

A PROSPECTIVE STUDY OF CHILD ADJUSTMENT TO CARDIAC PROCEDURES:
THE CONTRIBUTIONS OF COPING AND RECOVERY EXPECTATIONS

by

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Abstract

This study had three purposes. One, it examined the impact of Congenital Heart Disease (CHD) on both children's and parents' psychosocial adjustment and children's coping as compared to healthy controls. Two, it looked at the roles child pre-operative psychosocial adjustment, coping, and expectations for recovery play in predicting post-operative and in-hospital adjustment, short-term recovery, and functional disability and three, it investigated the relationship between parental pre-operative adjustment, coping, expectations for children's recovery, and post-operative adjustment. In total, 39 children and their parents participated in the study. Twenty-one children diagnosed with CHD who were undergoing either surgery or catheterization comprised the cardiac group and 18 healthy children, matched on age, gender, and location comprised the control sample. Results demonstrated that children with moderate levels of CHD and their parents are no more vulnerable when confronting life demands than healthy children and their parents. In regard to the second purpose of the study, results showed that child pre-operative adjustment was the best predictor of post-operative adjustment and in-hospital adjustment, although it played an insignificant role in predicting short-term recovery, or functional disability. Coping and expectations appeared to mediate post-operative behavior problems and in-hospital adjustment. The best predictor of parent post-operative adjustment, the third purpose, was pre-operative adjustment.

TABLE OF CONTENTS

Abstract	ii
Table of Contents	iii
List of Figures	iv
List of Tables	v
Acknowledgement	vi
INTRODUCTION	1
LITERATURE REVIEW	
Psychosocial Adjustment	2
Predicting Recovery	4
METHOD	
Subjects	12
Procedure	15
Measures	20
RESULTS	
Group Differences	26
Regression Analyses	31
DISCUSSION	
Psychosocial Adjustment	42
Coping	45
Predicting Child Recovery	46
Predicting Parent Recovery	50
Implications	51
Bibliography	53
Appendix A	62

List of Figures

- Figure 1. Conceptual Model of Stress and Coping for Invasive,
Cardiac Procedures

7

List of Tables

Table 1.	Respondents and Measures for Each of the Four Testing Sessions.	16
Table 2.	Group Means and Standard Deviations on the Psychosocial, Coping, and Functional Disability Measures.	28
Table 3.	Effect Sizes on Psychosocial Measures, Coping, and Functional Disability.	30
Table 4.	Correlations Among the Child Predictor Variables.	34
Table 5.	Correlations Among the Parent Predictor Variables.	34
Table 6.	Correlations Between Child Predictor and Outcome Variables.	35
Table 7.	Correlations Between Parents Predictor and Outcome Variables.	36
Table 8.	Blocked Hierarchical Multiple Regression Analyses Examining the Contributions of Prior Psychosocial Adjustment, Coping, and Expectations for Recovery on Children's Global Psychosocial Adjustment and Recovery.	38
Table 9.	Blocked Hierarchical Multiple Regression Analyses Examining the Contributions of Prior Psychosocial Adjustment, Coping, and Expectations for Recovery on Parent's Global Psychosocial Adjustment and Recovery.	41

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A Prospective Study of Child Adjustment to Cardiac Procedures: The Contributions of Coping and Recovery Expectations

Congenital Heart Disease (CHD) is a major health problem among children in the US and Canada; approximately 1 in 100 children are born with CHD (American Association of the Heart & Stroke Foundation, 1988). Improvements in the medical management of CHD have permitted children diagnosed with CHD, who in the past would have died, to survive and have allowed others to avoid its debilitating effects (Nadas, 1984). There is evidence of a two fold increase in the survival rates of children diagnosed with CHD (Newacheck & Taylor, 1992).

A direct result of the advances in medical technology is the increase in the number of surgeries and catheterizations performed on infants and very young children. These patients typically require further procedures later in childhood or adolescence to keep the child as symptom free as possible. However, little is known about the impact of invasive procedures which involve exposure to an unfamiliar and high-technology environment (i.e., surgery or cardiac catheterization) on children's and parents' psychological well being.

In order to address this dearth of research on the impact of surgery and catheterization on children and parents' psychosocial adjustment, this study examined whether coping and expectations for recovery mediated changes in adjustment, and if children's psychosocial adjustment, coping, and expectations for recovery predicted physical adjustment and disability following an invasive, cardiac procedure.

Research has also been inconclusive as to the degree of psychosocial risk associated with CHD. Children look to their peer group and family for friendship, leadership, and support, and having a physical disability or illness can cause numerous difficulties (Walker &

Greene, 1991). For example, symptoms of the disease may make it difficult to participate in the regular rough and tumble activities of youth and may cause stress in the family environment (Lavigne & Faier-Routman, 1992).

The present study evaluated the level of behavioral and emotional problems (i.e., psychosocial adjustment) and coping patterns in parents and their children who underwent cardiac surgery and/or cardiac catheterization, as compared to parents and their healthy children who did not undergo a medical procedure.

Literature Review

Psychosocial Adjustment

Thirty one percent of children under 18 years of age suffer from one or more chronic illnesses (Newacheck & Taylor, 1992). A recent meta-analysis, (Lavigne & Faier-Routman, 1992) showed that children with chronic physical disorders are at risk for psychosocial adjustment problems. This is not surprising as children with chronic physical disorders experience a variety of potentially stressful and threatening situations that otherwise healthy children do not (e.g., acute exacerbations of the chronic condition, complex and long term treatment regimens, multiple clinic visits; Wallander, Varni, Babani, Banis, & Wilcox, 1988). However, individual studies on the psychosocial adjustment of children with CHD have yielded mixed results. Some studies have found that children with CHD have higher levels of behavior and emotional (e.g., depression) problems, poorer school adjustment (i.e., lower academic achievement, higher absenteeism), and poorer peer relationships, compared with healthy peers or normative data (Aurer, Senturia, Shoop, & Biddy, 1971; Green & Levitt, 1962; Janus & Goldberg, 1995; Kashani, Lababidi, & Jones, 1980; Kitchen, 1978; Linde, 1975; Linde, Rasof, Dunn, & Rabb, 1966; Oates, Turnball, Simpson, & Cartmill, 1994;

Utens et al., 1993; Youssef, 1988). However, other studies have found that the level of psychosocial adjustment for many children with CHD is comparable to that of healthy peers or normative data (Baer, Freedman, & Garson, 1984; O'Dougherty, Wright, Garmezy, Loewenson, & Torres, 1983). These conflicting results could be due to methodological problems. Small samples, selection biases (e.g., sample only from one city, low participation rates), and comparison to norms on standardized measures rather than to matched or healthy controls are examples of methodological weaknesses present in the literature. Furthermore, studies have almost exclusively relied on parent and teacher reports of psychological adjustment without considering child self-report. As well, changes in medical technology have made many of the earlier studies out of date. The present study attempts to address these limitations. Additionally, the discrepant results may also be explained by recent research by Spurkland and colleagues (Bjørnstad, Spurkland, Lindberg, 1995; Spurkland, Bjørnstad, Lindberg, & Seem, 1993), who demonstrated that disease severity and physical capacity play a significant role in determining the extent of psychosocial adjustment difficulties. It is hypothesized that children with severe CHD, relative to matched physically healthy children, would have poorer psychosocial adjustment, as evidenced by higher global ratings of internalizing and externalizing problems.

Coping strategies children employ in stressful situations can be affected by the presence of a physical disorder. For example, a recent study by Phipps, Fairclough, and Mulhern (1995) demonstrated that children with cancer report using more blunting or avoidant coping than healthy children. The present study addressed the issue of whether there are differences in how children with CHD deal with a common stressor, everyday pain, as compared to healthy controls. It is expected that children with CHD would report relying

on avoidant coping, particularly problem-focused (e.g., distraction), more so than their healthy peers.

Having a child with a chronic illness places considerable demands on parents. In general, parents of chronically ill children have higher levels of marital stress and emotional distress (Eiser, 1990; Hauenstein, 1990). The few studies on parents of children with CHD, have found higher levels of maternal anxiety and over-protectiveness, but no differences in terms of marital adjustment, compared to parents of healthy children (Finley et al., 1979; Linde et al., 1965; Silbert, Newburger, & Fyler, 1982). These studies suffer from many of the same limitations as the research on children's psychosocial adjustment. Furthermore, no study appears to have examined overall psychosocial adjustment of parents of children with CHD. As it has been demonstrated that disease severity moderates the level of adjustment problems in children with CHD (Bjørnstad, et al., 1995; Spurkland, et al., 1993) it would not be unexpected to see a similar relationship in adults, i.e., parents of children with more severe CHD might be expected to have more adjustment problems than parents of children with moderate CHD. The present study examined the level of emotional symptoms (i.e., depression, internalizing disorders) in parents of children with CHD. It is expected that parents would have higher levels of psychosocial adjustment problems than those parents of healthy children only if the overall level of disease severity was severe.

Predicting Recovery: Psychosocial Adjustment and Functional Disability

Invasive, cardiac procedures are both physically and psychologically stressful. Although surgery and catheterization are not equally invasive (e.g., surgery requires a four to eight day hospital stay whereas catheterization is generally conducted on an outpatient basis, surgery requires deep sedation and catheterization requires a local anesthetic) both are known

to be associated with the presence of emotional distress, pain, and anxiety (Pederson & Harbaugh, 1995). As well, catheterization is no longer only a diagnostic procedure, it is now performed regularly in a therapeutic fashion.

In evaluating recovery from medical procedures both physical and psychological indices must be considered. Immediately following a medical procedure, there are a number of indices of recovery such as: time of first void, length of stay, time to first liquid intake, etc. (Field, et al., 1988; Peterson & Shigetomi, 1981). Following physical recovery (i.e., when tissue damage due to an intervention has physically healed), return to normal activities is of critical importance. For children, these activities include returning to school, playing with friends, and being physically active (Walker & Green, 1990). Similarly, psychological adjustment during hospitalization can be indexed in a number of ways such as child-ratings of emotional symptoms and physician ratings of cooperation. Emotional symptoms (e.g., anxiety, depression) and behavioral problems are most appropriately used as indices of psychological adjustment at the time of physical recovery. The present study evaluated both short-term and long-term functional recovery and psychological adjustment following cardiac procedures.

Although physical healing likely takes place at approximately the same time for most patients, psychological adjustment and return to daily activities occurs at different rates for different children. It is important to account for the variability in children's emotional, behavioral, short-term recovery, and functional disability (i.e., failure to return to day-to-day activities) following surgery and cardiac catheterization. Thompson, Gustafson, George and Spock (1994) present a model of stress and coping related to the adaptation of children with chronic illness and their parents. Figure 1 presents an adaptation of this model in which

factors that may account for the variability in psychological and medical adjustment of children with CHD and their parents are delineated. Adaptational processes are hypothesized to influence both the psychological

Insert Figure 1 Here

adjustment and medical recovery of children and their parents, over and above the contributions of illness parameters (i.e., medical experience, severity of illness) and demographic variables (e.g., socioeconomic status, age, gender). Adaptational processes include prior psychosocial adjustment, expectations for recovery, and coping. Knowledge of these adaptational processes can aid in developing interventions to ameliorate adjustment problems in children with CHD.

Illness parameters and demographic variables. A variety of illness parameters (e.g., disease severity, age of disease onset) have been examined in relation to adjustment and coping among children with CHD. However, results have been mixed (Baer, Freedman, & Garson, 1984; DeMaso et al., 1991; Utens et al., 1993; Youseff, 1988). For example, Youssef (1988) found that disease severity was related to higher levels of behavior problems reported by teachers, while Utens et al. (1993) found a non-significant relation between these same variables. Another study (Smith, Ackerson & Blotchky, 1989) found that children who were in the initial stages following a diagnosis of a chronic illness tended to use more avoidant coping strategies, whereas children who were in the later stages of adjustment to the disease/diagnosis used information gathering and/or positive self-statements more frequently. Similarly, a variety of demographic variables (e.g., gender, age) have also been examined in

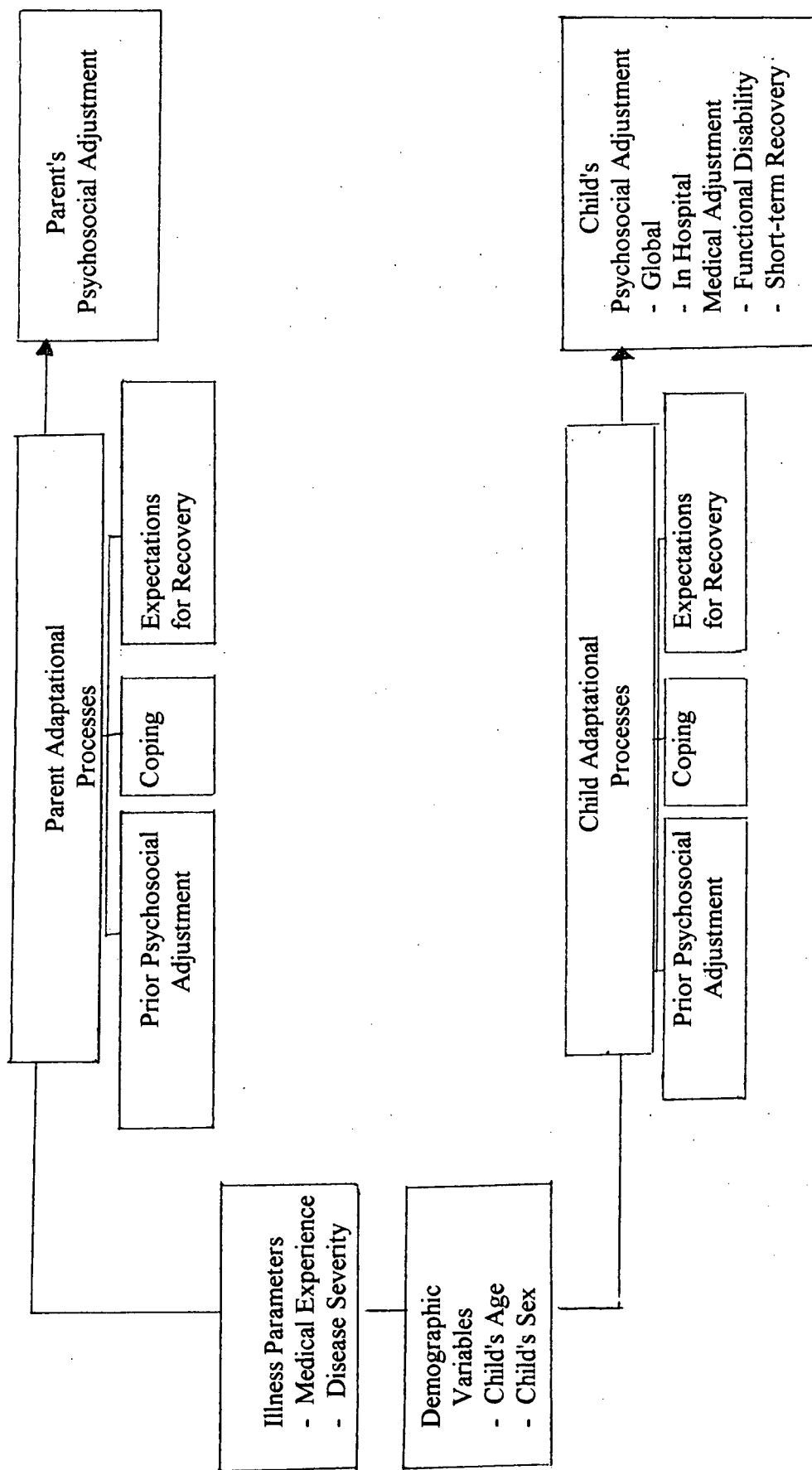


Figure 1. Conceptual Model of Stress and Coping for Invasive, Cardiac Procedures.

relation to adjustment among children with CHD and coping. Again, results have been mixed (DeMaso et al., 1991; Kitchen, 1978; Youssef, 1988). In regard to coping, one study found that as children age, they typically use less catastrophic cognitions and they employ more different types of coping strategies (Brown, O'Keeffe, Sanders, & Baker, 1986). Although the roles that illness parameters and demographic variables play in both the adjustment of children with CHD and coping strategies employed is presently uncertain, they are not the main focus of the present study and were consequently controlled for, when necessary, before testing the contributions of other factors to predicting psychological and medical adjustment and coping.

