The Experiences of Male Adolescents Living With Pectus Excavatum Deformities

By

Kristine Anne Edgington
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Abstract

Research examining social and psychological impacts of physical deformities shows that a difference in one's appearance affects the ways in which others perceive and interact with that individual. Additional outcomes include anxiety, depression and decreased self-esteem. Research consistently shows that there is a wide variation in responses to one's own physical deformity. The present study employed phenomenology to explore the experiences of six male adolescents living with a pectus excavatum deformity, and more specifically examined the ways in which deformity affects these individuals' quality of life. The study also examined the decision process the participants engaged in while deciding to undergo the Nuss surgical procedure for the correction of their physical deformity. Semi-structured interviews were conducted, transcribed verbatim, and thematically analyzed. Results indicate that these adolescents' social contexts and psychological well-being are affected by their physical deformity. Moreover, information regarding their deformity and available corrective options empowered these youth to take control over their pectus excavatum.

Supervisor: Dr. Jillian Roberts, (Department of Educational Psychology and Leadership Studies)

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Dedication

I dedicate this thesis to my husband, Jesse. I could not have done this without you. Thank you for your endless encouragement and your tremendous confidence in me. I love you, and I am so grateful to have you in my life.

I also dedicate this to my parents. Thank you for your support and encouragement. Thank you for instilling in me a love of learning and an understanding of the value of education.

Chapter One – Introduction

Overview

It is estimated that one percent of adults live with a physical deformity or disfigurement that affects their ability to lead a normal existence (Thompson & Kent, 2001). Defining disfigurement is a subjective practice as it relies not only on social norms and customs but on individual attitudes and values as well. In a broad sense a disfigurement can be defined as a noticeable difference of appearance (Thompson & Kent, 2001). In general there are three main causes of disfigurement, namely congenital malformations, traumatic events, and diseases, either directly or through treatment. Physical disfigurements are expansive, including cleft lip, pectus deformities, scoliosis, burns, and skin conditions such as acne, vitiligo, port wine stains, or psoriasis to name a few. Although only some of these conditions affect physical functioning, all of them effect some social and psychological aspects of affected individual's lives.

Examining the social and psychological effects of living with a physical disfigurement is an active area in research (Clarke, 1999; Thompson & Kent, 2001). This research primarily examines the effects of various conditions and diseases that cause an individual to appear different in some way. Research focuses on two major areas of inquiry, the first being the effect that physical disfigurement has on social interactions and others' perceptions of an individual (Bernstein, 1990; Liskey-Fitzwater, Moore & Gurel, 1993; Thompson & Kent, 2001). The second area of focus is the effect that disfigurement has on psychological functioning such self-esteem, anxiety, body image and emotional well-being (Einsiedel & Clausner, 1999; Hill-Beuf & Porter, 1984; Kent, 2000; Kent & Keohane, 2001; Sarimski, 2001; Thompson & Kent, 2001).

Research to date offers several consistent findings with regard to the social and psychological impacts of disfigurement. Individuals who are different in physical appearance are met with uncertainty, if not hostility, are often perceived as less competent and are frequently devalued (Bernstein, 1990; Clarke, 1999; Thompson & Kent, 2001). Findings also indicate that persons with physical disfigurements are at a greater risk for anxiety, depression, low self-esteem and social withdrawal (Einsiedel & Clausner, 1999; Sarimski, 2001; Thompson & Kent, 2001). This being said, the most consistent and important finding is that there is wide variation in individuals' responses to deformity (Anderson, 1982; Kent, 2000; Kent & Keohane, 2001; Sarimski, 2001; Thompson & Kent, 2001). The variation is the result of a number of interacting factors including visibility of the deformity, age, personal characteristics such as competency, anxiety levels, social skills and values, and social support (Anderson, 1982).

Pectus excavatum, a specific type of physical deformity, has received limited research attention with regard to its social and psychological impacts. More commonly known as funnel chest, pectus excavatum is the depression of the sternum in a concave shape. This deformity occurs in one to eight per every 1000 and is more common in males than in females (Emery, 2001). It is normally evident at birth and becomes more pronounced with skeletal growth. Rapid growth spurts during early adolescence lead to a marked deformity (Emery, 2001).

Two common types of surgical procedures are employed to correct this deformity; the Ravitch procedure, and the less invasive Nuss procedure (Emery, 2001). Surgical correction of pectus excavatum is often seen as cosmetic and unnecessary; less than 15% of persons with pectus deformities undergo surgical correction. To better understand the

impact and necessity of correction procedures, Emery (2001) suggests that, "it is vital to study the psychosocial outcomes, patient satisfaction and quality of life before and after surgical correction of pectus deformities" (p. 38).

The majority of research examining life with a physical disfigurement employs quantitative methodologies. Although these studies provide a wealth of information, Thompson and Kent (2001) suggest that qualitative studies are needed in order to provide a deeper understanding of the experience. Qualitative research can add depth and nuance to the knowledge already accumulated through quantitative research.

Statement of the Problem

Based on the aforementioned suggestions for further research, this study was conducted to answer the following question: What are the self-reported pre-surgery experiences of adolescents living with a pectus excavatum deformity?

Purpose of the Study

This phenomenologically informed study attempted to answer questions pertaining to the essence of adolescents' experiences of living with a physical deformity, and more specifically to develop a comprehensive understanding of the pre-surgery experiences of youth living with pectus excavatum. The study also sought to explore the decision process engaged in by these adolescents in opting to undergo the Nuss surgical procedure for the correction of their pectus excavatum. Answering this research question allows for a better understanding of pectus excavatum's effect on adolescents' quality of life as it pertains to both their social and psychological well-being. The study explores pectus excavatum as it influences the social interactions, self-concepts, emotions, and daily activities of youth. It provides valuable information as to the concerns and

experiences of others with similar conditions that may be utilized by youth with physical deformities. It also serves to inform parents, families, and medical and educational communities involved in caring for youth with pectus excavatum. That is, through developing a better understanding of adolescents' experiences, parents and professionals should enhance their ability to support and respond to the needs of the youth in their care.

Definitions of Terms

Certain specialized terms that are open to much interpretation will be used throughout the study. The following definitions are offered to ensure proper interpretation of the terminology used in this study.

Adolescence: a period in human development that marks the transition from childhood to adulthood, it begins with puberty and extends to the early 20's and includes changes in biological, psychological and social characteristics (Good & Merkel, 1973; Husen & Postlethwaite, 1994). The age of participants involved in this study ranges from ten to nineteen years.

Disfigurement/deformity: an impairment to the form of the body or misshape of a portion of the body, a hurt appearance (Webster's New World Dictionary, 1990).

Nuss Procedure: a minimally invasive, corrective procedure for pectus excavatum involving the placement of a curved steel bar behind the sternum forcing it into the correct shape (Emery, 2001).

Pectus excavatum: a congenital deformity of the sternum causing a sunken or caved-in chest (Smith, 2004).

Boundaries of the Study

This study is structured within a specific methodological and design framework. In order to ensure readers are able to comprehend and appreciate results within these restrictions they are acknowledged and explicated as follows:

1. In keeping with the objectives of qualitative methodology this study involved six adolescent males with pectus excavatum, living in western Canada.
2. The study was limited to those adolescents willing and able to participate in an in-depth, one-on-one interview and who gave permission to have that interview tape-recorded.
3. "The data a researcher collects are several times removed from the actual flow of experience" (Polkinghorne, 1989, p. 45). That is, the interview itself was an interruption to the natural flow of these adolescents' daily experience, the participants engaged in discussion and reflection on their experience, which removes them from the immediate experience, and finally all data is gathered through the questions and therefore presuppositions of the researcher.
4. The studies data were collected between May 15th and August 30th 2004.

Summary

Having a physical disfigurement can and does affect many aspects of an individual's daily life including social and psychological well-being. Appearing different alters others' perceptions and influences social interactions as well as leaving persons at higher risk for decreased self-esteem, high anxiety, and depression. However, research has found large variation in individuals' responses to, and dealing with, physical disfigurement. This variation is the result of a number of interacting factors including the

visibility of the deformity, age, social support and personal characteristics such as social skills, values, and competency.

Research to date has dealt with various disfiguring and deforming conditions and has primarily approached them with quantitative methods. These studies have provided a strong base of knowledge but further qualitative work is needed in order to add depth to current understanding. The social and psychological impacts of Pectus excavatum in particular have received little research attention. Therefore, the aim of this study is to pursue an in depth and comprehensive understanding of the experiences of adolescents with pectus excavatum.

Chapter two will provide a more detailed exploration of previous research in this area, covering such topics as social effects, psychological effects and factors influencing responses and coping. Chapter three identifies the methodology used in this investigation of adolescent experiences. Chapter four presents the results of this investigation and chapter five includes a discussion of those results as well as their implications for practice and further research.

Chapter Two – Literature Review

Many researchers address the social and psychological impacts of disfigurement (Anderson, 1982; Einsiedel & Clausner, 1999; Hill-Beuf & Porter, 1984; Kent, 2000; Kent & Keohane, 2001; Sarimski, 2001). There are two overlapping approaches to studying the effects of physical deformity; the first is a social perspective, described by Thompson and Kent (2001) as the "view from the outside." This approach examines the ways in which appearance impacts social interactions and others' perceptions of individuals. Findings from these types of studies indicate that being different in appearance most certainly affects the perceptions of others and social interactions. Visibly different individuals are seen as less competent, are devalued by others, and their social interactions are often uncomfortable (Bernstein, 1990; Liskey-Fitzwater et al., 1993; Thompson & Kent, 2001).

The second approach to research in this area looks specifically at individual thoughts, perceptions, and feelings, the "view from the inside" (Thompson & Kent, 2001). Findings from these studies indicate that individuals living with physical disfigurements can suffer from high social anxiety, depression and low self-esteem (Einsiedel & Clausner, 1999; Hill-Beuf & Porter, 1984; Kent, 2000; Sarimski, 2001; Thompson & Kent, 2001). However, the most consistent finding is a wide variation in individuals' responses to their disfigurement, best understood as the result of interactions between a large number of variables (Kent & Keohane, 2001; Sarimski, 2001; Thompson & Kent, 2001). A final focus of this type of research investigates the coping strategies that individuals with disfigurements use and the efficacy of those tactics (Anderson, 1982; Kent, 2000).

Chapter two will review the literature that has addressed physical deformity both from a social perspective and a psychological perspective. Research specifically related to pectus excavatum will be outlined, and interventions will be briefly discussed. Finally, the need for further research will be examined.

Social Effects: The "view from the outside"

Research shows that many of the personality traits that individuals attribute to a stranger are based upon physical appearance. Attractive people are perceived as more competent, more intelligent and better adjusted (Hill-Beuf & Porter, 1984; Thompson & Kent, 2001). In contrast, "the contents of an individual who is visibly marred are devalued" (Bernstein, 1990, p. 131). In social situations individuals who are visibly deformed are often met with uncertainty, if not hostility (Clarke, 1999). A physical difference is a novel stimulus and others often become caught between curiosity and the knowledge that staring is not socially acceptable. This "can lead to uncomfortable or curtailed interactions between physically handicapped and non-handicapped persons" (Liskey-Fitzwater et al., 1993, p. 16).

A stigma is "the relationship between a characteristic possessed by an individual and the devaluation that society places on that characteristic" (Kent, 2000, p. 118). Within sociology, the term *enacted stigma* is used to describe the instances of real social rejection that individuals with physical disfigurements encounter, while the term *felt stigma* encompasses the expectations of rejection that these persons with physical disfigurement develop. Felt stigma can be incredibly crippling in social situations and often leads to increased awkwardness of interactions (Kent, 2000).

For many children and adolescents with a difference in appearance, instances of enacted stigma are common. In his study examining the retrospective descriptions of childhood teasing of 111 college women, Cash (1995) confirmed that "appearance is the most common focus of interpersonal teasing in childhood" (p. 123). In this sample of individuals without physical disfigurement, facial features and weight were the most common targets of childhood teasing and peers were the most common perpetrators. In early adolescence, appearance becomes particularly important to self-concept as bodies begin to change (Anderson, 1982; Hill-Beuf & Porter, 1984). Appearing different is greatly feared by many adolescents as they begin to focus on clothing, and other aspects of appearance (Liskey-Fitzwater et al., 1993). As with a majority of children and teens without physical disfigurement, it is expected that individuals with a physical disfigurement would experience a similar focus on appearance and a certain amount of enacted stigma as a result.

Psychological Effects: The "view from the inside"

The extant literature reveals that as a result of their difference in appearance, individuals with physical disfigurements experience heightened social anxiety, depression and low self-esteem (Kent, 2000; Thompson & Kent, 2001). In their study of the psychological impacts of pectus excavatum (funnel chest), involving 56 patients, Einsiedel and Clausner (1999) found that as the length of an individual's case history increased, so did the instances of "neurotic reactions and inadequate coping strategies" (p. 736). These reactions included embarrassment, social difficulties, and feelings of stigmatization, anxiety and depression. In another study involving the parents of 25 children with craniofacial anomalies, Sarimski (2001) found that this particular

population was at an increased risk for social problems such as unsuccessful peer interactions, social anxiety and social withdrawal. However, Sarimski also found that there was great variability in individuals' reactions and adjustment to their disfigurement. In fact this variability in response is the most consistent finding in research examining the psychological impacts of physical deformity (Anderson, 1982; Kent, 2000; Kent & Keohane, 2001; Sarimski, 2001; Thompson & Kent, 2001).

Variation in Responses to Disfigurement

Several studies have attempted to discover the reasons for such wide variation in individuals' responses to disfigurement. The general conclusion is that an individual's response is the result of an interaction of a large number of variables, some playing more important roles then others (Anderson, 1982). Interacting factors include the severity or visibility of the deformity, demographic factors such as age, personal qualities such as values, anxiety level, competency and social skills, and finally, social support.

Severity and visibility.

