to the randomly generated list of patients with simple structural heart were assigned identification numbers and sent out by the research assistant. A code book that contained the identification number of the questionnaire that had been assigned to each participant was maintained by the research assistant. This ensured that neither the researcher nor her supervisor had access to participant names. Returned questionnaires were stored in a locked cabinet, separate from the code book, to which only the researcher and her supervisor have access. Participants are not named at any point in the study, nor will their names be used in subsequent publications. The data in SPSS 13.0 will be stored on the researcher's computer hard-drive that is password and firewall protected by the University of Calgary. Data will be kept for five years after the termination of the study. At the conclusion of this time, the data will be shredded and electronic data will be erased.

Ethical approval for the study was sought and obtained from the Conjoint Health Research Ethics Board, University of Calgary, Calgary, Alberta. Permission to conduct the study was obtained from the University of Calgary, Faculty of Nursing Student Supervisory Committee and the Adult Congenital Heart Clinic, Peter Lougheed Hospital, Calgary Health Region.

Consent

Patients who were sent a questionnaire also received a letter of invitation to participate that described the proposed research. Return of a completed questionnaire indicated patient consent to participate.

CHAPTER 5

Results

This chapter begins with a descriptive analysis of the results followed by inferential statistical tests relevant to the research questions. A summary of the research findings will close the chapter.

Response Rate

It will be recalled that prior to the initial mail-out, the original list of patients with complex structural heart defects generated on November 1, 2004 was reviewed and amended. Three of the 180 patients with complex structural heart defects had moved out-of-province with no forwarding address and two had died. The initial mail-out was sent March 26, 2005 to 175 patients with complex structural heart defects and 175 randomly selected patients with simple structural heart defects. Response rate for the initial mail-out is outlined in Table 5.1.

Table 5.1 Response Rate - Initial Mail-Out

Date	Group	Returned Complete N	Declined N	Lost/ Moved N	Deaths N	Un- returned N	Response Rate Complete N (%of total)
05-06-10	Simple	61	8	27	0	79	61 (35%)
	Complex	66	15	21	5	68	66 (38%)

On May 21, 2005 a second notification letter was sent to all those patients who had not yet returned the original questionnaire. In order to increase the likelihood of a 60% response rate within the simple structural heart disease group, it was decided to send out additional 30 questionnaires. The next 30 patients from the original randomized simple structural heart defect list were sent a questionnaire. This mail-out was completed on June 10, 2005. Table 5.2 outlines the response rate following the additional mail-out. As a result of this mail-out, thirty-nine percent of those with simple structural heart defects and

46% of those with complex structural heart defects responded for a total response rate of 43%.

Table 5.2 Response Rate Following Additional Mail-Out

Date	Group	Returned Complete N	Declined N	Lost/ Moved N	Deaths N	Un-Returned N	Response Rate Complete N (% of total)
05-06-10	Simple Complex	61 66	8 15	27 21	0 5	79 68	61 (35%) 66 (38%)
05-06-24	Simple Complex	6 12	0 1	2 0	0 1		
05-07-06	Simple Complex	6 0	1 1	0 2	0 0		
Total	Simple Complex	73 78	9 17	29 23	0 6	64 51	73 (36%) 78 (45%)

On July 6, 2005, those patients who had not yet returned their questionnaires following the additional mail-out were mailed a reminder letter. The final response rate for the survey is indicated in Table 5.3. A total of 85 out of 205 patients with simple structural heart defects and 78 out of 175 patients with complex structural heart defects returned completed questionnaires for a completion response rate of 41% and 45% respectively.

Table 5.3 Overall Response Rate

Date	Group	Returned Complete N	Declined N	Lost/ Moved N	Deaths N	Un-returned N	Response Rate Complete N (% of total)
05-07-28	Simple Complex	12 0	1 1	4 0	0 0		
Total	Simple Complex	85 78	10 18	33 23	0 6	47 50	85 (41%) 78 (45%)

Descriptive and Inferential Statistical Results

It may be recalled that the two major research objectives were to:

1. Measure the six dimensions of psychological well-being in two groups of adults with congenital heart disease.

2. Identify whether there is a difference in psychological well-being between adults with simple structural heart defects and adults with complex structural heart defects.

It should be noted that for the purpose of obtaining the mean group dimension scores, if a question had not been answered that individual questionnaire was excluded from the mean group score for that dimension. For example, if a participant had completed all the questions relative to the dimension of autonomy but not self-acceptance, that questionnaire would be used to compute the mean group score for autonomy but not the mean group score of self-acceptance. The range in scores possible for each dimension of PWB is 14 to 84 with 84 being the highest possible score for that dimension of PWB. A score of less than 49 for a particular dimension indicated poor PWB.

Complexity of Structural Heart Disease and PWB Dimension Score

The mean scores for the simple structural heart defect group and the complex structural heart defect group in each of the six dimensions are on Table 5.4. It will be recalled that the six dimensions are: positive relations with others (PR), autonomy (AU), environmental mastery (EM), personal growth (PG), purpose in life (PL), self-acceptance (SA). There was no statistically significant difference in the mean scores of each of the six dimensions of PWB between those participants with simple structural heart defects and those participants with complex structural heart defects. Cronbach's Alpha is reported in Table 5.5.

Table 5.4 Mean Dimension Score by Simple/Complex Group

PWB Dimension	Group	N	Mean	SD	SE	p value
Positive Relations with Others	Simple	84	64.95	11.92	1.30	0.245
	Complex	73	67.27	13.00	1.52	
Autonomy	Simple	83	62.16	10.46	1.15	0.288
	Complex	72	64.06	11.70	1.38	
Environmental Mastery	Simple	83	59.28	9.71	1.07	0.194
	Complex	72	58.47	11.75	1.39	
Personal Growth	Simple	83	68.73	10.41	1.14	0.194
	Complex	72	70.78	8.86	1.04	
Purpose in Life	Simple	82	66.01	12.25	1.35	0.890
	Complex	74	66.29	13.36	1.55	
Self-Acceptance	Simple	85	61.45	10.84	1.18	0.554
	Complex	75	60.43	10.87	1.26	

Table 5.5 Cronbach's Alpha

PWB Dimension	Cronbach's Alpha (α)	Number of Items
Positive Relations	0.896	14
Autonomy	0.861	14
Environmental Mastery	0.829	14
Personal Growth	0.871	14
Purpose in Life	0.910	14
Self-Acceptance	0.735	14

Age

The mean age of participants ($n = 161$) was 37 years, SD 13.42. The mean age and SD of the simple structural heart defect group and the complex structural heart defect group are presented in Table 5.6.

Table 5.6 Simple/Complex Group by Mean Age

Group	Mean Age	SD	Total N (%of total)
Simple	39	12.55	83 (52%)
Complex	35	14.06	78 (48%)
Total	37	13.42	161*

* Two participants did not indicate their age.

Table 5.7 Simple/Complex Group by Age Group

Simple/Complex Group	Age Group			Total N (% of total)
	Young Adult 18 – 30 years N (% of total)	Adult 31-60 years N (% of total)	Older Adult 61+ years N (% of total)	
Simple	23 (42%)	56 (57%)	4 (50%)	83 (52%)
Complex	32 (58%)	42 (43%)	4 (50%)	78 (48%)
Total	55 (34%)	98 (61%)	8 (5%)	161*

* Two participants did not indicate their age.

Ages ranged from 18 years to 87 years and in order to analyze the mean score in each dimension, three different age categories were established. The category of “young adult” included all those patients under the age of 18 to 30 years, “adult” included all those 31 to 60 years, and “older adult” included all those patients 61 years and older (Table 5.7).

There was no significant age group effect, simple/complex group effect, or age by simple/complex group interaction effect on the mean dimension scores for

any of the six dimensions of PWB when univariate two-way analysis of variance (ANOVA) was performed (Table 5.8).

Table 5.8 Two-way ANOVA Age by Simple/Complex Group

Dimension of PWB/Age Group		Group Mean (SD)		Age Group Effect F (df ₁ ,df ₂) [p]	Simple/Complex Group Effect F (df ₁ ,df ₂) [p]	Interaction Effect F (df ₁ ,df ₂) [p]
		Simple	Complex			
PR	young adult	66.35 (11.99) N=23	68.68 (10.94) N=31	0.484 (2,149) [.617]	3.002 (1,149) [.085]	1.103 (2,149) [.334]
	adult	65.11 (11.90) N=55	65.72 (14.68) N=39			
	older adult	57.75 (14.48) N=4	73.00 (8.19) N=3			
AU	young adult	59.32 (10.69) N=22	62.97 (10.92) N=30	2.280 (2,148) [.106]	0.456 (1,148) [.501]	0.141 (2,148) [.869]
	adult	62.68 (10.44) N=56	64.38 (12.37) N=39			
	older adult	69.75 (7.09) N=4	70.67 (11.72) N=3			
EM	young adult	57.91 (8.48) N=23	60.06 (11.97) N=31	0.107 (2,148) [.898]	0.236 (1,148) [.628]	0.471 (2,148) [.625]
	adult	60.16 (9.86) N=56	59.00 (11.83) N=38			
	older adult	56.00 (17.52) N=3	59.67 (12.34) N=3			
PG	young adult	67.95 (9.42) N=21	70.67 (9.11) N=30	1.400 (2,147) [.250]	3.151 (1,147) [.078]	0.7646 (2,147) [.468]
	adult	69.88 (10.42) N=56	71.00 (8.91) N=38			
	older adult	59.75 (12.45) N=4	69.50 (8.58) N=4			
PL	young adult	65.81 (10.60) N=22	67.84 (12.08) N=31	0.869 (2,149) [.422]	0.202 (1,149) [.653]	0.345 (2,149) [.709]
	adult	66.66 (13.01) N=56	65.45 (14.31) N=40			
	older adult	57.33 (10.26) N=3	61.67 (15.95) N=3			
SA	young adult	59.26 (8.724) N=23	61.06 (9.17) N=31	0.139 (2,152) [.870]	1.367 (1,152) [.244]	2.462 (2,152) [.089]
	adult	62.91 (11.33) N=56	59.35 (12.14) N=40			
	older adult	54.50 (14.91) N=4	66.25 (9.71) N=4			

Gender

Of the total of 162 patients who responded to the question on gender, there were 85 patients with simple structural heart defects and 78 patients with complex structural heart defects (Table 5.8). Of those patients with simple structural heart defects, 36% were male and 64% were female. Of those with complex structural heart defects, 42% were male and 45% were female.

Table 5.9 Simple/Complex Group by Gender

Group	Male N (% of total)	Female N (% of total)	Total N (% of total)
Simple	30 (36%)	54 (64%)	84 (51%)
Complex	33 (42%)	45 (58%)	78 (48%)
Total by gender	63 (39%)	99 (61%)	162*

* one patient did not indicate gender

A significant gender effect on the mean dimension score of positive relations with others ($p = 0.003$) was demonstrated by univariate two-way ANOVA. There was no significant simple/complex group effect or gender by simple/complex group interaction effect for this dimension. For the dimensions of environmental mastery, personal growth, purpose in life, and self-acceptance there was no significant group effect, gender effect, or gender by group interaction effect (Table 5.10).

