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Return to School Following Scoliosis Surgery: A Qualitative Analysis

by

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ABSTRACT

Previous studies demonstrate that recovering from Spinal Fusion with Instrumentation surgery for Adolescent Idiopathic Scoliosis is extensive and demanding. Consequently, adolescents who undergo the procedure must navigate challenges when returning to their daily lives. Arguably one of the most prominent aspects of adolescents' daily living is school, but the experience of returning to school following spinal surgery has not been investigated. Considering that successful school functioning is often considered a benchmark of childhood, the goal of this study was to examine the experience of returning to school following spinal surgery. Specific objectives were to (1) gain a firsthand account of participants return to school experience, (2) explore the challenges adolescents faced, (3) explore the supports they found beneficial, and (4) explore what role pain played in their return to school. Semi-structured interviews were completed and responses analyzed using Interpretative Phenomenological Analysis. Participants' overall experience was captured by the core theme *Recovery to Fitting in at School* in which adolescents were faced with the need to return to school and thus, a demand to find their way to a successful school reintegration. Two intersecting themes assist in bringing forth an understanding of the return to school experience. *Needing to Return to School* outlines the challenges participants faced in their return to school. *Finding Their Way* describes the process of learning to cope with challenges encountered. Implications for both healthcare and school teams are discussed.

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CHAPTER ONE

Literature Review

Idiopathic Scoliosis

Scoliosis is the most common deformity of the spine (Hresko, 2013). Scoliosis is defined as a lateral curve of the spine that is ten degrees or greater on a radiographic image while the patient is standing (Dobbs & Weinstein, 1999). Typically, scoliosis is categorized according to its cause. Congenital scoliosis is an anatomical anomaly that results from failure in the formation of the vertebral column, which, with growth, leads to progressive spinal deformity (Miller, 1999; Roach, 1999). Neuromuscular scoliosis is a deformity caused by dysfunction of the central nervous system or peripheral neuromuscular system (Hresko, 2013). In most patients with scoliosis, however, the cause is unknown and this condition is thus categorized as idiopathic. Idiopathic scoliosis is subcategorized according to the age of onset. *Infantile* idiopathic scoliosis is identified between the ages of birth to three years of age, *juvenile* idiopathic scoliosis is identified between the ages of 3 and 10 years of age, and *adolescent* idiopathic scoliosis is identified in children older than 10 years of age (Hresko, 2013). Typically, the main physical findings are chest, trunk, hip, and/or shoulder asymmetry in otherwise healthy individuals. Scoliosis is confirmed by radiography that reveals a spinal curvature of ten degrees or more (Hresko, 2013).

In growing children, the primary complication of idiopathic scoliosis is disfigurement of the torso, shoulder and waist asymmetry, trunk imbalance, and rib rotation (Miller, 1999; Roach, 1999). Mild pain is common among children and adolescents with clinically significant curvature but severe pain that disrupts functioning is atypical (Hresko, 2013). In most cases of idiopathic scoliosis, the curve of the spine does not continue to progress or worsen into adulthood; however,

the magnitude of the curve at the time of diagnosis appears to affect curve progression. Natural-history studies have shown that a curve of the spine less than 30 degrees towards the end of spine growth rarely worsens into adulthood, whereas a curve of greater than 50 degrees predictably worsens at a rate of one degree per year (Weinstein, Zavala, & Ponseti, 1981). Based on these studies, a young patient with an immature skeletal structure who demonstrates a spinal curve greater than 25 to 30 degrees is at significant risk for progression or worsening of the spinal curve (Weinstein, Zavala, & Ponseti, 1981).

In addition to the magnitude of the spinal curve at the outset of diagnosis, sex appears to be a risk factor for curve progression. Whereas the ratio of girls to boys with small spinal curves of 10 degrees or less is equal, the ratio increases as the degree of spinal curve increases (Reamy & Slakey, 2001). It is estimated that for every one boy with a spinal curve of 30 degrees or more there are 10 girls (Roach, 1999). Considering the magnitude of the spinal curve, scoliosis in girls tends to progress more often and, therefore, causes girls to more commonly require treatment than boys (Roach, 1999).

Adolescent Idiopathic Scoliosis. Adolescent idiopathic scoliosis (AIS) occurs in approximately two to four percent of children between the ages of 10 and skeletal maturity (Reamy & Slakey, 2001). Adolescent skeletal maturity is estimated to be between the ages of 17 to 19 years of age (Calfee, Sutter, Steffen & Goldfarb, 2010). Adolescent females are estimated to reach skeletal maturity between the ages of 16 and 18 whereas males are estimated to do so between the ages of 18 to 20 (Calfee, Sutter, Steffen & Goldfarb, 2010).

Whereas the Scoliosis Research Society acknowledges that significant efforts are being made to understand the cause of AIS, there is currently no identified single cause. Some of the most widely investigated causes include hormonal imbalance, asymmetric growth, and muscle

imbalance (Scoliosis Research Society, 2014). It is also estimated that approximately 30 percent of AIS patients have some family history of scoliosis, suggesting a genetic component to the deformity (Reamy & Slakey, 2001). The majority of AIS patients are typically otherwise healthy and has no significant concurrent or previous medical history (Scoliosis Research Society, 2014).

Treatment of Idiopathic Scoliosis in Adolescence

Of adolescents diagnosed with idiopathic scoliosis, only 10 percent have curve progression that requires intervention in the form of surgery (Miller, 1999). Upon diagnosis of AIS, risks of the curve being left untreated are assessed. In most patients, life threatening effects on pulmonary function do not occur until the spinal curve is 100 degrees or greater (Miller, 1999). However, like other forms of idiopathic scoliosis, spinal curves in AIS are estimated to progress at a rate of one degree per year, making appropriate intervention for high-risk adolescents imperative. In addition to the significance of continued curve progression, there is also an increased risk for psychological distress into adulthood. For example, the US Preventive Services Task Force (1993) found that 19 percent of females with curves greater than 40 degrees in adulthood experienced social isolation, limited job opportunities, and lower marriage rates. Potential physical and psychological negative outcomes in cases where curves are left untreated make effective intervention at an early age especially important.

Adolescent scoliosis can be monitored by a family physician if the curve has a low risk of progression; however, orthopedic subspecialists typically manage cases in which curves demonstrate significant progression (Reamy & Slakey, 2001). Evidence-based treatments for adolescent scoliosis in which there is marked curve progression or risk of curve progression include bracing and spinal surgery (Reamy & Slakey, 2001). Bracing techniques have historically been considered a fairly uncomfortable method of treatment; however, recently,

bracing has improved markedly to be more comfortable and tolerable, increasing adolescents' adherence to this form of treatment (Di Raimondo & Green, 1988). Bracing has been shown to have a 74 percent success rate at stopping curve progression in patients with small curves of less than 30 degrees (Nachemson & Peterson, 1995). In patients with curves greater than 45 degrees, spinal surgery using instrumentation is generally considered the most effective intervention (Pinto, Avanzi, & Dezen, 1994). Modern surgical methods are accompanied by spinal cord monitoring, which significantly minimizes the risk of unfavorable surgical complications (Roach, 1999). Improvements in surgical methods have allowed healthcare teams to broaden their focus from life preservation to include additional more psychosocial health and quality of life outcomes. In this population for instance, research has expanded from simply performing the procedure safely to outcomes such as pain, body satisfaction and activity level before and after surgery.

Spinal Fusion with Instrumentation Surgery. Spinal Fusion with Instrumentation (SFI) is the most common surgical procedure for AIS and is classified as a major procedure by the American Academy of Orthopedic Surgeons. The goal of SFI surgery is to correct the spinal deformity by stopping growth in the abnormal segment of the spine, and as a result, stop further spinal curve progression (Roach, 1999). The American Academy of Orthopedic Surgeons indicates that to achieve this goal, curved vertebrae are fused together so that they heal into a single solid piece of bone. Instrumentation such as metal rods, screws, hooks and/or wires are implanted into the spine to hold it in place until fusion occurs (American Academy of Orthopedic Surgeons, 2014). As a result of fusion, there is some loss of motion in the fused section of the spine (Hresko, 2013) and the magnitude of this restricted motion depends on the location of the fusion in the spine. Specifically, in upper regions of the spine, restriction is

minimal and patients tend to return to typical preoperative functioning (Hresko, 2013). In the lower regions of the spine, restriction appears to be more damaging and has been associated with reduced activity levels and in some cases arthritis (Hresko, 2013). Recovery from the procedure is long and demanding. The typical postoperative hospital stay is a point of debate and highly dependent on individual patient factors. In a resource aimed at preparing adolescents for SFI surgery, the American Academy of Orthopedic Surgeons estimates that patients typically spend a minimum four to five postoperative inpatient days in the hospital following surgery. This same reference also suggests that adolescents should be prepared to miss an additional four to six weeks of school during their recovery at home.

Quality of Life Following Surgery

Clinicians and adolescents anticipate improved long-term quality of life following SFI surgery (Rushton & Grevitt, 2013). Long-term retrospective studies of surgically treated adolescents are generally favorable and suggest either comparable or mildly lower quality of life than healthy controls in areas such as activity level and mental health (e.g., Andersen, Christensen & Thomsen, 2006; Bjerkreim, Steen & Brox, 2007; Danielsson & Nachemson, 2003; Mariconda et al., 2005; Takayama, Nakamura & Matsuda, 2009). Fallstrom, Cochran & Nachemson (1986) suggest that surgery has a positive effect on adolescents' overall development. For example, they found that adolescents who were surgically treated for AIS had more favorable ratings of themselves and felt more confident in their ability to achieve personal goals. In this study, adolescents identified that, although they experienced a significant amount of pain during their recovery, they felt better about their physical appearance following surgery, which helped them develop more positive opinions about the way their body looked and higher self confidence in the future (Fallstrom, Cochran & Nachemson, 1986). Despite this potential overall

improvement, studies examining quality of life following surgery do, however, also indicate persistent concerns regarding appearance, back pain, and social interactions following surgery (e.g., Bartie, Lonstein & Winter, 2009; Danielsson, et al., 2001; Edgar & Mehta, 1988; Goldberg, et al., 1994). Prospective studies have used validated patient-report outcome measures, mainly the Scoliosis Research Society Questionnaire, to further examine outcomes of SFI. This questionnaire assesses a number of quality of life domains including pain, self-image, activity level, and satisfaction with surgery. These studies consistently report that the pain and self-image domain scores reported by adolescents with AIS are statistically worse than non-AIS controls following surgery (Rushton & Grevitt, 2013; Weigert, 2006). Recent qualitative studies have been consistent with quantitative findings, and have identified that adolescents feel that activity level, self-perception, social relationships, and pain are central to their experience following surgery (e.g., MacCulloch, Donaldson, Nicholas, et al., 2009; Rullander, Isberg, Karling, et al., 2013).

Activity Level. In a 20-year follow-up study that compared adolescents who were surgically treated for AIS to healthy controls, Danielsson et al. (2001) found that patients surgically treated for AIS had slightly, but significantly, reduced physical function and activity in comparison to healthy controls. In this study, 49% of participants surgically treated for AIS (vs. 15% of healthy controls) reported limitation of social activities due to their back. Participants reported their limitation was mostly due to difficulties with physical participation and self-consciousness about appearance. In a short-term follow-up study two to three years following surgery, Kibsgard et al. (2004) found that surgical patients did not experience a higher rate of absence from work or school, but did report an overall reduced activity level in areas such as walking, standing, and sitting for lengthy periods as compared to healthy controls.

In qualitative examinations of adolescents' experience with activity following surgery, patients report difficulty with numbness, stiffness, sensitivity, and restricted mobility after spinal surgery (MacCulloch, et al., 2009). Adolescents discussed experiencing particular difficulty during the immediate recovery period, but that these difficulties decreased over time during recovery. Adolescents indicated some concern about the nature of the implanted hardware and expressed worry that they would feel the implants following their surgery. Additionally, adolescents expressed concerns about returning to previous sports teams such as gymnastics, basketball, and ballet, in some cases not returning at all. During the immediate recovery period and for up to a year following surgery, MacCulloch, et al. (2009) found that adolescents reported limiting their own activity level as a result of feeling the need to protect their back. Adolescents reported feeling the need to be particularly careful in busy environments such as school hallways, grocery stores, and malls and reported feeling fearful they may cause damage to their spine if they were bumped in these settings. In an examination of parents' experience with their child's surgery, Bull and Grogan (2010) found that parents observed their children return to normal activity for the most part and felt impressed by their child's determination to return to normal activities.

Mental Health. Findings related to mental health outcomes following surgery are mixed. For example, in a population-based case-control study adolescents with and without scoliosis were compared on psychosocial variables including peer relations, body image, and health-compromising behavior, such as suicidal thought and alcohol consumption. Payne et al. (1997) found that both male and female patients with scoliosis were more likely to have suicidal thoughts, be concerned about abnormal body development, consume alcohol and worry about peer relations than age-matched controls who did not have scoliosis or any other condition.

Based on these findings, Payne et al. (1997) concluded that scoliosis is a risk factor for psychological disturbance in adolescents. An important limitation of this study is that they did not identify whether participants with scoliosis had received treatment and if so, when. Whether or not adolescents had received treatment, were anticipating treatment or were not eligible for treatment may have important implications for results. Despite this limitation, Payne et al., (1997)'s study included a large sample size of 685 scoliosis participants each with age matched healthy controls and their results indicate that regardless of treatment, the condition of scoliosis alone poses risk factors for adolescents mental health. In qualitative interviews with adolescents following surgery, adolescents recalled feeling extremely anxious prior to the procedure (Rullander et al., 2013). During the immediate recovery period, adolescents reported feeling hopeless that their pain would ever ease and that their lives would return to normal. Adolescents also reported feeling isolated at times during recovery after their surgery, which they identified as "depressing" (Rullander et al., 2013). In a 20 year follow up study, Danielsson et al. (2001) found that depression and social isolation were reported by up to 43% of adolescents during and after bracing and/or surgical treatment for AIS. In this study, the treatment period in general had a more negative effect on brace-treated participants than those who were surgically treated. In contrast to this finding, they found that up to 40% of participants indicated that treatment did not bother them and, in fact, they felt surgery contributed to increased independence and maturity. Danielsson et al. (2001) demonstrate the diversity of experience following treatment for AIS and highlight that in at least some patients, a certain amount of psychological impact is expected as a result of surgery.

