

# Adolescents' Experiences of Scoliosis Surgery and the Trajectory of Self-Reported Pain

## A Mixed-Methods Study

Anna-Clara Rullander ▼ Mats Lundström ▼ Ulrika Östlund ▼ Viveca Lindh

Scoliosis surgery for adolescents is a major surgery with a difficult recovery. In this study, a mixed-methods design was used to broaden the scope of adolescents' experiences of surgery for idiopathic scoliosis and the trajectory of self-reported pain during the hospital stay and through the first 6 months of recovery at home. Self-reports of pain, diaries, and interviews were analyzed separately. The results were then integrated with each other. The trajectory of self-reported pain varied hugely between individuals. Adolescents experienced physical suffering and struggled to not be overwhelmed. The adolescents described the environmental and supportive factors that enabled them to cope and how they hovered between suffering and control as they strived toward normality. This study highlights areas of potential improvement in perioperative scoliosis care in terms of nursing support and pain management.

### Background

The etiology of adolescent idiopathic scoliosis (AIS) is multifactorial (Lowe et al., 2000). About 1%–3% of all adolescents have AIS and of them approximately 80% are girls (Konieczny, Senyurt, & Krauspe, 2013). Scoliosis surgery is a major surgical procedure. The surgery causes severe postoperative pain and requires advanced pain management (Borgeat & Blumenthal, 2008) and high levels of nursing skills both regarding pharmacological treatment and also psychological interventions of stress-reducing techniques (Chieng, Chan, Klainin-Yobas, & He, 2014).

Postoperative pain after scoliosis surgery can be severe and even excruciating (Connelly et al., 2014; Klatt et al., 2013). In previous studies, adolescents have described experiences of scoliosis surgery as extreme and unbearably painful (Rullander, Isberg, Karling, Jonsson, & Lindh, 2013; Rullander, Jonsson, Lundstrom, & Lindh, 2013). The level of pain decreases from the third day (Kotzer, 2000), but there can still be episodes of severe pain during recovery (Connelly et al., 2014). More studies are needed

concerning how adolescents cope with breakthrough pain after surgery and what supportive factors are utilized in this field.

In most cases, patients with AIS stay in the hospital for 5 to 7 days after surgery (LaMontagne, Hepworth, Cohen, & Salisbury, 2004; <http://ebooks-gratuits.me/recherche/Siadh:Definition/pdf/6>). Advanced pharmacological pain treatment is required to manage the acute postoperative phase (Buvanendran & Kroin, 2009). During the hospital stay, postoperative care aims to administer pain treatment, help patients with AIS to mobilize (including getting out of bed, walking, sitting, managing personal hygiene, going to the lavatory, chest physiotherapy), help with the parenteral nutrition and later oral intake of food and drink, and prevent postoperative nausea and vomiting (Basques, Bohl, Golinvaux, Smith, & Grauer, 2015; Tarrant et al., 2015). However in an earlier study from our research group (Rullander et al., 2013), adolescents described a lack of confidence in the nurses and their technical skills. The adolescents also described a lack of control and how it made them dissatisfied with the hospital stay (Rullander et al., 2013).

Traditionally, outcomes after spinal corrective surgery focused on the clinician's perspective including clinical and radiographic parameters, surgical approaches, or procedures (Yadla, Maltenfort, Ratliff, &

---

Anna-Clara Rullander, PhD, RN, Department of Nursing, Umeå University, Umeå, Sweden.

Mats Lundström, PhD, RN, Department of Nursing, Umeå University, Umeå, Sweden.

Ulrika Östlund, PhD, RN, OCN, Centre for Research & Development, Uppsala University/Region Gävleborg, Gävle, Sweden.

Viveca Lindh, PhD, RN, Department of Nursing, Umeå University, Umeå, Sweden.

This study was supported by Jerring Foundation, the Oskar Foundation, the Mayflower Charity Foundation for Children, the Solstickan Foundation, and the Kempe Foundation.

The authors have no financial interests to disclose.

DOI: 10.1097/NOR.0000000000000402

Harrop, 2010). Patient perspectives of corrective surgery for AIS through narrated stories or written diaries about the experience are few and far between. There is a lack of knowledge concerning patient experiences during the hospital stay and the following 6 months of recovery.

Parents tend to underestimate and undertreat their children's pain, and undertreated postoperative pain could be a risk factor for the development of persistent pain (Chambers, Reid, Craig, McGrath, & Finley, 1998; Kelly, Powell, & Williams, 2002). In a previous study, we noticed that 60% of a group of scoliosis patients who reported severe postoperative pain also indicated persistent or new-onset pain 5–12 months after surgery (Rullander et al., 2013). How adolescents report the pattern of pain after major surgery, during the immediate and later recovery, has not been extensively studied.

The recovery period after major surgery varies and can be up to 6 months or longer (Fabricant, Admoni, Green, Ipp, & Widmann, 2012). During the first 3 weeks at home after surgery, patients with AIS need assistance from a parent or other family member. It has been shown that the need for assistance mostly consists of pain management, mobilization, personal hygiene, eating, going to the lavatory, and other daily routines (Barnard et al., 2013). More insight is needed into what environmental support adolescents need to manage suffering after the surgery and strategies they can use for regaining normality.

A holistic perspective—which includes need for physical, psychological, sociocultural, and environmental comfort—is important in the perioperative care of adolescents. Also important is ongoing communication between the adolescent and the healthcare team (Kolcaba & DiMarco, 2005; Roy, 2011). Nurses need to know adolescents' strategies for managing pain, recovery, and how to respond to individual needs and differences among the patients (Roy, 2011). Research into adolescents' experiences with perioperative care can benefit from a mixed-methods design, which facilitates a more holistic perspective, broadens the scope, and contributes to a deeper understanding of the complexity of the perioperative period of scoliosis surgery.

In summary, the pattern of pain after major surgery in adolescents and the experiences of and strategies to handle severe pain and breakthrough pain during the postoperative and recovery period need to be studied.

Therefore, the aim of this study was to broaden the scope of adolescents' experiences of undergoing scoliosis surgery and the trajectory of self-reported pain during the hospital stay and the first 6 months of recovery at home after corrective surgery for idiopathic scoliosis.

## Methods

In this study, a Convergent Parallel Mixed-Methods design was used (Creswell, 2014) to capture both qualitative descriptions of adolescents' experiences and quantitative descriptions of the self-reported pain trajectory. Combining the qualitative and quantitative data contribute to a greater understanding of adolescents' experiences of scoliosis surgery.

