

# Young People's Experiences With Scoliosis Surgery

## A Survey of Pain, Nausea, and Global Satisfaction

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**BACKGROUND:** Scoliosis surgery is one of the most extensive elective surgical processes performed on young people. Although there is a great store of knowledge of surgical techniques, patients' experiences of going through surgery have not been extensively studied.

**PURPOSE:** The aim of this study is to describe how a cohort of young people and their parents retrospectively rate postoperative pain and nausea and describe their experiences of scoliosis surgery.

**METHODS:** In a retrospective cohort study, 87 young people aged 8–25 years with scoliosis who underwent corrective surgery from 2004 to 2007 were invited to complete a questionnaire, as were their parents. The semistructured questionnaire dealt with experiences of pain, nausea, and global satisfaction pre- and posthospitalization, assessed by visual analogue scales. The free text commentaries were analyzed using qualitative content analysis.

**RESULTS:** A total of 51 patients (59%) and 65 parents (75%) answered the questionnaires. Out of the completed questionnaires, 41 had idiopathic, 23 neuromuscular, and 6 other types of scoliosis. Postoperative patient-rated pain was severe 7.3 (median, interquartile range 5–8.4, visual analogue scale 0–10 cm), and the severe pain lasted for 5 (median, 2.7–7.0) days. Nausea was rated to a median of 5 (1.1–7.3) and lasted for a median of 3 (1–5.2) days. Global satisfaction was rated to a median of 3.2 (1.5–5.2). Postoperative pain was the most prominent issue, and present pain was found in 51% of respondents. Nausea and loss of appetite were common during the entire hospital stay. Waiting for the nurses' assistance, lack of control, and technical failures with the analgesia equipment caused discomfort. Parents experienced a lack of confidence in the nurses and felt helpless to support their child or relieve the child's suffering.

**CONCLUSION:** Young people who underwent scoliosis surgery reported severe postoperative pain and nausea during the hospitalization period and persistent and recent onset pain after discharge, although they did not indicate global dissatisfaction with the hospital stay.

Scoliosis surgery is one of the most extensive surgical procedures performed on adolescents (Taenzer & Clark, 2010). The goal of the surgery is mainly to prevent curve progression, trunk deformity, and spinal degenerative changes, and to preserve pulmonary function (Danielsson, 2007). Cognitive ability, pain before surgery, and the degree to which the scoliosis affects everyday life are of great importance for the surgical outcome and the experience of hospitalization (Borgeat & Blumenthal, 2008).

Postoperative pain is often severe and requires advanced pain management through epidural, intravenous, or spinal analgesia. Systemic opioids cause adverse effects such as nausea, constipation, pruritus, urinary retention, sedation, respiratory depression, and decreased blood pressure (Cashman & Dolin, 2004; Dolin & Cashman, 2005). Pain is strongly associated with metabolic stress, circulatory effects, constipation, impaired wound healing, prolonged hospitalization, and psychological sequelae, resulting in nightmares and panic attacks. It may also lead to great anxiety for both the child and the parents (Blumenthal, Borgeat, Nadig, & Min, 2006; Lamontagne, Hepworth, & Salisbury, 2001). Severe postoperative pain is also associated with a long-term risk of persistent pain (Kehlet & Rathmell, 2010) and mood changes such as anger. The feeling of being in control, and feeling confidence in the doctors and nursing staff, is of great importance in pain management and coping during the hospital visit for scoliosis surgery (Tomaszewski & Janowska, 2012). After scoliosis surgery, one retrospective

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survey reports that 7% of the patients had back or pelvic pain 12 months after surgery (Wong, Yuen, Chow, & Irwin, 2007), and Upasani et al. (2008) found an exacerbation of pain from 2 years after surgery to follow-up at 5 years after surgery as measured by Scoliosis Research Society (SRS)-24 patient questionnaire for outcome after surgery. The etiology of the worsening of pain could not be elucidated and needs further attention. Obstacles for good pain management such as failure of epidural catheters, lack of updated guidelines, and lack of education in advanced pain management for nurses are frequent and well-known clinical problems (Gauger et al., 2009; Mathiesen, Thomsen, Kitter, Dahl, & Kehlet, 2012).

Qualitative research on adolescents' experiences of scoliosis surgery is sparse. Previous studies have shown positive effects of information and coping skills on the adolescents' pain and anxiety (LaMontagne, Hepworth, Salisbury, & Cohen, 2003). A previous study reported that parents, in interviews, stated that their children had experienced severe postoperative pain and that confidence in staff was important (Bull & Grogan, 2010). In a recent interview study (Rullander, Isberg, Karling, Jonsson, & Lindh, 2010), adolescents described their experiences of severe pain and persistent symptoms, such as posttraumatic stress following scoliosis surgery. Patients' and their parents' subjective experience of undergoing surgery needs to be further elucidated.

