Adolescents’ experiences of undergoing scoliosis surgery
Psychological aspects and patterns of pain

Anna-Clara Rullander
Responsible publisher under Swedish law: the Dean of the Medical Faculty
This work is protected by Swedish Copyright Legislation (Act 1960:729)
ISBN: 978-91-7601-351-9
ISSN: 0346-6612
Cover photo: Anna-Clara Rullander
Electronic version available at http://umu.diva-portal.org/
Printed by: Print & Media, Umeå University
Umeå, Sweden 2015
Till Elsa, Nils och Tomas
# Table of Contents

**Table of Contents**

- Abstract 
- Abbreviations 
- Original Papers 
- Sammanfattning på svenska

**Introduction**

- Background  
  - Different types of scoliosis
  - Living with scoliosis
  - Treatment of Scoliosis
  - Being an adolescent and undergoing scoliosis surgery
  - Symptoms during the perioperative phase
  - Stress symptoms
  - Pain and nausea
  - Recovery

**Theoretical Framework**

- Rationale
  - Aim
  - Specific aims

**Methods**

- Study I
- Study II
- Study III
- Study IV

**Ethical Considerations**

**Results**

- In Study I
- In Study II
- In Study III
- In Study IV
- Summary and integration of findings

**Discussion**

- Convergent findings
- Stress symptoms before surgery
- Preoperative stress and postoperative pain correlates
- Occasional very high levels of postoperative pain, and pain during recovery
- Reported nausea, vomiting and constipation
- Postoperative pain associated with stress during recovery
- Persistent and/or new onset pain
- Divergent findings
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary of results in relation to Roy's Adaptation Model (RAM)</td>
<td>43</td>
</tr>
<tr>
<td>Discussion of Methods</td>
<td>44</td>
</tr>
<tr>
<td>Ethical discussion</td>
<td>48</td>
</tr>
<tr>
<td>Conclusion</td>
<td>48</td>
</tr>
<tr>
<td>Clinical implications and future research</td>
<td>49</td>
</tr>
<tr>
<td>Acknowledgements / Tack</td>
<td>53</td>
</tr>
<tr>
<td>Litteratur / references / källor</td>
<td>56</td>
</tr>
</tbody>
</table>
Abstract

**Background:** Adolescent idiopathic scoliosis (AIS) affects 1 – 3% of all children aged 10 – 16 years; of these approximately 80% are girls. Scoliosis surgery is a major (one of the most extensive) elective paediatric orthopaedic procedure and is known to cause severe and excruciating pain that requires advanced postoperative pain management. Until now, scoliosis surgery has mainly been studied in terms of corrective surgical outcomes, and techniques for surgery and pain management. Adolescents’ narratives and experiences of recovery after scoliosis surgery, as well as psychological aspects in correlation to postoperative pain have seldom been studied.

**Aim:** The overall aim of this thesis was to explore adolescents’ experiences of undergoing scoliosis surgery, experiences and self-reporting of pain, and psychological consequences.

**Methods:** This thesis comprises four studies. The participants in Studies I and II belonged to the same cohort, all of whom underwent corrective surgery in the period from 2004 to 2007. In Study I there was a cohort of 87 adolescents and young adults with different types of scoliosis, some of whom had impaired verbal communication. The patients and their parents/caregivers were asked to complete a survey with questions regarding experienced pain, nausea and overall satisfaction with the hospital stay. Study II was a qualitative study in which six adolescents from the cohort in Study I were interviewed. The adolescents included in Study II had idiopathic scoliosis, and the interviews took place about two years after they had undergone surgery. Study III, which included 37 adolescents, was a prospective study of adolescents with idiopathic scoliosis (AIS) from four spine centres in Sweden. They completed two psychometric instruments and one structured interview both before surgery and about six months afterward. They also self-measured pain on the third postoperative day. In Study IV the adolescents included belonged to the same cohort as in Study III. In this prospective, mixed-method study, the participants self-reported pain before surgery, every four hours for the first five days after surgery, once a day for the first fourteen days at home after discharge from the hospital, and finally at the six-month follow-up. They were also asked to keep a diary during the first two weeks at home after discharge from the hospital. At the six-month follow-up they were interviewed about the overall experience of undergoing scoliosis surgery: how they experienced the time before surgery, during the hospital stay and the recovery period up through the date of the interview.
Results: Study I showed that the patients experienced severe pain and nausea postoperatively during the hospital stay. The parents/caregivers felt helpless and sometimes lacked confidence in the nurses. Despite this, overall satisfaction with the hospital stay was rated as good. Study II showed that the adolescents experienced nervousness and fear before surgery, severe pain and postoperative nausea and vomiting (PONV) during the hospital stay, had problems with the scars and experienced social difficulties during recovery. Nightmares were reported for up to two years after surgery. In Study III, the ratings of stress symptoms were higher before surgery than after. There were significant correlations between stress symptoms before surgery and levels of postoperative pain. There were also significant correlations between levels of postoperative pain and stress symptoms at the six-month follow-up. In Study IV, postoperative pain ratings showed great individual variation, and in the analysis of drop-outs it was found that those who did not keep a diary at home self-reported higher levels of pain at the six-month follow-up as well as higher levels of stress symptoms and internalizing symptoms. The participants described experiences of severe pain at the hospital and also during recovery. Nausea, constipation and lack of energy emerged from the narratives - but so did the desire to get back to school, sports and friends. The adolescents described how they were hovering between suffering and control and also striving towards normality.

Conclusion: The results indicate a need for interventions among adolescent patients to reduce stress symptoms before major surgery. Nurses need to identify adolescents with stress symptoms, use stress-reduction techniques, and support adolescent patients with coping strategies aimed at reducing preoperative stress and managing postoperative pain. Postoperative pain management needs to be improved, both as regards pain assessment and pharmacological and non-pharmacological pain management. Nurses need to improve their medical technical skills in order to optimize pain treatment. After discharge from the hospital adolescents have to struggle with difficulties at home such as pain, nausea, constipation, mobilization and a lack of energy. An intervention with follow-up telephone calls during the second week at home could reduce stress and help resolve difficulties. Since this study indicates stress symptoms at the six-month follow-up, there should also be a nurse interview to check on well-being and to see if any further intervention is needed at that time.

If preoperative stress can be reduced, postoperative pain management optimized and the recovery period better supported, the overall experience of going through scoliosis surgery should improve.
Abbreviations

AIS: Adolescent Idiopathic Scoliosis
ASF: Anterior Spinal Fusion
ED: Epidural catheter
EDA: Epidural analgesia
IQR: Interquartile Range
K-SADS: Kiddie Schedule for Affective Disorder and Schizophrenia for children
LOCF: Last observation carried forward
PCA: Patient Controlled Analgesia
POM: Pain-O-meter
PONV: Postoperative Nausea and Vomiting
PSF: Posterior Spinal Fusion
PTS: Posttraumatic Stress
PTSD: Posttraumatic Stress Disorder
PTSS: Posttraumatic Stress Symptoms
SRS: Scoliosis Research Society
TSCC-A: Trauma Symptom Checklist for Children – Alternate version
VAS: Visual Analogue Scale
YSR: Youth Self-Report
Original Papers

This thesis is based on the following papers.


Sammanfattning på svenska

Bakgrund

Idiopatisk skolios drabbar cirka 1 – 3 % av alla barn och ungdomar mellan 10 och 16 år och av dem är cirka 80 % flickor. Skolioskirurgi är en stor elektiv barn- och ungdoms ortopedisk proceduren (en av de mest omfattande), och det kirurgiska ingreppet orsakar svår smärta som fordrar avancerad postoperativ smärtlindring.

Hittills har skolioskirurgi mestadels studerats i termer av utfall gällande kirurgisk korrigerande, operationstekniker och smärtbehandling. Ungdomar med idiopatisk skolios är sparsamt studerade vad gäller deras egna berättelser och upplevelser i anslutning till det kirurgiska ingreppet, den postoperativa smärtan och återhämtningen.

Syfte

Det övergripande syftet med studierna i denna avhandling har varit att belysa ungdomars upplevelser och erfarenheter av att genomgå skolioskirurgi, mönster av smärta och de psykologiska konsekvenserna av upplevelserna.

Metod

Studie II är en kvalitativ intervjustudie med sex ungdomar från kohorten i studie I. De inkluderade ungdomarna i studie II hade idiopatisk skolios och de blev intervjuade omkring två år efter genomgången kirurgi.


I studie IV var studiedeltagarna från samma kohort som i studie III. De skattade sin smärta före operationen, var fjärde timma de första fem dagarna efter operationen, en gång om dagen de första fjorton dagarna hemma efter sjukhusvistelsen samt vid sexmånadersuppföljningen. De ombads att skriva dagbok de första fjorton dagarna efter hemkomst. Vid sexmånadersuppföljningen blev de intervjuade om sina upplevelser av att genomgå skolioskirurgi: hur de hade upplevt tiden före operationen, under sjukhusvistelsen och återhämtningen fram till dagen för intervjun.

**Resultat**

Studie I visade att deltagarna upplevde svår smärta och illamående efter operationen under sjukhusvistelsen. Föräldrarna/vårdnadshavarna upplevde hjälpönskt och de beskrev även att de emellanåt sviktade i sitt förtroende till sjuksköterskorna. Trots detta skattades den generella nöjdheten med sjukhusvistelsen som god.

Studie II visade att ungdomarna upplevde nervositet och rädsla före operationen, svår smärta och illamående under sjukhusvistelsen och att de hade sociala svårigheter och även svårigheter med ärret under återhämtningsperioden. Mardrömmar beskrevs i upp till två år efter operationen.

Resultatet i studie III visade att nivåerna av stress var högre före operationen än efter sex månader. Det fanns signifikanta korrelationer mellan stressymptom före operationen och nivå av postoperativ smärta dag tre. Det fanns även signifikanta korrelationer mellan nivåerna av postoperativ smärta dag tre och stressymptom efter sex månader.

I studie IV visade det sig att nivåerna av smärta varierade kraftigt över tid och mellan deltagarna. I bortfallsanalysen visade det sig att de som inte skrev dagbok skattat högre nivåer av stressymptom och internaliserande beteende. Ungdomarna beskrev svår smärta både under sjukhusvistelsen och

Slutsats


Om den preoperativa stressen kan reduceras, den postoperativa smärtlindringen optimeras och ungdomarna få bättre stöd under återhämtningstiden skulle totalupplevelsen av att genomgå skolioskirurgi förbättras!
Introduction

This thesis is the result of a great interest in perioperative nursing care. Scoliosis surgery is a major procedure - perhaps the largest - which requires advanced perioperative nursing care; adolescents undergoing this procedure sometimes have life-changing experiences. As a specialized nurse in the fields of children and adolescent care, pain and pain management and urotherapy, I have had the opportunity to participate in the perioperative nursing care of adolescents undergoing scoliosis surgery. Meeting an adolescent who is waiting for, and preparing to undergo scoliosis surgery places high demands on the nurse. Prior to surgery, adolescents with idiopathic scoliosis have not always experienced symptoms from the curvation of the spine and may be unaware of the scoliosis. The adolescent might not display any nervousness or fear; at the same time, the nurse knows the difficulties and challenges awaiting the patient. Nurses are expected to prepare the adolescents in the best possible way, providing information about what to expect during the anaesthetic induction, and postoperative period as well as during short- and long-term recovery. This can be a delicate matter, as information regarding postoperative pain, postoperative nausea and vomiting (PONV) - as well as mobilization after surgery and pharmacological treatment - may be frightening. As a nurse, my experience is that perioperative care is often good, as are levels of patient and parental satisfaction and surgical outcome. Despite this, unfortunately, there are cases where perioperative care is suboptimal, and the adolescent patient is very nervous and anxious before surgery; parents suffer from anxiety and the adolescent suffers from severe postoperative pain and nausea. There are probably a number of factors at play in the reasons for these shortcomings; it could be a matter of educational need among nurses, a lack of communication, inadequate routines, or economic or other factors. Regardless of the reasons, these shortcomings need to be addressed. Studies exploring adolescents’ experiences of undergoing scoliosis surgery are sparse; the field needs to be studied further. Several spine clinics in Sweden perform scoliosis surgery; the surgery techniques, as well as the routines for pain management and perioperative care, vary among them. Over the last 25 years there has been improvement in all these fields, but there are still many things that can be improved.

At most spine clinics in Sweden, nurses meet the adolescent on the day of admission to the clinic - one day before surgery. During the hospital stay there are advanced nursing interventions such as assessment and treatment of pain, PONV, nutrition, and anxiety; help with mobilizing and also taking care of parents and/or caregivers. Nurses are not expected to provide good
nursing care to only one patient at the time; on the contrary, they are often responsible for several patients simultaneously. In addition there are also other duties and routines such as documenting, waiting for prescriptions, participating in rounds, answering phone calls, educating student nurses and taking care of parents.

In this thesis I have explored adolescent patients’ overall experiences of undergoing scoliosis surgery. The four studies in this thesis have different approaches for exploring adolescents’ perceptions and self-reported pain, stress symptoms and experiences of the perioperative procedure. The studies have qualitative/quantitative/mixed-method designs aimed at broadening the scope and widening the perspectives of the experiences of undergoing scoliosis surgery. A mix of designs might be a helpful strategy to facilitate the highlighting of those areas in perioperative care that can be improved. Doing so yields the possibility of pinpointing areas where improvement is most needed and thus ultimately optimizing perioperative care and the overall experience of undergoing scoliosis surgery.
Background

In this background section my intention is to guide the reader through the areas of these studies by describing scoliosis, its treatment, commonly experienced perioperative symptoms and recovery.