Psychosocial adjustment. Among both healthy and chronically ill children, prior psychological adjustment is the best predictor of later adjustment (e.g., Thompson, Gustafson, George, & Spock, 1994; Dubow, Tisak, Causey, Hryshko, & Reid, 1991). Thus, when examining recovery in terms of psychosocial adjustment, it is important to control for prior psychosocial adjustment. The assessment of psychological adjustment of children requires multiple raters and the use of well-validated measures (Thompson, Merritt, Keith, Murphy, & Johndrow, 1993). In the present study, parents, teachers, and children provided reports of psychological adjustment using standardized measures. Parents provided reports of their own emotional adjustment.

Children's ability to resume normal day-to-day activities following surgery (i.e., functional disability) is likely affected by their psychological state. For example, children who are depressed or anxious are less likely to engage in as many normal day-to-day activities (e.g., doing chores, being with friends) as those children who exhibit better psychosocial adjustment (Walker & Greene, 1991). The present study assessed the contributions of

children's psychosocial adjustment in predicting their long-term functional disability following a cardiac procedure which is likely to stress the child. It is hypothesized that children who exhibit better pre-operative adjustment, i.e., lower levels of internalizing and externalizing difficulties, would resume their normal day-to-day activities before those with poor pre-operative psychosocial adjustment.

The coping strategy employed by a child during a stressful situation may also be affected by, or it may affect, psychosocial adjustment. According to Compas (1987) optimal adjustment to a relatively uncontrollable stressor (e.g., surgery/catheterization) may require adjusting oneself to the stressor rather than trying to alter it. This notion was supported both by Compas' and his colleagues' research (e.g., Compas & Malcarne, 1988; Forsythe & Compas, 1987) and by Weisz, McCabe, and Denning (1994) who found that adjusting oneself to the stressor (e.g., cognitive strategies involving reframing the stressor) was associated with better behavioral adjustment as measured by the Child Behaviour Checklist (CBCL) and better illness specific adjustment. The present study examined the predictive relationship between children's psychosocial adjustment and coping. It is hypothesized that children who use more avoidant strategies would display poorer psychosocial adjustment as medical procedures and post-operative pain are relatively uncontrollable stressors which are better suited to approach strategies which reframe the stressor instead of changing it.

Coping. Coping can be defined as an effort to manage the demands of a stressor (Lazarus & Folkman, 1984). In other words, what people say, do and think when faced with a challenging situation. Not all of the coping strategies children employ are equally effective. Approach strategies (i.e., those which actively deal with the situation and manage emotional reactions) have been related to lower levels of distress behaviours and more rapid short-term

recovery among children undergoing minor surgery (Field et al., 1988; Peterson & Toler, 1986). In contrast, avoidance strategies (i.e., those that disengage the individual from the situation and avoid dealing with emotions in a positive manner) have been related to higher levels of maladaptive behaviours after minor surgery (Brophy & Erickson, 1990).

In a recent study (Campbell, Kirkpatrick, Berry, & Lamberti, 1995), children undergoing cardiac surgery were taught active coping skills, e.g., problem solving, and were supplied with information about the surgery. These children were compared to controls who received only the information portion (the standard hospital procedure) on the following measures: a) functional health status, b) cooperation during hospitalization, c) adjustment at home following discharge, and d) school functioning. The results showed that children who were taught to implement active coping strategies improved faster, were more cooperative and less upset in the hospital, were better adjusted at home, and had higher levels of school functioning than the controls. This suggests that children who spontaneously use similar coping strategies may do better following an invasive procedure than children who do not employ such strategies.

Research also suggests that adults who employ coping strategies which deal with the stressor, typically report less pain and stress than those who focus on or exaggerate the negative aspects of the situation (e.g., Auerbach, 1989; Brown, 1984; Jensen et al., 1991). In a later study by Brown, O'Keeffe, Sander, and Baker (1986) examining the strategies children use spontaneously when faced with a stressor (two imagined and one real personal stressor), it was demonstrated that children who employed coping cognitions to deal with the problems, as compared to those children who relied on catastrophizing, had less trait anxiety.

In regard to the relationship between coping and functional disability, Gil et al. (1993) found that among children with Sickle Cell Disease, active approach strategies (coping attempts) were significantly related to the level of school, household, and social activities children and adolescents engage in; children and adolescents high on coping attempts remained more active in a range of activities-school, social, and household activity. Children and adolescents who used passive adherence (i.e., resting) and/or negative thinking (i.e., catastrophizing, self-statements of fear and anger) were less active in school and social activities.

In the present study, children's coping in response to various stressors (i.e., everyday pain, surgery, postoperative pain) were assessed in relation to their psychological, short-term recovery, and functional disability. In addition, parental coping with their child's upcoming cardiac procedure was assessed in terms of parents' psychological adjustment. Similar arguments apply when examining the mediating effects coping strategies have on parental adjustment. It is hypothesized that children who employ more approach type coping strategies (e.g., "focus on the problem and see what I can do") would exhibit lower levels of psychosocial adjustment problems, better short-term recovery and functional disability. As well, adults who use avoidant coping strategies, e.g., avoidance or distraction, would have poorer adjustment than those parents who do not rely on avoidant strategies when dealing with their child's surgery.

Expectations for recovery. Expectations are beliefs about the probable outcome of a situation which influence an individual's actions and adjustment (Scheier & Carver, 1992). Among adults, positive expectations have been linked to less distress and more positive physical and psychological well being (Scheier & Carver, 1992). For example, adults who

had positive expectations about their medical outcome following coronary artery bypass surgery tended to resume vigorous physical exercise, returned to their prior recreational activities more quickly, and showed faster rates of recovery (Scheier and Carver, 1989). Gidron, McGrath, Goodday, & Precious (1994), in their study on adolescents recovery from dental surgery showed that expectations were a significant predictor of both disability and mouth opening (i.e., physical recovery); adolescents who had positive expectations were less disabled and were able to open their mouths wider and sooner following dental surgery. In the present study, children's expectations for their own recovery were examined as predictors of their psychological and medical adjustment. It is expected that children with positive expectations about the outcome would exhibit better psychosocial and medical adjustment (i.e., short-term recovery and functional disability). The role that parental expectations of child recovery plays in their own psychosocial adjustment would also be examined. It is hypothesized that optimistic expectations about children's recovery would mediate the level of emotional problems parents face post-operatively.

Method

Subjects

In total, 39 children (both healthy and those diagnosed with CHD) and their parents participated in the study. There were 21 children who had undergone either cardiac surgery (n=16) or cardiac catheterization (n=5) and they comprised the cardiac group. Thirty-one cardiac families had been contacted. Of the ten families who declined to participate, most refused after receiving the first interview package, as they believed the questions could cause their children to think too much about the upcoming surgery. Other families that refused at first contact typically were not telling the child that the surgery was taking place until shortly

before the procedure date. Patients with cardiac conditions were obtained from the Izaak Walton Killam (IWK) Hospital for Children in Halifax, Nova Scotia (n=12), and the British Columbia's Children's Hospital (BCCH) in Vancouver, British Columbia (n=9). Children were either new referrals or current patients and each family received \$25 for their participation.

An additional group of 18 healthy children were matched on the child's age, gender, and location (metropolitan --Halifax/Dartmouth, NS, Vancouver, BC-- versus non-metropolitan) with a surgical or catheterization patient and they comprised the control group. In total, 19 control families were contacted. All healthy controls were recruited from classrooms of the children with CHD. The next child on the class list who matched the cardiac patient's age and gender was asked to participate. Prior to any contact, permission was obtained from both the principal and the school board. Three controls for individual cardiac patients were not recruited as the children with CHD underwent the procedure during the summer.

Children with developmental disabilities (e.g., Down's syndrome) were excluded. All children were English speaking.

Children with CHD

Sample Characteristics. The sample comprised 10 girls (47.6%) and 11 boys with a mean age of 11.81 years (SD = 2.56, range 7-16). Grade in school ranged from 3rd to 10th, with a median of 7th grade. Of the adults who participated, there were 18 mothers and three fathers. The majority of families were two-parent families (81%) and had two or three children (71.4%). 85.7 percent of the families were Caucasian. Socioeconomic status (SES) was calculated using education level and career choice of both mother and father (when

applicable) according to the procedure outlined by Hollingshead (1965). Mean SES was 3.14 (SD = 1.46, range 1-5), with this level on the scale representing skilled craftsmen, clerical and sales workers.

Included in the cardiac sample were children who underwent both a catheterization procedure and a surgery during their hospital stay ($n=1$) and one child who was operated on twice during the hospital stay. As far as possible, the study protocol was maintained for these patients, i.e., session two was conducted the night before the first procedure and session three was conducted the third day following the final surgery.

Disease Severity Description. According to DeMaso et al. (1991) cardiac diagnoses do not necessarily reflect actual disease severity. Therefore, cardiologists provided information for a measure of severity which also included data from a comprehensive chart review of past medical experiences. The mean number of hospitalizations was 3.20 (SD = 4.71, range 0-13). There was a mean total of 43.75 (SD = 89.83, range 0-357) hospital days. The mean number of operations was 1.35 (SD = 2.06, range 0-6). The mean number of catheterizations was 1.76 (SD = 2.39, range 0-8). The mean number of outpatient visits was 13.57 (SD = 16.55, range 1-72). The mean length of time since diagnosis was 92.08 months (SD = 64.98, range 5-187). Physicians rated the majority of children as having no associated medical problems (80%) and the average severity rating was 2.67 (SD = 1.35, range 1-5), representing a moderate disorder where the children are asymptomatic but require cardiac operation with low risk.

Healthy Controls

Sample Characteristics. The sample comprised 11 boys (61.1%) and 7 girls with a mean age of 11.67 years (SD = 2.30, range 8-15). Grade in school ranged from 3rd to 10th,

with a median of 7th grade. Of the adults who participated, there were 17 mothers and one father. All families had both parents in the home and the majority had either two or three children (77.8%). 94.4 percent of the families were Caucasian. Mean SES was 3.39 (SD = 1.33, range 1-5), representing on the Hollingshead scale skilled craftsmen, clerical and sales workers.

Procedure

Children with CHD were assessed at four points in time. Control children completed only session 1. Families were contacted either in person or by telephone. Table 1 presents an overview of the entire study protocol.

 Insert Table 1 Here

Session 1: Prior to surgery

Children with CHD

Families of the children with CHD (i.e., catheterization, surgery patients) were contacted by their attending cardiologist and/or the clinic nurse and asked if they would allow a research assistant to telephone them about participating in a study on children with CHD. If after contact by the research assistant both the parent and child expressed an interest in participating, a packet containing consent forms and questionnaires was mailed to them.

At a date and time convenient for the family, a telephone interview was conducted. Informed consent was obtained from both the parent and child prior to providing detailed instructions for each questionnaire (Appendices A & B). Children completed their questionnaires over the telephone with the help of a research assistant and parents were asked

Respondents and Measures (as listed in Appendices)

	CHILD										PARENT										DOCTOR					TEACHER				
SESSION	A	C	D	E	F	L	M	N	O	S	B	E	G	H	I	N	O	P	Q	E	R	T	U	J	K					
Session 1	X	X	X	X	X						X	X	X	X	C _s									X	X					
Pre-operative																														
Session 2	C _s C _s C _s C _s C _x										C _s C _s C _s C _s										C _s									
Day Before																														
Procedure																														
Session 3	C _s C _s C _s										C _x										C _x C _x									
Postoperative																														
Session 4	C _s C _s C _s										C _s C _s C _s										C _s					C _s C _s				
Recovery																														

Table 1.

Respondents and measures for each of the four testing sessions

Note: X = test is administered to subjects and controls. C_s = test is administered only to subjects. Letters A through U at the top of the columns refer to the Appendices where the actual measures are presented. Measures are as follows: A = Child consent form; B = Parent consent form; C = Revised Child Manifest Anxiety Scale; D = Child Depression Inventory; E = Functional Disability Inventory; F = Coping Checklist; G = Symptom Checklist-90-Revised; H = Child Behavior Checklist; I = CISS; J = Child Behavior Checklist- Teacher Rating Form; K = Attendance; L = Emotional Rating Scale; M = Coping Effectiveness; N = Modified Functional Disability Inventory; O = Expectations for Recovery Interview; P = Demographic Questionnaire; Q = Past Medical History Form; R = Disease Severity; S = Pain Rating Scale; T = Child Observational Rating Scale; U = Short Term Recovery.

to complete their questionnaires while the research assistant was talking with the child. As well, children did not record their answers, the research assistant did. This was done to avoid the possibility of collusion between parents and children. Completed questionnaires were returned by mail using a self-addressed, stamped envelope.

Children. Children completed the following questionnaires:

- 1) Revised Child Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1978; Appendix C)
- 2) Child Depression Inventory-Short Form (CDI; Kovacs, 1985; Appendix D)
- 3) Functional Disability Inventory (FDI; Walker & Greene, 1991; Appendix E)
- 4) Coping Checklist (Reid et al., 1994; Appendix F)

Parents. Parents completed the following questionnaires:

- 1) Symptom Checklist-90 Revised (SCL-90R; Derogatis & Cleary, 1977; Appendix G)
- 2) Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1991; Appendix H)
- 3) Coping Inventory for Stressful Situations (CISS; Endler & Parker, 1990; Appendix I)
- 4) Functional Disability Inventory

Teachers. Teachers completed the Child Behavior Checklist-Teachers' Rating Form (Achenbach & Edelbrock, 1991; CBCL-TRF; Appendix J) and provided a record of the child's school attendance (Appendix K) for the previous six weeks. Teachers were mailed the forms and asked to return the questionnaires using a self-addressed, stamped envelope.

Healthy Controls

Names, addresses, and telephone numbers of control children were obtained from the teacher or principal of the children with CHD. Initial contact for the controls was made by the teacher or principal. If both child and parent expressed an interest in participating, a packet containing consent forms and questionnaires was mailed to them. Administration of the questionnaires and collection of teacher data followed the same procedure as with the cardiac patients, with the following exceptions: a) parents completed a demographic questionnaire and b) parents did not complete the CISS.

Session 2: Day before Cardiac Procedure

Children with CHD and their parents were interviewed the day before the procedure. Interviews with the surgical children took place in the hospital, either in the subject's hospital room if the patient had been admitted or in an interview room after his/her pre-admission clinic day. Interviews with the catheterization children took place during a telephone interview the day before the procedure.

Children. Children completed the following questionnaires:

- 1) Coping Checklist
- 2) Emotional Rating Scale (Bream et al., 1987; Appendix L)
- 3) Coping Effectiveness (Reid, Dubow, Carey, & Dura, in press; Appendix M)
- 4) Modified Functional Disability Inventory-expectations for recovery (Appendix N)
- 5) Expectations for Recovery Interview (Appendix O).

Parents. Parents completed the following questionnaires:

- 1) Demographic Checklist (Appendix P)
- 2) Past Medical Experiences-Child (Appendix Q)

3) Modified Functional Disability Inventory-expectations for recovery

4) Expectations for Recovery Interview.

Physician. Each child's cardiologist completed a measure of disease severity (DeMaso et al., 1991; Appendix R).

Sessions 3: Postoperative Pain

Children undergoing surgery were interviewed in hospital the third day following surgery. Children undergoing catheterization completed all questionnaires during a telephone interview the day after the procedure.

Children. Children completed the following questionnaires:

- 1) Coping Checklist
- 2) Emotional Rating Scale
- 3) Pain Rating Scale (Bieri et al., 1990; Appendix S)

Physician/ Medical Records. Each child's cardiologist provided a global rating, in relation to the child's entire hospitalization, of anxiety, cooperation, and tolerance for the procedure (Peterson & Shigetomi, 1991; Appendix T). Recovery room data on each subject was obtained from the child's medical record, including: time till first void, number of times child vomits, time of first liquid intake, length of recovery room stay (catheterization patients only) and length of stay in the ICU (surgical patients only; Appendix U).

Session 4: Recovery

Children with CHD

The final session took place at the time when most patients were expected to have made a nearly complete physical recovery (i.e., 6 weeks for cardiac surgery patients; 2 weeks for catheterization patients). A packet of questionnaires was given to each child at discharge.

A telephone interview was conducted to administer the questionnaires. Completed questionnaires were returned by mail using a self-addressed, stamped envelope.

Children. Children completed the following questionnaires:

- 1) Revised Child Manifest Anxiety Scale
- 2) Child Depression Inventory-Short Form
- 3) Functional Disability Inventory

Parents. Parents completed the following questionnaires:

- 1) Child Behavior Checklist
- 2) Symptom Checklist 90-R
- 3) Functional Disability Inventory

Teachers. Teachers completed the CBCL-TRF and provided a listing of when each child returned to school and his/her attendance since then.

Physician. Each child's cardiologist completed a measure of Disease Severity.