The aim of this survey study is to describe how a cohort of adolescents and their parents retrospectively recall postoperative pain and nausea and describe their experiences of scoliosis surgery.

## Methods

A questionnaire including information on informed consent was sent to a cohort of patients ( $n = 87$ ) aged less than 25 years who had scoliosis surgery at a university hospital in Northern Sweden from 2004 to 2007, and to their parents. The study was approved by the regional ethical review board in Umeå, Dnr 08-056. If no answer was received in 2 weeks, a reminder was sent and finally a telephone reminder was made. The questionnaire was sent out in the fall of 2008. Demographic data and information on type of anesthesia, surgery, method for postoperative pain administration (i.e., epidural or intravenous), impaired ability to communicate, length of hospital stay, and complications were retrieved from the patient records.

Of the 87 patients, 49 (56%) received epidural analgesia through continuous infusion of bupivacaine, fentanyl, and epinephrine, with extra doses administered by nurses. Thirty patients (34%) received intravenous administrations of morphine, and bolus doses were administered through either patient-controlled analgesia (PCA) or nurse-controlled analgesia. A combination of epidural and intravenous analgesia was administered to eight patients (9%). All patients received paracetamol regularly. Oxycodone was titrated before discharge. The doses were individualized and there were routines for regular pain assessment. The nurses were also allowed to increase the doses if the patient required more analgesia. At the time of the study, great effort was put into optimizing pain treatment.

The questionnaire was semistructured, using visual analogue scales (VAS 0–10 cm) to measure the patients' recall of postoperative pain (VAS 0–1.9 none or mild, 2–3.9 mild to moderate, 4–5.9 moderate, 6–7.9 moderate to severe, 8–10 severe; Bailey, Daoust, Doyon-Trottier, Dauphin-Pierre, & Gravel, 2010). Recall of nausea was rated 0 for no nausea and 10 for severe nausea (Boogaerts, Vanacker, Seidel, Albert, & Bardiau, 2000) and global satisfaction with the hospital care was rated 0 for satisfied and 10 for lack of satisfaction (inverted scale) (Bullens, van Loon, de waal Malefijt, Laan, & Veth, 2001). The scale was a 10-cm line with no numbers visible to the rater.

There were also free-text sections to all questions, where the respondents had the opportunity to write down their comments of subjective experiences from the hospital visit.

## Analysis

The VAS ratings were analyzed using SPSS (version 17; SPSS Inc, Chicago, IL), with descriptive statistics for pain, nausea, and global satisfaction. Patients' and parents' written comments were analyzed using qualitative content analysis.

The text was read several times by the author and the coauthors, and categories were generated from the text. Subcategories and main categories were sorted using deductive content analysis (Elo & Kyngäs, 2008) into three categories: pain, nausea, and global satisfaction.

## Results

The frequency of reply for the patients was 51 (59%) and for parents 65 (75%). Of the patients, 20 (23%) had impaired communication, and of them 16 (80%) were proxy rated. Of the responding parents, 52 were mothers, 8 were fathers, and 5 were some other caregiver who was present with the patient during the hospital stay. Of the families, 46 patients (53%) had parents who also responded to the questionnaire. In total, response was obtained from 70 of the families (80%) approached.

In spite of reminders, 17 families did not respond. When compared with the group of 70 families who completed the questionnaire, there were no significant differences in age, gender, type of surgery, or type of scoliosis between responders and nonresponders.

Demographics and clinical characteristics for the respondents are shown in Table 1.

### PAIN

Postoperative self-reported pain was rated high, VAS<sup>P</sup> (pain) median 7.3 (interquartile range: 5.0–8.4) (Figure 1), and the pain lasted for 5 (IQR 2.7–7.0) days. Among the patients with impaired communication, VAS<sup>P</sup> was proxy-rated 7.1 (IQR 5.7–8.7). Of those who experienced severe pain during the hospital visit ( $n = 24$ ), 60% indicated persistent pain or recent onset pain 5–12 months after surgery.