Different types of scoliosis

Scoliosis is a spine deformity characterized by lateral and rotational curvature of the spine (Richards & Vitale, 2008). Hippocrates stated: “There are many varieties of curvature of the spine even in persons who are in good health; for it takes place from natural conformation and from habit, and the spine is liable to be bent from old age and from pains” (Hippocrates, 400 B.C.E). There are different types of scoliosis; a common way of grouping them is to divide them into idiopathic (no associated abnormalities or diseases), neuromuscular, and other (for example caused by trauma, syndromic, tumours etc.)(Goldberg, Moore, Fogarty, & Dowling, 2008). Adolescents with neuromuscular scoliosis often have multifactorial impairments, including impaired verbal communication.

The curves can be further classified according to their apical location of vertebrae:

- Cervical C1-C6
- Cervicothoracic C7-T1
- Thoracic T2-T12
- Thoracolumbar T12-L1
- Lumbar L2-L4
- Lumbosacral L5-S1 (Rolton, 2014)

The aetiopathogenesis of adolescent idiopathic scoliosis (AIS) remains unknown, although it has been studied in clinical, epidemiological and basic scientific research. AIS is the most common type of scoliosis; it affects 1 - 3% of children and adolescents aged 10 - 16 years, approximately 80% of whom are girls (Weinstein, Dolan, Cheng, Danielsson, & Morcuende, 2008). The
magnitude of curvation of the spine is measured using the Cobb angle. The upper and the lower limits of the curve need to be determined radiologically; the intersection of the two lines - one parallel to the endplate of the superior vertebra, the other parallel to the endplate of the inferior vertebra - then forms the Cobb angle (Rolton, 2014). The magnitude of the Cobb angle is a criterion for treatment.

**Living with scoliosis**

Most adolescents with scoliosis are referrals from school scoliosis screening programmes to orthopaedic clinics, and are diagnosed after radiological examination (Adobor, Rimeslatten, Steen, & Brox, 2011; Nachemson & Peterson, 1995). Some adolescents diagnosed with scoliosis do not have any symptoms from the curvation of the spine; for them, the diagnosis might come as a surprise. Others can be aware of the curvation of the spine, experiencing symptoms such as pain, and may actually be aware of the curvation visually (Rushton & Grevitt, 2013). Studies concerning adolescents’ narratives about living with scoliosis are extremely rare; in fact I could not find any. There are “patient stories” on the Scoliosis Research Society website (srs.org) about what living with scoliosis is like, and there are blog sites as well. These stories contain some descriptions of experiences of living with scoliosis, but mainly concern life after surgery and stories about what treatment with a brace is like. There are quantitative studies, however, that explore specific topics such as pain, self-perceived appearance and quality of life in adolescents with scoliosis (Smith et al., 2006; Weinstein et al., 2008). Results from those studies indicate that there are adolescents with scoliosis who do not perceive any pain. In cases where pain does occur, it can be a limitation in physical activities and in daily life. Perceived appearance varies, as there are both descriptions of not being aware of the scoliosis and of perceiving the curved spine as an aesthetic limitation. Quality of life can be affected concerning lower self-esteem as compared to adolescents without scoliosis (Smith et al., 2006; Weinstein et al., 2008). Studies where adolescents narrate their experiences of living with scoliosis are sparse; studies regarding surgery techniques, postoperative pain management techniques, and postoperative radiological outcome in adolescent scoliosis are more extensive.
Treatment of Scoliosis

Treatment with a brace is sometimes employed with the aim of inhibiting curve progression. Braces can be an aesthetical problem for adolescents, since they are visible under clothing; compliance with brace treatment tends to decrease over the duration of the treatment. Since there is no clear evidence that treatment with a brace reduces the risks of curve progression, surgery is often required in the end. The trend is to not use a brace at all, but to perform corrective surgery in the first place (Weinstein et al., 2008). For adolescents with a large spinal curve (Cobb angle >45°), surgery is generally performed with the intent to achieve correction, improve appearance and keep short-term and long-term complications to a minimum. Aesthetical inclusion criteria play a role in making a decision regarding surgery. The intention is to achieve correction and improve appearance, though perceived appearance can diverge between adolescent and parents (Smith et al., 2006). Short-term complications of untreated scoliosis include curve progression, pain and physical limitations (i.e. in sports activities). Long-term complications include curve progression, decreased pulmonary function, pain, and physical limitations (Weinstein et al., 2008). There are different surgery techniques for correction of the spine: posterior spinal fusion (PSF), anterior spinal fusion (ASF), and a combination of both anterior and posterior (Weinstein et al., 2008). In PSF a long incision along the back is made, and the muscles are stripped from the spine to gain access. After that the spine is instrumented (there are different types of instrumentation, such as rods, screws and hooks) in order to straighten the spine. Bone is then added, often from the patients’ hip, inciting a reaction in which the bones in the spine begin fusing together. In ASF the front of the spine is approached via a thoracic incision, and includes removal of a rib. To optimize saturation and breathing, a chest-tube is required for the first 2 - 3 days after surgery (Potter, Kuklo, & Lenke, 2005)

Being an adolescent and undergoing scoliosis surgery

Adolescence is a dynamic period of life, and a time for teenage emancipation. During the hospital stay - especially postoperatively - the adolescent becomes dependent on others; unable to manage personal hygiene, eating, changing sitting position, or putting on and taking off clothing, they become dependent on support around the clock. In a study by Hutton (2002), adolescents with experiences of hospital stays longer than one week pointed out issues such as privacy and private spaces, that are important in the hospital environment (Hutton, 2002). Adolescence is a time for moving away from parents towards peers, for separating emotionally from parents, and finding an identity separate from one’s family (Rackley & Bostwick,
In adolescence, factors such as being in control, fitting in, and having friends, as well as esthetical parameters - family, school and activities outside school - are important for a sense of well-being (Leversen, Danielsen, Birkeland, & Samdal, 2012). In a situation that involves waiting for extensive surgery, knowing that there is a risk of becoming paralyzed, knowing that there might be severe pain, and knowing that there is going to be a lifelong scar down one’s back, the amounts of stress can be high. Stress symptoms might not be explicitly expressed, as adolescents tend to not always show nervousness and anxiety (Fortier, Martin, Chorney, Mayes, & Kain, 2011; Silverman & Ollendick, 2005).

**Symptoms during the perioperative phase**

During the perioperative phase there are many challenges for the adolescent. Well-being and preparation before surgery can have an impact on postoperative symptoms and the ability to recover. In this thesis I will explore symptoms that can occur during the perioperative phase. Before surgery there can be nervousness and anxiety about what to expect after surgery (Logan & Rose, 2005). During the acute postoperative phase, pain and PONV are often the most prominent issues of concern (Chandrakantan & Glass, 2011).

**Stress symptoms**

Stress symptoms associated with major surgery - when the adolescent may be very worried about the surgery itself, postoperative pain and difficulties during recovery - are issues of great concern. The term *stress* can refer to adolescents feeling tense, restless, nervous and worried, and having difficulties concentrating (Stromback, Malmgren-Olsson, & Wiklund, 2013). *Stress symptoms* are described in terms of stress, anger, depression and anxiety (Grant, Compas, Thurm, McMahon, & Gipson, 2004; Waaktaar, Borge, Fundingsrud, Christie, & Torgersen, 2004). In this thesis *stress symptoms* are studied. Internalizing symptoms is sometimes defined as a complex of symptoms; as a reaction to stress adolescents can display symptoms of being withdrawn, introverted, and anxious. On the other hand there are externalizing symptoms where adolescents display anger, rule-breaking behaviours, and defiance as a reaction to stress (Wilkinson, 2009).

It is known that highly anxious parents can influence their children’s level of anxiety; one study showed that highly anxious parents often had highly anxious children, and that highly anxious parents reported higher pain intensity on days 2 to 4 postoperative (Lamontagne, Hepworth, & Salisbury, 2001). Expected high levels of pain and pain catastrophizing can predict
severe postoperative pain (Sommer et al., 2010). Except for acute postoperative pain and duration of surgery, physical condition and fear of surgery are somatic and mental factors that can predict suboptimal recovery after surgery (Peters, Sommer, van Kleef, & Marcus, 2010).

Another aspect of stress is psychological traumatizing - which in children and adolescents is mainly studied after trauma and accidents - and high levels of distress during and immediately after a trauma. Anxiety and depression symptoms are significant risk factors for posttraumatic stress disorder (PTSD) (Olofsson, Bunketorp, & Andersson, 2009; Zatzick et al., 2006). PTSD-symptoms have been shown to affect the experience of pain, and there is an association between traumatized adolescents with PTSD-symptoms and long-lasting or chronic pain (Zatzick et al., 2008). Being of a young age at the time of the trauma is also a risk factor for developing PTSD (Chiu, deRoon-Cassini, & Brasel, 2011). Injuries (Olofsson et al., 2009; Olofsson, Bunketorp, & Andersson, 2012) and even minor trauma, as well as minor elective surgery, may cause post-traumatic stress in children (Ben-Amitay et al., 2006; Sanders, Starr, Frawley, McNulty, & Niacaris, 2005). The AIS population mostly comprises young girls, and post-traumatic stress is more common among girls and women (Holbrook et al., 2005; Olff, Langeland, Draijer, & Gersons, 2007). Pain itself is a risk factor for developing PTSD (Broman-Fulks et al., 2009; Gold, Kant, & Kim, 2008; Langeland & Olff, 2008; Sanders et al., 2005). In adolescents, the prevalence of PTS in correlation to scoliosis surgery has rarely been examined.

**Pain and nausea**

Pain and nausea are other prominent symptoms after scoliosis surgery. Postoperative pain after scoliosis surgery is known to be severe and excruciating because of the deep somatic pain and extensive surgical trauma in addition to episodes of severe reflex muscle spasms (Borgeat & Blumenthal, 2008). Adolescents undergoing spinal surgery have been reported as experiencing more pain than adults (Gillies, Smith, & Parry-Jones, 1999). Even if there are analgesic strategies that are proven to have good effect on postoperative pain in adolescents who underwent scoliosis surgery (Borgeat & Blumenthal, 2008; Taenzer & Clark, 2010), there are studies indicating that adolescents still receive insufficient postoperative analgesia after scoliosis surgery (Sommer et al., 2008). Severe postoperative pain in children and adolescents might result in chronic pain (Wong, Yuen, Chow, & Irwin, 2007).

Although scoliosis surgery is one of the largest surgical procedures performed electively on young people, there are only a few studies reporting
adolescents’ personal stories and narrated experiences of surgery. Unrelieved severe postoperative pain might lead to an increased incidence of persistent pain (duration >2 months) (Dahl, Mathiesen, & Kehlet, 2010; Sommer et al., 2010). Persistent severe postoperative pain after common surgery is estimated in 2-10% of all patients (Dahl et al., 2010) and after surgery in 7% of AIS patients (Wong et al., 2007). In one study back pain 1 to 2 years after surgery was shown to be reduced as compared to before the surgery, but 30% of the patients used analgesics for back pain both before and up to 2 years after surgery (Zachary, Mohammad, & Group, 2010) and pain at 5 years after surgery was shown to be increased as compared to the follow-up at 2 years (Upasani et al., 2008).

Postoperative pain management after scoliosis surgery often includes opioids administered intravenously, orally or via epidural. Morphine is often administrated as a postoperative analgesic drug, but the surgery itself and anaesthetic drugs also play an important role regarding the incidence of PONV (Edler, Mariano, Golianu, Kuan, & Pentcheva, 2007). Nausea after major surgery is a well-known postoperative problem that causes massive discomfort, further negative impact on nutritional status, delayed mobilization, and prolonged hospital stays (Blanco, Perlman, Cha, & Delpizzo, 2013). Predictors and risk factors for PONV are known to be young age (adolescence), female gender, a history of motion sickness, previous experienced PONV, duration of anaesthesia and postoperative opioid use (Apfel et al., 2012).

**Recovery**

Recovery is of utmost importance after major surgery. Since scoliosis surgery entails a large amount of tissue damage recovery is a demanding period for the adolescent patient.

The term postoperative recovery is defined as:

“an energy-requiring process of returning to normality and wholeness as defined by comparative standards, achieved by regaining control over physical, psychological, social and habitual functions, which results in returning to preoperative levels of independence/dependence in activities of daily living and an optimum level of psychological well-being” (Allvin, Berg, Idvall, & Nilsson, 2007).