In contrast to poor mental health outcomes, Kibsgard et al. (2004) found that young adults who were operated on for idiopathic scoliosis had no significant differences with healthy

age and sex matched controls on mental health measures two to three years following surgery. The AIS sample did not score differently on measures of mental health including energy level, mood or general affect, daily activity level, and engagement in social activities. Kibsgard et al. (2004) concluded that surgery for scoliosis is generally well tolerated and does not appear to traumatize or have a negative impact on the mental health of AIS patients.

Body Image. Experiencing an appearance altering condition during adolescence may be particularly detrimental to body image as compared to experiencing such a condition during adulthood (Ben-Tovim & Walker, 1993). Payne et al. (1997) highlight that adolescents with scoliosis tend to face challenges with physical deformity during a particularly sensitive developmental period where they are typically even more concerned about and sensitive to their physical appearance. Tones et al. (2006) conducted a systematic review of literature regarding the psychological impact of scoliosis. The review included 30 studies examining health related quality of life outcomes in adults with scoliosis, 21 psychosocial studies of patients with scoliosis and six intervention studies of scoliosis. Body image disturbance was one of the only psychosocial factors consistently demonstrated across the literature. Tones et al. (2006) found that body image concerns are evident in adolescents with scoliosis both before and after treatment. Drawing on the intervention literature, they found that exercise and coping skills training may serve to improve body image before and after treatment. Additional literature supports this conclusion and indicates that adolescents with scoliosis are more likely to fear that their bodies are developing abnormally than adolescents without scoliosis (Koch, Buchanan, Birch, et al. 2001; Liskey-Fitzwater, Moorse & Gurel, 1993; Payne et al., 1997). In a study examining concerns about physical appearance in young adults with scoliosis, Liskey-Fitzwater, Moorse & Gurel (1993) found adolescents with scoliosis were more likely to report lower overall

self-perception scores, and tended to have more negative feelings and beliefs about themselves prior to spinal surgery. Iwahara, Imai & Atsuta (1998) also found that patients with AIS were more likely to experience significant concern about how they look and rate themselves more poorly than healthy age matched controls.

Adolescents with scoliosis often report concerns with the fit of clothing. Liskey-Fitzwater, Moore & Gurel (1993) investigated the importance of clothing and self-perception in adolescent females with and without scoliosis. They found that adolescents with scoliosis were less likely to report feeling satisfied with the way their clothing fits and do not report using clothing to enhance their self-concept. Qualitative studies have also explored adolescents' experience with clothing and found that adolescents tend to dislike how their clothing fits prior to surgery and that thinking about clothing results in self-consciousness about appearance (MacCulloch et al., 2009). Parents also report difficulty shopping and finding clothing that fits their adolescent comfortably (Bull & Grogan, 2010).

Research has examined whether these concerns about body image are alleviated following spinal surgery in AIS patients, but findings have been mixed. Weigert et al. (2006) found that adolescents treated surgically for scoliosis reported significantly better self-image and satisfaction with their body following surgery, suggesting that surgery helps improve adolescents' feelings toward themselves. In a long-term comparison to healthy controls, Goldberg et al. (1994) found that female AIS patients who were treated surgically up to 10 years prior, responded more positively to body image questions after their treatment, indicating a more favorable perception of self and body image overall. Using recently published minimum clinically important difference (MCID) values for the Scoliosis Research Society Questionnaire, Rushton & Grevitt (2013) found that 80% of patients experienced clinically significant improvements in

the self-image domain of this questionnaire. Qualitatively, adolescents report feeling better about the way they look, less self-conscious about their body, and more satisfied with the way their clothing fits after surgery (MacCulloch et al., 2009; Bull & Grogan, 2010). Conversely, Noon (1997) reported that, in comparison to healthy controls, adolescents treated surgically for AIS continue to report a more negative body image even following their surgical procedure. Akazawa (2012) also found that AIS groups experienced a more negative self-image than age and sex matched controls up to 40 years following surgery. While research findings are clearly divided on the presence of improved body image following surgery, it is important to note that both Noon (1997) and Akazawa (2012) reported levels of statistical as opposed to clinical significance. As argued by Rushton & Grevitt (2013), considering whether results are clinically meaningful is critical for determining health-related quality of life following surgery. As is also the case for concerns other than body image (i.e., activity level, mental health, pain), studies that do not consider minimum clinical important difference (MCID) values may be limited in their ability to detect meaningful changes in participants' lives regardless of statistical significance.

Social Relationships. Social relationships after surgery have been studied less than other outcomes. LaMontagne et al. (2004) found that at one month following surgery adolescents experienced an initial drop from their baseline social activities. Participants' social activity gradually increased from this initial drop at three months and six months following surgery. Interestingly, however, participants never fully returned to their baseline social activity in the nine months they were followed for the study. Based on these findings, LaMontagne et al. (2004) concluded that surgery and recovery appear to have a long-term effect on patients' social lives. Considering the developmental importance of social relationships during the adolescent period, the authors argue that this long-term impact should be interpreted as a negative outcome of

surgery. In a review of psychosocial issues following surgical treatment for AIS, Tones et al. (2006) found that adolescents experience significant challenges with loss of social interaction during their recovery following surgery. They suggest that the loss of social interaction likely results, in part, from an extended absence from school, which is a primary social site for children and adolescents.

In qualitative interviews with adolescents, MacCulloch et al. (2009) found that adolescents struggled with time away from their friends and dating relationships. In fact, they reported this as one of the most difficult aspects of their surgery. At times, they described feeling isolated. Adolescents reported difficulty spending time away from their friends and indicated that it took a long time to reestablish some friendships. For the most part, adolescents found their friends and peers supportive and often identified their friends as some their biggest helpers as their recovery period progressed. In some instances, adolescents reported difficulty responding to the questions and overreactions of others and felt uncomfortable navigating social situations (MacCulloch et al., 2009).

Pain. Patients with scoliosis do not tend to experience long-term dysfunction that interferes with daily living due to back pain; however, back pain incidence does appear to be higher than the general population in patients surgically treated for AIS up to 20 years following surgery (Danielsson & Nachemson, 2003; Goldberg et al., 1994; Wong et al., 2007). Similar to other outcomes, the literature with respect to long-term pain outcomes following surgery is somewhat variable. In an examination of pain following surgery in adolescents with AIS, Wong et al. (2007) found that 50% of participants had ongoing pain after hospital discharge and 10% had back pain persisting beyond 12 months following surgery. Goldberg et al. (1994) found that 73% of participants who had surgery for AIS experienced back pain up to 10 years following

their surgery; this percentage was significantly higher than the non-AIS control group in which 56% reported experiencing back pain. In a similar study, Danielsson & Nachemson (2003) examined a series of patients who were surgically treated with spinal fusion up to 23 years following surgery. Danielsson & Nachemson (2003) found that mild lumbar pain was significantly more frequent among individuals who had surgery, with 65% of patients reporting back pain as compared to only 47% of controls. In this study Danielsson & Nachemson (2003) point out that despite these pain reports, no significant differences in back function were found. Although participants surgically treated for scoliosis reported significantly more pain than controls, their pain was not disabling to them in any way. In a previous study conducted by Danielsson et al. (2001) that examined patients surgically treated for AIS at least 20 years after treatment, only 1.5% of AIS participants were severely disabled due to back pain (i.e., unable to work and function independently in daily living due to back pain). In a short-term qualitative follow-up study, Rullander, et al. (2013) found that adolescents described feeling intense pain during the immediate surgical recovery and up to three months following surgery. Adolescents reported that pain restricted their mobility, made it difficult to reconnect with friends, and return to daily activities such as school; however, pain eased with time and did not disrupt their daily living beyond 12 months following surgery.

Currie & Wang (2004) conducted an investigation of back pain prevalence in the general Canadian population 12 years and older using data from 118, 533 household surveys. They estimated the prevalence of chronic back pain to be 9%. Comparing the rates of reported back pain across studies examining pain in patients surgically treated for AIS (50%; 73%; 65%) with the general population (9%), it appears that patients with AIS report higher levels of back pain than the general population. That being said, as Danielsson et al. (2001) highlight in their study

that only 1.5% of these participants were severely disabled by pain. Although patients surgically treated for AIS may be more likely to report higher levels of back pain than the general population, pain does not necessarily interfere with their level of function and/or overall daily living.

Reintegrating to Daily Living Following Surgery

School. School is typically considered the primary task of childhood and adolescence (e.g., Harris, 2009; Varni et al., 1994). School is necessary for the development of academic skills such as reading, writing, and mathematics that are essential for future employment and post secondary pursuits. However, school is also a place where adolescents interact with their peers, develop social relationships and skills, and establish independence and identify outside of their family (Geist, Grdisa, & Otley, 2003). Missing school can lead to practical problems in keeping up with academic work, and repeated problems with missing school can result in academic failure. Frequent and/or prolonged school absences can also negatively impact social relationships and identity development (Geist, Grdisa & Otley, 2003).

Research in the field of school refusal behaviour has illustrated many of the negative long-term outcomes associated with missing prolonged periods of school. Specifically, Kearny (2001) suggests that extended and/or frequent school absences can be one of the most disruptive events in the development of an adolescent and has found negative outcomes such as violence, substance abuse, psychiatric disorders and economic deprivation in students who experienced school refusal. Whereas adolescents who undergo surgery for SFI typically do not experience the same degree of school absence as students who exhibit school refusal behaviour, it is important to consider potential implications of school absenteeism in this population, as a prolonged school absence it may lead to similar concerns.

Chronic Illness and School Functioning. Approximately 15-20% of school-aged children and adolescents suffer from health-related disorders (Center for Disease Control and Prevention, 2008). Illnesses classified as health-related disorders vary; however, common examples include sickle cell disease, asthma, food allergies, seizure disorder, diabetes, scoliosis, cancer and heart disease (Daly, 2014). A significant subset of these children and adolescents experience negative school outcomes related to their illness. For example, Taras & Potts-Datema (2005) found that children with diabetes, sickle cell anemia and epilepsy are significantly more likely to miss school days and poorer grades than healthy peers. Smith et al. (2013) found that youth with sickle cell disease had significantly more school absences and were more likely to repeat grades than healthy peers. In a review of the educational effects of childhood chronic illness among Canadian children, Martinez & Erickson (2009) found that children with chronic illness performed worse on academic measures when compared with healthy peers.

These issues represent significant challenges for school-aged children, yet research indicates that many school-based personnel report inadequate training to work with children and adolescents with chronic illnesses (Hamlet, Gergar, & Schaefer, 2011; Smith et al., 2013). In an examination of teachers' knowledge and experiences related to chronic health conditions, teachers reported feeling inadequately prepared to identify and manage the needs of children with chronic illness in the classroom (Smith et al., 2013). Bradley-Klug et al. (2013) surveyed school psychologists' perceptions of communication and collaboration between healthcare professionals and school personnel regarding students with chronic illnesses and found that interdisciplinary communication and collaboration practices were relatively infrequent, making the school experience a difficult one for children with chronic illness.

School Reintegration Following Surgery and Chronic Illness. According to the American Academy of Orthopedic Surgeons (2013), adolescents typically return to school four to six weeks following SFI surgery. School absence prior to surgery is typically minimal, with only one to two days required for preparation. Literature on adolescents' school experience following surgery is limited; however, adolescents report that returning to school is a concern. In qualitative interviews with adolescents following their SFI surgery, MacCulloch et al. (2009) found that adolescents were concerned about their new appearance and wondered if people at school would notice a change in their height, rib prominence, and shoulder/hip balance. Rullander et al. (2013) found that patients experienced some pain and discomfort at school after their surgery, which interfered with concentration. For the most part, however, adolescents reported feeling able to manage their discomfort at school. Adolescents in this study also indicated concerns about responding to questions and reactions of peers and teachers and found it difficult to move through crowded and busy spaces while protecting their back.

While specific information about supporting adolescents in their return to school following surgery is lacking, limited information about supporting their more general recovery is available. For example, LaMontagne et al. (2004) examined the effects of preoperative educational and psychosocial interventions on postoperative pain, anxiety, and return to normal activities. These interventions ranged from providing information to providing explicit instruction on ways to cope following surgery. LaMontagne et al. (2004) found that providing information about what to expect during the recovery period combined with explicit instruction on coping strategies decreased both pain and anxiety ratings and increased the speed at which adolescents returned to daily activities following surgery. Adolescents who received an intervention that included both information and coping strategy instruction returned to daily

activities significantly sooner than adolescents who received only information or did not receive any intervention at all.

Additional information related to supporting adolescents in their return to school is available in the broader chronic illness literature. According to the American Psychological Association (2013), chronic illness is defined as a persistent medical condition expected to last and possibly worsen over time that impacts daily living by diminishing work performance and/or tasks such as walking, sitting, reaching and/or socializing. Studies have found that adolescents with chronic health conditions are at risk of increased difficulties with school performance and frequent and/or prolonged school absences for medical appointments and treatment (Geist, Grdisa & Otley, 2003; Sexson & Madan-Swain, 1993; Weitzman, 1986). Highlighting a determination to return to school, they found that most adolescents report wanting to go back to school, despite their health condition, in order to reunite with friends and catch-up on schoolwork (Geist, Grdisa & Otley, 2003). Caution must be used when applying chronic illness research to the surgical experience because patients undergoing surgery are not necessarily expected to worsen overtime, as is often the case with students with other chronic health conditions. Instead, the condition of surgical patients is expected to improve. That being said, similarities between these two populations exist, in that they both experience a prolonged school absence due to illness and associated medical treatment. This similar experience results in potentially similar motivators for returning to school despite their illness and/or surgery such as reconnecting with social networks and catching up on academic work.

Sexson & Madan-Swain (1993) suggest that any young person who misses school as a result of a chronic health condition should be highly supported in their return. They describe guidelines such as active preparation meetings with the youth, parents, and school personnel

about the student's return, and continued monitoring and follow-up once the student returns to attending school. They also emphasize that school re-entry should be discussed at the outset of diagnosis and throughout the treatment process with the healthcare team. School reintegration programs are another way of supporting school reintegration following prolonged absence.

Prevatt, Heffer & Lowe (2000) note that school reintegration programs provide a framework for consultation between school and health care systems. Most school reintegration programs take the form of school personnel workshops and information sessions, peer education initiatives, and/or the development of an individualized plan for the student who is returning to school.