Table 5.10 Two-way ANOVA Gender by Simple/Complex Group

Dimension of Well-Being/Gender		Group Mean (SD)		Gender Effect F (df ₁ ,df ₂) [p]	Simple/Complex Group Effect F (df ₁ ,df ₂) [p]	Interaction Effect F (df ₁ ,df ₂) [p]
		Simple	Complex			
PR	Male	59.60 (12.06) N=30	65.03 (12.67) N=30	9.41 (1,152) [.003*]	2.42 (1,152) [.122]	1.36 (1,152) [.246]
	Female	68.06 (10.90) N=53	68.84 (13.14) N=43			
AU	Male	62.48 (8.89) N=29	62.47 (12.16) N=32	0.41(1,151) [.521]	0.83 (1,151) [.365]	0.84 (1,151) [.361]
	Female	61.98 (11.29) N=54	65.32 (11.30) N=40			
EM	Male	59.10 (9.81) N=30	57.17 (11.14) N=29	1.66 (1,151) [.199]	0.002 (1,151) [.967]	1.090 (1,151) [.298]
	Female	59.54 (9.77) N=52	61.32 (12.02) N=44			
PG	Male	67.76 (11.08) N=29	69.30 (9.67) N=30	1.44 (1,151) [.232]	1.61 (1,151) [.206]	0.099 (1,151) [.754]
	Female	69.19 (10.19) N=53	71.74 (8.82) N=43			
PL	Male	64.79 (11.50) N=28	64.43 (12.54) N=30	1.50 (1,150) [.223]	0.018 (1,150) [.894]	0.088 (1,150) [.797]
	Female	66.77 (12.77) N=53	67.70 (14.03) N=43			
SA	Male	60.43 (11.04) N=30	57.63 (9.79) N=32	2.90 (1,155) [.091]	0.219 (1,155) [.641]	1.442 (1,155) [.232]
	Female	61.28 (9.39) N=54	62.51 (11.27) N=43			

* denotes significance

Multivariately, controlling for three age groups, young adult (18 to 30 years), adult (31 to 64 years), and older adult (65+ years) gender effect approached significance (Wilk's Lambda λ = 0.911, F (6,133) = 2.159, p = 0.051). There was no significant simple/complex group effect (Wilk's Lambda λ = 0.949, F (6,133) = 1.187, p = 0.317). There was no significant simple/complex group by gender interaction (Wilk's Lambda λ = 0.930, F (6, 133) = 1.673, p = 0.132).

Education

It may be recalled that for the question on education participants were required to indicate what level of education they had completed. Thirty-two percent of the total participants ($n = 163$) had a college or university degree, 25% had a trade or technical certificate, and 22% had completed high school. Of the complex structural heart disease patients ($n = 78$), 24% had a trade or technical certificate, and 31% had a college/university degree compared to the simple structural heart disease group ($n = 85$) where 25% had a trade or technical certificate and 33% a college/university degree (Table 5.11).

Table 5.11 Level of Education by Simple/Complex Group

Level of Education	Group		Total N (% of total)
	Simple N (% of total)	Complex N (% of total)	
Junior High School	2 (2%)	5 (6%)	7 (4%)
High School	19 (22%)	17 (22%)	36 (22%)
Trade/Technical	21 (25%)	19 (24%)	40 (25%)
Attending Trade/Technical	11 (13%)	5 (6%)	16 (10%)
College/University	28 (33%)	24 (31%)	52 (32%)
Attending College/University	2 (2%)	7 (9%)	9 (6%)
Other	2 (2%)	1 (1%)	3 (2%)
Total	85	78	163

For univariate analysis, the education groups were combined to form three groups: high school or less, technical, and university. For the dimensions of positive relations with others ($p = 0.043$), personal growth ($p < 0.001$), purpose in life ($p = 0.009$), and self-acceptance ($p = 0.006$) there was a significant education group effect but no significant simple/complex group effect or interaction effect.

For the dimensions of autonomy, environmental mastery there was no significant educational group effect, simple/complex group effect, or interaction effect on mean dimension scores (Table 5.12).

5.12 Two-way ANOVA Educational Group by Simple/Complex Group

Dimension of Well-Being/Education Group		Group Mean (SD)		Education Group Effect F (df ₁ ,df ₂) [p]	Simple/Complex Group Effect F (df ₁ ,df ₂) [p]	Interaction Effect F (df ₁ ,df ₂) [p]
		Simple	Complex			
PR	high school or less	63.25 (14.10) N=20	62.16 (12.54) N=18	3.219 (2,148) [.043*]	0.196 (1,148) [.916]	0.946 (2,148) [.391]
	technical	63.00 (12.28) N=32	68.74 (12.37) N=23			
	university	68.50 (69.68) N=30	69.68 (11.89) N=31			
AU	high school or less	61.10 (10.47) N=20	59.76 (11.05) N=17	1.908 (2,147) [.152]	0.805 (1,148) [.371]	0.579 (2,147) [.562]
	technical	63.31 (9.93) N=32	66.78 (11.66) N=23			
	university	61.93 (11.28) N=30	64.74 (11.76) N=31			
EM	high school or less	58.14 (10.21) N=21	55.74 (12.15) N=19	1.969 (2,147) [.143]	0.001 (1,147) [.973]	0.525 (2,147) [.593]
	technical	59.57 (9.054) N=30	60.09 (8.06) N=23			
	university	60.23 (10.33) N=30	62.30 (13.40) N=30			
PG	high school or less	63.24 (11.67) N=21	66.00 (9.88) N=18	8.846 (2,148) [.000*]	1.782 (1,148) [.184]	0.062 (2,148) [.940]
	technical	70.35 (8.77) N=31	72.21 (8.59) N=23			
	university	71.43 (9.61) N=30	72.87 (7.05) N=31			
PL	high school or less	62.95 (13.55) N=20	59.32 (16.43) N=19	4.925 (2,147) [.009*]	0.000 (1,147) [.991]	0.720 (2,147) [.489]
	technical	66.13 (11.21) N=31	68.70 (10.95) N=23			
	university	68.47 (12.10) N=30	69.50 (11.67) N=30			
SA	high school or less	58.05 (10.01) N=21	55.05 (12.50) N=21	5.335 (2,151) [.006*]	0.124 (1,151) [.725]	0.532 (2,151) [.589]
	technical	62.09 (8.39) N=32	63.36 (8.32) N=32			
	university	62.37 (11.26) N=30	62.35 (10.21) N=31			

* denotes significance

Multivariately, controlling for three age groups (young adult, adult, older adult), there was a significant education group effect (Wilk's Lambda $\lambda = 0.802$, $F(12,258) = 2.506$, $p = 0.004$). There was no significant simple/complex group effect ($\lambda = 0.965$, $F(6,129) = 0.778$, $p = 0.589$) and there was no significant simple/complex group by education group effect ($\lambda = 0.953$, $F(12,258) = 0.528$, $p = 0.896$).

Ethnicity

As may be seen in Table 5.13, of the total sample ($n = 163$), 91% were Caucasian.

Table 5.13 Ethnicity by Simple/Complex Group

Ethnic Group	Group		Total N (% of total)
	Simple N (% of total)	Complex N (% of total)	
Caucasian	78 (92%)	71 (91%)	149 (91%)
Asian	2 (2%)	3 (4%)	5 (3%)
Inuit, Canadian Indian	1 (1%)	0	1 (1%)
Other	4 (5%)	4 (5%)	8 (5%)
Total	85	78	163

Marital Status

Of the 161 participants who responded to this question, 33% were single, 52% were married, and 12% were divorced (Table 5.14).

Table 5.14 Simple/Complex Group by Marital Status

Group	Marital Status				Total N (% of total)
	Single N (% of total)	Married/ Common Law N (% of total)	Divorced N (% of total)	Widow/er N (% of total)	
Simple	20 (23.8%)	52 (61.9%)	11 (13.1%)	1 (1.2%)	84 (52%)
Complex	34 (44.6%)	33 (42.9%)	9 (11.7%)	1 (1.3%)	77 (48%)
Total	54 (33.5%)	85 (52.8%)	20 (12.4%)	2 (1.24%)	161*

* 2 respondents did not indicate marital status

For inferential statistical analysis the marital status groups were combined to form two groups, “attached” and “unattached”. Univariate two-way ANOVA found a significant marital status group effect on the mean dimension scores for environmental mastery ($p = 0.009$), purpose in life ($p = 0.024$), and self-acceptance ($p = 0.035$). There was no significant simple/complex group effect or interaction effect for the dimension of environmental mastery, purpose in life, and self-acceptance. There was no significant marital status group effect, simple/complex group effect, or interaction effect on the mean dimension scores for the dimensions of positive relations with others, autonomy, or personal growth (Table 5.15).

5.15 Two-way ANOVA Marital Status by Simple/Complex Group

Dimension of Well-Being/Marital Status		Group Mean (SD)		Marital Status Group Effect F (df ₁ ,df ₂) [p]	Simple/Complex Group Effect F (df ₁ ,df ₂) [p]	Interaction Effect F (df ₁ ,df ₂) [p]
		Simple	Complex			
PR	Unattached	63.28 (12.77) N=32	66.33 (13.10) N=39	1.454 (1,151) [.230]	1.953 (1,151) [.164]	0.009 (1,151) [.925]
	Attached	65.94 (11.48) N=51	68.61 (13.11) N=33			
AU	Unattached	59.97 (10.27) N=30	62.49 (11.08) N=39	3.514 (1,149) [.063]	2.275 (1,149) [.134]	0.015 (1,149) [.902]
	Attached	63.15 (10.42) N=52	66.13 (12.43) N=32			
EM	Unattached	56.06 (10.53) N=32	57.85 (12.62) N=39	7.009 (1,149) [.009*]	0.256 (1,149) [.614]	0.273 (1,149) [.602]
	Attached	61.56 (8.54) N=50	61.53 (10.64) N=32			
PG	Unattached	66.00 (12.67) N=30	70.25 (9.39) N=40	3.203 (1,149) [.076]	3.034 (1,149) [.084]	0.813 (1,149) [.369]
	Attached	70.32 (8.71) N=52	71.68 (8.28) N=31			
PL	Unattached	62.87 (14.25) N=30	64.48 (13.50) N=40	5.179 (1,150) [.024*]	0.402 (1,150) [.527]	0.019 (1,150) [.891]
	Attached	67.90 (10.76) N=51	68.94 (12.94) N=33			
SA	Unattached	59.00 (14.09) N=32	58.98 (11.08) N=42	4.536 (1,154) [.035*]	0.025 (1,154) [.875]	0.021 (1,154) [.885]
	Attached	63.00 (8.16) N=52	62.47 (10.58) N=32			

* denotes significance

Multivariately, controlling for three age groups, young adult, adult, and older adult, there was no significant marital status group effect (Wilk's Lambda $\lambda = 0.935$, $F(6,131) = 1.512$, $p = 0.179$). There was no significant simple/complex group effect (Wilk's Lambda $\lambda = 0.950$, $F(6,131) = 1.151$, $p = 0.337$) and there was no simple/complex group by marital status group interaction effect (Wilk's Lambda $\lambda = 0.993$, $F(6,131) = 0.160$, $p = 0.987$).

