

Quality of Life of Patients Who Have Undergone the Nuss Procedure for Pectus Excavatum: Preliminary Findings

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Background/Purpose: The current project is a preliminary qualitative exploration of changes in quality of life of patients who have undergone the Nuss Procedure. The current study explores quality of life after surgical repair from the perspectives of both the patients and the parent(s) of the younger participants.

Methods: This research constitutes the first segment in a mixed-method longitudinal design. The author conducted semistructured interviews based on the Keith and Schalock's quality of life model. Five youth who have undergone the Nuss Procedure and the parent(s) of the 4 younger participants were included in the study for a total of 10 participants. Textual analysis has been carried out using *Atlas.ti*, a qualitative data analysis program that facilitates such activities as selecting, coding, and comparing textual segments.

Results: Results based on these preliminary data indicate that the patients interviewed had significant improvement in overall quality of life, which they attributed to the surgery.

Specific examples of patients' expressions of improved self-confidence and renewed interest in physical activity are given.

Conclusions: The Nuss Procedure is a minimally invasive surgical option for correcting pectus excavatum deformities that may make important contributions to patients' self-perceptions and quality of life. The participants in the current study expressed satisfaction with both the physical results of the surgery and with how it improved their overall quality of life. The authors recommend further prospective longitudinal research that assesses pre- and postsurgery psychosocial status and the maintenance of perceived quality of life changes.

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INDEX WORDS: Nuss procedure, pectus excavatum, quality of life.

PECTUS EXCAVATUM is the most common congenital chest wall deformity, with an incidence rate of between 1 and 8 in 1,000 live births.^{1,2} The rib cage of individuals with pectus excavatum forms abnormally so that the distance from the sternum to the vertebrae is decreased, resulting in a caved-in or sunken chest, and, in many cases, the sternum is asymmetric.³ The chest deformity is present at birth in about 85% of individuals with pectus excavatum and usually progresses as the child grows, during the pubertal growth spurt, the defect often increases dramatically.² Pectus excavatum is 3 times more likely to occur in boys than in girls.¹

Patients with significant pectus deformities often experience embarrassment and shame over the perceived differences in their physical appearance. This silent suffering, often appreciated by family members, is palpable when they and their parents come to the office for assessment for corrective surgery. Research has found that this kind of hypersensitivity and preoccupation with negative perceptions of physical appearance can lead to lowered self-concept, feelings of inferiority, mild to moderate depression, shyness, social anxiety, and maladaptive social behavior.⁴⁻⁸ Defensive camouflaging with poor posture and folded arms, and restrictions in lifestyle that may include avoidance of swimming, shirtless sports, hugging, and intimate relationships are the outward manifestations of this inner embarrassment and shame.^{4,8}

Anecdotal accounts report improved endurance and participation in physical education activities after corrective surgery for pectus deformities. The conventional explanation for this has focused primarily on improvements in physiologic processes, notably an increase in cardiorespiratory performance.^{9,10} We believe, however, that dramatic feelings of satisfaction experienced by patients after pectus repair can hardly be accounted for solely on fractional improvement in heart and lung function. Our hypothesis is, therefore, that the improvement in physical appearance may affect determinants of a child or adolescent's quality of life. These determinants may be more than cosmetic and contribute significantly to the satisfaction experienced after corrective surgery.

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Fig 1. Roberts & Cairns pictorial representation of Keith and Shacklock's¹ QOL model. Reprinted with permission.²⁰

Limited research has focused on this potentially important issue.

Up until recently, the Ravitch Procedure was the most common technique used to correct pectus deformities. A more recent development, the Nuss Procedure, is a minimally invasive approach offering highly acceptable correction without the need for a large incision across the chest.^{11,12} Given the recent nature of these surgical developments, it is necessary to better understand the impact the surgery has on quality of life for children and adolescents.

This project represents the initial stage of a larger mixed-method, longitudinal program of study. As such, the current report uses qualitative methodology to better understand the quality of life (QOL) experiences of the 5 youths who have undergone the Nuss procedure. More specifically, our aims are 2-fold: first to understand the patients' experience of the surgical procedure and, second, to identify changes in QOL from the perspectives of both the patients and parents of the 4 younger participants.

