

The Emotional Functioning and Self-perceived Severity of Youth with Pectus Excavatum

by

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B.A., Simon Fraser University 2004

A Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF ARTS

in the Department of Educational Psychology

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University of Victoria

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ABSTRACT

Currently, there is little research on self-perception and the psychological impact of concealable deformities such as pectus excavatum (PE). The current study addresses this gap by comparing self-perceived severity, actual physical severity, and depressive symptoms in youth with PE. Substantiating parents' and physicians' concerns, participants' scores on the Youth Self-Report depression subscales were significantly higher than non-clinical normative samples, indicating more depressive symptoms. Analyses of self-perceived severity, the Haller Index (HI; a medical measure of PE severity), and depressive symptoms substantiated the importance of subjective self-perception. There were no significant correlations between the HI of physical severity and depressive affect; however, youths' perceptions of severity correlated strongly and predicted depressive affect. The results suggest that youth with PE may be at risk for depressive disorders, and that self-perception, not actual physical severity, is the better predictor of the psychosocial impact of the deformity.

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Acknowledgements

I would like to thank Dr. Joan Martin for her encouragement, knowledge, and expertise. Thank-you for those late-night discussions and emergency phone calls. My thesis would not be complete without your guidance and caring. To my committee members, Dr. Anderson, Dr. Gibbons, and Dr. Lauzon, thank-you for your time and valuable advice. To Dr. Harvey and Dr. Walsh, thank-you for your support and caring. Ms. Zoria Crilly, your assistance is greatly appreciated; you have been instrumental in helping me complete my degree. All of you, in one way or another have helped define my professional or personal pursuit; for that, I am forever grateful.

To my parents, Nirmal, Kamaljit, and Mohinder Gill: They raised, nurtured, supported, taught, and loved me. To them, I am forever indebted.

To the rest of my family: Thank-you for supporting and listening to me, and offering sincere advice over matters that may seem trivial or vital.

Dedication

To my Dad, the best teacher I have had. He continues to teach me things that are important for my mind, but more importantly, those that are good for my heart.

In memory of my Grandmother, Mohinder K. Gill.

To them, I dedicate this thesis.

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Chapter 1

Introduction

Overview

Regardless of one's culture, social class, gender, or ethnicity, adolescence is a time of physical, psychological, and social change. Adolescence is also a time marked by the formation of self-concept, an integration of all aspects of self-knowledge (Bornholt, 2005; Shapka & Keating, 2005). A salient component of adolescents' self-concept is body image. Body image is a multifaceted construct that includes an individual's perceptions, thoughts, and feelings regarding one's body, particularly its appearance (Cash & Szymanski, 1995). While a healthy body image supports the development of a positive self-concept and improves self-esteem, body image dissatisfaction can lead to emotional problems such as depression and anxiety (Carlson Jones, 2004; Pruzinsky & Cash, 1990). Unfortunately, adolescence is often a time of dissatisfaction with physical appearance (Carlson Jones, 2004). Therefore, it is likely that this is a particularly sensitive time for adolescents who have a disfigured appearance. Kent (2003) found that youth who have a disfigurement often report more emotional problems than youth without disfigured appearances. These emotional problems can include depressed mood, heightened anxiety, low self-esteem, and low self-confidence. In this study, I will assess depressive symptoms, and perceived disfigurement severity in adolescents with a congenital deformity called *pectus excavatum*.

What is Pectus Excavatum?

Pectus Excavatum (PE) is the most commonly occurring congenital chest deformity. The incidence of PE is approximately 4 in every 1000 births, with a three to one male-female predominance, and variable severity (Saxena, Schaarschmidt, Schleef, Morcate, & Willital,

1999). The medical community has found familial incidences of this congenital deformity, however, the majority of cases of PE occur sporadically (i.e. Saxena, et al., 1999). In PE there is an abnormally small distance from the sternum to the backbone and the sternum is often twisted (Saxena, et al, 1999). As a result, the chest has a concave and often an asymmetrical appearance. The size and depth of the indentation varies from a few millimeters to several centimeters. Although limited research on the physiological effects, PE may coexist with physiological problems such as asthma and total lung capacity may be reduced by PE (Boas & Massery, 2005).

How is PE Corrected?

In recent years, the *Nuss* repair has become the preferred choice for the surgical correction of PE (Nuss, Kelly, Croitoru, & Katz, 1998). The Nuss method has replaced the more expensive and invasive surgical method, the *Ravitch* procedure (Nuss, et al., 1998). Unlike the *Ravitch*, the Nuss technique is a minimally invasive procedure, which requires no cartilage incisions, and no large entrance incision in the middle of the chest which in-turn creates a large lasting scar. In the Nuss procedure, small incisions are made on each side of the chest cavity through which a curved steel bar is inserted through the thoracic cavity. The bar is then rotated into position to force the ribs out of their concave formation. This steel bar is left inside the chest cavity for up to two years (Nuss, et al., 1998). In a qualitative study of a small number of youth who had undergone the Nuss surgery, researchers found that the youth were very satisfied with the results and perceived that it had changed their lives significantly (Roberts, Hayashi, Anderson, Martin, Maxwell, 2003). Unfortunately, there is little prospective pre-surgical psychosocial research on youth with PE. Although in post-hoc studies youth report improvement in social and emotional functioning because of surgery (Roberts et al., 2003) to

what degree is their perception of improvement due to their investment in the surgery (pain)?

Does the perception of the severity of PE affect their recollection of functioning prior to surgery?

In order to determine if the surgery improves psychosocial functioning, we first need to measure their functioning prior to the surgery.

Purpose of the Study

PE is an example of a *hidden deformity* because it is only visible when the chest is bare; in other words, affected persons can intentionally conceal it. This complicates the psychosocial factors associated with PE. As the longitudinal study proceeds, we will be assessing how perceptions of PE severity actually change the perceptions of the surgical outcome. However, before these questions are answered, we first need to understand pre-surgical emotional functioning. Is perceived severity or the actual physical severity more predictive of depressive affect? Are youth with PE more depressed than youth without PE?

To answer some of these questions the current study describes the affective functioning of youth with PE. Then it examines how youth with PE score on two commonly used measures of emotional functioning, the Child Depression Inventory (CDI) and the depression subscales of the Youth Self-Report (YSR) and by comparing this data with normative data (Kovacs, 1981; 1982; 1985; Achenbach & Rescorla, 2001). Additionally, the convergent validity of the CDI and the YSR will be evaluated; that is, to what extent do the two measures of depression correlate with each other? This study will describe the self-perceived severity of the PE that youth have and compare it to their actual PE severity as measured by the medically based Haller Index (HI), a criterion that surgeons use to stratify the severity of the deformities (Croitoru, Kelly, Goretsky, Lawson, Swoveland & Nuss, 2002). This index is a measure (in centimeters) of the distance between the sternum and the backbone. An index of greater than 3 or 3.2 is normally considered

to be a severe case of PE, and an HI of 3 is the common cut-off for eligibility of the Nuss (Boas & Massery, 2005; Croitoru et al., 2002). Specifically, I contrast the HI as a predictor of depressive symptoms with youth's perceptions of severity. In other words, is self-perceived severity a better predictor of depressive symptoms than actual PE severity (based on the HI)?

Chapter 2

Review of Literature

The Role of Appearance in Adolescence

Physical appearance provides immediate, uncensored information; from this external aspect of self, others may quickly attempt to assess age, gender, ethnicity, socio-economic status, and even personality. During adolescence, we become acutely aware that persons are valued by their appearance; and, as with any new understanding, the novelty of this awareness skews our beliefs about the importance and power of appearance. Of all age groups, adolescents are the most appearance-focused (Cash, Winstead, & Janda, 1986) and experience the greatest degree of body dissatisfaction (Pruzinsky & Cash, 1990). However, it would be an over-simplification to say that this dissatisfaction is only an adolescent problem; persons of all ages may wish for physical attributes they do not have while not seeing what they do have.

Is this normative discontent of appearance a phenomena without consequence? Research and social commentary suggests that body image has profound effects on emotional life and mental health. For example, negative body image is related to poor self-concept, social anxiety, shyness, social isolation, and depression (Pruzinsky & Cash, 1990).

Pruzinsky and Cash (1990) suggest that self-consciousness about appearance is uniquely public because it focuses on observable aspects of the self. In adolescence, this self-consciousness about what others can see can become acutely painful for several reasons. First, there is a new cognitive capacity to compare observations of self with abstract representations of a range of possibilities (comparisons to normative youth). Second, this age group is also the most concerned about not being too different in relation to peers regarding appearance (e.g., the adolescent wishes to be not *too tall* nor *too short*) (Cash, 1990). Third, the assumption that

others are thinking about them as much as they think about themselves; this results in the adolescent having an *imaginary audience* that is evaluating them (Elkind & Bowen, 1979). As a result, adolescence is a time driven by social comparisons, which may lead to negative self-consciousness and negative self-concept if the comparisons are not in their favour. Therefore, adolescence may be a particularly sensitive time to receive feedback competency from peers.

Self-consciousness that arises from physical appearance concerns may also negatively impact areas of competence which makes adolescents vulnerable to depressive affect. For example, Pruzinsky and Cash (1990) suggest that severe self-consciousness and pre-occupation with appearance may reduce their attention to others and interfere with their social interactions. This may produce a cycle in which excessive self focus produces social rejection, or fear of rejection, and feelings of social inadequacy, which in turn increases self-consciousness. Pruzinsky and Cash (1990) found that individuals who are highly self-conscious about their physical appearance often develop feelings of inferiority, and as their self-concept worsens, mild to moderate depression may occur.

A useful way of analyzing the effects of physical appearance on self may be to divide the perceptions of it into two distinct categories or views. One is physical appearance on a social level, based on social perceptions, from peers for example, and interpersonal interactions. Cash (1990) refers to this as the “view from the outside”. The other view or “view from the inside” entails the internal physical self-concept and body image that one maintains (Cash, 1990). This distinction is particularly important in this discussion because adolescents make social comparisons to judge their physical attractiveness, but these may not be the entire basis of their body image or physical self-concept. For example, an individual may be very attractive from other persons’ perspectives, but because of negative self-information *from the inside* they do not

have a positive body image. Having favorable feelings about personal physical attributes may be critical to the development of a healthy body image, positive self-esteem and social competence, regardless of how individuals actually appear to others. Therefore, the more attractive an individual feels the better their overall self-esteem and the higher the social competence levels are (Pruzinsky & Cash, 1990). Likewise, having negative feelings about one's appearance are often related to poor social competence. Therefore, although youth with PE can conceal their deformity, they may still experience low self-esteem, as their "view from the inside" includes their feelings about their deformity. The "view from the outside" or other's perceptions of their appearance can also add self-image stress; if the PE is not completely hidden, teasing and awareness that others may know can contribute to further psychological problems (Cash, 1990).

Youth with PE often experience teasing from peers if they do not conceal the deformity (Roberts et al., 2003), and those who are not teased may have the fear of their condition being discovered by peers and result in teasing. Both teasing and fear of teasing can have negative mental health outcomes, even in normative populations (Keery, Boutelle, Van Den Berg, & Thompson, 2005; Carlson Jones, Newman, & Bautista, 2005). Cash (1995) found adults who were teased about physical appearance in their youth may have worse body images as adults, than those who were not teased, or not teased as much. In addition, the severity, frequency, and emotional impact of teasing about appearance in youth are often related to negative body images in women.

Disfigured Appearance and Emotional Adjustment

Since the aforementioned research indicates that appearance concerns often cause distress in adolescents without disfigurement, appearance concerns are likely to be more severe in youth with disfigurement. There are three general causes of disfigurement: (a) congenital

malformations (e.g., PE), (b) traumatic events (e.g., burns, accidents), and (c) disease processes (e.g., vitiligo) (Thompson & Kent, 2001). Research by Kent (2002) shows that people with disfigurement report higher levels of emotional distress. Their emotional reactions include depressed mood, heightened anxiety, low self-esteem, and low self-confidence. Behaviorally, people with disfigurements may avoid social situations; and they often report negative beliefs about themselves and their appearance.