In looking at self-concept and coping in 59 females with scoliosis, a curvature of the spine, Anderson (1982) found that severity and treatment method, which can drastically alter appearance, were not related to coping or self concept. In their study of 19 children with vitiligo, a disfiguring skin condition, Hill-Beuf and Porter (1984) found that visibility was far less important to children's coping then other factors. In studying children with craniofacial anomalies, Sarimski (2001) determined that "severe facial deformities are not more of a psychological burden than mild handicaps" (p. 589). Both severity and visibility are found to be less important to overall adjustment than other factors. When severity and visibility are compared, research reveals that severity is far

less relevant to overall coping and adjustment than visibility (Kent & Keohane, 2001). This is contrary to medical models, which focus on the severity of deformities.

Some researchers and theorists suggest that visibility may play a role in adjustment to deformity in a way that is contrary to prior speculation. The suggestion is that people with visible disfigurements will have an easier time adjusting than those whose disfigurement is easily hidden (Einsiedel & Clausner, 1999; Thompson & Kent, 2001). Although a less visible disfigurement is likely to decrease the incidence of enacted stigma, it also does not allow the person to experience what Einsiedel and Clausner (1999) call the sympathy bonus. Persons with visible deformities are faced with daily social confrontation and are therefore forced to adapt to their differences. However, persons with easily hidden deformities are not faced with this daily confrontation and are therefore able to avoid reality, making positive adjustment more difficult (Einsiedel & Clausner, 1999; Thompson & Kent, 2001). Individuals with less visible deformities who hide their differences rather than dealing with them are likely to experience difficulty in situations that expose their deformity, such as the high school locker room, the swimming pool or beach, or within intimate relationships.

Age.

Studies examining the influence of age on coping with a disfigurement have obtained mixed results (Thompson & Kent, 2001). In their study of youth with vitiligo, Hill-Beuf and Porter (1984) found that early adolescence was the most difficult period for these individuals, primarily due to an increased focus on appearance as well as anxiety around the transition to a new school, be it either junior or senior high school. They noted that there were also periods of difficulty for children during the initial transition of

starting school, but these typically subside as children become more familiar with their classmates. Very young children seemed relatively unaffected, as they did not have a focus on appearance but were preoccupied with family and the development of self. Older adolescents also managed more successfully as they began to "derive compensatory satisfaction from the acquisition of skills... by sports or artistic abilities, and by relationships with their peers" (p. 298). Other researchers agree that adolescents may have the most difficulty among individuals with physical disfigurements (Anderson, 1982; Forstenzer & Roye, 1988), particularly because young people "have been recognized as placing more importance on appearance than any other age group" (Liskey-Fitzwater et al., 1993, p. 20). This being said, it is still recognized that although age is a factor, it is not as important a factor as some of an individual's personal qualities and their social support in determining adjustment to deformity (Anderson, 1982; Thompson & Kent, 2001).

Self-concept, values, competency, anxiety, attributions and social skills.

In studying adolescents with scoliosis, Anderson (1982) found that an individual's reaction to, and coping with, deformity was shaped by their self-concept and values prior to the onset of the disorder. Through the use of self rating scales it was discovered that individuals with high self-concepts were able to cope with their deformity much more effectively than those who already suffered from low self-concept. Likewise, those individuals who highly valued appearance prior to onset were more likely to suffer decreased self-esteem than those who had placed a high value on other personal strengths and talents. Similarly, in studying children with vitiligo, Hill-Beuf and Porter (1984) found that competency was a good predictor of children's coping. Their research suggests

that "the satisfaction of ego and competency needs can go a long way in compensating for the degree of impairment in appearance" as "competency feelings mitigate against over-concern with appearance" (p. 299). Therefore, individuals who are competent, have a high self-concept and who place value in aspects other than appearance, are likely to cope more effectively with disfigurement.

In Kent and Keohane's (2001) study involving 181 people with the skin condition psoriasis, it was found that for individuals with a visible deformity, fear of negative evaluation and high social anxiety were associated with a decreased quality of life. Similarly, Forstenzer and Roye (1988) found that adolescents with scoliosis coped with their disorder based on "individual personality traits, such as anxiety, fearfulness, and cognitive and processing abilities" (p. 55). Social anxiety or felt stigma is also affected by one's attributional tendencies. Individuals who attribute any negative word or action from another as a direct response to their physical deformity are likely to have high social anxiety and overestimate the likelihood of rejection (Clarke, 1999; Thompson & Kent, 2001). In his study of childhood teasing, Cash (1995) found that it was not the presence of teasing, but the appraised severity of that teasing which significantly affected body image. Anxiety, fear and certain attributional tendencies can contribute to poor coping and negative adjustment in persons with physical deformities.

Research indicates that strong social skills can go a long way in compensating for physical disfigurement (Thompson & Kent, 2001). "The behavior of the individual rather than the physical appearance can be instrumental in influencing the response from other people... social skills are a better predictor of successful outcome than disfigurement" (Clarke, 1999, p. 130). Social skills training is a common intervention for individuals

with physical disfigurements because the attainment of these skills often decreases social anxiety and avoidance and builds confidence within interactions (Kent, 2000; Thompson & Kent, 2001).

Social support.

Many of the aforementioned factors that contribute to positive adjustment hinge on one highly important resource, that is, social support (Forstenzer & Roye, 1988; Thompson & Kent, 2001). A strong network of social support, people with whom one feels accepted and respected, is consistently found to result in better adjustment and more successful outcomes (Clarke, 1999). This is partly due to the influence that family and social groups have on values. When a person with a deformity is surrounded by others who view physical perfection as a priority, they are unlikely to adapt well. However, if they are surrounded by others who value them for other qualities such as intelligence, artistic or athletic ability, to name a few, they will likely have an easier time adjusting to their physical differences (Forstenzer & Roye, 1988). Social support can also influence attribution patterns and felt stigma. "The way in which individuals with a disfigurement think about their interactions with others will be dependent on past experiences and current levels of social support" (Thompson & Kent, 2001, p. 672). There remains a need for research that examines the specific aspects of social support, such as emotional support and problem solving, in order to determine which are the most beneficial and why. However, it is safe to assume "that social support is most effective where it most closely matches the needs of the individual" (Clarke, 1999, p. 132). Intervention programs and support groups will likely work best when they are able to model effective social support.

Coping Strategies

People with physical disfigurements utilize a wide variety of coping mechanisms around self-presentation and self-protection (Thompson & Kent, 2001). Self-presentation, or impression management, includes concealment, avoidant behavior, dealing with others' reactions, appearance checking, reassurance seeking, and compensating for appearance (Kent, 2000; Thompson & Kent, 2001). Commonly used concealment and avoidant behaviors demonstrated by individuals with pectus excavatum can include defensive camouflaging through poor posture and folded arms as well as lifestyle restrictions in the areas of sports and relationships (Roberts, Hayashi, Anderson, Martin & Maxwell, 2003). Although commonly used, these strategies tend to only exacerbate distress, as they do not address the underlying issues (Thompson & Kent, 2001). Avoidance behavior does not allow an individual to confront social reactions and build confidence. Self-presentation approaches can also include proactive behaviors such as educating others and assertively confronting negative reactions (Kent, 2000; Thompson & Kent, 2001). In research involving individuals with vitiligo, Kent (2000) discovered that "some respondents found that self disclosure... resulted in a reduction of embarrassment and self-consciousness" (p.126). While the aforementioned tactics can be effective, it must be noted that they do require a great deal of courage and confidence.

Self-protection strategies include such things as denial, social comparisons and attributional tendencies. Downward social comparisons with those who are seen as worse off can have a positive effect on emotions and self-regard. These effects, however, are usually very short lived, making social comparison unhelpful for long-term adjustment (Thompson & Kent, 2001). Denial is another technique that does not contribute to long-

term positive adjustment but is often exhibited by individuals who have recently acquired a physical disfigurement (Bernstein, 1990). Although numerous positive and negative coping tactics exist, individuals are best served by learning to use a variety of positive strategies, which can move them beyond merely coping.

Pectus Excavatum

Pectus excavatum is the most common form of chest wall deformities, being found in one to eight individuals per every 1000 and more common in males than females (Crump, 1992; Emery, 2001). It involves a depression of the sternum resulting in a caved-in or sunken chest (Emery, 2001). Pectus excavatum is normally detected at birth and becomes more apparent during the rapid growth spurts of early adolescence (Emery, 2001). Until recently, this deformity was regarded as strictly cosmetic, however it is now known to have other serious implications (Crump, 1992). Pectus excavatum can affect cardiopulmonary functioning and "common complaints from adolescents... include shortness of breath on exertion and chest pain" (Crump, 1992, p. 174).

Beyond physiological effects, pectus excavatum, like other physical deformities, can impact social and psychological adjustment and functioning (Einsiedel & Clausner, 1999; Roberts et al., 2003). Einsiedel and Clausner studied 56 pectus excavatum patients and found that the deformity can result in psychosocial problems including embarrassment, stigmatization, anxiety, depression and other social problems. In the preliminary findings of an ongoing investigation regarding youth with pectus excavatum, Roberts et al. (2003) report that this deformity affected children's self-concept and interfered with participation in various activities requiring exposure of the chest to some

degree. Beyond these studies, there is a paucity of research investigating the social and psychological impacts of this chest wall deformity.

Intervention

The extant literature addresses various methods of intervention for individuals with disfigurements. Although it is not within the scope of this chapter to review the entire body of literature, I will briefly discuss the currently used types of intervention. One common method of dealing with disfigurement is to seek medical intervention. Medical intervention has "the aim of reducing the discrepancy between an individual's ideal and actual appearance" (Thompson & Kent, 2001, p. 673). In the case of pectus excavatum there are currently two surgical procedures for the correction of the deformity of the sternum (Comarow, 2002; Emery, 2001; Fonkalsrud, 2003). The Ravitch procedure involves a large incision down the middle of the chest, the removal of cartilage and bone, and the replacement of the sternum with a metal plate (Comarow, 2002). The Ravitch surgical procedure takes several hours and many children develop "breathing problems years later because of extensive internal scarring" (Comarow, 2002, p. 50). The minimally invasive Nuss procedure avoids the removal of cartilage through the placement of a curved metal bar behind the sternum, re-shaping it (Comarow, 2002; Fonkalsrud, 2003). Surgery takes approximately 45 minutes and the bar is removed once the bones have been remolded, typically two or more years later (Comarow, 2002; Fonkalsrud, 2003). Although medical intervention is highly successful in many cases, there are some conditions for which it is not effective.

Other interventions have followed the psychological or sociological approaches to research and have dealt with either the external and social impacts or the internal and

psychological impacts of life with a deformity. Some were designed with the intention of changing stereotypes and negative behavioral reactions to physical differences. These interventions require an alteration of attitude and behavior on the part of the general public and, unfortunately have been relatively unsuccessful, thus requiring further development and testing (Thompson & Kent, 2001). Additional interventions focus on managing the psychological impacts of disfigurement. These interventions include social skills training, cognitive and behavioral therapies, and programs aimed at reducing anxiety and fear (Clarke, 1999; Thompson & Kent, 2001). These programs tend to have more success than those aimed at changing societal attitudes. It is important to realize that these approaches are not at odds with each other. As individuals are able to overcome the psychological impacts of their disfigurement they will become more confident and courageous and therefore become more present and active in society. This, in turn, may lead to a change in societal attitudes and actions towards individuals with differences in appearance (Clarke, 1999).

Quality of Life

As evidenced by the literature reviewed thus far, a majority of the research examining the effects of physical deformity has focused on specific areas of impact and individual coping strategies. Very little research has examined quality of life as it is affected by physical deformity. Coping is defined as fighting or contending, and dealing with problems (Webster's New World Dictionary, 1990). It is the opinion of this author that simply coping through life is insufficient and that individuals with physical deformities should be able to experience a life of quality. Quality of life is a highly important concept as it is "a social construct that is affecting program development and

service delivery in the areas of education, health care, mental retardation, and mental health" (Schalock, 2000, p.116).

According to Schalock (2000), quality of life has been defined in more than 100 ways. As research in the field of quality of life has progressed, researchers have come to agree on several key issues (Schalock, 2000). The first is that quality of life is a multifaceted and multidimensional concept, which precludes its reduction to a single *thing* (Flanagan, 1982; Keith & Schalock, 1992; Schalock, 2000). According to Schalock (2000), a second agreement is that a focus on satisfaction is key to the overall concept of quality of life. Finally, researchers tend to agree that quality of life is a subjective concept, different individuals will vary in the value they place on certain dimensions, and these values will shift across one's life (Keith & Schalock, 1992; Schalock, 2000). Beyond these noted areas of agreement, researchers still differ on the core dimensions they include in conceptualizing quality of life (Schalock, 2000).

Keith and Schalock (1992) have suggested that quality of life involves "at least four basic aspects including general feelings of satisfaction, well-being, social belonging, and empowerment or control over one's life" (p. 87). Roberts and Cairns (1999) further explain that, "quality of life is not solely dependent on one area, but relies on a fluid and transactional interplay of each individual area" (p. 33). This is a highly useful conceptualization of quality of life for research, as it is simple yet comprehensive. It is also highly useful for research involving adolescents as this model was developed specifically through questionnaires with youth and for the purposes of understanding the experiences of adolescents (Keith & Schalock, 1992). Roberts et al., (2003) have begun

to examine the experiences of individuals with pectus excavatum who have undergone the Nuss corrective procedure using this conceptual framework.

Need for Further Research

As previously mentioned, the majority of research in physical deformity utilizes quantitative methodology. Although these approaches are highly informative, Thompson and Kent (2001) recommend that qualitative studies be conducted in order to more fully understand the subjective nature of living with a physical deformity. Quantitative research to date has provided a basic understanding and structure of concepts; additional qualitative research will add depth and nuance to these basic concepts and create a more complete picture of the experience of being different in appearance.

