

**BODY DISFIGUREMENT AND THE  
QUALITY OF LIFE OF ADOLESCENTS WITH  
PECTUS EXCAVATUM:  
EFFECTS OF THE NUSS PROCEDURE**

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**ABSTRACT**

*This article takes a comprehensive look at the effects of pectus excavatum, a congenital deformity with psychosocial and physical ramifications, and the Nuss procedure on the quality of life of adolescents. The Nuss procedure is a minimally invasive corrective surgery. Twenty-five participants from Calgary, Alberta were interviewed (10 adolescents between the ages of 13 and 16, 8 mothers, and 7 fathers) regarding their experiences with pectus excavatum before, during recovery, and after surgery. We gathered qualitative data on four areas of quality of life: well-being, social belonging, satisfaction, and empowerment. Pectus excavatum had a negative effect on quality of life, with participants demonstrating decreased self-confidence, increased feelings of self-consciousness, and a variety of avoidance and concealment behaviors. After the Nuss procedure, all areas of adolescent quality of life improved. Adolescent and parent recommendations are provided. We also explore theoretical implications in relation to body disfigurement research, qual-*

*ity of life, and pectus excavatum. Finally, educational implications are included.*

Adolescence is a time of great physical, psychological, and social change. Cognitive development, physical and sexual maturation, identity development, a new capacity for intimate relationships, social networks, school changes, and the negotiation of increased responsibilities all impact the development of adolescent self-concept (Wynn et al., 1990). An important component of self-concept, especially during adolescence, is body image. "Body image is a multifaceted construct encompassing one's perceptions, thoughts, feelings, and actions regarding one's body, particularly its appearance" (Cash & Szymanski, 1995). While a positive body image supports the development of a healthy self-concept and high self-esteem, body image dissatisfaction is associated with depression, anxiety, and a lowered quality of life (Carlson Jones, 2004; Pruzinsky & Cash, 1990).

Unfortunately, for many youth, a significant feature of adolescence is increased body image dissatisfaction (Carlson Jones, 2004) and heightened self-consciousness (Smith, Handley, & Eldredge, 1998). On average, adolescents place more importance on body image and feel more negatively about their bodies than older persons do (Cash, Winstead, & Janda, 1986). Research demonstrating that physically attractive adolescents are more likely to be thought of as warm, friendly, successful, and intelligent (Lerner, Delaney, Hess, Jovanovic, & von Eye, 1990), and enjoy more popularity and peer acceptance (Koff, Rierdan, & Stubbs, 1990) lends support to the significance of body image to adolescents.

A consistent finding is that *normalcy* is an extremely important aspect of adolescent body image; adolescents fear appearing different (Carlson Jones, 2004; Liskey-Fitzwater, Moore, & Gurel, 1993; Lockhart, 2003). An important factor in adolescents' quality of life is their need to believe that they are physically normal (Cash & Fleming, 2002; Thompson & Kent, 2001). Feeling normal is particularly problematic for adolescents with physical disfigurements; they have more difficulty developing positive appearance self-concepts and resilient self-esteem than do adolescents with more average or normal appearances (Koff, Rierdan, & Stubbs, 1990). A positive body image can be difficult to achieve in adolescence and magnified for those bodies deemed disfigured (Kent, 2002; Liskey-Fitzwater et al., 1993; Thompson & Kent, 2001).

In the current study, we will explore the effects of a disfigurement called pectus excavatum on adolescents' quality of life. While quality of life is a

multi-dimensional phenomenological concept that lacks consistent definition (Roberts & Cairns, 1999), for the purposes of this study, we will be using Keith and Schallock's (1994) definition: quality of life is "an individual's reactions to and perceptions of life experiences" (p. 84). They identify satisfaction, well-being, social belonging, and empowerment as key determinants in the quality of life of adolescents. Keith and Schallock found these four areas to be especially pertinent when completing a quality of life questionnaire factor analysis specifically with adolescents. As a result, we believe that body image can positively or negatively affect any of these four components of quality of life.

#### PECTUS EXCAVATUM

Pectus excavatum occurs in 1 of every 300 individuals (Emery, 2001; Golladay & Golladay, 1997; Smith, 2004). Pectus excavatum, also referred to as funnel-chest, is a chest-wall deformity in which an individual's sternum depression results in a noticeably concave chest. While the depression is usually visible during infancy, it often increases dramatically during the adolescent growth spurt (Crump, 1992; Emery, 2001; Haller & Loughlin, 2000; Roberts et al., 2002; Smith, 2004). Boys are three times more likely to have pectus excavatum disfigurements than girls are (Saxena, Schaarschmidt, Schleeft, Morcate, & Willital, 1999). The psychological distress associated with pectus excavatum include increased social anxiety, preoccupation with appearance, dissatisfaction with body image, feelings of inferiority, depression, decreased self-esteem, and shyness (Crump, 1992; Emery, 2001; Hu et al., 2000; Roberts et al., 2002; Wynn et al., 1990). To accommodate this distress, individuals with pectus excavatum often attempt to conceal their disfigurement (e.g. by layering their clothing, slouching, or folding their arms in front of their chest) and avoid social situations (e.g. swimming or athletics) that may require them to expose their chest (Emery, 2001; Golladay & Golladay, 1997; Roberts et al., 2002; Willekes, Backer, & Mavroudis, 1999). Individuals with pectus excavatum also report feeling embarrassed and stressed when needing to change for physical education classes; this provides an increased opportunity for peers to view the deformity, make rude comments, or stare (Roberts et al., 2002).