The notion of cognitive schema is particularly important in individuals who have a disfigured appearance. This construct refers to a mental representation of the self that serves to organize and process incoming information (Kent, 2002). The schemas of a disfigured individual are important to the way they process stigmatization. Individuals with disfiguring conditions may be stigmatized or face actual incidences of rejection; consequently, it is the *felt* stigma (expectations of rejection) that are detrimental. Vigilance and constant expectation of rejection increases self-consciousness and lowers self-esteem and confidence (Kent, 2002). For example, Kent (1999) found that patients with a skin disorder, vitiligo, who believed that they were stigmatized, were more likely to recall events of actual stigmatization and incidents of felt stigma. It may be argued that because vitiligo is a visible disfigurement, the appearance-related stress and reactions are much different than those with a hidden deformity, such as PE. While the visibilities of deformities vary, youth who have hidden deformities may have fears of exposure. In fact, research by Roberts et al. (2003) suggests that youth with PE frequently conceal their deformity (i.e. some youth with pectus will not take off shirts when swimming and many layer their clothing so the indentation is less visible). Fear of exposure is likely to create appearance preoccupation and rumination about the imagined consequences of exposure of their funnel chest.

Rumination in and of itself may contribute to a variety of emotional and adjustment problems such as anxiety disorders and depression. Elkind and Bowen (1979) hypothesized that a developmental characteristic of adolescence is poor differentiation between their own thoughts and preoccupations and what others are thinking. Therefore, although PE is a hidden deformity, adolescents with PE may believe that it is more apparent than it is, and that it influences other's assessment of their appearance than it actually is. From a developmental perspective, this *imaginary audience* would intensify the self-consciousness that older or younger persons with PE would feel.

Romantic interest is a normal part of adolescence, (Buhrmester & Furman, 1987), but with it adolescents with PE may experience intensified appearance and intimacy concerns. For example, the breasts in females with PE are often poorly aligned (depending on the severity of the condition), which would only be apparent in intimate situations. These issues may cause additional stress and fear of rejection by the opposite sex.

All of these issues make it likely that the perceived severity, not actual severity, of adolescent's PE may be a better predictor of an unhealthy body image and low self-esteem. It is for this reason, that the proposed research will compare the influence of perceived severity of PE, as determined by the feelings of the youth, to a measure of actual severity, the Haller Index. Although there are a variety of emotional problems that may arise in individuals who have a deformity, the current research will examine the role that depressive affect plays in youth with PE.

Appearance and Emotional Functioning: Depressive/Anxious Affect

As hypothesized above those who ruminate most about appearance, that is, those who worry the most about their appearance may have more depressive symptoms if the self-

consciousness is significant. What is the relationship between physical appearance and depressive affect?

Beck's model of depression (1973) postulates that depressed individuals have negative views of themselves, the world, and the future. According to this model, depression is characterized by negative self-schemata (Beck, 1973). This supports the prediction that poor body image and heightened appearance self-consciousness may play a role in depression (Gotlib, Lewinsohn, Seeley, Rohde, & Redner, 1993). In particular, Beck hypothesized that depressed people have negatively distorted body images (Beck, 1973). The results of Noles, Cash and Winstead's (1985) study on appearance and depression support this hypothesis. In their investigation, Noles et al. (1985), hypothesized that depressed individuals will be less satisfied with their physical appearance, and will think of themselves as less physically attractive than non-depressed subjects. They found that depressed individuals underestimated their physical attractiveness and were less satisfied with their appearance than non-depressed individuals. Objective raters did not rate the depressed individuals as less attractive; the depressed persons had lower positive body images and were less satisfied with their overall physical appearance. Although causal inferences could not be made given the design of this study, another study found that youth who were happiest were also more likely to rate themselves as attractive teenagers (Berscheid, Walster & Bohrnstedt, 1973). This study did not tackle the issue of clinical depression, but both studies suggest a relationship between happiness and self-perceived appearance competence.

Consistent with Cole's (1991) competency-based model of depression in children, Cole, Martin, and Powers (1996) found low perceived appearance competence to predict depression over a six-month period. These studies support the idea that adolescents' significant public self-

consciousness about physical appearance may contribute to the development of depression (Cash, 1990).

In a study on emotional problems and self-competence, Ohannessian, Lerner, Lerner and Von Eye (1999) found that adolescent girls who have higher levels of perceived physical appearance, (using Harter's SPPC), had lower levels of anxiety. Similar results were found by Ohannessian et al., (1999) in boys where higher levels of perceived physical appearance were related to lower levels of emotional problems. This research also suggests that having poor self-images may be related to depression, anxiety and perhaps other emotional disorders. As previously discussed, the emotional problems that are associated with low perceived appearance may be more pronounced in youth who have disfigurements. Ohannessian et al. (1999) found that self-consciousness and self-esteem were specific psychosocial variables in adolescents with depression. In particular, depressed adolescents were more self-consciousness and had lower self-esteem than adolescents who had no psychopathology (Lewinsohn, Gotlib, & Seeley, 1997).

All of the aforementioned studies support the importance of self-perceived appearance in the development of depression or anxiety problems. The studies suggest that low self-perceived physical appearance may be one of the factors that leads to higher self-consciousness and lower self-esteem levels. High self-consciousness and low self-esteem may interact to produce depression and anxiety problems.

Need for Further Research

As outlined, significant research has been conducted on the appearance concerns in normative development in youth, and research in the area of deformity has received attention in recent years. However, no research has been done on the physical appearance concerns in youth who have PE. Further, there has been limited research on the role that depression plays in youth

who have deformity, and no research on the presence and impact of depression in youth with PE. Is the actual severity of PE a significant predictor of depressive symptoms? Do the self severity perceptions predict depressive symptoms in youth with PE? Are youth with PE more depressed than youth without PE? This study examined these research questions.

Chapter 3

Method

Design Overview

The current study was a cross-sectional analysis of the first wave of a larger longitudinal study of youth with PE who sought corrective surgery for their condition. The participants live in Victoria, Vancouver, or Calgary and were referred to the study by one of three participating surgeons. The larger study involves two waves of data collection before surgery, and then post-surgery waves at six months, one year, and two years following surgery.

Sample Characteristics

The 28 participants (22 boys and 6 girls) in the current study represent the entire surgery-eligible Pectus Project sample at the time of these analyses. Participants ranged from 12 and 17 years of age (mean = 16) and were predominantly Caucasian (26), with one being of East Indian and another Chinese decent.

Measures

1. *Perceived Severity of PE*: (Martin, 2003). This 4-item scale was designed for the larger longitudinal project by the principal investigator. We asked participants to rate the severity of their PE on a scale of 0 to 10, where 0 represents a normal chest and 10 represents a severe deformity. This questionnaire also asked the youth to indicate how they believed girls their age, boys their age, and their teachers would rate the severity of their PE. Only the self-perceived severity (first item) was assessed in this study (See copy in Appendix A).
2. *Depressive Symptoms*: The Children's Depression Inventory (CDI) (Kovacs, 1981; 1982; 1985) is a widely used 27-item self-report measure of children's depressive symptoms. The CDI is designed for ages 6-17. Each item contains three statements, scored 0, 1, or 2 in order

of increasing severity. Psychometric studies of the CDI suggest that the measure has relatively high levels of internal consistency (i.e. Cole et al, 1997 determined $\alpha = .90$), test-retest reliability, and predictive, convergent, and construct validity (Carey, Faulstich, Gresham, Ruggiero, & Enyart, 1987; Kovacs, 1985) (Appendix B).

3. *Depressive Symptoms*: The “Youth Self-Report” (YSR) (Achenbach & Rescorla, 2001) is a widely used self-report instrument used to derive ratings of behavioral and emotional problems. The YSR is designed for ages 11 to 21 and consists of 112 items. There are 8 problem subscales in the YSR; the current study utilized the anxious/depressed and withdrawn/depressed subscale (see Appendix C for items in each subscale). Youth self-report whether now or within the past 6 months they have experienced any of the target problems, using a 3-point scale: 0 (*not true or not at all*), 1 (*sometimes or somewhat true*), and 2 (*very true or often*) (Achenbach & Rescorla, 2001).
4. *Haller Index*: The Haller Index (HI) is a measure of the distance between the sternum and the backbone. An index of greater than 3 or 3.2 is normally considered to be a severe case of PE (Boas & Massery, 2005; Croitoru et al., 2002). Usually the referring surgeons provided a HI when they referred their patient to the pectus project. HI were unavailable for 5 participants. Of the 23 participants with available HI data, 17 had a HI above 3.2 which is the common medical standard for surgery eligibility (Daunt, Cohen & Miller, 2004). The entire sample’s mean HI was 4.12 (SD = 1.27, n = 23).

Procedure

Once a diagnosis and treatment decision had been made, the surgeon described the University of Victoria longitudinal study to the patient and asked if they would like to receive more information about it (see Appendix D for the guidelines surgeons use to introduce the study

to the patients). If the patient agreed or sought out more information, their contact information was provided to the University of Victoria researchers. Research assistants then contacted potential participants to describe and answer questions about the *Pectus Project*, a longitudinal study of the psychosocial effects of living with this congenital deformity. The research team provided patient's family with detailed information about the study; if the patient and parent(s) agreed to participate, we informed them of their rights and responsibilities and obtained written consents (see appendix E). Participants received \$20.00 for each wave of questionnaires as a stipend for their time and travel. We explicitly reminded patients that non-participation would not affect the availability or quality of their health care

Ethical Considerations

As the current study is part of a larger, longitudinal study at the University of Victoria, the university Human Subjects Committee has granted ethical approval. Ethics review was also provided by the hospitals and universities associated with each participating surgeon (i.e. Alberta Children's Hospital-University of Calgary, B.C. Women and Children's Hospital-University of British Columbia). This ethical approval includes clearance for the present study and an amendment adding myself as a co-researcher (see Appendix F). At each phase of the study, researchers again reminded participants of their rights, including their right to refuse to answer any questions they are uncomfortable with.

Research Questions and Treatment of Data

Preliminary data analyses. Prior to hypothesis testing, I examined the data for outliers and data entry errors by plotting each variable's distribution and examining their bi-variate correlations. I also assessed the convergent validity of the CDI and the YSR by examining the strength of their intercorrelation.

Primary data analyses. I conducted two sets of data analyses. First, I compared youth with PE with normative data from published norms and manual for the CDI and the Achenbach anxiety/depressed and withdrawn/depressed subscales. Second, I regressed depressive symptoms onto the Haller index and self-perceptions of PE severity.

The depressive affect of youth with PE compared to normative data. First, to determine how youth with PE compare to normative data on youth without PE, I conducted a series of z-tests. Normative scores for the CDI were taken as approximations of several studies that have normative data on the CDI (Craighead, Smucker, Craighead & Illardi, 1998; Craighead, Curry, & Illardi, 1995). Likewise, the validation and norming samples for the Achenbach depression subscales were used from the YSR manual (Achenbach & Rescorla 2001). Participants were matched with norms for youth of the same age group and gender.

The second set of analyses regressed depressive symptoms in youth with PE onto the Haller index and self-perceived severity. This analysis allowed me to compare a physiological index of malformation (Haller Index) to self-perceptions of severity as predictors of depressive symptoms.

Chapter 4

Results

Preliminary data analyses

Outliers

An outlier is an extreme score on a given variable (Tabachnick & Fidell, 2001). Outliers are problematic in research because in they can disproportionately influence the results (i.e. skew the results of the statistical analyses). Reasons for outliers can include data entry errors, inappropriate sample heterogeneity, and participant response errors. One way to detect outliers is to use graphical methods; if a case seems unattached to the distribution of the rest of the data, it may be an outlier. I examined the data for outliers by plotting distributions and examining unattached distributions. One case initially appeared to have an outlying HI value, which upon investigation was determined to be a data entry error. On the depression measures, there were a few cases with very high scores (i.e. scores on the CDI that ranged from 17.65 - 30). Although these scores may be outliers relative to others in the sample, their scores are consistent across other measures of the same constructs. The extreme scores they exhibit do not appear to be due to chance or error; for this reason they are retained in the analyses. (Refer to Appendix G for scatterplots that show the consistency of outliers across measures).

Missing Data

Since the current sample is relatively small ($n = 28$), I used pairwise deletion of missing data (cases are excluded only from calculations that actually involve the missing variable) rather than casewise deletion (only participants with complete data are retained) (Tabachnick & Fidell, 2001).