### PARTICIPANTS

Qualitative and quantitative data were collected in a cohort of AIS patients 12 to 18 years of age, scheduled for spinal fusion at one of four spine centers in Sweden during 2012 and 2013. Forty-four adolescents were consecutively approached prior to surgery for informed consent, and of them, 37 participants were included (32 girls, with a mean age of 15.8 years; and 5 boys, with a mean age of 16.1 years). The adolescents and their parents received oral and written study information, and both parents and the adolescent gave their written informed consent for the adolescent to participate in the study.

### Data Collection

Qualitative and quantitative data were collected before surgery, postoperatively, during the first 2 weeks of recovery, and 6 months after surgery (see Table 1).

### THE QUALITATIVE DATA COLLECTION

At the time of discharge from the hospital, the adolescents were asked to keep a diary the first 14 days at home. They were asked to record in their diaries their experiences of everyday life during this period of recovery.

The researcher also conducted a semistructured interview with each adolescent remaining in the study at 6 months after surgery. The first author (A.-C. R.) made an appointment with the adolescent; the appointment was usually on the same day as the follow-up with the physician at the hospital. However, in some cases, for logistic reasons, the interviews took place at the school nurse's clinic or via telephone. The intention of the interviews was to capture adolescents' overall experiences of going through surgery and recovery. During the interview, only the researcher and the adolescent were present in the room. The opening question was: "Can you tell me what it was like to go through scoliosis surgery, such as what it was like before surgery, during the hospital stay and at home after surgery?" Follow-up questions were asked if needed, for example, to clarify uncertain answers, or to gain a deeper understanding. The

**TABLE 1. SCHEDULE FOR DATA SAMPLING**

	Preoperation	During Hospital Stay	First 14 Days at Home	At 6-Month Follow-up
Pain-rating VAS	X	Every 4 hr	Once a day	X
Pain-o-Meter	X			X
Diary			X	
Interview				X

Note. VAS = Visual Analogue Scale.

28 interviews were between 8 and 55 minutes long (mean length of 14 minutes). All interviews were audio recorded and transcribed verbatim.

## THE QUANTITATIVE DATA COLLECTION

The day before surgery, the adolescents rated their pain over the last week on a Pain-o-Meter (POM). The POM (Gaston-Johansson & Asklund-Gustafsson, 1985; Gaston-Johansson, Johansson, Felldin, & Sanne, 1985) is a tool for measuring pain intensity and describing pain quality and location. The words used in POM to describe pain quality include, for example, grinding, burning, cutting, throbbing, pricking, and pressing—enabling the adolescent to describe his or her pain in his or her own words. Pain-o-Meter is psychometrically tested and has been found to be reliable and valid (Gaston-Johansson, 1996).

During the postoperation hospital stay, the adolescents rated their pain scores on a Visual Analogue Scale (VAS) as 0–10 cm (Huskiison, 1974) from the first day after surgery and every 4 hours for 5 days. Visual Analogue Scale is described as a valid instrument for self-reporting pain intensity and changes in pain intensity (Ferreira-Valente, Pais-Ribeiro, & Jensen, 2011).

At discharge, the adolescents were asked to rate their pain on the VAS once a day at 4:00 p.m. for 14 days and then send their ratings back to the researcher. At the time of follow-up at the spine clinic 6 months after surgery, the 28 participants remaining in the study rated, on a POM, the level of pain they had experienced during the last week.

## ETHICAL CONSIDERATIONS

When interviewing adolescents and asking them to recall their experiences of major surgery, there is a risk that they will recall traumatic memories. To reduce the risk of unanticipated harm, protect interviewees' information, and reduce the risk of exploitation (Dicicco-Bloom & Crabtree, 2006), the interviewer was flexible and open to the adolescents' stories and strived to respect their integrity. In this study, consultation with a

psychologist was available for the adolescents if needed. Above and beyond the risk of unanticipated harm, an interview can also be therapeutic because it gives word and voice to an experience (Morecroft, Cantrill, & Tully, 2004). During data collection, the first author (A.-C. R.) met and interviewed the adolescents both pre- and post-operatively. The fact that the adolescents met the same person on both occasions may have had a positive effect on their ability to express themselves.

Ethical approval was obtained from the regional ethical review board in Umeå, Sweden: Dnr 08-056M, 2011-99-31M, 2013-37-32M.

## Analysis

In Convergent Parallel Mixed-Methods analysis, the qualitative and quantitative data are analyzed separately and then merged (Creswell, 2014). The process and results of the analysis are presented together (see Figure 1). The key assumption of this approach is that both qualitative and quantitative data contribute equally in the analysis. During the integration phase, qualitative and quantitative results were compared for similarities and differences and then linked to each other. The focus for merging the data together was on results that pointed in the same direction, that is, had convergent results.

## QUALITATIVE ANALYSIS

Qualitative content analysis (Elo & Kyngas, 2008; Graneheim & Lundman, 2004) was used for the diaries and interviews. The amount of text in the diaries and the richness of descriptions in the interviews varied. Some of them were more extensive and detailed whereas others were either short or very short and written more like a bulleted list.

The text from all 18 diaries was read through several times and meaning units were selected. Codes were developed from the meaning units and the coded meaning units were categorized. Diaries that were written in an itemized style were directly sorted into categories. The interview text was read through several times and meaning

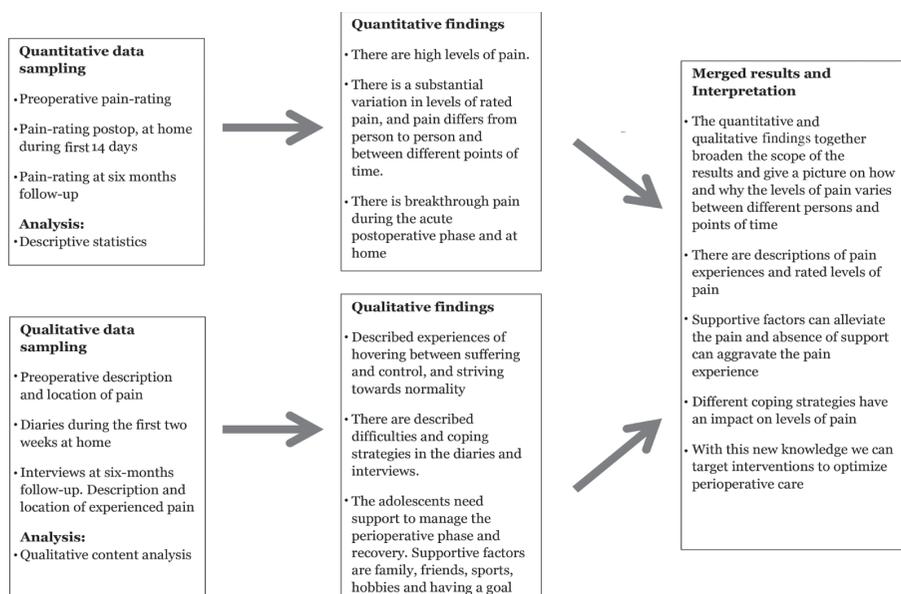


FIGURE 1. Parallel joint display.