Employment Status

A total of 35 participants (24%) were business professionals. Nine have complex structural heart disease and 6 were male (Table 5.16). Of the 25 participants who indicated they were "at home", 17 (female = 12, male = 5) of these participants have complex structural heart disease.

The majority of the participants (n = 115) are working either full time or part time (71%) (Table 5.17). Of the participants (n = 48) who were not employed, 48 are females, 14 are males. No statistically significant difference was detected between males and females that were not employed ($p = 0.598$). Fourteen percent are receiving disability pension and/or CPP. Only 4% of participants were receiving Assured Income for the Severely Handicapped (AISH).

Table 5.16 Employment Category by Simple/Complex Group and Gender

Employment Status	Male		Male Total N (%of total)	Female		Female Total N (% of total)	Total N (% of total)
	Simple	Complex		Simple	Complex		
Business	16	6	22 (63%)	10	3	13 (37%)	35 (24%)
Health	0	1	1 (7%)	8	5	13 (93%)	14 (9%)
Education	0	1	1(17%)	3	2	5 (83%)	6 (4%)
Trade	4	4	8 (89%)	0	1	1 (11%)	9 (6%)
Clerical	0	0	0	5	3	8 (100%)	8 (5%)
Retail	2	2	4 (50%)	0	4	4 (50%)	8 (5%)
Hotel/food service	2	3	5 (71%)	1	1	2 (29%)	7 (5%)
Self-employed	3	4	7 (70%)	2	1	3 (30%)	10 (7%)
Sales/service	1	4	5 (50%)	4	1	5 (50%)	10 (7%)
Police service	0	0	0	1	0	1 (100%)	1 (0.7%)
Student	0	1	1 (12%)	2	5	7 (88%)	8 (5%)
At home	0	5	5 (20%)	8	12	20 (80%)	25 (17%)
Retired	2	0	2 (29%)	2	3	5 (71%)	7 (5%)
Total	30	31	61 (41%)	46	41	87 (59%)	148*

* 15 participants did not respond to this question

Table 5.17 Employment Status by Simple/Complex Group and Gender

Employment/Assistance		Gender		Total N (% of total)
		Male (n = 65) N (% of total)	Female (n = 98) N (% of total)	
Full-time	Simple	23 (49%)	24 (51%)	47
	Complex	23 (56%)	18 (45%)	41
	Total full-time	46 (52%)	42 (48%)	88 (54%)
Part-time	Simple	2 (11%)	16 (89%)	18
	Complex	2 (22%)	7 (78%)	9
	Total part-time	4 (15%)	23 (85%)	27 (17%)
	Total employed	50 (43%)	65 (57%)	115 (70%)
Unemployed	Simple	1 (8%)	11 (92%)	12
	Complex	3 (21%)	11 (79%)	14
	Total unemployed	4 (15%)	22 (85%)	26 (16%)
Social Assist	Simple	0	1 (100%)	1
	Total social assist	0	1 (100%)	1 (.06%)
AISH	Complex	1 (17%)	5 (83%)	6
	Total AISH/GAIN	1 (17%)	5 (83%)	6 (3%)
CPP	Simple	3 (75%)	1 (25%)	4
	Complex	1 (25%)	3 (75%)	4
	Total CPP	4 (50%)	4 (50%)	8 (4%)
Disability	Complex		1 (100%)	1
	Total disability pension		1 (100%)	1 (.06%)
Disability + AISH or GAIN	Complex	2 (100%)		2
	Total disability + AISH or GAIN	2 (100%)		2 (1%)
Disability + CPP	Complex	1 (100%)		1
	Total disability + CPP	1 (100%)		1 (.06%)
Part-time + Disability	Simple	1 (100%)		1
	Total part-time +disability	1 (100%)		1
Social Assist + CPP	Simple		1 (100%)	1

For the univariate analysis, the employment status groups were combined to form three groups: employed, not employed, and other income source. There was a significant employment status group effect, for the dimensions of environmental mastery ($p = 0.012$), personal growth ($p = 0.004$), purpose in life ($p < 0.001$), and self-acceptance ($p = 0.011$). There was no significant employment status group effect for the dimension of autonomy. There was no significant simple/complex group effect and no significant interaction effect (Table 5.18).

Multivariately, controlling for three age groups, young adult, adult, and older adult, there was no significant employment status group effect (Wilk's Lambda $\lambda = 0.812$, $F(12, 262) = 2.392$, $p = 0.006$). There was no significant simple/complex group effect (Wilk's Lambda $\lambda = 0.946$, $F(6, 131) = 1.239$, $p = 0.291$) and no significant employment status group and simple/complex group interaction effect (Wilk's Lambda $\lambda = 0.912$, $F(12, 262) = 1.035$, $p = 0.417$).

5.18 Two-way ANOVA Employment Status by Simple/Complex Group

Dimension of Well-Being/Employment Status		Group Mean (SD)		Employment Status Group Effect F (df ₁ ,df ₂) [p]	Simple/Complex Group Effect F (df ₁ ,df ₂) [p]	Interaction Effect F (df ₁ ,df ₂) [p]
		Simple	Complex			
PR	employed	65.91 (11.64) N=64	69.21 (13.04) N=48	3.380 (2,151) [.037]	0.904 (1,151) [.343]	0.121 (2,151) [.886]
	not employed	64.50 (8.75) N=12	65.21 (10.78) N=14			
	other	58.00 (16.72) N=8	61.45 (14.31) N=11			
AU	employed	61.51 (10.69) N=65	65.55 (11.56) N=49	0.785 (2,149) [.458]	0.221 (1,149) [.639]	2.059 (2,149) [.131]
	not employed	63.50 (9.66) N=12	58.54 (11.70) N=13			
	other	66.50 (9.77) N=6	63.90 (11.32) N=10			
EM	employed	60.00 (9.49) N=65	62.44 (10.91) N=48	4.597 (2,150) [.012*]	0.086 (1,150) [.769]	0.750 (2,150) [.474]
	not employed	57.27 (5.62) N=11	55.07 (12.53) N=14			
	other	55.71 (15.72) N=7	53.45 (11.24) N=11			
PG	employed	69.98 (9.21) N=64	72.68 (8.09) N=47	5.859 (2,150) [.004*]	2.496 (1,150) [.116]	0.531 (2,150) [.589]
	not employed	66.67 (8.81) N=12	67.14 (9.90) N=14			
	other	60.86 (18.73) N=7	67.33 (8.51) N=12			
PL	employed	67.46 (11.45) N=65	69.86 (11.03) N=49	9.998 (2,149) [.000*]	0.000 (1,149) [.990]	0.416 (2,149) [.660]
	not employed	62.72 (9.52) N=11	63.86 (14.04) N=14			
	other	56.33 (20.25) N=6	52.70 (15.12) N=10			
SA	employed	61.72 (9.59) N=65	62.94 (9.63) N=48	4.660 (2,154) [.011*]	0.245 (1,154) [.438]	0.853 (2,154) [.428]
	not employed	61.00 (6.63) N=12	56.43 (10.84) N=14			
	other	55.25 (14.92) N=8	55.46 (12.95) N=13			

* denotes significance

Age at Diagnosis

Only 43% of the participants were diagnosed with a congenital heart defect at birth (n = 16, 10% with a simple structural heart defect; n = 53, 33% with a complex structural heart defect). Sixty-nine percent of the participants were diagnosed with a congenital heart defect by age 18 years. Thirty-two percent of participants were diagnosed between the age of 18 and 60 years. Three participants were diagnosed after the age of 60 years.

Followed by Pediatric Cardiology

Fifty-seven percent of all patients were followed by pediatric cardiologists (n = 93); 37% simple structural heart disease (n = 31), 79% complex structural heart disease (n = 62). Fisher's Exact Test showed a significant difference ($p < 0.001$) between those with simple structural heart disease and those with complex structural heart disease who were followed by pediatric cardiologists (Table 5.19).

Table 5.19 Followed by Pediatric Cardiology by Simple/Complex Group

Followed by Pediatric Cardiology	Group		Total N (% of total)
	Simple N (% of total)	Complex N (% of total)	
Yes	31 (37%)	62 (79%)	93 (57%)
No	53 (63%)	16 (21%)	69 (43%)
Total	84	78	162*

* 1 participant did not respond to this question.

Number of Heart Surgeries

In each of the three groups: those having had no intervention, those having had one intervention, and those with greater than two interventions, the number of participants is relatively evenly distributed. Thirty-six percent of participants have not had surgery, 30% have had one intervention, and 30% have had more than two (Table 5.20).

Table 5.20 Number of Heart Surgeries by Simple/Complex Group

# Heart surgeries	Group		Total N (% of total)
	Simple N (% of total)	Complex N (% of total)	
0	41 (49%)	17 (22%)	58 (36%)
1	32 (39%)	17 (22%)	49 (31%)
2	9 (11%)	21 (27%)	30 (18%)
3	0	11 (14%)	11 (7%)
4	1 (1%)	6 (8%)	7 (4%)
5	0	3 (4%)	3 (2%)
6	0	1 (1%)	1 (0.6%)
7	0	1 (1%)	1 (0.6%)
Total	83 (52%)	77 (48%)	160*

* 3 participants did not respond to this question

Rating of Health

The majority of participants rated their health as excellent to good (90%). Ten percent rated their health as fair to poor (Table 5.21).

Table 5.21 Simple/Complex Group by Health Rating

Group	Rating of Health					Total
	Excellent N (% of total)	Very Good N (% of total)	Good N (% of total)	Fair N (% of total)	Poor N (% of total)	
Simple	20 (24%)	28 (33%)	28 (33%)	8 (10%)	0	84
Complex	11 (14%)	28 (36%)	30 (38%)	7 (9%)	2 (3%)	78
Total	31 (19%)	56 (35%)	58 (36%)	15 (10%)	2 (1%)	162*

* 1 participant did not respond to this question.

To conduct the univariate two-way ANOVA, the ratings were combined to form three groups: "excellent" and "very good" were combined to form one group, "good" was a group to itself, and "fair" and "poor" were combined to form one group. There was a significant health rating group effect for the dimensions of environmental mastery ($p < 0.001$), personal growth ($p = 0.003$), purpose in life ($p < 0.001$), and self-acceptance ($p = 0.001$). There was no significant health rating group effect for the dimensions of positive relations with others, or autonomy. There was no significant simple/complex group effect and no significant interaction effect for any of the dimensions of PWB (Table 5.22).