In addition to psychological distress, individuals with pectus excavatum can also experience physiologic effects. Studies have consistently found an increased occurrence of cardiopulmonary restrictions such as decreased blood flow, decreased lung volume, and increased exercise intolerance (Crump, 1992; Emery, 2001; Ghory, James, & Mays, 1989; Golladay & Golladay, 1997; Haller & Loughlin, 2000; Hu et al., 2000; Kowalewski, Barcikowski, &

Brocki, 1998; Roberts et al., 2002; Saxena et al., 1999; Shamberger, 2000; Wynn et al., 1990). Their inability to keep up with their peers in sports and gym classes results in increased feelings of stress and inferiority. Given the quality of life implications of both its psychological and physiologic effects, pectus excavatum represents a type of body disfigurement in need of thorough investigation (Roberts et al., 2002; Wynn et al., 1990).

#### CORRECTIVE SURGERY

Unlike many body disfigurements, corrective surgery is an option for individuals with pectus excavatum. The traditional surgery, commonly referred to as the Ravitch procedure, requires an extensive incision across the chest (Roberts et al., 2002; Smith, 2004), thus exchanging a concave chest for a large and permanent scar. A newer surgery, known as the Nuss procedure, relies on thoroscopic surgical techniques to provide an equally effective, yet essentially scarless alternative in which a bent steel bar is inserted under the rib cage (Borowitz et al., 2003; Coln, Gunning, Ramsay, Swygert, & Vera, 2002; Croitoru et al., 2002; Hosie et al., 2002; Molik et al., 2001; Roberts et al., 2002). The steel bar, which elevates the sternum and ribs, remains in for approximately two years before surgically removing it.

The psychological effects of successfully correcting pectus excavatum, regardless of the type of surgical procedure, are consistent and positive. Individuals report feeling very satisfied with the surgery results, positive regarding their improved body image (with little to no visible deformity or concaveness), and glad they had the surgery (Crump, 1992; Hosie et al., 2002; Kowalewski et al., 1999; Molik et al., 2001; Roberts et al., 2002; Saxena et al., 1999; Smith, 2004; Willekes et al., 1999). However, very few studies have looked at changes in quality of life (Molik et al., 2001; Roberts et al., 2002; Wynn, 1990). Reports of cosmetic satisfaction often utilize a minimal number of unstandardized questions with little to no basis in our current understanding of the psychology or sociology of disfigurement or the role of appearance in adolescent development. To date there has only been one qualitative investigation of pectus excavatum patients' perceptions of the effects of surgical repair on their quality of life. This study, by Roberts et al. (2002), looking at the experiences of five patients, 12 to 21 years of age, found that patients perceived immediate improvements in their quality of life resulting from the Nuss procedure. In particular, patients reported greater levels of satisfaction, improved self-confidence, feelings of empowerment, and decreased social anxiety.

The impact of corrective surgery on the physiologic effects of pectus excavatum is not as clear as the psychological effects. While some studies

have demonstrated an improvement in cardiac volume output (Haller et al., 2000; Hu et al., 2000; Kowalewski et al., 1998; Saxena et al., 1999; Sigalet, Montgomery, & Harder, 2003), others have demonstrated no improvement at all (Shamberger, 2000; Wynn et al., 1990). With the exception of one study (Kowalewski et al., 1998), most studies have found that lung capacity never improves beyond preoperative levels (Borowitz et al., 2003; Haller et al., 2000; Hu et al., 2000; Kaguraoka et al., 1992; Saxena et al., 1999; Shamberger, 2000; Sigalet et al., 2003; Wynn et al., 1990). The Kowalewski et al. (1998) study did report an increase in lung capacity, but only in patients with severe pectus excavatum. Most studies have also found that, despite a lack of improvement in pulmonary output, exercise tolerance increases with patients reporting increased workloads and fewer breathing related difficulties (Haller et al., 2000; Hu et al., 2000; Saxena et al., 1999; Shamberger, 2000; Sigalet et al., 2003; Smith, 2004; Wynn et al., 1990). This improvement in exercise tolerance and workloads without a concurrent improvement in cardiopulmonary functions has left some researchers wondering whether the improvement in psychological functioning is responsible for the improved exercise tolerance (Haller & Loughlin, 2000; Kowalewski et al., 1998).

Given these mixed findings regarding improvement in physiological functioning following corrective surgery, the value of such an extensive surgery is an important question; are the primary gains cosmetic and psychosocial? Both Kent (2000) and Roberts et al. (2002) pose questions regarding the long term effects of corrective surgery on the quality of life of individuals with pectus excavatum; does the initial satisfaction experienced following surgery have a long term impact on the negative effects of concealment and avoidance behaviors? Does an individual's preoccupation with body appearance and self-consciousness dissipate when there is no longer an identifiable difference to the idealized norm or do the psychological effects of years spent concerned with body image remain post-surgery (Pruzinsky & Edgerton, 1990)? These important questions require thoughtful, in-depth analyses as well as an understanding of relevant body disfigurement literature.

#### BODY DISFIGUREMENT

How disfigurement is classified will vary depending on societal norms and cultural practices. However, according to Thompson and Kent (2001), a disfigurement is traditionally recognized as a deformity caused by a congenital defect (pectus excavatum, cleft lip/palate, etc.), traumatic event (fires, automobile accidents, etc.), or disease process (vitiligo, cancer treatments, etc.).

Research has demonstrated a consistent negative effect of disfigurement on the development of an individual's body image. This can result in increased anxiety, depression, stress, and suicidal thoughts, along with decreased self-esteem and social confidence, all of which can produce a lowered quality of life (Benrud-Larson et al., 2003; Kent, 2000; Pruzinsky & Cash, 1990; Thompson & Kent, 2001). However, while disfigurement appears to have a negative impact, there exist great variations among individuals (Benrud-Larson et al., 2003; Thompson & Kent, 2001). Several different mediators of the relation between disfigurement and negative outcomes are: (a) perception of the disfigurement, (b) investment in body image, (c) type of stigmatization, and (d) social skill level.