Canter & Roberts (2012) conducted a systematic review of these programs used for children and adolescents with chronic health conditions and found them to be effective at increasing school personnel knowledge about the specific illness and generating positive attitudinal change in teachers and peers. Increasing teacher and peer knowledge and fostering a more positive attitude leads to a heightened understanding of the chronically ill adolescents' unique needs and consequently, results in a more effective response to their needs when they return to school.

Summary

In general, surgical treatment for AIS is well tolerated by adolescents. However, research examining factors such as activity level, body image, social relationships and pain indicates at least some concern. Body image concerns appear to be the most widely supported area of difficulty for adolescents before and after surgery. Adolescents treated for scoliosis are more likely to experience negative feelings about their body and report higher levels of body dissatisfaction. Adolescents surgically treated for AIS also experience a slightly, but significantly, reduced activity level compared to healthy peers and are more likely to report experiencing back pain up to 20 years following surgery. Although this population is more likely to report experiencing pain, only a small percentage of patients treated for scoliosis report pain that

disables their daily living. Immediately following surgery, adolescents surgically treated for scoliosis experience reduced social activity, which appears to increase and return to previous levels of social activity as recovery progresses. Although research indicates that, in general, SFI surgery for AIS does not tend to cause a major disruption in adolescents' overall quality of life following surgery, patients clearly experience some degree of difficulty in a number of areas when compared with healthy peers. These difficulties, combined with an extended school absence, result in a challenging recovery period and need for increased support as adolescents return to their typical activities of daily living following surgery. Despite the need for increased support, no formal programs exist to facilitate return to school following spinal surgery in scoliosis patients; this is a shortcoming, given the role of school in healthy development across childhood and adolescence. Investigating adolescents' return to school experiences following SFI is an important preliminary step in providing recommendations to clinicians, families, patients, and educators when preparing an adolescent to return to school following a long absence as a result of spinal surgery.

CHAPTER TWO

Return to School Following Scoliosis Surgery: A Qualitative Analysis

Adolescent Idiopathic Scoliosis

Adolescent idiopathic scoliosis (AIS) is a structural curve of the spine that is greater than 10 degrees and has no underlying cause (Dobbs & Weinstein, 1999). It is first identified between the age of 10 and skeletal maturity (Dobbs & Weinstein, 1999). AIS occurs in two to four percent of children between the ages of 10 and 16, with a higher incidence in females than in males (Hresko, 2013). Curves measured at 50 degrees or more at skeletal maturity tend to continue to progress at a rate of one degree per year and therefore, generally require surgery (Miller, 1999). In extreme cases, continued curve progression without treatment can result in life-threatening effects on pulmonary and vital organ function making appropriate treatment critically important for children with scoliosis (Reamy & Slakey, 2001).

A relatively common surgical procedure for AIS is Spinal Fusion with Instrumentation (SFI). The goal of SFI surgery is to correct part of the spinal deformity by stopping growth in the abnormal segment of the spine and, as a result, stop further spinal curve progression (Roach, 1999). To achieve this goal, the curved vertebrae are fused together so that they heal into a single solid bone, with metal rods, screws, hooks and/or wires holding the spine in place until fusion occurs (American Academy of Orthopedic Surgeons, 2013). The American Academy of Orthopedic Surgeons (2013) classifies SFI surgery as a significant procedure that should be followed by an extensive recovery period of four to six weeks before returning to school and anywhere between 16-24 weeks before returning to non-contact sports (e.g., running).

SFI Surgical Experience

Given the invasive nature of SFI surgery coupled with the extensive period of recovery required following the procedure, it is not surprising that adolescents who undergo SFI surgery experience many challenges. The cumulative body of research related to outcomes following spinal surgery indicates that factors such as activity level, body image, social relationships and pain are impacted by surgery. Research indicates that adolescents who are surgically treated for AIS typically experience difficulty participating in physical activity, have poorer perception of body image and experience increased levels of pain (Tones et al., 2006).

In addition to these quantitative examinations, recent qualitative studies offer a rich personal account of adolescents' experiences following SFI surgery. MacCulloch et al. (2009) and Rullander et al. (2013) identified a range of emotional, physical and social challenges adolescents' report before, during and after surgery. Emotional challenges identified by adolescents included feeling fearful about becoming paralyzed during surgery, feeling worried about severe pain after surgery, and feeling a lack of control over their situation, especially when a lengthy period of time elapsed between receiving information about the surgery and actually having the procedure. Physically, adolescents reported difficulty with mobility following surgery and indicated that they found it hard to sit up, walk, and go to the bathroom after surgery. Additional physical challenges included being surprised by the size and appearance of the scar and the amount of pain experienced after surgery. Socially, adolescents reported that losing contact with friends and sports teams was difficult, and suggested they had to modify their previous sporting activities as a result of their surgery.

Another area of difficulty following SFI surgery is the return to school following the long post-surgery recovery period. Given that school is the primary job of childhood and adolescence (Varni et al., 1994), successfully returning to school following surgery is critical. Indeed,

evidence from the studies of school refusal behaviour indicates that extended school absences can have detrimental effects on development, resulting in negative long-term outcomes for students who do not attend school regularly (Kearney, 2001). Currently there is limited information about school-related challenges following SFI surgery; however, research in the area of school functioning in chronic illness populations is helpful in understanding some of the challenges that may be experienced by youth who undergo SFI surgery for scoliosis.

SFI Surgery and School Functioning

Despite a general lack of research investigating school functioning and the school experiences of patients who have had SFI surgery, some literature exists on the topic. For example, adolescents in a study conducted by MacCulloch et al. (2009) identified concerns regarding the impact of SFI surgery on school attendance and their friendships and dating relationships, as well as fear that others might stare at their scars or treat them differently after surgery. In the discussion of their results, both MacCulloch et al. (2009) and Rullander et al. (2013) anticipate that many of the social, emotional and physical challenges discussed above also affect school functioning; however, a firsthand account specifically focused on adolescents' school experience following SFI surgery is not currently available.

Adolescents are expected to return to school four to six weeks after SFI surgery (American Academy of Orthopedic Surgeons, 2013). Generally, frequent or extended school absences are problematic because school is thought to be a crucial environment for meeting a number of developmental needs for children (Weitzman, 1986). In addition to being necessary for the development of academic skills such as reading, writing, and mathematics, the school setting allows children to develop independence, their identity, and social relationships with other children and adults (Geist, Grdisa & Otley, 2003). Highlighting the critical importance of

school attendance, Kearny (2001) suggests that extended and/or frequent school absences can be one of the most disruptive events in the development of a child and result in negative outcomes such as violence, substance abuse, psychiatric disorders and economic deprivation. Given both the challenges adolescents face as a result of their surgery and the extended school absence that is necessary following surgery, it is important to consider how adolescents can be effectively supported in order to return to school successfully and minimize possible negative outcomes.

In addition to the social and academic factors that may contribute to the school reintegration experience for youth who have had SFI surgery, it is also important to consider the impact of pain on the school experience. Pain following surgery has been found to be especially impairing among SFI patients, with both patients and their parents noting that it was almost impossible to cope with immediately following surgery (LaMontagne, 2001) and was also a significant barrier to returning to daily activities, including school (Bull & Grogan, 2010). Pain experienced by adolescents immediately following surgery also extends longitudinally (Goldberg et al., 1994). This study found that 73% of participants who had surgery for AIS experienced back pain within the last 10 years following their surgery; this percentage was significantly higher than the non-AIS control group in which 56% reported experiencing back pain within the last 10 years. They also indicated that their pain caused restriction in daily activities including difficulty walking, lifting and socializing. In Rullander et al. (2013)'s qualitative interviews, adolescents discussed being surprised by the severity of the pain that they experienced, as well as by the persistence of the pain after surgery. When asked what future patients should be prepared for in advance of SFI surgery, adolescents suggested patients must be prepared to cope with severe pain (Rullander et al., 2013).

Whereas literature specifically discussing pain and school functioning following SFI surgery is not currently available, there is a limited amount of literature on the more broad influence of pain on school functioning. In a critical review of cognitive and school functioning in children and adolescents with chronic pain, Dick & Pillai Riddell (2010) identify difficulties in school attendance, academic achievement and social relationships. Particularly, children with pain have been shown to miss multiple school days each month and experience a decline in grades (Dick & Pillai Riddell, 2010). Importantly, on standardized intelligence and academic achievement tests, children with pain did not differ from the general population and performed, for the most part, in the average range, demonstrating that a decline in grades is not related to an overall underlying cognitive deficit (Dick & Pillai Riddell, 2010). That being said, children and adolescents with pain have been shown to have differences in cognitive functions such as attention when compared to healthy peers. Specifically, they have been shown to be more likely to attend to pain related stimuli and have a more difficult time disinhibiting their attention from pain and onto something else (Dick & Pillai Riddell, 2010). Finally, in a systematic review examining social functioning in children and adolescents with chronic pain, Forgeron et al. (2010) identified that children and adolescents with pain report having fewer friends, being subjected to more peer victimization, and experiencing more isolation at school.

Supporting Adolescents in Their Return to School

In a prospective longitudinal study examining coping strategies and long term activity outcomes, LaMontagne et al. (2004) suggest that providing information about coping strategies to adolescents prior to SFI surgery decreases both postoperative pain and anxiety (LaMontagne et al., 2004). Additionally, providing information about coping strategies helps adolescents more

successfully meet recovery demands such as minimizing hospital recovery time and attending school (LaMontagne et al., 2004).

Although little information exists about effective ways to support adolescents throughout their return to school following SFI surgery, there is available literature on supporting school reintegration and school functioning for other medical conditions and/or illnesses. One strategy commonly used to support children and adolescents with other medical conditions is the use of a school reintegration program. School reintegration programs provide a framework for consultation between school and health care systems (Prevatt, Heffer & Lowe, 2000). Most school reintegration programs are used following a prolonged school absence due to a medical illness (e.g., cancer, burn). They typically take the form of school personnel workshops, peer education initiatives, and/or the development of an individualized comprehensive plan for the student who is returning to school (Canter & Roberts, 2012). School reintegration programs have been shown to be effective in increasing illness-specific knowledge and generating positive attitudinal change in teachers and peers and can therefore serve as an evidence-based support strategy (Canter & Roberts, 2012).

A framework for supporting adolescents following SFI surgery similar to school reintegration programs developed for other medical illnesses is currently not available. This is not surprising, considering our currently limited understanding of adolescents' experiences in returning to school following SFI surgery. Considering their effectiveness for other conditions, however, the concept of a school reintegration program could be an important support strategy to consider for scoliosis populations. That being said, school reintegration programs developed for populations other than scoliosis cannot simply be applied without some modification and consideration of unique needs of adolescents returning to school following SFI surgery.

Although current school reintegration programs provide an important model, it is important to ensure a program applied to the scoliosis population addresses the unique needs of adolescents recovering from spinal surgery in a specifically tailored and comprehensive manner. For example, as reviewed above, research indicates that a school reintegration program for this population would likely need to specifically address body image and self-perception concerns, reduced activity level and pain.

Some of the unique challenges adolescents face following spinal surgery have been identified by the quality of life outcomes literature (e.g., body image, activity level, pain) however, an investigation specific to the school setting is lacking. Consequently, the school-related challenges adolescents face when returning to school after spinal surgery are not well understood. Prior to creating a program aimed at supporting adolescents with scoliosis following spinal surgery, the return to school experience must be examined more thoroughly. With this in mind, the goal of the current study is to explore adolescents' return to school experience following SFI surgery for idiopathic scoliosis. Specifically, the current study will examine three aspects of participant's school reintegration experience. First, it will explore challenges participants faced during their return to school. Second, it will explore whether or not pain influenced their return to school and if so, how. Third, it will explore supports participants received and believe would be useful for future patients.

By examining the school reintegration experience of adolescents who have undergone SFI surgery, this study will identify challenges adolescents face and consequently, will highlight areas in which school and health care professionals may wish to offer support in the future. This study will also identify strategies that adolescents who undergo SFI in the future and their parents may wish to use independently of their healthcare and school teams. This study will also

broaden our current understanding of the impact of pain on adolescents' return to school following SFI surgery and consequently, could inform the development of appropriate recommendations for school-based pain management. Finally, this study will identify current school reintegration supports that school and health care professionals can continue to use and could also inform recommendations regarding the development of a more comprehensive framework for supporting adolescents in their return to school.

Method

Research Design

Interpretative phenomenology, based on Heideggerian philosophy, was used to examine adolescents' return to school. An interpretative phenomenological study focuses on meaning being derived from the perspective of an individual's position within time and place (Conroy, 2003). Meaning is considered within a context of the past and present, which influences future possibilities and is shaped in relation to structures of the world. Therefore, an experience never exists in isolation and instead is subjectively lived in the world around the individual (Heidegger, 1926) and therefore is best understood from one's everyday experiences. Interpretative phenomenological research extends our understanding of a phenomenon beginning with the participant's interpretation of their own stories in the telling, and the researchers' interpretation of these experiences, which is informed by the literature (Conroy, 2003) and their own lived experiences (Smith & Osborn, 2008). As a result, adolescents' individual experiences with school reintegration were interpreted from the lens of the principal investigator and expanded by the co-investigators to generate meaningful insights within this participant group.

Participants

Participants for this study were recruited from a longitudinal study currently being conducted in the Centre for Pediatric Pain Research at the IWK Health Centre in Halifax, Nova Scotia. The goal of the longitudinal study is to examine the prevalence, predictors and consequences of pain following major surgery, particularly SFI surgery for AIS. The longitudinal study aims to recruit approximately 300 10-18 year old children scheduled to undergo SFI surgery at the IWK Health Centre and six additional participating sites across Canada. Participants from the IWK longitudinal study site who consented to being approached about future research and met the inclusion criteria discussed below were invited to participate in qualitative interviews about their return to school experience.

Sampling Strategy. To achieve saturated themes, Morse & Richards (2002) emphasize that the sample in qualitative research must consist of individuals who have an intimate knowledge about the research topic; therefore, this study recruited participants who recently underwent SFI surgery and returned to school. Differing from quantitative methodology, Morse & Richards (2002) indicate that qualitative methodology uses a homogenous, as opposed to random sample; thus, the current sample was limited to females between 13 and 17 years old. This study recruited only females because they make up the majority of the longitudinal sample and because females are more likely to require surgical treatment than males. Although SFI surgery can occur between the ages of 10 and approximately 18, the majority of participants in the longitudinal sample fell between the ages of 12 and 17, limiting the feasibility of recruiting a broader age range. Finally, to participate in this study, participants must have returned to school at some point before the interview, as their return to school experience is central to the investigation.