5.22 Two-way ANOVA Health Rating by Simple/Complex Group

Dimension of Well-Being/Health Rating		Group Mean (SD)		Health Rating Group Effect F (df ₁ ,df ₂) [p]	Simple/Complex Group Effect F (df ₁ ,df ₂) [p]	Interaction Effect F (df ₁ ,df ₂) [p]
		Simple	Complex			
PR	excellent + very good	66.00 (12.22) N=48	70.00 (10.11) N=36	2.788 (2,150) [.065]	0.051 (1,150) [.821]	1.059 (2,150) [.349]
	good	63.63 (12.94) N=27	66.79 (15.15) N=28			
	fair + poor	63.38 (6.48) N=8	57.89 (12.86) N=9			
AU	excellent + very good	63.02 (11.00) N=47	64.18 (11.82) N=38	0.272 (2,148) [.762]	0.401 (1,148) [.527]	0.440 (2,148) [.645]
	good	60.39 (10.55) N=28	64.59 (11.96) N=27			
	fair + poor	62.14 (5.84) N=7	61.29 (11.29) N=7			
EM	excellent + very good	62.21 (8.51) N=47	63.81 (11.22) N=36	10.660 (2,149) [.000*]	0.062 (1,149) [.804]	0.589 (2,149) [.567]
	good	55.71 (10.70) N=28	56.97 (11.46) N=29			
	fair + poor	55.29 (7.48) N=7	50.88 (8.03) N=8			
PG	excellent + very good	71.15 (10.46) N=47	73.11 (8.67) N=37	5.892 (2,149) [.003*]	1.000 (1,149) [.319]	0.228 (2,149) [.796]
	good	65.30 (10.19) N=27	68.86 (8.42) N=28			
	fair + poor	66.13 (8.54) N=8	66.38 (8.47) N=8			
PL	excellent + very good	69.17 (12.11) N=47	72.16 (9.18) N=37	13.077 (2,148) [.000*]	0.999 (1,148) [.319]	2.694 (2,148) [.071]
	good	60.81 (12.10) N=27	62.75 (12.56) N=28			
	fair + poor	64.43 (8.02) N=7	52.13 (18.86) N=8			
SA	excellent + very good	63.31 (9.19) N=48	63.81 (9.04) N=37	7.491 (2,153) [.001*]	0.736 (1,153) [.392]	0.996 (2,153) [.372]
	good	57.68 (11.00) N=28	58.62 (10.71) N=29			
	fair + poor	58.88 (7.41) N=8	52.33 (13.63) N=9			

* denotes significance

Spirituality

Of the participants ($n = 153$) who responded to this question, 57% indicated that spirituality was an important part of their life. There were 10 participants who did not respond to this question (Table 5.23).

Table 5.23 Simple/Complex Group by Spirituality

Group	Does spirituality play a role?		Total N (% of total)
	Yes N (% of total)	No N (% of total)	
Simple	41 (52%)	38 (48%)	79 (52%)
Complex	46 (62%)	28 (38%)	74 (48%)
Total	87 (57%)	66 (43%)	153*

* 10 participants (6%) did not respond to this question.

Univariate two-way ANOVA found a significant spirituality group effect for the dimension of environmental mastery ($p < 0.001$) (Table 5.24). There was no significant spirituality group effect for the dimensions of positive relations with others, personal growth, purpose in life, or self-acceptance. There was a significant simple/complex group effect for the dimension of self-acceptance ($p < 0.001$) but no significant simple/complex group effect for the dimensions of positive relations with others, autonomy, environmental mastery, personal growth, and purpose in life. There was a significant spirituality group effect on environmental mastery ($p < 0.001$). There was a significant simple/complex group interaction effect on autonomy ($p = 0.004$). There was no significant spirituality group and simple/complex group interaction effect on positive relations with others, environmental mastery, personal growth, purpose in life or self-acceptance.

Table 5.24 Two-way ANOVA Spirituality by Simple/Complex Group

Dimension of Well-Being/Spirituality		Group Mean (SD)		Spirituality Group Effect F (df ₁ ,df ₂) [p]	Simple/Complex Group Effect F (df ₁ ,df ₂) [p]	Interaction Effect F (df ₁ ,df ₂) [p]
		Simple	Complex			
PR	Yes	54.45 (7.82) N=40	54.50 (6.38) N=44	0.026 (1,144) [.873]	0.013 (1,144) [.908]	0.005 (1,144) [.943]
	No	54.55 (6.74) N=38	54.77 (6.47) N=26			
AU	Yes	51.15 (4.36) N=39	53.61 (4.83) N=44	0.000 (1,142) [1.000]	0.045 (1,142) [.832]	8.643 (1,142) [.004*]
	No	53.44 (5.36) N=38	51.32 (3.08) N=25			
EM	Yes	56.92 (6.16) N=39	55.71 (5.46) N=42	13.250 (1,142) [.000*]	0.000 (1,142) [1.000]	1.599 (1,142) [.208]
	No	52.23 (4.98) N=38	53.54 (6.23) N=27			
PG	Yes	54.78 (3.51) N=40	55.88 (5.17) N=43	2.953 (1,142) [.154]	0.994 (1,142) [.320]	0.295 (1,142) [.588]
	No	54.14 (3.72) N=37	54.46 (4.39) N=26			
PL	Yes	46.97 (5.11) N=39	48.05 (5.92) N=43	0.448 (1,142) [.504]	0.326 (1,142) [.505]	0.446 (1,142) [.505]
	No	46.97 (3.94) N=37	46.89 (5.37) N=27			
SA	Yes	50.05 (4.95) N=41	54.18 (5.81) N=45	1.089 (1,146) [.303]	16.042 (1,146) [.000*]	0.162 (1,146) [.688]
	No	51.39 (5.37) N=38	54.77 (7.54) N=26			

* denotes significance

Summary of Research Findings

The following is a summary of the key research findings in this sample of adults with structural heart disease:

1. Descriptive Findings:

- A total of 163 participants responded to the questionnaire.
- Ninety-nine participants were female and 63 participants were male.
- Eighty-five participants had a simple structural heart defect and 78 had a complex structural heart defect.
- Of the participants with simple structural heart defects, 30 were male and 54 were female. Of the participants with complex structural heart defects, 33 were male and 45 were female.
- Participants range in age from 18 to 87 years. The mean age for all participants was 37 years. The mean age for the simple structural heart defect group was 39 years and the mean age for the complex structural heart defect group was 35 years.
- Fifty-two percent were married or living common-law and 34% were single. Of the participants with a simple structural heart defect, 24% were single and 62% were married or living common-law. Of the participants with a complex structural heart defect, 45% were single, 43% were married or living common-law.
- The majority of the participants were Caucasian (91%).
- Fifty-two participants had completed college/university (32%); 25 of these had simple structural heart defects and 24 had complex structural heart defects.
- Forty participants had acquired a trade/technical certificate (25%); 21 of these had simple structural heart defects and 19 had complex structural heart defects.

- Thirty-six participants had completed high school (22%); 19 had simple structural heart defects and 17 had complex structural heart defects.
- Thirty-five participants (24%) were business professionals of which 16 of these were males and 10 were females with simple structural heart defects. Six males and 3 females were business professionals who had complex structural heart defects.
- Twenty-five participants (17%) indicated being "at home" as their occupation; 8 were females with simple structural heart defects while 12 females and 5 males had complex structural heart defects.
- The majority of the participants (70%) worked either full time or part time. Sixteen percent were not employed, 14% received disability pension +/- CPP, and 4% received AISH. Of those employed full time, 23 were male with simple structural heart defects and 24 were female. 23 males and 18 females with complex structural heart defects were employed full time. Of those employed part time, 2 males and 16 females had simple structural heart defects and 2 males and 7 females had complex structural heart defects. There was 1 male and 11 females with simple structural heart defects that were not employed and 3 males and 11 females with complex structural heart defects that were not employed. Of the 6 participants with complex structural heart defects receiving AISH, 5 of these were female.
- The age of initial diagnosis ranged from birth to 70 years.
- The majority of participants (69%) were diagnosed before 18 years of age; 42% diagnosed at birth.

- Twelve participants had their initial diagnosis between 50 and 70 years of age. The majority of participants were followed by a pediatric cardiologist (57%).
- Thirty-six percent of participants had not had a surgical intervention, the majority of which belonged to the simple structural heart defect group (71%). Thirty percent of participants have had one surgery, and 30% have had more than two surgical interventions, the majority of which belong to the complex structural heart defect group (27%).
- The majority of participants rated their health as excellent to good (89%). Ten percent rated their health as fair or poor.
- Fifty-three percent indicated that spirituality was important to their life.

2. Inferential Findings:

- There was no statistical difference in the mean scores for each of the six dimensions of PWB between those participants with simple and complex structural heart defects.
- There was no significant age group effect, simple/complex group effect, or age group by group simple/complex group interaction effect on the mean scores of any of the dimensions of PWB.
- There was a significant gender effect on the mean score for the dimension of PR. The mean dimension score for PR is higher for females than males for both the simple structural heart defect group and the complex structural heart defect group but not significant. Multivariately, controlling for three age groups, young adult, adult, and older adult, gender effect approached significance.
- There was a significant educational group effect on the mean dimension score for the dimensions of PR and PG. The mean

dimension scores for the dimensions of PR and PG were higher for both simple and complex structural heart defect participants who attend university. Multivariately, controlling for three age groups (young adult, adult, and older adult), there was a significant education group effect.

- There was a significant marital status (attached versus unattached) effect on the mean dimension score for EM, PL, and SA.
- There was a significant employment status group effect on the mean dimension score for EM, PG, PL, and SA.
- There was a significant health rating group effect on the mean score for the dimensions of EM, PG, PL, and SA.
- There was a significant spirituality group effect on the mean score for the dimension of EM. There was a significant simple/complex group effect on the mean score for the dimension of SA. There was a significant spirituality group and simple/complex group interaction effect on the mean score for the dimension of AU.

Chapter 6

Discussion and Recommendations

The focus of this chapter is to interpret the findings of the study. Findings of the study are presented with reference to prior research and literature where available. Methodological issues, strengths, and limitations to the study will be discussed, along with relevance to APN practice. Recommendations for future research will be presented.

Research Objectives

It will be recalled that the research objectives were to:

- measure the relationship between the six dimensions of psychological well-being in two groups of adults with congenital heart disease, and
- identify whether there is a difference in psychological well-being between adults with simple structural heart defects and adults with complex structural heart defects.

One would expect that there would be a difference in the mean scores of each of the six dimensions of PWB between those participants with simple and those with complex structural heart defects but no statistically significant difference was found.

There was no specific empirical evidence on the relationship between the severity of congenital heart defect and psychological well-being identified in the literature. No specific study has measured PWB in adults with congenital heart defects. Prior studies in psychopathology and QOL in CHD have used different conceptualizations, different methods, and different instruments to identify pathology which significantly impedes the comparability of prior results with this study. Given these differences, the psychosocial and QOL findings from the literature that may have some applicability to the current study will be included in the discussion.