The adolescents described periods of ineffective pain management, with activities such as getting out of bed and standing beside the bed and procedures of pulling

**TABLE 1. DEMOGRAPHICS AND CLINICAL CHARACTERISTICS FOR THE PATIENTS**

	Scoliosis		
	Idiopathic	Neuromuscular	Other
Patients (n)	35	8	8
Parent/caregiver (n)	35	19	11
Girls (n)/boys (n)	29/6	3/5	4/4
Age (mean years)	16	15	15
Impaired communication (N)	2	16	2
ASA (0/1/2/3/4) <sup>a</sup>	1/35/11/0/0	0/0/1/20/4	1/1/5/7/0
Type of surgery (ASF/PSF/ASF+PSF/other) <sup>b</sup>	22/18/8/0	1/16/8/0	0/8/6/0
Analgesia ED/PVB/PCA <sup>c</sup>	12/7/25	6/1/2	5/2/3
Length of hospital stay (mean days)	11	13	11

<sup>a</sup>American Society of Anesthesiologists (ASA) has a six-category physical status classification system.

<sup>b</sup>ASF = anterior spinal fusion; PSF = posterior spinal fusion; ASF + PSF = both procedures at the same time.

<sup>c</sup>ED: epidural analgesia with fentanyl, bupivacaine, and epinephrine; PVB: paravertebral block with chirocain; PCA: with intravenous opioids.

out the chest tube as the most painful situations. They described experiences of pain that was unmanageable and unbearable. The worst things described were unbearable pain, not being able to control the situation, and having to wait for pain relief.

I felt like I was hung up on meat hooks.

The worst thing was when the doctor pulled out the drainage.

Sometimes it feels like a knife is cutting into my back.

Parents described their experiences of their child's postoperative pain as difficult to handle. They described severe pain and crying.

She had fear in her eyes. We have never seen that expression before. She cannot express herself you know! I can't remember whether she screamed or moaned or if she stared at us with pure fear trying to say—help me!

Everything was OK until the catheter with analgesics stopped functioning. After that there were several difficult days with severe pain. My daughter has had nightmares about pain since then.

It was terrible to see my daughter having so much pain and not being able to help her.

## NAUSEA

Postoperative nausea was VAS<sup>N</sup> (nausea)—rated median 5.0 (IQR 1.1–7.3) (see Figure 1). The duration of nausea was rated 3 (IQR 1–5.2) days. The parents indicated that their child felt nauseous during the hospital stay and described the pharmacological treatment as ineffective.

Some of the adolescents could not recall being given any anti-nausea medication at all. Standing up beside the bed caused nausea. The nausea ceased only when opioid doses were reduced. Nausea adversely affected their appetites and moods. Patients recalled not being able to eat anything at all during the hospital visit and feeling nauseous at the smell of food. Some adolescents described the nausea as worse than the pain, indicating that nausea was a major cause of discomfort. In some cases, the loss of appetite continued for a long time, even at home after the hospitalization.

I felt nauseous the whole time at the hospital.

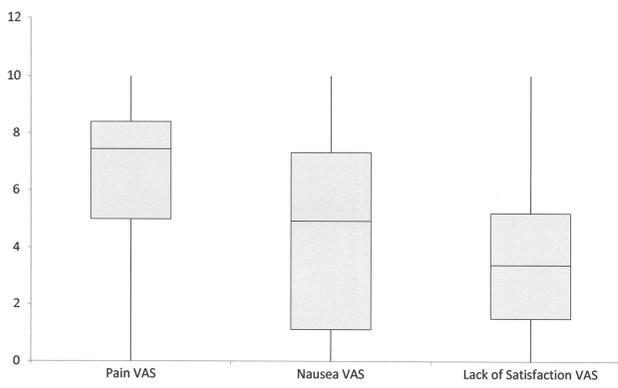
I vomited when I tried to eat, and could not eat at all during the hospital stay.

Parents indicated that their children suffered a lot from the nausea and said it was difficult and frustrating to deal with.

She had an internal feeding tube and she vomited a lot.

She felt nauseous and had a loss of appetite during the entire hospital visit. She was not able to eat or drink anything.

She got constipated, had stomachaches, felt nauseous, and vomited.



**FIGURE 1.** Self-reported pain, nausea, and lack of satisfaction, rated with visual analogue scales (VAS).

## GLOBAL SATISFACTION

Global satisfaction with hospital experience was VAS<sup>GS</sup> (Global Satisfaction)—rated median 3.2 (IQR 1.5–5.2) (see Figure 1). The patients and their parents found it

difficult to maintain confidence in the nurses on several occasions and felt that a number of nurses acted unkindly and even harshly. Waiting was a major problem. The patients experienced feelings of being out of control and not being able to control the situation; loss of bodily control was a source of major discomfort. Problems with the epidural catheter such as obstruction or dislocation resulting in an interruption in pain management were reported by patients and parents alike. In addition, there were descriptions of nurses not being familiar with the analgesia equipment.