As indicated by Smith, Bekker & Cheater (2011) the depth of data gathered is critical in qualitative data analysis. To ensure our ability to describe and interpret a range of themes associated with participants' school reintegration experience this study aimed to recruit 8-10 participants. A range of as low as five to as high as 15 participants has been indicated as an adequate number of participants to allow for in-depth and rich data analysis; however, sampling ceases once data collected is judged to provide an in-depth rich personal account of the phenomena with no new themes emerging from the interviews (Smith & Osborn, 2008).

Sample Characteristics. The final sample consisted of eight female participants. Nearing the sixth interview, data analysis began to reveal similar concepts. By the eighth interview, the interviewer did not hear any new concepts and no new codes were introduced, indicating that sampling was completed. Sample characteristics are detailed in Table 1. At the time of their participation in the study, participants ranged between the ages of 13-17 years with a median age of 15. They were in grades 8-12 with a median grade of 9. At the time of their surgery, participants ranged between the ages of 12-15 years with a median age of 14 and were in grades 7-10 with a mode grade of 8. Participants reported a hospital stay ranging between 5-8 days with a mode of 7 days. Participants reported missing between 0 (due to surgery occurring over summer break) to 9 weeks of school with a mode of 4 weeks. Three participants had surgery over the summer break. These participants spoke about many of the same challenges and supports as participants who had surgery during the school year and the final analysis is representative of their experiences as well.

Measures

Demographics Questionnaire. Participants completed a brief demographic questionnaire prior to participation in this study (see Appendix A). The questionnaire consisted

of questions about participants' current age, age at the time of surgery, grade at the time of surgery, school attended at the time of surgery, length of hospital stay following surgery, and number of school missed after surgery.

Semi-Structured Interview Guide. A semi-structured interview guide was used to interview participants about their return to school following SFI surgery (see Appendix B). Minor changes to question wording or format were made based on participant responses but content remained the same across interviews.

Procedure

Ethics. Prior to beginning data collection, ethics approval was obtained from the Research Ethics Boards at the IWK Health Centre and Mount Saint Vincent University. The methods used in this study adhered to the Canadian Code of Ethics for Psychologists (CPA, 2000) and the Canadian Institutes of Health Research Tri-council Policy Statement (2010).

Recruitment. Prospective participants who had consented to being contacted about future studies were sent an invitation letter describing the study and requesting that they contact the Centre for Pediatric Pain Research should they wish to participate. Prospective participants were also contacted via telephone to discuss whether or not they were interested in participating in the study. This telephone call was made by a research assistant who had previously collected data from participants in the broader longitudinal study. Prospective participants were not contacted any more than three times regarding participation (e.g., one letter, one voicemail, and one telephone conversation).

Data Collection. After participants expressed an interest to participate in this study, a time was scheduled between the interviewer and participant for an in-person interview. To make participation in the study accessible and convenient for participants, the interviewer travelled to

the participant's home to conduct the interview. In the event that a participant preferred not to have the interview take place in their home, the Centre for Pediatric Pain Research was offered as an alternative location. Daytime, evening, and weekend options were provided to meet the participants' needs. To protect the participants' confidentiality, the interviewer requested that the interview take place in a private room with a closed door or an open space where others were not close by.

Considering participants were recruited from across the Maritime provinces and interviews took place offsite in participant homes, a plan was developed to ensure the safety of the interviewer. Another researcher associated with the study, was informed about where the interviewer was going and when they anticipated returning from the interview. If the interviewer did not make contact at the anticipated time, the safety plan provided steps for the additional researcher to follow to ensure the interviewers safety. Previous researchers had multiple contacts with prospective participants through the longitudinal study and no concerns were raised about safety issues by the research staff. This fact enhanced confidence that participants were located in safe homes that did not pose a threat to the interviewer. Participants were also offered a choice to complete the interview by telephone if they were not comfortable doing so in person, as this has been shown to be an effective method for establishing rapport and conducting interviews (Lingley-Pottie & McGrath, 2006).

Informed consent was obtained from participants immediately prior to participation in the interview. The interviewer reviewed the informed consent form with the participant and allowed for questions and/or discussion prior to the participant signing the consent form.

Interviews. The length of participant interviews ranged from 30 minutes to 1.5 hours. The interviews were audio recorded and transcribed with all identifying information removed

from the transcripts. Both the audio recordings and transcripts were stored in a secure location in the Centre for Pediatric Pain Research at the IWK Health Centre in Halifax, Nova Scotia. Audio recordings were destroyed after transcription leaving the transcript as the only record of data.

The transcripts remained stored in a secure location in the Centre for Pediatric Pain Research at the IWK Health Centre in Halifax, Nova Scotia.

Data Analysis

Interpretative Phenomenological Analysis (IPA). Interpretative Phenomenological Analysis (IPA), as described by Smith and Osborn (2008), provides a flexible guide for conducting a thematic analysis of interview data to understand individual experiences of a phenomenon under study. Interpretative phenomenology is informed by the philosophical writings of Heidegger (1926) and acknowledges that experiences of a phenomenon can have multiple meanings. Phenomenology, more generally, generates knowledge through its goal to seek meaning and describe a phenomenon under investigation. It aims to increase the readers' sensitivity to the human condition rather than provide specific theory for generalization (Crist & Tanner, 2003).

IPA, in particular, is well suited to study phenomena or topics that are contextual, subjective and relatively understudied (Smith, 2004). IPA is also well suited for exploring how individuals make sense of their personal and social worlds (Smith, 2004). Considering the limited research on adolescents' return to school following SFI surgery, the use of IPA allowed participants to tell their stories and offer a foundation to build an understanding of their experiences. Furthermore, IPA has been noted as particularly appropriate for health related research due to the subjective nature of an individual making sense of their health condition (Smith, Jarman & Osborn, 1999). For example, chronic pain is thought to lend itself well to IPA

because it is widely recognized that the individual's subjective meaning of the pain experience influences the relationship between their pain, distress and disability (Smith, Jarman & Osborn, 1999). Given that participants in this study experience a chronic illness, scoliosis, and little is known about the experiences of adolescents returning to school after scoliosis surgery, IPA, with its attention to individual experiences, is appropriate for this study.

Conducting Analysis. IPA has a central principal of focus on idiographic findings, or attention to individual accounts, and therefore, the process of generating meaning is conducted by ensuring that each participant's experience is included in the analysis. Smith and Osborn's (2008) steps to IPA begin with a close examination of each interview. In this study, this step included listening to the audio recording of each interview and closely reading each transcript. As each interview was examined, initial impressions of the text were coded and recorded in the margin of the transcript. As indicated by Smith and Osborn (2008), codes were conceptualized as descriptors of significant or recurrent meaning in the transcripts and capture the meaning of the participants' words. After the initial examination of the transcript, emerging themes (informed by the codes) in each interview were generated. A theme differs from a code in that it is a higher-level interpretation of an underlying concept that draws codes together. This examination resulted in a list of primary themes for each interview. Within each primary theme, subthemes were also identified. Subthemes include information that supports the primary theme and demonstrates where it is located in the transcript. After this examination was conducted on each individual interview, themes representative of the entire participant group were established. At this point of the analysis, themes transitioned away from descriptions of an individual account towards an abstract entity that brings meaning and identity to a recurrent experience and consequently, unifies the individual experiences into a meaningful whole (DeSantis & Ugarriza,

2000). In the final phase of IPA, themes representative of the participant group were arranged into a narrative account supported by verbatim quotes from each participant. Participants were assigned pseudonyms to protect their anonymity. Further refinement of the themes occurred during the writing phase, which is supported by Crist & Tanner (2003). The interpretative component of IPA allowed the researcher to provide a critical and conceptual commentary on what it means for participants to have shared their individual experience in relation to broader contexts such as school and health care systems (Larkin, Watts & Clifton, 2006). At this point, a second reader reviewed the final written narrative along with the eight individual transcripts to ensure the analysis was grounded in participant interviews and all participants were equally represented.

Rigor. Rigor is the demonstration of integrity in the research process (Tobin & Beagley, 2004). The appraisal of rigor in qualitative research is a point of debate (Morse et al. 2002). Both the concepts of trustworthiness (Lincoln and Guba, 1985) and goodness (Tobin & Beagley, 2004) are considered to be acceptable methods for evaluating the legitimacy and rigor of a qualitative study. Trustworthiness and goodness, however, differ in the criteria they use in the evaluation of a qualitative study. Trustworthiness involves establishing credibility (i.e., confidence in the findings), transferability (i.e., findings have applicability in other contexts), dependability (i.e., findings are consistent and could be replicated) and conformability (i.e., findings are shaped by respondents not researcher bias). Goodness, in particular, has been advocated as appropriate for evaluating rigor when a more interpretative method is used (Arminio & Hultgren, 2002; Tobin & Beagley, 2004). Considering this study uses an interpretative approach (i.e., IPA), goodness as described by Tobin & Beagley (2004) and Morse et al., (2002) was used. As indicated by Morse et al., (2002) the six goodness criteria and means

by which this study implemented them are as follows: (1) foundation—IPA as it acknowledges individual experiences and multiple meanings; (2) approach—congruency between IPA, one-on-one interviews and inclusion of researchers interpretative lens; (3) method—audio-recorded and transcribed one-on-one interviews; (4) representation of voice—quotes included from each participant, meetings with committee including a qualitative expert to ensure that the themes are grounded in the interviews as advocated by IPA; (5) art of meaning making—interpretation focused on impact of SFI surgery on return to school from participant perspective; (6) recommendations—school and health care personnel/system implications and areas for future research were identified.

Representativeness and Transferability. The desire to generalize research findings to broad populations is common and, consequently, large, randomized samples are typically sought when conducting experimental studies. The goal of the current study is to provide an in-depth personal account of the phenomenon of returning to school following spinal surgery. With this in mind, the current study sample is representative (i.e., selected by means of theoretical sampling for their ability to provide information about the area under investigation, all participant voices are heard and represented by quotations) as opposed to generalizable (i.e., selected by statistical means where the study sample is matched to the study population at large to ensure comparability). Morse & Richards (2002) suggest that although qualitative research is not statistically generalizable, it is generalizable in a different sense. The term used to describe this is transferability. Transferability means that theory developed within one study can be used to provide an explanation of the experiences for other individuals who are in comparable situations experiencing the same phenomenon. Transferability is an activity taken on by the reader. After reviewing the findings, the reader decides whether or not the findings are potentially transferable

to those they care for and/or work with. In order to ensure potential transferability in the current study, the researcher was transparent about the research process and provided a detailed description embedded with participant quotations to communicate participants' return to school experience to the reader.

Results

The core theme that unifies the experiences of these participants was *Recovery to Fitting in at School*. These participants, who had been living with scoliosis for many years, not only had to recover from an extensive surgery but also had to find ways to cope during their recovery to enable them to return to school. Following surgery, adolescents experienced a process in which they had to recover and then work towards fitting in at school. This process was challenging and multifaceted. Participants were driven to return to a sense of normalcy and it became clear that there is an inextricable link between school and almost everything else in adolescents' life. Attending school is the job of childhood, making it a benchmark for normalcy. This left adolescents feeling that, until they returned to school, they hadn't returned back to normal. Two intersecting themes, *Needing to Return to School* and *Finding Their Way*, assist in bringing forth an understanding of the return to school experience of these adolescents. These two themes represent a conceptualization of participants' experiences; however, absolute delineation of a phenomenon into parts is artificial because it denies the integrative experience of the whole (DeSantis & Ugarriza, 2000). Thus, these two themes offer a concise retelling of participant experiences and overlaps between and among these themes exists. To fully represent the data these two themes are each further divided into two subthemes and these subthemes were further divided into discussion headings. A diagram of the findings are presented in Figure 1.

Theme 1: Needing to Return to School

School is a primary site of an adolescent's life. It is the setting in which they are expected to learn, develop relationships and mature towards independence. For participants in this study, their school life was temporarily disrupted by major surgery. Undergoing surgery precipitated what would prove to be a challenging return to school. Despite facing these challenges, participants both desired to and needed to return to school. Nevertheless, not all participants experienced the same challenges nor did they share the same motivating forces, illustrating the individuality of what underlies both struggle and motivation.

Theme 1 Subtheme 1: Facing the Challenges

Participants found themselves facing significant challenges in their return to school following surgery. Although there were individual differences in the nature and magnitude of the challenges faced, all participants found themselves navigating some challenges. One common challenge was pain, which had been present during their recovery and throughout their return to school. A second challenge faced by all participants was the tension they felt with their self-image and dissatisfaction with the way their body looked before and surgery. A third challenge faced by participants centered around managing varying levels of teacher and peer understandings.

Coping with Pain. As their surgery drew nearer, participants described experiencing an increasing amount of pain. This pain was described as being exclusively located in their back. Emily (age 15) identified that her biggest challenge in living with scoliosis and having surgery was the constant pain, "Just a constant, almost constant pain."

In other cases participants experienced less constant pain, however, they acknowledged that they regularly experienced pain that could be brought on by various activities both before and after surgery. Here Taylor (age 14) offers several examples of activities that exacerbated her

pain.

The only time it would hurt if like for um, my pain in the back if I was to stand for a long time, walk, or sit for a long time.

Usually it hurt a lot like if we were to go shopping, well it depends sometimes it was a couple hours sometimes it was an hour depending on the day.

If we were out like, on a little vacation or on a road trip or something, the more I was doing the more likely pain would happen.

Gym class was also identified as a possible precipitant for pain. All participants were advised to refrain from participating in gym class in order to allow for successful bone fusion and to reduce the likelihood of exacerbating pain during their recovery. Participants experienced mixed feelings about their inability to participate in gym class. Taylor (age 14), for example, indicated that, for the most part, she did not mind missing gym class. However, she highlighted that at times she found sitting on the sidelines difficult.

Gym I couldn't do for the whole year, I mean it didn't really hurt me because I don't really like gym but some things, some days I would have wanted to go out, like they were doing a fun thing and I couldn't do it like just like I would sit and do work.