Measures

Background Variables

Demographic Checklist/ Past Medical Experiences. Parents provided basic demographic data (i.e., parents' marital status, occupation, education, family composition). Following the procedure of Dahlquist et al. (1986) and Lumley and Melamed (1993), parents indicated the number of their child's past medical experiences with throat cultures, medical appointments, dental appointments, bloodwork, hospitalizations, cardiac catheterization, and surgery. Parents were asked to rate their child's reactions to each of these medical experiences on a 7-point Likert scale (1=very negative ; 7= very positive). Two scores were

derived, medical experience and quality of reaction (greater than 4 = positive, less than 3 = negative; Appendix P& Q).

Disease Severity (DeMaso et al., 1991). Each child's cardiologist assessed disease severity using the following scale: 1= No or insignificant disorder (disorder has no impact on child's health); 2 = Mild disorder (no operative intervention but requires long term follow-up); 3 = Moderate disorder (child is asymptomatic but requires further cardiac operation with low risk); 4 = Marked disorder (child is symptomatic and will require further cardiac operation of high risk); 5 = Severe disorder (cardiac lesion is uncorrectable or can only be palliated with complex repair). Associated medical problems were also noted (Appendix R).

Predictor Variables

Coping Checklist (Reid et al., 1994). The children's coping strategies were assessed using a measure by Reid et al. (1994). Children indicated how often they use a variety of coping strategies in response to the following three situations: a) everyday pain, b) having surgery, and c) postoperative pain. For each of the three situations, children were asked to indicate how often (1 = never to 5 = very often) they used each of the strategies during that particular stressor (Appendix F). Three scores (i.e., approach, problem-focused avoidance, emotion focused avoidance) were derived by averaging children's responses across the three coping situations.

Coping Inventory for Stressful Situations (CISS; Endler & Parker, 1990). Parents completed the Coping Inventory for Stressful Situations in relation to how they deal with "having a child undergo a cardiac procedure." Three scale scores were derived, task, emotion, and avoidance. The reliability and validity of the CISS is well documented (Endler & Parker, 1990; Appendix I).

Expectations of Recovery Questionnaire. A modified version of the Functional Disability Inventory (Walker & Green, 1991) was completed by parents and children. The instructions to the Functional Disability Inventory were changed to "After you have recovered from surgery/ catheterization (about six/ two weeks after the operation) how much physical trouble or difficulty do you think you will have doing these activities?" (Appendix N).

Expectations of Recovery Interview. This was an interview that assessed what children expected the hurt/pain to be like following surgery (Appendix O) using both the Faces Pain Scale and a 10 point Likert scale (1 = no difficulties following surgery, 10 = most amount of difficulties following surgery). Scores from this interview were standardized and averaged with the standardized child responses on the MFDI to create an overall expectations for recovery variable.

Outcome Variables

Global Psychosocial Adjustment

A variety of measures were used to assess children's overall psychosocial adjustment. Two adjustment scores were derived based on the various measures collected both prior to and following surgery. An overall internalizing problem score was obtained by averaging responses on the following questionnaires: child-ratings of anxiety and depression, teacher-ratings of internalizing, and parent-ratings of internalizing. An overall externalizing problem score was obtained by averaging responses for teacher- and parent-ratings of externalizing. Past research has demonstrated that this approach is an acceptable way of determining an overall adjustment score as there is a degree of consistency between different informants' reports on the presence or absence of behavioral/emotional problems (Achenbach,

McConaughy, & Howell, 1987). A meta-analysis on the correlations between parents, teachers, mental health workers, observers, peers, and the children themselves, demonstrated a mean r of .28, $p < .001$ for different types of informants (e.g., parent/teacher), and .22, $p < .001$ between children and other informants (Achenbach, McConaughy, & Howell, 1987).

Revised Child Manifest Anxiety Scale (RCMAS; Reynolds & Richmond 1992).

Children completed the RCMAS, a 37-item questionnaire designed to assess anxiety both prior to and following the cardiac procedure. The RCMAS has well established reliability and validity (Reynolds & Richmond, 1992; Appendix C).

Children's Depression Inventory-Short Form (CDI-S; Kovacs, 1992). Children completed the CDI-S, a 10 item, self-rated depressive symptom inventory both prior to and following the cardiac procedure. The reliability and validity of this measure is well established (Kovacs, 1992; Appendix D).

Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1991). Parents completed the CBCL and teachers completed the CBCL-TRF. Both are well-validated questionnaires that assess the presence and intensity of a child's current display of problematic behaviours and symptoms (Appendices H & J).

Symptom Checklist 90-Revised (SCL-90R; Derogatis, 1992). Parents completed the SCL-90R. This questionnaire yields two global indexes of psychosocial adjustment, Global Severity Index and Positive Symptom Distress Index (i.e., the number of symptoms endorsed as being a problem for each individual). Further descriptions of the scale, including normative results on reliability and validity can be found in Derogatis (1992; Appendix G).

Psychosocial Adjustment during Hospitalization

Children's adjustment to hospitalization was based on children's self-report of their coping effectiveness and emotions, and physicians' report of reactions to hospitalization. Scores on all measures were standardized and averaged to yield a single, overall score for in-hospital psychosocial adjustment.

Coping Effectiveness. Children rated, on a visual analogue scale, how effective they felt their coping efforts were in dealing with their medical procedure and postoperative pain (Appendix M). This measure has been used in other coping studies and has been found to have adequate reliability ($\alpha = .73$ to $.74$; e.g., Reid, Dubow, Carey, & Dura, in press; Reid et al., 1994).

Modified Emotional Checklist (Bream et al., 1987). Children's emotional reactions to dealing with their upcoming medical procedure and postoperative pain were assessed using a modified version of Bream et al.'s (1987) emotional rating checklist. Each child was asked to rate how happy, sad, angry, calm/relaxed, scared/afraid, and nervous/worried they feel on a four point rating scale (0 = not at all, and 3 = really; Appendix L). Internal consistency for this measure is adequate ($\alpha = .68$; Reid et al., 1994).

Child Observational Rating Scale (Peterson & Shigetomi, 1981). Each child's cardiologist rated the child's level of anxiety, cooperation, and tolerance for the entire hospital stay, on a 5-point Likert-type scale (1 = not representative of child's behaviour; 5 = very representative of child's behaviour; Appendix T).

Short-Term Medical Recovery

Children's recovery following their medical procedure was based on child-reports of their average pain and a variety of indices of physical recovery (number of days in hospital,

number of hours in ICU/Recovery Room, number of times child vomits, number of hours till first void, number of hours till first liquid intake). Scores on these measures were standardized and averaged to yield a single measure of short-term medical recovery.

Short-term recovery. Recovery room data on each subject were obtained from the child's medical record including: time till first void, number of times child vomits, time of first liquid intake, length of recovery room stay (catheterization patients only) and length of stay in the ICU (surgical patients only; Appendix U). These variables have been used in a number of other studies as an index of post-procedural recovery (Field et al., 1988; Peterson & Shigetomi, 1981).

Pain Rating Scale (Bieri et al., 1991). Children rated their average level of pain since their medical procedure using a 7-point faces scale (0 = no pain; 6 = worst possible pain). This scale has well established reliability and validity (Appendix S).

Functional Disability

Children's functional disability following hospitalization was based on child- and parent-reports of child's functional disability and school attendance. Scores on these measures were standardized and averaged to yield an overall disability score.

Functional Disability Inventory (FDI; Walker & Green, 1991). Both the child and parent completed the FDI. This scale, which measures a child's physical abilities has good validity and reliability (Walker & Green, 1991; Appendix E).

School Attendance. Teachers provided a record of children's attendance both prior to and following their medical procedure (Appendix K).

Statistical Analyses

T-tests, correlations, and hierarchical regressions were utilized in the data analyses. T-tests and effect size calculations were used to test differences between the cardiac patients and healthy controls. Similarly, t-tests and effect sizes were computed to test differences between parents of cardiac patients and healthy controls in terms of overall psychosocial adjustment.

As the study attempted to delineate the roles that psychosocial adjustment, coping, and expectations for recovery play in predicting post-operative psychosocial adjustment, in-hospital adjustment, short-term recovery, and functional disability, regression analysis were chosen as the most appropriate statistic. There was one regression equation run for each of the seven outcome variables, i.e., child internalizing scores, child externalizing, child in-hospital adjustment, child functional disability, child short-term recovery, parent psychosocial adjustment (GSI and PSDI). When demographic variables or illness parameters were significantly correlated with an outcome variable, they were entered in the first step and controlled. Psychosocial adjustment variables were entered in the next step as predictors followed by the coping and expectation variables. In each regression analysis all terms were forced into the equation. This analytic strategy was used to evaluate the percentage of variance in each outcome explained by the predictors, over and above that accounted for by the earlier variables.

Results

Group Differences

There were methodological differences in how data was collected for the cardiac patients. However, the rationale for combining the surgery and catheterization patients as

one group is as follows: 1) both surgery and catheterization are known to be associated with the presence of emotional distress, pain, and anxiety (Pederson & Harbaugh, 1995), and 2) identical guidelines were used by the cardiologists to determine when session three and session four should be administered. For example, session four was conducted when the child was expected to have recovered from the insult of the invasive procedure. Therefore, it is unlikely that differences that might have occurred because of the type of medical procedures or methodological protocols could account for any of the results.

Descriptive. As control children were matched on age, gender, and location, significant differences for these variables were not expected, nor were they found (n.s.). The two groups also did not vary in terms of SES or which parent completed the adult questionnaires (n.s.).

Psychosocial Adjustment. Independent sample t-tests were conducted on various measures of child and parent psychosocial adjustment including: internalizing, externalizing, Global Severity Index (GSI), and Positive Symptom Distress Index (PSDI) to determine if differences existed between the cardiac and control groups. The t-tests revealed no significant findings (Table 2).

Insert Table 2 Here

As the sample is relatively restricted, a better index of possible group variance is effect size. According to Cohen (1988), $d = 0.20$ represents a small effect, $d = 0.50$ a medium effect, and $d = 0.80$ a large effect size. Effect size calculations (Table 3) revealed small effects (range 0.07-.3741).

	<i>Cardiac</i>		<i>Control</i>		<i>T value of the Difference</i>
VARIABLE	M	SD	M	SD	<i>n</i> = 37
Parent Psychosocial Adjustment:					
Global Severity Index	56.81	10.04	53.17	9.36	1.16
Positive Symptom Distress Index	53.00	8.90	50.89	5.47	0.87
Child Psychosocial Adjustment:					
Internalizing	47.02	5.83	46.63	4.98	0.22
Externalizing	47.80	8.92	45.95	6.93	0.71
Child Coping:					
Approach Coping	3.15	0.45	2.81	0.73	1.76
E-F Avoidance	1.86	0.59	2.03	0.57	-0.92
P-F Avoidance	3.41	0.69	3.08	0.60	1.56
Coping Effectiveness	73.43	13.51	62.67	13.41	2.49 ^a
Control	2.93	0.50	2.96	0.48	-0.19
Functional Disability:					
Child Ratings	21.38	4.53	18.89	2.89	2.01 ^a
Parent Ratings	19.36	4.29	17.17	2.77	1.86
School Absences	1.84	2.12	1.46	1.41	0.65

Table 2

Group Means (M) and Standard Deviations (SD) on the Psychosocial, Coping, and Functional Disability Measures:

Note: ^a $p < .05$. E-F = Emotion Focused and P-F = Problem Focused.

Insert Table 3 Here

Coping. Independent sample t-tests were conducted on various measures of child coping including: approach (e.g., ask questions about the problem, focus on the problem and see how I can solve it), emotion-focused avoidance (e.g., say mean things to people, worry about the situation), problem-focused avoidance (e.g., go and play, try to forget it), control, and effectiveness to determine if differences existed in the types of coping strategies employed when dealing with everyday pain between the cardiac and control groups. The t-tests revealed one significant finding (Table 2). Children with CHD rated their coping attempts as more effective ($t(37) = 2.49, p < 0.05$) than control children.

Effect size calculations (Table 3) revealed medium effects for approach and problem-focused avoidant coping (children with CHD used these strategies more often), a large effect for coping effectiveness, and small effects for emotion-focused avoidance and control. With an increase in sample size, significant findings are probable with the medium and large effect size coping variables.

The pattern of coping was also examined. In both groups, cardiac and healthy, children used significantly more approach coping than emotion-focused avoidant coping ($F = 68.88, p < .0001$; $F = 21.49, p < .0001$, respectively). As well, all children used significantly more problem-focused avoidance than emotion-focused avoidance ($F = 48.66, p < .001$; $F = 27.15, p < .001$). Only cardiac children used significantly less approach coping than problem-focused avoidance ($F = 18.10, p < .0001$).

	<i>Cardiac Group Compared with Control Group</i>	
Measure	Variable	Effect Size (d)
Parent Psychosocial Adjustment	Global Severity Index	0.37
	Positive Symptom Distress Index	0.28
Child Psychosocial Adjustment	Internalizing	0.07
	Externalizing	0.23
Child Coping	Approach	0.57
	E-F Avoidance	0.29
	P-F Avoidance	0.50
	Coping Effectiveness	0.80
	Control	0.06
Functional Disability	Child Ratings	0.65
	Parent Ratings	0.60
	School Absences	0.21

Table 3

Effect Sizes on Psychosocial Measures, Coping, and Functional Disability

Note: 0.20 represents a small effect, 0.50 a medium effect, and 0.80 a large effect size (Cohen, 1988). E-F and P-F = Emotion and Problem-Focused.

Functional Disability. Independent sample t-tests were conducted on various measures of functional disability including: child and parent ratings of functional disability and the number of school absences, to determine if differences existed in the levels of disability in the groups' day-to-day activities. The t-tests revealed only one significant finding (Table 2). Cardiac children rated their level of functional disability as significantly higher $t_{37} = 2.01$, $p < 0.05$.

Effect size calculations (Table 3) revealed medium effects for both child and parent ratings of disability and a small effect for total number of school absences. With an increase in sample size, significant findings are likely for parent ratings of functional disability and unlikely for school absences.

Regression Analyses

Overview. Prior to conducting regression analyses, illness parameters and demographic variables were evaluated for their association with the predictor and outcome variables to determine which variables needed to be controlled in the individual regression equations. The illness parameters included: child medical experience (mean = 2.31, SD = 0.59), quality of past medical experiences (mean = 3.90, SD = 1.51, range = 1-7), and disease severity. The demographic variables were: child's age, child's sex, parent's age, and parent's sex. These variables were not significantly correlated with any of the outcome variables with the following exceptions: 1) disease severity was significantly correlated with child functional disability, $r(21) = .48$, suggesting that as the level of disease severity increases so does functional disability; 2) medical experience was significantly correlated with child functional disability, $r(20) = .46$, implying that the more medical procedures the child has undergone in the past the more disabled the child is; 3) medical experience was significantly

correlated with parent psychosocial adjustment (SCL90-R: Positive Symptom of Distress Index (PSDI)), $r(21) = -.47$, suggesting that parents habituate to the stress of having their child undergoing medical procedures the more the child and experience fewer emotional problems; and 5) subject's sex was significantly correlated with parent psychosocial adjustment (SCL90-R: Global Severity Index (GSI)), $r(21) = .52$. Generally, daughters undergoing cardiac procedures were associated with higher levels of psychosocial adjustment problems.

Illness parameters and demographic variables were not significantly correlated to any of the child predictor variables (i.e., internalizing, externalizing, approach coping, emotion-focused coping, problem-focused coping, and expectations for recovery). However, parent predictor variables (i.e., Time 1 GSI and PSDI scores, task coping, emotion coping, avoidance, and parental expectations for child recovery) were significantly correlated with illness parameters and demographic variables. Parent sex was related to the use of task coping, $r(21) = .48$, with mothers using this strategy more than fathers. Medical experience was negatively correlated with avoidance coping, $r(21) = -.45$. It appears that as children undergo more medical procedures, parents use less avoidance and distraction to deal with the stress of their child having another procedure. As well, quality of past medical experience was negatively related to parent psychosocial adjustment (GSI), $r(21) = -.44$, suggesting that a child's emotional reaction to medical procedures affects parents' level of emotional difficulties (i.e., more positive reactions are associated with lower parent psychosocial adjustment scores). As the sample size is restricted, it was decided that only those demographic variables that were significantly correlated with the outcome variables would be controlled for in the regression analysis, particularly as past research has shown that there

may indeed be a relationship between several of the illness parameters, demographic variables, and outcome measures (DeMaso et al., 1991; Smith et al., 1989).