Testing Convergent Validity

Bi-variate correlations among the depression measures were computed to evaluate the convergent validity of the CDI and the YSR; in other words, correlations were used to test for significant and meaningful covariance between measures purporting to measure the same construct.

Table 1

Correlation Matrix for All Measures

	Haller Index	Self-Perceptions of PE Severity	Children's Depression Inventory	YSR (withdrawn/depress ed)	YSR (anxious/de ed)
Haller Index n = 23	1.0				
Self- Perception of PE Severity n = 15	.10	1.0 n=20			
Children's Depression Inventory N=23	.14	.71** N=20	1.0 n=28		
YSR (withdrawn /depressed) N=21	.18	.67** N=18	.84** N=25	1.0 n=25	
YSR (anxious/de pressed) N=21	.13	.87** N=18	.65** N=25	.68** N=25	1.0 N=25

Note: ** Correlation is significant at the 0.01 levels (2-tailed).

All three measures of depressive affect, the two YSR subscales and the CDI, were strongly related to each other with intercorrelations ranging from .65 to .87 (See Table 1). Self-perceptions of severity were also highly correlated with the depression measures (ranging from 0.67 to 0.87), but not with the HI, a medical measure of severity. The HI was not significantly correlated with any measure of depressive affect. (Refer to Appendix H for scatterplots illustrating these correlations.)

Primary data analyses

I conducted two sets of data analyses. The first set focuses on determining how the sample of youth with PE compares to normative scores for youth on the CDI and the YSR anxious/depressed and withdrawn/depressed subscales. The second set uses linear regression to understand the relation of depression with perceived versus medically determined PE severity in youth with PE.

The depressive affect of youth with PE. A series of z-tests compared the current sample to published norms for the CDI and YSR depression scale (treated as population means). Commonly used CDI (Craighead, Smucker, Craighead & Illardi, 1998; Craighead, Curry, & Illardi, 1995) and Achenbach (Achenbach & Rescorla, 2001) validation and norming scores provided the normative means and standard deviations. Comparison groups were matched by age and gender for the Achenbach subscales; however, this information was not available for the CDI

For each comparison I performed a Z-test of the difference between the PE sample and its corresponding normative sample. Appendix I shows the Z-test formulas and calculations for effect sizes (ES).

Boys in the pectus sample had significantly higher YSR anxious/depressed scores ($z = 3.49$, $p < .05$, $ES = 0.78$) and YSR withdrawn/depressed scores ($z = 2.69$, $p < .05$, $ES = 0.60$) than did the corresponding normative groups. Although the sample size ($n = 5$) is not a large enough representative of girls with PE, z-tests for girls were computed as well. When compared to normative data on girls, there were no significant differences on both the YSR anxious/depressed ($z = 1.35$, $p > .05$, $ES = 0.58$) and the YSR withdrawn/depressed ($z = 1.35$, $p > .05$, $ES = 0.58$). PE sample and normative means and standard deviations are shown in Table 2.

Since normative data was only available for both boys and girls, girls were included in the analyses for the CDI. Boys and girls in the pectus sample did not have had significantly higher CDI scores ($z = 0.88$, $p > .05$, $ES = 0.20$) than the boys and girls in the corresponding normative group. PE sample and normative means and standard deviations are shown in Table 2

Table 2

Means (Standard Deviations) on the CDI scale, YSR-anxious/depressed subscale, and YSR-withdrawn/depressed subscale for the current study's PE sample and Normative samples.

	Children's		YSR		YSR	
	Depression Inventory		(anxious/depressed)		(withdrawn/depressed)	
	PE	Normative	PE	Normative	PE	Normative
	Participants	Sample	Participants	Sample	Participants	Sample
Boys	9.79 (7.88)	-	5.74 (3.60)*	3.4 (3.0) ²	4.15 (3.45)*	2.7 (2.4) ⁴
	N = 23		N = 20		N = 20	
Girls	11.21 (8.67)	-	7.40 (3.78)	5.1 (4.0) ³	4.54 (3.82)	3.1 (2.5) ⁵
	N = 5		N = 5		N = 5	
Boys	10.38 (8.55)	9.0 (7) ¹	6.07 (3.68)	-	4.23 (3.45)	-
&	N = 28		N = 25		N = 25	
Girls						

Notes: * = $p < .05$ that the difference between the PE sample and its corresponding normative sample is significant; ¹ Data taken from Craighead, Smucker, Craighead & Illardi, 1998; Craighead, Curry, & Illardi, 1995; ² Data on 11-18 year old boys taken from Achenbach and Rescorla, 2001; ³ Data on 11-18 year old girls taken from Achenbach and Rescorla, 2001; ⁴ Data on 11-18 year old boys taken from Achenbach and Rescorla, 2001; ⁵ Data on 11-18 year old girls taken from Achenbach and Rescorla, 2001.

Prediction of depressive symptoms in youth with PE. To determine whether perceived severity mediates the relation between depression and a physiological index of malformation (Haller Index), I computed the following set of regression equations for each of the three measures of depression (CDI, YSR anxious/depressed, and YSR withdrawn/depressed).

$$\text{(Model 1) } Y_{\text{cdi}} = \beta_0 + \beta_{\text{Haller}}$$

$$\text{(Model 2) } Y_{\text{cdi}} = \beta_0 + \beta_{\text{Perceived Severity}}$$

$$\text{(Model 3) } Y_{\text{cdi}} = \beta_0 + \beta_{\text{Haller}} + \beta_{\text{Perceived Severity}}$$

$$\text{(Model 4) } Y_{\text{cdi}} = \beta_0 + \beta_{\text{Haller}} + \beta_{\text{Perceived Severity}} + \beta_{\text{Haller}} \times \beta_{\text{Perceived Severity}}$$

Equations 1 and 2 test for the significance of the relation between the Haller and Perceived Severity measures respectively with the depression outcome measure (in this case the CDI). Equation 3 tests the combined relation of the Haller and Perceived Severity with the depression outcome measure. Finally, Equation 4 tests the combined relation of the Haller by Perceived Severity interaction and its component main effects with the depression outcome measures. If perceived severity mediates the relation between actual physical severity and the measure of depressive symptoms the interaction between the two predictors should be significant.

Independently (Model 1), the Haller Index was not a significant predictor of the CDI, the YSR anxious/depressed, or YSR withdrawn/depressed scales. Self-perceived severity was a significant predictor of all three measures of depressive symptom scales (Model 2); the CDI ($\beta_{\text{CDI}} = .706, p = .001$), the YSR anxious/depressed ($\beta_{\text{YSR anxious/depressed}} = .868, p = .000$), and the YSR withdrawn/depressed ($\beta_{\text{YSR withdrawn/depressed}} = .672, p = .002$). In other words, the actual severity of the PE is not a predictor of depressive affect, however, the self-perception of severity is a significant predictors of depressive affect.

Joint regression of the Haller and self-perceived severity onto each of the three measures of depressive symptoms (Model 3) mirrored the results of the single predictor models (Models 1 and 2). The Haller was not a significant predictor of depressive symptoms on either the CDI, the YSR anxious/depressed, or YSR withdrawn/depressed. In contrast, the CDI ($\beta_{\text{CDI}} = .70$, $p = 0.00$), the YSR anxious/depressed ($\beta_{\text{YSR anxious/depressed}} = 1.05$, $p = 0.00$), and the YSR withdrawn/depressed ($\beta_{\text{YSR withdrawn/depressed}} = .66$, $p = 0.01$) were all significantly predicted by the self-perceived severity measure. Within this small homogeneous sample, depression appears unrelated to the physical severity of youth's PE, while it is significantly related to their perception of their deformity.

Inclusion of the interaction of physical severity (HI) with perceived severity (see model 4) produced mixed results depending upon the measure of depressive symptoms used. For prediction of the CDI and the YSR withdrawn/depressed the interaction terms were not significant. In contrast, for the prediction of the YSR anxious/depressed, the interaction term was significant ($\beta_{\text{YSR anxious/depressed}} = -.37$, $p = 0.04$). Figure 1 presents a graph illustrating the direction of the interaction. Youth's self-perception of severity mediates the relation between the actual severity of their PE and the depressive symptoms. Overall, the findings suggest that rather than the objective severity (HI), the self-severity perceptions are the predictors of depressive affect on all measures used. The YSR anxious/depressed measure was the only measure where an interaction effect was found between the actual severity and the self-perceived severity. Table 3 presents the final model for each regression equation: model 4 for the YSR anxious/depressed, and model 3 for the YSR withdrawn/depressed and CDI.

Table 3

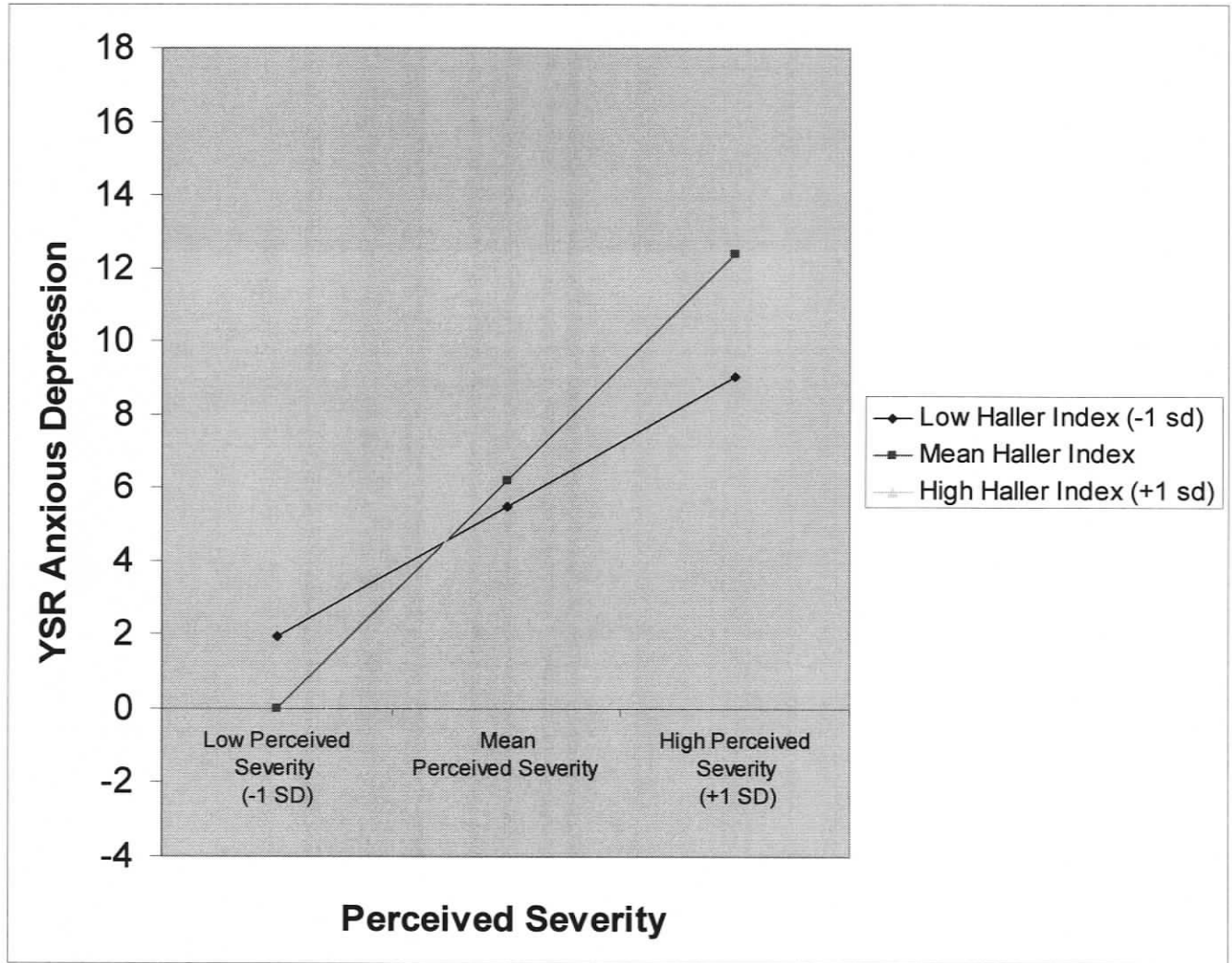
Summary of Regression Analyses Predicting CDI, YSR anxious/depressed, and YSR withdrawn/depressed.