units identified and sorted. The meaning units were coded and categorized. A mind map software was used as a tool (www.creaeducation.com) to sort the codes and categories from the diaries and interviews. Overall, the content was visualized and patterns emerged from the results. From the categories, subthemes and themes emerged.

## QUANTITATIVE ANALYSIS

The POM assessments gave a description of the quality and location of experienced pain. The POM words for quality and location of pain were counted for each adolescent and then compared for similarities and differences between the preoperative assessment and the assessment at the 6-month follow-up.

Visual Analogue Scale ratings from the hospital stay and home were analyzed using SPSS (IBM SPSS Statistics Data Editor Version 22) descriptive statistics and calculated for median and interquartile range each day and for each adolescent. In cases in which there were missing values in the VAS ratings, Last Observation Carried Forward was used for adjustment (Shao & Zhong, 2003; Streiner & Geddes, 2001).

## DROPOUTS

Out of the 37 participants, 18 sent back a diary and 19 did not. To find out whether there were any differences

between those who wrote a diary and those who did not, a dropout analysis was conducted. Because this study population is part of a larger study including psychometric ratings, the psychometric instrument YSR (Broberg et al., 2001; Ivarsson, Gillberg, Arvidsson, & Broberg, 2002) was used to perform the dropout analysis. Using SPSS, mean values were calculated and compared between the two groups (see Table 2).

The dropouts in this study ( $n: 19$ ) were shown to have significantly higher levels of stress symptoms both before and after surgery than those who returned a diary. Levels of pain were also significantly higher in the dropout group at the 6-month follow-up.

## Results

### DEMOGRAPHICS

The intention for this study was to include the total population of scoliosis patients from the four spine centers, but some of the eligible patients declined participation ( $n: 7$ , all girls); some scheduled patients were not approached for the study since the surgeries were cancelled because of infection ( $n: 7$ , one boy and six girls) or for logistic reasons ( $n: 5$ , one boy and four girls). Out of the 37 included participants, one went to reoperation and was assessed with postoperative pain ratings on both surgery occasions. One of the participants provided pain ratings during the postoperative hospital stay only. Out of the 18 participants who returned the diary, 16 also returned the pain self-reports. Twenty-eight adolescents were interviewed during the follow-up. One of the participants declined to continue the study after discharge from hospital and eight participants could not be reached for their follow-up appointment.

### QUALITATIVE FINDINGS

Four subthemes emerged from the diaries and interviews (see Table 3). These were as follows: *Perceiving physical suffering*, *Struggling not to be overwhelmed*, *Coping with difficulties*, and *Supportive factors*. From those, two themes emerged: *Hovering between suffering and control* and *Striving toward normality*.

### HOVERING BETWEEN SUFFERING AND CONTROL

After surgery, there were many physical difficulties that affected well-being, with a number of physical sensations described.

### Perceiving Physical Suffering

The adolescents described the effect of postoperative pain and breakthrough pain during recovery and the disturbing influence it had on daily living: "I felt that wow this is hurting very much! It was on the edge, I wanted to faint, but I could not!" (Day 2 after surgery).

Pain disturbed the adolescents' sleep and disrupted their ability to eat, sit, and walk. Pain had a negative impact on their everyday lives and they needed extra doses of opioids after physical activity or at night and early mornings until Day 14. As described by one

**TABLE 2. DROPOUT ANALYSIS<sup>a</sup>**

YSR	Diary		No Diary		<i>p</i>
	Mean	<i>SD</i>	Mean	<i>SD</i>	
Anxiety/depression					
Preoperation	4.17	2.55	6.81	3.76	.026
Postoperation	3.2	2.27	5.15	3.29	.076
Internalizing					
Preoperation	9.89	5.67	14.38	6.77	.043
Postoperation	7.40	3.06	12.62	6.61	.011
Aggression					
Preoperation	5.56	3.69	7.87	2.94	.053
Postoperation	5.33	3.22	7.69	2.17	.034
Thoughts problems					
Preoperation	3.06	2.31	5.00	2.80	.034
Postoperation	2.06	1.33	4.69	3.61	.026
PTS					
Preoperation	6.61	3.09	9.25	3.15	.019
Postoperation	5.40	2.41	8.08	2.43	.007
Somatic complaints					
Preoperation	2.61	2.20	4.50	3.54	.068
Postoperation	1.87	1.30	4.38	3.59	.031
VAS					
Preoperation	3.48	2.93	3.34	2.31	.872
Postoperation	1.59	1.63	4.00	2.31	.005

Note. PTS= post-traumatic stress; VAS = Visual Analogue Scale; YSR = youth self-report.

<sup>a</sup>*p* value ≤ .05 was considered significant.

**TABLE 3. ANALYSIS SCHEDULE**

Theme	Hovering Between Suffering and Control		Striving Toward Normality	
Subthemes	Perceiving physical suffering	Struggling not to be overwhelmed	Coping with difficulties	Supportive factors

adolescent: “Sometimes the pain does not feel too bad, but other times I have so much pain in my neck” (Day 9 at home). “Today was a difficult day. I have had a lot of pain” (Day 13 at home). “I still have a lot of pain in the skin on my back and on my hips and a little pain in my neck” (Day 4 at home).

The adolescents also described distressing symptoms of opioid withdrawal that affected sleep and caused nightmares or hallucinations. Sleeping disturbances were common and eventually affected mood and energy during the day. Another disturbing and painful procedure was the subcutaneous thromboprophylaxis injection administered daily at home by a parent. “Today the injection did not work well, it was very painful!!! Mothers should get more education in giving injections!” (Day 10 at home).