In addition, correlations within child predictor variables (Table 4) and parent predictor variables (Table 5) were computed. In general, child and parent coping strategies were significantly, positively correlated with the use of similar child and parent coping. As well, adjustment, both child and parent, was related to the use of specific coping strategies.

Insert Tables 4 & 5 Here

Correlations were also computed between the predictor and outcome variables for both child and parent (Table 6 & 7). In general, prior psychosocial adjustment and the use of avoidant

Insert Tables 6 & 7 Here

coping were significantly, positively correlated with child post-operative adjustment. Good in-hospital adjustment appeared to be related to low prior internalizing, the use of avoidant coping, as well as positive expectations. Finally, it seemed that poor medical recovery was associated with more negative expectations.

Child Psychosocial Adjustment During and Following Cardiac Procedures. Separate regression equations were run for child internalizing, externalizing, and in-hospital adjustment scores and are presented in Table 8. After accounting for the influence of prior internalizing

<i>Variable</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>
1. Internalizing	.58 ^c	-.04	.41 ^a	.003	.05
2. Externalizing		.22	.48 ^b	.28	.11
3. Approach Coping			.10	.09	-.13
4. Emotion-Focused Avoidance				.72 ^d	-.04
5. Problem-Focused Avoidance					-.19
6. Child Expectations for Recovery					

Table 4.

Correlations Among the Child Predictor Variables

Note: ^ap<.10; ^bp<.05; ^cp<.01; ^dp<.001.

<i>Variables</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>
1. Global Severity Index	.72 ^d	.40	.59 ^c	.29	.11
2. Positive Symptom Distress Index		.14	.46 ^b	.10	-.29
3. Task Coping			.27	.49 ^b	.20
4. Emotion Coping				.13	.10
5. Avoidance Coping					.22
6. Parent Expectations for Recovery					

Table 5.

Correlations Among the Parent Predictor Variables

Note: ^ap<.10; ^bp<.05; ^cp<.01; ^dp<.001.

Predictor Variables	Outcome Variables				
	Internalizing Time 4	Externalizing Time 4	In Hospital Adjustment	Functional Disability	Medical Recovery
Internalizing Time 1	.77 ^d	.48 ^b	.53 ^b	.01	.01
Externalizing Time 1	.54 ^c	.69 ^d	.22	-.12	-.02
Child Expectations for Recovery Approach Coping	-.02	-.04	.40 ^a	.35	.44 ^a
P-F Avoidant Coping	.22	.34	-.46 ^b	.06	.29
E-F Avoidant Coping	.14	.56 ^c	-.27	-.25	-.11
	.54 ^c	.67 ^d	.21	-.07	-.05

Table 6.

Correlations Between Child Predictor and Outcome Variables

Note: ^ap<.10; ^bp<.05; ^cp<.01; ^dp<.001

Predictor Variables	<i>Outcome Variables</i>	
	Global Severity Index Time 4	Positive Symptom Distress Index Time 4
Global Severity Index Time 1	.36	.26
Positive Symptom Distress Index Time 1	.24	.65 ^c
Task Coping	.26	-.01
Emotion Coping	.15	.05
Avoidance Coping	.35	.27
Parent Expectations for Recovery	.09	-.25

Table 7.

Correlations Between Parent Predictor and Outcome Variables

Note: ^ap<.10; ^bp<.05; ^cp<.01; ^dp<.001.

scores which accounted for 59% of the variance, F change = 27.84, $p < .001$, child coping and expectations for recovery explained an additional 12% of the variance in Time 4

Insert Table 8 Here

psychosocial adjustment, which was not significant, F change = 1.53, $p > .10$, Total $R^2 = .71$. In regard to post-operative behavioral scores, Time 1 externalizing accounted for 47% of the variance, F change = 16.89, $p < .001$, while child coping and expectations for recovery accounted for an additional 21% of the variation in post-operative externalizing scores, which also was significant, F change = 2.43, $p < .10$, Total $R^2 = .68$. It appears as if the best predictor of post-operative psychosocial adjustment is prior psychosocial adjustment, although coping and expectations seem to play a role in predicting behavioral difficulties.

With respect to in-hospital adjustment, pre-operative adjustment scores accounted for 29% of the variance, which was significant, F change = 3.64, $p < .05$. Coping and expectations for recovery accounted for an additional 43% of the variance which was significant, F change = 5.63, $p < .05$, Total $R^2 = .72$. This suggests that in-hospital adjustment was related to pre-operative psychosocial adjustment, coping, and expectations for recovery.

Medical Recovery. Two regression equations examining short-term medical recovery and functional disability were run. Results are presented in Table 8. Time one psychosocial adjustment accounted for negligible variance in short-term medical recovery. Coping and expectations for recovery accounted for 32% of the variance, although this was not significant, F change = 1.55, $p > .10$, Total $R^2 = .32$.

Variables	R ² -change	F change	Standardized β^a
Outcome: Internalizing Time 4			
Block 1	.59	27.84 ^e	
Internalizing Time 1			.63
Block 2	.12	1.53	
Approach Coping			.21
E-F Avoidance Coping			.36
P-F Avoidance Coping			-.14
Child Expectations			-.03
Total R ² = .71 F = 7.40 ^e Adjusted R ² = .62			
Outcome: Externalizing Time 4			
Block 1	.47	16.89 ^e	
Externalizing Time 1			.45
Block 2	.21	2.43 ^b	
Approach Coping			.18
E-F Avoidance Coping			.27
P-F Avoidance Coping			.22
Child Expectations			-.01
Total R ² = .68 F = 6.34 ^d Adjusted R ² = .57			
Outcome: In-hospital Adjustment			
Block 1	.29	3.64 ^c	
Internalizing Time 1			.20
Externalizing Time 1			.06
Block 2	.43	5.63 ^d	
Approach Coping			-.44
E-F Avoidance Coping			.64
P-F Avoidance Coping			-.67
Child Expectations			.23
Total R ² = .72 F = 6.21 ^d Adjusted R ² = .61			
Outcome: Medical Recovery			
Block 1	.001	.01	
Internalizing Time 1			.18
Externalizing Time 1			-.22
Block 2	.32	1.55	
Approach Coping			.37
E-F Avoidance Coping			-.07
P-F Avoidance Coping			.05
Child Expectations			.47

Total R^2 = .32 F = 1.04			
Adjusted R^2 = .01			
Outcome: Functional Disability			
Block 1	.32	4.13 ^c	
Medical Severity			.37
Medical Experience			.30
Block 2	.001	0.001	
Internalizing Time 1			.06
Externalizing Time 1			-.04
Block 3	.13	0.67	
Approach Coping			.06
E-F Avoidance Coping			.05
P-F Avoidance Coping			-.05
Child Expectations			.36
Total R^2 = .45 F = 1.17			
Adjusted R^2 = .07			

Table 8.

Blocked Hierarchial Multiple Regression Analyses Examining the Contributions of Prior Psychosocial Adjustment, Coping, and Expectations for Recovery on Children's Global Psychosocial Adjustment and Recovery (N=21).

Note: E-F = Emotion-Focused and P-F = Problem Focused. ^aStandardized betas are from the final block of the regression equation, and reflect the unique contribution of the variable controlling for other variables in the regression model.; ^bp<.10; ^cp<.05; ^dp<.01; ^ep<.001

After controlling for disease severity and medical experience which accounted for 32% of the variance in functional disability, F change = 4.13, $p < .05$, internalizing and externalizing scores accounted negligible variance while coping and expectations accounted for an additional 13%, both of which were not significant, F change = .001, $p > .10$, F change = 0.67, $p > .10$, respectively, Total $R^2 = .45$. It appears that the predictor variables did not mediate short term medical recovery or functional disability but that disease severity and medical experience did.

Parent Psychosocial Adjustment Following Cardiac Procedures. Individual regression equations were run for both the GSI and PSDI Time 4 adjustment scores. Results are presented in Table 9. After accounting for the influence of medical experience which accounted for 23% of the variance, F change = 5.21, $p < .05$, prior psychosocial adjustment (PSDI Time 1) explained an additional 18% of the variance in Time 4 psychosocial adjustment, which was significant, F change

Insert Table 9 Here

= 4.80, $p < .05$. Parental coping and expectations explained 16% of the variance in PSDI Time 4, which was not significant, F change = 1.08, $p > .10$, Total $R^2 = .57$. Again, although it appears that parental coping and expectations are accounting for a substantial proportion of the variance, the sample size makes it unlikely that significance would be found. It appears that Time 1 PSDI scores and past medical experience are the best predictors of Time 4 adjustment.

Variables	R ² -change	F change	Standardized β^a
Outcome: Positive Symptom Distress Index -PSDI			
Block 1	.23	5.21 ^c	
Medical Experience			-.11
Block 2	.18	4.80 ^c	
PSDI Time 1			.77
Block 3	.16	1.08	
Task Coping			-.17
Emotion Coping			-.38
Avoidance Coping			-.23
Parent Expectations			.001
Total R ² = .57 F = 2.63 ^b Adjusted R ² = .35			
Outcome: Global Severity of Index - GSI			
Block 1	.25	5.73 ^c	.58
Subject Sex			
Block 2	.15	3.88 ^b	
GSI Time 1			.35
Block 3	.19	1.39	
Task Coping			.18
Emotion Coping			-.15
Avoidance Coping			.34
Parent Expectations			-.15
Total R ² = .59 F = 2.86 ^c Adjusted R ² = .38			

Table 9.

Blocked Hierarchical Multiple Regression Analyses Examining the Contributions of Prior Psychosocial Adjustment, Coping, and Expectations for Recovery on Parent's Global Psychosocial Adjustment (N=21).

Note: ^aStandardized betas are from the final block of the regression equation, and reflect the unique contribution of the variable controlling for other variables in the regression model.;

^bp<.10; ^cp<.05; ^dp<.01; ^ep<.001.

In regard to the Global Severity Index (GSI), after accounting for the influence of child gender which accounted for 25% of the variance in Time 4 adjustment, F change = 5.73, $p < .05$, Time 1 GSI scores explained an additional 15% which was significant, F change = 3.88, $p < .10$. Coping and expectations for recovery accounted for 19% of the variance over and above that accounted for by child sex and prior psychosocial adjustment, which was not significant, F change = 1.39, $p > .10$, Total $R^2 = .79$. It appears that child gender and Time 1 GSI scores are the best predictors of post-operative adjustment.

Discussion

Psychosocial Adjustment

The present study examined the psychological impact of CHD on both children and their parents as compared to healthy controls. Results indicated that CHD is not a significant risk factor for the development of global adjustment problems in parents or children. Effect size calculations also suggest that even with an increased number of children and parents, significant differences would be unlikely. The majority of children, cardiac and healthy, and their parents were well within the normal range for internalizing and externalizing problems. Thus, children with CHD appeared to be no more vulnerable when confronting life demands than other children.

The children in this sample had a moderate level of disease severity. According to a study by Spurkland, Bjørnstad, Lindberg, and Seem (1993) children diagnosed with severe heart defects (e.g., valvular disease, Ebsteins anomaly), as compared to children with defects of moderate severity (e.g., atrial septal defect), have higher rates of psychiatric problems. As well, that study demonstrated an association between psychosocial functioning and physical capacity suggesting that physical capabilities are of crucial importance for mental health and

the functioning of adolescents with CHD, although the reverse causal relationship or third causal variables remain possibilities. Further, a recent study examining the impact of severe CHD on physical and psychosocial functioning demonstrated that children and adolescents with reduced physical capacities, which were a function of CHD, were at risk for developing psychiatric problems such as Overanxious and Dysthymic disorder more so than adolescents who, although having a severe heart defect, had good physical capacities (Bjørnstad, Spurkland, & Lindberg, 1995). This suggests that a diagnosis of CHD has its most deleterious effects on psychosocial adjustment when associated with poor physical functioning. As most children in this study had little reduction in physical capacities, as evidenced by the low functional disability scores provided by both parents and children in the cardiac sample as compared to what is typically reported by parents and children with other physical disorders (Walker and Greene, 1991), and were diagnoses with moderate levels of severity, it is not particularly surprising that CHD did not have a negative impact on adjustment. It is important to note, that the finding that children's adjustment does not appear to be negatively affected by the presence of CHD has limited generalizability to children with more severe diagnoses.

Not only did our sample consist mainly of children diagnosed with moderate levels of disease severity, the majority of the children were also rated by the cardiologists as asymptomatic, i.e., were not cyanotic, although they did tire more easily, making it difficult to tell by appearance alone that these children suffered from CHD. Many of the studies examining the impact of chronic physical disorders assess children who have been diagnosed with what would be considered "visible" diseases, e.g., spina bifida, cerebral palsy, or ones that have chronic, identifiable symptoms, e.g., juvenile rheumatoid arthritis or hemophilia. It

may be that the psychosocial adjustment problems identified in these studies can be attributed to the noticeable presence of the disorders. Perhaps significant differences in the level of emotional and behavior problems would have been apparent between the two groups if the children in this sample were symptomatic (e.g., were cyanotic).

The low to moderate disability ratings reported by both children and parents, besides suggesting that these children were not particularly disabled by the CHD, also offer a potential reason as to why all the children, both healthy and ill, were rated as having no significant emotional or behavior difficulties. Research by Walker and colleagues (e.g., Walker & Greene, 1991) indicates that high levels of disability are associated with more psychosocial adjustment problems, i.e., anxiety and depression. The levels of disability for ill children are typically much higher than what was reported by parents and children in this sample. For example, research has demonstrated that children with recurrent abdominal pain and their parents report substantially higher levels of functional disability than those reported by children with CHD and their parents (Walker & Greene, 1991). The disability scores by healthy children and their parents in this study were almost identical to those reported by controls in a study by Walker and Greene (1991). Perhaps the level of disability apparent in the cardiac children was too low to have a negative impact on psychosocial adjustment.

Another possible explanation for apparent similarity between children with CHD and healthy controls can be found in research examining the influences illnesses have over perceptions of child responsibility. Walker, Garber, and Van Slyke (1995) found that parents held children with medically explained pain less responsible for misbehavior, viewed the behavior as more excusable, and due to causes that were less internal to the children. This suggests that parents of children with CHD may be underreporting the presence of

misbehaviors typically found on the CBCL (e.g., lying argues, disobedient at school).

Perhaps this trend to minimize accountability may explicate, in part, why children with CHD do not appear to have higher levels of externalizing or internalizing problems.

The finding that parents of children with CHD are not at an increased risk for developing psychosocial adjustment problems is consistent with past research (e.g., Finley et al., 1979; Silbert et al., 1982), and can be explained by many of the same reasons that applied to their children. Having a child who is not particularly disabled by a disease and who appears to have no adverse emotional or behavioral difficulties as a consequence of having CHD is likely to lessen the negative impact the diagnosis may have had on parent functioning than if the child required continual care or who stressed the family situation by requiring special treatment (e.g., altered diet, complicated medical regimes).

Coping

Differences in coping strategies between healthy controls and children diagnosed with CHD were also examined in response to an everyday pain stressor. Children with CHD rated their coping attempts as more effective than control children. Perhaps these children have had more stressors to deal with in their lives (e.g., more doctors appointments, more invasive medical procedures) and have found the strategies they rely on in these situations to be helpful, and therefore rate them as more effective than the healthy children who may not have had as many opportunities to prove the effectiveness of their strategies. As well, a trend was identified within the use of different types of coping strategies, i.e., children with CHD reported using higher levels of approach and problem-focused avoidant coping in response to everyday pain than controls. This is not surprising, as research with ill children has demonstrated an increased reliance on avoidant strategies, e.g., blunting, when confronted

with stressful situations although typically, similar levels of approach type coping are reported between ill and healthy children (Phipps, Fairclough, & Mulhern, 1995). Again, the increased use of approach strategies may be, in part, related to the higher ratings of effectiveness. In other words, CHD children realize that these strategies are particularly effective so utilize them more.

Even though there were differences in the degree children with CHD used approach and problem-focused strategies as compared to healthy controls, there appeared to be a consistent pattern whereby both groups used approach and problem-focused coping more often than emotion-focused coping. This may explain why the children in this study, both cardiac and control, were within the normal range for psychosocial adjustment. Several researchers have shown approach coping to be linked to lower levels of emotional and behavior problems (e.g., Dubow, Tisak, Causey, Hryshko, & Reid, 1991; Herman-Stahl, Stealer, & Peterson, 1995). Further, it has been suggested that the use of problem-focused avoidance strategies (e.g., distraction, blunting) may influence self-report of depression and anxiety (Phipps et al., 1995). Perhaps, the cardiac children, who used more problem-focused avoidant coping, underreported the presence of externalizing or internalizing symptoms which made them appear to be functioning with few emotional or behavior difficulties.