In addition to the need for qualitative research, there is a need to examine physical deformity as it relates to quality of life, as the majority of previous research has focused on specific impacts and coping strategies. An understanding of the effects of deformity on quality of life "would be of great help to the health professions in focusing treatment on the total well-being of their patients, rather than providing remedies for their immediate problems only" (Flanagan, 1982, p. 59)

Finally, there is a need for research examining the experiences of individuals with pectus excavatum. Although medical researchers have examined the effects of pectus deformities on cardiopulmonary functioning (Crump, 1992) very few studies have examined the impact of this chest wall deformity on individuals' social and psychological well-being. The proposed research addresses several of these needs for further investigation.

Summary

In examining the challenges of living with a physical disfigurement, research takes two perspectives, an external or sociological approach and an internal or psychological approach. Research examining social impacts shows us that a difference in appearance will affect the ways in which others perceive and interact with an individual, and can result in enacted stigma and teasing. Research examining psychological impacts shows that a difference in appearance can result in anxiety, depression, and decreased self-esteem, however, it has more consistently demonstrated a wide variety in individuals' responses to their disfigurement. This variation cannot be attributed entirely to severity or visibility, but is likely that result of the interaction of a variety of factors including age, self-concept, competency, attributional tendencies, social skills, social support and coping strategies. Interventions based on these approaches to research have been developed, however those addressing the psychological impacts of disfigurement are most successful. Finally, the concept of quality of life and the need for further research is discussed.

Chapter Three – Methodology

This chapter will outline the research approach used in addressing the question, "What are the self-reported pre-surgery experiences of adolescents with pectus excavatum?" The chapter will outline the general approach and research paradigm. The researcher will present her biases and assumptions. Finally, the participants and interview style will be presented as well as the processes for data collection and data analysis.

General Approach/Paradigm

The purpose of this study is to develop a comprehensive understanding of adolescents' experiences of living with pectus excavatum. In order to achieve this, a qualitative approach has been employed as qualitative research seeks to understand and bring meaning to experiences (Anderson & Arsenault, 1998). A qualitative approach to research is interactive, humanistic and emergent as it attempts to view social phenomena holistically (Creswell, 2003). "A fundamental assumption of the qualitative research paradigm is that a profound understanding of the world can be gained through conversation and observation in natural settings rather than through experimental manipulation under artificial conditions" (Anderson & Arsenault, 1998, p. 119). As previously mentioned, other researchers in the field of physical deformity have suggested that qualitative research is needed in order to create a more complete understanding of the experience of deformity. As the purpose of this research is to gain a deeper understanding of a particular human experience, the qualitative paradigm is the most appropriate approach.

Research Design

This study employed a phenomenological research design, with a purpose that is "aimed at understanding the meaning of experiences in our everyday lives" (Anderson & Arsenault, 1998, p. 121). The goal of this research design is to "produce clear and accurate descriptions of a particular aspect of human experience" (Polkinghorne, 1989, p. 44). Unlike natural scientific research, phenomenology does not seek to predict and control the topic of interest, it seeks to create a deeper and more meaningful understanding of an individual's experiences. Phenomenological approaches stem from specific ontological and epistemological positions. In an ontological sense "people are considered to be tied to their worlds – embodied – and are understandable only in their contexts... human behavior occurs in the context of relationships to things, people, events, and situations" (Morse & Richards, 2002, p. 45). The epistemological position holds the underlying assumption that individuals' perceptions and experiences are evidence of the world as it is lived, rather than as it is thought to be (Morse & Richards, 2002). It is based on the understanding that "all knowledge is ultimately grounded in human experience" (Polkinghorne, 1989, p. 45). In other words, we cannot know things outside of our experiences of them.

Phenomenological research employs no single method; rather the phenomenon under investigation and the aims and objectives of the researcher evoke a particular method (Colaizzi, 1978). This being said, there are general guidelines and procedures that are accepted among phenomenological researchers. "Evidence from phenomenological research is derived from first-person reports of life experiences" (Moustakas, 1994, p. 84). It involves participants who are living, or have lived, the experience under

investigation, and who are interested in and willing to participate in an exploration of the nature and meanings of that experience (Moustakas, 1994). Data sources within phenomenological research can include written participant descriptions, observations of lived-events, outside depictions, in-depth interviews, and the researcher's own reflections (Colaizzi, 1978; Polkinghorne, 1989).

Analysis procedures vary according to the phenomenon being investigated and the aims of the researcher; however both Colaizzi (1978) and Polkinghorne (1989) outline some general steps and guidelines for the analysis process. According to Polkinghorne (1989) the purpose of data analysis in phenomenological research "is to derive from the collection of protocols... a description of the essential features of that experience" (p. 50). Typical analysis procedures include an overall reading in order "to acquire a feeling for them, a making sense out of them" (Colaizzi, 1978, p. 59). Following this, significant statements or meaning blocks are extracted and meanings are formulated. Colaizzi (1978) elaborates on this process by stating that "meanings are given with the protocol but are not in it, so the researcher must go beyond what is given in the original data and at the same time stay with it" (p. 59). Typical analysis procedures then group the extracted meanings into theme clusters; both Colaizzi (1978) and Polkinghorne (1989) recommend that theme clusters be referred back to the original protocols or transcripts in order to test their correctness. One other step that can be included in analysis is participant checking, in which participants review and validate the researchers analysis (Colaizzi, 1978; Moustakas, 1994; Polkinghorne, 1989). Finally the theme clusters are used to create a composite description of the experience under investigation (Colaizzi, 1978; Leedy & Ormrod, 2001).

Polkinghorne (1989) describes several important outcomes of phenomenological research:

> The research results amplify our understanding of these experiences and lead to several consequences: (a) we can appreciate and be more sensitive to those involved in these experiences, a particularly significant consequence for those in the helping professions; (b) some of the understandings derived from logical-mathematical theories and research can be enlarged on, deepened, and, in some cases, corrected; and (c) social action and public policy can be amended so as to be more responsive to the way in which we experience various situations. (p. 58)

These outcomes are achieved through in-depth, comprehensive descriptions of the experiences of individuals who have lived with or through the phenomenon in question. Phenomenology is an appropriate methodology for this study, which seeks an in-depth and comprehensive understanding of the essence of adolescents' experiences of living with pectus excavatum deformities.

Entering Assumptions

Within phenomenological, and qualitative research in general, epoche or bracketing is considered "important for locating the presuppositions and biases the researcher holds as well as clarifying the parameters and dimensions, of the experience" (Polkinghorne, 1989, p. 46). Bracketing has been described as a holding of prior knowledge and assumptions in suspension in order to enter the research process free of presuppositions (LaVasseur, 2003; Morse & Richards, 2002). According to Colaizzi, (1978) within phenomenology "objectivity is fidelity to phenomena... it is a refusal to tell the phenomenon what it is, but a respectful listening to what the phenomenon speaks

of itself" (p. 52). The practice of bracketing, or epoche, increases the researcher's ability to assume "an unfettered stance" (Moustakas, 1994, p. 85) and approach the phenomenon under investigation "as if for the first time" (Moustakas, 1994, p. 85). LaVasseur (2003) suggests that, "the project of bracketing attempts to get beyond the ordinary assumptions of understanding and stay persistently curious about new phenomena... this provides opportunity for fresh experience and the possibilities of new horizons of meaning" (p. 419). As part of the bracketing process many authors acknowledge and present their own assumptions and positions in regards to the research topic, bringing a measure of honesty and authenticity to the research (Lincoln, 1995). Although the author does not believe it possible to completely disengage from one's worldview for the purposes of research, she does see value in the process of reflexivity, exploring biases and presuppositions and presenting these to the reader. This increases the researcher's awareness of their personal biases and presuppositions as well as creates a lens through which the reader can understand the study. For this reason the author has kept a journal outlining the research experience and has included portions of this within the following sections, in order to acknowledge the process involved in the analysis and presentation of the data. In keeping with this same approach the following assumptions are acknowledged and presented:

1. The participants were expected to be honest with their responses.
2. The participants were expected to accurately carry out the instructions provided by the researcher.
3. It was expected that having pectus excavatum does impact one or more areas of an individual's quality of life, at the same time it is acknowledged that previous research has found a wide variation in individuals' responses to their physical

deformity (Anderson, 1982; Kent, 2000; Kent & Keohane, 2001; Sarimski, 2001; Thompson & Kent, 2001). The author entered this project prepared to conduct a thorough examination of the lived experiences of adolescents with pectus excavatum with an open mind.

4. It is the researcher's belief that living with a physical deformity, particularly pectus excavatum, is particularly difficult during adolescence for two reasons; this is the time in life when pectus excavatum becomes more pronounced (Crump, 1992), and this is a time in life when one's self-concept is undergoing both change and consolidation, and peer groups are playing "an especially significant role as contributors to development" (Coleman & Hendry, 1999, p. 155).
5. It is expected that an examination of the experiences of adolescents with pectus excavatum will contribute to greater sources of information accessible to other adolescents with similar physical deformities.
6. It is expected that the perspectives and contributions of these adolescent participants are as valuable as those of experts in the field.

Participants

In this study the sample is a purposive, criterion-based sample; each participant had lived the experience under investigation. Participants were drawn from a larger group of individuals who have volunteered to participate in a larger, longitudinal study. These participants were identified through contact with surgeons who perform the Nuss procedure for the correction of pectus excavatum. Six participants between the ages of ten and nineteen who had not yet undergone corrective surgery were invited to participate in this study and agreed. All participants were male; this is largely due to the fact that

pectus excavatum is more common in males (Emery, 2001). This does imply that the results of this investigation are primarily applicable to males. Although females with pectus excavatum may have some similar experiences of physical deformity they may also have different ones and may respond to their experiences differently. Participants had to be willing to participate in a one-on-one in-depth interview and had given permission for the interview to be tape-recorded. All participants reside in western Canada.

Interviews

In order to gain detailed descriptions of participants' experiences, the study involved semi-structured, in-depth interviews, consisting of open-ended questions. This format is the most common in phenomenological research (Leedy & Ormrod, 2001). Open-ended interviews give the participants a large degree of control over their time with the researcher, balancing what the participants feel is relevant and important, with the researcher's goal of maintaining focus on the phenomenon under investigation (Leedy & Ormrod, 2001; Polkinghorne, 1989). Moustakas (1994) describes the phenomenological interview as follows,

> The phenomenological interview involves an informal, interactive process and utilizes open-ended comments and questions. Although the primary researcher may in advance develop a series of questions aimed at evoking a comprehensive account of the person's experience of the phenomenon, these are varied, altered, or not used at all when the co-researcher shares the full story of his or her experience of the bracketed question. (p. 114)

The interviews for this study began with the question, "What is it like for you to live with pectus excavatum?" Follow up questions were based on the four main aspects of quality of life presented by Keith and Schalock (1992), and are structured similarly to the interview questions used by Roberts and Cairns (1999), as well as those used by Roberts et al. (2003). Questions addressed the impact that pectus excavatum has on the participants satisfaction, well-being, empowerment and control, and social belonging. Each interview was concluded with a question that asks participants for any further information that they felt was pertinent to the research (For the interview guide see Appendix A).

Data Collection

Each potential participant was contacted via phone by the researcher. The researcher introduced herself and invited each adolescent to participate in the study. The purpose of the study, as well as the concept of informed consent, and the contents of the informed consent form (see Appendix B) were discussed. If both the parent, or guardian, and the adolescent consented to their participation, a time and location (either the participants home or an office at the University of Victoria) for the interview was established.

At the beginning of each interview the researcher reviewed the informed consent form with the participant and their parent or guardian, answered any questions they had, and had them sign the form. Given the varying ages of the participants it was decided by the researcher to allow each participant to decide for themselves who would participate in the interview. Of the six participants, three chose to be interviewed with one or both parents present. The remaining three were interviewed alone. It is the author's opinion

that allowing the participant to choose was best for creating an interview environment in which the participant was most comfortable.

> *From my journal: I have now completed two interviews one in which the participant chose to be interviewed alone and the other in which the participant chose to have a parent present. These were certainly two very different interviews but also two very different young people. With the first participant I left feeling that it was probably best to have interviewed him alone. He shared very openly with me and seemed very relaxed and I wondered if having a parent present would have interfered with this? However, the second participant was also very willing to share and the data resulting from his conversations with his parent, and the insight the parent provided were very interesting. I believe allowing each participant the freedom to choose how to be interviewed is the right decision for creating the most comfortable atmosphere as well as for respecting their individual preferences, but I wonder how it will affect the data, would the interviews have been drastically different if I had made this decision for them?*

All interviews were tape-recorded and proceeded as outlined in the semi-structured interview guide (Appendix A). At the completion of the interview, participants were thanked and informed that they would receive a copy of the interview transcript and initial analysis for verification.

Procedure for Data Analysis

Each tape-recorded interview was transcribed verbatim and analyzed for central themes and meanings. Transcriptions included the entire interview including statements made by parents when they were present. Analysis procedures were similar to those described by Colaizzi (1978) and were modeled after the analysis process established by Roberts and Cairns (1999). The researcher began by listening to each tape repeatedly in order to gain a sense of the overall meaning in each interview. Next, the researcher extracted significant statements from each paragraph of the transcript. Each statement was considered for its significance to the research question and the details it held pertaining to the participant's experience. Following this, central meanings or themes

were formulated for each extracted statement. Themes reflected the essential point or meaning of the participant's statement and, as often as possible, included the same words the participants themselves had used.