Kate (age 13) on the other hand, enjoyed gym class and found it challenging to miss out on this experience. "I really like gym, so it was kinda hard to sit there and watch everyone do it."

For participants, managing pain at school before and after surgery was difficult. Some described how pain made it difficult for them to meet even the simplest demand of school—to sit in class. Courtney (age 17) highlights here that sitting for extended periods of time in class chairs was challenging. "Going to school and sitting in class all day, that was really hard for me cause I was constantly in pain." School presented other physical challenges to these participants when trying to manage their pain at school. Not only did classroom chairs exacerbate pain, but many participants struggled to manage school materials including books and bags or navigate the other physical demands of school. These adolescents found carrying heavy book bags on top of their

preexisting pain difficult both before and after surgery, while others found bending and reaching into their locker painful. Courtney (age 17) describes these physical challenges, which others voiced as well.

When you have to carry like a heavy bag, that was hard cause my back would already be hurting and then to have to carry a bag on top of that would hurt. I had a bottom locker so like, it was hard for me to always bend over cause my back would always hurt.

Pain also proved to have implications for participants' ability to pay attention in class and, in some cases, sustain full day attendance. Emily (age 15) talks about having difficulty focusing on anything other than pain and how her pain took a toll on her coping ability by the end of the day.

Harder to concentrate yeah. Cause when you are in pain you don't really concentrate on much else. I would be miserable and exhausted when I'd get home and be in so much pain, but I'd just, grin and bear it, grin and bear it, grin and bear it.

Other participants were unable to tolerate the severity of their pain and occasionally had to go home as noted here by Courtney (age 17) "A couple times I went home early just cause it was so bad."

Managing Body Dissatisfaction. Scoliosis is a visible illness presenting physical abnormalities in the back, shoulders, hips and ribs. Considering this, combined with the importance of body image during adolescence, it is not surprising that all the participants discussed the need to manage complicated feelings about their physical appearance. Participants were clear that, for the most part, they were not satisfied with the way their body looked prior to surgery. They highlighted characteristics such as bumps on their back, protruding ribs and disproportionate hips. For example, Julia (age 15) discussed a dislike for her back and hips, saying, "I didn't like the lump on my back and I didn't like my hips or anything." Others described their structural body differences in negative terms such as 'weird' as noted by Kelly

(age 13), “There was a bump. It was weird” and Lisa (age 15), “It’s just weird. I had a rib popping out.” Negative language to describe their bodies was not uncommon, as evidenced by Emily talking about being physically deformed by scoliosis, “The way that it kind of physically deformed me.”

When reflecting on the implications of feeling ‘weird’ and ‘deformed’ as a result of scoliosis, participants longed for a sense of normalcy in their physical appearance. They felt self-conscious about the way they looked and viewed themselves as different. In describing her body image, Emily (age 15) described feeling self-conscious about her body and expressed her wish to appear the same as other adolescents; “It’s so annoying because I just want to be a normal person.”

A critical consequence of participants’ structural abnormalities was finding clothing that fit their body in a satisfactory way. Participants described finding clothing difficult, Kate (age 13) discussed how challenging it was to find clothing before surgery. She also discussed how this made shopping, a frequently enjoyable activity for adolescent girls, unenjoyable for her.

I was so twisted before it was hard to get clothes. Back to school shopping was really hard because everyone took the nice clothes that might have actually fit me, and then left the stuff that probably wouldn’t fit me so that sucked.

Emily (age 15) echoes Kate’s challenging experience with shopping. Unfortunately for Emily, the difficulty in finding clothing that fit continued after her surgery, which she acknowledges here.

It’s gonna be a bit hard for me to buy certain clothes later on...Cause my rib and my shoulder blade sort of stick out. They sort of stick out, and my rib prominence is still there. One side of me is relatively straight, the other one it nips in at an angle.

An additional critical consequence of their structural abnormalities was the reduced activity level participants experienced before and after surgery. Participants discussed how the physical limitations posed by the condition itself further impacted negative feelings about

themselves. Courtney (age 17) illustrates this point in her discussion of not being able to perform to the level of her peers in gymnastics.

I was in gymnastics and as you start to progress like you do more flips and stuff and it would be harder for me to do the backwards flips because, like, my spine was crooked and they just like, they didn't look as clean as it should when you do them so, I also started to get angry with that cause I, it was preventing me from progressing with gymnastics.

For most of the participants, but not all, their body image improved after surgery. For those who experienced an improvement in body image, the result was a positive effect on their view of self. Courtney (age 17) expressed that she no longer felt like an outcast as she did prior to surgery, "I finally felt like, okay I don't look like an outcast anymore." Others like Lisa (age 15) declared the positive change in her view of self as no longer looking different, "It [surgery] really helps to bring up your self esteem."

Nevertheless, concerns with body image continued even for those with an overall improvement in the way they viewed their body. This speaks to the importance of body image during adolescence. The most common physical appearance concern post-surgery was that of the large scar resulting from surgery. The need to conceal this scar highlights the continued struggle to be physically normal. For example, Courtney (age 17), who identified no longer feeling like an outcast, talked about actively hiding her scar:

It's [scar] visible and it doesn't look pleasant so I don't like wearing my hair in ponytails cause I feel like people will just look at it and think that it's something weird. I just I think it looks gross.

The range of emotions that their surgical scar caused ranged from dislike of its appearance as being ugly to feeling ashamed. Despite improvements in many participants' body satisfaction following surgery, feelings of shame imply some form of responsibility for the appearance and

may contribute to one's continued negative body image. As an example, Emily (age 15) describes her fear of her scar being seen by others:

I am terrified by the, should anyone see it [scar] cause I don't know it's sort of like, I don't know, I don't know why but I feel sort of ashamed of it.

Kelly (age 13) echoes Courtney and Emily's concern about their post surgical appearance and the continued body image challenges:

I went shopping a little while back and there were these beautiful tops. And it was beautiful except for the fact was it had a cut out back and even though there were ribbons across. I'm very self-conscious about my scar, I don't want to show anybody.

Overall, the majority of the participants reported feeling happier with their body. Yet, many continued to report concern. For some this continued concern was centered on hiding their scar, whereas a few still experienced physical differences such as protrusions of their hip or shoulder blade in addition to the surgical scar. Thus, for these adolescents, it was not the case that surgery completely eliminated body image concerns. Surgery improved the way most adolescents felt about their body, but some concerns persisted, demonstrating the complex nature of their feelings of body satisfaction.

Navigating Variable Teacher and Peer Understandings. The last prominent challenge adolescents faced in their return to school following surgery was navigating the range of teacher and peer understandings. Participants had mixed experiences when describing their teachers' and peers' understanding of their condition and of their surgery. Most found that their teachers were sympathetic and tried to be responsive to their needs; however, most found that their teachers did not always understand the extent of their surgery and/or needs during their return to school. For example, Lisa (age 15) said, "I don't think they got it necessarily. The extent of the surgery." Echoing Lisa's concern, Kate (age 13) highlighted the variable nature in people's understandings.

She found that while some people understood the needs associated with scoliosis and surgery, others did not: “Some people didn’t really understand it as well as other people.”

Participants wished that people around them, particularly their teachers and peers, had an increased understanding of their needs. Kelly (age 13) says, “[I want] people to understand it more.” In some cases, not only did participants wish teachers had a greater understanding of their needs but they actually faced resistance from teachers when attempting to advocate for themselves. For example, Kate (age 13) discussed an experience before her surgery where a teacher did not allow her to stop an activity she felt she was unable to do and suggested instead that she was intentionally avoiding it.

In gym class like I know my teacher would normally never let me stop like even if I said my back is killing me, I can’t do anything anymore, some of my teachers would not be accepting and they’d go on and be like no you still have to do it like you’re not getting out of it.

Demonstrating the variability in participant experiences, some participants felt their teachers understood and responded to their needs adequately. For example, Sara (age 15) was satisfied with her teachers degree of understanding, “I find the teachers were very understanding.” Lisa (age 15) found that not only were her teachers understanding but they actively engaged in supporting her recovery, “They helped me with my work and they made sure that I was lifting the right amount.”

A similar trend was voiced with respect to peer understandings of the condition and the surgery. That is, participants felt that some of their peers understood their condition and were responsive to their needs whereas other peers and friends were not. Emily (age 15) found her peers to be very helpful during her recovery.

My classmates were incredibly awesome to me because I was still recovering and I was still at home. They sent me this giant gift basket, gift box.

However, Kate (age 13) found her peers to be less understanding and helpful at times:

If someone says ‘come on let’s do this’, I’d say like ‘no I can’t’ and if they ask why or something I’d just say like I can’t do this, doctors said I can’t do that and some of them, they can be not understanding.

Courtney (age 17) observed a difference between males and females. While she found her peers to be unhelpful and not understanding overall, she found her female peers to be more understanding than her male peers.

They just didn’t understand like how much pain it can actually cause. Sometimes they just say like ‘oh, that’s not even a big deal’ and I know they were just saying that just to be, like, supportive but in my mind I was like you don’t understand like I’m always hurting, you’ll never understand. I found that the girls were more like accepting of it than the guys cause the guys would kinda make fun of you.

In some cases, participants’ experience extended beyond feeling that peers didn’t understand them to facing taunts and slurs from peers and even friends at school. These comments on their physical limitations and appearance contributed to negative views of self. Kate (age 13) shares how she was bullied by peers she once considered her friends.

It affected a couple of my friendships. They were just rude, sometimes, to me. I’d get bullied a lot for it from my friends so they weren’t really my friends, I guess. They’d call me ‘hunchback’, they’d like, yell at me like, ‘sit up straight’.

Courtney (age 17) also discussed the impact of facing negative comments from peers suggesting that peers did not recognize the effect of negative comments.

What they would say is like ‘oh so when you grow up like you’re gonna be a hunchback’ and it was just kinda like, you know, honestly I didn’t really know like maybe I would be a hunchback so it was just kinda like, it kinda scared me when they said stuff like that. It’s like you don’t understand, like don’t say that cause it freaks me out.

Theme 1 Subtheme 2: Being Motivated to Return

Adolescents faced significant challenges throughout their recovery and return to school; however, despite these challenges, participants were motivated to return to school. While some participants were motivated to return to school for academic reasons, the most salient motivators for participants were their peers and social networks.

Return to Friendships. As a result of the above-described challenges, most of the participants described being exhausted and perhaps not ready physically for the long periods of sitting and concentrating required in the classroom upon their return to school. Lisa (age 15) described returning to school as, “It’s tiring. It’s exhausting.” Despite this difficulty, participants discussed a number of motivators for their return to school. For participants the social function of school was more important than its academic function. Sara (age 15) expresses how her friends were a driving force for her return to school:

I see my friends there [at school] which is good because my friends don’t typically live too close...so this way I can at least see them and it feels good because I really really really love my friends, they’re like my sisters.

The desire to meet and interact with friends was echoed by most of the participants as a motivation to return to school and is shared here by Emily (age 15).

I like interacting with my friends and uh like, I don’t know, like I can’t say I like doing schoolwork.

Considering the importance of peer relationships during adolescence, it is not surprising that the social function of school was a primary motivator for participants’ return to school. They also indicated that their absence from school left them feeling somewhat isolated, as they were disengaged from what was taking place socially. Lisa (age 15) described being away from school during her recovery as “lonely, cause all your friends are at school.” Others, like Sara (age 15), voiced the need to re-engage with friends, “Cause I was like getting done with being at home and needed to go socialize.”

Although school as a social site was a significant motivator for many of the participants to return to school, other participants voiced that re-engaging with social activities outside of school was of equal or more importance. This need to engage with friends and feelings of loss that resulted when they missed social activities highlights the importance of socializing with

peers for adolescents. Undergoing scoliosis surgery and its subsequent recovery was disruptive not only to peer socialization at school but also outside of school. For example, Lisa (age 15) and other participants reported that she was "...not able to do some of the stuff. Like go out shopping with my friends. Like I wasn't able to do that." Similarly, Kate (age 13) recalled feeling "...quite upset that I couldn't go [to sleepover] cause all my friends were going."

Return to Academics. In addition to social relationships, participants also acknowledged a desire to return to school for more academic reasons, such as avoiding becoming further behind in their schoolwork and ensuring their future academic success. Julia (age 15) indicated that she wanted to return to school in order to learn and avoid missing schoolwork. "I like learning so I can look forward to my future...I don't like missing much schoolwork." Others discussed being fearful of failing classes and even the school year if they did not return to school relatively soon as noted in this quote from Emily (age 15). "I knew I had to go back cause otherwise I would have failed grade 8 and I was not doing that."

Theme 2: Finding Their Way

In the face of challenges presented by surgery, adolescents were left to find their way through recovery to their return to school. The participants in this study were highly motivated to overcome the challenges they face and reintegrate to school. They discussed a range of strategies they discovered individually to assist them during their return to school. Although returning to school was not easy, participants successfully learned to cope with the challenges they faced. Throughout the school reintegration process, it became clear that navigating the complexities of the return to school would largely fall to themselves or their parents.

Theme 2 Subtheme 1: Learning to Cope

Due to the large number of challenges these adolescents faced in their return to school, participants talked at great length about the strategies they developed to support themselves. As opposed to being explicitly coached by adults around them, adolescents talked of discovering the majority of these strategies on their own. They discussed ways in which they handled the challenges they faced in order to ensure their successful school reintegration.

Managing Pain. Participants drew on a number of strategies that aligned with pain management strategies discussed in the literature including distraction, relaxation, and breaks and/or pacing. Interestingly, when adolescents were asked if they had been instructed to use these strategies by the healthcare team, their response was overwhelmingly no. Participants identified trying a number of different strategies independent of specific coaching and continuing with the ones that they found helpful. For example, Emily (age 15) noted that both resting and distraction were helpful in managing her pain during her recovery at home and for her first two weeks back at school, stating, “lying down, sleeping, distraction. Sometimes with books, sometimes with the television, sometimes with my hand-held game console, other times with a computer.” Courtney (age 17) also talked about using distraction while recovering from surgery at home.

I was always focusing on something so whether it would just be reading a magazine or doing something on the computer like I was always occupying myself so that I couldn't think about the pain as much.