Predicting Child Recovery: Psychosocial Adjustment & Functional Disability. This study also examined the contributions of prior psychosocial adjustment, expectations for recovery, and coping to both the medical and psychological recovery of children following an invasive cardiac procedure. After controlling for the effects of disease severity, prior medical experience, age, and gender, when necessary, it appeared that statistically significant support

was obtained for each of the models only in part, which is not surprising considering the small sample size.

In regard to psychological recovery, Time 1 internalizing and externalizing scores, i.e., pre-operative adjustment, were the best predictors of child adjustment following surgery or catheterization. Child coping strategies and expectations for recovery accounted for a significant amount of the variance in post-operative externalizing scores, however a similar relationship was not found with internalizing scores. Both problem-focused and emotion-focused avoidance were significantly, positively correlated with Time 4 externalizing scores and emotion-focused avoidant coping was correlated with post-operative internalizing ratings. This is consistent with past literature, which suggests that the use of avoidant strategies in dealing with medical procedures is less adaptive (Brophy & Erickson, 1990; Campbell et al., 1995). Perhaps with an increased sample size one could expect the use of problem- and emotion-focused avoidant strategies to account for a significant proportion of the variance in internalizing post-operative adjustment scores.

Although expectations were entered in the same step as coping, it is unlikely that they had any significant impact on the level of post-operative behavioral difficulties as they were not shown to be associated with externalizing scores. Expectations for recovery also was not a significant predictor for post-operative internalizing scores. As little research has examined this relationship in children it may be that the adult association between optimistic expectations and better adjustment (Scheier & Carver, 1992) does not hold true in children.

Support was obtained for the predicted relationship between in-hospital adjustment, Time 1 adjustment, coping, and expectations for recovery. Results show that pre-operative internalizing ratings, coping, and child expectations for recovery were positively related to in-

hospital adjustment. Past research suggests that coping does play a significant role in how children adjust to the hospital environment. For example, Campbell et al. (1995) demonstrated that the use of active coping skills was related to better cooperation and lower levels of disturbed behavior during hospitalization in children undergoing surgery. This is consistent with what was found both in the regression equation and in the correlations between predictor and outcome variables. In particular, it appears that the use of approach coping is associated with better in-hospital adjustment, although examination of the standardized β s indicates that both problem-focused and emotion-focused avoidance appear to be playing a substantial role, with problem-focused coping being significantly, negatively associated with in-hospital adjustment and emotion-focused coping being significantly, positively associated. As well, child expectations for recovery were associated with in-hospital adjustment. It appears that children who have more optimistic expectations have an easier time adjusting to the hospital environment. This too is consistent with past research which shows that adults who are more optimistic about the hospital experience are rated by nurses as more cooperative and demonstrate better compliance with medical regimes (Scheier & Carver 1989; 1992).

The predictions for medical recovery did not hold true. Prior psychosocial adjustment, coping, and expectations for recovery did not account for a significant proportion of the variance. However, coping and expectations may mediate recovery as they explained a sizable amount of the variance although it was not statistically significant. Past research has shown that child expectations for recovery were related to medical recovery, i.e., those children who had positive expectations about their procedure had better medical recovery. As well, studies have demonstrated a relationship between approach coping, optimistic

expectations, and good medical recovery (e.g., Brown, 1984; Campbell et al., 1995; Gidron et al., 1994; Scheier & Carver, 1989). Perhaps examining the individual variables comprising medical recovery separately would detect significance.

As research suggests that psychosocial adjustment, the use of approach coping, and positive expectations do indeed play a substantial role in children's ability to return to day-to-day activities, it was surprising that none of the predictions in regard to their relationships with functional disability held true. Specifically, Walker and Greene (1991) have shown that children with higher levels of anxiety and/or depression typically are more disabled than children who exhibit normal psychosocial adjustment. Perhaps the restricted variability in psychosocial adjustment, i.e., the majority of children were rated by parents, teachers, and self as well within the normal range, underscored the relationship demonstrated by Walker and her colleagues. Further, active coping attempts (i.e., approach coping) have in the past been associated with the amount of school, household, and social activities children diagnosed with Sickle Cell Disease report doing (Gil et al., 1993). Expectations for recovery too are associated, according to past research, with functional disability. For example, in adults Scheier and Carver (1989) ascertained a link between optimistic expectations and the ability to resume vigorous activities following heart surgery. In children, Gidron et al. (1994), determined that children with positive expectations were less disabled following molar extraction. Perhaps the predictions would be significant if we examined the outcome variables separately (i.e., functional disability score and school absences), although the two have been shown to be significantly correlated (Walker & Greene, 1991). As well, our small sample makes it difficult to determine if the connection between psychosocial adjustment, coping, expectations, and functional disability does in fact exist. However, the illness

parameters controlled for in this equation, medical severity and medical experience, were significantly associated with functional disability. It appears that children who have higher levels of disease severity are more disabled following an invasive, cardiac procedure, and that children with more past medical experience have higher rates of post-operative disability.

Predicting Parent Psychosocial Adjustment

Parent predictions were supported in part. After controlling for medical experience, Time 1 PSDI ratings were significantly associated with post-operative PSDI ratings. This is not unexpected as prior psychosocial adjustment is typically the best predictor of post adjustment, as evidenced by the high correlation in this study. In regard to GSI ratings, Time 1 scores were also predictive after controlling for child gender, although it looks as if having a daughter undergo surgery or catheterization is more predictive of emotional problems than prior psychosocial adjustment. As well, it is important to note that the quality of children's emotional reactions to medical procedures was related to pre-operative GSI scores, but due to the insufficient sample size it was not controlled in the regression equation.

Coping and expectations did not account for a significant amount of variance in Time 4 PSDI or Time 4 GSI scores, although both accounted for a sizable portion of the variance. Past research has shown that approach strategies are more effective in the long term in reducing emotional distress (Mullen & Suls, 1982), and that the use of social support is typically associated with better psychosocial adjustment than if an individual has a poor social network and does not discuss their feelings with friends or family (e.g., Cohen & Wills, 1985; Lesar & Maldonado, 1996). Avoidant strategies, e.g., distraction, have been shown to be effective in reducing emotional distress when it is used as a sort of "time-out" strategy and may even serve a recuperative function that subsequently allows an individual to use the more

effective approach/problem-focused strategies (Aldwin, 1995). However, it may be that using distraction as a coping method with your child's surgery may obviate attempts to solve the problem which could potentially lead to adjustment problems. Perhaps with an increased sample size the above relationships between coping and adjustment can be better examined.

It was hypothesized that parents' expectations regarding their child's recovery would play a significant role in determining their level of adjustment problems following surgery or catheterization. However, no such relation was found. This is somewhat surprising, as parents with children diagnosed with HIV, who had an optimistic view of the situation, typically experienced fewer personal strains than those parents who had more negative views (Lesar & Maldonado, 1996).

Implications

A strength of this study is the use of multiple sources of information for child psychosocial adjustment and a focus on processes not previously studied in children with CHD undergoing surgery or catheterization (e.g., expectations for recovery) and their parents. However, recruitment difficulties resulted in a small sample and there is some concern regarding the self-selecting out of highly distressed families. Additionally, because of the number of analyses, some results may be due to chance, although every effort was made to reduce the number of variables entered in the regression analyses. Therefore, results should be interpreted with caution and await replication with a larger sample. Currently, efforts are being made to increase the sample size.

There are a number of implications for this line of research. a) It provided valuable data on the psychosocial adjustment of both children with CHD and their parents, although further research is required to assess the role disease severity plays. b) As it appeared that

child expectations for recovery may play a role in predicting medical recovery and in-hospital adjustment, it is plausible to assume that children who may benefit from psychological interventions, i.e., those with pessimistic or unrealistic expectations, could be identified and helped. c) Although the relationship between specific coping strategies and better medical and psychological adjustment was not as clearly defined as one would like, results suggest that children who rely on avoidant coping to deal with the stress of an invasive, cardiac procedure are indeed at risk for adjustment difficulties. Therefore, identifying potentially "poor" copers prior to surgery or catheterization might help to ameliorate the problems these children face both during and after recovery.

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Appendix A
Child Consent Forms-CHD and Control Subjects

**A Prospective Study of Adjustment to Cardiac Procedures:
The Contributions of Coping and Recovery Expectations**

Dr. Human, Dr. Bennett, Ms. Laurie Cender, and Ms. Cheryl Gilbert are doing a project about what children like you say, do and think when you have surgery. We will meet four different times in the next few months for about 30-45 minutes each time. We will ask you questions at different times about how you feel in general, and about the things you say, do and think to help you handle your stay in the hospital. There are no right or wrong answers to any of the questions we will be asking you. You are the expert on what works for you. We will also be asking your doctor, teachers, and parents questions, but nobody except us will see your answers, not even your parents or your teachers. Your name will not be on any of the questionnaires and we will keep all your answers in a locked filing cabinet. We would also like to contact another child in your class who is the same age and gender as you are and ask them some of the same questions that we will ask you.

Most children enjoy answering these questions for us, but if you want to stop at any time just let us know, or if you do not want to do this, just tell us and we won't do it. Remember, your answers will help us learn about the ways people your age think and feel about different things, so be as honest as you can. You and your family will be given 25 dollars to help make up for the time you spend me. If you agree to take part, please sign your name on the line below.

Name _____

Date _____

Witness Signature _____

A Prospective Study of Adjustment to Cardiac Procedures:
The Contributions of Coping and Recovery Expectations

Dr. Human, Dr. Bennett, and Ms. Cheryl Gilbert are doing a project about children with heart disease and we would also like to ask children without this disease questions about their moods and feelings. If you agree to participate in this study we will ask you to answer a few questions during a telephone interview. We will ask you questions about how you feel in general and about the things you do, think and say if you are ever hurt or in pain. It should take no more than 30 minutes for you to answer all the questions. There are no right or wrong answers to any of the questions we will be asking you. We will also be asking your parents and teachers questions about the things you do. Any information you give us will remain confidential. All questionnaires will be coded with numbers, at no time will your name appear on any of the questionnaires. All data will be kept in a locked filing cabinet at the University of British Columbia. Nobody but us will see your answers; not your teachers, parents, or anyone else. So be as honest as you can.

Most people do not mind answering these questions for us, but if you want to stop at any time just let us know. If you do not want to take part, you do not need to. Your answers will help us to learn about people's moods and feelings. Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. If you agree to participate please sign your name on the line below.

Name

Witness Signature

Date

Appendix B
Parent Consent Forms-CHD and Control Subjects

A Prospective Study of Adjustment to Cardiac Procedures: The Contributions of Coping and Recovery Expectations

Undergoing cardiac procedures like surgery or catheterization is a challenging experience for both children and their parents. However, there is little know about the things children and parents do to help them cope with surgery. Dr. Human of the Department of Cardiology, Dr. Bennett of the Department of Psychology, Ms. Laurie Cender, Clinical Nurse Specialist for the Department of Cardiology, and Ms. Cheryl Gilbert, a psychology graduate student at the University of British Columbia are conducting a study to determine how children and adolescents with chronic heart problems deal with cardiac procedures. This study will be part of Ms. Gilbert's Master's Thesis.

If you agree to participate, you and your child will be asked to complete a number of questionnaires over four sessions in the next few months. You will be asked questions concerning your moods and feelings, how you are coping with your child's surgery, your child's past medical experience, your expectations for your child's recovery and your child's physical abilities following surgery. Your child will also answer questions about his moods and feelings, how he is coping with his surgery and his physical abilities following surgery. We would also like to ask your child's teacher, with your permission, to complete questionnaires about your child's attendance for the past six weeks and his behaviour at school. Finally, we would also like to ask another child in your son's class to answer questions on their own moods and feelings to provide a physically healthy comparison group. To compensate you for your time, your family will be given 25 dollars for your participation in this study.

First, before your child's surgery you and your child will be mailed five short questionnaires. At a date and time convenient to both you and your child a telephone interview will be arranged to complete the questionnaires. It will take no more than 45 minutes to complete this first session. At this time we will also be contacting your child's teacher.

Second, on the day before your child's surgery you will be met a place most convenient for you, or you will be telephoned by a researcher. The researcher will conduct an interview with your child about the types of things he is doing, thinking, or saying to help deal with having to have surgery (about 40 minutes), as well as his expectations for recovery. During this time you will be asked to complete five short questionnaires and answer a few questions concerning your expectations for recovery (about 20 minutes). Your child's doctor will also complete a questionnaire on his/her expectations for your child's recovery.

Third, a few days after your child's surgery a researcher will ask your child questions about the types of things he is doing, thinking, or saying to help deal with the discomfort he may feel after surgery.

Finally, 6 weeks after the surgery, you and your child will be asked to complete the last set of questionnaires during a telephone interview. This final session should take, at most 45 minutes. At this time we will also contact your child's teacher for a record of his school attendance for the previous six weeks and ask him to complete a questionnaire on your child's behaviour at school.

Parent Authorization to Contact Schools

As part of a project being conducted by researchers at the British Columbia Children's Hospital, I have agreed to allow my child's school teacher to be contacted. I understand that teachers will be asked to complete a brief checklist of my child's strengths and weaknesses in dealing with school and his or her peers. I also understand that when teachers complete this questionnaire they will also provide a record of my child's school attendance for the previous six weeks. Teachers will be asked to complete the questionnaires and provide attendance records on two separate occasions. Furthermore, I agree to allow the teacher to contact another family in my child's class to ask them if they would be interested in participating in this research as a child of the same age and gender without Congenital Heart Disease.

Parent's Signature

Date

Parent's Name (Please Print)

Witness' Signature

Child's Name (Please Print)

Child's School (Please Print)

Teacher's Name (Please Print)

Parent Authorization to Contact Schools

As part of a project being conducted by researchers at the B.C. Children's Hospital, I have agreed to allow my child's school teacher to be contacted. I understand that teachers will be asked to complete a brief checklist of my child's strengths and weaknesses in dealing with school and his or her peers. I also understand that when teachers complete this questionnaire they will also provide a record of my child's school attendance for the previous six weeks. Teachers will be asked to complete the questionnaires and provide attendance records.

Parent's Signature

Date

Parent's Name (Please Print)

Witness' Signature

Child's Name (Please Print)

Child's School (Please Print)

Teacher's Name (Please Print)

Appendix C
Revised Child Manifest Anxiety Scale

"WHAT I THINK AND FEEL"

Here are some sentences that tell how some people think and feel about themselves. Read each sentence carefully. Circle the word "YES" if you think it is true about you. Circle the word "NO" if you think it is not true about you. Do not circle both "Yes" and "No" for the same question.

- | | | |
|---|-----|----|
| 1) I have trouble making up my mind. | YES | NO |
| 2) I get nervous when things do not go the right way for me. | YES | NO |
| 3) Others seem to do things easier than I can. | YES | NO |
| 4) I like everyone I know. | YES | NO |
| 5) Often I have trouble getting my breath. | YES | NO |
| 6) I worry a lot of the time. | YES | NO |
| 7) I am afraid of a lot of things. | YES | NO |
| 8) I am always kind. | YES | NO |
| 9) I get mad easily. | YES | NO |
| 10) I worry about what my parents will say to me. | YES | NO |
| 11) I feel that others do not like the way I do things. | YES | NO |
| 12) I always have good manners. | YES | NO |
| 13) It is hard for me to get to sleep at night. | YES | NO |
| 14) I worry about what other people think about me. | YES | NO |
| 15) I feel alone even when there are people with me. | YES | NO |
| 16) I am always good. | YES | NO |
| 17) Often I feel sick to my stomach. | YES | NO |
| 18) My feelings get hurt easily. | YES | NO |
| 19) My hands feel sweaty. | YES | NO |
| 20) I am always nice to everyone. | YES | NO |
| 21) I am tired a lot. | YES | NO |
| 22) I worry about what is going to happen. | YES | NO |
| 23) Other people are happier than I. | YES | NO |
| 24) I tell the truth every single time. | YES | NO |
| 25) I have bad dreams. | YES | NO |
| 26) My feeling get hurt easily when I am fussed at. | YES | NO |
| 27) I feel someone will tell me I do things the wrong way. | YES | NO |
| 28) I never get angry. | YES | NO |
| 29) I wake up scared some of the time. | YES | NO |
| 30) I worry when I go to bed at night. | YES | NO |
| 31) It is hard for me to keep my mind on my schoolwork. | YES | NO |
| 32) I never say things I shouldn't. | YES | NO |
| 33) I wiggle in my seat a lot. | YES | NO |
| 34) I am nervous. | YES | NO |
| 35) A lot of people are against me. | YES | NO |
| 36) I never lie. | YES | NO |
| 37) I often worry about something bad happening to me. | YES | NO |

Appendix D
Child Depression Inventory

Name: _____ Date: _____

Directions

Below are statements which boys and girls use to describe themselves or their feelings. These statements are presented three at a time. Choose the statement from each group of three which best describes the way you have been feeling lately. Then, put an X in the space in front of the statement you have chosen. In each group of three statements, do not put an X in front of more than one statement, but please choose one statement from every group of three statements. There are no right or wrong answers.