#### PERCEPTION OF THE DISFIGUREMENT.

Perception of the severity and importance of a disfigurement involves recognizing a difference between one's actual self and one's idealized self (Cash & Symanski, 1995; Kent, 2002). This idealized self usually forms through comparisons with media, peers, and family (Carlson Jones, 2004). For children and adolescence, the school environment provides the greatest opportunity for body comparisons. This perception of difference appears as either positive or negative. In most cases, a body disfigurement appears negative when it is different from the norm and often not valued by society (Elliot, Ziegler, Altman, & Scott, 1982; Kent, 2002; Thompson & Kent, 2001). This negative perception is often more important than actual physical differences (Cash & Symanski, 1995; Liskey-Fitzwater et al., 1993). Studies demonstrating that the severity and visibility of a disfigurement did not account for significant variations in body image dissatisfaction additionally support this notion (Benrud-Larson et al., 2003; Kent, 2000; Lawrence et al., 1998; Thompson & Kent, 2001).

#### INVESTMENT IN BODY IMAGE.

Having a negative body image due to disfigurement does not necessarily result in a lowered quality of life. An individual's *investment* in his or her body image can moderate the effects of having a disfigurement (Benrud-Larson et al., 2003; Cash & Fleming, 2002; Cash & Szymanski, 1995). For example, when individuals highly value their physical appearance, the effects of a body disfigurement will be more traumatic than it would be for individuals who value other areas of competence such as academic excellence or artistic skills. Unfortunately, adolescents are highly invested in their physical appearance (Carlson Jones, 2004; Liskey-Fitzwater et al., 1995). As a result, the effects of a negative body image can be quite devastating.

## TYPE OF STIGMATIZATION.

The type of stigmatization experienced by an individual can also moderate the effect of disfigurement on body image. Disfigurements such as pectus excavatum, burns, cleft palate, and scleroderma can make individuals feel different in an unfavorable way (Elliott, Ziegler, Altman, & Scott, 1982). Individuals can experience stigmatization in two ways; *enacted* or *felt*. Teasing, being picked on, or having fun made at your expense are all examples of enacted stigmatization. Unfortunately, “peer criticism of and teasing about appearance and physical characteristics are well documented in the lives of young adolescents” (Carlson-Jones, 2004, p. 824), making high school a breeding ground for enacted stigmatization. Studies have repeatedly documented the negative effects of enacted stigmatization, resulting in psychological distress, depression, anxiety, and lowered self-esteem (Cash, 1995; Kent, 2002; Thompson & Kent, 2001). Due to this psychological distress, stigmatized individuals can begin to avoid social situations and attempt to conceal their disfigurement (Liskey-Fitzwater et al., 1993; Kent, 2002; Roberts et al., 2003; Thompson & Kent, 2001). By avoiding social situations, individuals decrease both opportunities to develop effective social skills to deal with the stigmatization and opportunities to experience positive reactions to their disfigurement from others (Benrud-Larson et al., 2003).

Concealment behaviors can be just as detrimental to individuals attempting to deal with the distress associated with stigmatization. Wearing multiple layers of clothing, altering body postures and gestures, and using make-up as methods of concealment, while they may reduce the occurrence of enacted stigmatization, have been shown to increase the *felt* stigmatization experienced by individuals with a disfigurement (Kent, 2000; Kent, 2002; Kent & Keohane, 2001). According to Kent and Keohane (2001), *felt*, or anticipated, stigmatization results from a fear that others will reject you. This anticipation may be due to previous enacted experiences of rejection or simply to expectations of rejection. Concealment behaviors have resulted in increased feelings of guilt and shame (Elliott et al., 1982; Kent, 2002; Thompson & Kent, 2001). In addition, attempting to conceal their disfigurement often increases preoccupation with and self-consciousness about physical appearance (Liskey-Fitzwater et al., 1993; Pruzinsky & Cash, 1990). This preoccupation and self-consciousness can result in a spiral of negative reinforcement: when preoccupied with their disfigurement and appearance, individuals “are more likely to notice others’ comments and to interpret them as indicative of rejection” (Thompson & Kent, 2001). This then feeds their negative body image by increasing their desire to conceal and avoid.

## SOCIAL SKILL LEVEL.

The final factors mediating the effect of a negative body image on quality of life are social skills. Studies comparing individuals with and without disfigurements have found individuals with disfigurements more likely to be shy, socially isolated, socially incompetent, and socially anxious (Kent, 2000; Kent, 2002; Pruzinsky & Cash, 1990; Thompson & Kent, 2001). Explanations for these social skill deficits are varied and complex. One explanation is that a lack of practice produces underdeveloped social skills; social anxiety due to a fear of rejection causes individuals to avoid social situations that results in fewer social learning opportunities (Kent, 2000; Kent, 2002). Another explanation focuses on the negative repercussions of discrimination; negative social experiences due to discrimination (enacted stigmatization) result in self-consciousness and negative self-attributions that inhibit social skill development by decreasing the occurrence of pro-social behaviors (Pruzinsky & Cash, 1990; Thompson & Kent, 2001). A third explanation focuses on individuals' preoccupation with their disfigurement (Kent, 2000); when preoccupied with their own appearance, they may be less attentive to the needs and concerns of others, thus producing less meaningful and reciprocal relationships (Pruzinsky & Cash, 1990). Most likely, all three of these proposed mechanisms contribute to the poor development of social skills in persons with disfigurements. Studies that have found social skills training to decrease social anxiety and increase social confidence after training further support the concept of social skill deficits (Kent, 2002; Thompson & Kent, 2001). Also supporting these proposed social skills deficits are studies that have found that being open about a disfigurement in social situations reduces anxiety for the individual with the disfigurement (Kent, 2000; Thompson & Kent, 2001). The positive effects of this openness could be due to both increased social practice and/or a decrease in the guilt or shame associated with concealment behaviors.

