Idiopathic scoliosis: managing pain before and after spinal surgery

Lucy Bray and Jennie Craske present a study into the information that young people need to be given about pain when undergoing surgery to correct spinal curvature.

Abstract

Idiopathic scoliosis surgery is performed to correct a curvature of the spine. This is a painful surgical procedure which is carried out on otherwise healthy young people. This article reports on a small evaluation project which focused on young people’s opinions and experiences of their pain information needs, pain management and pain assessment. Nine young people completed written activity sheets before and after scoliosis surgery. Most of the information provided on the activity sheets involved positive comments about the surgical experience although some indicated that the management of pain continued to be a challenge after spinal surgery. The project has highlighted that there is more work to be done to ensure that young people are prepared for surgery and they are helped to convey their experiences of pain to health professionals during their treatment and recovery.

Keywords
adolescent idiopathic scoliosis, child health, information, paediatrics, pain assessment, pain management, spinal surgery

Adolescent idiopathic scoliosis (AIS) is a curvature of the spine, commonly diagnosed between the ages of 7 and 18 years. AIS affects 1-3% of young people (Weinstein et al 2008), is often progressive and can lead to severe disfigurement and respiratory and cardiovascular deterioration (Weinstein et al 2008). AIS is managed through either monitoring, bracing or surgical correction (Abbott et al 2013). There remains a lack of robust evidence demonstrating the efficacy of either conservative or surgical treatments (Negrini et al 2006).

The incidence of young people who have AIS requiring surgical correction is reported as 0.1-0.3% (Yagi 2014). The surgical procedure is a major operation to correct the curvature through the insertion of metal rods into the spine. Scoliosis surgery has been described as the most invasive planned orthopaedic surgery performed on young people (Kotzer 2000, Rullander et al 2013). After surgery, young people usually stay in hospital for a week or more and can have an extended recovery period of six months or longer (Connelly et al 2014, LaMontagne et al 2004).

Pain teams currently use a multi-modal approach to post-operative pain management after scoliosis surgery and there are ongoing advances in the introduction and combination of pain medications used for these young people. Post-operative pain medications include intravenous patient-controlled analgesia, opioid medication, benzodiazepines and oral or intravenous acetaminophen (Blanco et al 2013, Reynolds et al 2013). Opioid side effects are treated with antiemetics, antipruritics and laxatives. Despite advances in pain management, the control of pain after scoliosis surgery continues to be a real challenge for health professionals (Borgeat and Blumenthal 2008, Mayell et al 2014). Evidence suggests that young people continue to experience severe pain and nausea during the post-operative period and can be dissatisfied with the care they receive from health professionals (Rullander et al 2013).

Young people’s experiences of pain and loss of control during the post-operative period (Rullander et al 2013, Connelly et al 2014) can be exacerbated by a lack of information, knowledge and preparation. Evidence suggests that young people and their parents may not be given enough
information before scoliosis surgery (Bull and Grogan 2010), which can lead to anxiety, uncertainty and reduced satisfaction with care (van Schaik et al 2007, Khetani et al 2008). This project was prompted by the anaesthetists and pain team in an acute regional children’s hospital who were keen to evaluate and act on suggestions to improve the pain service delivered to young people undergoing spinal surgery.

Background
This project aimed to evaluate how pain information, pain assessment and pain management was experienced by young people undergoing idiopathic scoliosis surgery. This project collected written opinions from young people through short, structured activity sheets, designed to be engaging and easy to complete. The activity sheets encouraged them to describe their pre-operative information needs and pain experiences before, during and after their scoliosis surgery (Table 1).

The method took into account the anxiety and stress that can be associated with a surgical admission. The young people were able to determine when and how they completed the activity sheets and it was hoped that it might be a welcome activity for the unoccupied time which can dominate an inpatient stay. The activity sheets were designed with the help of two young people who had previously undergone this surgery to ensure the questions were appropriate and meaningful for this group of patients.

The use of methods to actively and directly engage with young people was underpinned by the recognition that young people have a right to be consulted, heard and to influence the services provided for them (Coad and Lewis 2004, Darbyshire et al 2005) and ensure that young people are meaningfully involved in any consultation process (Lightfoot and Sloper 2003, Kirk 2007).