The worst thing was to wait so long for help from the nurses.

Since the nurse could not operate the infusion pump I am not satisfied at all.

I felt that the staff did not listen to me.

The complexity of the parental role of wanting to guard, protect, and help their child while at the same time being forced to depend on nurses and doctors was described as frustrating. Parents felt helpless when they were unable to relieve their child from suffering resulting from pain or fear. Some of the parents found it difficult to get information and were frustrated by having to wait for so long to get help or assistance.

The worst thing was to watch one's child in such severe pain and not being able to help!

It was difficult to be in the intensive care unit. Everything was chaotic and she was in a lot of pain.

A lot of waiting and not knowing what was happening and the lack of information. Not being able to help. The PCA-pump<sup>1</sup> that stopped functioning.

## Discussion

The main findings in this study were that postoperative management of pain and nausea was insufficient for the majority of the adolescents. Nurses' shortcomings regarding technology and treatment skills, and the parents' frustration and lack of confidence in the nurses, also emerged in the written comments. Long waiting times were a stressor for both patients and parents. Despite this, the parents and patients rated their global experience of the hospital stay as relatively satisfactory.

During the data sampling, the pain treatment protocol was regarded as successful in the clinic. However, the results from the questionnaire with the reports of severe pain reveal ineffective pain management. As shown in other postsurgical settings (Mathiesen et al., 2012), it is likely that compliance with the pain management protocol in the present study was incomplete. Regular audits of pain management and implementation of Acute Pain Services according to new guidelines for postoperative pain management (Savoia et al., 2010) might have improved the outcome. Parents also indicated that they found it difficult to maintain confidence in the nurses' pain management skills. There might have been a knowledge gap regarding pain expressions in

children of different ages or the misconception that children suffering severe pain will express the pain vividly, when they may instead stay still and quiet (Tesler, Holzemer, & Savedra, 1998). An educational program could have improved staff knowledge of and attitudes toward pain and pain management (Abdallah, Majali, Stomberg, & Bergbom, 2010).

At the time of the study, patient-controlled epidural analgesia (Saudan et al., 2008) had not yet been introduced in the clinical protocol. Patient-controlled epidural analgesia allows patients to be in control of their own pain (LaMontagne, Hepworth, Salisbury, & Cohen, 2003). The feeling of being in control is an important psychological factor in the patient's experience (LaMontagne, Hepworth, Cohen, & Salisbury, 2003; Logan & Rose, 2005; Rullander et al., 2010). However, according to the patients, the most painful situations occurred when the epidural (ED) catheters malfunctioned, which is a known disadvantage of epidural analgesia (Gauger et al., 2009). The transfer from ED analgesia to oral administration of oxycodone was also described as a period of severe pain, which might have been connected to a suboptimal dose of the oral medication (Czarnecki, Jandrisevits, Theiler, Huth, & Weisman, 2004).

Several patients in this sample reported recent onset and persistent pain. Recent onset pain after surgery has been shown to have a negative impact on physical functioning and quality of life (Peters, Sommer, van Kleef, & Marcus, 2010). After various common operations, persistent postoperative pain is reported in 5%–50% of the patients (Kehlet & Rathmell, 2010).

Anxiety and nightmares after the hospitalization were mentioned by a few parents in this study, although no questions were posed on the topic. However, symptoms of posttraumatic stress were vividly described in narrative interviews with some of the adolescents in this study sample (Rullander et al., 2010). In unintentional trauma, acute pain is strongly related to stress reactions and could be a trigger for later pain symptoms and psychological responses (Gold, Kant, & Kim, 2008). On the contrary, morphine seems to have a mediating effect on the development of posttraumatic stress in children with burns (Saxe et al., 2001; Stoddard et al., 2009) and early pain management interventions are shown to have long-lasting beneficial effects (Beck et al., 2010; Ward-Begnoche, 2007).

The patients felt more or less nauseous during the entire hospital stay, and the pharmacological treatment was described as ineffective in spite of the fact that there were guidelines for the administration of antiemetic drugs in the pain management protocol. However, the protocol did not yet include a multimodal strategy for postoperative nausea and vomiting management, which is now advocated (Kranke & Eberhart, 2011). Besides being a major cause of malaise, postoperative nausea and vomiting has negative effects on appetite and nutrition. With poor nutritional status, wound healing as well as mobilization and recovery might be delayed because of the lack of energy (Lalueza, Colomina, Bagó, Clemente, & Godet, 2005; Ljungqvist, Soop, & Hedström, 2007; Niemi-Murola et al., 2007). In young children, nausea has been shown to be a risk factor for the

<sup>1</sup>PCA: patient-controlled analgesia.

development of behavioral problems after surgery (Karling, Stenlund, & Hägglöf, 2007).