In the early postoperative period, physical suffering in terms of postoperative nausea and vomiting was particularly distressing, sometimes making it impossible for the adolescent to move without vomiting. “I vomit almost all the time!” (during the hospital stay).

While at home, nausea and constipation were major problems. Adolescents talked about not being able to eat and drink, having stomachaches, vomiting, not having bowel movements for several days, and actually visiting the emergency department for the treatment of constipation. “Yesterday evening, night, and morning were the worst. I was totally constipated. I wanted to poop but it was too painful and almost impossible. Yesterday evening I sat on the toilet for almost two hours” (Day 2 at home). “I felt nauseous the whole day after lunch” (Day 8 at home).

The adolescents experienced having no appetite during the first 2 weeks at home, which was not always linked to nausea or constipation but rather a lingering side effect of the surgery itself.

Body appearance (such as having a wound or a new scar) was another physical phenomenon that elicited negative feelings and was described as a burden. The wound and/or scar were sometimes a problem and precipitated visits to the hospital to check for infection or exuding.

The adolescents experienced discomfort during the hospital stay, when leaving the hospital, and at home. Symptoms included itching, dizziness, breathlessness, neck stiffness neurological sensations such as tingling, and numbness. “My foot drives me crazy!” (Day 7 at home).

### *Struggling not to be overwhelmed*

The adolescents described being nervous before surgery and feeling overwhelmed during the entire period. They struggled with worries and fear and experienced stress about possible surgical failure and reoperations. Some described regretting the surgery.

I was very nervous before surgery! I have been worried about the surgery ever since I got the information that I needed surgery. It made it harder at home

and at school, because knowing I needed surgery made me feel not so good. (Interview, 6 months after surgery.)

The feeling of being overwhelmed occurred during the difficult recovery period and could cause regret about going through surgery. “[I] want my old body back.” “I feel like a freak that never will be normal” (Day 3 at the hospital).

Worries about how to cope with the pain, about relations with friends, and worries about school and grades emerged in the diaries: “Today I have done quite a lot of homework and that feels good. The thing is, I have at least five tests to do when I go back to school. Stress...” (Day 12 at home).

Even when the feeling of being overwhelmed was at its worst, the adolescents struggled to regain control over their bodies and minds. Adolescents experimented with stress-reducing techniques such as deep breathing and positive thinking. Despite the difficulties described, they exhibited a strength and determination to reclaim their bodies and body functions. “I thought that if I walked the whole corridor maybe I could go home earlier!” (a description of the hospital stay, as recalled during the interview 6 months after surgery). “I thought that the medicine would help me soon, and I tried to calm down and breathe deep, to manage the pain” (a description of the hospital stay, as recalled during the interview 6 months after surgery). “I watched cooking shows on TV just to get used to the idea of eating” (Day 9 at home).

When the adolescents encountered these difficulties, they were determined to overcome the unfamiliar body sensations and reclaim normality.

## **STRIVING TOWARD NORMALITY**

### *Coping With Difficulties*

The adolescents described how coming home from the hospital after AIS surgery was challenging, and it was difficult to adjust to the home environment. Although it was a relief to be home, there were many practical problems to solve. Despite a lack of energy, trying to find strength was a strategy to achieve normality.

The adolescents set modest goals as a way of coping. They took outdoor walks to gain physical strength and massages to relieve stomachaches and constipation. “I think my back will get better if I set small goals that I know I can reach!” (Day 6 at home).

### *Supportive Factors*

Support from family members was described as crucial for comfort and help. They stated that it was sometimes easier to ask for help from a parent than from nurses. However, the nurses were also good at supporting them by being kind, having a sense of humor, and listening to the adolescents’ needs. “The nurses were the best!

Especially XX. He listened to me, and he really wanted to help!” (a description of the hospital stay during the interview 6 months after surgery).

Adolescents described the importance of going back to school after surgery to normalize their daily lives. It was recuperative to have contact with teachers and school nurses and to visit school as early as during the second week at home. Although they were very tired after the surgery, they struggled to avoid getting behind in schoolwork.

Family, peers, boyfriends, and girlfriends were described as important supporters in their striving to achieve normality during the recovery period. “I think my back feels better when I can be with my friends” (Day 4).

Helpful activities that supported the adolescents’ normality included being a part of activities with peers such as sports activities, singing in a choir, visiting church, and participating in confirmation camp. Hobbies such as painting, scrapbooking, and playing computer games had the same potential to distract and support recovery. Adolescents engaged in baking and cooking in their struggle to regain an appetite and to eat and enjoy food again without nausea. They felt that the worst thing was not having anything to do and being bored, although sometimes it was frustrating to not be able to do what they actually wanted to do.

## QUANTITATIVE FINDINGS

### Levels of Pain

During the hospital stay and at home, the levels of pain varied substantially. The median aggregate values descended with time from surgery, but single values show a different pattern. Breakthrough pain with VAS ratings from 6 and above occurred both during the hospital stay and at home 2 weeks after discharge (see Figure 2 and Table 4).

## Location and Quality of Experienced Pain

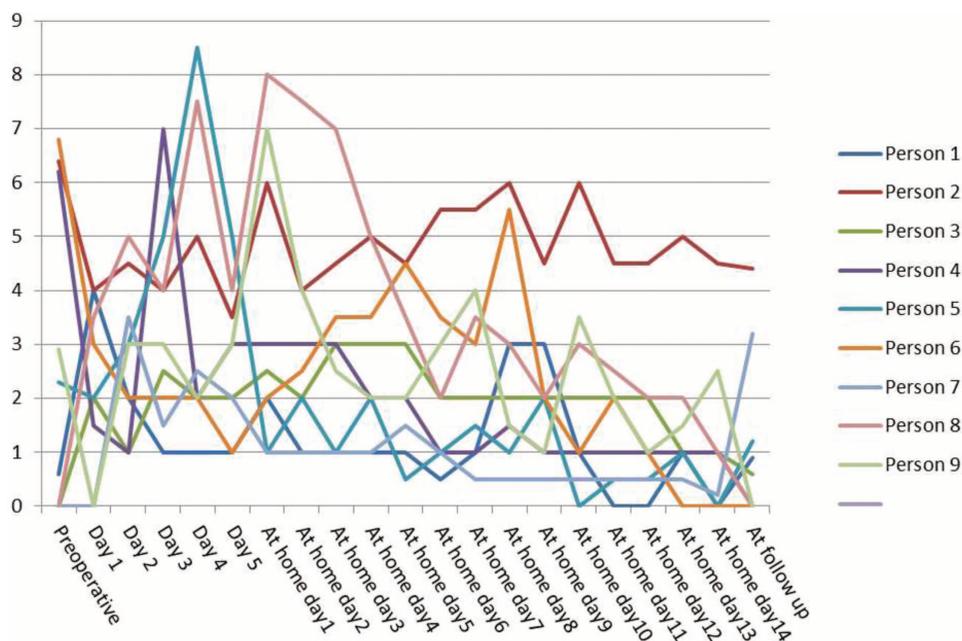
In the POM assessments of pain, the words *pressing*, *grinding*, and *cutting* were the most common choices both before surgery and at the 6-month follow-up. They described the pain as located in the lumbar and thoracic regions and over the shoulders. The adolescents also described numbness in the skin and tingling in the legs and the feet. Out of the 28 participants at follow-up, 12 reported new-onset pain and/or new physical/neurological symptoms.