Participants found taking breaks from activities both inside (e.g., break from class blocks) and outside (e.g., grocery shopping) of the school environment necessary for managing their pain. Taylor (age 14), echoed the sentiments of other participants when she noted that she would “...sit down for a while and take a break from whatever I was doing” when she began to feel pain or fatigue. In contrast, Julia (age 15) found walking to be helpful for managing her pain at

school, noting that this activity allowed her to move and stretch her back: “I just went outside one day for a walk and it helped.” Kate (age 13) echoed Julia’s point and also found movement helpful; Kate’s teachers were also understanding and supportive of incorporating this into her school routine:

Move around, ask to go to the bathroom, just to walk around and get back to normal, but my teacher’s really understanding. Okay, her back’s sore, we can just let her go to the bathroom.

Whereas the majority of participants felt comfortable using strategies such as breaks and stretching, not all participants felt willing to do so. Kelly (age 13), for example, felt apprehensive about leaving class for fear of what others around her might think. Again, demonstrating the powerful influence of self-perception during adolescence, Kelly and other participants preferred to tolerate pain and/or allow it to build up as opposed to appear different in front of their peers. For participants, the desire to appear “normal” was important. Instead of modifying the typical school routine, Kate talks about waiting until regular scheduled breaks to get up and stretch.

I don’t like to go to the bathroom and get a drink in class cause I just, don’t like doing that so I just like sit through it and then, when the bell rings I just like get up and walk around then go to class.

New Ways to Manage Materials and Self. For participants, managing heavy books and school materials was difficult during their immediate return to school. Adolescents were advised not to lift more than five pounds by their healthcare team and consequently, needed to navigate managing their school materials, which often exceeded this limit. Lisa (age 15) suggests that figuring out how to manage materials at school is challenging, “Managing like the amount I can lift and not, even still now it’s pretty hard cause I only have a certain amount I can lift.” Kate (age 13) echoes Lisa’s concern and highlights the wide range of materials that she had to transport from class to class, “Textbooks, scribbles, and binders, and that to each class so it was

kinda hard.” Lisa (age 15) found leaving certain books in the classroom as opposed to carrying them from class to class helpful as she states here, “Certain books, like if I had a lot of books, I would set them aside so I didn’t have to bring them all.” Whereas others, like Courtney (age 17) arranged to have a top locker to alleviate the need to bend and lift heavy books. “I had to request a top locker so I wouldn’t have to bend over anymore just in case my books were heavy.”

In addition to managing their materials, participants also had to find new ways of moving through busy school hallways and environments to protect their back during recovery. Similar to the trend observed with pain management strategies, participants’ openness to doing things that may cause them to appear different than their peers was a concern. Participants spoke of being given permission to use the school elevator or leaving class a few minutes early to avoid busy hallways. Whereas participants generally acknowledged these strategies to be helpful, most reported they did not use them and preferred to walk through the hallways with their peers the same way they had done prior to surgery. Rather than implementing strategies that would single them out among their peers, many participants, such as Kate (age 13), talked about using caution in busy school hallways and spaces such as the cafeteria for the first few months back at school: “I was careful like, okay I have to be careful not to get bumped into like the wall or another person.” Again, this point highlights the sensitivity of adolescents to the image they present to others around them and their careful consideration of ways in which they can fit into regular school routines and appear “normal”.

Keeping up with School Demands. Participants found attending school for the entire day and completing schoolwork difficult when they returned after surgery. They discussed a few critical strategies they used to cope. First, a number of participants found that a gradual return to

school was helpful, rather than immediately attending school for full days when they first returned to school. Sara (age 15) described her gradual return to full time school.

For like the first couple days I just went for like an hour and a half in the afternoon and then like it was like two and a half hours, like you just, after a couple of days of doing like an hour and a half.

Emily (age 15) hypothesized that had she attempted to return to school for full school days at the outset she may have become overwhelmed and discouraged from attending school at all.

I would go for a few hours in the morning then I'd go back home. So getting back gradually really did help. Because otherwise I would have been, I would have been like 'nope, I'm not doing this'.

Reflecting participants' need to return to normalcy, many of the participants indicated that, whereas gradually increasing the time spent at school was helpful, they looked forward to being at school for the full day. This desire to return to full days is illustrated here by Lisa (age 15) when she says, "[Returning gradually] was helpful, but I didn't really like it. I liked being there for the full day."

Second, both private tutoring and public tutoring offered by the school was mentioned as a frequent method to help manage missed instruction and schoolwork. Some participants reported receiving private tutoring from a family member, whereas other families hired a private tutor. Emily (age 15) discusses receiving support from a grandparent during her recovery at home. She describes the consequences and feelings of urgency shared by many participants to complete missed schoolwork efficiently to protect themselves against negative outcomes such as a drop in grades.

Eventually I got my schoolwork and had to get caught up cause otherwise it wouldn't have been good cause some of my marks would have dropped. My grandmother came and she started home schooling me a little bit.

Some participants had the advantage of working with a private tutor, which had the benefit of instruction to facilitate their understanding of concepts thus making it easier to complete the missed schoolwork. Lisa (age 15) reports that she "...did a lot of school work at home with [her] tutor. It was really helpful I think because she could explain it if I didn't get it", indicating that, for some participants, the added support of a tutor was a useful strategy to facilitate return to school.

It appears that privately arranged tutoring options tended to produce more favorable results for participants than publically offered services. Depending on the nature of individual families socioeconomic factors, this could limit access to tutoring for some adolescents having spinal surgery. Whereas a few participants mentioned that tutoring was discussed with their school, and in some cases even formally offered, publically supported tutoring through the school system did not materialize for any of the participants. The frustration associated with this is highlighted by Taylor (age 14):

We were supposed to have a tutor and we talked to the school district and everyone and they said they were gonna give us a tutor and we technically should have had one but the girl we had never came she kept cancelling on us. We were pretty mad about that. We phoned the school and told them but no one really seemed to...so that really upset me how no one in the school board or the tutor really cared when it's like a month of school so it's like a lot. We thought we'd get more support in that way.

Accessing Support and Educating Peers. As indicated above, peers' level of understanding of scoliosis and the surgery was variable. In some cases, participants found their peers to be helpful during their return to school. In particular, adolescents identified that their close friends helped them manage materials, protect their backs and checked in to ensure their needs were being met. Not all peers, however, possessed a strong understanding of participants' needs and, consequently, were not perceived to be overly helpful. Participants found that

providing specific peer education about scoliosis and surgery was a helpful way to increase understanding and compassion for their unique needs.

Demonstrating the helpfulness of close friends, Julia's (age 15) noted that "[her] friends carried my book bag and my books." Sara (age 15) described her friends as "protective" when they ensured that she wasn't bumped in the school hallways. Courtney (age 17) appreciated how her friends frequently checked in with her to see how she was managing and whether or not she required additional support: "They were always like asking me, do you need help with this, like, are you okay to do this." Finally, Kelly (age 13) found it helpful to talk to her friends as a form of distraction to manage her pain. "I guess just talking [helped] get my mind off of it."

Drawing on their ability to share their personal experience of living with scoliosis and articulate the experience of recovering from surgery, participants found ways to educate their peers about their condition. These adolescents found that sharing their personal story helped provide peers with increased illness-specific knowledge and understanding. Participants' individual creativity varied from giving class presentations, leading discussions, and/or showing images of their personal x-rays. For example, Emily (age 15) provided a presentation to her classmates with general information about scoliosis and included her personal x-rays:

I showed them my x-rays before and after. I was trying to find certain pictures, certain pictures cause for my class I wanted to show them something that wasn't too crazily severe. So I just showed them ones that had a slight curve like a tiny little 'c' curve to it, and with the after picture after surgery the spine was straight, straight as a line. It looked great and cured, it's gone. I had to show them my x-rays so I showed them what is, what the average would be and then I showed them mine.

Lisa (age 15) also showed her x-rays to her classmates. She highlights how openly sharing her experience helped increase peer understanding about scoliosis and the magnitude of the surgery:

Actually bringing in a picture of my x-rays was pretty cool. When they saw them they were like, 'wow, that's really cool and serious'. They got it more. I think they weren't sure how the spine was actually curving. And then the process of straightening it.

Taylor (age 14) reported that “I have a blog so the teachers and students looked that up during class a couple of times to see my story.” This was an effective way of sharing her personal story with peers and classmates.

Although some of the participants found educating teachers and classmates formally about their condition to be helpful, individual differences existed in participants’ comfort level with sharing their personal story. Given many of the participants’ significant concerns about body image, it may not be the case that all participants would necessarily endorse providing educating their peers themselves. Although participants in this sample discussed being open about sharing their personal story, it is possible that not all teens would be comfortable doing so. Interestingly, a number of participants who expressed apprehensions about using coping strategies that might have caused them to appear different from their peers also reported providing education to their classmates; this finding illustrates the highly complex, and sometimes contradictory, nature of coping in the context of returning to school following surgery.

Drawing on Others’ Experience. For participants, the process of preparing for, undergoing, and recovering from surgery was full of unknowns. Adolescents acknowledged that their healthcare team answered any questions that they had about the surgery and recovery; however, they also indicated that they would have liked to hear about the experience from others patients who had experienced it. A number of participants used online and in-person meetings with other youth and adults who had experienced spinal surgery to discuss the surgery and to clarify questions about the procedure. Participants reported feeling more at ease about the surgery after these conversations. Julia (age 15) spoke with another youth who had surgery and continued the friendship after recovery. Julia noted that even now that she has recovered it is useful to reflect on the experience with others who understand it from a first hand perspective:

Well there was this girl. She's graduated now, but she had the same surgery as me. And I talked to her a bit about, well before my surgery, what happened with her, and then I've just been talking to her afterwards. And she was pretty helpful.

Courtney (age 17) turned to the online community for support and found reading blogs and chatting on the Internet to be helpful:

There was a lot of blogs on the computer for like people with scoliosis. There's one called curvy girl's scoliosis and that one was really good it's like a bunch of girls around the world who have scoliosis and they just share their stories and you can talk to them about it.

Taylor (age 14) also actively sought out information online and found reading and watching videos answered many specific questions she had about surgery and recovery. Taylor noted that having answers to these questions helped ease her worry about the procedure and made her more confident about her ability to return to everyday life:

I'd do like, some research on the Internet and watch other people's like videos on YouTube to see what they went through. Yeah cause it got to show like, from the pictures and videos, what they would do in the hospital, what it was like when they went back to school.

In some cases, seeing and hearing about other peoples' experiences played a role in adolescents' decision to have surgery in the first place. In all cases, participants had little choice about proceeding with surgery due to the nature and severity of curve progression, but in some cases there was flexibility in the timing of surgery (e.g., this year or next year) and participants could elect to have surgery now or later. Participants found observing some of the potential long-term effects in others, either in-person or online, motivated them to have surgery sooner.

Courtney (age 17), for example, described seeing an individual who did not have surgery for scoliosis; witnessing the consequences of not having surgery helped her decide to have surgery.

My dad works with a lady that has scoliosis but she never had the surgery and she's like completely bent over now and she's always in pain and he just kinda said to me you don't wanna be like that, you don't wanna wait until it's too late and then regret it. And I would

look up images and stuff and see the degree that it could get to and I just realized like, I'm young I didn't even start high school yet I might as well do it now.

Maintaining a Positive Perspective. The last strategy adolescents used as a method for coping with the challenges they faced in their return to school was maintaining a positive perspective. Due to the severity of the procedure, participants were not always able to maintain feelings of hopefulness and optimism, but they indicated that they made a concerted effort to do so. At times, participants felt hopeless about their ability to cope. For example, when she first heard about the details of the procedure Courtney (age 17) recalled her reluctance to proceed, stating that, “the thought of, having rods in your back I was like, that's, I can never do anything again, that's what I thought.” At times during her immediate recovery, she also felt hopeless: “In the hospital I said to myself multiple times, I'm never gonna go home, I'm never gonna get better.” At the outset of her experience Taylor (age 14), spoke for most other participants when she described feeling overwhelmed and uncertain about her ability to cope.

I think like before it was like, kinda really got me nervous. It's kinda invasive so, it was kinda like I didn't know what to expect, and like I wasn't, I was afraid like I didn't know how it would effect my going back after the surgery, like how would I, what would I be able to do, how much pain would I be in, not be able to do any activities with the other kids, would it effect how I would live the rest of my life.

Despite their initial doubts and the magnitude of the challenges they faced, participants proudly acknowledged that they managed to pull through to a successful recovery. For the most part, they returned to a normal and satisfactory level of function. They identified a sense of accomplishment for having coped with the challenges they faced and when asked what advice they would offer others having surgery for scoliosis they would provide encouragement, as, although it is a difficult process, they all recovered. For example, Courtney (age 17) said:

What I tell everyone is that you're gonna feel really bad about yourself. You're gonna feel like it's not gonna get better but you just have to remember that it will. I know you're

not gonna believe me because I didn't believe other people but you, you will get back to normal you just have to believe in that.

Lisa (age 15) offered similar advice to others having surgery for scoliosis and provides a message of resiliency following her experience. She said, "Even though it's hard you can do it." Lisa's comment is representative of all participants, indicating that, although their surgery and recovery experience presented demands and challenges that, at times, they felt they would not overcome, they did so successfully.

Furthermore, maintaining a positive perspective during their recovery and return to school allowed participants to view their current state through a more positive lens. As previously indicated, participants were not completely satisfied with all aspects of their recovery. Largely, concerns about their scar and reduced activity level in some areas persisted. Participants found, however, that relative to their condition prior to surgery they were more satisfied with the way their bodies looked. In coming to terms with some of the negative sequelae (e.g. their scar) of their surgery, participants were able to frame this against the potentially more serious long-term consequences of not having surgery and reflect that the challenges they encountered were worthwhile. Demonstrating this point, Courtney (age 17) described that, while she could no longer engage in certain activities, the fact that she no longer experienced pain was worth it:

I still, like there's still times where I wish like, I wish I could do like a back flip on my front lawn like I think about that a lot, but I know that I don't have any pain anymore so I can't, I honestly can't even believe how they got rid of my pain because it used to be constant and now I don't even think about the pain anymore.

Emily (age 15) expressed dissatisfaction with her scar but said, "Well it's better than dying in a few years." Kate (age 13) and others agreed that the scar was not desirable but it was preferable to the extent of her physical deformity prior to surgery because surgery allowed her to be able to wear clothes that fit.

So the scar, it's like who cares I can find clothes now, because before the hump on the one side meant shirts wouldn't fit how you would expect them to. Just to be able to wear clothes that fit nice.