During recovery there are many factors to be dealt with. Few studies have been found in which adolescents narrated their experiences of the first weeks of recovery at home after major surgery. Postoperative pain after being
discharged home after surgery has mainly been studied after outpatient surgery in adults (Brattwall et al., 2011; Rosén, Bergh, Lundman, & Mårtensson, 2010) and children (Karling, Ljungman, & Thornberg, 1999; Karling, Renström, & Ljungman, 2002; Segerdahl, Warrén-Stomberg, Rawal, Brattwall, & Jakobsson, 2008), and after tonsillectomy in children (Vallée, Lafrenaye, Tétrault, Mayer, & Dorion, 2008). Parents are found to under-treat children’s pain after surgery (Rony, Fortier, Chorney, Perret, & Kain, 2010). After discharge from hospital, the home environment might not be adapted to postoperative recovery. There are many parameters that can affect recovery, and stressful experiences during the hospital stay are one of them. Hart and colleagues (Hart, Perry, Hiratzka, Kane, & Deisseroth, 2013) studied 73 adults who had undergone lumbar spinal fusion. About 20% of the study population had PTSD-symptoms after one year, which reduced the clinical benefit of the surgery. In another study there was also found that higher positive affect at six weeks after surgery had a positive effect on functional outcome at three months after surgery, and negative affects at six weeks was a predictor of pain interference and disability at three months after surgery (Seebach et al., 2012). Health-related quality of life was measured among 114 adolescents with AIS five years after corrective surgery. The findings were that common symptoms included occasional back pain, a limited range of motion, limitations in activity, waistline imbalance, rib prominence, wound/scar problems, and shortness of breath (Spanyer et al., 2015). In another study, postoperative recovery was studied in 88 adolescents with idiopathic scoliosis. It showed that the recovery period was strongly disruptive to their usual activities and social life, especially during the first three months. Over a nine-month period the activities increased, but they never got back to their base-level activity, either physically or socially (LaMontagne, Hepworth, Cohen, & Salisbury, 2004a). Keeping the definition of postoperative recovery in mind, recovery after scoliosis surgery can be longer than nine months. Recovery is a dynamic process with changes, challenges and difficulties over time. Adolescents have to adapt to new conditions such as being dependent on others, coping with pain, and having a changed body. According to Roy, the person is an open, adaptive system who uses coping skills to deal with stressors. As an adaptive system the person has two regulating subsystems acting to maintain adaptation to new situations (Roy, 2011): the regulator subsystem and the cognator subsystem. The regulator coping subsystem is an innate automatic, unconscious system that responds to stimuli; through the nervous system it affects fluid, electrolyte, and acid balances as well as the endocrine system. The cognator coping subsystem processes changes thorough cognitive and emotional channels. This involves personal perception, processing of information, emotion, judgement and learning (Fawcett, 2013; Sosha, 2012). During recovery, new situations appear frequently and adaption must be an ongoing
process. Since recovery differs among various types of surgery, and orthopaedic surgical procedures have a prolonged recovery compared to other surgical procedures (Allvin et al., 2011), the adolescent patient faces severe obstacles during this period. The ability to cope and adapt - in this case, to postoperative difficulties - is, according to Roy, a concept of survival (Roy, 1981)

Few studies have been found regarding adolescents’ experiences of recovery from scoliosis surgery. There is a gap in knowledge about experiences before surgery, after surgery during the hospital stay and after discharge, and their effect on well-being and the ability to recover from scoliosis surgery. Adolescents’ experiences of the recovery period at home during the first two weeks, six months and up to two years after surgery have so far seldom been studied.

**Theoretical Framework**

In this thesis I have the intention of exploring adolescents’ experiences of undergoing scoliosis surgery from a broad perspective. To gain a deeper understanding of the complexity of adolescents’ perceptions, a mix of methods was used. Based on Callista Roy’s Adaption Model (RAM) I have tried to capture more of a multi-dimensional perspective where individual aspects of experiences could be parts, acting together to form a unified being. The RAM includes four adaptive modes: **physiologic-physical, self-concept/group identity, role function, and interdependence**. The physiologic-physical mode involves physical and chemical processes that enable the functions and activities of a living organism, including basic needs and processes. The self-concept/group identity mode has two components: self-concept composites of beliefs and feelings that a person holds about oneself, and group identity mode referring to identifying and perceiving oneself as part of a group. Role functioning refers to roles in society and social integrity. Interdependence is behaviour pertaining to relationships, giving and receiving love, respect and value (Fawcett, 2013; Roy, 1976). The goal of nursing according to Roy is to promote adaptation in these four adaptive modes.

The studies in this thesis with different designs were used to capture as many modes as possible according to RAM. The four adaption modes will be a guide to facilitate the mixed methods integration of the quantitative and qualitative results.
Rationale

The phenomenon of adolescents undergoing scoliosis surgery has seldom been researched. Especially studies in which young people’s perspectives on the process have been made visible are lacking. Adolescents’ experiences and self-reporting of symptoms both before and after major surgery, and also of their needs during recovery need to be highlighted.

Throughout the perioperative period there is a lack of knowledge regarding several areas, such as preoperative stress, anxiety, postoperative pain and PONV, traumatization, and short- and long-term recovery. Further studies relating these specific perioperative aspects of adolescents’ narratives of their experiences of the hospital stay, as well as of recovery, are needed. Therefore, in this thesis I have focused on different perspectives with a mix of research methods in order to explore adolescents’ and young peoples’ self-reported symptoms and their experiences of undergoing scoliosis surgery separately and merged together.

Aim

The overall aim of this thesis was to explore adolescents’ experiences of undergoing scoliosis surgery, and their experiences and self-reports of pain and the psychological consequences.

Specific aims

**Study I:** To describe how young people and their parents retrospectively recall the postoperative pain and nausea, and describe their experiences of scoliosis surgery

**Study II:** To describe adolescents’ narrated experiences of going through scoliosis surgery

**Study III:** To describe stress symptoms among adolescents before and after scoliosis surgery and to explore correlations with postoperative pain.

**Study IV:** 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 six months of recovery at home after corrective surgery for idiopathic scoliosis.
Methods

This thesis applied qualitative, quantitative and mixed methods for the purpose of gaining a deeper and broader understanding of adolescents’ overall experiences of undergoing scoliosis surgery.

Table 1. A schematic overview of Studies I – IV.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Instrument</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Questionnaire study</td>
<td>51 adolescents and young adults who had undergone scoliosis surgery, and 65 caregivers</td>
<td>Study-specific questionnaire, VAS, Free text sections</td>
<td>Qualitative content analysis and Descriptive statistics</td>
</tr>
<tr>
<td>II</td>
<td>Interview study</td>
<td>6 AIS patients from the cohort in Study I, who had undergone corrective surgery</td>
<td>Semi-structured interviews</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>III</td>
<td>Quantitative study</td>
<td>37 AIS-patients undergoing corrective surgery</td>
<td>YSR, TSCC-A, K-SADS, VAS</td>
<td>Linear regression</td>
</tr>
<tr>
<td>IV</td>
<td>Convergent Parallel Mixed methods</td>
<td>The same cohort as in Study III.</td>
<td>VAS, Pain-o-Meter Diary, Semi-structured interview</td>
<td>Mixed methods: Qualitative content analysis, Descriptive statistics</td>
</tr>
</tbody>
</table>

Study I

Design: A study with both a qualitative and a quantitative approach, based on a study-specific questionnaire.

Participants: In this study, 87 adolescents and young adults between the ages of 12 and 25 were invited together with a parent or caregiver. They had different types of scoliosis: idiopathic, neuromuscular and other types (for example caused by trauma, syndromic, tumours, etc.), and they had all gone through corrective surgery for scoliosis between 2004 and 2007 at a University Hospital of Northern Sweden. They received information and an invitation to the study in a letter. Fifty-one patients and 65 parents/
caregivers gave their informed consent to participation in the study. Sixteen of the 51 patients had impaired verbal communication (Table 2).

Table 2. Demographics in Study I.

<table>
<thead>
<tr>
<th></th>
<th>Scoliosis</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Idiopathic</td>
<td>Neuromuscular</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Patients (n)</td>
<td>35</td>
<td>8</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Parents/caregivers (n)</td>
<td>35</td>
<td>19</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Girls (n)/boys (n)</td>
<td>29/6</td>
<td>3/5</td>
<td>4/4</td>
<td></td>
</tr>
<tr>
<td>Age (mean years)</td>
<td>16</td>
<td>15</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Impaired communication (n)</td>
<td>2</td>
<td>16</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Length of hospital-stay (mean days)</td>
<td>11</td>
<td>13</td>
<td>11</td>
<td></td>
</tr>
</tbody>
</table>

Data collection: A study-specific questionnaire consisting of VAS-ratings of experienced pain, nausea and global satisfaction was used. The questionnaire also had free text sections for every VAS-rating and yes/no questions. The authors could not find any validated instrument available that covered the aims of this study. In ratings for pain, nausea and global satisfaction the Visual Analogue Scale (VAS) 0 – 10 cm (Bailey, Daoust, Doyon-Trottier, Dauphin-Pierre, & Gravel, 2010; Huskisson, 1974) was used. VAS is a well-tested scale and often used for self-reporting. During the hospital stay, the VAS was used for self-reported pain. Two questionnaires with eight questions were sent home to the families, one to the adolescent/young adult and one to the parent/caregiver. In cases where the adolescents/young adults had impaired verbal communication, a parent or caregiver had the opportunity to answer for them as proxy. The frequency of reply for the patients was 51 (59%) and for parents 65 (75%). Of the patients, 20 (23%) had impaired verbal communication, of those, 16 (80%) were rated by proxy. Of the responding parents, 52 were mothers, 8 were fathers, and 5 were another caregiver present with the patient during the hospital stay. Of the families, 46 patients (53%) had parents who also responded to the questionnaire. In total, responses were obtained from 70 (80%) of the families approached. In spite of reminders 17 of the families did not respond.

Analysis: The free-text responses from the patients and parents/caregivers were analysed using qualitative content analysis (Graneheim & Lundman, 2004). The free text varied, as regards content and comprehensiveness, and also as regards richness and length. Some of the free-text answers were therefore condensed and sorted into subcategories and main categories, but other free-text answers were too short for all these steps. In those cases subcategories emerged at once. VAS ratings were analysed using SPSS.
(Version 17; SPSS Inc, Chicago, IL) with descriptive statistics, median values, for pain, nausea and global satisfaction. The pain ratings were calculated with data both from the patients and parents/caregivers, but this was not the case with nausea and global satisfaction. The reason for pain being calculated for both patients and parents/caregivers was that pain often can be interpreted and understood by a parent or caregiver, but nausea and global satisfaction with the hospital stay is more complex. The results therefore do not include proxy-ratings in those cases; the free-text responses, however, are included from both patients and parents/caregivers in all three domains.

**Study II**

**Design:** An interview study.

**Participants:** In this study, adolescents with AIS from the cohort in Study I (Table 2) were invited to participate. Inclusion criteria were: age between 12 and 18 years, idiopathic scoliosis, and being able to understand and speak Swedish. There were 15 adolescents eligible from the cohort; six adolescents - two boys and four girls - agreed to participate in the interview study. Reasons for not wanting to participate were: not having anything to say, not remembering much from the hospital stay and not wanting to remember the time of surgery since it was “the worst experience ever”.

**Data collection:** The semi-structured interviews were conducted about two years after the adolescents had gone through surgery for idiopathic scoliosis. The interviews took place at a location of the adolescent’s choice (at home, in the home clinic or at the orthopaedic clinic where they had gone through surgery) and lasted for 10 to 45 minutes. The interviewer also took notes regarding participant behaviour and demeanour during the interview, including body language and emotional/affective expressions. Only the interviewer and the adolescent were present in the room. An open-ended question with some helping questions was used. The main question was:

- “Can you tell me about the experience of going through scoliosis surgery and how it felt before, during and after the hospital visit?”

The interviewer concluded the interviews by summarizing the answers in short, and asking if everything was correctly interpreted.

**Analysis:** In this study qualitative content analysis (Downe-Wamboldt, 1992; Graneheim & Lundman, 2004; Huberman & Miles, 2002) was used for the
analysis. The interviews were rich and descriptive and the text was transcribed verbatim. The data - in this case the written narratives and interviewer’s notes - were analysed, and read through several times; a list of codes was constructed, describing topics of significance. The text was read through again several times, meaning units were created, and recurring topics emerged. Similarities and differences were compared and sorted into categories. From these subcategories, three main categories were identified.
Study III

Study IV

Included participants from four spine centers during 2012 and 2013 n=37

Included data n=37

YSR K-SADS TSCC-A

Preoperative self-reports

YSR K-SADS TSCC-A POM VAS

Self-report of pain every four hours during the first five postoperative days at hospital

Self-report of pain every four hours during the first five postoperative days

First fourteen days after discharge every day measured Diary VAS

Six months follow-up

YSR K-SADS TSCC-A Interview POM VAS n=28

Diary VAS

Interviews POM VAS n=28

Study III

Includes participants from four spine centers during 2012 and 2013 n=37

Preoperative self-reports

YSR K-SADS TSCC-A POM VAS

Self-report of pain every four hours during the first five postoperative days at hospital

Self-report of pain on the third day

First fourteen days after discharge every day measured Diary VAS

Six months follow-up

YSR K-SADS TSCC-A Interview POM VAS n=28

Diary VAS

Interviews POM VAS n=28

Study IV

Included data n=37

YSR K-SADS TSCC-A

Self-report of pain every four hours during the first five postoperative days

Diary VAS

Six months follow-up

YSR K-SADS TSCC-A Interview POM VAS n=28

Diary VAS

Interviews POM VAS n=28

Figure 1. Flowchart over Studies III and IV. The column in the middle shows data collected for both studies. From that data-collection two studies are presented. Under “Study III” data used for this study is listed. Under “Study IV” data is listed for Study IV.
Design: A quantitative study.