> *From my journal: I find myself fully immersed in the process of qualitative analysis. This is a new and uncomfortable place for me, not the simple entry of numbers that I am accustomed to. Who am I to determine which statement holds more meaning than another? I find myself with a strong desire to do justice to the experiences of these participants and I wonder if the sum of all these parts will accurately reflect the whole. I find comfort in knowing that each participant will review this initial stage of analysis and have the chance to confirm or change it. I also find I am completely consumed by this process, I find myself up in the middle of the night because I am struck by a thought about something in a transcript or have rethought a theme decision. It is a process that has been a continual back and forth and I wonder how I will know when it is completed.*

Each transcript, along with the initial analysis, was returned to the participants in written form to be reviewed for accuracy and validation. In a follow-up phone call, participants were invited to share their feedback. This verification procedure involved both the adolescent participants and those parents that had been included in the interview process. During the telephone reviews the researcher took extensive notes. Only one of the six participants requested minor changes to transcript and themes and these were completed accordingly. Many of the participants noted that the themes assigned to their various statements were accurate reflections of their experiences. Following participant verification the individual themes were organized into clusters and each cluster was labeled according to its overall meaning. Clusters were further arranged into categories which served as an organizational structure for the data. The percentage of participant accounts in which each theme or meaning was found, has been calculated and reported within the results. In order for a theme to be included in the analysis it had to be addressed by at least two of the six participants. These categories and clusters were then

used to create a composite description of the experiences of adolescents with pectus excavatum.

> *From my journal: As I begin to organize the emergent themes into clusters and categories I am faced with the decision of what should be included. In how many interviews should a theme be found in order to be included in the final analysis? The quantitative part of me tells me that in order to be relevant a theme must have appeared in a majority of the interviews. However using this thinking I find myself excluding themes that I know were important to my participants, themes that are salient and meaningful to their experience. This is qualitative research, salience holds as much, if not more, weight than prominence. I need to include those salient themes in order to remain true to the participants and to the research.*

Rigour

"Establishing and maintaining rigour is recognized across disciplines as an essential element of research" (Mill & Ogilvie, 2003, p. 80). There are a variety of methods for establishing rigour within qualitative research (Creswell, 2002). At a basic level "systematic and self-conscious research design, data collection, interpretation and communication" are required (Mays & Pope, 1995, p. 110). For this reason a systematic research method was pre-selected and followed; an interview guide was created and evaluated prior to beginning data collection and a systematic method of data analysis was selected, described, and closely followed. Creswell (2002) describes three primary forms of validating findings in qualitative research; these include triangulation, member checking, and external audits. In the current study member checking was employed. Participants were asked to review a copy of their interview transcript along with the themes that had been applied to their various statements. In a follow up phone call participants were given the opportunity to provide feedback and recommend changes. Finally, the researcher's supervisor reviewed each phase of data collection and analysis in order to gain insight and comment from a more experienced investigator, although this

does not equate to what Creswell (2002) describes as an external audit it does add to the rigour of this study.

Ethical Considerations

As previously indicated, this study is part of a larger, longitudinal study being conducted at the University of Victoria. Ethical approval for the longitudinal study was obtained from the University of Victoria. This ethical approval included clearance for the present study, an amendment adding this author as a co-researcher was submitted and approved (see Appendix C).

All participants were informed that their participation was voluntary and they were free to withdraw from the study at any time. Participants were also assured that their anonymity would be ensured, as their names would not be attached to any data. All records are contained in a locked filing cabinet and will remain there until they are destroyed five years after the completion of the study.

Summary

Chapter three has outlined the qualitative approach and phenomenological methodology used in this study. The importance of entering researcher assumptions was acknowledged and the participants, interviews, and procedures for data analysis were also discussed. Finally a brief explanation of the ethical considerations was presented.

Chapter Four – Results

This chapter presents the results of data analysis. The first section introduces the participants by providing a brief description. The second section outlines the essential structure of the experience investigated. Following this, the categorical, cluster, and thematic structures that compose this experience are presented and described. Direct quotations from participants are included here to convey the meaning of their experiences.

Participant Profile

Within the following brief descriptions of participants all names have been changed in order to protect the identity of the participants and their families. Dr. Aston is the name that has been used for the participants' surgeon.

Paul is sixteen years old and attending grade ten. He has four older siblings and chose to be interviewed alone. Paul's surgery was scheduled for five days after the interview.

David is thirteen years old and attending grade eight. He has two younger siblings and chose to include his mother *Sandra* in the interview. David's surgery was scheduled for six weeks after the interview.

Jack is fifteen years old and attending grade ten. He has one younger sibling and chose to include his mother *Kelly* in the interview. Jack's surgery was scheduled for six weeks after the interview.

Sam is ten years old and attending grade four. He has one older sibling and chose to include his father, *Gordon* and his mother, *Janet* in the interview. Sam's surgery was scheduled for five weeks after the interview.

Jordan is thirteen years old and attending grade eight. He has one older sibling and chose to be interviewed alone. Jordan's surgery was scheduled for three weeks after the interview.

Bruce is nineteen years old and has completed two years of university education. He has four older siblings and was interviewed alone. At the time of the interview Bruce was still waiting for his surgery to be scheduled.

Essential Structure of the Experience

The present study focused on the experiences and perceptions of six adolescent males with pectus excavatum. Participants had decided to undergo the Nuss Procedure to correct their chest wall deformity. The goal of this research was to understand what life is like for adolescents with a physical deformity. More specifically this investigation was aimed at describing the participants' lived experience of pectus excavatum and to explore their pre-surgery perceptions.

Participants described their sense of social belonging and the influence that their pectus excavatum has had within their social context. All participants had a peer group who had acknowledged and accepted their physical difference and with whom they felt comfortable and accepted. However, many participants also described dealing with social curiosity and some ridicule or teasing within their larger social context. For many, this resulted in a sense of embarrassment and isolation and at the very least was a complicating factor in their decisions regarding social activities.

Beyond its influence on social activity decisions, many of the participants felt that their pectus excavatum played a role in their sense of personal empowerment. For most, there was a period of limited knowledge and unanswered questions about their chest wall

deformity; they were unsure of what it was and if it could be treated. The adolescents found that this lack of knowledge limited their sense of control over this aspect of their lives. When they were able to gather information about pectus excavatum, many of the participants felt empowered through this knowledge as well as through the support they received from their families and friends.

The adolescents described their sense of wellness and satisfaction with life. Generally the participants were satisfied with their lives, however they tended to feel that their pectus held them back in many ways. They found no true benefit to their pectus excavatum and frequently expressed embarrassment, self-consciousness, and uncertainty. They had developed a number of coping strategies including avoidance and humor. Participants expressed satisfaction in the support and acceptance they received from family and friends as well as in their ability to accept their own differences and have confidence in themselves in spite of those differences.

Finally, the adolescents shared their journey of making the decision to have the Nuss procedure for the correction of their pectus excavatum. They shared about the search for information and the factors surrounding their surgery decisions. They spoke of their sense of control over this decision as well as the influence that their parents and doctors had on this decision. They also shared their concerns and expectations for their surgery experience and its results.

Categorical, Cluster, and Thematic Structures

Four categories were identified through the analysis: 1) social context, 2) empowerment and control, 3) well-being and satisfaction, and 4) surgery. The first two categories are composed of three thematic clusters; the second two each include four

clusters. Table 1 provides an overview of each category and the clusters that compose it. Tables 2, 3, 4, and 5 present the themes that compose each cluster within a category. Included in the tables is the percentage of participants who addressed each theme within their interview. All of the themes included were addressed by at least one third of the participants.

Table 1: Categories and Clusters

Categories			
Social Context	Empowerment and Control	Well-Being and Satisfaction	Surgery
Clusters within each Category			
Social Belonging	Lack of Knowledge	Coping Strategies	Information
Social Reactions	Knowledge and Personal Responsibility	Social Support	Catalyst for Correction
Social Limitations	External Impacts	Satisfaction	Issues Surrounding Surgery
		Negative Affect	Post-Surgery Expectations

Category One: Social Context

Issues of social belonging and acceptance were of central importance to the lives of the participants as they are for most of us. The quality of one's social relationships greatly affects one's overall quality of life. Participants were open in discussing their personal sense of social belonging. They discussed those relationships in which they felt accepted and understood. Most of the participants indicated that pectus excavatum has impacted their social relationships, be it through the reactions that they received from others or the impact this disfigurement has on their own confidence and willingness to

engage in social activities and relationships. The social context category is made up of three clusters: social belonging, social reactions, and social limitations. The themes that emerged from the interviews are arranged within these three clusters and are presented in Table 2. Each cluster is then discussed and further explained through direct quotations from the participants.

Table 2: Category One: Social Context

Clusters		
Social Belonging	Social Reactions	Social Limitations
Themes within each Cluster		
Peer acceptance (100%)	Peer acceptance (100%)	Socially limiting and/or complicating (67%)
Peer acknowledgement (83%)	Social curiosity (83%)	Embarrassment (67%)
	Social ridicule and teasing (33%)	Lack of confidence (50%)
		Self-consciousness (67%)
		Difference in appearance (50%)

Theme cluster one: Social belonging.

Throughout the interviews, all of the participants spoke of their relationships with peers, most specifically with their friends. Participants explained that their peers were aware of, and had acknowledged their physical difference and in the majority of cases those close to them had simply accepted the difference. Therefore, the youth affected by pectus felt accepted by their circle of friends, regardless of their physical differences.

Each participant spoke of friends and peers who were aware of, and acknowledged, their pectus excavatum, although the majority did not know what it was called or how to explain it. Jack explained that his pectus excavatum was public knowledge in his school: "Everybody knows... probably people who aren't my friends know." There were a variety of ways in which their peers had become aware of their pectus excavatum. For many of these youth, their peers became aware during some activity that involved removing their shirt. Sam explained, "some people in class know... at gym class we were changing, and they saw the hole." Others decided to tell their friends about it. Jordan said, "my closest friends know about it... I told them."

When asked if their friends' awareness of their pectus excavatum had impacted their relationships, all participants claimed that it did not. They all felt accepted by their peers. David explained this acceptance: "I think most people that I meet with already know that I have it, and they just kind of... that's David." Jack and Bruce described similar experiences: "Just kind of, hey it's Jack with his hole in his chest," "Yeah, they know, and they uh, they don't really say anything about it, it's just like, you know, my body." The youngest participant, Sam also felt this way: "They don't really care, they just play, we just play together." Although Paul felt self-conscious about his pectus excavatum around his friends, he also felt that they have accepted him and are not concerned about his physical difference:

> Um, they never really ask me many questions about it I guess, they don't really know how self conscious I feel about it but it doesn't really matter to them, they don't really care, it's not that interesting for them to talk about.

In general, these youth had a positive sense of social belonging, which in turn, has a positive effect on their overall quality of life.

Theme cluster two: Social reactions.

Each of the youth affected by pectus excavatum spoke of having to deal with the reactions of others to their physical deformity. In some cases those reactions were positive, friends who were accepting regardless of the physical difference and who did not allow it to interfere with the relationship. In other cases these youth have answered to a lot of social curiosity, and sometimes have even faced social ridicule or teasing about their pectus excavatum.

As previously mentioned, all of the youth interviewed have a peer group that has accepted them regardless of their pectus excavatum, and in fact pay very little attention to it. As David stated: "I have a couple of really close friends... we just kind of leave it alone, we don't ever talk about it." Paul was also confident about his closest friends, "it doesn't really change anything with them." One mother, Janet, had also observed that her son had been accepted regardless of the physical deformity: "Nobody's mean to him about the hole, everybody is nice to him, so he's thinking that it's okay."

A majority of the youth had also dealt with a great amount of social curiosity about their physical condition. Some of these youth claimed the questions they were frequently asked by others were the most difficult aspect of having pectus excavatum. David explained:

> The hardest thing is somebody asking you what it is, trying to explain to them, what pectus is... I sometimes get discouraged about like the pools and stuff, when

> I hang out with my friends, and like, in the locker room people say, 'hey you've got a hole in your chest', so, I try to deal with it...

For Paul, part of the difficulty dealing with the social curiosity was not having any answers to provide, as he had not yet discovered what pectus excavatum was:

> I didn't know what was wrong and they kept on asking me and asking me, and they would make up theories and, yeah, it was uncomfortable... I had people ask me if I was shot and everything.

Some of the participants experienced the curiosity of others simply through the actions of strangers. Jack told a story depicting the curiosity of individuals outside of his peer group:

> Two experiences in one car ride, I didn't have my shirt on in the car, and we were just sitting in the parking lot, cause my Mom was in the grocery store, and uh, this guy he sort of, you could tell that he had, he had sunglasses on, and you could tell that he was staring at me, trying not to make it look as though he was staring as he slowly walked by, he sort of kept his head tilted, however not enough to make it sure that he was actually looking but, you know, he had sunglasses on, he noticed. And then in the same car ride this guy takes a triple take, he looks over three times, and that was pretty funny.

In some cases, the curiosity of others arose not from the physical difference itself but the circumstances that surround the condition of pectus excavatum. Jordan explained that his friends were curious about his frequent absences from school when he was at various appointments with doctors and surgeons. "I told my closest friends 'cause they asked why I'm always not at school." The oldest participant, Bruce, found that his peers expressed

curiosity as concern, "if they do say anything, they just, you know they point it out pretty much, and it's like yeah, I knew that." Bruce also mentioned that his pectus excavatum received more attention when he was younger, "I've had it all my life, and you know kids would say stuff to me more when I was younger."

Experiences of teasing and ridicule were less frequent than those of sincere curiosity. However, there were two participants who told of experiencing teasing. The two seemed to deal with these situations in very different ways. For Paul, it was a highly unpleasant experience:

> At school everyone knows about it and everything, and um, they don't realize that, like they're just doing it in a joking manner, not to be mean but they don't realize how self conscious I really am about it, and they're always like, 'oh, can I poke your hole, can I see it" and that makes me feel kind of embarrassed I guess.

Jack has had similar experiences but seemed to have a sense of humor about them:

> People poke it quite hard, some people, it's kind of strange... with one person, the poker, he comes up and pokes me every time... he, I don't know, it's just something we make jokes about, we made a handshake where he pokes me in the chest, stuff like that...

Each of the participants has experienced both positive and negative social reactions to their pectus excavatum and, for the majority, there is a close peer group that has been positive and supportive. Each participant has also dealt with curiosity and possibly some teasing, primarily from individuals they are not particularly close to.