At the hospital, postoperative pain ratings were highest on Day 2, with a median value of 4.42 (interquartile range, 3.10–5.13). At home, levels of pain were the highest the first 4 days and after that, values descended. Median value of self-rated pain at the 6-month follow-up was 2.70 (interquartile range, 0.00–4.42).

The trajectory of pain was in most cases descending, but among the adolescents who did not return a diary, the level of pain was higher at the 6-month follow-up than among those who returned a diary (see Table 5).

## Integration of the Qualitative and Quantitative Results

Figure 1 shows the integration of the qualitative and quantitative results and that they verify each other. In the qualitative findings, the description of pain at different time points — and how it was dealt with—converged with the fluctuations in self-reported VAS ratings and POM descriptions. Descriptions of supportive measures (from the qualitative results, including how they reduced pain and struggled to achieve normality) correlate with the pain ratings and descriptions. The substantial and individual variations in self-reported pain converge with the qualitative descriptions of sudden changes in experienced pain—showing the impact of family and peer activities. The adolescents described



**FIGURE 2.** An example of pain ratings: nine adolescents rated their pain before surgery, during the first five postoperative days, and the first 14 days at home after discharge from the hospital. Pain scores on Visual Analogue Scale: 0–10.

**TABLE 4. MEDIAN VALUES OF PAIN RATINGS**

Occasion of Measurement	<i>n</i>	Median	IQR
Preoperative	37	3.20	0.57–5.50
Day 1	31	4.15	3.09–5.27
Day 2	31	4.42	3.10–5.13
Day 3	31	4.00	3.00–4.67
Day 4	29	3.50	2.37–4.67
Day 5	28	4.00	2.40–5.17
At home Day 1	16	3.00	2.00–6.00
At home Day 2	16	2.75	2.12–4.00
At home Day 3	16	3.00	2.00–4.00
At home Day 4	16	3.00	2.00–4.75
At home Day 5	16	2.75	2.00–4.50
At home Day 6	16	2.25	1.00–3.50
At home Day 7	16	2.50	1.12–3.50
At home Day 8	16	2.25	1.62–3.50
At home Day 9	16	2.00	1.25–3.00
At home Day 10	16	1.75	1.00–3.37
At home Day 11	16	2.00	0.62–3.00
At home Day 12	16	1.50	0.62–3.00
At home Day 13	16	1.25	1.00–2.50
At home Day 14	15	1.00	0.00–2.50
At follow-up	28	2.70	0.00–4.42

Note. IQR = interquartile range.

how they were hovering between suffering and control, which is illustrated in the pain self-reports and descriptions of their experiences. The strive toward normality was highlighted in the qualitative results, indicating that having support and coping strategies to manage recovery was essential (see Figure 1).

## Discussion

### RESULTS DISCUSSION

In this mixed-methods research, we studied adolescents' experiences of pain just before, during, and after corrective surgery for idiopathic scoliosis. Interpretation of quantitative findings was complemented by adolescents' qualitative descriptions as recorded in their diaries and

findings from interviews. The supportive factors described by the adolescents elucidated how to alleviate pain and strengthen recovery.

This study highlighted that adolescents fight to cope with physical suffering. Pain was the most salient concern and it was expressed in many ways. It could be unbearable, tiring, hopeless, and scary. The pain described was intense postoperative pain that could be experienced as neck or low back pain after 6 months' recovery. The adolescents lived a roller-coaster ride hovering between suffering and gaining control. The adolescents sought to achieve normality and they described the environmental and supportive factors that could alleviate and distract them from pain, making it possible to overcome their difficulties during recovery. Another important finding was the large intra- and interindividual pain report descriptions, which required nurses to listen to their patients and provide a variety of support strategies.

In this study, pain differed strikingly between individuals and between time points, as evidenced in the self-reports. Typical individual trajectories were difficult to identify although median aggregate values of VAS scores decreased over the study period for all participants. In contrast, Connelly et al. (2014) found that after AIS surgery, patients had a typical pain trajectory, with the highest level of pain postoperatively during the hospital stay and then decreasing.

The physical suffering from severe pain, including breakthrough pain, seemed to reflect a lack of pain management which, in turn, generated a fear of pain. Reflection on these results questions the current quality of postoperative nursing care when it comes to pain assessment and ability to comfort patients. Nursing care quality was also put into question with regard to adolescents' experiences of not being listened to during the postoperative period and their observation that nurses did not have the skills to use medical technical equipment. It has been shown that patient education is a crucial source of support for both patients and their families to help them cope with back surgery (Leikkola, Helminen, Paavilainen, & Astedt-Kurki, 2014). The other area for quality improvement is the implementation of pain management programs, particularly those with regular pain measurements (Devin & McGirt, 2015; Huguet, Stinson, & McGrath, 2010).