This paper presents the results of a qualitative investigation into the quality of life of adolescents with pectus excavatum who chose to undergo the Nuss procedure. Specifically, we explore how satisfaction, well-being, empowerment, and social belonging provide a detailed account of how pectus excavatum and the Nuss procedure affect adolescent quality of life, providing suggestions for continued research, family support, theoretical development, and educational support.



## METHOD

### RESEARCH DESIGN

The current study is a phenomenologically-informed study (Colaizzi, 1978; Creswell, 1998; Giorgi, 1985; Moustakas, 1994; Polkinghorne, 1989; Tesch, 1990), designed to obtain comprehensive descriptions and understanding of individuals' experiences. By exploring the perceptions and experiences of adolescents with pectus excavatum, we aim to describe the essences of living with pectus excavatum, the decision to have the Nuss procedure, and living with the results of surgery. As with phenomenological studies, this study involves the thematic analysis of participants' descriptions in order to derive meaning from each person's experience.

### PARTICIPANTS

Ten adolescents with pectus excavatum and their parents participated in the present study. As identified by Creswell (1998), this is more than adequate for a phenomenological study. All participants (adolescents and their parents) resided in Alberta, Canada and were recruited by surgical staff through the Alberta Children's Hospital where they had undergone the Nuss surgical correction of their pectus excavatum six months to one year prior to the interview. Of the 25 people interviewed, 10 (7 boys, 3 girls) were adolescents with pectus excavatum, and 15 were parents (8 mothers, 7 fathers) of the youth. All adolescents were between 13 and 16 years of age. In some cases, only one parent was present due to either conflicting work schedules or single-parent families. Prior to each interview, we provided each family with an informed consent package describing the purpose of the study, the benefits of participation, and written confirmation of their anonymity.

### DATA COLLECTION

The goal of the semi-structured interviews we conducted with each adolescent and their parent(s) was to obtain a thorough understanding of the families' experiences with pectus excavatum and the Nuss Procedure (see Appendix 1 for interview guide). We conducted the interviews at the Alberta Children's Hospital in 2004. During each interview, the interviewer posed questions to participants in order to elucidate participants' experiences regarding pectus excavatum before surgery, the surgical and recovery process, and post-recovery quality of life.

### DATA ANALYSIS

Upon completion of data collection, we transcribed the interviews verbatim and analyzed them thematically. We based our thematic analysis on Colaizzi's (1978) procedure, later modified by Roberts and Cairns (1999). We conducted the analysis in five stages. First, we re-read the interviews in order to understand the essence of each family's experiences. Second, we identified and extracted meaningful phrases that captured important aspects of their experiences. Third, we assigned theme words to each extracted phrase; theme words reflected the meaning or point of their phrases. In the present study, a theme was included if it was common to approximately 50% of the families.

Once we had identified the themes, we returned transcripts and analyses to the families for their review and consent for use. We then conducted a second telephone interview with each family to ensure accuracy of the typed transcript and the thematic representations. Identified by Lincoln and Guba (1985) as "the most critical technique for establishing credibility" (p. 314), this verification procedure enabled participants to review and verify the entire interview and theme words.

Similar themes were grouped together to form theme clusters. We labeled each cluster according to the central meaning of the theme group. Subsequent to cluster formation, similar clusters were grouped together to form categories. We then labeled categories to represent the principal meaning of the cluster group. Finally, categories were "integrated into an exhaustive description of the investigated topic" (Colaizzi, 1978, p. 61).

## RESULTS

Four of the ten adolescents purposively waited to have their pectus excavatum surgically corrected until they found out about the Nuss procedure as they felt the Ravitch was too invasive. In addition, one child who had the Ravitch when he was six, due to the concavity returning at puberty, returned for the Nuss procedure. We identified prevalent themes for adolescent well-being, social belonging, satisfaction, and empowerment prior to surgery, during recovery, and post-surgery (see Table 1). In addition, we also identified prevalent concerns of parents.

### PRE-SURGERY

Living with pectus excavatum dramatically affected the quality of life of adolescents in the areas of well-being, social belonging, and satisfaction. They

reported an adverse affect on their physical well-being due to breathing problems (90%), pain or illness (50%), and fatigue (50%). Adolescents reported that “breathing was a little bit harder. . . Like I couldn’t run for that long without getting tired. I had to take a five minute break” (Adolescent 1). Some even reported that it felt as though they were “gasping for air” (A3); they “couldn’t keep up with breathing and getting oxygen” (A5). In addition to breathing problems, adolescents reported having chest pains and heart palpitations. “I had throbbing pain, throbbing and shooting pains in the upper part of my chest” (A7). In addition, they reported asthma, muscle spasms, and pneumonia. In the majority of cases, this affected adolescents’ ability to participate effectively in sports and physical education classes.

Psychologically, adolescents reported a negative self-esteem (80%) that affected their feelings of well-being. They consistently voiced concerns over not feeling “normal.” Many adolescents noted not feeling very different from others when they were younger, but this quickly changed during puberty. Usually precipitating this change was a dramatic increase in concavity as well as entry into middle or high school.

I didn’t really notice it and nobody else really noticed it, but when I entered middle school and we had to change in gym and all that, that’s when people started noticing it and I started to get comments on that and it wasn’t until grade 8 that I started getting made fun of for it. That’s when I really wanted to get rid of it. (A5)

Repeatedly linked to this negative self-esteem were concerns of social belonging. Adolescents reported feeling very self-conscious (80%) about their pectus excavatum. They had to continually field questions (80%) regarding their “bowl chest thing” (A9), as well as suffer ridicule from others.