The current study results bear similarity to that of the research conducted by Rose et al., (2005). It will be recalled that the Rose et al., (2005) study found that the level of cardiopulmonary function, a biophysical measure of functional ability and the degree of cardiac dysfunction, had no significance on health related QOL in the psychological domain. Rose et al., (2005) measured personality traits and concluded that the psychological domain was influenced by depressive personality disposition. The complexity of the structural heart defect for this study was delineated by the classification set out by ACC (Webb and Williams, 2001) rather than cardiopulmonary testing. This study did reach the same conclusion in that the degree of structural complexity had no bearing on the six dimensions of psychological well-being. However, no comment as the influence of personality traits can be made as this was not measured in the current study.

Conversely, the findings of the current study contradict the findings of the study by Brandhagen et al., (1991) and Spurkland et al., (1993). Brandhagen et al., (1991) found a statistically significant difference in psychological test scores between adults with CHD compared to the standardized normative data for the Symptom Checklist 90 Revised (SCL-90-R). However, the Brandhagen et al., (1991) study failed to establish correlations between the severity of the cardiac defect and the presence or degree of psychological dysfunction. Spurkland et al., (1993) found more adolescents with complex CHD met criteria for DSM-III psychiatric problems than adolescents with simple CHD ($p < 0.001$). The difference between the current study and the study by Spurkland et al., (1993) is that the number of participants was small, the researchers used instruments to look for psychiatric disorders, and the participants were adolescents. It may well be that in adolescence there are confounding factors that play a role in how adolescents cope with CHD such as the insecurity that comes with not being able to keep up to the peer group or overprotection by parents. The psychological development that occurs with adulthood may decrease the impact of other

factors and thus the differences between simple and complex patients that were found in adolescence is no longer significant in adulthood.

Similarly, the study conducted by Lane et al., (2002) found that the surgically cured group, which could conceivably fall in the ACC classification (Webb & Williams, 2001) of a simple structural heart defect, had significantly poorer mental health ($p = 0.003$).

Looking at the study by Popelová et al., (2001) on depression in cyanotic adults, who by the ACC classification (Webb & Williams, 2001) were complex, it was found that depression was associated with worse functional class but this was independent of the severity of cyanosis. These findings suggest that if a worse functional class is one measure of psychopathology, patients who have a worse functional class, (ie. complex patients), should score lower on the six dimensions of PWB. This hypothesis was not supported in the current study as there was no statistically significant difference found in the mean dimension scores of PWB between those with simple and those with complex structural heart defects. Functional class would certainly have an impact on the dimension of environmental mastery. Although the mean group scores for this dimension were slightly lower than the other dimensions, there was no significant difference in mean group scores between those patients with simple structural heart defects and those with complex structural heart defects (those with a worse functional class).

The breadth of the theoretical framework of PWB used by Ryff, (1989) to develop the instrument used in the current study underscores the multidimensionality of PWB. In the CHD literature, psychological well-being was equated with the absence of psychopathology. The findings of the current study, when compared to what has been found in the literature, supports the fact that assessment of the multidimensional concept of PWB cannot be made by measuring one factor such as functional class or looking for psychopathology such as depression.

Age

The original validation study conducted in the general population by Ryff (1989) compared young adults (18 to 29 years), adults in midlife (30 to 64 years), and adults in old-age (65+ years). This validation study found incremental age profiles (the older the respondent, the higher the score) for EM and AU, decremental age profiles for PL and PG, and no age differences for SA and PR. The age related differences that were demonstrated in the original validation study were not found in the current study. There are two potential explanations for this. Firstly, the original validation study compared young (18-29 years), to midlife (30-64 years), to old age (65+ years). Ninety-five percent of the participants in this study are between the ages of 18 and 64 years. Therefore, because the majority of participants fall within the young adult to adult age range, the usual age related differences in the mean group scores of the six dimensions of PWB may not be apparent. Secondly, it may well be that other factors such as the experience of living with CHD may influence perceptions of well-being. A replication of the current study comparing simple and complex structural heart defect patients to a healthy peer group would help to clarify whether chronic illness influences the age related differences found in the original validation study by Ryff, (1989).

Gender

In the original validation study by Ryff (1989) and in the study by Ryff and Keyes (1995) females scored significantly higher for the dimension PR ($p = 0.003$). Although females scored higher in all dimensions of PWB than males in the current study, the difference was not statistically significant. With further multivariate analysis, controlling for three age groups, young adult, adult, and adult, the gender effect on the mean group scores between males and females for the dimension of positive relations with others approached significance ($p = 0.051$).

The socially accepted cultural norm in Canadian society is that the adult female tends to look for warm, satisfying relationships and is capable of strong empathy, affection, and intimacy. The adult female is also more expressive when it comes to discussing relationships with others. It would be expected that the current study results should yield the same findings in the dimension of positive relations with others as the original validation study.

Education

Kokkonen & Paavilainen, (1992), found that a severe heart defect predisposed young adults to poor success at school; however, it is difficult to determine which complex defect was classified as severe. In addition, studies conducted by Oates et al., (1995), Wernovsky et al., (2000), and Sensky & Wray, (2005) found evidence to suggest that in children, the complexity of the structural heart defect continues to affect cognitive and academic performance even after surgery. Although these studies were done in children, it could be hypothesized that this would result in adults with complex structural heart defects having attained lower levels of education than their healthy peers. In this study there was no comparison group of healthy peers. However, this study found no statistically significant difference between level of education completed in adults with simple structural heart defects and adults with complex structural heart defects ($\chi^2 = 6.878$, $df = 6$, $p = 0.332$). Either both adults with simple structural heart defects and adults with complex structural heart defects have poor success at school as compared to their healthy peers or there is no difference between those with structural heart defects and their peers in level of education attained by the time they reach adulthood. It is possible that other factors influence the educational outcomes that were not measured in this study such as socioeconomic status or parental support. The study would need to be replicated to compare adults with simple and complex structural heart defects with their healthy peers and incorporate questions relative to other influencing factors in order to test these hypotheses. Another way to clarify this would be to test the

cognitive ability of adults with simple and complex structural heart defects and compare it to an age-matched group of healthy peers.

Univariate two-way ANOVA found a significant educational group effect on the mean dimension score for the dimension of PR ($p = 0.043$) and PG ($p < 0.001$). Participants with university education scored significantly higher in the dimension of positive relations with others and personal growth than those with technical or high school or less education. The higher the level of education was, the higher the mean score for the dimensions of positive relations with others and personal growth.

As a result of the age differences noted in the original validation study by Ryff, (1989) and the study by Ryff and Keyes, (1995), it was anticipated that age may impact the significance of level of education completed on the mean group scores for the six dimensions. Multivariately, controlling for three age groups (young adult, adult, and older adult), a significant education group effect ($p = 0.004$) was still present regardless of the age group. Therefore the level of education does positively influence PWB in adults with CHD.

Marital Status

Spurkland et al., (1993) found no significant difference in social competence between adolescents with simple structural heart defects and adolescents with complex structural heart defects. Most adolescents do not want to appear different from their peers in any way. This researcher's experience has found that these feelings are echoed by the young adults that attend clinic. Despite the severity of their structural heart defect, when young adults present to the adult clinic for the first time, they all have numerous questions about marriage and raising families. These young adults with CHD have the same hopes and dreams as their peers. As with their peers, if these hopes and dreams do not become a reality, it may affect the way young adults with CHD view themselves. It would be reflected in the dimensions of PR, PG, and SA. The current study found no significant differences in mean scores in these dimensions between

those with simple and those with complex structural heart disease. This would support the findings of Spurkland et al., (1993).

Ryff, (1989) found that for both midlife and older men and women, quality relationships with others was found to be the most frequent factor when discussing positive functioning. Ryff and Keyes, (1995) did not refer to marital status and well-being other than to indicate that of the 70% of midlife respondents were married. Stephens et al., (2000) found social support was strongly and positively associated with SOC, self-esteem, mastery and happiness. Those with high levels of social support had only half the odds of being affected by distress.

The studies by Spurkland et al., (1993), Ryff, (1989), Ryff & Keyes, (1995), and Stephens et al., (2000) imply that quality relationships with others effect individual happiness and well-being. However, researchers have been cautious about making definite cause and effect correlations and this is likely due to the fact that there are many types of quality relationships. In the current study, the researcher was cautious not to consider marital status alone as a reliable measure of quality relationships choosing to use “attached” and “unattached”. Yet, this is not necessarily an indicator of quality relationships per se. Despite this, univariate two-way ANOVA did find a significant marital status group effect. Those participants who were “attached” scored significantly higher on the mean dimension scores of EM ($p = 0.009$), PL ($p = 0.024$), and SA ($p = 0.987$) independent of a simple/complex group effect or interaction effect. These findings support those of Spurkland et al., (1993), Ryff, (1989), Ryff & Keyes, (1995), and Stephens et al., (2000) and underscores the importance of significant relationships with others in PWB no matter how significant the heart defect.

Employment Status

There are conflicting results in the literature as to the influence of the severity of structural heart defects on the outcomes of employment. There is a suggestion in the research conducted by Crossland et al., (2005) and Simko &

McGinnis, (2005) that there is reduced job participation in those with more complex disease.

In the current study, 76% of patients with simple structural heart defects and 64% of patients with complex structural heart defects were working either full or part-time. It is possible to look at the study findings on employment in this study and compare it with the employment findings from the QOL study done by Simko & McGinnis, (2005) on acyanotic and cyanotic CHD patients. According to the ACC classification, (Webb & Williams, 2001), cyanotic patients are complex patients. Simko & McGinnis, (2005) found that there was a significant difference in the quality of life as measured by mean SIP scores between acyanotic and cyanotic CHD patients in the category of "work" ($p < 0.001$). The current study contradicts the study by Simko & McGinnis, (2005). Univariate two-way ANOVA comparing simple to complex structural heart defect patients found a significant employment status group effect for the dimensions of EM ($p = 0.012$), PG ($p = 0.004$), PL ($p = 0.000$), and SA ($p = 0.011$). Those who were employed scored significantly higher in the dimensions of EM, PG, PL, and SA than those with other income sources. The complexity of the structural heart defect did not influence the employment status group effect on these dimensions.

The current study supports the fact that financial security is an important determinant of health (Health Canada, 2001) and employment status a social determinant of health (Public Health Agency of Canada, 2002). A chronic health condition can easily drain limited financial resources by consuming sick leave, disability, and depending on the employer, may threaten employment status. While the clinical experience of this researcher has shown that for most of their lives, adults with CHD are self-sustaining, there are predictable times when some individuals may be in need of either special consideration from employers or financial help as they require time off of work for invasive medical tests and/or

repeat surgeries which have recovery periods of three to six months. In addition, those without health benefits carry the financial burden of the cost of medications, supplemental oxygen, dental care and aids to daily living. Dental care is a routine priority for congenital heart conditions because some cardiac defects are at high risk for infective endocarditis. Therefore, it is important for patients to be working in order to have access to health benefits to cover these costs.