Participants: In this study adolescents from four spine centres in Sweden were included consecutively, and 44 adolescents with AIS were invited to participate. Thirty-seven adolescents consented to participate. They were aged 12 to 18 years and scheduled for corrective surgery during 2012 and 2013. Of the 37 adolescents in the sample, 32 were girls, with a mean age of 15.8; 5 were boys, with a mean age of 16.1 (Table 3). The intent of this study was to include the total population of scoliosis patients from the four spine centres, but some of the eligible patients declined (n=7, all girls). The reasons for not wanting to participate have not been fully clarified, but not being interested in participating, being unwilling to spend time answering questions, and having parents who were unwilling to let their child participate were among those stated. One of the patients studied did not want to continue with the study after being discharged from hospital and eight participants could not be reached by the researcher after they had been discharged from hospital. At the time of the follow-up six months after surgery, there were 28 adolescents remaining to complete the study.

Table 3. Demographics of included participants in Studies III and IV. Age is presented in years and months.

<table>
<thead>
<tr>
<th></th>
<th>Girls</th>
<th>Boys</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants (n)</td>
<td>32</td>
<td>5</td>
<td>37</td>
</tr>
<tr>
<td>Age mean years</td>
<td>15.8</td>
<td>16.1</td>
<td>15.7</td>
</tr>
<tr>
<td>Age min/max</td>
<td>12/18.10</td>
<td>12.9/17.10</td>
<td>12/18.10</td>
</tr>
</tbody>
</table>

Data collection: The participants completed two psychometric instruments and a structured interview before surgery (in most cases one day before surgery) and about six months after surgery (Figure 1). The instruments were the Youth Self-Report (YSR), Trauma Symptom Checklist for Children – Alternate version (TSCC-A) and the structured interview was Kiddie Schedule for Affective Disorder and Schizophrenia for children (K-SADS).

The YSR is completed by youths in order to describe their own functioning. For this study one part of the instrument - Problem checklist was used. This consists of a 112-item questionnaire in which the adolescent scores symptoms/behaviours on a three-point scale (0=Not true; 1=Somewhat true; 2=Very true or Often true). The youths rate their experiences at the present time and what they experienced over the past six months. The problem checklist comprises eight core Syndrome Scales (1. Anxious/Depressed, 2. Withdrawn/Depressed, 3. Somatic Complaints, 4. Social Problems, 5. Thought Problems, 6. Attention Problems, 7. Rule-breaking Behaviour, 8. Aggressive Behaviour) and two broad band domains of internalizing (1 – 3)
and externalizing problems (7 – 8) (Achenbach, 2001). There is also a domain for Post-Traumatic Stress Problems. This instrument has been validated and translated into Swedish (Broberg et al., 2001) for young people 6 - 18 years of age. Reliability (internal consistency) was 0, 66 (Ivarsson, Gillberg, Arvidsson, & Broberg, 2002). Validity for the YSR is tested by content, criterion and construct validity; all show good validity when tested in a clinical and a referred group (Achenbach & Rescorla, 2001). The YSR is tested in a Swedish context (Broberg et al., 2001) on a normative sample consisting of 2522 adolescents aged from 13 to 18 years.

TSCC-A (Briere, 1996) is a 44-item self-report questionnaire used to measure trauma-associated psychological sequelae in children and adolescents who have experienced trauma (physical, major loss, natural disaster or witness to violence). It has been translated into Swedish and validated in a Swedish context (Nilsson, Wadsby, & Svedin, 2008). Reliability (internal consistency) in the Swedish context was 0.94 (Cronbach’s alpha), and test-retest between 0.56 and 0.81 (Person correlation). Validity is tested with factor analysis, correlations, and criterion validity. The TSCC-A consists of two validity scales (under-response and hyper-response) and five clinical scales (anxiety, depression, posttraumatic stress, dissociation and anger). Each symptom item is rated according to its frequency of occurrence using a four point scale ranging from 0 (“never”) to 3 (“almost all of the time”). The Swedish manual for TSCC (Nilsson & Svedin, 2010) contains reference-scores from a normative test-group of 728 children and adolescents aged from 10 to 17 years.

K-SADS is an instrument for structured interviews (Kaufman et al., 1997) with questions used to investigate earlier and/or current episodes of psychopathology among children and adolescents. In this study it was used to screen for confounders (traumatic events not associated with the surgery or hospital stay) that might affect the outcome in this study. The instrument contains questions about experienced traumas, and a supplemental part with questions about symptoms that could be associated with the trauma. Each item in the structured interview is scored from 0 to 3, where 0 is no information, 1 is no symptom, 2 is a symptom but not pathological, and 3 is a symptom that requires further investigation and treatment (Ambrosini, 2000). The instrument has been translated into Swedish and was approved by the author in 2001. It is tested according to reliability 0.77 – 1.0 and validity interrater agreement 93 – 100% (Kaufman et al., 1997).

The participants also self-measured pain using VAS (Huskisson, 1974) on the third day after surgery. The results from the psychometric instruments were
compared for differences before and after surgery and pain measurement was tested against the instruments to detect any correlations.

**Analysis:** The results from the psychometric instruments were analysed using SPSS (IBM SPSS Statistics Data Editor Version 22). Descriptive statistics were shown as mean values before and after surgery. Differences between preoperative measures and follow up measures were compared using paired sample t-test. Simple linear regression was used to investigate the associations between postoperative pain on day three and ratings from the three instruments preoperatively and at the six-month follow-up. Missing values in the pain ratings on day three after surgery were managed in the analysis with Last Observation Carried Forward (LOCF) (Shao & Zhong, 2003; Streiner & Geddes, 2001), a method to adjust for missing VAS ratings.

**Study IV**

**Design:** A Convergent Parallel Mixed Methods design (Creswell, 2014).

**Participants:** The same group of participants as in **Study III**.

**Data collection:** Before surgery the included adolescents rated pain on a Pain-o-Meter (POM) (i.e., VAS and location of experienced pain and description of pain) (Gaston-Johansson & Asklund-Gustafsson, 1985). From the first day after surgery, VAS self-reports of pain were obtained every four hours over five days. After discharge, the adolescents were asked to keep a diary on paper for the first fourteen days at home about everyday life, and also rate experienced pain, using VAS once a day at 16 pm. At the six-month follow-up after surgery, the adolescents rated pain on the POM and they were interviewed (semi structured) about their overall experiences of undergoing scoliosis surgery and of recovery. Eighteen of the adolescents returned their diaries to the researcher. The YSR ratings from study III, as well as the VAS ratings, were analysed in order to conduct a dropout analysis and screen for differences and similarities between those who kept diaries and those who did not.

**Analysis:** In this study, Convergent Parallel Mixed Methods (Creswell, 2014) were used for the analysis. The diaries were analysed using qualitative content analysis (Elo & Kyngas, 2008; Graneheim & Lundman, 2004); they varied substantially according to length and comprehensiveness. Some of the diaries had rich text with many details and descriptions; others were written in an itemized style. The interviews were between eight to 55 minutes long.
They were transcribed verbatim, and analysed using qualitative content analysis.

Pain ratings were analysed using SPSS (IBM SPSS Data Editor Version 22) with descriptive statistics. Mean, minimum and maximum values were calculated; in cases where the skewness was too high median, min and max values were calculated for each adolescent and each day.

The YSR was used in the dropout analysis; mean-values were calculated for each domain according to the manual (Achenbach & Rescorla, 2001; Nilsson, 2010), and the two groups (those who kept diary and those who did not) were compared. Pain-ratings were correlated to YSR and between the two groups of those who kept a diary and those who did not. The quantitative and qualitative results were integrated and merged together using a Mixed Methods model.

**Ethical Considerations**

Interviewing adolescents about recalling and experiencing major surgery can be complicated. There is a risk of recalling traumatic memories and there are a number of concerns to keep in mind. The interviewer needs to reduce the risk of unintended harm, to protect the interviewee’s information, and to reduce the risk of exploitation (Dicicco-Bloom & Crabtree, 2006). In this study there was a readiness on the part of the interviewees for consultation with a psychologist. An interview can also be therapeutic, in the sense of giving word and voice to an experience (Morecroft, 2004) and thereby be positive. In a study, where bereaved siblings (young adults) were asked about their perception of participating in research, the majority of the participants found conducting such a study valuable, and they also perceived participation as a positive experience (Eilegard, Steineck, Nyberg, & Kreicbergs, 2013).

In **Study I**, the adolescents/young adults - and the parents/caregivers - received information regarding the study in a letter. This letter also contained information on how to get in contact with the researcher if further information was requested. In **Studies II, III** and **IV** the adolescents and parents received information both verbally and in writing. In all of these studies it was stated clearly that participation was voluntary, and that termination at any time was permitted. The data and information collected has been confidential and participants’ names and other personal
information were anonymised. All the data obtained was coded and anonymised to protect the participants from exploitation and harm.

**Ethical approval** was obtained from the Regional Ethical Review Board in Umeå, Sweden. Dnr: 08-056M, 2011-99-31M, 2013-37-32M

## Results

The results in this thesis indicate essential issues affecting the overall experience of undergoing scoliosis surgery.

**In Study I**, the main findings were that the adolescents experienced and self-reported severe pain and PONV, but overall satisfaction with the hospital stay was rated as good. The patients reported postoperative pain to a median of 7.3 (interquartile range 5.0 – 8.4); among the patients with impaired communication, the parent/caregiver proxies rated the pain to a median of 7.1 (IQR: 5.7 – 8.7). The pain lasted for five days (IQR: 2.7 – 7.0). Of those who reported severe pain (VAS 6 – 10) during the hospital stay (n=24), 60% indicated persistent pain or recent onset pain 5 – 12 months after surgery (Table 4).

**Table 4. Results of ratings in Study I.**

<table>
<thead>
<tr>
<th></th>
<th>VAS 0 – 10 Median (IQR)</th>
<th>Duration in days Median (IQR)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>7.3 (5.0 – 8.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proxy-rated pain</td>
<td>7.1 (5.7 – 8.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of pain</td>
<td>5.0 (2.7 – 7.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td>5.0 (1.1 – 7.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of nausea</td>
<td>3.0 (1.0 – 5.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of satisfaction</td>
<td>3.2 (1.5 – 5.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Persisting or new onset pain</td>
<td>24 (60)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

There were descriptions of ineffective pain management during activities, such as getting out of bed, and standing up beside the bed; the procedures for removing the chest tube were described as the most painful situations. The patients described experiences of pain that was unmanageable and unbearable.
“It felt like I was hung up on meat hooks”
“Sometimes it feels like a knife cutting into my back”

Parents/caregivers described their experiences of their child’s postoperative pain as difficult and stressful to handle. They described severe pain and a lot of crying.

“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.”

Postoperative nausea was rated to a median of 5.0 (IQR: 1.1 – 7.3) lasting for a median of 3 (IQR: 1.0 – 5.2) days. The parents/caregivers indicated that their children felt nauseous during their hospital-stay and described the pharmacological treatment as ineffective. Some of the patients described the nausea as worse than the pain, indicating that nausea was a major cause of discomfort.

“I felt nauseous the whole time at the hospital.”

Parents/caregivers were frustrated over the patients’ nausea.

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

Lack of satisfaction with hospital experience was rated median 3.2 (IQR: 1.5 – 5.2). The patients and their parents/caregivers found it difficult to maintain confidence in the nurses on several occasions. There were also descriptions of feeling out of control and feeling unable to control the situation.

“I felt that the staff did not listen to me.”
“I am not satisfied at all”

Parents felt helpless when they were unable to relieve their child of the suffering resulting from fear or pain.

“The worst thing was to watch one’s child in such severe pain and not being able to help!”
“A lot of waiting and not knowing what was happening, and the lack of information. Not being able to help. The PCA-pump that stopped functioning.”
In Study II, three main categories emerged from the interviews: emotional, physical and social aspects. Which subcategory was indicated the most differed throughout the perioperative period: preoperatively, emotional aspects were most salient; postoperatively, it was physical aspects and during recovery, social aspects were the most prominent (Table 5).

Table 5. Main- and subcategories from Study II.

<table>
<thead>
<tr>
<th>Emotional aspects</th>
<th>Physical aspects</th>
<th>Social aspects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear</td>
<td>Pain</td>
<td>Power</td>
</tr>
<tr>
<td>Nervousness</td>
<td>Nausea</td>
<td>Sports</td>
</tr>
<tr>
<td>Helplessness</td>
<td>Mobilization</td>
<td>Coaching and comfort</td>
</tr>
<tr>
<td>Nightmares</td>
<td>Urinary catheter</td>
<td>Friends</td>
</tr>
<tr>
<td></td>
<td>Appetite</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Different hip-levels</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Scars</td>
<td></td>
</tr>
</tbody>
</table>

Nervousness and fear were strong in the preoperative period. The adolescents narrated about feelings of fear about becoming paralyzed during surgery and not wanting to go through surgery because of it.

“*I was scared to death and I did not want to go through with it anymore.*”

“I was scared of being paralyzed and not being able to walk again, to sort of have to be bound to a wheelchair.”

In the acute postoperative phase, the factors that emerged in the interviews were pain, nausea, helplessness, mobilization, power, the urinary catheter, and coaching and comfort. The adolescents narrated of postoperative pain that was unbearably severe, both when lying in bed, as well as during mobilization and when the chest tube was removed. Nausea was described as a very strong discomfort that affected the ability to eat. A feeling of helplessness during the hospital stay, with difficulties in moving and managing personal hygiene, was described. A sense of powerlessness being unable make their own decisions was described; the urinary catheter was described as the worst experience!