The adolescents described how they tried to cope with their difficulties; they attempted to get up and out of bed and mobilize because they wanted to go home. Adolescents' coping strategies during recovery have an

**TABLE 5. PAIN SELF-REPORTS FROM PARTICIPANTS AND DROPOUTS DURING THE TRAJECTORY OF THE STUDY**

	Participants From Start, <i>n</i> = 37	First 14 Days After Hospital Discharge		Six Months Follow-up After Surgery	
		Diaries, <i>n</i> = 18 VAS, <i>n</i> = 16 Returned	Diary/VAS Not Returned, <i>n</i> = 19	Interviews, <i>n</i> = 28	Dropouts, <i>n</i> = 9
Pain median hospital (IQR)	3.76 (2.76–4.67)	3.10 (2.46–4.38)	3.77 (3.47–5.08)	3.65 (2.68–4.85)	3.98 (3.49–4.67)
Pain median home (IQR)	2.43 (1.35–3.46)	2.43 (1.35–3.46)		2.43 (1.35–3.46)	
Pain median follow-up (IQR)		1.30 (0.00–3.20)	4.50 (3.12–5.89)	2.70 (0.00–4.42)	

Note. IQR = interquartile range; VAS = Visual Analogue Scale.

impact on recovery outcomes (LaMontagne et al., 2004). LaMontagne showed that adolescents with a proactive coping strategy (e.g., seeking information, problem solving, relying on others) had better long-term activity outcomes than avoidant copers. In the present study, the adolescents who choose to take an active part in diary writing had lower pain scores and less anxiety. This suggests that further study is needed to discover what activities are suitable for supporting the adolescent recovery process. It also seems that activities such as hobbies or sports motivate the adolescents to move on in their recovery. The adolescent who set up individual goals, such as walking a bit further each day, seemed to manage the hardship better. Nurses coached adolescents through the first 2 weeks of recovery at home and helped to solve some of their difficulties through follow-up phone calls. In her study, Flanagan (2009) showed that a follow-up phone call after day surgery was helpful for the patients as it gave nurses the opportunity to coach and comfort patients.

After hospital discharge, patients require support from their families to manage the recovery demands. It is probably during this transition from hospital to home that patients and families need the most patient education and support from staff for coping and self-care (Boughton & Halliday, 2009). If nurses were available during this period, it could increase the patient experience of being listened to (Leikkola et al., 2014).

In the present study, adolescents took part in sports, hobbies, or other activities as strategies for recovery. Having a goal and something to strive toward was a motivating factor in managing pain and other difficulties. Other studies have indicated that social supportive factors such as participating in sports activities and leisure activities can also increase adolescents' well-being (Leversen, Danielsen, Birkeland, & Samdal, 2012; Marsh, Clinkinbeard, Thomas, & Evans, 2007). The adolescents described how support from friends and family was important before surgery, during the hospital stay, and throughout recovery. In their study, Kain et al. (2007) showed that family-centered preoperative behavioral intervention reduced anxiety before surgery, which resulted in shorter hospital stays after surgery and reduced analgesic consumption. Involving family members, friends, and/or other important persons can improve the overall satisfaction and experience of scoliosis surgery (Clay & Parsh, 2014). During long-term recovery, the adolescents describe that they wanted to go back to school, and they longed for friends, sports, and leisure activities. The adolescents, however, need support to manage the tough recovery period. Involving family and friends during the hospital might empower them to provide good overall support and facilitate the recovery back to normality.

Achieving normality can be disrupted by prolonged pain and new-onset pain. In this study, the 6-month follow-up levels of pain were in some cases higher than after 14 days at home, and several adolescents had new-onset pain or physical/neurological symptoms. We also showed in a previous study (Rullander et al., 2013) that adolescents who experienced severe postoperative pain after scoliosis surgery reported persistent or new-onset pain 5 to 12 months after surgery. Keeping in mind that severe pain might lead to persistent pain (Wong, Yuen, Chow, &

Irwin, 2007), it is important to provide pain management during the acute postoperative phase and recovery.

## METHODS DISCUSSION

In a mixed-methods design, the qualitative together with the quantitative results add different views, strengthen the understanding of a phenomenon (Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009), and, therefore, expand and broaden the scope of the results. However, when conducting this type of study, both appropriate qualitative and quantitative methods need to be used to add quality to each of the data sets and subsequently the integrated results (Pluye et al., 2009).

Both diaries and individual interviews were used to collect qualitative data. Using a paper diary might be a limitation in this study as earlier studies indicate that electronic diaries yield higher compliance, especially among adolescents (Stone, Shiffman, Schwartz, Broderick, & Hufford, 2003). On the contrary, Stinson et al. (2013) pointed out some drawbacks regarding electronic diaries in terms of technical issues. However, the dropout analysis in our study indicated that the adolescents who did not keep a diary scored higher levels of pain, stress symptoms, and internalizing symptoms, pointing to factors other than the diary format to explain compliance. The diaries varied in terms of comprehensiveness; some were rich and descriptive, whereas others were short or only itemized. The interviews also varied in length and the amount of description and richness. Analyzing the very short texts differed from the analysis of the descriptive ones with regard to condensing text and creating meaning units. However, together the qualitative data gave a substantial picture of the adolescents' experiences.

For the quantitative data collection, pain was self-measured using VAS as this was the most commonly used pain measurement tool at the study settings. An alternative might have been the Numeric Rating Scale, recommended for adolescents because it might be easier so use (Page et al., 2012). There were missing values in pain ratings during the hospital stay, and in the analysis, Last Observation Carried Forward was used to adjust for single missing values. Of the ratings, 18.3% are adjusted values, which ignore the irregular trajectory of pain experienced by these adolescents (Streiner & Geddes, 2001). There was still missing data despite using this method, because we adjusted only for one missing value at a time. However, the authors consider this method for adjustment to be accurate for this study and sample. Had specially trained nurses carried out the pain measurements, there might have been less missing data. However, despite the limitations in the design, we argue that this study gives a comprehensive picture of these adolescents' experiences of undergoing scoliosis surgery at a spine clinic in Sweden because the qualitative and quantitative results when integrated both verified and complemented each other.

## CONCLUSION AND CLINICAL IMPLICATIONS

This study highlights fields of potential improvement in perioperative scoliosis care. The adolescents in this study described how they hovered between suffering and

control, as they strived toward normality. It is a challenge for nurses to meet individual adolescents' needs and identify their pain trajectories. However, because scoliosis surgery is an elective surgical procedure, nurses have the opportunity to intervene before surgery. At that time, coping strategies could be highlighted and included in patient education. Preoperative interviews would give nurses an opportunity to recognize the adolescent's anxiety level and coping strategies and then encourage the adolescent to use these strategies during the perioperative and recovery period. Overall, nurses need to improve their knowledge and performance of advanced pain management and knowledge of medical technical equipment. It is also important for nurses to support the patient and his or her family with patient education in a supportive atmosphere during the transition to home, reminding patients to set small goals and be motivated to engage in activities they enjoy and self-care. To identify adolescents and families who need extra support, nurses could provide active follow-up through telephone calls or online.