Theme cluster three: Social limitations

Several of the participants described the phenomena of physical deformity as limiting their social experiences. This was due to a desire to avoid negative attention, a lack of confidence due to previous social experiences, or general anxiety and self-consciousness arising from their difference in appearance.

Many of the participants reported avoiding social activities that involved removing their shirt, specifically swimming. Paul explained his discomfort with swimming and told of a recent experience:

> My friends always ask me to go swimming with them, and I just, usually I'm too self-conscious to even go. Yeah, it just makes me feel really self-conscious... I guess it was last Monday, we had a Pro-D day and everyone was going to the beach, and I got, I kind of wanted to go, I don't really like swimming that much but I still really wanted to go to the beach just to like, hang out with them and everything, but I just didn't really want to go and take my shirt off and show them all.

Paul declined the trip to the beach that day; he wanted to avoid the questions from peers that would certainly have been asked when he removed his shirt. In this way his social activities have been limited by pectus excavatum. David has also experienced some discomfort with swimming:

> I've got a good life, it only affects me in the social area, when I go to see my friends and stuff, or when I meet girls at the pool... it's a bit harder to do, like, people are 'oh just come swimming', and it's like, no, it's a little bit more complicated than that.

Although David did often choose to go swimming with his friends, it was frequently a difficult decision to make. His mother, Sandra, had noticed this, "We didn't talk about it a lot except I knew with swimming sometimes it was an issue... he's been hesitant about swimming situations where obviously he's exposing it." Bruce also mentioned avoiding activities such as swimming:

> It can be difficult at times, like, sometimes I do avoid activities where I have to take my shirt off... I always liked swimming but as I got older I kind of got a little uncomfortable with it... I just avoid social situations like that, even locker rooms and stuff, I try to switch my shirt as fast as possible.

At the time of the interview Sam was not bothered by activities that required the removal of his shirt however, his father, Gordon pointed out that, "he has gone through a stage earlier where he didn't want to take his shirt off anymore." Gordon had noticed a general self-consciousness in his son and went on to explain this further:

> I don't know how old he was when he didn't seem to want, and it may not have been his hole in his chest that he didn't want to take his shirt off in public, like it may just be showing your upper body naked... you know, all people, well especially boys go through that at some point, so whether it was related to the pectus we don't know, but there was a period where I noticed that he didn't like to take off his shirt.

Gordon's statement depicts how difficult it is for others to distinguish the extent of the psychological and social impact pectus excavatum has on individuals. The older participants where clear in ascribing their discomfort with certain activities to their pectus

excavatum, but as an observer it may be difficult to appreciate the complexity of avoidance behaviors.

Beyond discomfort with specific activities, several participants described a general sense of self-consciousness and a lack of confidence that they believed to be the result of their difference in appearance. Paul described his lack of confidence as the most difficult aspect of having pectus excavatum, "the way it like kills my confidence, and having to deal with everyone always staring and when I'm swimming with them or when I have my shirt off, and just all the questions I get asked." Although a lack of confidence may not be a direct result of pectus excavatum it develops as a result of negative social experiences. Bruce also described social anxiety across many contexts:

> I can be very self-conscious about it, like uh, even just walking down the street or whatever, it's uh, sometimes I feel it's pretty obvious but it's really not...it gives me a lot of anxiety at times... if I'm around people I don't really know, I'll get self-conscious thinking about my chest, and um, you know I'll often tug on my shirt, or whatever, to try and hide it a bit... the anxiety that comes out of it sometimes does affect some of my socializing.

Overall, all participants reported having a peer group with whom they felt accepted and comfortable, the majority of these peers were aware of the participants pectus excavatum but chose not to focus on it. Participants also described some less desirable social reactions that they have had to deal with, including social curiosity and teasing. For the majority of these young people, pectus excavatum has limited their social experiences in one way or another. It is clear that pectus excavatum has played a role in the socialization of these participants.

Category Two: Empowerment and Control

Issues of empowerment and control were prevalent throughout the interviews. The majority of participants expressed a strong sense of control over the decision to pursue surgery. They lacked control most when they were without knowledge about pectus excavatum and the various procedures available for correction. Participants spoke of the sense of empowerment that came when they had finally received some answers about what pectus is and what options were available to them. Many of the participants were also empowered through the concern and support of their parents and the acceptance of their peers. The empowerment and control category is made up of three clusters: lack of knowledge, knowledge and personal control, and external impacts. The themes that emerged from the interviews are arranged within these three clusters and are presented in Table 3. Each cluster is then discussed and further explained through direct quotations from the participants.

Table 3: Category Two: Empowerment and Control

Clusters		
Lack of Knowledge	Knowledge and Personal Responsibility	External Impacts
Themes within each Cluster		
Lack of knowledge about pectus excavatum (83%)	Proactive seeking of information (67%)	Parental concern and support (100%)
Lack of knowledge about correction (50%)	Empowerment through information (83%)	Peer acceptance (100%)
	Personal control (100%)	

Theme cluster one: Lack of knowledge.

Although many of the parents who participated in interviews reported that their child's pectus excavatum was evident at birth, not one of the participant's condition was properly diagnosed at that time. Each of the participants lived for a period of time with no explanation or label for the condition of their chest. Many of these individuals received incorrect or incomplete information from their doctors. Sandra explained her experience when David was an infant:

> I remember when he was younger, you know, asking what's this, and I don't ever recall ever getting an answer, that I really knew, it was sort of like 'oh, that's sort of the way it is', and okay, as a mother I went on and never thought anything more about it... I think there's part of me that wishes I had known earlier, been more vigilant about it, so maybe we could have corrected it earlier for him...

The lack of information available to this family resulted in a lack of control over the situation, and has ultimately caused some regret. Bruce's parents had also received misleading information at his birth and eighteen years passed before he was able to find answers:

> My Mom knows about it, cause I had it when I was born and the doctor told her that I would grow out of it... I didn't know what it was, I didn't have a clue, I really didn't find out until you know, last year I think, I found out that there was actually a name for it and that it was actually like a relatively common thing.

Paul also received misinformation, "I remember going to the doctor once and they told me I was missing a rib, and I don't know how they could think that." As previously mentioned, Paul found that lack of information made it difficult to deal with the many

questions he received from his peers. The lack of information about pectus excavatum was necessarily tied to a lack of information about its correction, without a name for their condition, participants could not pursue potential treatments. Paul explained, "I always wanted to like get something done about it, but I never knew if anything could be done. Sometimes I'd look for research on the internet and see if I could find anything, but I never could." This lack of knowledge about pectus excavatum and the corrective procedures available immobilized participants from taking action and control over their condition.

Theme cluster two: Knowledge and personal responsibility.

Many of the participants described a sense of empowerment that came when they finally found information about pectus excavatum and its correction. Participants and their families were proactive in seeking this information, with several of them doing their own research on the Internet and being proactive in seeking physician referrals. Bruce explained how he discovered what pectus excavatum was and became connected with his surgeon:

> I was just looking on the Internet and I actually saw, this study at the University, some of that stuff, and then um, I noticed it was taking a lot of the study from Dr. Ashton and that he was working in Victoria, so I got a hold of the researcher and then she referred me to him, and of course I had to get a doctor, like a physician referral... then I went to the physician, and he said yeah, and then he couldn't find Dr. Ashton, in his little index, so I actually gave him the number, and then he called and checked that out, and then he referred me to him.

Gordon, Sam's father, described his family's experience with trying to access information, and their need to remain proactive in that search:

> At first I thought, I mean we knew about the pectus excavatum, I don't know, whatever the condition, and we were told that it's not a physical impairment as far as development, so we weren't, I wasn't concerned at all, I went okay that's just the way it is, and uh, completely happy to let him live his life that way. Then my wife had uh, discovered in Japan, or heard about, that there is a corrective surgery available, and I guess that was the, the previous procedure, not the Nuss, I don't know what you call the other procedure... the Ravitch procedure, so she found out about that, and I was like, well you know it doesn't have to be done, so why are we going to put him through that, and uh, and then we started to think more about it, and we didn't even, we weren't even aware of the Nuss procedure, um, but we decided to have another doctor look at him to see what can be done and that was Dr. Ashton... and he suggested, well we have this other procedure, the Nuss procedure which is far less invasive, so I guess that was, you know the deciding factor was it seemed less painful...

Gaining knowledge about pectus excavatum and the correction options available empowered these individuals and families to make decisions for themselves about what action to take, if any.

Sandra explained this empowerment, "We went to see Dr. Ashton... and he gave us the options, a couple of them, and what it was, and what it meant, and that's when David was able to make his decision." When asked what he would like done for other youth with

pectus excavatum David described the need for information in order to give individuals control:

> Just talk to them, and like tell them what it is, cause if I had known what it was a while ago I don't know, I think I might be doing something else, I don't know what though... I just have a, I'd be doing something different I think, I don't know what it is but, I don't know, if I knew what it was three years ago or something.

Finally, Paul also found that having the correct information empowered him in his interactions with peers:

> Dr. Ashton, he told me what it is, I had no clue what it was until they explained it to me, and that was a little easier when people asked me what was wrong with me, I could actually tell them. Before it was a little more uncomfortable because I didn't know what was wrong and they kept an asking me and asking me...

When the time came to make a final decision regarding surgical correction all participants felt that they had personal control over this decision, with the exception of the youngest participant, Sam, whose parents were a very active part of the final decision. Paul described his sense of personal control over this important decision, "Yeah, of course it was my decision, no one has ever forced me to do anything, and I've been able to make all the decision, like getting surgery and, all that stuff."

Theme cluster three: External impacts.

Several of the participants spoke of the support and encouragement they received from their parents, family members, and peers which empowered them to make their own choices surrounding their pectus excavatum and its potential correction. For several of

the participants, it was their parents that first suggested that they see a doctor about their pectus excavatum and explore potential treatments or corrections, which ultimately gave them a choice to make in the first place. According to Paul, his father had supported him in this way:

> About two years ago we went to the Dominican Republic and we were on the beach and everything, and they never really see me with my shirt off, and my dad saw it, like they always knew I had it, but like he saw it had gotten worse I guess when I started going through puberty, and he like made the arrangements for me to like see a doctor about it and started the whole surgery thing.

Jordan's father also noticed the change in the severity of his pectus and started him on the road to surgery. His parents also helped him make his decision through exploring the costs and benefits of the surgery with him, "Well, my Dad pointed it out last summer, they like pointed out some facts about the surgery and then, yeah that made me want it."

All of the participants also reported that their parents have been supportive of their decision to have surgery. As Bruce explained, "My Mom, yeah, she was pretty for it, she said if that, you know if that would make you happier then go ahead and do it... she was supportive I guess." David also felt the support of his parents; Sandra explained her position concerning David's surgery decision:

> If he chose not to do it, hey, it's his decision, and that's, you know it makes no difference to me, um, I believe that um, you know I'm very supportive of David's decision, I've ultimately let it be his, and um, because I feel that he's mature enough, he's thirteen, you know he's still a kid on one side, but he's very mature and I have to respect that and trust that...

Aside from parental support, David also described a feeling of support and acceptance on the part of a particular peer, "I told my closest friend, uh, when we met with Dr. Ashton, what it actually was, and he was just kind of like, oh, okay, you're having surgery, okay good luck..."

Each of the participants has decided to have their pectus excavatum corrected. For the majority of participants this decision was one, over which, they have had control. Many of them expressed a sense of empowerment that has come from the support and encouragement they have received from their parents and even from some friends.

Category Three: Well-Being and Satisfaction

Issues surrounding and impacting well-being and satisfaction were prevalent in all of the interviews. Although these two items are considered unique aspects of quality of life within Keith and Schalock's (1992) model they have been combined here to form one category. During the interviews the participants had a difficult time differentiating between well-being and satisfaction. Through the data collected it became clear that each participant viewed these as overlapping concepts if not two ideas that are subsumed within each other. Although researchers and theorists working to define quality of life have differentiated between well-being and satisfaction, for these young men, the two concepts were one in the same. The well-being and satisfaction category is made up of four clusters: coping strategies, social support, satisfaction, and negative affect. The themes that emerged from the transcripts are arranged within these three clusters and are presented in Table 4. Each cluster is then further described and explained through direct quotations from the participants.

Table 4: Category Three: Well-Being and Satisfaction

Clusters			
Coping Strategies	Social Support	Satisfaction	Negative Affect
Themes within each Cluster			
Avoidance of attention regarding pectus (83%)	Parental concern and support (100%)	Confidence (83%)	Self-consciousness (67%)
Humor (50%)	Peer acceptance (100%)	Acceptance/familiarity (67%)	Embarrassment (67%)
Hypothetical benefits (50%)		Peer acceptance (100%)	Uncertainty (83%)
			Lack of benefits (100%)

Theme cluster one: Coping strategies.

Throughout the interviews the participants shared a few of the strategies they had developed in order to cope with their physical difference. The most prominent of these was simply avoiding attention regarding their pectus. When asked about the reactions of peers to their pectus excavatum many of the participants responded that they had little to tell, as they tried to stay out of situations that would draw attention to this aspect of their physical appearance. Paul commented, "I don't really have anything to say, I don't really have any stories, I just try to keep it hush." Similarly Bruce stated that, "There's not many stories about it because all the stories I would have avoided right... with my friends it's been a pretty null subject, pretty ignored." For David as well, it is a topic that has been avoided in conversation with peers, "We just kind of leave it alone, we don't ever talk about it." Paul described his discomfort with attention regarding his pectus excavatum and how important it is for him to that this topic be avoided:

> Well for me, well this is just me, but I really like to avoid the subject, I really hate when people talk about it to me, like just out of the blue and everything, and it makes me feel uncomfortable talking about it... I like to avoid stuff like that, I don't know if other kids with pectus would feel the same way though... I know I'd feel uncomfortable if my teacher started asking, or like trying to help me out with pectus, and like talked to me about it, I wouldn't like that very much at all.