“It was very painful, and nothing helped. They had to turn me over in bed.”

“I felt very nauseous and I don’t know if any medicine helped.”

“You felt so darned helpless.”
Coaching from the nurses and comfort from the parents and family members were described as important factors for rehabilitation and well-being. The adolescents longed for their friends, and wanted to go back to their sports activities. During the recovery period the most problematic factors were nightmares, scarring, different hip levels and problems regaining appetite. The nightmares they described, referred to the feelings of nervousness and fear they had before surgery and anaesthesia, but also about the postoperative pain.

“I wake up with panic.”
“The feeling keeps coming back to me.”

The scar was difficult to handle and to live with, affecting the choice of clothing and social life, as did different hip levels.

“I cannot visit a swimming pool or go to a beach because I don’t want anyone to see the ugly scar, and I don’t want anyone to touch it or ask about it.”

Lack of appetite and difficulties regaining appetite were described as a discomfort affecting mood and energy level. The recovery period included a period of not participating in sports activities, leading to a loss of social network and friends among sports participants, and team/club members.

“I lost contact with them during the hospital visit, and I still haven’t got them back. I miss them!”

During the interviews the adolescents had strong physical and emotional reactions such as crying, feeling nauseous, becoming pale, and shivering.

**In Study III**, the main findings were that levels of stress symptoms decreased after surgery. Anxiety/depression and internalizing behaviour were significantly higher before surgery than at the six-month follow up (Table 6).
Table 6. Differences in ratings of stress symptoms preoperatively and postoperatively.

<table>
<thead>
<tr>
<th></th>
<th>Preoperative values, Mean (SD)¹</th>
<th>Follow-up values, Mean (SD)</th>
<th>P-value²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anger³</td>
<td>3.00 (2.33)</td>
<td>2.25 (2.40)</td>
<td>0.07</td>
</tr>
<tr>
<td>Anxiety/depression⁴</td>
<td>5.39 (3.49)</td>
<td>4.11 (2.91)</td>
<td>0.05</td>
</tr>
<tr>
<td>Social problems⁴</td>
<td>2.79 (1.89)</td>
<td>2.43 (1.83)</td>
<td>0.28</td>
</tr>
<tr>
<td>Attention problems⁴</td>
<td>5.04 (3.10)</td>
<td>5.21 (3.09)</td>
<td>0.70</td>
</tr>
<tr>
<td>Internalizing⁴</td>
<td>12.18 (6.74)</td>
<td>9.82 (5.60)</td>
<td>0.05</td>
</tr>
</tbody>
</table>

¹SD= Standard Deviation  
²Paired samples t-test. P-value≤0.05 was considered significant  
³TSCC-A  
⁴YSR

Levels of preoperative stress symptoms - anger, social problems and attention problems - correlated significantly with postoperative levels of pain on day three, calculated with Simple linear regression analyses using the dependent variable pain on day three and the psychometric ratings as independent (Table 7).

Table 7. Simple linear regression analyses investigating correlations between the dependent variable “Pain day three” and preoperative stress symptoms as independent variables.

<table>
<thead>
<tr>
<th>Preoperative measurement of stress symptoms Independent variable ↓</th>
<th>Dependent variable: Pain day three (mean = 4.03) SD: 1.62</th>
<th>St. Beta coefficient</th>
<th>P-value²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anger³</td>
<td></td>
<td>0.42</td>
<td>0.02</td>
</tr>
<tr>
<td>Anxiety/depression⁴</td>
<td></td>
<td>0.32</td>
<td>0.10</td>
</tr>
<tr>
<td>Social problems⁴</td>
<td></td>
<td>0.48</td>
<td>0.01</td>
</tr>
<tr>
<td>Attention problems⁴</td>
<td></td>
<td>0.37</td>
<td>0.05</td>
</tr>
<tr>
<td>Internalizing⁴</td>
<td></td>
<td>0.31</td>
<td>0.11</td>
</tr>
</tbody>
</table>

¹SD: Standard Deviation  
²P-value≤0.05 was considered significant  
³TSCC-A  
⁴YSR
There were also significant correlations between levels of postoperative pain on day three and the stress symptoms of anxiety/depression, social problems and attention problems at the six-month follow-up (Table 8).

Table 8. Simple linear regression analyses investigating correlations between dependent variables “Stress symptoms” at six-month follow-up, and the independent variable “Postoperative pain on day three”.

<table>
<thead>
<tr>
<th>Six month follow-up. Dependent variables: Stress symptoms</th>
<th>Independent variable: Postop pain day 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>St. Beta coefficient</td>
</tr>
<tr>
<td>Anger(^2)</td>
<td>0.27</td>
</tr>
<tr>
<td>Anxiety(^2)</td>
<td>0.42</td>
</tr>
<tr>
<td>Social problems(^3)</td>
<td>0.54</td>
</tr>
<tr>
<td>Attention problems(^3)</td>
<td>0.41</td>
</tr>
<tr>
<td>Internalizing(^3)</td>
<td>0.22</td>
</tr>
</tbody>
</table>

\(^1\)P-value≤0.05 was considered significant

\(^2\)TSCC-A

\(^3\)YSR

In Study IV, the main findings were that adolescents undergoing scoliosis surgery occasionally experienced high levels of postoperative pain during the hospital stay, during the acute postoperative phase, and at home during the two first weeks of recovery. The self-reports of pain intensity varied substantially both between and within individuals over the period of time studied, though overall there was a declining trend of pain intensity from surgery through the two weeks of recovery at home (Figure 2).

Of the 37 participants, 18 submitted a diary and 19 did not. Out of the diary-writers, 16 participants submitted daily self-reports of pain and two did not (Table 9)
Table 9. Pain self-reports from participants and drop-outs during the trajectory of Study IV.

<table>
<thead>
<tr>
<th></th>
<th>First 14 days after hospital discharge</th>
<th>Six months after surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Included From start n= 37</td>
<td>Diaries n=18 VAS n=16 returned</td>
<td>Interviews n= 28</td>
</tr>
<tr>
<td>Pain median hospital (IQR)(^1)</td>
<td>3.76 (2.76-4.67)</td>
<td>3.77 (3.47-5.08)</td>
</tr>
<tr>
<td></td>
<td>3.10 (2.46-4.38)</td>
<td></td>
</tr>
<tr>
<td>Pain median home (IQR)</td>
<td>2.43 (1.35-3.46)</td>
<td>2.43 (1.35-3.46)</td>
</tr>
<tr>
<td>Pain median follow-up (IQR)</td>
<td>1.30 (0.00-3.20)</td>
<td>4.50 (3.12-5.89)</td>
</tr>
</tbody>
</table>

\(^1\)IQR Inter Quartile Range
Despite descriptions of hovering between suffering and control, perceiving physical suffering (e.g. pain, nausea, constipation, lack of energy), struggling not to be overwhelmed by stress, opioid abstinence, worries and fear, the adolescents were striving towards normality. Coping strategies and supportive factors emerged from the diaries and interviews. There were descriptions of supportive factors such as family, friends, hobbies and school. Further how the adolescents had strategies to cope with perceived difficulties was described. Another finding was that those who did not keep a diary had higher levels of stress symptoms and levels of pain at the follow-up. Protective factors emerging from those who kept a diary seemed to be family, friends, and sports and leisure activities.

The most common description of pain both before surgery and at the six-month follow-up were pressing, grinding and cutting. Locations were the lumbar region and thoracic regions, and over the shoulders. In some cases there was more than one description for each adolescent. The quality of pain could differ during the same day, manifesting one way at rest and another during physical activity. There were also descriptions of new-onset pain.
and/or neurological/physical sensations, such as tingling in the foot or numbness in the skin, at the six-month follow-up (Table 10).

Table 10. Self-reports on POM before surgery and at the six-month follow-up. Measurements are presented in numbers of mentioned qualities of pain. Each adolescent can have more than one self-reported quality of pain.

<table>
<thead>
<tr>
<th></th>
<th>Preoperative n=37</th>
<th>Six-month follow-up n=28</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of marked pain qualities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grinding</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Burning</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Cutting</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Throbbing</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Pricking</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Pressing</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>Others</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>New onset pain</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>Tingling/numbness</td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>
Before these studies we knew that undergoing scoliosis surgery was related to:

- Anxiety preoperatively.
- High levels of pain after surgery.
- Nausea postoperatively.

And that:

- Roy’s Adaption model is a multi-dimensional concept for nursing care, and in research aiming at widen perspectives.

Theoretical level

Empirical level

Quantitative findings were:

- Substantial variations in levels of self-reported pain both individual and between points of time.
- Levels of stress were assessed higher pre- than postoperatively.
- Levels of preoperative stress correlated significantly with levels of postoperative pain.
- Occasionally very high levels of postoperative pain, but also pain during recovery.
- High levels of PONV.
- Postoperative pain correlated significantly with levels of postoperative stress.
- Persistent and/or new onset pain after surgery.

Qualitative findings were descriptions of:

- Experienced stress, nervousness and fear before surgery.
- Postoperative pain.
- PONV, loss of appetite, constipation and urinary retention postoperatively.
- Helplessness and lack of control at the hospital postoperatively.
- Experienced lack of confidence in nurses.
- Difficulties regarding the scar, social contacts, friends and school.
- Coping strategies and how to manage difficulties both preoperative, postoperative and during recovery.
- Despite severe difficulties, a strive towards normality.
With the new knowledge we can:

Understand more of the complexity of the experiences of going through scoliosis surgery.

Develop intervention studies aiming at educate nurses in techniques for support of coping strategies aiming at promote adaption.

Improve pain management, follow-up and backing the adolescents striving towards normality, minimize suffering and promote the feeling of being in control.

Target interventions aiming at improve perioperative nursing care.

Integration of findings:

The described experiences together with self-reported levels of stress, pain and nausea broadens the scope and increases the comprehensiveness of adolescents' experiences.

The descriptions of strategies and supportive factors, such as positive thinking, deep breathing, setting a reachable goal and also distraction using hobbies and being with friends increases the understanding of the trajectory of pain and how to intervene.

The quantitative self-reports together with the qualitative descriptions gives nurses new understanding of preoperative stress which can give nurses tools to intervene and prevent difficulties.

Roy’s multi-dimensional perspective in the adaption model is of importance in perioperative care. Nurses need to promote adaption and support coping processes. In research, a mix of quantitative and qualitative studies contributes to facilitate new knowledge aiming at optimize perioperative care including the four adaptive modes.

Figure 3. An illustration of what was known before these studies, and what the quantitative, together with the qualitative findings contributes with in new understanding regarding scoliosis surgery.
Summary and integration of findings

In short, the main findings from these studies are that the adolescents undergoing scoliosis surgery described suboptimal perioperative care with a hovering between suffering and control, and a striving towards normality. The experiences described, together with self-reported levels of stress, pain and nausea broadens the scope and increases the comprehensiveness of adolescents’ perceptions and experiences of undergoing scoliosis surgery.

The qualitative and quantitative results mainly converge. The descriptions of supportive factors and coping strategies increase the understanding of the trajectory of pain.

The quantitative self-reports of stress, together with the qualitative descriptions, gives a new understanding of perioperative stress. The qualitative descriptions of the quantitative self-reports increases the comprehensiveness of the self-reports. My belief is that from all these descriptions, we can better understand how to prevent difficulties and support adolescent patients in their recovery. Roy’s adaption model can be a guide to data collection by using the four modes, and a mix of methods can facilitate adding new knowledge to a broad perspective of optimizing perioperative care.
Discussion

The overall aim in this thesis was to explore adolescents’ experiences of undergoing scoliosis surgery; their experiences and self-reports of pain and the psychological consequences. Both qualitative and quantitative methods were used with the intention of achieving a deeper understanding, broadening the perspectives and the scope of adolescents’ experiences, and giving us the ability to spearhead perioperative care interventions and to improve perioperative care.

The results from the four studies are merged together and shown in a figure (Figure 3), inspired by Creswell (2014) and his description of Parallel Convergent Mixed Methods (Creswell, 2014). The quantitative results were shown in most cases to be converging with the qualitative results; furthermore the qualitative results make it possible to interpret the quantitative results with descriptions of the experiences. Divergent results will be discussed at the end of the discussion section. With descriptions of how it feels and what happens when, for example, an adolescent experience severe pain - and if there are supportive factors - we can better understand how to intervene. In this section I will discuss the results of the studies from a Mixed Methods perspective. As part of the integration of qualitative and quantitative findings the results will be mirrored and summarized in the light of Roy’s four adaptation modes.

Convergent findings

Individual variations in pain

Pain is a highly subjective and individual experience (IASP, 1979). Undertreated pain can lead to traumatic experiences that affect the person for a long time (Page, Stinson, Campbell, Isaac, & Katz, 2012). It is important to keep in mind that every individual person shows differences in nociception and perception, and they also vary in response to pharmacological pain treatment and the adverse effects of treatment (Sommer et al., 2010). The quantitative results converged with the qualitative descriptions of experienced pain. The participants in these studies self-reported pain at various levels during the hospital stay; occasionally, the pain was severe. The quantitative self-reports of pain are salient with a substantial variation in rated pain, particularly during the hospital stay. There is also a substantial variation in descriptions of
experienced pain in the diaries, the free-text answers and the interviews. There are descriptions of lack of confidence in the nurses postoperatively, of nurses’ shortcomings as regards medical technical skills, and even failures in pharmacological treatment and pain management. Failures in pain treatment - occlusion in intravenous catheters, epidural failures, patient controlled analgesia (PCA) pumps stopping and pain in unexpected locations, for example - are some of the experiences described that were linked to breakthrough pain and severe pain. Failures in pain management during the acute postoperative phase is, unfortunately not rare (Walker, 2015). There are guidelines available for pain management, but there seem to be discrepancies between these guidelines and nursing practice in perioperative nursing care (Dihle, Bjolseth, & Helseth, 2006). Nurses cannot expect the trajectory of pain to descend the same way - and by itself - in every adolescent. Pain is known to be severe during the first days and needs to be measured and treated; the treatment has to be evaluated and adolescents must to be listened to.