We were at the pool. . .and it was the first time I’ve really visualized, I mean, he’s seen kids stare at him and he’s had to deal with it. I haven’t really seen it as much and these two teenage boys would like bluntly stare and point and talk to each other and I was uncomfortable for him. (Mother 1)

Sometimes, the ridicule was also physical. “Some people would...find out and be like poking at my shirt and stuff” (A10).

Due to the felt stigmatization of not being “normal,” and the enacted stigmatization experienced by adolescents, certain activities, especially swimming, were actively avoided (70%). For example, “I kind of always didn’t want to take my shirt off and go swimming a whole lot and. . .just didn’t like how people would like stare at me and stuff” (A10). In addition, adolescents used clothing and body gestures to try to conceal their deformity (50%). “Taking off his shirt, he would always have his vest on because it was

**TABLE I.**  
**Pre-Surgery, Recovery, and Post-Surgery Quality of Life Clusters**

	Pre-Surgery	Recovery	Post-Surgery
Concerns	<ul style="list-style-type: none"> <li>• Nervous about having surgery (90%)</li> <li>• Worried about recurring health problems (90%)</li> <li>• Difficult to decide on best time for surgery (60%)</li> <li>• Worried about future health problems (60%)</li> </ul>		<ul style="list-style-type: none"> <li>• Concerns with bar shifting (60%)</li> </ul>
Physical Experiences	<ul style="list-style-type: none"> <li>• Breathing problems (90%)</li> <li>• Pain and illness (50%)</li> <li>• Complaints of fatigue (50%)</li> </ul>	<ul style="list-style-type: none"> <li>• Felt severe pain (90%)</li> <li>• Recovery took longer than expected (80%)</li> <li>• Difficult to lie on back for extended periods of time (50%)</li> </ul>	<ul style="list-style-type: none"> <li>• Increased muscle tone (90%)</li> <li>• Increased energy (90%)</li> <li>• Pain and swelling from bars (50%)</li> </ul>
Psychological Experiences	<ul style="list-style-type: none"> <li>• Disliked appearance (90%)</li> <li>• Negative self-esteem (80%)</li> <li>• Felt self-conscious (80%)</li> <li>• Felt uncomfortable responding to questions about their chest (80%)</li> </ul>	<ul style="list-style-type: none"> <li>• Satisfied with pain management team (100%)</li> <li>• Satisfied with doctors and nurses (90%)</li> </ul>	<ul style="list-style-type: none"> <li>• Satisfied with appearance (100%)</li> <li>• Glad they had surgery (90%)</li> <li>• Increased self-confidence (90%)</li> <li>• Felt supported by others (90%)</li> <li>• Increased social status (70%)</li> </ul>

**TABLE I.**  
*(Continued)*

	Pre-Surgery	Recovery	Post-Surgery
	<ul style="list-style-type: none"> <li>• Patient deciding to have surgery increased feelings of control over life (80%)</li> </ul>		<ul style="list-style-type: none"> <li>• Felt relieved to be open with others (60%)</li> <li>• Eager to have bar removed (60%)</li> </ul>
Behaviors	<ul style="list-style-type: none"> <li>• Avoided swimming (70%)</li> <li>• Used clothing or body gestures to conceal (50%)</li> </ul>		More adventurous (increased feelings of freedom) (70%)

quite deep, like this little hole in the middle of the chest” (M4). At times, attempts to conceal the deformity also affected their posture.

I wasn’t very active and I wore a lot of shirts and a hoody and I was very self-conscious. (A3) She slouched a lot. She was tall so it was a painful thing because bathing suits would be wet which would definitely show the recess. (M3)

Another common body gesture used to conceal the deformity was the crossing of arms in front of the chest.

Adolescents’ feelings of dissatisfaction ultimately resulted in deciding to have the Nuss procedure. Adolescents equally expressed a dislike for their appearance (90%) and a concern for recurring health problems (90%). In addition, both parents and adolescents expressed concern over future health problems (60%) such as heart or lung complications due to the concavity. In the majority of cases, adolescents were responsible for deciding whether to undergo surgery. In 80% of the cases, this resulted in feelings of control and empowerment.

Well, the fact that I chose to do it and chose to do it myself like without people trying to

convince me to do it. It was my decision so I feel, yeah, I feel almost more brave. (A9)

Adolescents reported a “wonderful feeling. That sense of, you know, that sense that this is my body, my life” (A2).

One difficulty expressed by parents and adolescents was deciding on when to have the surgery (60%). They felt caught between wanting to have the surgery prior to increased levels of social stigmatization during adolescence and being worried about growth spurts that may reverse the effects of the surgery. In most cases, the decision to have the surgery came after noticing a marked increase in indentation in early adolescence. Once they made the decision to have the surgery and the surgery booked, adolescents expressed nervousness regarding the surgery (90%). However, it was felt that “any amount of pain. . . would probably be better than the emotional pain” (A5).

#### DURING RECOVERY

Adolescents reported being satisfied with their pain management team (100%) and the doctors and nurses (90%) that supported them in the hospital during recovery. The majority reported that recovery took longer than they had expected (80%) and that the pain was very severe (90%). Adolescents also reported difficulty with having to lie on their back for extended periods of time (50%).

He said, “You’ll be in pain,” he never said that I wouldn’t be able to shift, he never said, you know, I’d get so nauseous. . . I just spent like three days with just my eyes closed because I couldn’t move. I wouldn’t let anyone touch my bed because even if they moved it a little bit I’d be like completely gone. (A7).

Management of the pain with the epidural was very important and repeatedly mentioned.

The epidural was really good. It astonished me how it could just concentrate on one area, numb just one single area. I mean, I can feel everything else except just a bar across. (A9)

The epidural enabled them to start moving and working on their physiotherapy. However, they had trouble when they had the epidural removed.