When asked about what kind of attention pectus excavatum receives in their household Sam's father, Gordon explained that it was simply not a topic of conversation, "No, in fact, I don't even think he, I mean this is probably the most attention, well is definitely is the most attention anyone has ever given it." In this case, it is difficult to determine if this is the result of Sam attempting to avoid the topic or if it was simply avoided by the family as a whole as a group coping strategy.

Evidenced throughout several of the interviews was the use of humor as a coping strategy. When asked about any benefits of their pectus excavatum, none of the participants were able to think of a true benefit but many came up with a humorous hypothetical benefit, this ability to joke about the condition came across as a mechanism for coping. Bruce commented that, "I can hold a beer in it sometimes... I could probably eat cereal out of it... I'm just speculating there, and definitely it would heat the milk up, so I wouldn't want to do that." Jack also came up with two humorous potential benefits:

> I haven't eaten cheerios out of it or anything, everybody says I should, so that could be something that it actually adds to, the weird eating experience... maybe if you wanted to plaster it up and then have something explode out of it, or something, I don't know, you could scare people or something.

Jack also described the use of humor with his peers, "It's just something we make jokes about, we made a handshake where he pokes me in the chest, stuff like that." Finally, Jack also reported finding situations in which people reacted to his pectus as being funny rather than uncomfortable.

For most participants, the most pervasive coping strategy that emerged from the interview was avoidance of situations that would draw attention to their pectus excavatum. For some of these, when these circumstances could not be avoided, they employed humor as a coping strategy. Finally, for one participant in particular humor stood out as an important coping strategy.

Theme cluster two: Social support.

As previously described, all of the participants described a sense of support from parents and friends. Just as this social support has contributed to the participants' sense of personal empowerment it also contributed to their well-being and satisfaction. For many of the participants, the support they described from their parents was related to their health and, more specifically, their surgery decisions. This was evident in the previously mentioned stories of parents initiating the search for correction options and empowering their children in this manner.

Many of the participants described their social relationships as being typical of individuals their age. Paul commented, "I go to my friends' houses or they come here and we just like watch TV or play video games." For most this seemed a very positive aspect of their lives. Although they were very aware of their physical differences they were also aware of their ability to have normal social interactions and relationships. David explained:

> I have a couple of really close friends, and then I just have like a bunch of middle friends, and I have lots of friends that are older than me, like in grade ten and stuff, and I feel that's pretty normal...

Bruce also felt that despite his pectus excavatum he has been able to develop satisfying peer relationships, "I can get along, I have quite a few friends so, [pectus excavatum] hasn't really hurt that too much." Generally, the participants described social relationships and support networks that contributed to a positive sense of well-being and satisfaction.

Theme cluster three: Satisfaction.

Throughout the interviews the participants and their families made comments and statements indicating satisfaction in many areas. There were several participants who demonstrated confidence, as well as many who displayed an acceptance of their condition that allowed them to carry on and enjoy life, despite whatever setbacks this deformity may have caused. Finally, as previously discussed, all participants indicated a sense of social belonging and peer acceptance that contributed to their satisfaction.

Confidence in these adolescents allowed them to participate in activities without worry about how others might respond to their physical difference. Although many participants spoke of times when pectus excavatum did limit their confidence and their willingness to engage in certain activities, they also related experiences of confidence. For example, David explained his ability to go swimming with his friends, "Usually I do end up going swimming anyways, and just, whatever this is the way I am, so if somebody's going to ask me then I'm going to tell them what it is." David's mother also commented on his confidence, "I think overall with David... from a parent's perspective,

he's a pretty confident young man... we talk pretty openly about things and overall I haven't seen it affect his life in a terribly negative way." Kelly, Jack's mother, also spoke of her son's confidence, "He runs around outside with his friends with his shirt off all the time... Jack is a well adjusted person, actually in the last few years he's become less shy at school than he used to be, he used to be a lot shyer at school." Gordon also spoke of an increased confidence in his son Sam, "He has gone through a stage earlier where he didn't want to take his shirt off anymore, but he's actually even much better now, he doesn't care as much." Finally, when asked what advice he had for others with pectus excavatum Bruce volunteered advice on being confident:

> I'd just tell them not to worry about it I guess, just like, that's who you are and you can't really change it, for the time being, so just, if anybody ever tells you that it's weird or wrong just don't listen to them 'cause it's not.

Although having self-confidence was not always easy for many of these adolescents, when they were able to muster some courage or confidence, they were able to enjoy activities and social outings that they would otherwise have avoided, and this contributed to their overall satisfaction.

Although each of the participants had decided to have their pectus excavatum surgically corrected there were several statements made throughout several of the interviews that indicated the participant's familiarity with and acceptance of this physical difference. Being able to accept this as part of their lives allowed these participants to move on and enjoy other aspects of life. When explaining how he addressed the curiosity of his peers David said, "I just say that I've got a hole in my chest and that's the way it is." David's mother also expressed this sort of acceptance, "We knew it was there and we

didn't really, you know it wasn't, I don't think it was terribly affecting anybody, I mean I knew it was there, but he's perfect to me..." Finally, Sam made several comments expressing his acceptance of this condition, "It feels normal" and "I kind of like it there", his father agreed that, "It doesn't really bother him." Although these adolescents had not accepted their condition to the extent that they would chose not to have it changed, they had accepted it enough to allow them some freedom from constant concern and worry about it, and this also contributed to their satisfaction.

Theme cluster four: Negative affect.

Each of the participants described ways in which their pectus excavatum had a negative impact on their well-being and satisfaction. As previously described, for most, the negative aspect of their physical condition was primarily related to their sense of social belonging. It caused many of them feelings of embarrassment, self-consciousness, and uncertainty. As Paul stated, "It makes me feel really self-conscious and embarrassed." Bruce suggested that it takes away from his ability to engage in the larger community, "It probably causes me to think more about myself, you know, than the world around me."

Although some of these adolescents developed humorous hypothetical benefits for their pectus excavatum, all of them reported that there are no actual benefits of this condition for them. Most of the participants simply stated "No" when asked if there were any benefits. After relaying some interesting hypothetical ideas Jack acknowledged, "Actual benefits, I'm not sure of." Bruce also claimed, "There's nothing really cool about it at all." While many of the participants found that the social support they received and

their ability to overcome this obstacle added to their satisfaction, the condition itself did more to detract from their well-being and satisfaction then add to it.

Category Four: Surgery

Each of the participants had decided to undergo the Nuss procedure for the correction of their pectus excavatum. The participants willingly shared their journey through acquiring information and making informed decisions about this surgical correction option. A majority of the participants were nearing their surgery date at the time of the interview and shared some of their concerns and hopes for the surgical experience and its outcome. The surgery category is made up of four theme clusters: information, catalyst for correction, issues surrounding surgery and post surgery expectations. The themes that emerged from the interviews are arranged within these four clusters and are presented in Table 5. The clusters are then further described through the use of direct quotations from the participants' interviews.

Table 5: Category Four: Surgery

Clusters			
Information	Catalyst for Correction	Issues Surrounding Surgery	Post Surgery Expectations
Themes within each Cluster			
Lack of knowledge about pectus excavatum (83%)	Recognition of physical difference (100%)	Parental concern and support (100%)	Physical post-surgery expectations (83%)
Lack of knowledge about correction (50%)	Physical repercussions (83%)	Anxiety around surgery (83%)	Social and Psychological post-surgery expectations (50%)
Proactive seeking of information (67%)	Concern regarding potential future physical issues (50%)	Inconvenience (50%)	
Empowerment through information (83%)	Concern regarding potential future psychological issues (33%)		

Theme cluster one: Information.

Prior to making any decision about surgical correction, the participants had to first gain knowledge about their condition and the correction options. As previously discussed, many of the participants went through an extended period during which they had little information, or even incorrect information, about their pectus excavatum. Most of the participants and their families needed to be proactive in seeking out information about their condition and about the correction options. Several of the participants found that having accurate information empowered them to make decisions for themselves.

All of the participants claimed that there was a time when they did not know what their condition was called, what its prognosis might be and whether anything could be done about it. Sandra said, "We really didn't know at that time what we were getting into, or what this all meant, at the time... we didn't really see a need to, or didn't know if we could correct it." As previously explained, many of the participants were active in their own search for information and found that knowledge was crucial in empowering them to make their own decisions and gain control their condition. Paul explained:

> I always wanted to like get something done about it, but I never knew if anything could be done... then we saw the doctor and I realized that something could be done about it so I started researching it more, and found out what the two different procedures were, and we saw Dr. Ashton... and we found out that it really wasn't that big a surgery, you know to get done.

For each of the participants, accurate information played a role in leading them to the decision to have their pectus excavatum corrected through the Nuss procedure.

Theme cluster two: Catalyst for correction.

Participants were asked about their reasons for pursuing corrective surgery. There were several common themes within their various reasons. For many of these adolescents the decision process began during middle school when their pectus excavatum became more pronounced due to growth spurts. For others, whose pectus excavatum had been obvious and visible from birth, the decision process began when they were made aware of corrective options. Many of the participants spoke of the repercussions of their condition on their physical health as a reason for pursuing correction. There were also a few participants and families who expressed concern about potential complications in the

future, either health related or psychological in nature, and decided to avoid these issues through correction now.

For some of these adolescents the rapid changes of puberty brought about an increased pronouncement in their chest wall deformity and this ultimately began the search for more knowledge about pectus excavatum. Bruce spoke of when he first became cognizant of his physical difference, "Maybe around grade eight or so... I started thinking, well hey, this isn't very normal, you know." Paul had a similar experience, "Probably around grade seven or grade six... yeah that's when I really realized I had it." Jack's pectus excavatum also became noticeable during puberty; he explained that it was his parents who first brought his attention to it:

> I never actually noticed, hey what's this, um, 'cause I guess it was gradual. It was about half way through grade seven I think... that we actually noticed it. We were playing tennis, and I didn't have my shirt on and my parents were like, what's that? So, yeah, I hadn't really taken notice of it, or really thought anything of it, or noticed at all, I'm not sure, before then, before my parents noticed it.

David's parents had noticed his pectus excavatum at birth and were cognizant of it becoming more pronounced as he grew. It was when a physician expressed concern about it that they began to seek corrective options. Sandra said:

> Since he's been little, I've noticed that, it's a little bit different, and then over time it's, as he's grown obviously, it's become more pronounced... we had actually gone to our GP prior to that, it wasn't specifically about the chest it was more so about a physical, the boys really hadn't had a physical and I thought well you know, maybe they should have one, and that instigated this whole process, and

> our GP was concerned enough about, about the pectus that he felt he should go to Dr. Ashton.

Apart from a basic awareness of their physical difference, many participants expressed concern about their physical health. Although few were completely certain that their health concerns were directly related their pectus excavatum, many sincerely believed that this chest wall deformity was making a difference to their ability to breath. David said, "Well, I don't really notice it when I'm running or doing anything like that, but I have a hard time breathing at night sometimes." His mother commented on this as well:

> Yeah, he's complained about breathing a lot over the years, and we've had him to the doctor, we thought maybe it was tonsils, who knows, you know cutting off air, but nobody's ever really, again us being vigilant and pushing further and further, we've had the allergy test thinking maybe it was that, or whatever, but I think you you've seemed to have felt that it has affected your breathing, to a certain degree, even though we've had all the tests done and it doesn't look like it's doing any, it's causing any issues, he seems to feel that it is, and fair enough.

Bruce also spoke of difficulties sleeping, which he attributed to his pectus excavatum, "If I lie the wrong way for too long, it can start to hurt, like, I guess it's just not supportive for my back, or something, so often I toss and turn at night because of that." Kelly has noticed that Jack's lung capacity does not allow him to keep up with his family when they participate in physical activity:

> He doesn't notice the being winded himself because he has nothing to compare it to, but we definitely notice it, that, like we all do karate together as a family and

> he'll get winded before the rest of us, same thing if we're all out on a bike ride, he can't keep up, if there's any sort of incline then he can't keep up with everybody else. And as he said his brother is younger and smaller than him, he definitely has bigger, stronger muscles than his brother. He's got very strong legs, he's got very powerful kicks when we're doing karate, um, but he definitely gets, he definitely gets winded, there's no question about that.

Finally, Sam also spokes of feeling tired when playing sports, "I just get tired easily… I don't know why, but I feel tired pretty fast." Although these adolescents cannot be sure that their health concerns are directly related to their pectus excavatum, they maintain hope that the Nuss corrective procedure may alleviate or at least reduce some of their cardiovascular difficulties.

Apart from immediate concerns about the appearance of their pectus excavatum and its possible implications for their current state of health, several of the participants expressed concern about possible complications they may face in the future if they do not pursue corrective surgery now. Jack described his concern about potential future health risks:

> I want to have the surgery, you never know, it may cause complications later on, you never know, things can change, and uh, doctoring and stuff, there's still kind of, well it could change. Like one minute they're saying, well we don't encourage it, and then the next… it's something that's wrong, there must be a reason why people don't have this, a chest like this, right, I mean it's pushing on my liver or something like that, now there must be a reason that your organs are given that

> much room normally, otherwise why wouldn't we all just be slightly skinnier. So there must be a reason, maybe there isn't, but anyway.

Sam's mother, Janet, expressed similar concerns about the possibility of future complications for her son's health, "I'm worried about um, not mental position, I'm worried inside body, heart, you know stomach, but the doctor said don't worry, but I'm not believing him one hundred percent, because I'm thinking maybe something is bothering his body." Jordan expressed similar concerns, as well as a fear that the surgery may become more complex if he waited till he was older and no longer growing, "If I didn't get it done now maybe I would want to get it done later and it would, like hurt a lot more... and something might go wrong with my breathing." Finally, Gordon, Sam's father, expressed concern about the future of his son's psychological state:

> I guess what was a deciding factor beyond the Nuss procedure being a less invasive type of surgery, was I was concerned about him growing up in his teenage years and going down to the beach and taking his shirt off in public because, he's not that self conscious about it now... my concern was later on in life, in his teenage years, I believe he may be very self-conscious, and if this procedure is available then why not do it.