Even if the parents and patients experienced imperfect care, they rated their global experience of the hospital stay as relatively satisfactory, which seems somewhat inconsistent. Many patients out of those who described experienced severe pain rated the hospital visit as satisfying or as mildly dissatisfying. It might be that the level of pain was expected or that the global satisfaction was associated with other factors. However, Carreon et al. (2011) found low to moderate associations between some of the domain scores of SRS-22 and scoliosis patient satisfaction with treatment. This contrasts to cancer patients, whose ratings of satisfaction with care have been shown strongly correlated to the quality of pain management (Beck et al., 2010).

Parents in this study felt helpless while watching their child in pain. Similar opinions were expressed by parents of adolescents going through scoliosis surgery in an interview study by Bull and Grogan (2010). It might have been beneficial to the pharmacological pain management for nurses to learn and use nonpharmacological pain-reduction methods, which could also be learned by parents to alleviate their child's postoperative suffering (Gerik, 2005; Pölkki, Vehviläinen-Julkunen, & Pietilä, 2001, 2002).

## Methodological Considerations

One limitation of the study was its retrospective design, with some responders evaluating their experiences up to 2 years after the surgery. For procedural pain, Chen, Zeltzer, Craske, and Katz (2000) showed that children displayed considerable recall accuracy for event details after a lumbar puncture, and that their accuracy increased with age. However, children who experienced a higher degree of distress during the lumbar puncture exaggerated the negative experiences afterward and also reported higher distress from a subsequent procedure. Noel, McMurtry, Chambers, and McGrath (2010) showed that children who reported high levels of pain during a procedure seemed to overestimate the level of prior anxiety over time. They recalled the painful procedure 2 weeks postsurgery as scarier than they reported it immediately after the actual painful experience. These findings are similar to the negative memories of traumatic events that children with posttraumatic stress recall (Langeland & Olff, 2008). It is also shown that children can remember painful procedures and that the level of pain is related to the level of anxiety (Noel, Chambers, McGrath, Klein, & Stewart, 2012). In a study of intensive care unit patients, 46% of the participants had memories of pain 5 years after they experienced the trauma (Zetterlund, Plos, Bergbom, & Ringdahl, 2012). To our knowledge, the accuracy of young people's recall of postoperative pain has not been extensively studied.

Another limitation was the use of a nonvalidated questionnaire. We do not believe that there was any validated instrument available covering the aims of this study. For health-related quality-of-life aspects, including pain, the instrument SRS-22 is an instrument frequently used in scoliosis follow-up, although among young people there seems to be a lack of responsiveness

in measuring changes in several domains, including pain (Laluzza et al., 2005). The VAS scale was included in the questionnaire because the patients had used VAS during their hospitalization and were consequently familiar with the scale. The VAS scale is a well-known scale with good validity indicated by quantitatively appropriate changes in scores that move in parallel with corresponding qualitative, verbal descriptors of changes over time. The scale can be used in several different domains. The reliability (test-retest;  $r = .95-.97$ ) is also shown to be strong (Boogaerts et al., 2000; Bullens et al., 2001; Frank-Stromborg & Olsen, 1997; Gallagher, Bijur, Latimer, & Silver, 2001; Jensen & Karoly, 2011). For patients with cognitive impairments, observational pain scales would have given a more accurate measurement during hospitalization.

In the cases in which the patients could not answer the questionnaire by themselves because of cognitive impairments, a parent or caregiver answered for the patients in the VAS measurements for pain as well as in all the free text questions. Although since parental and child reports do not always correlate (Zhou, Roberts, & Horgan, 2008), we chose to present those results separately.

## Conclusion

This study underlines some important areas for improvement, including compliance with pain and nausea management guidelines in the clinical setting and nursing staff education. Patients' and parents' negative experiences indicated that the nursing staff provided substandard pain and nausea management, causing long-lasting traumatic memories of painful events. The severe postoperative pain elucidated in this study calls for better methods of measurement and treatment. There is a need to further explore the consequences of severe pain after major surgery and the risk of developing posttraumatic stress disorder symptoms. Adolescents' narrated experiences of undergoing scoliosis surgery should also be highlighted.

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