	B (SE)	β	T	R ²
<i>Predicting YSR withdrawn/depressed</i>				
Intercept	4.23 (.73)	--	5.77***	
Haller Index	0.39 (.77)	0.11	0.51	
Self-Perceived Severity	2.28 (.77)	0.66	2.98***	0.465
<i>Predicting YSR anxious/depressed</i>				
Intercept	6.20 (.44)	--	13.97***	
Haller Index	0.57 (.49)	.16.	1.16	
Self-Perceived Severity	3.82 (.55)	1.05	6.96*	
Haller by Self-Perceived Severity	-1.28 (.55)	-.37	-2.31*	0.84
<i>Predicting CDI</i>				
Intercept	10.38 (1.68)	--	6.18***	
Haller Index	0.57 (1.74)	0.07	0.33.	
Self-Perceived Severity	5.98 (1.74)	.70	3.42***	0.50

* $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$

Figure 1

Graph of Interaction on the YSR anxious/depressed Measure



Chapter 5

Discussion

The findings suggest that youth with PE have significantly higher depressive affect than normative groups on the YSR measures, but not the CDI. The HI was not a significant predictor of the depressive affect on the CDI and the YSR withdrawn/depressed subscale; however, an interaction effect was found between the actual severity and the self-perceived severity on the YSR anxious/depressed measure. Therefore, self-perceptions mediate the relation between the HI and the anxious/depressed symptoms. In sum, the current study found that regardless of how severe the actual deformity is, the perception of severity of PE is more important than the actual severity that is measured physiologically. At present, there is no psychological criteria when determining eligibility for surgery; rather, an arbitrary HI is used (i.e. currently a Haller Index of approximately 3.2 is used by most surgeons). No statistical difference was found between the girls with PE and the girls in the normative group; this may be due to sample size limitations. However, the 5 girls in the PE sample are not representative of the population of girls with PE, but were representative for the sample since PE occurs more commonly in boys (Saxena et al., 1999; Boas & Massery, 2005).

This study found that all three measures of depressive affect, the two YSR subscales and the CDI, were strongly related. The three measures of depressive affect appear to measure the same underlying construct' and supports convergent validity. That is, all three measures are highly correlated (i.e. if an individual has a high depression score on the CDI, he or she is likely to have a high score on the YSR subscales). The self-perceptions of severity were highly correlated with all three depression measures, but not with the HI, a medical measure of severity. The HI was not significantly correlated with any of the three measures of depressive affect. This

suggests that actual severity, as measured by the HI, may not be a factor in the presence and impact of depressive symptoms, but the self-perceptions are. The findings from these analyses were confirmed with the regression analyses; the self-perceptions were statistically significant predictors of depressive affect, and the HI was not. The importance of self-perceptions is illustrated by characteristics of individuals with body dysmorphic disorder (BDD). BDD occurs when individuals without any defect are distressed about some part(s) of their physical appearance. The distress leads to a preoccupation with the appearance concern and if this preoccupation is excessive, social avoidance may occur (Phillips, 1998; Rosen, Reiter, Orosan, 1995). Therefore, the self-perceptions often determine how individuals with and without physical defects feel about themselves.

To an extent, it is normative for adolescents to be dissatisfied with certain parts of their appearance. For example, adolescence is a time of pubertal transition that is accompanied by physical changes such as acne, and weight changes (Levine & Smolak, 2002). Since these physical changes are often sudden and may be embarrassing, youth may report dissatisfaction with their physical appearance. Although many youth have normative discontent, if this concern is excessive, there may be negative consequences (i.e. low self-esteem, negative body image, depression and anxiety.. The results of the current study are supported by research that has consistently found that youth with deformity may be more distressed about their appearance (Kent, 2002; Rumsey, 2002; Pruzinsky, 2002). As a result, youth with deformity are more likely to suffer the adverse affects of self-consciousness, such as depression and anxiety problems (Thompson & Kent, 2001).

Limitations and Need for Future Research

In the current study, there are a few caveats that future studies may improve on. First, the sample size of 28 may have decreased the power of the analyses. A small sample increases the probability of making a type II error (Tabachnick & Fidell, 2001). Since some of the analyses were dichotomized by gender, the sample size was decreased on these analyses. In particular, since there were only five girls for some of the analyses, this limitation may have affected the results; in particular, if there were more girls, there may have been a difference between girls with PE and girls without PE. .

In addition, although the self-perceptions were predictors of depressive affect on all three depression measures, a statistically significant difference was not found between the normative group and the PE group on the CDI. Since the CDI is highly correlated with both YSR subscales, it is surprising that significance was not found as it was in the two other depression measures. This may be because the CDI has less specificity than the YSR. The YSR differentiates anxious symptoms of depression from withdrawn (see Appendix C for list of items on the YSR); in contrast, the CDI includes all symptoms. The YSR anxious subscale may be more sensitive to depression in youth with PE because of the possible social anxiety, embarrassment, and fear of exposure that youth with PE may experience. Constant rumination and fears of exposure are more characteristics of a depression with anxiety, rather than withdrawn traits. Research has found that anxiety symptoms often occur before depressive symptoms (Cole, Peeke, Martin, Truglio & Seroczynski, 1998). It is possible that in the current sample the youth with PE had more anxious/depressive symptoms. Also, the CDI scores for both boys and girls were compared to gender specific normative data. However, since there were more boys ($n = 23$) than girls ($n = 5$), this may have affected the analyses and why a difference

was not found on this measure. If data on the CDI were separated for boys and girls, the results may have differed. In addition, to increasing the sample size, future studies may be improved by not only having more participants, but having somewhat equal groups of boys and girls for comparison analyses.

The findings suggest that for two of the measures (CDI and YSR withdrawn/depressed) the self-perception did not mediate the relationship between the HI and depressive affect. In contrast, the self-perceptions of severity do mediate the relation between the HI and the YSR anxious/depressed subscale. Why is the HI unrelated to the CDI and the YSR withdrawn/depressed measures? One reason may be because the PE group is quite homogenous in terms of their HI because it was used to determine eligibility (i.e. only youth who were candidates for surgery were referred to the study). However, the self-perceived severity item has a broader range of scores as it was not a selection factor for surgery. The interaction on the anxious/depressed subscale was strong enough to appear despite these potential range restriction problems. This may have implications for the role of anxiety in youth with PE. For example, youth with more severe PE may be more anxious about their PE, use more camouflaging techniques, or may ruminate more about their PE than youth with lower HI. This potential restriction of range issue may have affected the results for the other two measures.

The current study only assessed the first of two waves from pre-surgery data because sufficient data was not available at the time of analyses from the second pre-surgery wave. Although this does not have a negative impact on the results, (i.e. in terms of missing data) future studies may wish to include both waves in the analyses. This will provide us with information on how stable the depressive states are in youth with PE.

An important future research question is whether or not there are any differences from the pre-surgery emotional functioning of youth with PE and post-surgery functioning. If youth's psychosocial functioning improves following surgical repair of PE, then it follows that this may be important information for surgeons, especially when considering candidacy for the surgery. Although the current study only examined pre-surgery data, the results suggest that the perceptions youth have about their PE are more likely to determine depressive or anxious symptoms than the objective physiological severity of their PE. But it does not necessarily follow that surgical correction of pectus excavatum will automatically ameliorate either youths' depression or negative perceptions of themselves. We need to understand the psychological factors that contribute making corrective surgery for congenital deformities successful. For example, youth who have a high degree of appearance investment may have higher expectations following surgery; there may be psychological effects of not meeting these expectations (i.e. regardless of correction of disfigurement, the youth may always feel that he/she is not "normal") (Pruzinsky, 2002). Further research is also needed on the psychological effects of living with a hidden deformity such as PE, and visible disfigurements such as vitiligo, burns, etc., and changes in these effects after corrective surgical procedures (Pruzinsky, 2002).

Only patients who have PE and were candidates for the Nuss surgery were included in this study. Eligibility for surgeries is decided by surgeons by using a particular Haller Index cut-off (i.e. 3.2) (Boas & Massery, 2005). I expect persons who have PE but are not eligible for surgery to have similar appearance concerns and similar depressive symptoms as those who will undergo the Nuss procedure. Future studies may include youth who are not eligible or opt not to have the surgery, but have PE. However, it is possible that those who choose not to have surgery, regardless of the HI, do not perceive their PE to be severe. Studying this group could

provide additional information on the emotional functioning of youth with PE. Do youth with PE who decide to have surgery show more depressive symptoms than youth who have PE but do not have surgery? Are youth with PE who are not eligible for surgery (i.e. do not have a particular HI) more depressed than those who are eligible? For example, youth with deformity may feel a sense of being “born broken” and having a condition that cannot be corrected may cause additional stress for youth. Are there are psychological advantages from surgery? Or, do individuals who undergo surgery continue to feel self-consciousness, anxiety, depression or other emotional problems? Are there improvements only after the bar has been removed, or do the improvements take place as soon as change is made to appearance? Overall, more longitudinal research is needed to ascertain whether having corrective surgery results in psychological improvements (Phillips, 1998, Boas & Massery, 2005).

This study may have been limited culturally, as the majority of the participants were Caucasian and from North American culture. For example, in North American culture, appearance is overemphasized; thinness is valued for females and muscular builds for males (Jackson, 2002). Other cultures may not value thinness as much; in fact, in countries where food is scarce, thinness is not favored and the obese are not viewed unfavorably as they are in Western societies (Jackson, 2002). In addition to body preferences, there are differences in what cultures perceive as attractive (Altabe & O’Garo, 2002). Media influences, that many youth are exposed to often further this ideal depiction of beauty. Adolescents often compare themselves to unrealistic media depictions of attractiveness; this “upward” comparison can decrease self-esteem and increase self-consciousness (Levine & Smolak, 2002).

The normative data that was used in the analyses was derived from American populations, and the measures were American; the participants in this study were from

Vancouver, Calgary and Victoria. Therefore, demographic differences may have caused slight differences in the results. Further, since the majority of the participants in the study, and several of the analyses consisted of male adolescents only, the results may be more generalizable to males with PE. Future studies may be informative if more female participants were included, as their self-perceptions and emotional functioning may be much different than males. Research has found that females often have more concerns with physical appearance and often have more body image related problems than males, and females with this chest wall deformity may be more adversely affected than males (Striegel-Moore & Franko, 2002).

The current study examined depressive affect and perceptions of severity, using one measure. Future studies may wish to examine other aspects of self-perceptions that may provide additional information of the self-concepts of youth with PE. For example, the study could measure the extent that youth with PE hide their chest, or how comfortable they feel disclosing their deformity. Factors such as rumination, preoccupation and camouflaging may provide additional, albeit indirect information about self-perceived severity, self-consciousness, anxiety or depressive affect.

Other issues that contribute to negative self-perceptions may also be related to depressive affect. Adolescents are at an age where social comparisons are often made and others' opinions (especially peers) may be important to their own opinions (Levine & Smolak, 2002). Therefore, if friends or family members place importance on appearance and attractiveness, this social pressure may contribute to negative self-perceptions, and consequently negative affect. In fact, the research on teasing has found that youth who are teased about their appearance have more emotional problems than youth who are not teased (Cash, 1995; Keery, Boutelle, Van Den Berg, & Thompson, 2005; Carlson Jones, Newman, & Bautista, 2005). Therefore, factors like teasing

and family importance on attractiveness may affect self perceptions and the emotional functioning of the youth with PE. Future studies may include measures of these issues to examine how factors moderate self-perceptions and negative affect in youth.

Implications and Anticipated Contributions

The current study contributes to our understanding of the psychosocial status of youth with the hidden disfiguring condition of PE. In particular, this research will allow researchers a deeper insight into behavioral, emotional, and appearance related issues that youth with PE experience. These issues include the appearance concerns and self-perceptions about appearance that youth with PE have, as well as the presence and impact of depressive symptoms. In addition, this research is the first to examine the presence of these issues in youth with PE.