MATERIALS AND METHODS

A qualitative research methodology informed by phenomenology was used to interview children who have undergone the Nuss procedure.¹³⁻¹⁸ Qualitative methodology was used to provide a contextual understanding of the complex emotions and cognitions experienced by the children (and their parents). Our goal was to inform, enhance professional sensitivity, and to provide a foundation for a larger mixed method (quantitative and qualitative) study.

Central to this project is the concept of quality of life (QOL). Our definition of QOL is grounded in Keith and Schalock's¹⁹ theoretical framework that focuses on general feelings of satisfaction, well-being (including both physical and emotional well-being), social belonging, and empowerment. Our conceptualization of Keith and Schalock's QOL model is illustrated in Fig 1.

We gathered data through in-depth, semistructured interviews and questionnaires. Four of the younger patients (ages 12 to 14) and their parent(s) were interviewed and completed the questionnaire. Further, an additional participant (age 21) completed a questionnaire. This constituted a total of 10 participants and 100% of the patients/families who were eligible for participation in the study. Because the patients ranged from 3.7 to 9.5 on the "Haller Index," all of the youth were considered to have a significant defect before undergoing the Nuss

procedure. Data collection took place between November 2001 and July 2002. They were conducted 6 to 9 months after the surgery to allow patients adequate recovery time. The QOL interview format outlined in the work of Roberts and Cairns was followed.²⁰

All 4 of the younger participants and their parent(s) were interviewed twice. The first interview was used to gather primary data. The second interview, conducted by telephone, was to validate the transcribed interviews and to gather additional information and insights. The interviews were transcribed and analyzed for themes and patterns of experience following a protocol analysis procedure informed by the work of Colaizzi¹³ and Haase.²¹ Textual analysis was assisted with Atlas.ti, a qualitative data analysis program. After the first 3 participants were interviewed, the generated data were used to create the "Pectus Project Questionnaire"—a series of 12 questions addressing 4 areas of quality of life. This questionnaire will provide descriptive data to supplement the qualitative component.

RESULTS

This section is organized into 2 components: qualitative findings and descriptive data. The *qualitative findings* component provides an overview of the data generated from the semistructured interviews. These data have been organized into preoperative and postoperative experiences (Table 1), with key themes highlighted below each heading. The *descriptive data* component outlines some of the data generated from the "Pectus Project Questionnaire."

Qualitative Findings

Preoperative preliminary findings. Before the procedure, affected children and their parents described how they worried about the "chest hole." Some concerns centered primarily around health issues, whereas others centered around issues of self-consciousness, self-esteem, and self-confidence. All children had experienced either actual teasing or profound worry about teasing, both of which produced a hypervigilance about keeping the deformity (and consequent surgery) a secret. It is clear that the deformity affected their self-concept and interfered (to varying degrees) with their participation in activities requiring removal of clothing (eg, swimming or group sports requiring a tank top as part of the uniform). Moreover, parents explained how the distress experienced by their children also affected them. This distress was constant, pervasive, and increased as the children

Table 1. A Summary of the Data Generated From the Semistructured Qualitative Interviews

Preoperative	Postoperative
<ul style="list-style-type: none"> • Physiological concerns • Self-consciousness and secrecy • Self-esteem and confidence issues • Teasing or worry about harassment • Limited participation in certain activities 	<ul style="list-style-type: none"> • Satisfaction with surgery • Greater physical strength • Improved confidence • Greater participation in certain activities • Postoperative discomfort for 4 to 6 weeks • Parent and child worries about implanted bar

matured. Below are direct quotes that illustrate these points:

Youth: "I've always been pretty comfortable around people, but *not* when I had my shirt off. It was really obvious. I'd feel a bit embarrassed or a lot embarrassed, I guess."

Parent: "He didn't seem to feel as comfortable just having his chest showing—he was *layering* clothing."