Remember: Pick out the statements that best describe your feelings and ideas in the PAST TWO WEEKS.

- | | |
|---|---|
| 1. <input type="checkbox"/> I am sad once in a while.
<input type="checkbox"/> I am sad many times.
<input type="checkbox"/> I am sad all the time. | 6. <input type="checkbox"/> Things bother me all the time.
<input type="checkbox"/> Things bother me many times.
<input type="checkbox"/> Things bother me once in a while. |
| 2. <input type="checkbox"/> Nothing will ever work out for me.
<input type="checkbox"/> I am not sure if things will work out for me.
<input type="checkbox"/> Things will work out for me o.k. | 7. <input type="checkbox"/> I look o.k.
<input type="checkbox"/> There are some bad things about my looks.
<input type="checkbox"/> I look ugly. |
| 3. <input type="checkbox"/> I do most things o.k.
<input type="checkbox"/> I do many things wrong.
<input type="checkbox"/> I do everything wrong. | 8. <input type="checkbox"/> I do not feel alone.
<input type="checkbox"/> I feel alone many times
<input type="checkbox"/> I feel alone all the time. |
| 4. <input type="checkbox"/> I hate myself.
<input type="checkbox"/> I do not like myself.
<input type="checkbox"/> I like myself. | 9. <input type="checkbox"/> I have plenty of friends.
<input type="checkbox"/> I have some friends but I wish I had more.
<input type="checkbox"/> I do not have any friends. |
| 5. <input type="checkbox"/> I feel like crying everyday.
<input type="checkbox"/> I feel like crying many days.
<input type="checkbox"/> I feel like crying once in a while | 10. <input type="checkbox"/> Nobody really loves me.
<input type="checkbox"/> I am not sure if anybody loves me.
<input type="checkbox"/> I am sure that somebody loves me. |

Appendix E
Functional Disability Inventory

FDI-Child

When people are sick or not feeling well it is sometimes difficult for them to do their regular activities. In the last few days, would you have had any physical trouble or difficulty doing these activities?

1. Walking to the bathroom.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
2. Walking up stairs.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
3. Doing something with a friend	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
4. Doing chores at home.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
5. Eating regular meals.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
6. Being up all day without a rest or nap.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
7. Riding the school bus or travelling in a car.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
8. Being at school all day.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
9. Doing activities in gym class or playing sports.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
10. Reading or doing homework	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
11. Watching TV.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
12. Walking the length of a football field.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
13. Running the length of a football field.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
14. Going shopping	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
15. Getting to sleep at night and staying asleep.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible

Appendix F
Coping Checklist

COPING WITH EVERYDAY PAIN

Everyone has had a time when they have been hurt or in pain for a few hours or longer. For example, you might have had a headache, a stomach ache, a bad muscle pull, or pain in your joints (e.g., elbow, knee), etc. Below are some things that people might say, do, or think when they are hurt or in pain. We are interested in the things you do when you are in pain for a few hours or days. Do NOT think about things like a needle, bumping your knee OR things like having an operation or a broken bone. Circle one word for each question to show how often you do each thing listed: never, hardly ever, sometimes, often or very often. Reach each question carefully.

WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I

- 1) Ask questions about the problem.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 2) Focus on the problem and see how I can solve it.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 3) Talk to a friend about how I feel.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 4) Tell myself, don't worry everything will be ok.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 5) Go and play.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 6) Forget the whole thing.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 7) Say mean things to people.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 8) Worry that I will always be in pain.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 9) Ask for, or take, a pill.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 10) Cry so someone will help me.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

- 11) Ask a nurse or doctor questions.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I

12) Think about what needs to be done to make things better.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

13) Talk to someone about how I am feeling.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

14) Say to myself, be strong.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

15) Do something fun.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

16) Ignore the situation.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

17) Argue or fight.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

18) Keep thinking about how much it hurts.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

19) Put heat or ice on the sore spot.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

20) Moan or groan so someone will help me.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

21) Find out more information.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

22) Think of different ways to deal with the problem.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

23) Tell someone how I feel.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

24) Tell myself it's not so bad.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

25) Do something I enjoy.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I

26) Try to forget it.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

27) Yell to let off steam.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

28) Think that nothing helps.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

29) Rub the part of me that is sore.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

30) Ask someone to hold my hand.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

31) Learn more about how my body works.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

32) Figure out what I can do about it.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

33) Talk to a family member about how I feel.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

34) Say to myself, things will be ok.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

35) Do something active.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

36) Put it out of my mind.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

37) Get mad and throw or hit something.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

38) Think that the pain will never stop.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

39) Treat myself to a favourite food or snack.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I

40) Cry to let my feelings out.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

41) Try different ways to solve the problem until I find one that works.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

42) Let my feelings out to a friend.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

43) Tell myself I can handle anything that happens.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

44) Do something to take my mind off it.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

45) Don't think about it.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

46) Curse out loud.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

47) Worry too much about it.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

48) Treat myself to something special.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

49) Cry about it.

Never	Hardly Ever	Sometimes	Often	Very Often
-------	-------------	-----------	-------	------------

Appendix G
Symptom Checklist-90-Revised

SCL-90-R

Name: _____	Technician: _____ Ident. No. _____
Location: _____	Visit No.: _____ Mode: S-R _____ Nar _____
Age: _____ Sex: M _____ F _____ Date: _____	Remarks: _____

INSTRUCTIONS

Below is a list of problems and complaints that people sometimes have. Read each one carefully, and select one of the numbered descriptors that best describes HOW MUCH DISCOMFORT THAT PROBLEM HAS CAUSED YOU DURING THE PAST _____ INCLUDING TODAY. Place that number in the open block to the right of the problem. Do not skip any items, and print your number clearly. If you change your mind, erase your first number completely. Read the example below before beginning, and if you have any questions please ask the technician.

EXAMPLE	EXAMPLE
<p>HOW MUCH WERE YOU DISTRESSED BY:</p> <p>Ex. Body Aches Ex. 3</p> <p style="text-align: right; margin-right: 50px;"><small>Answer</small></p> <p style="text-align: right;"><small>Descriptors</small></p> <p style="text-align: right;">0 Not at all</p> <p style="text-align: right;">1 A little bit</p> <p style="text-align: right;">2 Moderately</p> <p style="text-align: right;">3 Quite a bit</p> <p style="text-align: right;">4 Extremely</p>	<p>HOW MUCH WERE YOU DISTRESSED BY:</p> <p style="text-align: right; margin-right: 50px;"><small>Descriptors</small></p> <p style="text-align: right;">0 Not at all</p> <p style="text-align: right;">1 A little bit</p> <p style="text-align: right;">2 Moderately</p> <p style="text-align: right;">3 Quite a bit</p> <p style="text-align: right;">4 Extremely</p>
<ol style="list-style-type: none"> 1. Headaches <input type="checkbox"/> 2. Nervousness or shakiness inside <input type="checkbox"/> 3. Repeated unpleasant thoughts that won't leave your mind <input type="checkbox"/> 4. Faintness or dizziness <input type="checkbox"/> 5. Loss of sexual interest or pleasure <input type="checkbox"/> 6. Feeling critical of others <input type="checkbox"/> 7. The idea that someone else can control your thoughts <input type="checkbox"/> 8. Feeling others are to blame for most of your troubles <input type="checkbox"/> 9. Trouble remembering things <input type="checkbox"/> 10. Worried about sloppiness or carelessness <input type="checkbox"/> 11. Feeling easily annoyed or irritated <input type="checkbox"/> 12. Pains in heart or chest <input type="checkbox"/> 13. Feeling afraid in open spaces or on the streets <input type="checkbox"/> 14. Feeling low in energy or slowed down <input type="checkbox"/> 15. Thoughts of ending your life <input type="checkbox"/> 16. Hearing voices that other people do not hear <input type="checkbox"/> 17. Trembling <input type="checkbox"/> 18. Feeling that most people cannot be trusted <input type="checkbox"/> 19. Poor appetite <input type="checkbox"/> 20. Crying easily <input type="checkbox"/> 21. Feeling shy or uneasy with the opposite sex <input type="checkbox"/> 22. Feelings of being trapped or caught <input type="checkbox"/> 23. Suddenly scared for no reason <input type="checkbox"/> 24. Temper outbursts that you could not control <input type="checkbox"/> 25. Feeling afraid to go out of your house alone <input type="checkbox"/> 26. Blaming yourself for things <input type="checkbox"/> 27. Pains in lower back <input type="checkbox"/> 	<ol style="list-style-type: none"> 28. Feeling blocked in getting things done <input type="checkbox"/> 29. Feeling lonely <input type="checkbox"/> 30. Feeling blue <input type="checkbox"/> 31. Worrying too much about things <input type="checkbox"/> 32. Feeling no interest in things <input type="checkbox"/> 33. Feeling fearful <input type="checkbox"/> 34. Your feelings being easily hurt <input type="checkbox"/> 35. Other people being aware of your private thoughts <input type="checkbox"/> 36. Feeling others do not understand you or are unsympathetic <input type="checkbox"/> 37. Feeling that people are unfriendly or dislike you <input type="checkbox"/> 38. Having to do things very slowly to insure correctness <input type="checkbox"/> 39. Heart pounding or racing <input type="checkbox"/> 40. Nausea or upset stomach <input type="checkbox"/> 41. Feeling inferior to others <input type="checkbox"/> 42. Soreness or your muscles <input type="checkbox"/> 43. Feeling that you are watched or talked about by others <input type="checkbox"/> 44. Trouble falling asleep <input type="checkbox"/> 45. Having to check and doublecheck what you do <input type="checkbox"/> 46. Difficulty making decisions <input type="checkbox"/> 47. Feeling afraid to travel on buses, subways, or trains <input type="checkbox"/> 48. Trouble getting your breath <input type="checkbox"/> 49. Hot or cold spells <input type="checkbox"/> 50. Having to avoid certain things, places, or activities because they frighten you <input type="checkbox"/> 51. Your mind going blank <input type="checkbox"/> 52. Numbness or tingling in parts of your body <input type="checkbox"/>

PAGE ONE

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PLEASE CONTINUE ON THE FOLLOWING PAGE

SCL-90-R

<p>HOW MUCH WERE YOU DISTRESSED BY:</p> <p><u>Descriptors</u></p> <p>0 Not at all</p> <p>1 A little bit</p> <p>2 Moderately</p> <p>3 Quite a bit</p> <p>4 Extremely</p>	<p>HOW MUCH WERE YOU DISTRESSED BY:</p> <p><u>Descriptors</u></p> <p>0 Not at all</p> <p>1 A little bit</p> <p>2 Moderately</p> <p>3 Quite a bit</p> <p>4 Extremely</p>
<p>53. A lump in your throat <input type="checkbox"/></p> <p>54. Feeling hopeless about the future <input type="checkbox"/></p> <p>55. Trouble concentrating <input type="checkbox"/></p> <p>56. Feeling weak in parts of your body <input type="checkbox"/></p> <p>57. Feeling tense or keyed up <input type="checkbox"/></p> <p>58. Heavy feelings in your arms or legs <input type="checkbox"/></p> <p>59. Thoughts of death or dying <input type="checkbox"/></p> <p>60. Overeating <input type="checkbox"/></p> <p>61. Feeling uneasy when people are watching or talking about you <input type="checkbox"/></p> <p>62. Having thoughts that are not your own <input type="checkbox"/></p> <p>63. Having urges to beat, injure, or harm someone <input type="checkbox"/></p> <p>64. Awakening in the early morning <input type="checkbox"/></p> <p>65. Having to repeat the same actions such as touching, counting, washing <input type="checkbox"/></p> <p>66. Sleep that is restless or disturbed <input type="checkbox"/></p> <p>67. Having urges to break or smash things <input type="checkbox"/></p> <p>68. Having ideas or beliefs that others do not share <input type="checkbox"/></p> <p>69. Feeling very self-conscious with others <input type="checkbox"/></p> <p>70. Feeling uneasy in crowds, such as shopping or at a movie <input type="checkbox"/></p>	<p>71. Feeling everything is an effort <input type="checkbox"/></p> <p>72. Spells of terror or panic <input type="checkbox"/></p> <p>73. Feeling uncomfortable about eating or drinking in public <input type="checkbox"/></p> <p>74. Getting into frequent arguments <input type="checkbox"/></p> <p>75. Feeling nervous when you are left alone <input type="checkbox"/></p> <p>76. Others not giving you proper credit for your achievements <input type="checkbox"/></p> <p>77. Feeling lonely even when you are with people <input type="checkbox"/></p> <p>78. Feeling so restless you couldn't sit still <input type="checkbox"/></p> <p>79. Feelings of worthlessness <input type="checkbox"/></p> <p>80. The feeling that something bad is going to happen to you <input type="checkbox"/></p> <p>81. Shouting or throwing things <input type="checkbox"/></p> <p>82. Feeling afraid you will faint in public <input type="checkbox"/></p> <p>83. Feeling that people will take advantage of you if you let them <input type="checkbox"/></p> <p>84. Having thoughts about sex that bother you a lot <input type="checkbox"/></p> <p>85. The idea that you should be punished for your sins <input type="checkbox"/></p> <p>86. Thoughts and images of a frightening nature <input type="checkbox"/></p> <p>87. The idea that something serious is wrong with your body <input type="checkbox"/></p> <p>88. Never feeling close to another person <input type="checkbox"/></p> <p>89. Feelings of guilt <input type="checkbox"/></p> <p>90. The idea that something is wrong with your mind <input type="checkbox"/></p>

Appendix H
Child Behavior Checklist

CHILD BEHAVIOR CHECKLIST FOR AGES 4-18

For office use only
ID #

CHILD'S NAME _____			PARENTS' USUAL TYPE OF WORK, even if not working now. (Please be specific - for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant) _____			
SEX <input type="checkbox"/> Boy <input type="checkbox"/> Girl	AGE _____	ETHNIC GROUP OR RACE _____	FATHER'S TYPE OF WORK _____			
TODAY'S DATE Mo _____ Date _____ Yr _____		CHILD'S BIRTHDATE Mo _____ Date _____ Yr _____	MOTHER'S TYPE OF WORK _____			
GRADE IN SCHOOL _____	Please fill out this form to reflect your view of the child's behavior even if other people might not agree. Feel free to write additional comments beside each item and in the spaces provided on page 2.		THIS FORM FILLED OUT BY			
NOT ATTENDING SCHOOL <input type="checkbox"/>			<input type="checkbox"/> Mother (name): _____ <input type="checkbox"/> Father (name): _____ <input type="checkbox"/> Other - name & relationship to child: _____			

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc. <input type="checkbox"/> None	Compared to others of the same age, about how much time does he/she spend in each?	Don't Know	Less Than Average	Average	More Than Average	Compared to others of the same age, how well does he/she do each one?	Don't Know	Below Average	Average	Above Average
a. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, cars, singing, etc. (Do not include listening to radio or TV.) <input type="checkbox"/> None	Compared to others of the same age, about how much time does he/she spend in each?	Don't Know	Less Than Average	Average	More Than Average	Compared to others of the same age, how well does he/she do each one?	Don't Know	Below Average	Average	Above Average
a. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

III. Please list any organizations, clubs, teams, or groups your child belongs to. <input type="checkbox"/> None	Compared to others of the same age, how active is he/she in each?	Don't Know	Less Active	Average	More Active
a. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.) <input type="checkbox"/> None	Compared to others of the same age, how well does he/she carry them out?	Don't Know	Below Average	Average	Above Average
a. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. _____		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- V. 1. About how many close friends does your child have? ☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more
(Do not include brothers & sisters)
2. About how many times a week does your child do things with any friends outside of regular school hours?
(Do not include brothers & sisters) ☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

VI. Compared to others of his/her age, how well does your child:

- | | Worse | About Average | Better | |
|---|--------------------------|--------------------------|--------------------------|---|
| a. Get along with his/her brothers & sisters? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> Has no brothers or sisters |
| b. Get along with other kids? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| c. Behave with his/her parents? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| d. Play and work by himself/herself? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |

VII. 1. For ages 6 and older – performance in academic subjects. If child is not being taught, please give reason _____

- | | Failing | Below average | Average | Above average |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Reading, English, or Language Arts | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. History or Social Studies | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Arithmetic or Math | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Science | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other academic subjects – for example: computer courses, foreign language, business. Do not include gym, shop, driver's ed., etc. | | | | |
| e. _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

2. Is your child in a special class or special school? ☐ No ☐ Yes – what kind of class or school?

3. Has your child repeated a grade? ☐ No ☐ Yes – grade and reason

4. Has your child had any academic or other problems in school? ☐ No ☐ Yes – please describe

When did these problems start?