The long-term goal of the current study and the subsequent longitudinal research will be to provide surgeons and policy makers with a better *psychological* understanding of when the Nuss corrective surgery is appropriate. This is in contrast to the current sole reliance on physiological measures such as the HI. In addition, while retrospective research has been conducted on the benefits of the Nuss procedure (i.e. Roberts et al., 2003), no prospective pre-surgery psychosocial research has been conducted on youth with PE.

Overall, this data supports the consideration of social-emotional functioning when parents, surgeons, and youth are deciding whether to pursue corrective surgery. This research provides parents, surgeons, and researchers with a better understanding of the psychosocial effects of having this condition; the perceptions that youth have about their PE are more important than the objective severity that is measured physiologically.

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Appendix A
Perceived Severity of PE

We need your opinion.....

Instructions: We can get objective physical information about your chest from your physician, but often this doesn't tell us the whole story. So, we would like your perspective.

1. Could you rate your perception of the severity of your chest deformity on the following scale?

A Normal Chest

A Severe Deformity



2. If boys at school knew about your chest, how do you think they would rate it?

A Normal Chest

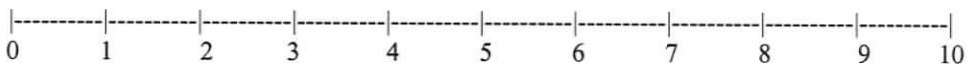
A Severe Deformity



3. If girls at school knew about your chest, how do you think they would rate it?

A Normal Chest

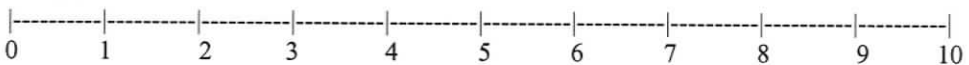
A Severe Deformity



4. If your teachers or other adults knew about your chest, how do you think they would rate it?

A Normal Chest

A Severe Deformity



Appendix B

The Children's Depression Inventory

Instructions: Please pick **ONE** sentence from each group that best fits you for the *past two weeks*. There are no right or wrong answers. Just be as honest as possible.

- | | |
|--|---|
| <p>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.</p> | <p>15. <input type="checkbox"/> I have to push myself all the time to do my schoolwork.
 <input type="checkbox"/> I have to push myself many times to do my school work.
 <input type="checkbox"/> Doing schoolwork is not a big problem.</p> |
| <p>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.</p> | <p>16. <input type="checkbox"/> I have trouble sleeping every night.
 <input type="checkbox"/> I have trouble sleeping many nights.
 <input type="checkbox"/> I sleep pretty well.</p> |
| <p>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.</p> | <p>17. <input type="checkbox"/> I am tired once in a while.
 <input type="checkbox"/> I am tired many days.
 <input type="checkbox"/> I am tired all the time.</p> |
| <p>4. <input type="checkbox"/> I have fun doing many things.
 <input type="checkbox"/> I have fun doing some things.
 <input type="checkbox"/> Nothing is fun at all.</p> | <p>18. <input type="checkbox"/> Most days I do not feel like eating.
 <input type="checkbox"/> Many days I do not feel like eating.
 <input type="checkbox"/> I eat pretty well.</p> |
| <p>5. <input type="checkbox"/> I am bad all the time.
 <input type="checkbox"/> I am bad many times.
 <input type="checkbox"/> I am bad once in a while.</p> | <p>19. <input type="checkbox"/> I do not worry about aches and pains.
 <input type="checkbox"/> I worry about aches and pains many times.
 <input type="checkbox"/> I worry about aches and pains all the time.</p> |
| <p>6. <input type="checkbox"/> I think about bad things happening to me once in awhile.
 <input type="checkbox"/> I worry that bad things will happen to me.
 <input type="checkbox"/> I am sure that terrible things will happen to me.</p> | <p>20. <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.</p> |
| <p>7. <input type="checkbox"/> I hate myself.
 <input type="checkbox"/> I do not like myself.
 <input type="checkbox"/> I like myself.</p> | <p>21. <input type="checkbox"/> I never have fun at school.
 <input type="checkbox"/> I have fun at school only once in a while.
 <input type="checkbox"/> I have fun at school many times.</p> |
| <p>8. <input type="checkbox"/> All bad things are my fault.
 <input type="checkbox"/> Many bad things are my fault.
 <input type="checkbox"/> Bad things are not usually my fault.</p> | <p>22. <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.</p> |
| <p>9. <input type="checkbox"/> I do not think about killing myself.
 <input type="checkbox"/> I think about killing myself but would not do it.
 <input type="checkbox"/> I want to kill myself.</p> | <p>23. <input type="checkbox"/> My schoolwork is alright.
 <input type="checkbox"/> My schoolwork is not as good as before.
 <input type="checkbox"/> I do very badly in subjects I used to be good in.</p> |
| <p>10. <input type="checkbox"/> I feel like crying everyday.
 <input type="checkbox"/> I feel crying many days.
 <input type="checkbox"/> I feel like crying once in a while.</p> | <p>24. <input type="checkbox"/> I can never be as good as other kids.
 <input type="checkbox"/> I can be as good as other kids if I want to.
 <input type="checkbox"/> I am just as good as other kids.</p> |
| <p>11. <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.</p> | <p>25. <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.</p> |
| <p>12. <input type="checkbox"/> I like being with people.
 <input type="checkbox"/> I do not like being with people many times.
 <input type="checkbox"/> I do not want to be with people at all.</p> | <p>26. <input type="checkbox"/> I usually do what I am told.
 <input type="checkbox"/> I do not do what I am told most times.
 <input type="checkbox"/> I never do what I am told.</p> |
| <p>13. <input type="checkbox"/> I cannot make up my mind about things.
 <input type="checkbox"/> It is hard to make up my mind about things.
 <input type="checkbox"/> I make up my mind about things easily.</p> | <p>27. <input type="checkbox"/> I get along with people.
 <input type="checkbox"/> I get into fights many times.
 <input type="checkbox"/> I get into fights all the time.</p> |
| <p>14. <input type="checkbox"/> I look O.K.
 <input type="checkbox"/> There are some bad things about my looks.
 <input type="checkbox"/> I look ugly.</p> | |

Appendix C
Youth Self-Report

The following are the problem items that will be examined for depressive affect

Anxious/depressed

- 14. Cries a lot
- 29. Fears
- 30. Fears school
- 31. Fears doing bad
- 32. Must be perfect
- 33. Feels unloved
- 35. Feels worthless
- 45. Nervous
- 50. Fearful
- 52. Feels too guilty
- 71. Self-consciousness
- 91. Talks of suicide
- 112. Worries

Withdrawn/Depressed

- 5. Enjoys little
- 42. Rather be alone
- 65. Won't talk
- 69. Secretive
- 75. Shy, timid
- 102. Lacks energy
- 103. Sad
- 111. Withdrawn

Appendix D
Guidelines for Surgeons

**Overview of Procedures
for surgeons and staff**

- **First contact**
 - At initial consultation: advise patient and family of the study, and give them a Pectus Project brochure.
 - If patient is interested, office staff forwards patient's name, age, phone number and name of parent or guardian to the Pectus Research Team at pectus@uvic.ca.

- **Surgery Booking**
 - When office staff knows the surgery date, send information to the Pectus Research Team

- **3-6 months pre-surgery**
 - On-site Stroop person organizes and runs patient and a parent through Stroop protocol. Pectus Research Team will advise the office when this needs to be done, and will liaise between the family and the on-site Stroop person to set up this appointment.

- **Surgery**
 - Pectus Research Team will send surgery questionnaires to the surgeon's office, and will follow up with a reminder (if needed).

- **6 months post-surgery**
 - Pectus Research Team will contact on-site Stroop person with a reminder to arrange another Stroop session (it is also possible that an interview will be conducted in conjunction with this Stroop session). The research team will liaise between the family and the Stroop person to set up this appointment.

- **1 year post-surgery**
 - Pectus Research Team will contact on-site Stroop person to arrange for another Stroop session, and will liaise between the family and the Stroop person to set up this appointment.

- **6 months post-bar removal**
 - Pectus Research Team will contact on-site Stroop person to arrange for another Stroop session, and will liaise between the family and the Stroop person to set up this appointment.

After the initial referral from the surgeon's office, the Pectus Research Team will make all appointments, and will send reminders about any on-site duties. We hope to make this as non-intrusive as possible for the surgeons and their staffs.

Appendix E
Informed Consent -quantitative
Informed Consent

Psychosocial effects of surgical repair of pectus excavatum in children, youth, and young adults: A longitudinal study of changes in body image awareness, self-concept, affect, and quality of life

You are being invited to participate in a study entitled "Psychosocial effects of surgical repair of pectus excavatum or "funnel chest" deformities in children, youth, and young adults: A longitudinal study of changes in body image awareness, self-concept, affect, and quality of life" that is being conducted by Dr. Joan Martin, Dr. Jillian Roberts and Dr. Allen Hayashi. Dr. Roberts and Dr. Martin are research and teaching faculty in the department of Educational Psychology and Leadership Studies at the University of Victoria. They can be reached by phoning 721-7817 (Roberts) or 721-7792 (Martin). Dr. Hayashi is a pediatric surgeon at Victoria General Hospital.

FUNDING:

This research is being funded by the Canadian Institutes of Health Research.

PURPOSE:

The purpose of this research project is to evaluate the impact of the Nuss procedure for the repair of Pectus Excavatum. We hope to better understand the quality of life experiences of patients who have undergone the Nuss Pectus Excavatum Procedure. We want to understand how you feel, how the deformity does or does not affect your behavior and social relationships, and how the medical treatment changes the way you feel.

IMPORTANCE:

Research of this type is important because until recently patients and families who wanted to correct pectus excavatum only had the option of undergoing the invasive "Ravitch Repair." This procedure resulted in significant scarring and postoperative pain. However, a recent surgical development, the Nuss procedure, provides a corrective option that is both less invasive and expensive than the older Ravitch Repair; thus, this treatment is more feasible to use on a routine basis. Even so, this new procedure has not become the mainstream option and few surgeons have learned to perform it. The Nuss procedure has just become available to children, youth, and young adults in British Columbia through Dr. Hayashi, a Victoria pediatric surgeon. Scientific evaluation of the Nuss procedure's impact will provide important information for public health policy makers, physicians, psychologists and parents allowing them to better care for those who have pectus excavatum.

WHY WE WOULD LIKE YOU TO PARTICIPATE:

You are being asked to participate in this study because you and your family have been affected by pectus excavatum and have decided to seek medical treatment. Gathering information on your thoughts and experiences will be valuable for this study and will help medical professionals better care for others in a similar position.

WHAT WE WILL ASK YOU TO DO:

If you agree to voluntarily participate in this research, your participation will include completing a series of questionnaires, a computerized color-naming test, and a family interview. We will mail you 4 packets of questionnaires, once before the surgery and then 3 times after the surgery. You can complete these questionnaires at your leisure but please complete them on your own

and without talking to any other family members. Then put your answered questionnaires into the postage paid envelope and seal it so that no one else can see your answers.

We will also ask you to come to the University of Victoria on five separate occasions; twice before surgery, at 6 months and 1 year following surgery, and finally 6 months after the bar is removed. When you come to our lab, you will complete a few other questionnaires, do a timed color-naming task on the computer and take part in an interview so that we can understand how you feel personally and about the medical treatment. Finally, because we would like to follow you over a period of about two years, we will need you to let us know of any changes in address, phone, or medical treatment related to the pectus excavatum.

WHAT KINDS OF RISKS AND COSTS ARE INVOLVED?

Volunteering for this study will not cost you anything other than your time. We are not aware of any psychological risks to you other than feeling uncomfortable answering questions about feelings (for example, you might think about something sad). You are free to not answer any question that you are not comfortable with. If any procedure brings distressing personal emotional issues into awareness, we will help you in any way we can and will provide information on and referrals to available local counseling services. In particular you can contact Dr. Laila Thaiss, Ph. D., Department of Psychology, Victoria General Hospital, 250-721-4101.

WHAT ARE THE BENEFITS OF PARTICIPATING?

We hope that this research will help doctors and policy makers understand how persons feel and think when their bodies are different from others, and that it will help doctors to make more informed decisions about when it is important to fix a deformity. We will write about the results of this study for scholarly journals and will present it to professional groups with the goal of informing policy makers, physicians, and psychologists.