On reflection it would have been helpful to ask study participants about their annual income. Although 70% are employed in the current study, this does not necessarily mean that the participants are able to make ends meet. The clinical experience of this researcher indicates that a good portion of adults with CHD are the working poor. In a survey conducted at the ACHD clinic on 600 patients where dental health is imperative to prevent complications from infective endocarditis, 27% reported delays in seeking annual dental care because of financial concerns (Balon, Yee, & Sieppert, 2001).

Further, of the patients that have been assessed by the clinic social worker to see if they are eligible for the subsidized dental program, although these patients are working, they all fall substantially below the poverty line. In other words, many patients sustain themselves and their families on incomes that by national definition are near, on, or below the poverty line. While employed, most of these families do not access provincial financial support as noted by the current study findings (only 7 of the 163 patients who responded to this question rely on Support for Financial Independence (SFI) or Assured Income for the Severely Handicapped (AISH). However, during surgery and recovery, their financial resources are substantially depleted and the effect is felt by patients and their families for a long time.

In addition to having lower incomes, many individuals with CHD are faced with changing career paths in early adulthood, prompted by new physical

restrictions imposed by their changed health status. Despite all of this, only a small number (1 – 2%) actually end up applying for SFI. For those who qualify, most of these patients will still need to supplement their SFI by accessing subsidized housing, the food bank, the Mustard Seed, and other local charities, during recovery periods. It is during these inherently stressful times when patients often present with depression, anxiety or panic. (Balon, Yee, & Sieppert, 2001).

It is not surprising, then that employment status would significantly affect the dimensions of EM, PG, PL, and SA in adults with CHD. What is surprising in the current study is that complexity of the structural heart defect did not impact the mean dimension scores by employment status. However, this study represents the results at one point in time. It may be that participants were questioned during a period of stability. It would be interesting to conduct a longitudinal study with this same group of patients at various points in their lifespan to see if the findings hold true throughout the course of their chronic illness.

Age at Diagnosis

There were no significant differences in mean dimension scores between those who were diagnosed between birth and 18 years and those who were diagnosed after 18 years. Thirty-two percent of participants were not diagnosed with CHD in childhood. A future consideration would be to look at this group to see what impact a mid-life diagnosis might have on career and lifestyle as compared to those who have been diagnosed as children. The researcher's clinical experience has found that those who grow up with CHD, on the whole, appear to function very well in all realms of life. It may be easier to do so in that they have no other frame of reference. Someone who is diagnosed in midlife has known a life without chronic illness and specialists, procedures, hospitals, and surgeries. Suddenly life, as they know it, changes and may become very complicated.

Followed by Paediatric Cardiology

The significant difference between the number of simple structural heart defect patients and complex structural heart defect patients followed by pediatric cardiology is to be expected. Of those with simple structural heart defects, only 37% had been followed by a pediatric cardiologist. There can be many reasons for this. Not all simple structural heart defects are diagnosed at birth. Many defects remain undetected until later in life. For example, diagnosis may be prompted by the young adult pregnant female who presents with palpitations or shortness of breath because of the effect of increased volume load on her already enlarged right heart as a result of her atrial septal defect; or the young adult who presents with transient ischemic attack because of a patent foramen ovale; or the young adult male bodybuilder who presents with syncope because of aortic stenosis due to a bicuspid aortic valve. As well, if a relatively benign congenital heart defect is diagnosed in late adolescence or young adulthood, the adult internist or cardiologist making the diagnosis may elect to follow that patient until such time that an intervention must be done. It is at this point that the referral is then made to a regional ACHD clinic as per the recommendations of ACC, 32nd Bethesda Conference, *Care of the Adult with Congenital Heart Disease* and the CCS Consensus Conference 2001 Update: *Recommendations for the Management of Adults with Congenital Heart Disease* (Webb & Williams, 2001).

Number of Heart Surgeries

There were 17 participants with complex structural heart defects that have not had a surgical intervention to date. This is not a surprising finding. Patients with complex structural anatomy with multiple defects may have increased surgical risk and therefore, if they are well compensated, surgery is not an option. Although a transplant may be a possibility, according to transplant classification they may be functionally too well to be listed.

Those CHD patients who have had multiple surgeries as children face increased psychological issues as a result of potential developmental stage delays, effect of anesthesia on cognitive function, and interruptions to education (Oates et al., 1995; Sensky & Wray, 2005; Wernovsky et al., 2000). Although multiple surgeries may be equated with level of structural complexity, it is difficult to compare these studies with the current study. The researcher did not look for psychological issues. This research measures psychological well-being and found no statistically significant difference in the dimensions of PWB between those with simple and those with complex structural heart defects. In addition, the current study did not test adult cognitive functioning or question adult participants as to whether their education had been interrupted because of their health. Cognitive function testing would be important to incorporate in future studies.

Rating of Health

Ninety percent of participants with simple structural heart defects and 88% with complex structural heart defects rated their health as good to excellent. Univariate two-way ANOVA showed a significant health rating group effect on the mean score for the dimensions of EM, PG, PL, and SA. The complexity of the structural heart defect had no significance on the mean dimension scores of PWB.

As may be recalled Ryff & Singer, (1998) proposed that it is the connection between a life with purpose, quality relationships with others, self-acceptance, autonomy, environmental mastery, and personal growth and the lens through which one views their life that combines to inform the individual differences in response to life challenge. In this researcher's opinion, the response to this question may be a measure of the participant's outlook or the lens through which they view their life. The results fit with what has been observed through this researcher's clinical experience. Regrettably, a control group of healthy peers was not included in this study. It would be interesting to

see if there would be a significant difference between those with CHD and a healthy peer group on the mean dimension scores and the rating of health.

Spirituality

Spiritual well-being may be an important internal resource for persons forced to adjust to uncertainty related to long-term health illness (Landis, 1996). Spiritual well-being is described as a satisfaction with one's life in relationship to God or a higher power and a perception of life as having meaning (Miller, 1985; Stoll, 1989). Fifty-seven percent of participants indicated that spirituality was important in their life. Those who indicated that spirituality was important in their lives had a significantly higher mean dimension score for EM. There was however, no difference in the mean dimension score for PL which was anticipated. There was a significant simple/complex group effect on the dimension of SA with complex structural heart patients having higher mean dimension scores than simple structural heart patients. There was a significant interaction effect between the spirituality group and the simple/complex group on the mean dimension score for AU. It may be that participants who have complex defects look to spirituality as a way of making sense and accepting what life has to offer. If there is a higher power that controls that in life which one has no control over and all other areas of life are autonomous, this may allow a perception of greater autonomy.

Methodological Limitations

Recruitment and Data Collection

Although the sample size is large when compared to prior studies in adults with congenital heart defects (Cox et al, 2002; Horner et al, 2000; Kokkenen & Paavilainen, 1992; Popelová et al, 2001; Rose et al, 2005; Simko & McGinnis, 2003) the study is limited in that it was conducted at one adult congenital heart clinic. Sample size could be increased and the study could be strengthened if it was replicated as a multi-center national or international study.

The difficulty in conducting a mail-out survey lies in the ability to maintain a current database in a young, mobile, adult patient population. There are frequent relocations, whether that is for education purposes, marriage, or job advancement. A total of 350 participants were sent questionnaires initially (175 to each group). Forty-eight were lost to follow-up or had moved (27 simple structural heart defects and 21 complex structural heart defects). The complex structural heart defect group totalled 175 and therefore nothing could be done to increase response rate. In order to increase the response rate for the simple structural heart defect group, an additional 30 participants were sent questionnaires. As a result the final tally of participants that were lost to follow-up or had moved was 56 (33 simple structural heart defect patients; 23 complex structural heart defect patients). One participant had moved three times in less than a year. Unless the patient is experiencing cardiac complications and coming to clinic for more than an annual visit, this researcher's clinical practice shows that on any given clinic day, four out of seven patients in for their annual visit will have relocated since their last appointment. There are also occasions where a patient has died because of non-cardiac complications and the clinic will not have been notified. In this study, six patients had died and the clinic had not notified. Researchers must be sensitive to these situations. Fortunately, telephone numbers do not change with the same frequency as addresses and patient demographics can then be updated by the clinic secretary.

Another difficulty that was encountered during data collection was that many of the patients with patent foramen ovale were told on assessment at the clinic that their anatomy was a variant of normal. It had been picked up because of the sensitivity of new technology but was not now, nor likely would it ever cause them any specific problems. They were told that their structural variation would have no hemodynamic significance on the function of their heart. They should consider themselves normal and go out and live a full and active life with no restrictions. A number of calls were received from these patients to say they

were told they were normal and therefore they felt they should not participate in the study. It is reassuring to know that these patients are getting the appropriate message from the clinic but it did create difficulties in data collection. According to the ACC classification (Webb and Williams, 2001), patent foramen ovale falls into the classification of a simple structural heart defect and as such these patients need to be included in research.

The first part of the questionnaire was developed as a result of the literature review, the researcher's clinical experience, and discussions with the supervisor and committee members. It would have been helpful to include a question on financial income. This would have provided a clearer picture of the issues surrounding education and employment. The second part of the questionnaire, is a scale of PWB (Ryff, 1989). The reliability and validity of this instrument has been tested in a young adult population (ages 18 to 29 years), with adults in midlife (ages 30 to 64 years), and in seniors (ages 65 and older). It is an instrument used to measure psychological well-being. It is the best instrument to measure the research question in this patient population.

To control for the age differences found between the age groups set by Ryff (1989) in the original validation study, participants in this study were broken into three age groups, young adults (18 to 29 years), adults (30 to 64 years), and older adults (65+ years). As the number of adults with complex CHD living to 65+ years is limited, it is difficult to obtain an appropriate sample in this age category.

Strengths of the Study

Psychosocial research in adults with CHD has only recently begun to appear in the literature. These studies have used instruments to measure psychological pathology and QOL (Brandhagen et al., 1991; Cox et al., 2002; Gupta et al., 1998; Horner et al., 2000; Popelová et al, 2001; Spurkland et al, 1993; Utens et al., 1998) and then equated the absence of psychopathology

and/or QOL as a measure of psychosocial well-being. This study used a psychological well-being instrument to measure PWB in CHD. There has been no research found in the literature that has focused on PWB in adults with CHD. The research on PWB in chronic illness suggests that high scores in the six dimensions of PWB may reduce the incidence of psychological dysfunction in chronic illness. CHD is a chronic illness and therefore it is incumbent upon those working with this patient population to examine ways of assessing and intervening on dimensions of PWB in order to prevent psychological dysfunction.

In previous QOL studies in CHD the NYHA Functional Classification (1964) and the Ability Index (Sommerville, 1989) have been used to classify patients according to the complexity of structural heart defect. Although reliable and valid, the NYHA functional classification was designed for use in ischemic heart disease and congestive heart failure. The Ability Index, although developed for use in CHD has, to date, no evidence to support its reliability and validity.

The ACC classification (Webb & Williams, 2001) of congenital heart defects used in this study is the universal classification system developed specifically for use in this patient population. It is well published and well recognized around the world. Assigning participants to groups according to structural complexity based on a recognized classification system allows for consistency in comparison with future research findings.