Yeah, he walked well like off the start afterwards. He did really, really well with the epidural in and not feeling much at all. He did great and then once they started tapering that off he was really uncomfortable. I don’t know who cried more, him or me. (M1)

## POST-SURGERY

Adolescents reported an immediate improvement in all four areas of quality of life following surgery: well-being, satisfaction, social belonging, and empowerment.

He was pretty proud the first night even though he was in as much pain as he was. His grandpa came to see him, “look grandpa,” so he was pretty proud. That made getting through the night bearable, I think, knowing how much he wanted it and the reward was there right away. (Father 5)

Parents and adolescents described improvement in well-being, noting that they felt an increase in self-confidence (90%), increase in muscle tone (90%), and an increase in overall energy levels (60%).

Especially, like with my age, it’s just I’ve had a better self-appearance about myself and how my body is now that I’ve gotten it done. It’s changed a lot. I don’t have a deformity now which is psychologically, you kind of think, “oh, you aren’t weird,” you know. . . I feel that I have a better chance at doing things that I’m going to want to do like say singing or music or even sports that I never could do before because I was always so short of breath and that I have more of a chance once the bar comes out. That I’ll be able to do these things and live with it more normally. . . I feel a lot better about myself. (A2)

Parents reported that their adolescent stood “taller, you know, more self assured” (F9); the increased self-confidence made a visible difference in posture as well as appearance. Repeatedly, adolescents noted how great it was to “just be a normal person” (A10). Some adolescents did note some pain and swelling from the bars (50%). This did improve over time, with adolescents feeling as though “there is more room. . . I could feel it after the surgery after, like, the pain went away” (A10).

All adolescents were satisfied with their appearance (100%) with the majority glad they had the surgery (90%). Adolescents reported no longer feeling “shy to take off [their shirt] when [they] were getting changed in the locker rooms” (A4). They felt that they were more “able to talk to people now. . . [that they] don’t have to worry about [people] making fun of [them] for having a dent in [their] chest” (A5). Some adolescents did express concerns over being able to feel the bar shift (60%) and that they were eager to have the bar removed (60%). Adolescents identified that they could feel the bar in place, noting where the bar ended on their side; however, this did not impede their activities or endurance levels. Instead, adolescents reported feeling a greater sense of freedom after surgery (70%). They were more adventurous, taking part in more physical and social activities than before

the surgery. "I was more talkative, I was more energetic kind of thing. A lot more energy, I was more outgoing" (A3). Adolescents identified this as giving them a greater feeling of control over their choice of activities.

Along with increases in self-confidence, self-esteem, and freedom, adolescents also reported increased feelings of social belonging. "I have more friends now and not as many people making fun of me and all that" (A5). They also noted this improvement concerning intimate relationships. "I assume most girls would be grossed out by [pectus excavatum] and they usually were. So now the dating situation might be somewhat more optimistic" (A8). Throughout the process, adolescents felt supported by friends, family, and their schools (90%). A majority even identified an increase in social status because of their surgery (70%). Adolescents enjoyed telling people about their surgery and identifying that they had a steel bar in their chest. "It's pretty cool to say I've got 2 bars in my chest. Like, hey, do you want to feel the bolts" (A9). Adolescents also identified that they felt relieved to be open with others regarding their pectus excavatum and their surgery (60%). This relief was due to the cessation of concealment behaviors; they no longer felt the need to hide anything.

#### PARENTS

Throughout interviews, parents provided feedback on what it was like to support their child through the Nuss procedure. Prior to surgery, parents viewed a videotape of the Nuss procedure. The majority were shocked at the gore of the video (80%), but found that this did not prepare them for seeing their child in so much pain after surgery (70%).

It did say in the movie about the pain and stuff like that, but until you actually go through it with your child, I don't think you realize the pain they are going to be in. She would lay there the first couple of days and cry. Even though she was numb the pain was pretty intense. (M3)

Parents also identified that more information was required regarding the epidural, catheters, and chest tubes (70%). While they felt very well informed regarding the actual surgery, they were missing information on the other aspects associated with being in the hospital, pain medications, and recovery equipment. The other 30% who did not report needing additional information were families where one parent was a nurse.

When it was time for their child to return to school, parents said that the school was supportive. Their biggest concern was setting up a procedure for the distribution of pain medication at school (60%); it was important that, if needed, their child could have access to medications for managing their pain. Additional salient points regarding support from schools included setting up