Postoperative preliminary findings. Participants described improvements in each aspect of QOL (satisfaction, social belonging, well being, and empowerment/control). Children and families described great satisfaction with the results of the procedure, and they explained how the results were immediately noticeable. One mother put into words how she felt about the changes in her son's chest: "I think it's amazing. It's incredible. Like the difference is instant. Like you know, he came out and he was under going to try to find the part that was caved in and it was gone. To me it was incredible." Further, children and parents describe how the benefits of the procedure go beyond simple improvements in appearance and affect the way children feel about themselves. Children talked about how they felt stronger, more confident, more likely to participate in activities and less worried about the perceptions of others—all of which suggest greater personal empowerment. As one youth explained, "I think I have more self-confidence now and self-esteem. I am happier with how I look." Parents described how they too noticed great improvements in their children's self-esteem. When commenting about her son's well-being after the procedure, a mother responded, "He's a lot happier. I can tell he's just incredibly happy that this has happened. He's proud of his chest."

Parents did caution, however, that for about 4 to 6 weeks after the procedure their children experienced significant postoperative pain and discomfort. (Pain and

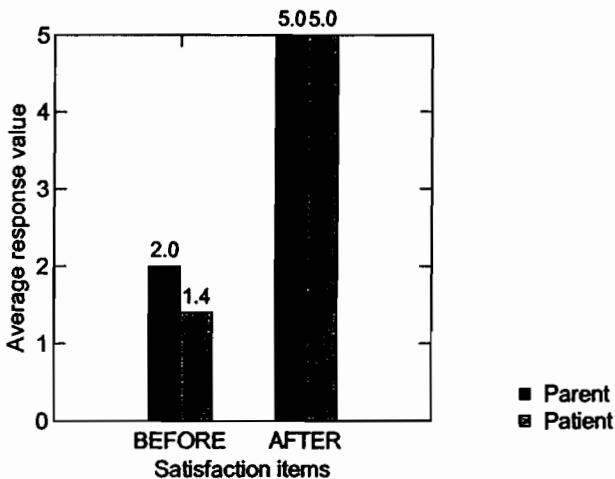


Fig 2. Satisfaction responses.

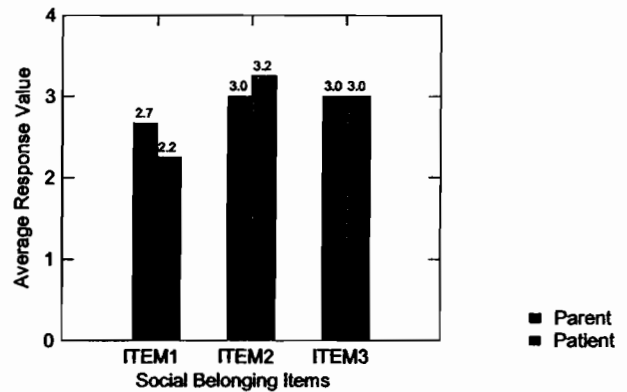


Fig 3. Social belonging items.

discomfort lessened at about four to six weeks.) Some parents also described worrying about the surgically implanted bar used to correct the pectus deformity. These worries primarily centered around the bar "dislodging" during sports activities. However, all families reported that the risks associated with the procedure are well worth the benefits. One child summed up this feeling by stating, "I *knew* in the back of my head that I'd rather go through the pain and stuff just to get rid of it." Another child described the hope he felt once he learned there was a way to repair the funnel chest, and how he hoped that more affected children could undergo the procedure: "Just [get] the knowledge out there so—'cause I'd been hoping there was a way to fix it and I didn't even know."

Descriptive Data

A 12-item questionnaire was administered to the 5 patients and the 4 parents of the younger patients. The questionnaire asked for responses related to 5 areas: satisfaction, social belonging, empowerment and well-being. The findings indicate that both patients and parents perceived an improvement in all 4 areas of quality of life. The perceptions of patients and parents were generally similar.

Two items measured satisfaction. The first asked how satisfied the respondent was with the patient's appearance of their chest before the surgery on a scale ranging from "not satisfied" (1) to "very satisfied" (5). The second item asked about satisfaction with chest appearance after surgery. The results (Fig 2) show that there was low satisfaction before surgery (parent average, 2.0; patient, 1.4) and very high satisfaction after the procedure (parent, patient, 5.0).