Relevance to APN Practice

The experience of living with a structural heart defect is a very personal one. By having an understanding of what is important to the adult with CHD, the APN can tailor their assessment to include not only the biophysical but also the cognitive, psychological, social, cultural, and spiritual realms in order to identify the issues relative to each patient.

Because the experience of living with a chronic disease is a personal experience, it is unique to the individual. It is difficult to make generalizations

about the experience of living with a chronic illness without randomized studies. This study found no significant differences in PWB between adults with simple structural heart defects and adults with complex structural heart defects.

There are no standardized screening instruments for use in this specific patient population. The APN must have a thorough understanding of the biophysical, psychological, social, and spiritual issues facing the CHD adult. It is only through this knowledge, assisted by skilled interviewing techniques and supported by a keen intuition, through which the APN can identify concerns facing the adult with CHD. Once identified, the APN is then able to work collaboratively with the multidisciplinary team to find appropriate resources to support and maintain PWB. It is at this point where the role of the APN becomes one of a coordinator for multidiscipline care, ensuring that the team members and community partners work collaboratively to address the needs of these patients.

Recommendations

The University of Calgary Adult Congenital Heart Clinic in Calgary, Alberta services a unique and vulnerable patient population. In the ACHD clinic, the simplicity of heart defects in infants and children is replaced by the complex interplay of the health-illness trajectory on an adult life with its natural progression through education, career development, marriage, family, and other non-cardiac medical issues.

The APN in CHD functions as a practitioner, an educator, a counselor, a researcher, an advocate, and a professional leader. The findings of this study support that education and employment significantly influence PWB in adults with CHD. The recommendations that follow have been developed as a result of this research and reflect how the APN in CHD, practicing within the proposed conceptual framework, can promote PWB in adults with a congenital heart defect.

- Psychosocial assessment is a necessary component of each clinic visit for adults with CHD, independent of the complexity of the

structural heart defect. The APN must work with patients and their families to gain an understanding of the both the positive and negative in patients' lives to have a complete picture of their overall level of functioning. This picture will become the foundation for the development of the multidisciplinary plan of care and provide a basis upon which treatment effectiveness can be assessed.

- It will be recalled from the literature review that patients with structural heart defects may have a combination of physical disabilities, mental health issues and developmental disabilities. By conducting a thorough psychosocial assessment, the APN is able to identify individual differences and issues and anticipate the impact this will have on the plan of care.
- Education and employment are determinants of health. The findings of this research suggest that education and employment significantly influence PWB in adults with CHD. Young adults who are in the process of preparing for further education in a particular career or profession are assisted by the APN to make responsible choices in anticipation of future health concerns. If additional counseling and guidance is needed, the APN works collaboratively with the multidisciplinary team to find appropriate resources for the young adult and their family. Once employed, if the occupation is found to be inappropriate relative to the current health status or future health status, the APN provides the encouragement, support and coordination of resources to facilitate retraining of the individual.
- The APN must act as the patient advocate by coordinating patient tests and visits to ensure there is minimal disruption to school or work schedules. Given the large catchment area of the clinic, many patients travel long distances to the clinic. Through the

development of liaison relationships with other disciplines, the APN is able to coordinate multiple tests and appointments to meet the needs of patients and families and ensure minimal disruption to school and work schedules.

- CHD in adults is a relatively new subspecialty in cardiology and certainly it does not have the strength of numbers of other chronic diseases. The APN in CHD must be a strong voice for this patient population. The APN must educate patients, families, peers, members of other disciplines, and other government agencies as to the unique needs of these patients.
- Financial security is a social determinant of health. If for example, the patient does not have disability coverage and the disability is profound but amenable to surgical correction, the APN must collaborate with other multidisciplinary team members to find creative ways to meet the financial needs of the patient. Preventative action may include government lobbying to allow for greater flexibility within the current programs (ie. career counseling, short-term disability, long-term disability) to meet the needs of this patient population based on the medical situation.

Recommendations for Future Research

The following are recommendations for future research to clarify and enhance this project:

1. A national multicenter study on PWB in adults with CHD to strengthen and support these research findings.
2. Replication of this study to compare simple and complex structural heart defect patients to a healthy peer group.
3. A pilot study on PWB in one or more other chronic conditions to look for similarities and differences among patients with other chronic diseases. If similarities are found, it may provide the

incentive to create new programs and possibly even share multidisciplinary resources.

Conclusion

Traditional medicine continues to be very effective in developing surgical therapies to prolong and improve the quality of life for those born with a congenital heart defect. However, therapies that focus on improving physical outcomes alone do not necessarily improve the psychological well-being of the patient. This domain is to a much larger extent dependent on other determinants. It is recommended that medical professionals who manage adults with CHD are aware of these determinants and collaborate with government and community partners to develop flexible programs to support the psychological and social needs of these patients to further foster and preserve PWB.

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APPENDIX A
CONCEPTUAL FRAMEWORK

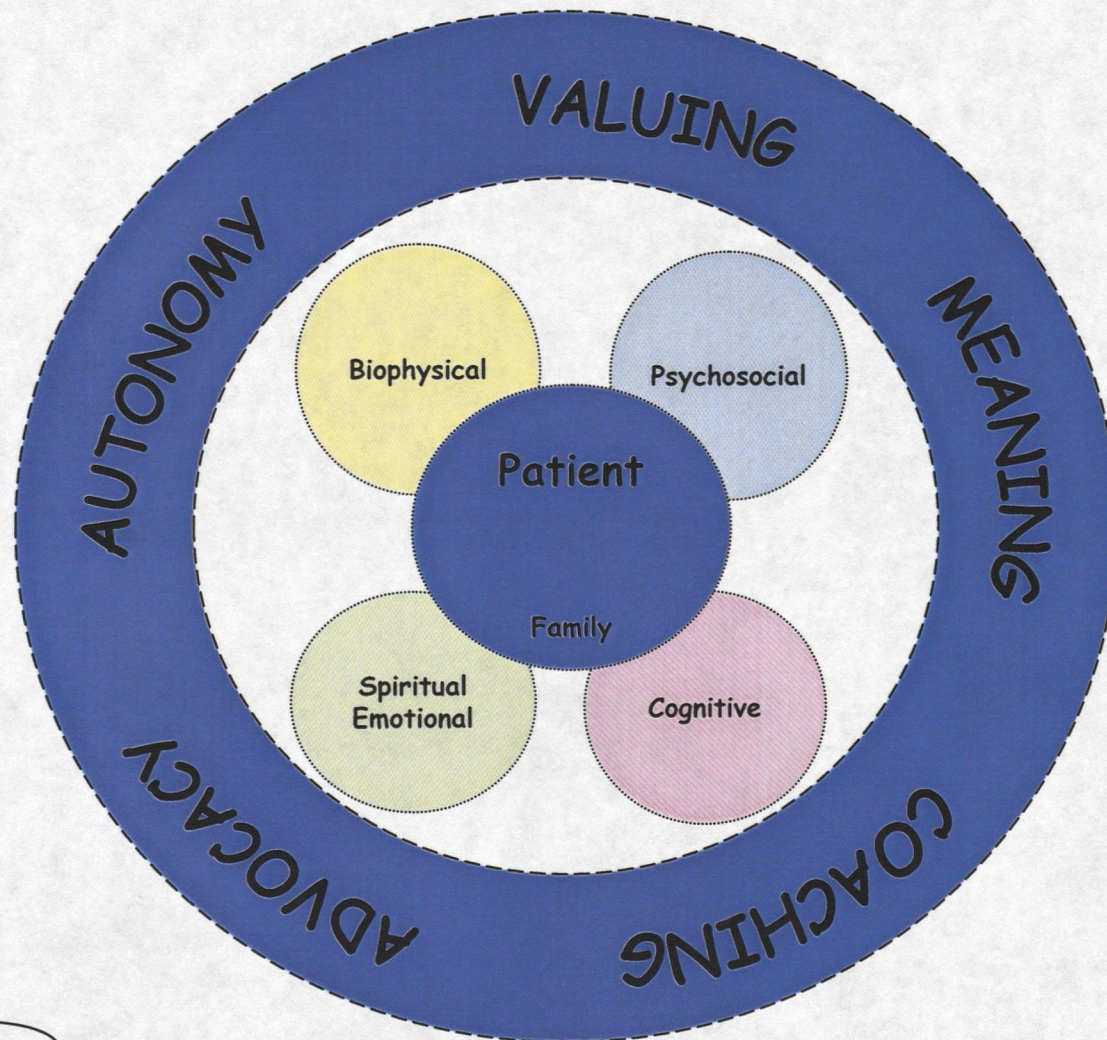
Collaborative
Care

Education

Counseling

Research

Professional
Leadership



Positive Human Health
& Well Being

Autonomy

Self-acceptance

Environmental Mastery

Positive Relations
with others

Purpose in Life

Personal Growth



Human Flourishing

Young Adult

Life Transitions

End of Life

↑ Stressors ↑
Uncertainty

Health-Illness Trajectory

APPENDIX B
QUESTIONNAIRE
Part A and Part B

Part A:

1. Age: (as of today) _____
2. Sex: (please circle the number) 1. Male 2. Female
3. Education: (please circle number)

1. elementary school (grades 1 - 6)	5. college/university degree
2. junior high school (grade 7 - 9)	6. attending trade/technical
3. high school (grade 10 - 12)	7. attending college/university
4. trade/technical diploma/certificate	8. other (please specify) _____
4. Ethnic Background: (please circle number)

1. White	4. Inuit
2. Black (African American)	5. Other (please specify) _____
3. Asian	
5. Marital status: (please circle number)

1. single	2. married/common-law	3. divorced	4. widow/widower
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6. Please state your occupation: _____
7. Are you: (please circle number)

1. Working full time	5. Receiving AISH/GAIN
2. Working part time	6. Receiving Canada Pension
3. Not employed	7. Receiving a disability
4. Receiving social assistance	pension
8. What was your age when you were first diagnosed with your structural heart problem: _____

9. Were you followed by a pediatric cardiologist as a child? (please circle number)

1. Yes 2. No

10. How many heart surgeries have you had: (do not include catheterizations) _____

11. In general, would you say your health is: (please circle number)

1. Excellent

4. Fair

2. Very good

5. Poor

3. Good

12. Does spirituality play an important role in your life? (please circle number)

1. Yes

2. No

Part B: The following set of questions deals with how you feel about yourself and your life. Please remember that there is no right or wrong answer.