COMPENSATION:

As a way to compensate you for any inconvenience related to your participation, you will be given \$20 after receipt of each completed questionnaire packet and an additional \$50 at the end of the final lab session. It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive. If you would not otherwise choose to participate if the compensation was not offered, then you should decline.

CONSENT: *please initial each box if you have read and agreed with the statement*

I understand that my participation in this research must be completely voluntary. If I do decide to participate, I may withdraw at any time without any consequences or any explanation. If I do withdraw from the study my data will be destroyed unless I specifically give permission for it to be used.

Initial disclosure of the study comes from Dr. Hayashi. However, participation in this study is completely separate from any treatment from Dr. Hayashi as my physician. Dr. Hayashi did not describe the study or invite me to participate until after we reached our final decision regarding medical treatment.

_____ The researchers will periodically update me about the progress of the study by phone or written correspondence. During these updates they will remind me that participation is voluntary and that I can choose to withdraw without any negative consequence.

_____ In terms of protecting my anonymity all identifying information will be stripped from the self-report measures and replaced with a confidential ID number. My confidentiality and the confidentiality of the data will be protected by keeping any papers that link my identity with the ID number in a secure location that only the principal investigators can access.

_____ I understand that questionnaire and Stroop data will not be destroyed but it will be made anonymous by the removal of all identifying information at the conclusion of the study. Interview data will be kept for 5 years after completion of the study. After this, the transcribed interviews will be shredded and the audio-cassettes will be burned.

_____ I understand that the results of this study will be shared with others by presenting and/or publishing in the results in scholarly meetings and journals.

_____ In addition to being able to contact the researchers at the above phone numbers, I may verify the ethical approval of this study, or raise any concerns I might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4362) or by contacting Dr. Peter Kirk, Director of Research and Evaluation for the Vancouver Island Health Authority (250-370-8261).

_____ My signature below indicates that I understand the above conditions of participation in this study and that I have had the opportunity to have your questions answered by the researchers.

Name of Patient

Signature

Date

Name of Parent

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix F
Ethics Approval Certificate (attached)



University of Victoria

Human Research Ethics Board
Office of Research Services
University of Victoria
Room A240 University Centre
Tel (250) 472-4545 Fax (250) 721-8960
Email ovprhe@uvic.ca Web www.research.uvic.ca

Human Research Ethics Board Certificate of Approval

<u>Principal Investigator</u>	<u>Department/School</u>	<u>Supervisor</u>	
Joan Martin Faculty	EPLS	N/A	
<u>Co-Investigator(s):</u>			
Dr. J. Roberts, Co-Investigator, UVic		Kristin McLennan, RA/MA student, UVic	
Dr. Sigalet, MD Researcher/Surgeon, Alberta Children's Hospital		Jennie Gill, RA/MA student, UVic	
Dr. A. Hayashi, MD Researcher/Surgeon, VIHA			
Dr. Skarsgard, MD Researcher/Surgeon, University of British Columbia			
Dr. Peter Fitzgerald, MD Researcher/Surgeon, McMaster Children's Hospital			
<u>Project Title:</u> A Yoked Control Group for a Longitudinal Study of the Psycho-Social and Quality of Life Effects of Surgical Repair of Pectus Excavatum Deformities in Children and Adolescents			
<u>Protocol No.</u>	<u>Approval Date</u>	<u>Start Date</u>	<u>End Date</u>
547-04	14-Feb-05	14-Feb-05	13-Feb-06

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

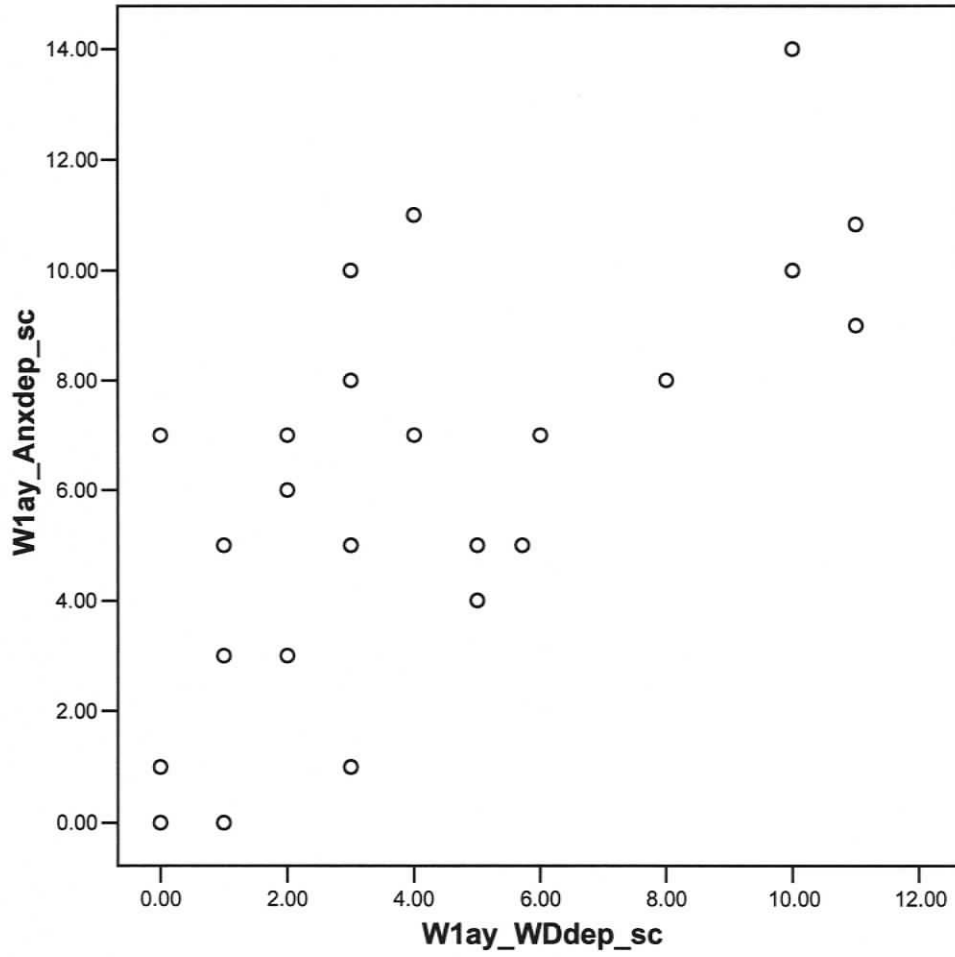
Dr. Richard Keeler
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions or minor amendments may be granted upon receipt of a "Research Status" form.

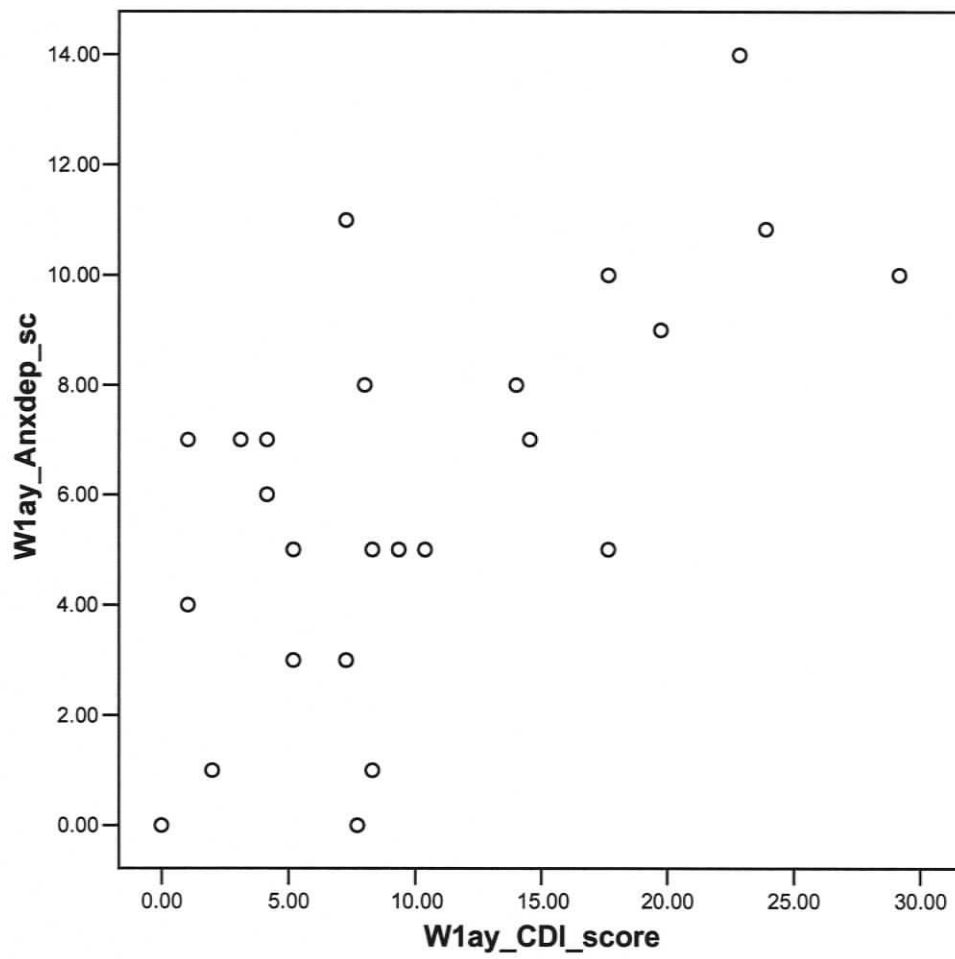
547-04
Martin, Joan

Appendix G
Scatterplots of Outlying Depression Scores

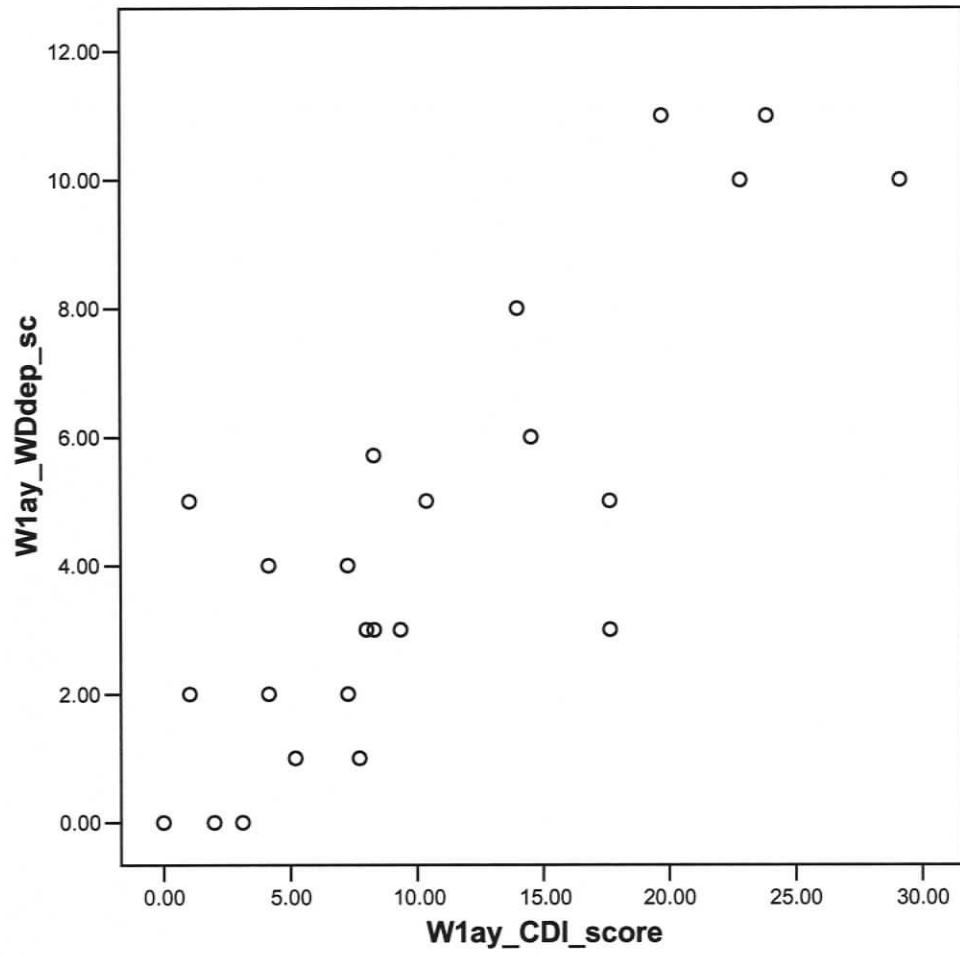
Scatterplot of YSR anxious/depressed and YSR withdrawn/depressed