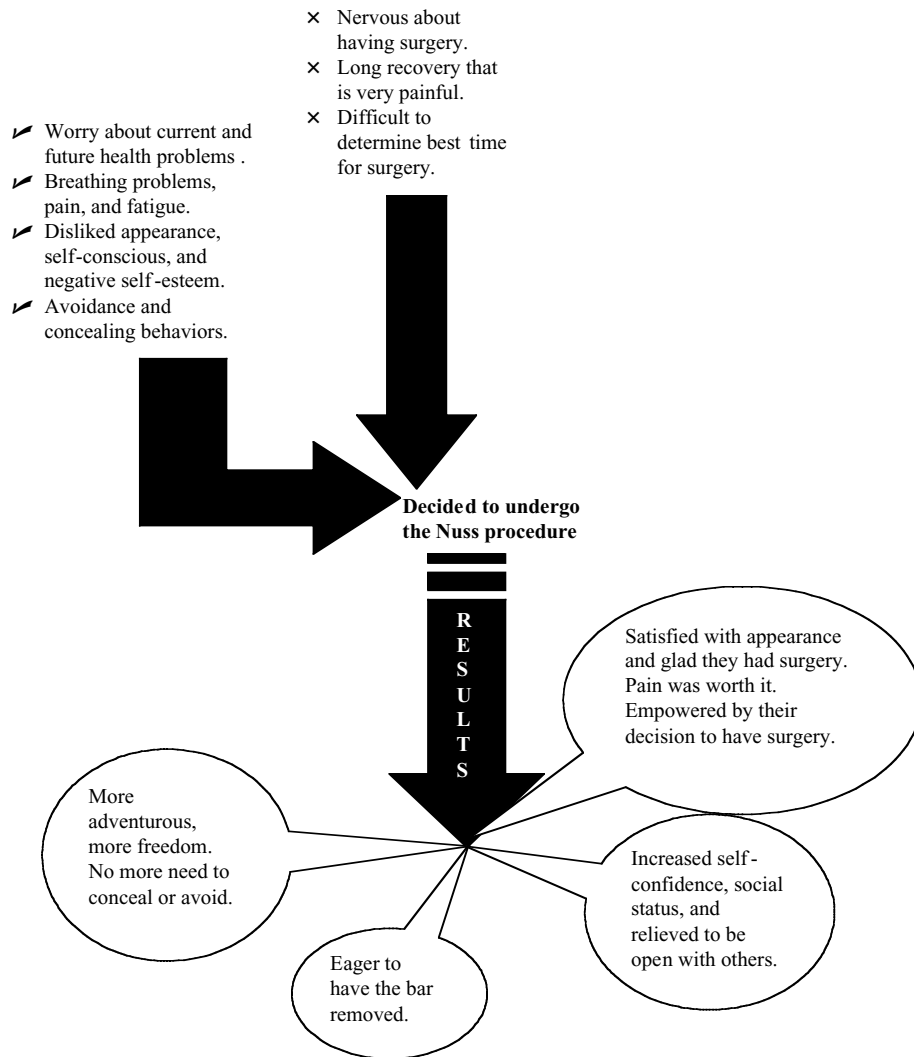
a procedure so their child could switch classes early to avoid congestion in the hallways and arranging for a second copy of textbooks to keep at home so that their child did not have to carry them back and forth to school. Parents also reported driving their child to and from school for the first couple of weeks because the bus rides were quite painful.

## DISCUSSION

For adolescents, deciding to have the Nuss procedure to treat their pectus excavatum was an important decision that had physical, psychological, and behavioral ramifications. Figure 1 provides an illustration of the retrospective look at living with pectus excavatum, the decision to undergo surgery, and the effects of the Nuss procedure. It was important for the adolescents to be involved in the decision to undergo the Nuss procedure; it gave them a feeling of control over their disfigurement. When making their decision, adolescents weighed the effects of negative self-esteem, self-consciousness, physical fatigue and breathing problems, and worry about current and future health concerns against their nervousness regarding the surgery. Also entering into the decision was a concern over timing. Both parents and adolescents felt caught between having the surgery early enough to decrease negative stigmatizations, but late enough to ensure that growth spurts did not reverse the correction. Ultimately, the increased indentation upon entering adolescence helped finalize the decision.

The amount of pain involved with recovery from surgery surprised parents and adolescents; the recovery took longer and the pain was more intense than either had been prepared for. This is an important finding for health professionals to note: prior to surgery, patients and their parents need to be more aware of the pain and discomfort that will follow surgery. However, even having experienced this, adolescents were glad that they underwent the surgery. It was felt that the improved appearance, self-esteem, self-confidence, social status, and relief reported by adolescents were worth the pain of surgery. Adolescents no longer engaged in avoidance or concealment behaviors, feeling more adventurous and free to engage in activities they had previously avoided. While adolescents eagerly await the removal of their bar(s), they feel that their quality of life has dramatically improved after the Nuss procedure.

The exploration into the essence of living with pectus excavatum and the effects of the Nuss procedure provides interesting connections to stigmatization literature, attribution theory, and impression management research. Adolescents who decided to have the Nuss procedure felt empowered by tak-



**Figure 1.**

**Deciding to undergo the Nuss procedure**

ing action towards becoming what they perceived as *normal*, despite the risks and pain costs. Adolescents shared experiences of felt and enacted stigmatization, relating how these stigmatizations had a negative impact on their self-esteem, self-confidence, and willingness to take part in a variety of activities. This is consistent with research of other types of body disfigurements (Cash,

1995; Kent, 2000; Kent & Keohane, 2001; Thompson & Kent, 2001). After corrective surgery, adolescents identified that they felt *normal*, attributing feelings of increased self-confidence, self-esteem, and social status both to their decision to have the surgery and the surgery itself. Attribution theory and research (Graham & Weiner, 1996; Weiner, 1986) would describe this as moving from an unhealthy causal belief system that promotes helplessness to a healthy one that empowers the individual to act on his or her own behalf. Thompson and Kent (2001) have reported “an exaggerated tendency [for those with disfigurements] to attribute the negative behavior of others to their disfigurement. . . [These] internal, global, and stable attributions” (p.670) leave individuals feeling helpless, often leading to feelings of shame, humiliation, embarrassment, hopelessness, and ultimately depression (Abramson, Seligman, & Teasdale, 1978; Alloy, Lipman, & Abramson, 1992; Gladstone & Kaslow, 1995). By attributing improvements in their quality of life to the Nuss procedure, a procedure they decided to have and endured at some cost, adolescents were able to take control of what they previously perceived as uncontrollable and shameful. They were also able to take credit for the positive outcome. In future research on the stigmatization and surgical repair of pectus excavatum we need to consider the presence or absence of different attributions as potential variables that may mediate or moderate the relation between disfigurement and psychosocial outcomes.