The young people were invited to participate in the project by the spinal nurse specialist when they attended the outpatient clinic several weeks before their surgical admission. The young people and their parents were provided with an information sheet, one for parents and one for young people, along with a slip to post back to the project team if they wished to take part. When the slip was returned, the project lead, who was unconnected to their clinical care, spoke to the family on the telephone and arranged to come and see them on the orthopaedic ward the night before their surgery.

The project lead discussed the project with the family, and left the activity sheets with the young person. A sealable envelope was given to place the completed sheets in, which was collected after the young person had gone to surgery. When making contact with the participants, the project lead was mindful of the other professionals who were seeing the young person and parent/s before the operation and the stress that can be associated with a hospital admission. The ‘after your operation’ booklet of activity sheets was given to the young person on the ward four to five days after their operation for them to complete before being discharged home. When this was completed the young person placed it in a sealed envelope and it was collected by the project team.

The project was deemed a service evaluation (Health Research Authority 2013) as the focus was on finding out what is going on in a service (Bray 2015). The project was reviewed internally by the appropriate committee in the participating hospital NHS trust. Content analysis was applied to the data (Graneheim and Lundman 2004) due to the short nature of the responses. The young peoples’ comments were confidential and the activity sheets were returned to the project team in sealed envelopes.

Findings
From the 42 young people who were approached, nine chose to participate in the project, six completed the activity sheets before and after their surgery and three completed the ‘after your operation’ activity sheets. The participants were

<table>
<thead>
<tr>
<th>Table 1</th>
<th>The questions that led each section of the activity sheets</th>
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<tbody>
<tr>
<td><strong>Questions asked before the operation</strong></td>
<td><strong>Questions and prompts given after the operation</strong></td>
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<tr>
<td>Do you think you have been told enough information about the operation and what it will be like for you afterwards?</td>
<td>The information I was given</td>
</tr>
<tr>
<td>Are there other things that you want to know but have not asked or been told about?</td>
<td>The pain medicine I was given</td>
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<tr>
<td>Is there anything which is worrying you about having the operation?</td>
<td>What worked well for you?</td>
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<tr>
<td>Is there anything which is worrying you about after the operation?</td>
<td>Were you asked about your pain and how well the medicines were working?</td>
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<tr>
<td>What could be changed to make it better for you to come in for your operation?</td>
<td>What could have been better for you when you had your operation? (write two things which you would change)</td>
</tr>
<tr>
<td>Is there anything else you would like to tell us about coming in to the hospital for your operation?</td>
<td>What I would say to someone else having the operation</td>
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aged 11-17 years old, with six girls and three boys taking part. This resulted in 15 completed activity sheets. The young people provided information on the activity sheets about their feelings and experiences and engaged well with this method of data collection. Recruitment was a challenge over the period of the project, with theatre closures, operation cancellations, disruptions to staffing in the spinal clinic and poor uptake by families who wished to be involved. Data were collected between 2012 and 2014.

Most of the information provided on the activity sheets involved positive comments about the surgical experience, with the young people expressing thanks to the health professionals who had cared for them during their stay. Several took the opportunity to comment on the hospital food and lack of DVD players. The findings will be structured around the provision of information and the young people’s pain experiences.

**Information provision** All of the young people who completed the activity sheets before their operation (n=6) identified that they had received enough information before their surgery and had no unanswered questions. A typical answer was: ‘I have been told lots of times about what the operation is and what happens after. I am happy with the information I’ve been told’ (boy aged 15).

One young person commented that too much information had been provided about the anaesthetic and this had increased her anxiety. ‘I understand the need to inform a patient of what the anaesthetic consists of but it made me feel more nervous because of all the things explained’ (girl aged 17).

Although most participants said they were satisfied with the information they had received before the operation, three said after their operations that they wished they had been given more information about recovery, pain medicines and complications.

One young person commented that her admission would have been improved by an opportunity to talk to her surgeon about the operation. ‘Maybe a five minute or more chat with my surgeon about what he has done and how they feel about what has been done and improvements’ (girl aged 16).