Scatterplot of YSR anxious/depressed and CDI

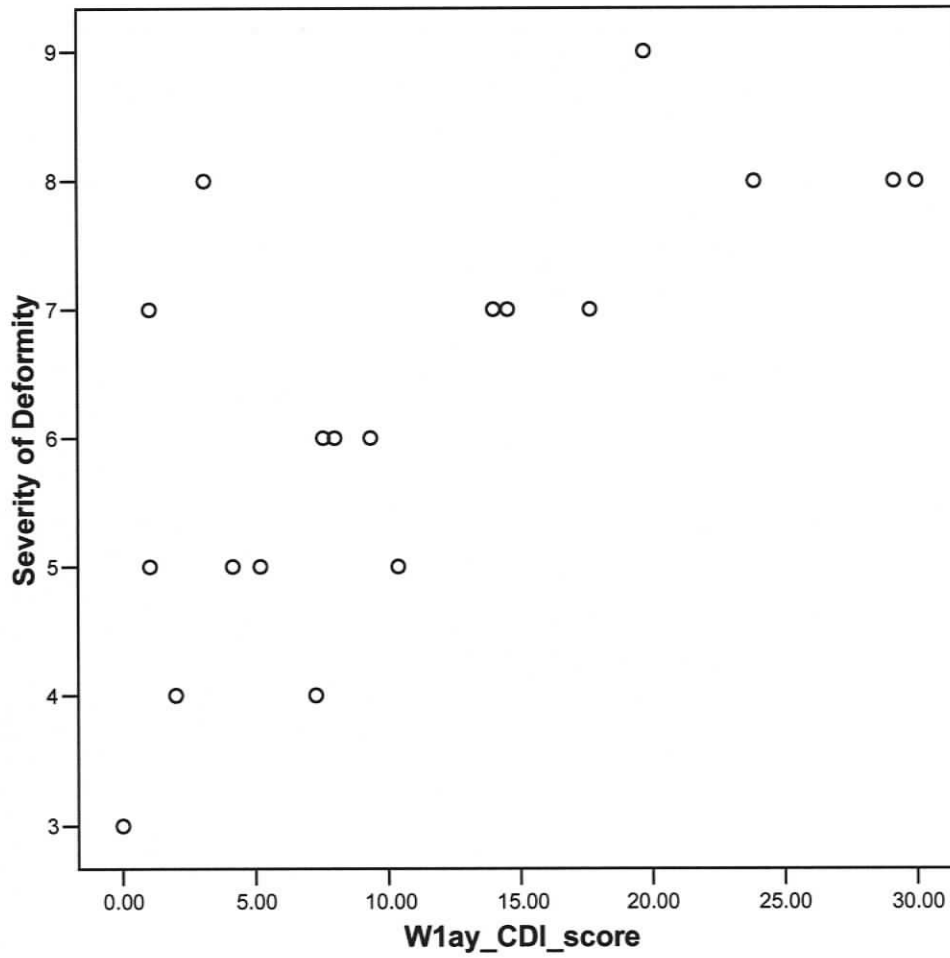


Scatterplot of YSR withdrawn/depressed and CDI

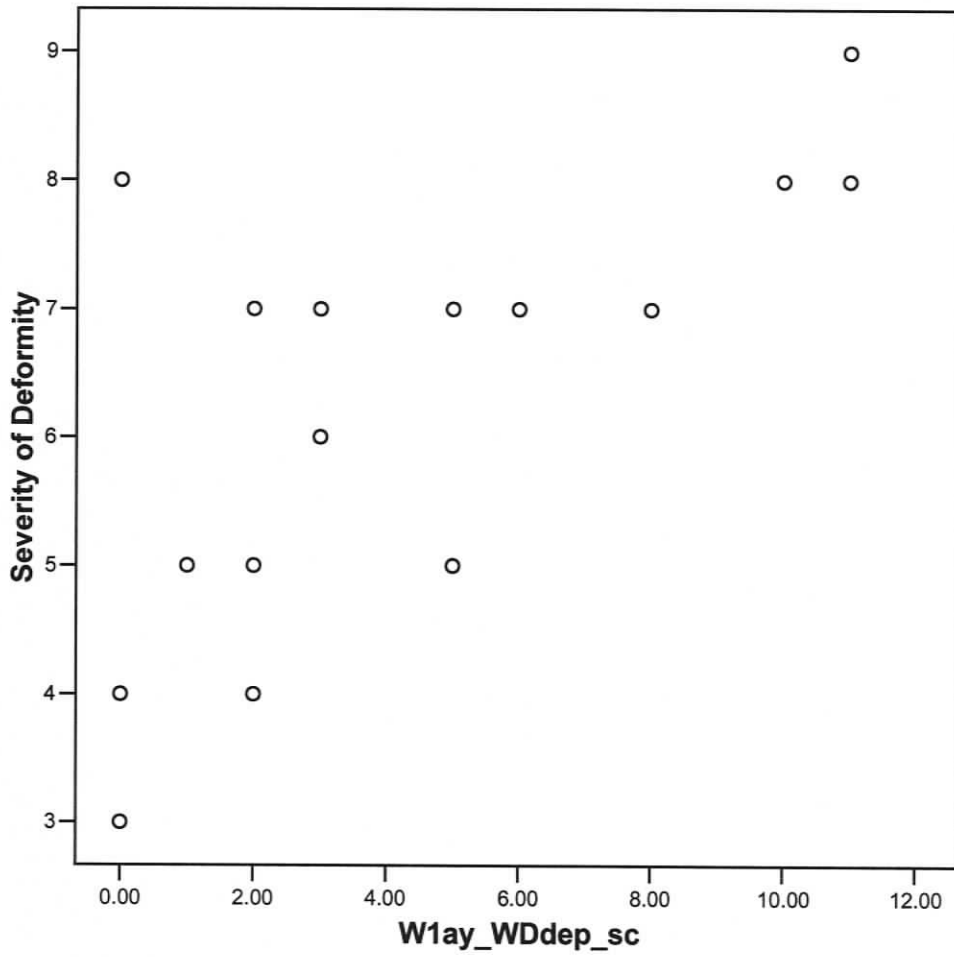


Appendix H
Scatterplots of Measures: Preliminary Analyses.

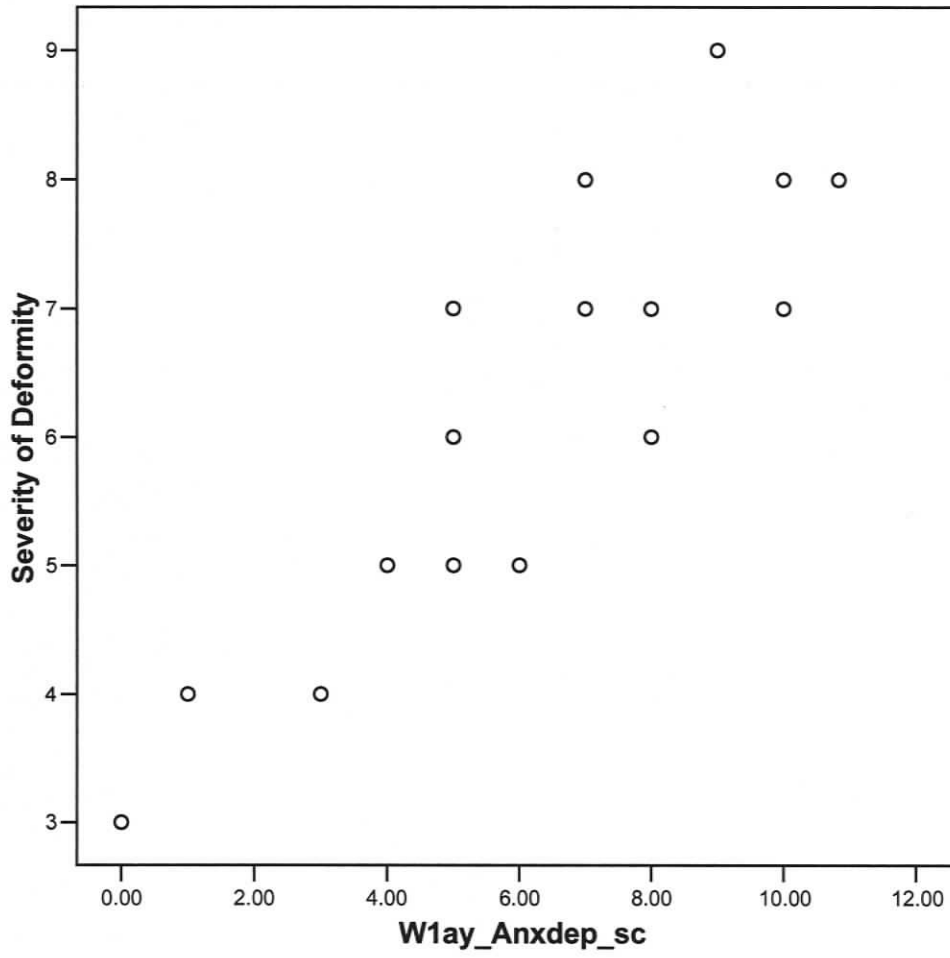
Scatterplot of Self-Perceived Severity and CDI



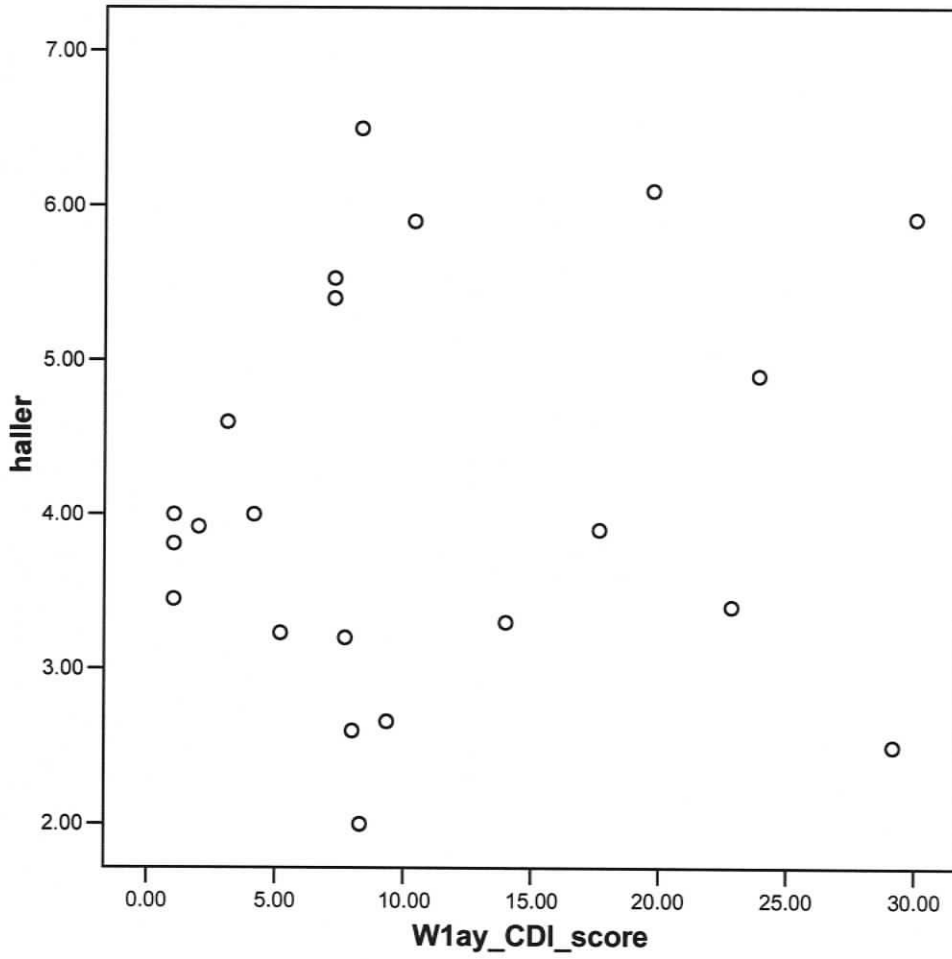
Scatterplot of Self-Perceived Severity and YSR withdrawn/depressed