Have these problems ended? ☐ No ☐ Yes – when?

Does your child have any illness, physical disability, or mental handicap? ☐ No ☐ Yes – please describe

What concerns you most about your child?

Please describe the best things about your child:

Below is a list of items that describe children and youth. For each item that describes your child now or within the past 6 months, please circle the 2 if the item is very true or often true of your child. Circle the 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know)

1 = Somewhat or Sometimes True

2 = Very True or Often True

0	1	2	1	Acts too young for his/her age	0	1	2	31.	Fears he/she might think or do something bad
0	1	2	2	Allergy (describe): _____					

0	1	2	3.	Argues a lot	0	1	2	32.	Feels he/she has to be perfect
0	1	2	4.	Asthma	0	1	2	33.	Feels or complains that no one loves him/her
0	1	2	5.	Behaves like opposite sex	0	1	2	34.	Feels others are out to get him/her
0	1	2	6.	Bowel movements outside toilet	0	1	2	35.	Feels worthless or inferior
0	1	2	7.	Bragging, boasting	0	1	2	36.	Gets hurt a lot, accident-prone
0	1	2	8.	Can't concentrate, can't pay attention for long	0	1	2	37.	Gets in many fights
0	1	2	9.	Can't get his/her mind off certain thoughts; obsessions (describe): _____	0	1	2	38.	Gets teased a lot
				_____	0	1	2	39.	Hangs around with others who get in trouble
0	1	2	10.	Can't sit still, restless, or hyperactive	0	1	2	40.	Hears sounds or voices that aren't there (describe): _____
0	1	2	11.	Clings to adults or too dependent					
0	1	2	12.	Complains of loneliness	0	1	2	41.	Impulsive or acts without thinking
0	1	2	13.	Confused or seems to be in a fog	0	1	2	42.	Would rather be alone than with others
0	1	2	14.	Cries a lot	0	1	2	43.	Lying or cheating
0	1	2	15.	Cruel to animals	0	1	2	44.	Bites fingernails
0	1	2	16.	Cruelty, bullying, or meanness to others	0	1	2	45.	Nervous, highstrung, or tense
0	1	2	17.	Day-dreams or gets lost in his/her thoughts	0	1	2	46.	Nervous movements or twitching (describe): _____
0	1	2	18.	Deliberately harms self or attempts suicide					
0	1	2	19.	Demands a lot of attention	0	1	2	47.	Nightmares
0	1	2	20.	Destroys his/her own things	0	1	2	48.	Not liked by other kids
0	1	2	21.	Destroys things belonging to his/her family or others	0	1	2	49.	Constipated, doesn't move bowels
0	1	2	22.	Disobedient at home	0	1	2	50.	Too fearful or anxious
0	1	2	23.	Disobedient at school	0	1	2	51.	Feels dizzy
0	1	2	24.	Doesn't eat well	0	1	2	52.	Feels too guilty
0	1	2	25.	Doesn't get along with other kids	0	1	2	53.	Overeating
0	1	2	26.	Doesn't seem to feel guilty after misbehaving	0	1	2	54.	Overtired
0	1	2	27.	Easily jealous	0	1	2	55.	Overweight
0	1	2	28.	Eats or drinks things that are not food — don't include sweets (describe): _____					

0	1	2	29.	Fears certain animals, situations, or places, other than school (describe): _____	0	1	2	56.	Physical problems without known medical cause:
				_____	0	1	2	a.	Aches or pains (not headaches)
0	1	2	30.	Fears going to school	0	1	2	b.	Headaches
					0	1	2	c.	Nausea, feels sick
					0	1	2	d.	Problems with eyes (describe): _____
					0	1	2	e.	Rashes or other skin problems
					0	1	2	f.	Stomachaches or cramps
					0	1	2	g.	Vomiting, throwing up
					0	1	2	h.	Other (describe): _____

0 = Not True (as far as you know)			1 = Somewhat or Sometimes True			2 = Very True or Often True					
0	1	2	57.	Physically attacks people		0	1	2	84.	Strange behavior (describe): _____	
0	1	2	58.	Picks nose, skin, or other parts of body (describe): _____						_____	
				_____		0	1	2	85.	Strange ideas (describe): _____	
				_____						_____	
0	1	2	59.	Plays with own sex parts in public		0	1	2	86.	Stubborn, sullen, or irritable	
0	1	2	60.	Plays with own sex parts too much		0	1	2	87.	Sudden changes in mood or feelings	
0	1	2	61.	Poor school work		0	1	2	88.	Sulks a lot	
0	1	2	62.	Poorly coordinated or clumsy		0	1	2	89.	Suspicious	
0	1	2	63.	Prefers being with older kids		0	1	2	90.	Swearing or obscene language	
0	1	2	64.	Prefers being with younger kids		0	1	2	91.	Talks about killing self	
0	1	2	65.	Refuses to talk		0	1	2	92.	Talks or walks in sleep (describe): _____	
0	1	2	66.	Repeats certain acts over and over; compulsions (describe): _____						_____	
				_____		0	1	2	93.	Talks too much	
0	1	2	67.	Runs away from home		0	1	2	94.	Teases a lot	
0	1	2	68.	Screams a lot		0	1	2	95.	Temper tantrums or hot temper	
0	1	2	69.	Secretive, keeps things to self		0	1	2	96.	Thinks about sex too much	
0	1	2	70.	Sees things that aren't there (describe): _____						_____	
				_____		0	1	2	97.	Threatens people	
				_____		0	1	2	98.	Thumb-sucking	
0	1	2	71.	Self-conscious or easily embarrassed		0	1	2	99.	Too concerned with neatness or cleanliness	
0	1	2	72.	Sets fires		0	1	2	100.	Trouble sleeping (describe): _____	
				_____						_____	
0	1	2	73.	Sexual problems (describe): _____		0	1	2	101.	Truancy, skips school	
				_____		0	1	2	102.	Underactive, slow moving, or lacks energy	
				_____		0	1	2	103.	Unhappy, sad, or depressed	
0	1	2	74.	Showing off or clowning		0	1	2	104.	Unusually loud	
0	1	2	75.	Shy or timid		0	1	2	105.	Uses alcohol or drugs for nonmedical purposes (describe): _____	
0	1	2	76.	Sleeps less than most kids						_____	
0	1	2	77.	Sleeps more than most kids during day and/or night (describe): _____		0	1	2	106.	Vandalism	
				_____		0	1	2	107.	Wets self during the day	
0	1	2	78.	Smears or plays with bowel movements		0	1	2	108.	Wets the bed	
0	1	2	79.	Speech problem (describe): _____		0	1	2	109.	Whining	
				_____		0	1	2	110.	Wishes to be of opposite sex	
0	1	2	80.	Stares blankly		0	1	2	111.	Withdrawn, doesn't get involved with others	
0	1	2	81.	Steals at home		0	1	2	112.	Worries	
0	1	2	82.	Steals outside the home						_____	
0	1	2	83.	Stores up things he/she doesn't need (describe): _____		0	1	2	113.	Please write in any problems your child has that were not listed above:	
				_____						_____	
				_____						_____	

Appendix I
CISS

CISS-Adult by Norman S. Endler, Ph.D., F.R.S.C. and James D.A. Parker, M.A.

Name: _____

Instructions: The following are ways people react to various difficult, stressful, or upsetting situations. Please circle a number from 1 to 5 for each item. Indicate how often you engage in these types of activities when dealing with your child's upcoming medical procedure (i.e., surgery/catheterization).

Not at all					Very Much
1	2	3	4	5	1. Schedule my time better.
1	2	3	4	5	2. Focus on the problem and see how I can solve it.
1	2	3	4	5	3. Think about the good times I've had.
1	2	3	4	5	4. Try to be with other people.
1	2	3	4	5	5. Blame myself for procrastinating.
1	2	3	4	5	6. Do what I think is best.
1	2	3	4	5	7. Preoccupied with aches and pains.
1	2	3	4	5	8. Blame myself for having gotten into this situation.
1	2	3	4	5	9. Window shop.
1	2	3	4	5	10. Outline my priorities.
1	2	3	4	5	11. Try to go to sleep.
1	2	3	4	5	12. Treat myself to a favourite food or snack.
1	2	3	4	5	13. Feel anxious about not being able to cope.
1	2	3	4	5	14. Become very tense.
1	2	3	4	5	15. Think about how I have solved similar problems.
1	2	3	4	5	16. Tell myself that it is really not happening to me.
1	2	3	4	5	17. Blame myself for being emotional about the sit.
1	2	3	4	5	18. Go out for a snack or meal.
1	2	3	4	5	19. Become very upset.
1	2	3	4	5	20. Buy myself something.
1	2	3	4	5	21. Determine a course of action and follow it.
1	2	3	4	5	22. Blame myself for not knowing what to do.
1	2	3	4	5	23. Go to a party.
1	2	3	4	5	24. Work to understand the situation.
1	2	3	4	5	25. "Freeze" and don't know what to do.
1	2	3	4	5	26. Take corrective action immediately.
1	2	3	4	5	27. Think about the event and learn from my mistakes.
1	2	3	4	5	28. Wish I could change what had happened/how I felt.
1	2	3	4	5	29. Visit a friend.
1	2	3	4	5	30. Worry about what I am going to do.
1	2	3	4	5	31. Spend time with a special person.
1	2	3	4	5	32. Go for a walk.
1	2	3	4	5	33. Tell myself that it will never happen again.
1	2	3	4	5	34. Focus on my general inadequacies.
1	2	3	4	5	35. Talk to someone whose advice I value.
1	2	3	4	5	36. Analyze the problem before reacting.
1	2	3	4	5	37. Phone a friend.
1	2	3	4	5	38. Get angry.

Not at all			Very Much			
1	2	3	4	5		39. Adjust my priorities.
1	2	3	4	5		40. See a movie.
1	2	3	4	5		41. Get control of the situation.
1	2	3	4	5		42. <u>Make an extra effort to get things done.</u>
1	2	3	4	5		43. Come up with different solutions to the problem.
1	2	3	4	5		44. <u>Take time off and get away from the situation.</u>
1	2	3	4	5		45. Take it out on other people.
1	2	3	4	5		46. <u>Use the situation to prove that I can do it.</u>
1	2	3	4	5		47. Watch TV.
1	2	3	4	5		48. <u>Try to be organized to be on top of the situation.</u>

Appendix J
Child Behavior Checklist-Teacher Rating Form

TEACHER'S REPORT FORM

For office use only
ID #

Your answers will be used to compare the pupil with other pupils whose teachers have completed similar forms. The information from this form will also be used for comparison with other information about this pupil. Please answer as well as you can, even if you lack full information. Scores on individual items will be combined to identify general patterns of behavior. Feel free to write additional comments beside each item and in the spaces provided on page 2.

PUPIL'S NAME			PARENTS' USUAL TYPE OF WORK, even if not working now. (Please be as specific as you can—for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)		
PUPIL'S SEX <input type="checkbox"/> Boy <input type="checkbox"/> Girl	PUPIL'S AGE	ETHNIC GROUP OR RACE	FATHER'S TYPE OF WORK: _____		
			MOTHER'S TYPE OF WORK: _____		
TODAY'S DATE Mo. _____ Date _____ Yr. _____		PUPIL'S BIRTHDATE (if known) Mo. _____ Date _____ Yr. _____	THIS FORM FILLED OUT BY:		
GRADE IN SCHOOL		NAME OF SCHOOL	<input type="checkbox"/> Teacher (name) _____		
			<input type="checkbox"/> Counselor (name) _____		
			<input type="checkbox"/> Other (specify) name: _____		

I. How long have you known this pupil? _____ months

II. How well do you know him/her? 1. ☐ Not Well 2. ☐ Moderately Well 3. ☐ Very Well

III. How much time does he/she spend in your class per week?

IV. What kind of class is it? (Please be specific, e.g., regular 5th grade, 7th grade math, etc.)

V. Has he/she ever been referred for special class placement, services, or tutoring?

☐ Don't Know 0. ☐ No 1. ☐ Yes—what kind and when?

VI. Has he/she ever repeated a grade?

☐ Don't Know 0. ☐ No 1. ☐ Yes—grade and reason

VII. Current school performance—list academic subjects and check column that indicates pupil's performance:

Academic subject	1. Far below grade	2. Somewhat below grade	3. At grade level	4. Somewhat above grade	5. Far above grade
1. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

VIII. Compared to typical pupils of the same age:	1. Much less	2. Somewhat less	3. Slightly less	4. About average	5. Slightly more	6. Somewhat more	7. Much more
1. How hard is he/she working?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. How appropriately is he/she behaving?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. How much is he/she learning?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. How happy is he/she?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

IX. Most recent achievement test scores (if available):

Name of test	Subject	Date	Percentile or grade level obtained

X. IQ, readiness, or aptitude tests (if available):

Name of test	Date	IQ or equivalent scores

Does this pupil have any illness, physical disability, or mental handicap? ☐ No ☐ Yes – please describe

What concerns you most about this pupil?

Please describe the best things about this pupil:

Please feel free to write any comments about this pupil's work, behavior, or potential, using extra pages if necessary.

Below is a list of items that describe pupils. For each item that describes the pupil now or within the past 2 months, please circle the 2 if the item is very true or often true of the pupil. Circle the 1 if the item is somewhat or sometimes true of the pupil. If the item is not true of the pupil, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to this pupil.

0 = Not True (as far as you know)			1 = Somewhat or Sometimes True	2 = Very True or Often True			
0	1	2	1. Acts too young for his/her age	0	1	2	31. Fears he/she might think or do something bad
0	1	2	2. Hums or makes other odd noises in class	0	1	2	32. Feels he/she has to be perfect
0	1	2	3. Argues a lot	0	1	2	33. Feels or complains that no one loves him/her
0	1	2	4. Fails to finish things he/she starts	0	1	2	34. Feels others are out to get him/her
0	1	2	5. Behaves like opposite sex	0	1	2	35. Feels worthless or inferior
0	1	2	6. Defiant, talks back to staff	0	1	2	36. Gets hurt a lot, accident-prone
0	1	2	7. Bragging, boasting	0	1	2	37. Gets in many fights
0	1	2	8. Can't concentrate, can't pay attention for long	0	1	2	38. Gets teased a lot
0	1	2	9. Can't get his/her mind off certain thoughts; obsessions (describe): _____	0	1	2	39. Hangs around with others who get in trouble
				0	1	2	40. Hears sounds or voices that aren't there (describe): _____
0	1	2	10. Can't sit still, restless, or hyperactive	0	1	2	41. Impulsive or acts without thinking
0	1	2	11. Clings to adults or too dependent	0	1	2	42. Would rather be alone than with others
0	1	2	12. Complains of loneliness	0	1	2	43. Lying or cheating
0	1	2	13. Confused or seems to be in a fog	0	1	2	44. Bites fingernails
0	1	2	14. Cries a lot	0	1	2	45. Nervous, high-strung, or tense
0	1	2	15. Fidgets	0	1	2	46. Nervous movements or twitching (describe): _____
0	1	2	16. Cruelty, bullying, or meanness to others				
0	1	2	17. Daydreams or gets lost in his/her thoughts	0	1	2	47. Overconforms to rules
0	1	2	18. Deliberately harms self or attempts suicide	0	1	2	48. Not liked by other pupils
0	1	2	19. Demands a lot of attention	0	1	2	49. Has difficulty learning
0	1	2	20. Destroys his/her own things	0	1	2	50. Too fearful or anxious
0	1	2	21. Destroys property belonging to others	0	1	2	51. Feels dizzy
0	1	2	22. Difficulty following directions	0	1	2	52. Feels too guilty
0	1	2	23. Disobedient at school	0	1	2	53. Talks out of turn
0	1	2	24. Disturbs other pupils	0	1	2	54. Overtired
0	1	2	25. Doesn't get along with other pupils	0	1	2	55. Overweight
0	1	2	26. Doesn't seem to feel guilty after misbehaving	0	1	2	56. Physical problems without known medical cause:
0	1	2	27. Easily jealous	0	1	2	a. Aches or pains (not headaches)
0	1	2	28. Eats or drinks things that are not food - don't include sweets (describe): _____	0	1	2	b. Headaches
				0	1	2	c. Nausea, feels sick
				0	1	2	d. Problems with eyes (describe): _____
0	1	2	29. Fears certain animals, situations, or places other than school (describe): _____				
				0	1	2	e. Rashes or other skin problems
0	1	2	30. Fears going to school	0	1	2	f. Stomachaches or cramps
				0	1	2	g. Vomiting, throwing up
				0	1	2	h. Other (describe): _____