**Stress symptoms before surgery**

In the quantitative findings stress symptoms were rated higher before surgery than six months after surgery. In the qualitative results, the adolescents’ reported in the interviews, the surveys and the questionnaires that they experienced preoperative fear, nervousness and stress. They were concerned about postoperative pain, about failures in the surgery such as the risk of being paralyzed, and also about school. As a nurse there is a risk of not noticing this nervousness and preoperative stress, since adolescent patients tend not to express their feelings of nervousness (Podeszwa, Richard, Nguyen, De La Rocha, & Shapiro, 2015). Prior to surgery, the adolescent patients and the family members present are informed about the procedures ahead, including estimated surgical outcomes, benefits and risks. One study by Rhodes and colleagues (Rhodes et al., 2015), aimed at investigating the impact of preoperative anxiety, tested an intervention of information and orientation prior to surgery. This study indicated that the intervention group perceived a higher level of both patient and parental satisfaction with perioperative hospital care. The day before surgery is a busy one with information, examinations and tests (Gambrall, 2007). Wisselo and colleagues (Wisselo, Stuart, & Muris, 2004) studied the impact of preoperative information on parents of children for whom surgery was planned. They found that individual differences in understanding and coping with information affect whether information increases or decreases anxiety in adolescents and their parents. The question is whether or not the standardized information may sometimes aggravate rather than allay adolescents’ fear and nervousness.
In these four studies, there were various descriptions of experiences prior to the induction of anaesthesia. Severe anxiety was described, but so also were feelings of being calm and being taken care of. Anxiety during the induction of anaesthesia can be reduced through parental presence (Astuto et al., 2006). It is of importance that the parents can be calm and supportive of the child, since LaMontagne and colleagues (Lamontagne, Hepworth, Salisbury, & Riley, 2003) showed that parental anxiety had a negative impact on the child’s level of stress and anxiety. In the interviews and diaries in Study IV the adolescents mentioned trying not to worry their parents, because they knew - or assumed - that a worried parent could not be supportive. This is also shown in a study by Kain and colleagues (Kain, Caldwell-Andrews, Maranets, Nelson, & Mayes, 2006): highly anxious parents cannot be supportive of their children prior to surgery, but instead transmit their anxiety to the child.

The parents in Study I reported that although they wanted to help and support their child, they didn’t know how. If both adolescents and parents are prepared before surgery and the parents are given the tools to alleviate anxiety, pain and PONV, they might feel more secure, with a sense of coherence and control during the hospital stay (Leikkola, Helminen, Paavilainen, & Astedt-Kurki, 2014). Lack of control is described in Study I (both adolescents and parents) and in Study II (the adolescents) as an important factor in dissatisfaction during the hospital stay. By knowing what to do and how to take control of a situation, a feeling of control and comfort can occur (Williams, Golding, Phillips, & Towell, 2004). Coping strategies are individual and can differ from person to person. Coping is regarded as an ongoing dynamic process in response to stressful events; it can be problem- or emotion-focused coping and engagement - disengagement coping (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001). According to Roy, acquired coping processes are developed through strategies such as learning. In cognator coping the subsystem processes changes through cognitive and emotional channels (Fawcett, 2013). The ability to learn and process information plays an important role; this means that there is an ability to learn and develop strategies for coping. Prior to major surgery there are many things that could be perceived as stressful, especially for the adolescent patient.
Preoperative stress and postoperative pain correlates

Quantitative ratings of preoperative stress symptoms varied among the participants in Study III; there were statistically significant correlations between levels of stress symptoms and levels of postoperative pain. There were also qualitative descriptions of preoperative nervousness and fear regarding postoperative pain in the questionnaires, the diaries and the interviews. In a review, Ip and colleagues (Ip, Abrishami, Peng, Wong, & Chung, 2009) studied predictors for postoperative pain; they showed that preoperative anxiety, preoperative pain and orthopaedic major surgery were predictors for postoperative pain.

In Study IV, the adolescents described how they were hovering between suffering and control, and they perceived physical suffering from the postoperative pain. They were struggling, however, not to be overwhelmed by difficulties such as pain and fear. Descriptions of using coping techniques such as deep breathing and positive thinking emerged from the interviews and diaries. Adolescent patients need support in coping with preoperative nervousness and stress in addition to postoperative pain. In focus group interviews the need for information and support was studied among adolescents with AIS (Macculloch et al., 2009). The adolescents wanted the information to focus, (in order of importance), on recovery at home, recovery in hospital, post-surgical appearance, the emotional impact of surgery and coping, intrusion of surgery and recovery, daily activities, the impact of surgery on school, peer relationships and other social interactions, decision-making about surgery, being in the operating room and future worries (Macculloch et al., 2009). There is also a need to support the parents with the aim of providing them with information about what to expect and how they can support their child. In one study, parents were interviewed regarding their experiences of supporting their adolescent children during surgery. Findings suggested that parents need appropriate information and support from health professionals throughout their experience in order to help minimize uncertainty and distress, and that pain management is a major source of stress for parents (Bull & Grogan, 2010). Papanastassiou and colleagues (Papanastassiou, Anderson, Barber, Conover, & Castellvi, 2011) studied the impact of preoperative education and its impact on pain control and satisfaction with care. They found that preoperative education had a positive effect on both patients’ perceived pain management and satisfaction with care. Anxiety among adolescents before surgery, coping strategies learned, cognitive-behavioural interventions for pain relief after spinal surgery, and coping processes during recovery were studied by La Montagne et al (LaMontagne, Hepworth, Cohen, & Salisbury, 2003; LaMontagne, Hepworth, Salisbury, & Cohen, 2003; LaMontagne, Hepworth, Cohen, &
Salisbury, 2004b; L. L. Lamontagne et al., 2003) their main findings were that concrete information and coping instructions pre- and postoperatively had a positive impact on postoperative pain and anxiety for the adolescent patient.

**Occasional very high levels of postoperative pain, and pain during recovery**

The quantitative self-reported pain on the VAS was occasionally very high; in these studies many of the adolescent patients described experiences of severe postoperative pain. In retrospect they could recall how painful it was, and some of the patients had nightmares about those memories. In some cases the patients in these studies experienced being without analgesia, for example when the epidural catheter stopped functioning; this was described as *unmanageable, unbearable, feeling as if being hung up on meathooks*. Parents described it with phrases such as “*pure fear in her eyes*”.

In elective surgery the possibility of making individual plans for postoperative pain management exists. These plans should be carefully thought through and discussed with the family - an approach advocated by the American Academy of Paediatrics, together with the American Pain Society, that could be implemented in spine clinics in Sweden (American Medical Association, 2013). It is also of importance that the nurses are familiar with the plan, have the education and skills to provide pharmacological pain treatment, and are familiar with the medical technical equipment. A recent study by Ewertsson and colleagues (Ewertsson, Gustafsson, Blomberg, Holmstrom, & Allvin, 2015) evaluated the technical skill of nurses. They found that nurses rated themselves highly on medical technical skills; they also, however, considered themselves in need of continued practical training, which was limited. One finding was also that over 35% of the nurses did not use existing local or general guidelines when performing unfamiliar technical skills or handling unfamiliar medical devices.

Breakthrough pain was described as a major discomfort, severe and difficult to manage for the adolescent. It occurred, for example when the analgesia abruptly stopped functioning (ED-failure, IV failure) or during mobilization, physiotherapy and breathing exercises. In *Studies I, II and IV* this was described in the free text, the interviews and the diaries but it was also rated with the VAS. In the qualitative descriptions, the adolescents provided a picture of how it was perceived and how they were trying to manage the severe pain. From those descriptions we can learn which parameters are the most important for the adolescent patient after AIS surgery (Chow, Quine, &
Nurses have an important role of promoting coping. Adapt to the situation of experiencing severe pain is a challenge, and through adolescents’ descriptions of coping strategies nurses can learn how to promote this in the future. Adolescents described not only perceived pain but also coping strategies and supporting factors for alleviating the pain. Nurses must be active in initiating regular patient self-reports of pain, at the same time asking about the location and the quality of the pain. Self-reported pain is the gold standard; proxy ratings from a parent seems to be the best alternative among verbal communicative impaired adolescents, since the correlation between proxy (parent) and adolescent correlates most (Khin Hla et al., 2014). Nurses’ rating of children’s and adolescents’ pain levels seem to correlate poorly with adolescents’ self-reported pain and parent proxy ratings; nurses tend to under-estimate the amount of pain patients experience (Yildirim et al., 2015), and if pain is not self-reported there is a risk of underestimation. Nurses must listen to the patient and parents, and be supportive and honest.

Reported nausea, vomiting and constipation

In Study I, the patients self-reported levels of PONV using the VAS. The quantitative ratings were convergent with the qualitative descriptions by both the patients and the by parents or caregivers in this study, and in the interviews and the diaries in Studies II and IV. The incidence of PONV is higher among adolescents than among adults (Pergolizzi, Raffa, & Taylor, 2011). The predictors and risk factors for PONV are known, (Apfel et al., 2012), and in scoliosis surgery there are many of these factors to take into account. During the hospital stay the adolescents reported that they felt nauseous, that they vomited and that they lost their appetite. Nausea caused strong discomfort and despair. There were reports of not knowing whether antiemetic drugs had been administered, and of being given antiemetic drugs but without effect. Pharmacological postoperative pain management after scoliosis surgery often consists of various types of opioids, which are known to cause nausea and often vomiting. Assessment of nausea is as important in perioperative care. Nausea is a psychologic and physical mode, and nurses have to intervene to relieve the suffering, since the ability to adapt to and cope with nausea and vomiting in many cases are beyond the adolescents control (Fawcett, 2013; Roy, 2009) is not unusual that PONV causes prolonged hospital stays (Edler et al., 2007) and that PONV is frequently undertreated (Hohne, 2014). PONV is sometimes described as a worse distress than pain. Guidelines from 2014 suggest that prior to surgery, patients’ risk for PONV should be assessed and prophylactic antiemetic intervention induced (Gan et al., 2014).
Constipation was described in the interviews, the surveys and the diaries. It is not unusual for constipation to occur postoperatively (Holte & Kehlet, 2000); the reasons for constipation after scoliosis surgery are multifactorial; it can be owing to pharmacological reasons because of the opioids used in pain management, and furthermore to the surgery itself. During the hospital stay, constipated patients tend to receive more postoperative opioids than non-constipated patients (Stienen et al., 2014). High levels of pain require pain management - often consisting of opioids - that leads to an increased risk of constipation; constipation then leads to increased postsurgical pain and decreased mobility which in turn decreases bowel function (Stienen et al., 2014). Low levels of energy and lack of appetite can also be a reason for being constipated (Brodner et al., 2001). Constipation can be prevented, however, by using pharmacological and/or non-pharmacological treatment (Miedema & Johnson, 2003; Poulsen, Brock, Olesen, Nilsson, & Drewes, 2014) and by providing proper nutrition so as to keep energy levels adequate. Preventing constipation can in turn prevent nausea (Holte & Kehlet, 2000) and make the overall perioperative experience more positive.

In these studies the included participants were treated according to different local guidelines for preoperative and postoperative nutrition. Corrective surgery for AIS is a major procedure, sometimes with large amounts of blood loss (Shapiro & Sethna, 2004; Yu, Xiao, Wang, & Huang, 2013), and there is a series of reactions - including release of stress hormones and inflammatory mediators - that have an impact on body metabolism. Adolescents require substantial amounts of energy peri- and postoperatively to be able to cope with wound healing, becoming mobile, and preventing infections, PONV and constipation (Braga et al., 2009). Nutritional status has an impact on bowel-function, nausea and constipation as well as on both short- and long-term recovery after surgery (Brodner et al., 2001). Many of the participants in these studies mentioned a loss of appetite and that they were unable to eat; this was associated with a large amount of dissatisfaction. One result mentioned in many of the interviews was that the pleasure of enjoying food had temporarily vanished.