Although Sam's pectus excavatum was not currently impacting his personal sense of social belonging, Gordon is aware that, as he becomes older, appearance and peer acceptance may begin to play a more important role in his social context. All of these issues and concerns played key roles in leading these participants to examine the corrective options and choose to undergo the Nuss surgical procedure.

Theme cluster three: Issues surrounding surgery.

Several concerning issues regarding surgery emerged from the interviews. Many participants, as well as their parents expressed anxiety around having surgery. They were concerned about various aspects of the surgery experience including the anesthetic, the recovery process and simply having a metal bar placed in their chest. Many participants also spoke of the inconvenience that the surgery would have on their daily life.

Several of the adolescents and their families expressed some anxiety about having surgery, which is typical of individuals facing any type of major medical procedure. For Bruce, the anxiety was centered on what he believed would be a painful recovery process, "Well, they stick a metal bar in my chest, it's probably going to be pretty painful, I'm not sure how long the rehabilitation is but it's probably going to be pretty hectic." Gordon also expressed concern about the pain that Sam may have to endure during his recovery:

> Well I guess uh, our concerns is the, it's a painful procedure, not painful but I mean, the afterwards, the four or five days in the hospital, when the doctor uses the words "pain management" it kind of like sends a shiver through you, cause you know it's, you know a lot of drugs, and it is, it will be painful for him, um, so that makes us anxious. As far as worried about, personally worried about the surgery, I'm not, I have full faith in the doctor and the medical system, so I'm not worried that Sam's not going to come out of it, so that's not even a concern, but it's more just the pain that he'll have to go through.

Others expressed concern about specific aspects of the surgery, for Paul the concept of the bar caused some anxiety, "Well, I'm nervous cause I've never had surgery before, I'm kind of scared about the pain and everything... it sounds pretty brutal, well it's not

that invasive I guess, but it's still a little nerve racking to have a titanium bar strapped to your chest." Jordan's previous surgery experience has caused him to be anxious about certain aspects, "I had surgery for my appendix... it hurt a lot when I had the stitches out, that's the part I am most scared about... and having the bar." Finally, David expressed concern about having a general anesthetic, " I'm a bit nervous of the anesthesia, that's the one thing I'm nervous about." His mother agreed:

> He's never had anesthesia before, so I brought up the question of well, he's never had it before, you know, that makes me nervous, like any surgery, any surgery is dangerous, obviously... I'm nervous about it all, he knows that, uh, scared to death about it all, I mean here's this metal object going through my child's chest, and it's going to push out his sternum, I'm more than a little nervous about that. You know there's some vital stuff in there that this thing has to move by, I'm nervous about it then slipping afterwards, um, and what that means for his life and what it means for all of us actually, it's not just David who's having surgery, we're all having surgery, we're all going to be affected by what is happening to him.

A few of the participants expressed concern about the inconvenient ways in which the surgery would impact their daily lives and their ability to participate in activities that they enjoy. For Jordan, the necessary appointments prior to surgery interfered with his routine, "We have to go out of town a lot for appointments, it means that I miss school." Sandra spoke of her concern about the post-surgery recovery time:

> I'm fully prepared to be there 24-7 to make sure everything is okay for him, and I'll do what I can, but I can't watch him all the time and ultimately he's got to not

> turn the wrong way, or, you know he wants to play rugby as soon as possible, and we're like I don't think so, maybe in the spring afterwards, we'll see how it goes, like Dr. Ashton doesn't seem to think it's a major issue, not right away, but maybe in the spring, so yes it's going to affect his life and ours.

Gordon had similar concerns for his son Sam:

> The fact that he will be out of commission for two to three months, he's a very active boy, plays a lot of soccer, so that's why we tried to schedule it right at the end of school, so that he has the summer actually to recuperate, to start the fall in school and back to his normal sports routine.

Finally, Sandra was the only participant to speak of a resolved concern about the nature of the surgery and what it meant:

> We actually just saw Dr. Ashton again yesterday morning, my husband still had some pretty major concerns, cause he hadn't been in the other meetings with Dr. Ashton, it was always David and I, so he was feeling like, well wait a minute here, and he has an idea of what cosmetic surgery means, like you know he relates it more to a nose job or a breast implant or something, and it's not the same, you know we talked to Dr. Ashton and he said you know there is a different level of vanity here, and that made him feel better. You know he wasn't quite equating it... I look at it as if, I saw some adds not that long ago about somebody who has depression versus somebody who has heart disease and how we, we give more validity to somebody with heart disease versus somebody who has depression, but really it's a disease in the brain... and they both deserve equal status I guess, or equal support, and I look at this in the same way, it's a psychological need to

> change his, his outer well-being and his outer surface to make himself feel better, then I think that deserves exactly the same support as if he needed heart surgery or anything else, because it's a part of his body that needs some fixing, that he feels needs fixing. If he didn't want to fix it, I'm okay with that too.

Sandra was the only participant to address this concept of the Nuss procedure being a cosmetic procedure, but perhaps one important to psychological and social well-being. However, each of the participants offered reasons for their surgery decision that addressed far more than simple vanity requiring cosmetic intervention.

Although each of these participants has weighed the costs and benefits of this surgical procedure and has opted to have their pectus excavatum corrected, they still have a variety of concerns about the surgery experience. These concerns range from anxiety about the pain associated with the surgery and recovery, to worry that this recovery time will impact their daily lives and routines in a negative way.

Theme cluster four: Post surgery expectations.

Participants were asked about their hopes and expectations for the results of their corrective surgery. Within the interviews there were a variety of expectations expressed including those focused on physical appearance and those related to psychological and social wellness. The majority of the participants were cautiously optimistic about the physical results of their surgery. David explained, "I don't expect it to be absolutely perfect, like that's what they said form the beginning, but I just expect it to come up a bit, just be a little more normal." Jack had similar expectations:

> Well, I don't think my chest should be, the hole in my chest should at least be diminished. Um, it would be nice if I could run farther, but if not well, oh well.

> And uh, that would be it. I expect it to be out more than it is now, having surgery and it staying the same would be kind of a bummer.

Bruce also expressed a similar expectation:

> I don't really expect too much out of it actually... Just uh, a little bit of correction, but I really don't expect to be Swartzenegger, just like if they can do a little bit I'll be happy with that... the only thing I'd be upset about is if they made it worse, which I don't think they can do, so even if they make it a little bit better I'll be happy with that, I don't really expect too much out of it.

Sandra had expectations for a physical change as well as a hope that the physical change would bring about other changes:

> I just hope that he gets the result that, that he's looking for with it all, and I hope that it's relatively easy and not much pain, and at the end of the day he feels better about who he is as a result of this happening.

Finally, Paul shared his expectations about changes in his confidence and social activities:

> I just hope it will boost my self-confidence a lot, and like, I don't know, hopefully I won't be self conscious about my body after I go through the surgery and everything. Be able to go swimming a lot more with my friends go to the beach and everything. Yeah just boost my self-confidence.

The majority of participants shared only expectations related to their physical appearance after surgery, some also shared hopes for increased physical endurance and a few discussed hopes that their change in physical appearance would bring about changes in their psychological and social well-being.

Summary

Chapter four presented the results of data analysis. The participants were introduced followed by an outline of the essential experience. The major categories and thematic structure that resulted from the data were presented. The clusters and themes that emerged within each category were further described through the use of direct quotations from the participants.

Chapter five will discuss the findings of the study in the context of the existing literature. The limitations of the study will be presented as well as the implications of the study for both future practice and research.

Chapter Five – Discussion

Chapter five presents a comprehensive summary and discussion of the study's results. The first section provides an overview of the results and research contributions followed by a detailed discussion of the findings. The results are explored in relation to the purpose of the study and within the context of related extant literature. Limitations of the study are presented along with its implications and directions for further research. The chapter concludes with a final summary of the investigation.

Summary

The present study employed a phenomenological method to develop a comprehensive understanding of the experiences of adolescent males living with pectus excavatum and awaiting surgical correction. In-depth interviews were used in order to acquire knowledge regarding the effects of pectus deformities on the quality of life experienced by these adolescents. Participants provided insight into the effect of their chest wall deformity on their social context, their sense of personal control, and their overall well-being and satisfaction. Moreover, the researcher has gained an understanding of the decision process engaged in by the participants, surrounding the surgical correction of their pectus excavatum.

Research Contributions

Through examining the experiences of adolescents with pectus excavatum, the present study has addressed a number of areas and issues that have received limited empirical attention. Specifically, the analysis investigated how a less visible or easily camouflaged deformity affects the quality of life experienced by adolescents and how these individuals decide to seek surgical correction for a deformity that does not always

seriously impact an individuals physical health. Furthermore, the study has detailed the participants' expectations for their surgery experience. Although the body of research examining these particular issues is limited, integration of the present study's results with the extant literature, enhances current understanding and discussion.

Purpose one: Examine adolescents' experiences of pectus excavatum.

Pectus Excavatum was a part of these adolescents' lives from birth, however, for many it only began to seriously affect their daily lives when they experienced the rapid growth of puberty, which caused their chest wall deformity to become more pronounced. The participants confirmed previous research in their affirmation that pectus excavatum strongly affects their social context. Liskey-Firzwater et al. (1993) report that the curiosity of others regarding an individual's physical difference can cause uncomfortable social interactions. Several of the participants in this study expressed that one of the most challenging aspects of living with pectus excavatum is dealing with the numerous questions about their deformity that they receive from their peers.

Cash (1995) indicates that appearance is the most common focus of enacted stigma in childhood and adolescence. Others have indicated that appearance becomes a matter of great importance for youth, and as their bodies change they begin to focus on clothing and other items important to appearance (Anderson, 1982; Liskey-Fitzwater et al., 1993). For the youth in this study, appearance, particularly the difference in their appearance caused by pectus excavatum, was the focus of several incidents of enacted stigma they had encountered. Experiences of enacted stigma result in the development of felt stigma, which can be equally debilitating in social situations (Kent, 2000). Sarimski (2001) found that individuals living with deformity were at an increased risk for social

problems such as social anxiety and withdrawal. This is confirmed by the participant's accounts of how their pectus excavatum has resulted in a lack of confidence, self-consciousness, embarrassment, and has in turn, limited their ability and willingness to participate in certain social events; particularly those social activities that do not allow them to camouflage their deformity with clothing.

The most consistent finding among the extant literature is a wide variability in the responses of individuals to their physical deformity (Anderson, 1982; Kent, 2000; Kent & Keohane, 2001; Sarimski, 2001; Thompson & Kent, 2001). The participants in the present study also demonstrated variability in response. Although there were several common themes found within the interviews, the overall impression the researcher had of each participant varied greatly. For example, some participants spoke of pectus as being highly debilitating in their social contexts while others indicated that it certainly affected their social context but not to the extent of causing them to have dramatically different experiences from their peers. Research indicates that this variability is the result of a number of interacting variables including severity of the deformity, age, personal values, competency, social skills, and finally social support (Anderson, 1982). The participants involved in this study all had pectus deformities that were similar in severity and visibility. It is also difficult to compare their personal qualities such as anxiety level and competency, as it is not possible to separate those qualities that are a result of their experiences with pectus excavatum and those that are long standing qualities of their personalities. However, the current study may add to discussions surrounding the contributions of age and social support.

The participants in the present study ranged in age from ten to nineteen years of age, providing examples of early to late adolescence. The youngest participant expressed the least concern about his pectus excavatum, he did not find that it affected his relationships with peers and was generally very comfortable in his social context regardless of his physical difference. For this participant it was largely his parents concern about future complications that had caused the family to pursue surgical correction rather than current concerns about the impact pectus excavatum was having in his life. The oldest participant also presented himself as one who had adjusted well to his physical difference. Although he recounted social anxiety and incidents of enacted stigma from earlier in his life he found that he was now generally more comfortable in social situations. The remaining participants ranged in age from thirteen to sixteen years of age. Although there was variability in the responses from these four individuals, in relation to the oldest and youngest participant, they expressed a more immediate discomfort with their appearance and anxiety in social situations. Although it is possible that the apparent differences among the varying ages are only related to different personalities and experiences, they do correspond with the age related findings of Hill-Beuf and Porter (1984). The findings of their study suggested that physical deformity was most difficult for those individuals in early to mid adolescence, young children seemed relatively unaffected and older adolescents were able to manage successfully through a shift in focus from appearance to other skills and abilities (Hill-Beuf & Porter, 1984).

The extant literature indicates that, of all the factors influencing positive adjustment to physical deformity, social support is the most important resource (Forstenzer & Roye, 1988; Thompson & Kent, 2001). An individual with a strong social

support network, which values them for positive qualities other than appearance, is likely to have an easier time adjusting to their disfigurement (Forstenzer & Roye, 1988). Each of the participants in this study spoke of close friends with whom they felt accepted. Many of them indicated that these friends do not focus on their pectus excavatum, it is not something they typically talk about and it does not interfere in social activities with these particular individuals. This being said, for many these were also the friends that they were able to talk to about their upcoming surgery without feeling judged. Beyond these strong peer relationships the participants spoke of support from their parents and other family members. Parents played a key role in empowering many of these adolescents to examine the options and consider correction of their chest wall deformity. As they sought information about their options many of the participants found that their parents were a strong support to them through discussing the costs and benefits of surgery and empowering them to make their own decision. Overall, the participants expressed a great appreciation for their close friends and family, thus confirming the importance of a strong social support network for positive adjustment to living with a physical deformity.

Purpose two: Examine adolescents' surgery decisions and expectations.