It may be the case that participants' ability to reframe their poor health status before surgery and/or the consequences of not having surgery may serve as a protective factor so they do not live with regret about lasting implications of the procedure (e.g., scar).

Theme 2 Subtheme 2: Leading School Reintegration

When asked about the role of their healthcare and school teams in planning for their extended absence and return to school, participants discussed varying levels of involvement. A number of participants could not recall specific discussions or explicit planning with doctors, nurses, teachers, and/or principals. Participants indicated that if they, or their parent, asked specific questions or initiated a discussion about returning to school then both healthcare and school teams were open to engaging in some planning. Importantly, however, this planning was almost exclusively initiated and driven by these adolescents and their parents.

Variable School and Healthcare Team Planning. In cases where planning or support was provided by school teams, it appeared to be somewhat sporadic and inconsistent in nature. For example, Sara (age 15) reported that when she returned to school she was not systematically (i.e., involving an intentional method or plan) provided with the work she missed, but instead was provided with materials in a 'here and there' fashion: "When I got back to school there wasn't an overload of work. It was just like 'oh, here's a sheet that you might have missed,' like here and there." Taylor (age 14) stated, "They didn't really like teach me it, they'd just pretty much gave me the worksheets", highlighting that she was not provided with explicit instruction on what she had missed but instead was left to learn the material independently. Lisa (age 15)

experienced inconsistency within her individual school team, with some teachers providing support and others not. “Some teachers gave me stuff to do. Others didn’t.”

An area in which the lack of explicit planning at school was particularly evident was gym class. As previously indicated, participants experienced a reduced activity level following their surgery leaving them unable to participate in gym class, in some cases, for up to a year.

Participants struggled with the fact that their gym time was often not replaced with anything structured. In some cases, participants were asked to help the teacher or complete additional physical education assignments. However, in the majority of cases, participants were left to sit out and fill their own time. For example, Sara (age 15) said, “I kinda just chilled out, it was like a free class almost.” Kelly (age 13) also sat out of gym class with nothing structured planned to fill the class time. “I just sat on the bench.” Kate (age 13) talked about how she felt like she was not provided with productive alternative activities and was left to observe her peers having fun in gym class. For Kate, who previously enjoyed gym, this was difficult:

Gym teacher was just like, ‘you can do this for me’, it was like okay. They just didn’t give me really much of anything to do. They just said you can work on this wall thing or you can just sit there and watch everyone have fun.

Even in cases where participants were provided with more productive alternatives, it tended to occur in a variable as opposed to a consistent manner. Taylor’s (age 14) comment demonstrates this point.

Sometimes they would give me like extra sheets, if they remembered. Like they would print off a sport sheet and I’d have to like read about it, and fill it out. Or sometimes they’d just tell me to finish up on my work or read a book.

Although their healthcare teams tried to support and prepare them for surgery and recovery, discussions about planning for the significant school absences post-surgery were mostly initiated by the participants or their parents. Some of these adolescents acknowledged that

more discussion tended to happen with their healthcare team compared with the school team but this was not the case for all participants. While there was certainly some overlap in the points covered by healthcare teams, there was also variability depending on the individual healthcare provider. Julia (age 15) talked about being advised not to take the stairs and to carry no more than five pounds. “They just told me not to take the stairs and to take it easy. I was only allowed to carry five pounds.” Taylor (age 14) discussed returning to school with her doctor; however, this discussion came at the request of her and her parent and was primarily driven by a number of their specific questions.

Well we asked them about like, what like how much I would miss, how much it would affect my grades, and how much I learned. They were talking about tutoring and also I was wondering about like my back, if the pain, what would I do if I was in a lot of pain. We talked about if I needed to go out in the hallway to like take a walk or something, if like, we could talk to my teachers so they know it’s okay, or to leave, sometimes, to leave a couple minutes before the bell rung for the next period, because it would be a big rush in the hallway and if someone was to like, shove cause, if someone was to shove me it wouldn’t be good on the back so to let me go a little bit early.

In addition to discussions with their healthcare and school teams, participants were asked if their healthcare and school team ever talked with one another directly. In some cases, participants indicated that their doctor sent a letter to the school explaining that the student had undergone surgery and would experience an extended school absence and a reduced activity level upon their return. Although some participants recall their health care team providing a letter for the school teachers, clear communication of this occurring was not always obvious, as noted by Lisa (age 15): “I’m pretty sure they sent a letter,” and some participants did not recall a letter ever being sent.

Parents Advocating to Schools. Participants identified that throughout their surgery and return to school, their parents were their biggest advocates. Participants worked with their parents to ask important questions and strategize for their return to school. Parents, most often

mothers, spent time having meetings with healthcare and school teams to learn how to manage their child's needs at home and school following surgery. Sara (age 15) described how her mother talked to both the school and healthcare team.

What my mom did was she like talked to the principal about it and then she like understood and then one day she sat the doctor down and like if I had any questions I could call them.

Courtney's (age 17) also noted that, "My mom called them [teachers] and told them what was going on." Acknowledging the fact that she and her mother tend to have a lot of questions,

Taylor (age 14) highlighted how her mother worked with the school team to put environmental supports and strategies in place for her return to school.

My mom went in and told them about it, like the principal and my teachers and so they all knew. We talked to them about like if I had pain or something, what I'd have to do and if I could leave the class or something or take a pill. Also I asked them [about] what I brought, I brought like a back rest type of thing and I'd bring that around to class.

Overall, adolescents faced challenges during the return to school period, which extended from their immediate recovery. Despite these challenges adolescents were motivated to return to school and determined coping strategies to ensure their successful reintegration. Although it was difficult, adolescents demonstrated determination and resourcefulness. Healthcare and school teams were open to supporting adolescents throughout their return to school; however, they did not drive the process. This left adolescents and their parents as the primary facilitators of school reintegration. Implications of these results have begun to emerge throughout the initial presentation of the results themselves. The results provide the reader with insight into the experience of returning to school following spinal surgery and allow for a deeper understanding of the process from the perspective of the patients. Overlap between and amongst the results and their implications for the contexts in which adolescents exist are inherent and will be further detailed in the discussion below. Importantly, discussion of the results serves to place

participants' experience into broader contexts and offer a commentary on some of the potentially important lessons that can be taken from these participants' experiences.

Discussion

The general goal of this study was to examine the experience of returning to school following spinal surgery, and to contribute to the limited body of literature on this topic. To accomplish this goal, a number of objectives were proposed for this study. Specifically, the objectives were (1) to gain a firsthand account of participants' return to school experience, (2) to explore the challenges participants faced, (3) to explore the supports they found beneficial, and (4) to explore what role pain played in their return to school. Based on information collected through semi-structured interviews and analyzed using the IPA approach, participants' overall experience is summarized by the theme 'Recovery to Fitting in at School' in which adolescents are faced with a need to return to school and thus, a demand to find their way to successful school reintegration. Two intersecting themes, 'Needing to Return to School' and 'Finding Their Way', contribute to understanding the return to school experience. 'Needing to Return to School' outlines the many challenges participants faced throughout their school reintegration. Interestingly, despite these challenges, adolescents were motivated to return to school. 'Finding Their Way' describes adolescents' process of learning to cope with the challenges they faced. This theme outlines the coping strategies that allowed participants to return to school successfully. Importantly, adolescents and their parents developed the majority of these coping strategies independent of coaching by their healthcare and/or school team and, consequently, led the overall school reintegration process. This study supports previous research findings in a number of areas; however, it moves beyond an explanation of the quality of life outcomes via

questionnaires and provides a deeper firsthand account of the consequences of such outcomes on adolescents school functioning.

Returning to School

Findings indicated that adolescents' school career was temporarily disrupted by major surgery. Despite this disruption, adolescents were motivated to return to school to reconnect with their friends and peer group. Participants in this study acknowledged that returning to the academic aspect of school was important; however, returning to social interactions in the school setting was a much more salient motivator. For school and healthcare teams supporting adolescents in their return to school, being aware of this motivator is critical. Adults surrounding adolescents during their return to school may be more likely to consider the academic function of school as a priority, but the importance of returning to the social aspect of school was emphasized by adolescents in this study as being more important. For school and healthcare teams, this motivator is vital to understand, as it can likely be leveraged or used to influence/sway adolescents in a time during which they face agonizing pain, wavering levels of self-confidence, and variable levels of teacher and peers understanding of their condition and needs.

Consistent with previous research, adolescents in this study reported facing a number of challenges during their recovery. In previous qualitative examinations, MacCulloch et al. (2009) identified nine areas of concern, including recovery at home, recovery in hospital, post-surgical appearance, emotional impact, intrusion on daily activities, impact on school and peer relationships, decision-making, operating room, and future concerns. Participants in the current study echoed similar areas of concern, touching on each of these points in one way or another. When asked about school, participants indicated that the challenges they faced during their

recovery extended into the return to school period. Specifically, participants identified coping with pain, dissatisfaction with their body image, and navigating variable teacher and peer understandings as the major challenges that impacted their school functioning. Whereas these challenges are currently represented in the broad literature related to spinal surgery, participants in the current study shed light on how these challenges manifest themselves in the school context. Considering the implications for school and healthcare teams, further discussion on each of these areas of concern is provided.

Pain. Participants in the current study discussed high levels of pain during their immediate recovery period (approximately up to four to six weeks following surgery); however, as their recovery progressed their pain decreased. This finding is consistent with an extensive literature review that revealed that pain following surgery is not uncommon. A number of studies report higher back pain incidence following surgery as compared to the typical population (see Danielsson & Nachemson, 2003; Goldberg et al., 1994). Wong et al. (2007), however, found that during the immediate recovery period (up to 12 months following surgery) participants treated for AIS reported significantly higher levels of pain than healthy controls but beyond 12 months following surgery the prevalence dropped to 10%. Interestingly, back pain prevalence in the general Canadian population is estimated to be 9% (Currie & Wang, 2004). These mixed findings indicate that either pain prevalence remains significantly higher in patients surgically treated for AIS than the general population or prevalence is initially higher and then trends towards a rate closer to the general population.

Considering the timing in which adolescents typically return to school following surgery (i.e., four to six weeks following surgery), this has important implications for the school setting. Adolescents who undergo spinal surgery likely return to school with at least mild pain.

Interestingly, participants in the current study did not identify their pain as overly disruptive in their return to school, as it did not prevent them from returning. Pain did, however, pose challenges to school functioning and require participants to use coping strategies to get through the school day. For example, pain made sitting for long periods of time, reaching, and bending difficult. It also caused reductions in activity level and the inability to participate in activities such as gym class. Danielsson & Nachemson (2003) observed a similar trend in their study, in which participants reported experiencing back pain on a daily basis, but indicated that this pain did not significantly disrupt their function. Danielsson & Nachemson (2003)'s findings combined with the current findings demonstrate that, while pain can be present, it is not necessarily debilitating. It is critical for both healthcare and school teams to recognize that, whereas adolescents returning to school after surgery may be present at school, they are not necessarily pain-free and will likely experience limited function in some areas. It is important for school staff to be sensitive to the fact that adolescents are often coping with at least some pain in their return to school and that support strategies may be necessary for the student to cope.

To cope with pain at home and at school, participants in the current study drew on a number of strategies including distraction, relaxation, and breaks/pacing. The use of these strategies has been shown to be effective in managing several types of pain, including procedural pain and chronic pain (e.g., Uman, Chambers, McGrath & Kisely, 2008; Mannerkorpi & Henriksson, 2007). It is particularly interesting that participants independently elected to use these strategies, considering they reported not being formally instructed to do so by their healthcare team. The fact that adolescents discovered effective pain management strategies on their own is positive; however, this may be an area in which healthcare providers can offer additional support. Considering adolescents typically return to school with at least some mild

pain following spinal surgery, it is critical that healthcare teams work with the adolescent to strategize about how they will effectively manage pain at school. Although adolescents successfully developed pain management strategies on their own, this was likely time consuming and could have resulted in a trial-and-error process before the adolescent found a suitable strategy. Offering more explicit suggestions and coaching about ways in which adolescents can manage pain at school may help adolescents learn effective strategies sooner and, ultimately, streamline their return to school experience.

Physical Appearance. Consistent with the findings in a systematic review conducted by Tones et al. (2006), participants in this study were dissatisfied with their physical appearance and spoke negatively about their bodies, using terms such as “deformed” to describe the effect of scoliosis. Participants longed for a sense of normalcy and reported that their physical abnormalities made activities such as shopping difficult. Fitzwater, Moore & Gurel (1993) found that adolescents with scoliosis are less likely to report feeling satisfied with the way clothes fit their body and do not report using clothes to enhance their self-concept. Similarly, in the current study, clothing did not appear to enhance participants’ self-concept and instead seemed to draw attention to their physical abnormalities further contributing to their negative feelings about their bodies. Prior to surgery, adolescents reported being aware of their physical appearance at school. Since participants identified school as an important site in which to socialize and engage with others, it is conceivable that school can be a possible site for peer judgment and victimization about participants’ physical abnormalities. In some cases, participants faced peer victimization and were taunted and called names such as “hunchback.” It is important for school staff to remain mindful of this population’s potentially increased risk for

such peer victimization and consider supports the student may access prior to their return to school (e.g., a safe person to whom to report concerns).

Adolescents in this study expressed hope that surgery would improve their physical appearance, resulting in more positive feelings about the way they looked and feeling more comfortable around their peers. For most participants, this was indeed the case, as they reported feeling more comfortable about the way they looked and reported improvements in their self-confidence. This finding is consistent with a number of studies, which also found improvements in body satisfaction and self-confidence (e.g., Goldberg et al., 2004; Rushton & Grevitt, 2013; Weigert et al., 2006). While improvements in the overall way that participants viewed their body were observed in the current study, some continued concerns were reported. The most common physical appearance concern post- surgery was the appearance of the surgical scar. Many participants reported feeling the need to conceal the scar, highlighting the continued struggle to feel physically “normal”, even after surgical correction of scoliosis. Strategies with which adolescents coped with continued concern about their physical appearance varied, but a common approach was to weigh their dissatisfaction against the negative results of continued spinal curve progression (e.g., more pronounced physical deformity, vital organ complications). For example, participants acknowledged that they were happier to have a scar than to be dead or to be hunched over. In this case, participants may have been facing cognitive dissonance or mental discomfort as a result of holding two contradictory beliefs at one time. Specifically, on one hand, participants were pleased to improve their overall physical appearance and preserve vital organ function, while on the other hand, they were unhappy with lasting implications of surgery (i.e., the scar). For participants in this study, remaining positive about the lasting implications of surgery helped them cope and allowed them manage any ongoing difficulties. It is important for

individuals providing care to adolescents after spinal surgery (e.g., doctors, nurses, teachers, parents) to be aware of this tendency, as it may serve as a protective factor that can be leveraged during a time when an adolescent is struggling to cope.