Many of those who kept a diary described experiences of nausea and constipation during the first two weeks of recovery. Some of the adolescents had to contact primary healthcare - and even the emergency wards - at the local hospitals to get help in solving issues with constipation at home. The nausea during the first two weeks at home in some cases caused a lack of appetite, which in turn caused a lack of energy and delayed recovery.
Postoperative pain associated with stress during recovery

The quantitative self-reported levels of postoperative pain correlated with levels of stress symptoms six months after surgery. In the interviews, the participants described the hospital stay as something they did not want to go through again, and reported that the pain was difficult to cope with. Severe postoperative pain is a risk factor for traumatizing and persistent pain. It is of great importance that acute postoperative pain is adequately treated (Borgeat & Blumenthal, 2008). Pain itself can cause medical traumatic stress and be debilitating for a long time (Marsac, Kassam-Adams, Delahanty, Widaman, & Barakat, 2014). In the qualitative findings there were descriptions of difficulties associated with postoperative pain. The post-surgical scar was one such problem. After scoliosis surgery there is a scar; the length and location depends on the type of surgical technique performed. ASF leaves a scar on the side; PSF leaves a scar near the middle of the back from the upper scoliotic level downwards; when these two techniques are combined, there are two long scars. There can also be smaller scars from the thoracic chest tube and central intravenous catheter. In the beginning, the scars are red and swollen, but they lighten with time. The self-concept as regards body-image and perception of oneself can change after surgery. Views on important outcome measures seem to differ between the adolescent, the parents, and the surgeon. One important goal of surgery is to improve appearance. There seem to be discrepancies, however, between adolescents’ satisfaction and perception of postoperative appearance and that of their parents: the adolescents tend to be less satisfied (Smith et al., 2006). Even if the adolescents were given information about the postoperative scar prior to surgery, some had difficulties accepting it after the surgery and felt ashamed about it. They did not want to think about the scar - thereby remembering the postoperative period – or to think about the pain they experienced, and they did not want any comments or questions about the scar. They had a sense of their bodies being changed; some of the adolescents described that they did not want to have clothes that exposed the scar, change clothes in a dressing room with others, or be on a beach or in a swimming pool where there was a risk of others seeing the scar. Even being hugged was described as shameful, because the person hugging could feel the scar. The scar reminded them of the severe postoperative pain and their experiences during the hospital stay.

Friends and family members are important as regards comfort and support for adolescents: family members during the initial period of recovery, and friends later on during recovery when it was time to go back to school (Allvin, Ehnfors, Rawal, & Idvall, 2008). School was described as something they looked forward to coming back to, but schoolwork was also described as
a major stressor (Hjern, Alfven, & Ostberg, 2008). School stressors such as schoolwork pressure have been shown to be a risk factor for pain, and might in this case have a negative effect on recovery and pain rehabilitation (Hjern et al., 2008). Hobbies and sports activities were described as supportive factors. A sense of coherence is of importance, and in the social network, social integrity. Hobbies such as scrapbooking and painting helped to distract from the pain and focus on something else than the difficult recovery. Sports activities helped, by providing a goal to fight for and struggle towards. Physical activities have been shown to have an effect on postoperative pain and the consumption of analgesics (Sandhu & Sandhu, 2015). Going to church, and singing in a choir also had positive effects. It could be the activity itself, or the fact that it puts the person in a context different from the one at home during recovery: a healthy environment not associated with the surgery at all.

**Persistent and/or new onset pain**

In Study I, both patients and parents or caregivers reported persistent or new onset pain. Pain was self-reported, proxy-rated, and described in the free text. At the six-month follow-up in Study IV the adolescents self-reported pain on the VAS and the POM. The ratings showed that out of 28 adolescents who completed the study, 12 had persistent and/or new onset pain. In the interviews, the adolescents described problems with persistent pain or new onset pain located in the lumbar region, thoracic region and over the shoulders. There were also descriptions of other physical sensations such as tingling in a foot, burning sensations in the skin or numbness. Persistent or new onset pain is not a rare problem after scoliosis surgery (Hawes & O’Brien, 2008). In a Swedish two-year follow-up study after scoliosis surgery, 57% of the adolescents with idiopathic scoliosis reported pain (Ersberg & Gerdhem, 2013). Predictors of persistent pain are found to be high levels of postoperative pain, pain catastrophizing, amount of tissue damage and female gender (Kehlet & Rathmell, 2010; van Gulik et al., 2011).

At home after discharge from the hospital, the adolescents are dependent on parents or caregivers and family members for coaching and additional comfort in order to get daily life and routines to function. They are not fully mobilized and often need help with going to the lavatory, personal hygiene, indoor- and outdoor walks, and pain relief (Allvin et al., 2008). The role function mode as regards being in adolescence and being in the emancipation process, and at the same time being dependent on others to manage daily routines was described as difficult. Parents and caregivers need information about what to expect during the first two weeks at home and how to support their child (Leikkola et al., 2014). Prior to discharge, it is
important to emphasize the need for support at home during recovery. Nurses need to inform both the adolescent and the parents as regards expected needs and what to expect (Allvin et al., 2007; Allvin et al., 2008). In Study I the parents and caregivers mentioned feelings of helplessness and not knowing how to help their child. In the diaries and the interviews some type of inner strength emerged from the adolescents’ narratives. Despite difficulties they decided to take control and set goals to make progress. There seems to be an association between levels of preoperative stress, levels of postoperative pain, levels of postoperative stress and the ability to cope with difficulties during recovery.

**Divergent findings**

**Traumatic memories**

In the quantitative self-reports there were no indications of traumatization. Measurement was conducted using TSCC-A, a trauma-specified questionnaire, and YSR. The K-SADS structured interview were also used, but those instruments did not indicate any traumatization caused by surgery in the self-reports from the adolescents. In the qualitative studies using free-text answers, diaries and semi-structured interviews the adolescents talked about traumatic memories. Especially in Studies I and II there were descriptions of traumatic memories, nightmares and anxiety, concerning preoperative fear, postoperative pain and feelings of helplessness and being out of control. There were also descriptions of social difficulties after six months’ recovery: difficulties regarding sports activities, social networks and friends, which set the interdependence mode at play (Roy, 1981) as regards their support systems; friends and team members. The loss of relations and interactions in their social network was described as traumatic.

Medical traumatic stress can occur after experienced pain during the hospital stay, but can also be caused by other traumatic experiences such as separation from parents and loss of control (Kazak et al., 2006). The feeling of being in control is an important issue, especially for the adolescent patient (L. LaMontagne, J. T. Hepworth, M. H. Salisbury, et al., 2003). During the postoperative period at hospital the adolescents were dependent on nurses and allied personnel, family members, and others. Losing control and not being in charge of one’s own body and bodily functions are factors that have been described in these present studies. Not being able to manage getting out of bed, getting dressed, going to the lavatory, or personal hygiene can be difficult for any patient, especially for adolescents (Allvin et al., 2008). A sense of controllability and perceived control affects well-being in general, but also the ability to cope with pain. For pain management, a PCA is
described in these studies as something positive in the sense of having control (Grass, 2005), additionally, being able to take part in decisions concerning daily routines at the hospital, such as time to go to the lavatory, getting out of bed and exercising with the physiotherapist.

**Summary of results in relation to Roy’s Adaptation Model (RAM)**

As part of the integration of qualitative and quantitative findings the results will be mirrored and summarized in the light of Roy’s four adaptation modes.

*The physiologic-physical mode* includes essential physical bodily functions and senses (Roy, 1981). This includes some important issues regarding perioperative experiences during major surgery, such as pain, nausea, constipation, the ability to eat and physical recovery after surgery. The adolescents experienced severe pain after surgery and pain assessment was suboptimal during the acute postoperative phase. Support of pain management at home during recovery, was insufficient. Persistent and/or new onset pain and postoperative nausea and vomiting caused distress among the adolescents. Nausea caused a lack of appetite, lack of energy, and fatigue. The adolescents suffered from constipation both during the hospital stay and after discharge.

*The self-concept mode*, according to Roy, is the individual person’s perception of themselves, such as body image (Roy, 1981). It is a challenge for an adolescent to undergo scoliosis surgery and to adapt to a changed body. Having a scar and adapting to it was perceived as difficult, not only as regards the scar itself, but also that the scar reminded them of the severe pain and anxiety during the acute postoperative phase.

*Role function mode* is referring to roles in society and social integrity (Roy, 1981). Adolescence is a time of constant change and adaptation to friends, family and self. In the postoperative phase, the adolescents were dependent on nurses to manage daily hospital routines; during the recovery period, the adolescents become dependent on parents, which can be difficult in the emancipation process.

*Interdependence mode* is described as relationships, relational integrity, and giving and receiving love, respect and value (Roy, 1981). Here adolescents reported not being listened to and not having confidence in nurses. In these studies changes and loss of social network is described as a severe drawback.
Losing contact with friends and not being able to continue with sports activities were difficulties the adolescents had to contend with.

Stress symptoms such as anxiety activate all these modes (Fawcett, 2013; Roy, 1976). Acquired coping processes are developed through strategies such as learning. The regulator coping subsystem is an innate system that responds not only to stimuli such as light, sound, and smells, but pain as well. This system does not entail a conscious act, it is automatically responding to stimuli through the nervous system (Fawcett, 2013). The cognator coping subsystem processes changes through cognitive and emotional channels. In these studies, stress symptoms and anxiety are prominent during the perioperative process and the adolescents used different coping strategies to manage stress. The ability to learn and process information plays an important role in the cognator coping subsystem; this means that there is an ability to learn and develop strategies for coping (Fawcett, 2013; Roy, 1981).

**Discussion of Methods**

These studies had some limitations that must be acknowledged. The most prominent limitation was the relatively small sample size for the quantitative parts of the studies. On the other hand data collection persisted over a long period of time and the data came from four spinal clinics, thereby reaching the majority of adolescents undergoing this type of surgery, which suggests that there is an generalizability in the data and results (Tashakkori, 2010). In the following section I will review other limitations I have identified.

In this thesis I used a variety of research methods both applied separately and mixed. The qualitative results together with the quantitative results are supposed to add different perspectives and strengths to the understanding of a phenomenon (Morse & Cheek, 2015), and therefore to expand and broaden the scope of the results. The mixed methods approach is used in healthcare quality research, in order to grasp more of the complex picture of healthcare quality and how to improve it (Hearld, Alexander, Fraser, & Jiang, 2008). When conducting such studies, however, appropriate qualitative and quantitative methods need to be implemented.

According to Creswell (Creswell, 2014) the core assumption of Mixed Methods research design is that the combination of quantitative and qualitative approaches provides a more complete understanding than either could achieve separately. In Convergent Parallel Mixed Methods Design, the researcher collects quantitative and qualitative data and then analyses the
data separately. The results of the two datasets are integrated and the integration can be visualized with a figure. The integration of the datasets is then examined for convergent and divergent findings.

In Study I and Study IV both qualitative and quantitative data was used in the analysis. Each dataset was still analysed separately; it is only in the discussion in Study IV that they were linked to each other to increase understanding. Bringing together data representing information from two different perspectives of knowledge was not considered possible but in the theorization of the results both perspectives have been mixed (Johnson, Onwuegbuzie, & Turner, 2007). I think that by comparing the results of the two types of data, the interviews, the diaries and the pain-ratings, a deeper understanding is gained regarding these young people’s experiences of undergoing surgery and on conclusions about shortcomings in care during the perioperative period.

Interviews were used in two of the studies. The number of interviews was relatively small in Study II. Fifteen adolescents were invited to participate in the study, but only six of them consented to participate. One of the reasons for decline to participate was never wanting to think about the surgery again because it was the worst experience ever. In the interviews there were also stories about trauma-like experiences though there were also stories about the surgery as something they now had left behind. The size of the sample depends on the nature of the phenomenon and the complexity to be captured as well as the quality of the interviews (Morse, 2015). In this case, the interview texts yielded a broad and deep range of descriptions of the topic, and the first author had an extensive experience of interviewing adolescents, giving them time to get to know her before the interview started. The interviews in Study IV varied in richness, as did the text in the diaries, though the sample was larger. During the interviews and in the diaries there were many similar issues that were spontaneously brought up by the participants forming the results. This lends strength and validity to the qualitative results in the studies (Creswell, 2014).

For collecting qualitative data both diaries and individual interviews were used as complements to each other. The quality of the information from the diaries varied. The paper diaries in this study might be a limitation as previous studies indicate that electronic diaries yield higher compliance, especially among adolescents (Stone, Shiffman, Schwartz, Broderick, & Hufford, 2003). On the other hand Stinson and colleagues (Stinson et al., 2013) pointed out some drawbacks regarding electronic diaries, in terms of technical issues.
The dropout analysis in **Study IV** indicated that there were differences among the adolescents, as regards levels of stress symptoms and internalizing symptoms, between those who kept a diary and those who did not; the latter group scored higher levels of stress, internalizing symptoms and pain. Anxiety and stress among adolescents before major surgery has been described in earlier studies (Fortier et al., 2011; Kain, Mayes, Caldwell-Andrews, Karas, & McClain, 2006). Fortier and colleagues showed in her study that some predictors such as preexisting anxiety and depression, somatizing problems and frightening earlier events could be addressed. Another finding from this study was that those who did not keep a diary had higher levels of pain after surgery with the exception of the first postoperative day, and a significant higher level of pain at the six-month follow-up. The drop-out analysis indicates that there is a risk of not noticing those adolescents since they seem to internalize their difficulties, and not express them in words (e.g. diaries).

The VAS is a frequently used scale with good validity indicated by quantitatively appropriate changes in scores that move in parallel with corresponding qualitative, verbal descriptors of changes over time. (Boogaerts, Vanacker, Seidel, Albert, & Bardiau, 2000; Gallagher, Bijur, Latimer, & Silver, 2002). VAS-ratings were used to estimate pain, nausea and global satisfaction with the hospital experience in **Study I**, and to estimate pain in **Studies III** and **IV**. The VAS was included in the questionnaire because the patients had used it during their hospitalization and were consequently familiar with the scale. One alternative to the VAS could have been the Numeric Rating Scale (NRS), recommended for adolescents because it might be easier to use (Page, Katz, et al., 2012; von Baeyer et al., 2009).