In addition, the number of stigmatizations, both enacted and felt, decreased. Adolescents identified feeling less self-conscious and more willing to involve themselves in social situations. Adolescents and their parents reported an increase in the number of friends, number of social interactions, and level of social competence post-surgery. This suggests that corrective surgery not only provides a clinical improvement, but also a social improvement. This is contradictory to Kent’s (2000) research into medical interventions. More investigation is required to look at the amount of social skill an adolescent has before and after corrective surgery. It is unclear whether the surgery, by decreasing levels of self-consciousness, automatically improved social competence or if the increased practice from not avoiding social situations was responsible.

This study also supports work describing the negative psycho-social effects of impression management techniques (Benrud-Larson et al., 2003; Kent, 2000; Thompson & Kent, 2001). Adolescents used avoidance and concealment behaviors to mask their pectus excavatum. Adolescents also experienced feelings of shame, self-consciousness, and low self-esteem. In contrast, after surgery they stopped using avoidance and concealment behaviors and also reported feeling more self-confident, higher self-esteem, and

relieved that they could be open about their disfigurement. As a phenomenological exploration into the essence of living with pectus excavatum and the Nuss procedure, we cannot assume a cause and effect relationship between the impression management techniques of avoidance and concealment and levels of self-esteem and shame; however, a relationship does appear to exist. This warrants additional multi-method studies that look at the direct, possibly causal, relationship between psychosocial variables and impression management techniques.

Finally, given the importance adolescents place on peer acceptance and the increased indentation that occurs as students enter middle and high school, there are important educational implications that exist for teachers and administrators. Prior to surgery, physical education teachers and coaches need to be aware of the physical limitations that may exist for students with pectus excavatum. They may have difficulty with breathing, fatigue easily, and experience chest pains when exercising. Given the enacted and felt stigmatization associated with exposing one's disfigurement, understanding and alternatives should be discreetly provided for students when changing for gym classes or when allocating teams as *shirts* and *skins*. In addition, given the negative effects of enacted stigmatization, it is important that teachers take an active role in ensuring that students with pectus excavatum do not suffer ridicule for their disfigurement.

If students do undergo the Nuss procedure, realize that time at school will be missed. When the student returns, pain management will still be required and procedures for the student to self-administer medications will need to exist. Given that the bar(s) will remain in for approximately two years following surgery, some discomfort may be experienced. For the six weeks following surgery, students will need to limit any jarring of the bars. Students may need to switch classes earlier to avoid congestion in the halls. Copies of school books may be required at home to decrease the weight of backpacks. If the bar(s) is hit and pain or swelling results, medical attention may be required. Approximately six weeks after surgery, students should be fully participating in physical activities. Encourage as much involvement in physical activity as possible as this will help increase exercise tolerance levels and improve breathing. In addition, while adolescents in this study were enthusiastic of sharing their experiences with their peers, it is important that information regarding an adolescent's pectus excavatum or surgery remain confidential. Be sure to discuss disclosure with the student prior to sharing information with other students or teachers.

Some limitations do exist when generalizing the results from this study. While 25 people were interviewed, this data is truly only looking at the expe-

periences of 10 adolescents. Additional work needs to occur with a larger sample size. In addition, more boys than girls (consistent with the statistical occurrence of pectus excavatum) were included in this study. It is possible that important and salient experiences specific to girls may have been excluded due to a lack of prevalence in this population sample. Qualitative research looking at pectus excavatum and corrective surgery would benefit from studies looking at the experiences of boys and girls separately. Finally, given that our interviews took place after surgery, their perceptions of living with pectus excavatum were retrospective. A longitudinal study that provides adolescents with the opportunity to share their perceptions before, immediately following, and a year after surgery would be very beneficial.

More literature exists on the cardiopulmonary effects of corrective surgery for pectus excavatum than on quality of life. Given the lack of significant cardiopulmonary improvements following surgical correction, some researchers have suggested that its primary value is cosmetic. The label of *cosmetic surgery* is misleading and potentially harmful as it ignores important psychosocial and workload benefits of the surgery. According to adolescents in this study, while the purely cosmetic improvement was valued, the resultant psychosocial impact of surgery on quality of life was far more valuable. The adolescents felt that their increased self-confidence, improved social involvement, and fewer avoidance and concealment behaviors were the direct result of the Nuss procedure. If researchers replicate these findings with a larger sample, find them to be enduring and substantive changes over time, and support them with diverse methodologies, society cannot overlook the importance of providing surgical repair of pectus excavatum.

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## **APPENDIX I**

### **SEMI-STRUCTURED INTERVIEW GUIDE FOR PARENTS AND CHILDREN**

I invite you to share with me what life is like when you have, or your child has, pectus excavatum and has undergone the Nuss procedure. Hopefully, through better understanding what life has been like for you, we will be better able to care for future children who may go through the same procedure. I will invite you to share with me any other thing that comes to mind, and then follow up with questions specific to quality of life issues. Please let me know if my questions don't make sense. I will be happy to reword them

Can you tell me about what life was like before you had surgery?

Can you tell me about what life was like around the time you had surgery?

Can you tell me about what life is like for you now?

Satisfaction

How satisfied are you with the results of the surgery?

How satisfied are you in other areas of your life (school, activities, etc.)?  
(*address pre and post surgery*)

Well-Being (*address pre and post surgery*)

How would you judge your well-being since undergoing the procedure?  
(*address pre surgery as well*)

Social Belonging

How would you evaluate your social belonging (or any changes in social belonging) since the operation?  
(*address pre surgery as well*)

Empowerment/Control

Has your sense of empowerment or control changed since the surgery?  
(Yes/No). Please tell me more.

Has your ability to control your life changed since the operation?  
(Yes/No). Please tell me more.  
(*address pre surgery as well*)

What has been the biggest benefit?

What has been the hardest thing?

What good/helpful things have the medical professionals done for you?

What recommendations do you have for medical professionals?

Do you have any other comments, suggestions, or concerns you would like to share with me?

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