There is a paucity of research examining the decision process that individuals engage in when considering corrective surgery for their physical deformity, and their expectations prior to that surgery. The present study found that for all participants a key concept in this process was the search for information. The participants found they had a lack of information about their deformity and the potential for correction. This lack of information often included some misinformation, for example several families were told that their child's pectus excavatum would spontaneously correct itself. This substantiates

Smith's (2004) claim that this is an incorrect belief that is often expressed by families and patients. The participants described their need to take personal responsibility for researching the options available. One participant in particular described informing his general practitioner about the Nuss procedure and the fact that it was available in his home city. Discovery of what their condition was called, and that there were correction options available was an empowering experience for all of the participants. They were then able to explore those options and make some decisions about how they would manage their chest wall deformity. For some this information was empowering in social situations as well, as they were now equipped to answer questions from curious peers.

The participants had a variety of reasons for pursuing corrective surgery. Many experienced physical symptoms commonly associated with pectus excavatum such as shortness of breath or decreased physical endurance in comparison to their peers. The participants expressed a desire to have these physical symptoms improve as one of their reasons for pursuing correction. Some of the participants also indicated concerns about potential future complications that may result from their chest wall deformity if they do not have it corrected. For most, these were concerns about potential physical symptoms, however, for some there was also concern about a continued effect on their social context and personal satisfaction. This being said, the most common reason participants gave for pursuing surgical correction was simply to improve the appearance of their chest. The participants desired an appearance that was typical and did not stand out from their peers. This is in keeping with Smith's (2004) claim that "most people initially seek correction of pectus excavatum because of aesthetic purposes" (p. 191). It is important to note that although the participants expressed a desire for aesthetic change, they also believe that

their difference in appearance has been the source of discomfort within their social context. Therefore, they believe that aesthetic change will also bring changes to their social context and sense of self-confidence.

The participants described several issues surrounding their upcoming surgery. The most common issue expressed was anxiety regarding the surgical procedure, hospitalization, and the recovery process. Both the participants and their families experienced this anxiety. Heightened levels of anxiety prior to hospital admission have been found to be common to all surgical patients (Johnston, 1980). Another issue surrounding the participants' pre-surgery experiences was the inconvenience of repeated medical appointments and consultations. This was particularly difficult for participants living outside of the city where they would be having surgery. Some participants felt that their repeated absences from school and extra-curricular activities drew increased attention to their physical deformity. This increased attention likely added to the participants' anxiety.

Finally, participants were invited to share their expectations for their upcoming surgery. All of the participants expected the surgery to improve the appearance of their chests. However, they remained realistic about the changes that would occur, not expecting dramatic changes in their appearance but anticipating less of a noticeable difference from their average peers. Several of the participants shared expectations of a reduction in their experience of the physical symptoms associated with pectus excavatum such as shortness of breath. Although many seemed to think that this would be a welcomed affect of surgery few were convinced that it would become a reality. Some of the participants also shared expectations for the ways in which this change in physical

appearance would affect their social context and sense of self-confidence. Many of them held the belief that much of their discomfort in certain social situations would be relieved when they no longer had an obvious physical difference from their peers. Overall, the participants held expectations for surgery that would be expected, some with greater hopes for the outcome than others. Further research examining surgical outcomes and patient satisfaction is needed in order to determine if these expectations are regularly met.

Limitations

As with all research, the present investigation had methodological restrictions, which influence its results and implications, thus the limitations to the current study are presented. Several of the limitations stem from the participant demographics. For example, the study was limited to six adolescent males, all of whom resided in southwestern British Columbia. As such, the results of the study are representative of a specific population and may not be characteristic of all adolescents' experiences of living with pectus excavatum.

The study was also limited to the experiences of adolescents who had decided to undergo the Nuss surgical procedure in order to correct their pectus excavatum. Thus, the results may not characterize the experiences of adolescents who have decided to undergo other surgical or medical correction procedures, or those who have decided to leave their chest wall deformity untreated. The study's findings may not represent the experiences of youth with other types of physical deformities as well. More severe or more visible deformities may result in much different experiences, and different corrective options may also result in different decision processes.

Finally, the present investigation was limited to the information that participants provided in response to the questions posed throughout the interview. Although each interview began with a very general, open-ended, question designed to allow the participants an opportunity to freely discuss their experience, the following questions were semi-structured and, as such, focused on specific aspects of the participants' experience. Beyond the limitation of the interview structure the data are also limited by the willingness and ability of these young males to verbally present their experiences with a new person, in particular a female. It should be noted that mention of romantic relationships was missing from the data, it is likely that these relationships are relevant to the lives of these participants but were not mentioned due a discomfort with sharing this aspect of their experience. Although time was taken to build rapport prior to the interview and participants were given the choice of having a parent present in order to increase comfort, the participants' level of comfort and ability to verbalize their experiences and perceptions may still have been somewhat limited in comparison to other populations.

Although the intention of qualitative research is not to generalize to larger populations, the results of the current study may reflect the experiences of other adolescents with physical deformity. As such, implications of the study's findings are presented for consideration. Due to the limitations on these results, based on factors previously outlined, directions for future research are also provided.

Implications

The descriptions the participants have given of their experiences have implications for adolescents living with pectus excavatum and their families, as well as, medical professionals and other professionals who support them. The participants'

descriptions highlight the importance of social support. They spoke of support from both their parents and from a group of close friends. Therefore, it is important for parents to be aware of the struggles their child may face due to their physical deformity, and make a concerted effort to provide them with support and encouragement. Teachers can also participate in creating supportive social networks through being mindful of their schools social environment and encouraging a focus on students positive attributes rather than appearance. It is also important that parents and teachers are mindful of those activities and situations that cause the adolescent anxiety due to increased exposure of their physical difference. It is important to give the adolescent choices that allow them to face these situations with more confidence. For example, teachers may offer alternative changing arrangements for physical education classes that allow the youth to attend these classes without added social anxiety.

Adolescents living with pectus excavatum are encouraged to be proactive in seeking out information about their condition and the available correction or treatment options. The youth in this study found that access to information empowered them. They felt that information allowed them to make choices and take some control over their deformity. Parents should also encourage and support their child in seeking out this information. For many of these youth, it was a parent that instigated the search for answers, which ultimately led to their empowerment. Empowerment has been identified as a key factor in student quality of life (Keith & Schalock, 1992; Roberts & Cairns, 1999).

The fact that these adolescents had to be proactive in seeking information, as well as in separating the false information from the true, leads to another implication of the

current study. There is a need to educate general practitioners, pediatricians, nurses, and the general public about pectus excavatum and the available corrective procedures. Participants and their families were frequently misinformed and frustrated at the lack of information that was available from their doctors. Through providing accurate information about pectus excavatum, doctors and nurses will be empowering their young patients. Education of these professionals might occur through the publication of articles regarding pectus excavatum and available correction procedures in academic journals and magazines frequently accessed by medical professionals. The creation of an informative pamphlet to be made available in doctors' offices may also lead to increased access to accurate information. It may be argued that it is impossible to educate all general practitioners about all of the possible physical deformities and their potential treatments, as such, it is important that medical professionals take on the responsibility of researching answers to their patients specific questions when they themselves are unsure of the available options.

Finally, each of the participants in this study expressed the importance of being able to make their own decisions about surgery. Therefore, both parents and medical professionals are encouraged to include youth in the decision process. Ensure that they are given adequate information on which to base their decisions and encourage them to weigh the costs and benefits of the corrective procedure. The amount of involvement and control an adolescent has regarding surgery decisions, as well as the information provided certainly needs to be developmentally appropriate. In the case of the participants involved in this study the nineteen year old is certainly capable of more control over this decision then the ten year old. However, regardless of age, it is

important that youth feel they have been included, both by their parents and their surgeon, in discussions surrounding the potential surgery experience. When parents and professionals are mindful of this, adolescents will feel empowered and gain a sense of control over their situation.

Directions for Future Research

This study is the first of its kind, and considering its several limitations, there are many possible directions for future research. Given that there were only males involved in this study, researchers should examine the experiences of female adolescents with pectus excavatum. This type of research may yield several differences but also similarities in the ways that male and female adolescents are affected by a physical deformity such as pectus excavatum. Further research examining the experiences of those youth living with pectus excavatum who have chosen other surgical procedures or decided not to undergo a corrective procedure are also warranted. Each of the participants involved in this study had decided to undergo the Nuss procedure; perhaps there are differences in experience that cause youth to make different decisions. Within examining the experiences of youth with physical deformity there is also a need introduce a variety of data collection methods. Researchers should allow participants creative methods of self-expression that may result in more rich and complex data. For example, photographs, artwork, and even electronic journaling may give adolescent participants more opportunity to express their experiences and perceptions.

Beyond a focus on adolescents with pectus excavatum there is also a need to examine the experiences of those living and working with these youth. For example, researchers should examine the perspectives of parents, siblings, peers, educators and

medical professionals in order to gain a more rich understanding of the effects that physical deformity has on the life of, not only individuals, but also those around them. Finally, there is a need to address these issues with quantitative studies as well. Quantitative and qualitative approaches to research provide differing types of information (Creswell, 2003). In order to fully understand a phenomenon it is important to utilize research of both approaches. Many of these needs for further research are being addressed by the larger, longitudinal research project being conducted at the University of Victoria, of which this study is one small aspect.

Final Summary

This qualitative study employed a phenomenological approach in order to explore the experiences of adolescent males with pectus excavatum and the decision process they underwent in choosing to have their physical deformity surgically corrected. It is important to acknowledge that the experiences explored within this study are all those of individuals who have made a decision to undergo corrective surgery. Although this is only an initial step in understanding the experience, it does shed light on the issues and challenges faced by these youth on a regular basis.

The inquiry highlights the effect that pectus excavatum has on an adolescent's social context, sense of personal control and overall well-being. Due to the increased focus on appearance and the heightened importance of peer acceptance during adolescence, these youth face a significant challenge living with a physical deformity. The study illustrates the incidents of enacted stigma experienced by youth with physical deformity as well as the increased social anxiety and lack of self-confidence that can result from these experiences. It also highlights the importance of strong social support

networks for positive adjustment to living with pectus excavatum. Each of the participants expressed a strong sense of support from family members and close friends, and described the important role these individuals have in their lives.

The study also provides an understanding of the process that these youth have engaged in, in deciding to undergo the Nuss surgical procedure for the correction of their pectus excavatum. The youth found that they had to be highly proactive in seeking out information and were often met by inaccurate and insufficient knowledge on the part of general medical professionals. They gave a number of reasons for the decision they had made including a desire to have their appearance more closely reflect that of their peers, and concerns about potential complications that may arise in the future. The youth also shared their anxieties about undergoing surgery and their expectations for the results of the procedure.

Through inquiry into the lives of adolescents with pectus excavatum, this study has provided an understanding of their experiences and perceptions. Through outlining the implications of the study's results and providing direction for future research this investigation has contributed to both theory and practice. As such, this study can educate families, educators, and healthcare professionals and enhance their endeavors to provide support to youth with physical deformity. It can also inform and inspire future research in the area of youth and physical deformity.

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Appendix A

Semi-Structured Interview Guide

I invite you to share with me your experiences of living with pectus excavatum. Hopefully through better understanding what life is like for you, we will be better able to care for and support future youth who have the same condition. I will invite you to share with me anything that comes to mind, and then follow up with questions specific to quality of life issues. If any of the questions do not make sense please let me know, I will be happy to reword them for you. (* The interviewer will simplify questions as needed and appropriate).

What is it like for you to live with pectus excavatum (funnel chest)?

Satisfaction

- How satisfied are you in your daily life, and how does pectus excavatum affect your satisfaction?
  * How happy are you and how does pectus excavatum affect your happiness?

Well-Being

- How would you judge your well-being in relation to your pectus excavatum?
  * Are you okay in relation to your pectus excavatum? Please tell me more.

Social Belonging

- How would you describe your sense of social belonging, and how does pectus excavatum affect your social belonging?
  * How are things with your friends, and how does pectus excavatum affect your relationship with your friends?

Empowerment/Control

- How does pectus excavatum affect your sense of personal empowerment?
  * How does pectus excavatum affect your ability to control things in your life?

Other Questions

Please share with me any other comments, suggestions, or concerns you may have had in relation to having pectus excavatum.

- What is the most difficult aspect?
- What is the best aspect?
- What has led you to pursue corrective surgery?
- What are your expectations for corrective surgery?
- Is there anything else you would like to share?

Appendix B

Informed Consent Form: Qualitative

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. Kristine Edgington is a graduate student and researcher working on the project and conducting interviews, she can be reached by phoning 370-2140.

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 and the experiences of their families. We want to understand how family members feel, how the deformity does or does not affect their behavior and social relationships, and how the medical treatment changes the way individuals 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 scaring 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 proved important information for public health policy makers, physicians, psychologists and parents allowing them to better care for those who have pectus excavatum and their families.

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. 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, you will participate in an interview so that we can understand how you and your family feel about Pectus Excavatum and the Nuss procedure.
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 individuals and their families are affected by pectus excavatum. 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.
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.

____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 my 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 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. E. Higgs of the Vancouver Island Health Authority (250-727-4110).

_____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.

University of Victoria

Appendix C

Ethics Approval Certificate

University of Victoria - Human Research Ethics Committee

Certificate of Approval

Principal Investigator	Department/School	Supervisor
Dr. Joan M. Martin Faculty	EPLS	

Co-Investigator(s):

Dr. Jillian Roberts, University of Victoria
Dr. Allen Hayashi, Victoria General Hospital

Title: **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**

Project No.	Approval Date	Start Date	End Date
294-03	07-Aug-03	07-Aug-03	06-Aug-04

Certification

This is to certify that the University of Victoria Ethics Review Committee on Research and other Activities Involving Human Subjects has examined the research proposal 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.

J. Howard Brunt
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions/minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.

Office of Vice-President, Research - UVic
Room 424, BEC - P.O. Box 1700
Victoria, BC V8W 2Y2

Tel: (250) 472-4362
Fax: (250) 721-8960
E-mail: ovprrc@uvic.ca

294-03 Martin, Joan M.