There were missing postoperative pain ratings during the hospital stay; the Last observation carried forward (LOCF) was used for adjustment of single missing values in the analysis. Methods for adjusting missing values might ignore the trajectory and changes of pain for the measurements adjusted (Streiner & Geddes, 2001). There was still data missing despite using this method, however, since not more than one missing value at a time was adjusted for. Nonetheless, I consider this method for adjustment to be accurate for this study and sample.

The study protocol in **Study IV** was designed with the intention that the nurses in the ward should measure the patients’ pain every four hours during the five first postoperative days at the hospital. Unfortunately, this resulted in poor compliance with the protocol. For good quality research Morse
(Morse, 2015) states that prolonged engagement and persistent observation are necessary to produce thick, rich and valid data. Had it been possible to have special designated research assistants performing the data collection in the wards, I could have obtained a more complete dataset. Still, I estimate that the lack of VAS values has not influenced the results. For the sampling of scales and interviews, the same person conducted the entire data sampling herself.

The preoperative ratings took place on the day of admission, as the patients in the study had preoperative information about what to expect during and after the hospital visit. The preoperative measurement may therefore have been influenced by that information and by preoperative stress, which can occur prior to surgery - possibly starting even on the date the surgery is first scheduled.

This thesis is based on two samples of adolescents who have undergone scoliosis surgery. In the first sample (Studies I and II) surgery was performed between 2004 and 2007 at one spine centre and in the second sample (Studies III and IV) between 2012 and 2013 at four different spine centres. The intent in both samples was to include as many participants as possible who met the inclusion criteria for the studies, and were subjected to surgery during the period in question. Although this objective was not fully reached, I consider the samples to be representative. The techniques for surgery and the pain management methods varied between samples and between spine centres. Pain management has changed over the years, and it is possible that the more salient narratives on traumatic memories in the interviews from the first sample as compared to the second sample depend on more systematic overall pain management (Devin & McGirt, 2015) in the later sample. Additionally, the participants in the first sample had to recall their pain, nausea, global satisfaction and what to say in the interviews up to two years after the surgery. Recall of traumatic and painful experiences in adolescents is sparsely researched, though in younger children it is known that strong memories of pain and anxiety influence their subsequent experiences of medical care (Noel, Chambers, McGrath, Klein, & Stewart, 2012). It has also been shown that children who experienced a high degree of distress during a medical procedure exaggerate the negative experiences afterwards; two weeks after surgery, they remember the painful procedure as being scarier than they did immediately after the actual event. Memories of pain after surgery in children is influenced by parents' distress and catastrophic thinking (Noel, Rabbitts, Tai, & Palermo, 2015). Adolescents' explicit memories of pain might be more influenced by other developmental factors than parent-child interaction such as knowledge of pain, peers and autonomy (Noel, Palermo, Chambers, Taddio, & Hermann, 2015).
Ethical discussion

When involving adolescents in research there are significant issues to consider (Mack, Giarelli, & Bernhardt, 2009). In these studies the adolescents and their parents had given their informed consent to participate, and it was clearly emphasized that participation was voluntary, and that termination at any time was permitted. The experiences of participants with impaired verbal communication in Study I were mediated through a parent or caregiver. Pain was proxy-rated by a parent or caregiver who also mediated the free-text answers. There is always a risk of misinterpretation in proxy ratings (Zhou, Roberts, & Horgan, 2008); if the participants with verbal communication impairment had not been included, however, their experiences would not have been shown at all.

In some cases traumatic memories came up during interviews, especially in Study II. There were strong reactions, emotions and affects during the interviews such as crying, growing pale, feeling nauseous and shivering. However, it has been shown that participation in research interviews can positively affect well-being even for vulnerable participants describing distressing issues and memories, even if there are strong emotional reactions and affects during the interview (Biddle et al., 2013). Participants were offered psychological support, but nobody requested it. It could be argued that these adolescents should not be put under pressure and asked to participate in a research study, since they were undergoing a major surgical procedure, that it might do them harm, and that they experienced pressure from researchers and/or parents to participate (Broome & Richards, 2003). There were positive reflections regarding participation, however, mentioned during the information prior to the study, in the interviews, and in the diaries. In the diaries it was mentioned that routine writing felt good. Some of those keeping a diary mentioned that writing about their experiences of difficulties and progress had a therapeutic effect on them.

Conclusion

Adolescents undergoing scoliosis surgery receive suboptimal perioperative care, and perioperative nursing care needs to be improved. The adolescent patient is a vulnerable person in a period of life when there are many things to adapt to. According to Roy, adaptation to being in adolescence could be described in terms of finding self-concept, role-function and interdependence (Fawcett, 2013). In many cases, preparing for, and
undergoing scoliosis surgery is a life-changing procedure that forces the adolescent to find a new orientation in this process. Adolescents therefore need to be well-prepared and the perioperative procedure carefully planned ahead of surgery.

Perceived stress before surgery has been shown to be associated with levels of postoperative pain, and levels of postoperative pain were occasionally very high. Roy states that there are different responses to stimuli: adaptive responses and ineffective responses. Preoperatively there are perceived stress symptoms; those with high levels of stress also reported high levels of postoperative pain. According to Roy’s physiologic-physical mode and cognator coping subsystem, pain catastrophizing and stress symptoms prior to surgery play a role in the level of perceived postoperative pain (Fawcett, 2013; Roy, 2009). This means that an ineffective response to the stimuli (stress), risks resulting in high levels of postoperative pain. The adolescents described not only physical symptoms but also a loss of control, fear, and lack of confidence in nurses. The adolescents described how they were hovering between suffering and control and how they were struggling not to be overwhelmed by the difficulties. According to Roy, the cognator subsystem means that coping can be achieved through perceptual and information processing as well as learning and memory (Roy, 2009). Nurses’ short-comings regarding medical technical skills and pain measurement appeared explicitly in the results. An absence of routines regarding nurses’ support for discharge and recovery was also salient. Adolescents need support in order to be able to adapt to the extreme changes in their lives during the perioperative phase and recovery. Despite the difficulties, the adolescents mentioned supportive factors such as hobbies, being with friends and setting goals as helping in their striving towards normality. With RAM in mind, perioperative nursing care could be optimized since - according to Roy - the goal of nursing is to promote adaptation in all four adaption modes (Roy, 1976).

Clinical implications and future research

Preoperative preparation needs to be improved as regards screening for stress symptoms and adolescents’ prior experiences. Roy’s multi-dimensional perspective in the adaption model is of importance in perioperative care. Adolescent patients can feel anxious and nervous, before major surgery, worrying about what will happen after surgery and whether - and if so, how - life will change. Since coping skills and coping strategies are individual they need to be emphasized before surgery both to the adolescent
and their parents, aiming for an increased perceived sense of control and improve the ability to cope with difficulties pre- and postoperatively and during recovery (LaMontagne et al., 2004b). Family members need support and information on what to expect so they, in turn, can be supportive of the adolescent. If nurses had the opportunity to interview the adolescent patients and their parents prior to surgery with the intention of capturing previous experiences, screening for predictors of postoperative pain and determining how difficulties have been solved, it could be a pathway to discussion together with the adolescent patient and to intervention with coping strategies. Nurses have to learn more about coping strategies to be able to support adolescents and their parents in their adaption processes. If the adolescents and parents were supported with coping strategies, distraction, focusing and interventions such as music (Nguyen, Nilsson, Hellstrom, & Bengtson, 2010), breathing and guided imagery (Charette et al., 2015), a sense of control and feeling able to cope might relieve difficulties pre- and postoperatively and during recovery.

Pain assessment and pain management need to be improved during the acute postoperative phase. Pain measurement is of importance in detecting patterns of pain and breakthrough pain. In previous studies there seem to be some failures in assessment, and this might be a reason for breakthrough pain. Nurses need to improve their knowledge of advanced pain management, including knowledge of medical technical equipment. Evaluating the impact of pain management through patient self-reported pain after administering pain treatment is of importance. This thesis also shows that adolescents experience a lack of control during the hospital stay. Participation in decision-making, pain management, becoming mobile and a sense of privacy are mentioned in these studies, and these are areas for interventions.

Nurses have an important role in preparing for recovery. Previous experiences, personality, coping strategies and parental support are factors that can have an effect on the adolescent in the perioperative period and can also improve the ability to cope with the difficulties that arise after major surgery. The parents need support, so as to be able to be supportive of their child, and it is necessary to capture every individual and personal need.

Seeing the individual, the whole person, and that person’s individual needs are of great importance in providing good nursing care. There is a constant interaction between living systems, persons and environments and a constant exchange of information, matter and energy (Roy, 2011). Adolescents are in a phase of teenage emancipation, but at the same time dependent on support and coaching; family and friends are important in the
latter regard, but so is also privacy. The adolescent patient is vulnerable, and recognizing that chronological age does not always match developmental stage is important (Lerwick, 2013); in adolescence there is constant adaptation to changes in the body and mind. In perioperative care Roy’s Adaption Model with its four adaptive modes can be a guide to providing multi-dimensional nursing care and helping an adolescent cope with and adapt to preoperative stress, postoperative pain and new situations after surgery. Nurses must engage in efforts to promote patient adaptation, and coping with difficulties. Having RAM and the four adaptive modes in mind is essential for elucidating adolescents’ needs even in making the decision to undergo surgery.

**Intervention studies**

Multiple perspectives have much to add to our world, and they need to be interconnected. The Roy Adaption Model evolved from a combination of inductive and deductive thinking. Additionally, Roy advocates qualitative and quantitative methods, as well as a combination of both, in nursing research. Roy’s adaption model can be a guide to data collection using the four modes, and a mix of methods can facilitate adding new knowledge to a broad perspective of optimizing perioperative care. Adolescents’ experiences can enable improvement in nursing care of adolescents undergoing scoliosis surgery.

Follow-up after surgery by using a mobile app containing a recovery questionnaire (Jaensson, Dahlberg, Eriksson, Gronlund, & Nilsson, 2015) might improve well-being during the first two weeks at home in recovery. The app has so far been tested after outpatient surgery, but may well be a tool for providing ongoing contact between the adolescent and a nurse after discharge from scoliosis surgery. The mobile app gives adolescents the possibility to report their health status to a nurse; the nurse, thereby has the ability to intervene and to resolve difficulties. Since the studies in this thesis indicate a lack of support for the adolescent during recovery, which leads to prolonged pain, nausea, lack of energy and constipation, the mobile app might be a convenient easy-to-use, informational channel, for the improvement of postoperative care and recovery.

A face-to-face follow-up interview six months after surgery could improve long-term recovery (Pattison, Dolan, Townsend, & Townsend, 2007). It is known that patients during recovery need support from health-care professionals who have knowledge of the type of surgery or treatment the patient have underwent (Allvin et al., 2008). The intention of the interview
would be both for the adolescent to describe their current situation to indicate whether there are any difficulties the adolescent needs support with, additionally, to evaluate the perioperative process in retrospect to help minimize the negative effects of traumatic memories.
Tack


Först ett tack till alla studiedeltagare. Utan er hade den här avhandlingen aldrig blivit gjord!

Till mina handledare vill jag rikta ett stort tack. I de första två studierna fanns Mats Karling med i projektet. Mats Karling var min bihandledare fram tills det att han lämnade jordelivet på tok för tidigt. Mats var en av dem som startade projektet, med ett genuint intresse för barn och ungdomars välmående. Mats hade enastående kunskaper som barnanestesiolog, och hans okonventionella och modiga sätt satte från start en prägel på projektet som jag försökt bevara sedan dess.


Marie Lindkvist, utan din expertkunskap i statistik hade jag antagligen aldrig tagit mig ut ur alla tabeller och beräkningar med förståndet i behåll.

Personalen på Barn 2 och Barnmottagningen vid Norrlands Universitetssjukhus för att ni varit stöttande och intresserade av studierna. Ni har också hjälpt mig att samla in data. Stort tack!

Håkan Jonsson och Stefan Isberg som var med i starten av projektet. Ni har med er entusiasm och expertkunskaper i ortopedi och anestesiologi fått mig att vilja fortsätta studera och slutföra denna avhandling.


Kerstin Ahlman, för luncher med givande samtal, och roligt resesällskap till Island. Din förmåga att alltid lyssna och pepa är unik!

Eva Danielsson, för våra samtal om allt från långlöpning till jobb.

Anders Ringnér, som alltid har något positivt att säga, och som lyckas på mig på bra humor oavsett hur vissen jag känt mig! Extraskärmen - den har varit toppen! Tack för lånet!

Peder ”Boppe” Blomqvist, min racepartner i vått och torrt. I vår erfarenhetsryggsäck från tävlingarna finns nu brutna revben, vilse-sinning, brännskador, utmattning, förvirringstillstånd, nerkylning och en oändlig massa skratt. Jag ser fram emot nästa race med skräckblandad förtjusning.


References


10.1177/1359105309351607


Research Support, Non-U.S. Gov't


Comparative Study

Controlled Clinical Trial

Multicenter Study


Rushton, P. R., & Grevitt, M. P. (2013). Comparison of untreated adolescent idiopathic scoliosis with normal controls: a review and statistical analysis of the literature. [Case Reports

Comparative Study

Research Support, Non-U.S. Gov't


10.1111/j.1399-6576.2008.01669.x


10.1097/BRS.OB013E31816F2849