Participants were asked also how the surgery affected their social belonging and sense of empowerment (Fig 3). Item 1 asked whether the pectus deformity interfered with their participation in activities with friends. The response scale ranged from sometimes (1), frequently (2), most of the time (3), to significantly (4). Results indicate that the pectus deformity did interfere

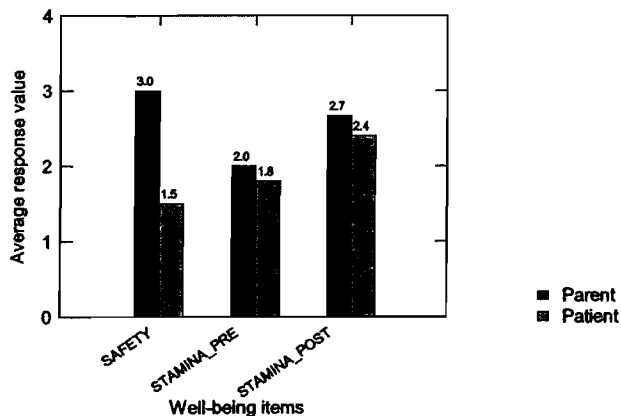


Fig 4. Well-being responses.

with social activities frequently or most of the time (parent, 2.7; patient, 2.2). Item 2 asked patients and their parents if participation in activities “involving some removal of clothing” increased after the surgery. The response scale ranged from a bit (1), somewhat (2), quite a lot (3), to significantly (4). Results indicate that participation did increase quite a lot (parents, 3.0; patients, 3.2). Empowerment was measured by item 3, which asked the extent to which patients’ self-confidence had increased as a result of the surgery. Responses indicate that self-confidence improved significantly (patients, 3.0; parents, 3.0) by all participants.

Well-being was measured by 3 items. The first item asked about the level of worry about safety after having an implanted bar in the chest (response scale ranged from “a bit” [1] to “significantly” [4]). The second item asked about the effect of pectus excavatum on physical stamina (response scale of “a bit” [1] to “significantly” [4]). The third item asked if their stamina improved after surgery (“marginally improved” [1] to “significantly improved” [3]). Results (Fig 4) show that parents are more concerned (average, 3.0, “quite a lot”) about safety of the implanted bar than are the patients themselves (average, 1.5, “a bit” to “somewhat”). In terms of stamina, both patients and parents thought that stamina was “somewhat” (parents, 2.0; patients, 1.8) affected by the pectus condition, but that the surgery had improved stamina “somewhat” to “significantly” (parent, 2.7; patient, 2.4).

DISCUSSION

Beyond ratings of overall satisfaction, there has been relatively little research into the psychological aspects of

pectus deformities or even of disfiguring conditions in general and medical procedures used to correct them.²²⁻²⁶ Although the psychological importance of body image—including the notion that medical treatment can improve quality of life (QOL)—has been described in some detail,^{27,28} very little empirical work has been done. Thompson and Kent²⁶ conclude that there is a need for longitudinal and qualitative studies to foster increased understanding of the processes involved in the impact of disfiguring conditions. The multifaceted nature of body image, self-esteem, and environmental variables interacting in complex ways with physical conditions suggests that qualitative analyses aimed at garnering in-depth descriptions and detailed understanding of such variables is a possible avenue to better informed practice.

Further work is needed, however, to verify that the information the current study obtained from a small number of participants is representative of the larger population. Additionally, there are important questions that the current study is unable to address. For example, to what extent does the surgery produce lasting positive changes in self-confidence? The current interviews were done 6 to 9 months after surgery, which is a time when the novelty and investment of discomfort still is quite fresh in the minds of the participants. At this point we could expect a placebo-like enthusiastic response to this experience. Further longitudinal research is needed to confirm that the positive effects remain. A related question is whether cognitive perceptions of appearance and vigilance for exposure threat change “automatically” and completely with the physical change brought about by surgery. We cannot assume that negative cognitions and preoccupation with appearance just “disappear” with surgery. It may be that psychological intervention is also needed in conjunction with surgery.

The preliminary data outlined in this paper suggest that the improvement in patient QOL after undergoing the Nuss procedure is profound and wide reaching. In each of the 4 areas of QOL outlined by Keith and Shacklock¹⁹ (satisfaction, social belonging, well-being, and empowerment/control) improvement was noted. These are changes deserving of further study.

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