0 = Not True (as far as you know)			1 = Somewhat or Sometimes True			2 = Very True or Often True		
0	1	2	57. Physically attacks people	0	1	2	84. Strange behavior (describe): _____	
0	1	2	58. Picks nose, skin, or other parts of body (describe): _____	0	1	2	85. Strange ideas (describe): _____	
0	1	2	59. Sleeps in class	0	1	2	86. Stubborn, sullen, or irritable	
0	1	2	60. Apathetic or unmotivated	0	1	2	87. Sudden changes in mood or feelings	
0	1	2	61. Poor school work	0	1	2	88. Sulks a lot	
0	1	2	62. Poorly coordinated or clumsy	0	1	2	89. Suspicious	
0	1	2	63. Prefers being with older children or youths	0	1	2	90. Swearing or obscene language	
0	1	2	64. Prefers being with younger children	0	1	2	91. Talks about killing self	
0	1	2	65. Refuses to talk	0	1	2	92. Underachieving, not working up to potential	
0	1	2	66. Repeats certain acts over and over; compulsions (describe): _____	0	1	2	93. Talks too much	
0	1	2	67. Disrupts class discipline	0	1	2	94. Teases a lot	
0	1	2	68. Screams a lot	0	1	2	95. Temper tantrums or hot temper	
0	1	2	69. Secretive, keeps things to self	0	1	2	96. Seems preoccupied with sex	
0	1	2	70. Sees things that aren't there (describe): _____	0	1	2	97. Threatens people	
0	1	2	71. Self-conscious or easily embarrassed	0	1	2	98. Tardy to school or class	
0	1	2	72. Messy work	0	1	2	99. Too concerned with neatness or cleanliness	
0	1	2	73. Behaves irresponsibly (describe): _____	0	1	2	100. Fails to carry out assigned tasks	
0	1	2	74. Showing off or clowning	0	1	2	101. Truancy or unexplained absence	
0	1	2	75. Shy or timid	0	1	2	102. Underactive, slow moving, or lacks energy	
0	1	2	76. Explosive and unpredictable behavior	0	1	2	103. Unhappy, sad, or depressed	
0	1	2	77. Demands must be met immediately, easily frustrated	0	1	2	104. Unusually loud	
0	1	2	78. Inattentive, easily distracted	0	1	2	105. Uses alcohol or drugs for nonmedical purposes (describe): _____	
0	1	2	79. Speech problem (describe): _____	0	1	2	106. Overly anxious to please	
0	1	2	80. Stares blankly	0	1	2	107. Dislikes school	
0	1	2	81. Feels hurt when criticized	0	1	2	108. Is afraid of making mistakes	
0	1	2	82. Steals	0	1	2	109. Whining	
0	1	2	83. Stores up things he/she doesn't need (describe): _____	0	1	2	110. Unclean personal appearance	
				0	1	2	111. Withdrawn, doesn't get involved with others	
				0	1	2	112. Worries	
				0	1	2	113. Please write in any problems the pupil has that were not listed above: _____	
				0	1	2	_____	
				0	1	2	_____	
				0	1	2	_____	

Appendix K
School Attendance

Attendance Record

Student's Name: _____

For the time period _____, please indicate how many days
_____ was absent from school. If possible, please list the actual dates of
absence and the reason if known, e.g., sickness or vacation.

Total Number of Days Absent: _____

Dates: (e.g., 05/09/96 to 05/10/96)

Reason(s):

- | | |
|----------|-------|
| 1) _____ | _____ |
| 2) _____ | _____ |
| 3) _____ | _____ |
| 4) _____ | _____ |
| 5) _____ | _____ |
| 6) _____ | _____ |
| 7) _____ | _____ |
| 8) _____ | _____ |

Appendix L
Emotion Rating Scale

People have different feelings when they are going to have surgery or a catheterization. For each of the 7 feelings listed below, circle the one statement that shows how you feel when you are going to have surgery or a catheterization. Circle one of the following statements for each question:

Happy



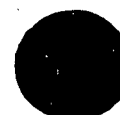
Not at all
Happy



A little
Happy



Pretty
Happy



Really
Happy

Sad



Not at all
Sad



A little
Sad



Pretty
Sad



Really
Sad

Excited



Not at all
Excited



A little
Excited



Pretty
Excited



Really
Excited

Angry



Not at all
Angry



A little
Angry



Pretty
Angry



Really
Angry

**Calm/
Relaxed**



Not at all
Calm/Relaxed



A little
Calm/Relaxed



Pretty
Calm/Relaxed



Really
Calm/Relaxed

**Scared/
Afraid**



Not at all
Scared/Afraid



A little
Scared/Afraid



Pretty
Scared/Afraid



Really
Scared/Afraid

**Nervous/
Worried**



Not at all
Nervous/Worried



A little
Nervous/Worried



Pretty
Nervous/Worried



Really
Nervous/Worried

Appendix M
Coping Effectiveness

B) Circle one word for each of the following questions.

When you are hurt or in pain for a few hours or a few days, how often do you think you can do something to change it?

Never Hardly Ever Sometimes Often Very Often

Being hurt or in pain can be hard or easy to deal with. How hard or easy is it for you to deal with being in pain?

Really Easy Kind of Easy Kind of Easy/
Kind of Hard Kind of Hard Really Hard

How often do you think you can do something to change your moods or feelings when you are hurt or in pain?

Never Hardly Ever Sometimes Often Very Often

Put a mark on each line to show how your problems with hurt or pain turned out:

I handled my hurt or pain....

Very Poorly _____ Very Well

In dealing with my hurt or pain, I learned...

Very Little _____ A Lot

I handled my feelings in dealing with my hurt or pain...

Very Poorly _____ Very Well

I solved the problems that came up...

Very Poorly _____ Very Well

The things that I did when I was in hurt or in pain....

Not at all _____ Very
Helpful Helpful

How I felt about myself ...

Very Bad _____ Very Good

Appendix N
Modified Functional Disability Inventory

MFDI-C

After you have recovered from surgery (about six weeks after the operation) or your cath (about two weeks after the procedure) how much physical trouble do you think you will have doing these activities?

1. Walking to the bathroom.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
2. Walking up stairs.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
3. Doing something with a friend	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
4. Doing chores at home.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
5. Eating regular meals.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
6. Being up all day without a rest or nap.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
7. Riding the school bus or travelling in a car.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
8. Being at school all day.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
9. Doing activities in gym class or playing sports.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
10. Reading or doing homework	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
11. Watching TV.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
12. Walking the length of a football field.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
13. Running the length of a football field.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
14. Going shopping	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible
15. Getting to sleep at night and staying asleep.	No Trouble	A Little Trouble	Some Trouble	A Lot Of Trouble	Impossible

Appendix O
Expectations for Recovery Interview

Expectations of Recovery Interview- after subject has completed the Modified Functional Disability Inventory.

- 1) When you are recovered, in about six/two weeks, do you think you will be able to stop taking your _____ (medication #1)? Would it be:

Very Easy Kind of Easy Kind of Easy/
Kind of Hard Kind of Hard Very Hard

taking your _____ (medication #2)? Would it be:

Very Easy Kind of Easy Kind of Easy/
Kind of Hard Kind of Hard Very Hard

- 2) Do you think you will have to have any more surgeries/catheterizations after this?

No Maybe Probably Yes I'm not Sure

We are interested in why you think it will be hard or easy to do different activities after your surgery/catheterization. Why do you think you will have some trouble with these (REFER TO CHILD'S ANSWERS ON MODIFIED FUNCTIONAL DISABILITY INVENTORY) activities?

- 1) Do you think these activities might be hard or easy to do because of how you usually heal or get better after things like a cut, bruise, muscle pull, or operation?

- 2) Do you think that these activities might be hard or easy to do because of how you usually deal with being sick?

a) Are you the kind of child/teenager who usually takes it easy for a couple of days just to make sure you are O.K.?

b) Or are you the kind of child/teenager who usually just goes on as if nothing happened?

- 3) What did your dad tell you about how things would be after your surgery?

What did your mom tell you ... ?

What did your friends tell you ... ?

What did your doctor. tell you ... ?

- 4) How much hurt/pain do you think you will feel after your surgery/catheterization?
(Use pain faces scale)

- 5) How difficult do you think it will be for you to return to regular activities after this surgery?

0	1	2	3	4	5	6	7	8	9	10
no difficulties										impossible

Appendix P
Demographic Questionnaire

Demographics.

Parent Information Sheet**1. Your Relationship to the Child** (circle one number):

1. Mother 2. Father 3. Stepmother 4. Stepfather
 5. Other _____

2. Your Current Age: _____ (years)**3. Your Race** (circle one): White Black Oriental Native Other _____**4. Your Current Marital Status** (circle one number):

- | | |
|------------------------|------------------|
| 1. Married | 4. Widowed |
| 2. Divorced/ Separated | 5. Never married |
| 3. Remarried | 6. Other _____ |

5. Your Education (circle one number):

- | | |
|---|--------------------------------|
| 1. Graduate School/ Professional training | 5. High School graduate |
| 2. University graduate (4 year college) | 6. Some high school |
| 3. Partial university (at least 1 year) | 7. Junior high school graduate |
| 4. Trade School/Community College | 8. Less than 7th grade |

6. Your Occupation (please describe): _____**7. Your Spouse's Partner's Current Age:** _____ (years)**8. Your Spouse's Race** (circle one): White Black Oriental Native Other _____**9. Your Spouse's Partner's Education** (circle one number):

- | | |
|---|--------------------------------|
| 1. Graduate School/ Professional training | 5. High School graduate |
| 2. College graduate (4 year college) | 6. Some high school |
| 3. Partial college (at least 1 year) | 7. Junior high school graduate |
| 4. Trade School/Community College | 8. Less than 7th grade |

10. Your Spouse's Partner's Occupation (please describe) _____

11. **Number of Family Members:** _____ Adults (20) _____ Children

For each child in your family please list their age, sex, and whether or not they currently reside in your home.

Age: _____ Sex (circle one): Male Female Living at home? (circle one): No Yes

Age: _____ Sex (circle one): Male Female Living at home? (circle one): No Yes

Age: _____ Sex (circle one): Male Female Living at home? (circle one): No Yes

Age: _____ Sex (circle one): Male Female Living at home? (circle one): No Yes

Age: _____ Sex (circle one): Male Female Living at home? (circle one): No Yes

Child Information Sheet

Please complete these questions in reference to your child.

1. **Child's Age:** _____ (years)

2. **Child's Date of Birth:** _____ (month) _____ (day) _____ (year)

3. **Child's Race** (circle one): White Black Oriental Native Other _____

4. Does your child have any **chronic illnesses** (circle one): No Yes

If yes, please list the illnesses:

6. **Child's Current Grade in School** _____

Appendix Q
Past Medical Experiences

Please indicate how many times your child has experienced each of the following medical procedures:

0 = never

1 = one or two times

2 = three or four times

3 = more than four times

Throat Cultures	0	1	2	3
Medical Appointments	0	1	2	3
Dental Appointments	0	1	2	3
Bloodwork (i.e., finger poke and/or venipuncture)	0	1	2	3
Hospitalizations	0	1	2	3
Cardiac Catheterization	0	1	2	3
Surgery	0	1	2	3

Please rate your child's reactions to each of these medical experiences:

<u>Throat Cultures</u>						
1	2	3	4	5	6	7
negative			no reaction			positive

<u>Medical Appointments</u>						
1	2	3	4	5	6	7
negative			no reaction			positive

<u>Dental Appointments</u>						
1	2	3	4	5	6	7
negative			no reaction			positive

<u>Bloodwork (i.e., finger poke and/or venipuncture)</u>						
1	2	3	4	5	6	7
negative			no reaction			positive

<u>Hospitalizations</u>						
1	2	3	4	5	6	7
negative			no reaction			positive

<u>Cardiac Catheterization</u>						
1	2	3	4	5	6	7
negative			no reaction			positive

<u>Surgery</u>						
1	2	3	4	5	6	7
negative			no reaction			positive

Appendix R
Disease Severity

Cardiologist's Perception of Medical Severity

Medical data will be collected on all children from the medical chart review and any missing information will be obtained by contacting the parents by phone. Information will be obtained on the following pre-admission variables:

a) Total hospitalizations, b) total hospital days, c) total number of prior cardiac operations, d) total number of prior cardiac Catheterizations, and e) number of outpatient visits since the diagnosis of the congenital heart disease. The length of time from the initial diagnosis to the hospitalization under study will be recorded. Associated medical problems will be defined as medical conditions requiring ongoing monitoring or medication. These are to be coded as None, Minor (e.g., otitis media), or Major (e.g., seizures).

In order to assess accurately the degree of medical severity, the children will be ranked by the staff cardiologist on the following scale: 1. No or insignificant disorder which has no impact on the child's future health; 2. Mild disorder which will not require operative intervention but does require long term follow-up (e.g., small residual ventricular septal defect); 3. Moderate disorder where the child is asymptomatic but will require further cardiac operation with low risk (e.g., residual atrial symptomatic defect); 4. Marked disorder where the child is quite symptomatic and will require further cardiac operation of high risk (e.g. tetralogy of Fallot); 5. Severe disorder where the cardiac lesion is uncorrectable or can only be palliated with complex repair (e.g., pulmonary vascular obstruction, Fontan repair, valve replacement). Two Pediatric Cardiologists will independently rate the child using this scale. This scale has previously been standardized for children with congenital heart disease by DeMaso et. al., *Journal of Pediatric Psychology*, vol. 16., pp. 137-149, 1991.

Physician: _____

Date: _____

Patient's Name: _____

Patient's Hospital Number: _____

Gender: _____

1) Total Hospitalizations: _____

2) Total Hospital Days: _____

3) Total Number of Prior Cardiac Operations: _____

4) Total Number of Prior Cardiac Catheterizations: _____

5) Number of Outpatient Visits since Diagnosis: _____

6) Length of Time from Initial Diagnosis to this Hospitalization: _____

- 7) Associated Medical Problems (circle):
- a) None
 - b) Minor (e.g., otitis media)
 - c) Major (e.g., seizures)

8) Medical severity (circle):

- 1) No or insignificant disorder with no impact on child's future health
- 2) Mild disorder no operative intervention but requires long term follow-up
- 3) Moderate disorder child is asymptomatic but requires further cardiac operation with low risk
- 4) Marked disorder child is symptomatic and will require further cardiac operation of high risk
- 5) Severe disorder cardiac lesion is uncorrectable or can only be palliated with complex repair.

Appendix S
Pain Rating Scale

Pain Rating Scale

This is called the Faces pain scale. It is sometimes used to help assess children's and teenagers's pain. Because it is often hard for children and teenagers to express their pain in words, they are asked to point to the face that shows best how they are feeling.

POSTOPERATIVE PAIN

Can you show how much hurt/pain you have felt most of the time since your surgery or catheterization? _____

Appendix T
Child Observational Rating Scale

Child Observational Rating Scale-Cardiologist

Please rate _____ behaviour in terms of anxiety, cooperation, and tolerance. Use his/her entire hospital stay. For example, if you perceived a child as being very anxious throughout his/her entire hospitalization, then you would circle number 5.

Please rate _____ level of anxiety for his/her entire hospital stay:

1	2	3	4	5
not representative of child's behaviour				very representative of child's behaviour

Please rate _____ level of cooperation for his/her entire hospital stay:

1	2	3	4	5
not representative of child's behaviour				very representative of child's behaviour

Please rate _____ level of tolerance for his/her entire hospital stay:

1	2	3	4	5
not representative of child's behaviour				very representative of child's behaviour

Appendix U
Short Term Recovery Chart Review

Patient Name: _____

Subject Number: _____

Surgery/Catheterization Date: _____

Surgery/Catheterization Start: _____

Surgery/Catheterization Over: _____

Time till first void: _____

Number of times child vomits: _____

Time of first liquid intake: _____

Length of stay in recovery room (catheterization patients only): _____

Length of stay in the ICU (surgery patients only): _____

Length of hospitalization: _____