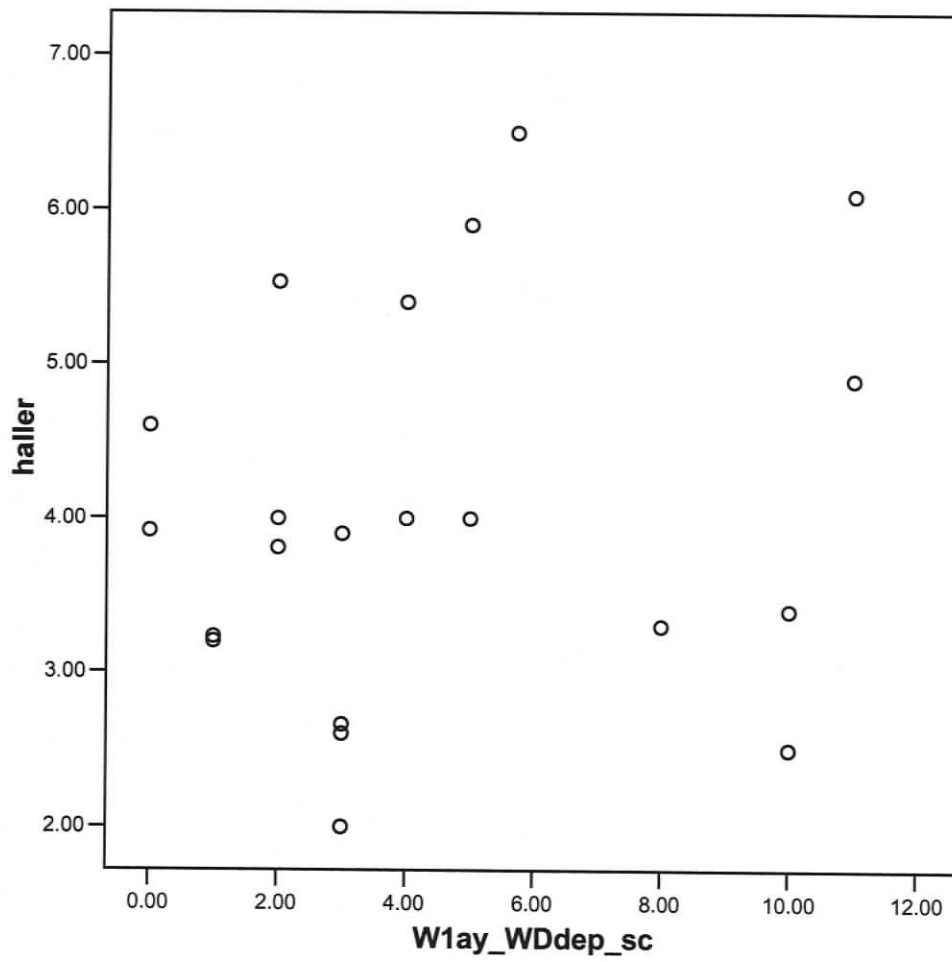
Scatterplot of Self-Perceived Severity and YSR anxious/depressed

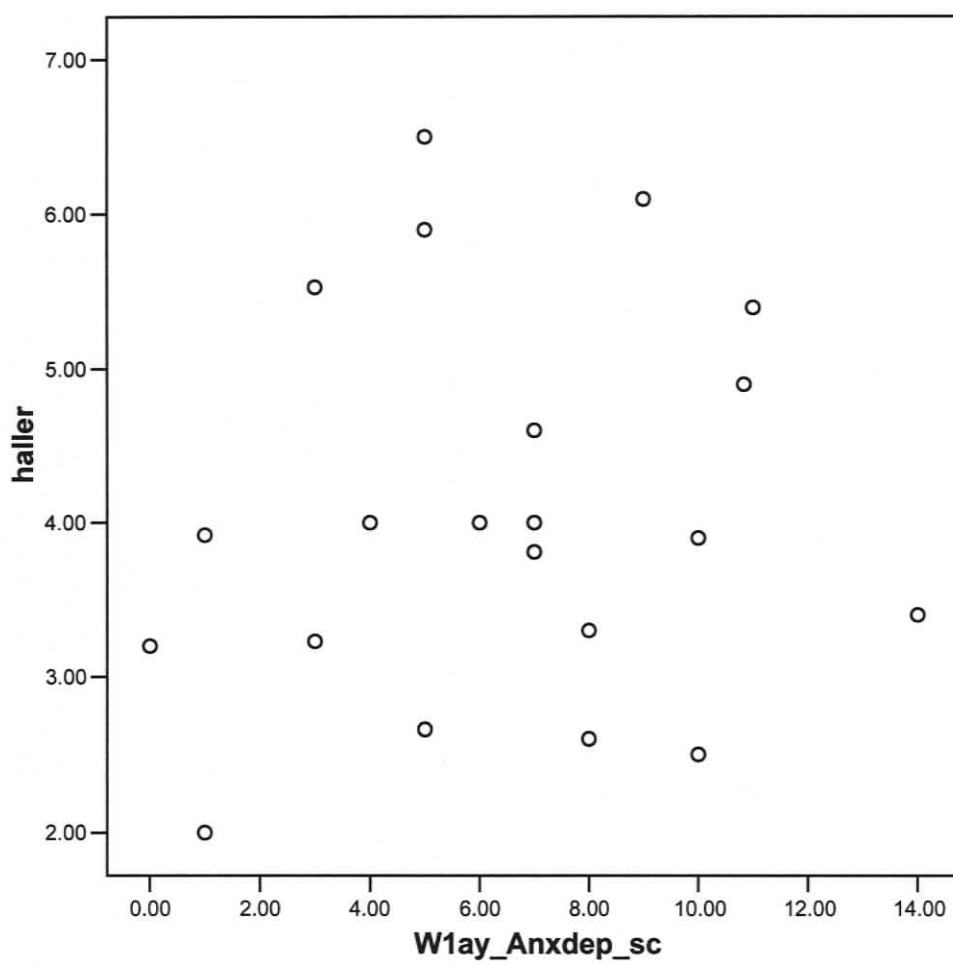


Scatterplot of Haller Index and CDI

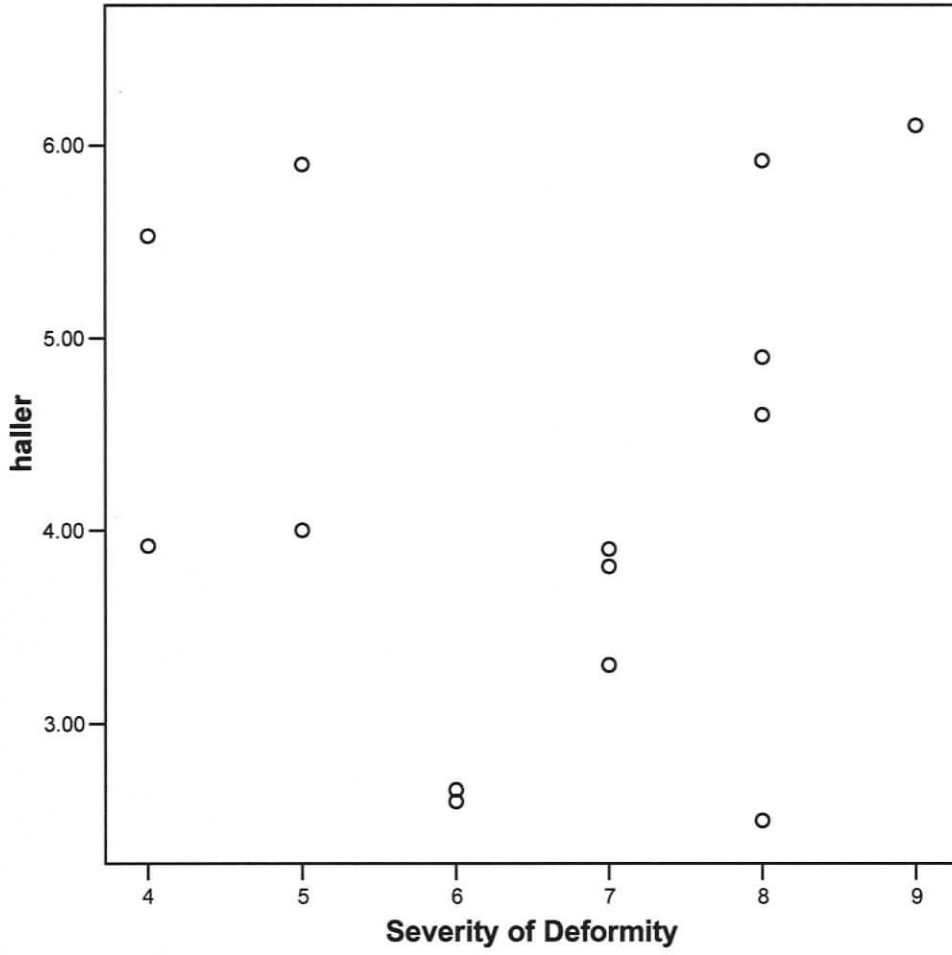


Scatterplot of Haller Index and YSR withdrawn/depressed



Scatterplot of Haller Index and YSR anxious/depressed

Scatterplot of Self-Perceived Severity and Haller Index



Appendix I
Calculations of Z-tests and Effect sizes

a) For the Anxious/Depressed YSR the following is the Z score for boys:

$$Z = \frac{x - \mu}{\frac{\sigma}{\sqrt{n}}} = z = \frac{5.74 - 3.4}{\frac{3.0}{\sqrt{20}}} = \frac{2.34}{\frac{3.0}{4.47}} = \frac{2.34}{0.67} = 3.49$$

$$\text{effect size} = \frac{x - \mu}{\sigma} = \frac{5.74 - 3.4}{3.0} = \frac{2.34}{3.0} = 0.78$$

b) For the Withdrawn/Depressed YSR, the following is the z-score for boys:

$$Z = \frac{x - \mu}{\frac{\sigma}{\sqrt{n}}} = z = \frac{4.15 - 2.7}{\frac{2.4}{\sqrt{20}}} = \frac{1.45}{\frac{2.4}{4.47}} = \frac{1.45}{0.54} = 2.69$$

$$\text{effect size} = \frac{x - \mu}{\sigma} = \frac{4.15 - 2.7}{2.4} = \frac{1.45}{2.4} = 0.60$$

c) For the CDI, since normative data is available for both boys and girls, girls will be included in the analyses:

$$Z = \frac{x - \mu}{\frac{\sigma}{\sqrt{n}}} = z = \frac{10.38 - 9}{\frac{7}{\sqrt{20}}} = \frac{1.38}{\frac{7}{4.47}} = \frac{1.38}{1.57} = 0.88$$

$$\text{effect size} = \frac{x - \mu}{\sigma} = \frac{10.38 - 9}{7.0} = \frac{1.38}{7.0} = 0.20$$

d) For the Withdrawn/Depressed YSR, the following is the z-score for girls:

$$Z = \frac{x - \mu}{\frac{\sigma}{\sqrt{n}}} \quad z = \frac{4.54 - 3.1}{\frac{2.5}{\sqrt{5}}} = \frac{1.44}{\frac{2.5}{2.34}} = \frac{1.44}{1.07} = 1.35$$

$$\text{effect size} = \frac{x - \mu}{\sigma} = \frac{4.54 - 3.1}{2.5} = \frac{1.44}{2.5} = 0.58$$

e) For the Anxious/Depressed YSR the following is the Z score for girls:

$$Z = \frac{x - \mu}{\frac{\sigma}{\sqrt{n}}} \quad z = \frac{7.40 - 5.1}{\frac{4.0}{\sqrt{5}}} = \frac{2.3}{\frac{4.0}{2.34}} = \frac{2.3}{1.71} = 1.35$$

$$\text{effect size} = \frac{x - \mu}{\sigma} = \frac{7.40 - 5.1}{4.0} = \frac{2.3}{4.0} = 0.58$$