## REFERENCES

- Barnard, J. G., Albright, K., Morrato, E. H., Nowels, C. T., Benefield, E. M., Hadley-Miller, N. A., ... Erickson, M. A. (2013). Paediatric spinal fusion surgery and the transition to home-based care: provider expectations and carer experiences. [Research Support]. *Health & Social Care in the Community*, 21(6), 634–643. doi:10.1111/hsc.12049
- Basques, B. A., Bohl, D. D., Golinvaux, N. S., Smith, B. G., & Grauer, J. N. (2015). Patient factors are associated with poor short-term outcomes after posterior fusion for adolescent idiopathic scoliosis. *Clinical Orthopaedics and Related Research*, 473(1), 286–294. doi:10.1007/s11999-014-3911-4
- Borgeat, A., & Blumenthal, S. (2008). Postoperative pain management following scoliosis surgery. [Review]. *Current Opinion in Anaesthesiology*, 21(3), 313–316. doi:10.1097/ACO.0b013e3282f82baa
- Boughton, M., & Halliday, L. (2009). Home alone: Patient and carer uncertainty surrounding discharge with continuing clinical care needs. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, 33(1), 30–40.
- Broberg, A. G., Ekeröth, K., Gustafsson, P. A., Hansson, K., Hagglof, B., Ivarsson, T., & Larsson, B. (2001). Self-reported competencies and problems among Swedish adolescents: A normative study of the YSR. Youth Self Report. *European Child and Adolescent Psychiatry*, 10(3), 186–193.
- Buvanendran, A., & Kroin, J. S. (2009). Multimodal analgesia for controlling acute postoperative pain. [Review]. *Current Opinion in Anaesthesiology*, 22(5), 588–593. doi:10.1097/ACO.0b013e328330373a
- Chambers, C. T., Reid, G. J., Craig, K. D., McGrath, P. J., & Finley, G. A. (1998). Agreement between child and parent reports of pain. [Comparative Study Research Support]. *The Clinical Journal of Pain*, 14(4), 336–342.
- Chieng, Y. J., Chan, W. C., Klainin-Yobas, P., & He, H. G. (2014). Perioperative anxiety and postoperative pain in children and adolescents undergoing elective surgical procedures: A quantitative systematic review. *Journal of Advanced Nursing*, 70(2), 243–255. doi:10.1111/jan.12205
- Clay, A., & Parsh, B. (2014). Patient- and family-centered care: Not just for kids. *Nursing*, 44(5), 57–58. doi:10.1097/01.NURSE.0000445764.18817.d2
- Connelly, M., Fulmer, R. D., Prohaska, J., Anson, L., Dryer, L., Thomas, V., ... Schwend, R. (2014). Predictors of postoperative pain trajectories in adolescent idiopathic scoliosis. [Research Support]. *Spine (Phila Pa 1976)*, 39(3), E174–E181. doi:10.1097/BRS.0000000000000099
- Creswell, J. W. (2014). *Research design, qualitative, quantitative & mixed methods approaches*. Fourth edition (4th ed.). Thousand Oaks, CA: SAGE Publications.
- Devin, C. J., & McGirt, M. J. (2015). Best evidence in multimodal pain management in spine surgery and means of assessing postoperative pain and functional outcomes. [Review]. *Journal of Clinical Neuroscience*, 22(6), 930–938. doi:10.1016/j.jocn.2015.01.003
- Dicicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. [Research Support, N.I.H., Extramural Research Support]. *Medical Education*, 40(4), 314–321. doi:10.1111/j.1365-2929.2006.02418.x
- Elo, S., & Kyngas, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. doi:10.1111/j.1365-2648.2007.04569.x
- Fabricant, P. D., Admoni, S., Green, D. W., Ipp, L. S., & Widmann, R. F. (2012). Return to athletic activity after posterior spinal fusion for adolescent idiopathic scoliosis: Analysis of independent predictors. *Journal of Pediatric Orthopedics*, 32(3), 259–265. doi:10.1097/BPO.0b013e32824b285f
- Ferreira-Valente, M. A., Pais-Ribeiro, J. L., & Jensen, M. P. (2011). Validity of four pain intensity rating scales. *Pain*, 152(10), 2399–2404. doi:10.1016/j.pain.2011.07.005
- Flanagan, J. (2009). Postoperative telephone calls: timing is everything. [Research Support]. *AORN Journal*, 90(1), 41–51. doi:10.1016/j.aorn.2009.04.001
- Gaston-Johansson, F. (1996). Measurement of pain: the psychometric properties of the Pain-O-Meter, a simple, inexpensive pain assessment tool that could change health care practices. [Comparative Study]. *Journal of Pain Symptom Manage*, 12(3), 172–181.
- Gaston-Johansson, F., & Askund-Gustafsson, M. (1985). A baseline study for the development of an instrument for the assessment of pain. [Research Support]. *Journal of Advanced Nursing*, 10(6), 539–546.
- Gaston-Johansson, F., Johansson, G., Felldin, R., & Sanne, H. (1985). A comparative study of pain description, emotional discomfort and health perception in patients with chronic pain syndrome and rheumatoid arthritis. [Comparative Study Research Support]. *Scandinavian Journal of Rehabilitation Medicine*, 17(3), 109–119.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. [Review]. *Nurse Education Today*, 24(2), 105–112. doi:10.1016/j.nedt.2003.10.001
- Huguet, A., Stinson, J. N., & McGrath, P. J. (2010). Measurement of self-reported pain intensity in children and adolescents. *Journal of Psychosomatic Research*, 68(4), 329–336. doi:10.1016/j.jpsychores.2009.06.003
- Huskisson, E. C. (1974). Measurement of pain. [Clinical Trial Comparative Study]. *Lancet*, 2(7889), 1127–1131.
- Ivarsson, T., Gillberg, C., Arvidsson, T., & Broberg, A. G. (2002). The Youth Self-Report (YSR) and the Depression Self-Rating Scale (DSRS) as measures of depression and suicidality among adolescents. [Evaluation Studies]. *European Child & Adolescent Psychiatry*, 11(1), 31–37.