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
1. Most people see me as loving and affectionate.	1	2	3	4	5	6
2. Sometimes I change the way I act or think to be more like those around me.	1	2	3	4	5	6
3. In general, I feel I am in charge of the situation in which I live.	1	2	3	4	5	6
4. I am not interested in activities that will expand my horizons.	1	2	3	4	5	6
5. I feel good when I think of what I've done in the past and what I hope to do in the future.	1	2	3	4	5	6
6. When I look at the story of my life, I am pleased with how things have turned out.	1	2	3	4	5	6
7. Maintaining close relationships has been difficult and frustrating for me.	1	2	3	4	5	6
8. I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.	1	2	3	4	5	6
9. The demands of everyday life often get me down.	1	2	3	4	5	6
10. In general, I feel that I continue to learn more about myself as time goes by.	1	2	3	4	5	6
11. I live life one day at a time and don't really think about the future.	1	2	3	4	5	6
12. In general, I feel confident and positive about myself.	1	2	3	4	5	6
13. I often feel lonely because I have few close friends with whom to share my concerns.	1	2	3	4	5	6
14. My decisions are not usually influenced by what everyone else is doing.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
15. I do not fit very well with the people and the community around me.	1	2	3	4	5	6
16. I am the kind of person who likes to give new things a try.	1	2	3	4	5	6
17. I tend to focus on the present, because the future nearly always brings me problems.	1	2	3	4	5	6
18. I feel like many of the people I know have gotten more out of life than I have.	1	2	3	4	5	6
19. I enjoy personal and mutual conversations with family members or friends.	1	2	3	4	5	6
20. I tend to worry about what other people think of me.	1	2	3	4	5	6
21. I am quite good at managing the many responsibilities of my daily life.	1	2	3	4	5	6
22. I don't want to try new ways of doing things - my life is fine the way it is.	1	2	3	4	5	6
23. I have a sense of direction and purpose in life.	1	2	3	4	5	6
24. Given the opportunity, there are many things about myself that I would change.	1	2	3	4	5	6
25. It is important to me to be a good listener when close friends talk to me about their problems.	1	2	3	4	5	6
26. Being happy with myself is more important to me than having others approve of me.	1	2	3	4	5	6
27. I often feel overwhelmed by my responsibilities.	1	2	3	4	5	6
28. I think it is important to have new experiences that challenge how you think about yourself and the world.	1	2	3	4	5	6
29. My daily activities often seem trivial and unimportant to me.	1	2	3	4	5	6
30. I like most aspects of my personality.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
31. I don't have many people who want to listen when I need to talk.	1	2	3	4	5	6
32. I tend to be influenced by people with strong opinions.	1	2	3	4	5	6
33. If I were unhappy with my living situation, I would take effective steps to change it.	1	2	3	4	5	6
34. When I think about it, I haven't really improved much as a person over the years.	1	2	3	4	5	6
35. I don't have a good sense of what it is I'm trying to accomplish in life.	1	2	3	4	5	6
36. I made some mistakes in the past, but I feel that all in all everything has worked out for the best.	1	2	3	4	5	6
37. I feel like I get a lot out of my friendships.	1	2	3	4	5	6
38. People rarely talk to me into doing things I don't want to do.	1	2	3	4	5	6
39. I generally do a good job of taking care of my personal finances and affairs.	1	2	3	4	5	6
40. In my view, people of every age are able to continue growing and developing.	1	2	3	4	5	6
41. I used to set goals for myself, but that now seems like a waste of time.	1	2	3	4	5	6
42. In many ways, I feel disappointed about my achievements in life.	1	2	3	4	5	6
43. It seems to me that most other people have more friends than I do.	1	2	3	4	5	6
44. It is more important to me to "fit in" with others than to stand alone on my principles.	1	2	3	4	5	6
45. I find it stressful that I can't keep up with all of the things I have to do each day.	1	2	3	4	5	6
46. With time, I have gained a lot of insight about life that has made me a stronger, more capable person.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
47. I enjoy making plans for the future and working to make them a reality.	1	2	3	4	5	6
48. For the most part, I am proud of who I am and the life I lead.	1	2	3	4	5	6
49. People would describe me as a giving person, willing to share my time with others.	1	2	3	4	5	6
50. I have confidence in my opinions, even if they are contrary to the general consensus.	1	2	3	4	5	6
51. I am good at juggling my time so that I can fit everything in that needs to be done.	1	2	3	4	5	6
52. I have a sense that I have developed a lot as a person over time.	1	2	3	4	5	6
53. I am an active person in carrying out the plans I set for myself.	1	2	3	4	5	6
54. I envy many people for the lives they lead.	1	2	3	4	5	6
55. I have not experienced many warm and trusting relationships with others.	1	2	3	4	5	6
56. It's difficult for me to voice my own opinions on controversial matters.	1	2	3	4	5	6
58. I do not enjoy being in new situations that require me to change my old familiar ways of doing things.	1	2	3	4	5	6
59. Some people wander aimlessly through life, but I am not one of them.	1	2	3	4	5	6
60. My attitude about myself is probably not as positive as most people feel about themselves.	1	2	3	4	5	6
61. I often feel as if I'm on the outside looking in when it comes to friendships.	1	2	3	4	5	6
62. I often change my mind about decisions if my friends or family disagree.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
63. I get frustrated when trying to plan my daily activities because I never accomplish the things I set out to do.	1	2	3	4	5	6
64. For me life has been a continuous process of learning, changing, and growth.	1	2	3	4	5	6
65. I sometimes feel as if I've done all there is to do in life.	1	2	3	4	5	6
66. Many days I wake up feeling discouraged about how I have lived my life.	1	2	3	4	5	6
67. I know that I can trust my friends, and they know they can trust me.	1	2	3	4	5	6
68. I am not the kind of person who gives in to social pressures to think or act in certain ways.	1	2	3	4	5	6
69. My efforts to find the kinds of activities and relationships that I need have been quite successful.	1	2	3	4	5	6
70. I enjoy seeing how my views have changed and matured over the years.	1	2	3	4	5	6
71. My aims in life have been more a source of satisfaction than frustration to me.	1	2	3	4	5	6
72. The past had its ups and downs, but in general, I wouldn't want to change it.	1	2	3	4	5	6
73. I find it difficult to really open up when I talk with others.	1	2	3	4	5	6
74. I am concerned about how other people evaluate the choices I have made in my life.	1	2	3	4	5	6
75. I have difficulty arranging my life in a way that is satisfying to me.	1	2	3	4	5	6
76. I gave up trying to make big improvements or changes in my life a long time ago.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
77. I find it satisfying to think about what I have accomplished in life.	1	2	3	4	5	6
78. When I compare myself to friends and acquaintances, it makes me feel good about who I am.	1	2	3	4	5	6
79. My friends and I sympathize with each other's problems.	1	2	3	4	5	6
80. I judge myself by what I think is important, not by the values of what others think is important.	1	2	3	4	5	6
81. I have been able to build a home and a lifestyle for myself that is much to my liking.	1	2	3	4	5	6
82. There is truth to the saying that you can't teach an old dog new tricks.	1	2	3	4	5	6
83. In the final analysis, I'm not so sure that my life adds up to much.	1	2	3	4	5	6
84. Everyone has their weaknesses, but I seem to have more than my share.	1	2	3	4	5	6

APPENDIX C

NEW YORK FUNCTIONAL CLASSIFICATION

Class	Patient Symptoms
Class I (Mild)	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or dyspnea (shortness of breath).
Class II (Mild)	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnea.
Class III (Moderate)	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnea.
Class IV (Severe)	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

APPENDIX D

UCLA CONGENITAL HEART DISEASE FUNCTIONAL CLASSIFICATION
(Presence and Degree of Symptoms)

Class I	Asymptomatic at all levels of activity
Class II	Symptoms are present but do not curtail average, everyday activity.
Class III	Symptoms significantly curtail most, but not all, average everyday activities.
Class IV	Symptoms significantly curtail virtually all average, everyday activities and may be present at rest.

APPENDIX E
ABILITY INDEX

- | | |
|---|--|
| 1 | Normal life.
Full time work or school.
Can manage pregnancy. |
| 2 | Able to work.
Intermittent symptoms.
Interference with life.*
Pregnancy possible. |
| 3 | Unable to work.
Limitation all activities.
Pregnancy risk. |
| 4 | Extreme limitation.
Dependent.
Almost housebound. |

*Socio/Community imposition
because of CARDIAC ANOMALY

APPENDIX F

ACC 32nd BETHESDA CONFERENCE, Task Force 1: The Changing Profile of Congenital Heart Disease in Adult Life, *Journal of the American College of Cardiology*, 37(5), 2001.

CLASSIFICATION OF ADULT CONGENITAL HEART DEFECTS

Types of Adult Patients With Simple Congenital Heart Disease*

Native disease

Isolated congenital aortic valve disease

Isolated congenital mitral valve disease (e.g., except parachute valve, cleft leaflet)

Isolated patent foramen ovale or small atrial septal defect

Isolated small ventricular septal defect (no associated lesions)

Mild pulmonic stenosis

Repaired conditions

Previously ligated or occluded ductus arteriosus

Repaired secundum or sinus venosus atrial septal defect without residua

Repaired ventricular septal defect without residua

*Those patients can usually be cared for in the general medical community.

Modified from Connelly MS, et al. Canadian Consensus Conference on Adult Congenital Heart Disease, 1996. *Can J Cardiol* 1998;14:395–452.

Types of Adult Patients With Congenital Heart Disease of Moderate Severity*

Aorto-left ventricular fistulae

Anomalous pulmonary venous drainage, partial or total

Atrioventricular canal defects (partial or complete)

Coarctation of the aorta

Ebstein's anomaly

Infundibular right ventricular outflow obstruction of significance

Ostium primum atrial septal defect

Patent ductus arteriosus (not closed)

Pulmonary valve regurgitation (moderate to severe)

Pulmonic valve stenosis (moderate to severe)

Sinus of Valsalva fistula/aneurysm

Sinus venosus atrial septal defect

Subvalvar or supravalvar aortic stenosis (except HOCM)

Tetralogy of Fallot

Ventricular septal defect with

Absent valve or valves

Aortic regurgitation
 Coarctation of the aorta
 Mitral disease
 Right ventricular outflow tract obstruction
 Straddling tricuspid/mitral valve
 Subaortic stenosis

*These patients should be seen periodically at regional adult congenital heart disease centers. Modified from Connelly MS, et al. Canadian Consensus Conference on Adult Congenital Heart Disease, 1996. Can J Cardiol 1998;14:395– 452.

HOCM 5 hypertrophic obstructive cardiomyopathy

Types of Adult Patients With Congenital Heart

Disease of Great Complexity*

Conduits, valved or nonvalved
 Cyanotic congenital heart (all forms)
 Double-outlet ventricle
 Eisenmenger syndrome
 Fontan procedure
 Mitral atresia
 Single ventricle (also called double inlet or outlet, common or primitive)
 Pulmonary atresia (all forms)
 Pulmonary vascular obstructive diseases
 Transposition of the great arteries
 Tricuspid atresia
 Truncus arteriosus/hemitruncus
 Other abnormalities of atrioventricular or ventriculoarterial connection
 not included above (i.e., crisscross heart, isomerism, heterotaxy
 syndromes, ventricular inversion)

*These patients should be seen regularly at adult congenital heart disease centers. Modified from Connelly MS, et al. Canadian Consensus Conference on Adult Congenital Heart Disease, 1996. Can J Cardiol 1998;14:395– 452.