The young people were asked if they were worried about anything before their operation. The concerns raised focused on the pain and sickness they may experience, the risks involved in the operation and the complications that may be encountered. Several of the young people said that they were worried and scared about coming in for their operation.

**Pain assessment and management** Most of the comments about pain assessment were positive. One stated that they had not been directly asked about their pain, all the others (n=8) had been asked regularly about their pain levels by the health professionals caring for them.

The young people’s experiences of post-operative pain was mixed. Five of the young people stated that their pain had been managed well after the spinal surgery. ‘The pain medicines were really good, I wasn’t in any pain and was very comfortable’ (girl aged 16).

Several described periods of pain which had not been managed well. ‘I was nearly always in pain and I didn’t think the meds were working as well as I thought they would’ (boy aged 14).

Many of the young people were positive about the ‘button’ (patient controlled analgesia) and how it worked well for them in controlling their pain. ‘You have a lovely button which has lovely morphine that you can’t taste’ (boy aged 14).

Some said that their intravenous pain medication had been ‘taken down too early’ which had led to them having pain, especially when their oral pain medications were ‘given late’. Several of the young people had experienced side effects from the medications prescribed, including sickness, allergic reactions and nightmares. ‘I would of preferred not to be so sick because it made it harder to do anything’ (girl aged 13).

The young people were asked what they would say to someone else who was going to have the operation. The written responses identified that it had been ‘hard’ but that it was ‘worth it’. Even those who had experienced a difficult post-operative trajectory still shared a positive message. ‘I am so pleased that I had the operation. Even though it was a tough week with the pain and sickness. I know it will all be worth it’ (girl aged 15).

‘Do it, it’s really hard and the pain really hurts but once you are up and about and home it will all be worth it and in two year’s time we will be normal and we will be able to laugh about it’ (boy aged 14).

**Discussion** The young people engaged actively in this project and the activity sheets were completed with lots of information. Participants expressed a range of pain experiences after surgery for idiopathic scoliosis. Some described extended periods of pain when their prescribed medications did not work well which was more commonly experienced when the intravenous medications were described as having been discontinued ‘too early’. Although the patient-controlled analgesia was sometimes
associated with nausea, it was thought to be working well. The mixed experiences of pain management demonstrate the challenge of establishing effective pain management. Scoliosis surgery continues to be a painful experience for some young people.

The young people were questioned and wrote at length about their pain information needs and their experiences of information provision. Although all the young people felt they had enough information when they were asked before the operation and wrote positively about the information they had been given, after the operation they wished they had been given more information before the operation.

Several participants expressed high levels of apprehension on admission to hospital for their operation which focused on pain, sickness and complications which they might experience. This reflects the difficulty that can be encountered in providing information to patients before people seek different levels and types of information.

Young people and parents may not know what to ask and may not be aware of what they need to ask about (Bray et al. 2012). Previous work has reported how parents and young people can lack information before scoliosis surgery (Bull and Grogan 2010) and that relevant information on the internet is inadequate (Mathur et al. 2005). This service evaluation suggests further work needs to be done to examine how young people and their parents can be helped to gain the right information and knowledge before scoliosis surgery.

The findings showed that, despite young people reporting that their pain was assessed well, they continued to experience pain which was, at times, at high levels. Despite this the young people were keen to thank health professionals for their kindness and care and gave positive messages to other people who may need to have this surgical procedure. This project has highlighted that more work needs to be carried out to rigorously investigate how young people are prepared for surgery and how they can be helped to convey their experiences of pain to health professionals.

Limitations This was a small project that collected data over 18 months. Difficulties were encountered in recruiting young people to take part in the project due to theatre closures for a period of six months, the relocation of surgical procedures during this time, operation cancellations and disruptions to the staffing in the spinal clinic.

Conclusion This small project has highlighted that further investigation is needed to examine how young people are prepared for AIS surgery and how they seek and obtain information before their operation. The responses on the activity sheets illustrate how some young people continue to experience high levels of pain after AIS surgery and there is a need for further work to help young people convey their experiences of pain to health professionals.

References


Bray L (2013) Research essentials. The differences between audit, service evaluation and research. Nursing Children and Young People. 27, 1, 12.