- Kain, Z. N., Caldwell-Andrews, A. A., Mayes, L. C., Weinberg, M. E., Wang, S. M., MacLaren, J. E., & Blount, R. L. (2007). Family-centered preparation for surgery improves perioperative outcomes in children: a randomized controlled trial. [Randomized Controlled Trial Research Support, N.I.H., Extramural]. *Anesthesiology*, *106*(1), 65–74.
- Kelly, A. M., Powell, C. V., & Williams, A. (2002). Parent Visual Analogue Scale ratings of children's pain do not reliably reflect pain reported by child. [Clinical Trial Comparative Study Randomized Controlled Trial]. *Pediatric Emergency Care*, *18*(3), 159–162.
- Klatt, J. W., Mickelson, J., Hung, M., Durcan, S., Miller, C., & Smith, J. T. (2013). A randomized prospective evaluation of 3 techniques of postoperative pain management after posterior spinal instrumentation and fusion. [Randomized Controlled Trial]. *Spine (Phila Pa 1976)*, *38*(19), 1626–1631. doi:10.1097/BRS.0b013e31829cab0b
- Kolcaba, K., & DiMarco, M. A. (2005). Comfort Theory and its application to pediatric nursing. [Case Reports Review]. *Pediatric Nursing*, *31*(3), 187–194.
- Konieczny, M. R., Senyurt, H., & Krauspe, R. (2013). Epidemiology of adolescent idiopathic scoliosis. [Review]. *Journal of Childrens Orthopaedics*, *7*(1), 3–9. doi:10.1007/s11832-012-0457-4
- Kotzer, A. M. (2000). Factors predicting postoperative pain in children and adolescents following spine fusion. [Research Support]. *Issues in Comprehensive Pediatric Nursing*, *23*(2), 83–102.
- LaMontagne, L. L., Hepworth, J. T., Cohen, F., & Salisbury, M. H. (2004). Adolescents' coping with surgery for scoliosis: Effects on recovery outcomes over time. [Research Support]. *Research in Nursing and Health*, *27*(4), 237–253. doi:10.1002/nur.20026
- Leikkola, P., Helminen, M., Paavilainen, E., & Astedt-Kurki, P. (2014). Staff support for back surgical patients and family members: Does it improve coping at home? *Orthopaedic Nursing*, *33*(6), 352–358. doi:10.1097/NOR.0000000000000099
- Leveresen, I., Danielsen, A. G., Birkeland, M. S., & Samdal, O. (2012). Basic psychological need satisfaction in leisure activities and adolescents' life satisfaction. [Research Support]. *Journal of Youth and Adolescence*, *41*(12), 1588–1599. doi:10.1007/s10964-012-9776-5
- Lowe, T. G., Edgar, M., Chir, M., Margulies, J. Y., Miller, N. H., Raso, V. J., ... Rivard, C. H. (2000). Current concepts review—Etiology of idiopathic scoliosis: Current trends in research. *Journal of Bone and Joint Surgery-American Volume*, *82A*(8), 1157–1168.
- Marsh, S. C., Clinkinbeard, S. S., Thomas, R. M., & Evans, W. P. (2007). Risk and protective factors predictive of sense of coherence during adolescence. [Research Support]. *Journal of Health Psychology*, *12*(2), 281–284. doi:10.1177/1359105307074258
- Morecroft, C., Cantrill, J., & Tully, M. P. (2004). Can in-depth research interviews have a “therapeutic” effect for participants. *International Journal of Pharmacy Practice*, *12*, 247–254.
- Page, M. G., Katz, J., Stinson, J., Isaac, L., Martin-Pichora, A. L., & Campbell, F. (2012). Validation of the numerical rating scale for pain intensity and unpleasantness in pediatric acute postoperative pain: Sensitivity to change over time. [Research Support]. *The Journal of Pain*, *13*(4), 359–369. doi:10.1016/j.jpain.2011.12.010
- Pluye, P., Gagnon, M. P., Griffiths, F., & Johnson-Lafleur, J. (2009). A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. [Research Support]. *International Journal of Nursing Studies*, *46*(4), 529–546. doi:10.1016/j.ijnurstu.2009.01.009
- Roy, C. (2011). Research based on the Roy Adaptation Model: Last 25 years. *Nursing Science Quarterly*, *24*(4), 312–320. doi:10.1177/0894318411419218
- Rullander, A. C., Isberg, S., Karling, M., Jonsson, H., & Lindh, V. (2013). Adolescents' experience with scoliosis surgery: a qualitative study. *Pain Management Nursing*, *14*(1):50–59.
- Shao, J., & Zhong, B. (2003). Last observation carry-forward and last observation analysis. [Research Support]. *Statistics in Medicine*, *22*(15), 2429–2441. doi:10.1002/sim.1519
- Stinson, J. N., Huguet, A., McGrath, P., Rosenbloom, B., Soobiah, C., White, M., & Coburn, G. (2013). A qualitative review of the psychometric properties and feasibility of electronic headache diaries for children and adults: Where we are and where we need to go. *Pain Research and Management*, *18*(3), 142–152.
- Stone, A. A., Shiffman, S., Schwartz, J. E., Broderick, J. E., & Hufford, M. R. (2003). Patient compliance with paper and electronic diaries. *Controlled Clinical Trials*, *24*(2), 182–199. doi:10.1016/S0197-2456(02)00320-3
- Streiner, D., & Geddes, J. (2001). Intention to treat analysis in clinical trials when there are missing data. *Evidence Based Mental Health*, *4*(3), 70–71.
- Tarrant, R. C., Nugent, M., Nugent, A. P., Queally, J. M., Moore, D. P., & Kiely, P. J. (2015). Anthropometric characteristics, high prevalence of undernutrition and weight loss: Impact on outcomes in patients with adolescent idiopathic scoliosis after spinal fusion. [Research Support]. *European Spine Journal*, *24*(2), 281–289. doi:10.1007/s00586-014-3622-2
- Wong, G. T., Yuen, V. M., Chow, B. F., & Irwin, M. G. (2007). Persistent pain in patients following scoliosis surgery. *European Spine Journal*, *16*(10), 1551–1556. doi:10.1007/s00586-007-0361-7
- Yadla, S., Maltenfort, M. G., Ratliff, J. K., & Harrop, J. S. (2010). Adult scoliosis surgery outcomes: A systematic review. [Meta-Analysis Review]. *Neurosurgical Focus*, *28*(3), E3. doi:10.3171/2009.12.FOCUS09254