As became clear in this study, adolescents had high hopes that their physical appearance would improve as a result of spinal surgery. Healthcare teams should be aware of the implications of results of surgery not meeting adolescents' expectations. Whereas participants in this study were satisfied with their physical improvements and demonstrated the ability to cope with persistent physical abnormalities, healthcare teams may wish to consider ways in which to support adolescents who continue to experience negative feelings about their body after surgery or whose surgeries do not fully correct the curvature.

Teacher and Peer Understandings. The extent of teacher and peer understanding about scoliosis and spinal surgery is relatively underrepresented in the current literature. In previous qualitative studies examining adolescents' experience with spinal surgery, MacCulloch, et al. (2009) and Rullander, et al. (2013) both found that adolescents reported feeling concerned about whether their teachers and classmates would understand their surgery. These studies also found that adolescents felt fearful about how they would be treated when they went back to school and whether or not others would treat them differently. In the current study, participants faced varying degrees of teacher and peer understanding. In some cases, teachers and peers understood and responded to participants' needs, whereas in other cases, they did not. Adolescents identified that, overall, they wished teachers and peers understood more about the nature of their condition, the magnitude of the procedure and the extensiveness of their recovery. Adolescents in the current study spoke about providing teacher and peer education by leading class discussions and doing presentations to facilitate understanding of their condition. Adolescents found that

providing peer education helped to increase peer understanding which then allowed participants to feel more comfortable using coping strategies freely without judgement from peers. It is important for healthcare and school teams to consider that once adolescents returning to school from surgery feel that their peers and teachers understand their experience and needs, they are more likely to seek support and engage in coping strategies.

Interestingly, participants reported that their parents assumed the responsibility of educating teachers and school staff on these topics. Adolescents felt their parents were capable of providing this education to school staff and found their parents' conversations with teachers helpful. Given parents' roles as caregivers, the extent to which they are involved in the planning process is not surprising and is perhaps expected. Parents are certainly a valuable support for planning and facilitating an adolescent's recovery and return to school. However, parents face extensive demands providing basic care for their adolescent during recovery and not all are knowledgeable about what they need to advocate at the school level for in terms of support for their child's reintegration. Therefore, parents may benefit from added supports in this planning process. As such, healthcare teams may wish to offer education and support to the parent about how to talk to their child's school, or they may wish to provide direct education about student needs to the school.

School and Healthcare Team Collaboration

This study highlights implications for school and healthcare team collaboration. Authors such as Sexson & Madan-Swain (1993) suggest that adolescents who miss school for a health-related absence should be highly supported in their return to school. Specifically, this literature recommends supports such as active preparation meetings with the youth, parents, and school personnel about the student's return, and continued monitoring and follow-up once the student

returns to school. These authors also emphasize that school re-entry should be discussed at the outset of the treatment process with the healthcare team. In the current study, participants did not describe receiving this level of support from either their school or healthcare team. This being said, most adolescents in the current study felt both their healthcare and school team were open and invested in providing support when it was explicitly requested, but neither school nor healthcare teams offered this support proactively as recommended in the literature. Given the importance of school in an adolescent's life and that return to school is an important part of a return to daily function following surgery, this lack of clear school planning and poor communication between health care team, school team, parents, and patients is concerning.

It is often the case that adolescents are expected to function more independently in the school setting in preparation for the responsibilities of adulthood. This demand for increasing independence may, in part, influence school teams tendency not to offer extensive support or proactive preparation for their extended school absence following surgery. Whereas older children are likely more able to advocate for themselves than younger children, expecting them to navigate the school and healthcare system independently to meet their own needs following surgery may be too much for adolescents to manage on their own. Adolescents in the current study were clear that increased support throughout their school reintegration process would have been beneficial. One method for increasing support is the use of a school reintegration program. School reintegration programs for chronic illnesses other than scoliosis have been proposed and developed and shown in randomized control trials to be effective for increasing illness specific knowledge and a positive attitude in both teachers and peers (see Canter & Roberts, 2012). Prevatt, Heffer & Lowe (2000) indicate that these programs provide a framework for consultation between school and health care systems. They typically take the form of school

personnel workshops and information sessions, peer education initiatives, and/or the development of an individualized plan for the student who is returning to school. Although some participants in the current study indicated that their healthcare team sent a letter to the school, formal consultation between the two systems was lacking. School reintegration programs developed for other populations could serve as an important model for effective consultation between schools and healthcare teams in supporting adolescents' return to school following spinal surgery.

Based on the results of the current study, more structure around school planning before, during, and after surgery is necessary. In the application of a school reintegration program to the scoliosis population, their unique needs should be considered and the content of existing programs should be modified to reflect these needs. Interestingly, the results of the current study showed that participants wanted their teachers and peers to know more about their condition and have more favorable attitudes towards them/about scoliosis/about surgery. Canter & Roberts' (2012) systematic review demonstrates that school reintegration programs produce these results. Furthermore, participants in the current study demonstrated a commitment to providing peer education to their classmates via classroom presentations, projects, and discussions. Similar to adolescents' intuitive use of evidence-based pain management strategies without explicit instruction to do so, many adolescents intuitively used this peer education strategy. Based on their concerns and current activities in this area, the results of the current study strongly support further consideration of developing a specific school reintegration framework for adolescents returning to school following surgery.

In his discussion of school and healthcare team collaboration for school reintegration, Harris (2009) indicates that the appointment of an individual to act as a consultant-liaison is a

key component of a comprehensive and successful school reintegration plan. The consultant-liaison is informed about all the needs of the child and takes responsibility for communicating important information between the family, health care team, and school team. Harris (2009) suggests the consultant-liaison can assist in ongoing monitoring and implementation of the formal plan and/or other supports that have been recommended by school and health care teams. Recognizing the already overwhelming workloads of both health care and school team members, Harris (2009) suggests that the school psychologist can be an appropriate professional to fill this role. Many psychologists who work in schools are knowledgeable about both health care and education systems, as well as the immediate school environment. They often also have the necessary training in consultation skills to effectively liaise between the family, health care system, and school system. Psychologists working in schools with this expertise could be valuable assets in supporting children and adolescents with pediatric health issues in school. In an investigation of school psychologists' perceptions of healthcare and school partnerships, Bradley-Klug et al. (2013) found that school psychologists infrequently participate in and/or observe interdisciplinary communication and collaboration between school and healthcare systems. Consistent with this research, participants in the current study speculated that their school and healthcare teams did not effectively communicate or collaborate with one another. For many years, the profession of school psychology has advocated for an expansion of their role from assessment-focused to include consultation on a wide-range of issues in schools (Cherame & Sutter, 1993; Jordan, Hinds & Saklofske, 2009). Providing a consultative role to facilitate planning between youth, parents, schools, and healthcare systems is one example of a potential area for role expansion, which may interest the profession of school psychology in the future.

Clinical Implications

Overall, these results have important real-life implications for school and healthcare staff working with adolescents undergoing major spinal surgery. In particular, these results highlight that, to reintegrate to school successfully following surgery, adolescents must overcome challenges including coping with pain, managing dissatisfaction with their body, and navigating variable teacher and peer understandings of their condition. Fortunately, adolescents' return to school is highly motivated by school's social function and they independently use a wide-range of strategies to cope and, eventually, successfully reintegrate. Although adolescents find their way to successful school reintegration, this study indicates that for this group of participants, they did so independent of high levels of school and healthcare system collaboration and/or systematic planning. This study suggests that developing a school reintegration program specifically for this population may serve as an important method for filling, what is for some, a current gap and would support adolescents' who have undergone surgery for scoliosis return to school. Assisting in the development and facilitation of such a school reintegration program would be an important role for school psychologists. Enhancing cross-disciplinary communication and problem solving between school and healthcare systems would be beneficial for supporting not only adolescents with scoliosis but children and adolescents with additional chronic health conditions as well. School psychologists with training in consultation are likely the most skilled school personnel to liaison with healthcare systems and may wish to advocate for the expansion of their role in this area in the future.

As suggested through the experiences of these participants there are several components that may be important for a return to school program to address. School as a social site, a desire to appear normal, managing pain at school and physical challenges in the school environment are components that should be included in determining a school return plan. Planning for the

significant school absence by having a pre-surgery discussion about a return to school plan may have helped to alleviate some of the worry adolescents in this study and their parents experienced. Clinicians can use the insights offered in this study to start a discussion about what others found challenging and helpful in their return to school. For example, school as a social site was a major motivator for many of the participants in this study. Informing teachers of this and suggesting that perhaps teachers and classmates could provide a tangible form of social support by sending get well wishes and an update on class activities so that the adolescent does not feel separate from others when they return may be helpful in easing their return.

Although not experienced by the adolescents in this study, it is possible that if a student struggles with the social components of school, this may become a barrier to school return after a prolonged absence. Thus, strategies to remain connected with close friends and classmates throughout their recovery (e.g. via online platforms such as social media or face to face video calls) may decrease the potential for school to be perceived negatively. In addition to drawing on close friends for support, adolescents in the current study also accessed others who underwent spinal surgery for scoliosis. Adolescents found discussing the surgery and return to school experience with others who could share a firsthand perspective of the experience very useful. In order to support these links, healthcare professionals may wish to consider creating a database of previous patients who consent to being contacted by others about the surgical experience in the future. These contacts could be provided to future patients who are interested in hearing about others' experience.

Acknowledging that a student may have to manage pain at school upon their return but that their needs can be accommodated would be important to communicate to school staff. The student may benefit from discussing the use of distraction techniques as a way of managing their

pain at school and plan for ways in which the student may be able to use distraction techniques within their classroom or school environment. Additionally, knowing if the student would need to follow a school policy on taking medication at school would be helpful so that any written documentation can be completed when they have their clinic visits.

Whereas these qualitative findings are not generalizable to all adolescents who have spinal surgery for scoliosis due to the methodology, the results are transferable. Reviewing these results can broaden the depth of clinicians' overall understanding of the difficulties many adolescents face throughout the surgery and recovery experience, thereby informing clinical judgment and sensitivity. Clinicians can use these results in clinical practice by referencing the experience of the participants in this study and using them to generate discussion about their individual clients return to school. Furthermore, these findings may assist clinicians in advocating for their clients by providing research-based evidence of the challenges adolescents undergoing major spinal surgery may experience.

Strengths and Limitations

When interpreting the results of the current study, strengths and limitations should be considered. In general, this study investigated a novel aspect of the SFI surgical experience. Although SFI surgery quality of life outcomes have been both quantitatively and qualitatively examined, an investigation of the school experience following this surgery was lacking. Results of the current study provide insight into the experience of adolescents undergoing SFI surgery and their return to life and school. There are several strengths to this study. First, by conducting the interviews face to face, it was possible to incorporate body language in the analysis of the data, thereby understanding the meaning associated with the words. Second, the semi-structured nature of interviews (although guided by an interview guide) allowed adolescents to describe

their experiences without being hampered by trying to fit their experiences into pre-determined answers (e.g., Likert scales); instead the participants were able to focus on aspects of their experience that were important to them. Third, incorporating others on the team in the analysis process helped to ensure that the themes and quotes were representative of the data and that no one voice dominated. Fourth, the richness embedded in the voices of the adolescents can provide clinicians without first-hand experience an understanding of the potential experiences of their clients.

There are several limitations to this study. First, although the incidence of scoliosis is higher in females than males there are males who require SFI surgery. This study only included females and therefore it is unknown if there are sex differences in school experience following SFI surgery. Thus, understanding the experiences of boys undergoing SFI surgery and school re-integration warrants further research. Second, although there may be similarities experienced in school return for adolescent girls who have experienced other major surgeries this study is specific to the experiences of those who had major spinal surgery for scoliosis repair. The voiced concerns over body image may be different for adolescent girls undergoing other types of major surgery that are not associated with a visible difference in physical appearance. Third, all of these participants accessed their health care services at one pediatric tertiary care centre so it is unknown if those who access their care at other centres have a different experience.

Future Directions

In order to disseminate the findings of this study, our research team will create a lay-term handout summarizing the results for healthcare professionals and school staff who work with this population. The key challenges adolescents face in their return to school along with the strategies they found useful in overcoming these challenges will be highlighted. Our research team will

also seek opportunities to continue to discuss issues related to healthcare and school system collaboration through publications and presentations. As research in this area progresses to include generalizable samples and a range of healthcare centers, the development of clinical guidelines for supporting children in their return to school following medical procedures that can be more widely disseminated will be useful.

An extensive literature search conducted as part of the current study revealed gaps in a few critical research areas. One area in which this was evident was related to pain. Based on the extensive research related to pain before and after SFI surgery, a systematic review investigating these outcomes further would be beneficial. Similarly, investigations related to scoliosis and body image concerns are well documented; however, studies examining the impact of spinal surgery on body image are lacking. Specifically, the current study highlighted the high levels of optimism and hope adolescents place on surgery resulting in a more normal physical appearance. Based on this finding, further examination of cases in which changes in physical appearance do not satisfy the patient should be considered. Adolescents in this study struggled to cope with pain at school. While some research is available on the impact of pain on school functioning (e.g., see Dick & Pillai Riddell, 2010), this is mainly focused on chronic pain. Adolescents recovering from spinal surgery experience acute pain and, as such, specific research on pain and school functioning in this population is important.

The current study found that many individuals are central to adolescents' return to school experience. Parents, teachers, physicians, and nurses were all identified as being an important part of the overall experience and, consequently, have valuable perspectives to offer on this topic. All of these perspectives could not logistically be represented in the current study however, should be investigated in the future. Since parents currently plan and facilitate the school

reintegration process for their children, it is critical to consider the potential burden this may place on parents. A qualitative examination exploring how parents manage this responsibility would be useful. For example, factors such as parents' illness-specific knowledge, ability to provide school education and manage their child's needs simultaneously, and comfort level approaching schools and school staff should be investigated. A similar investigation of how healthcare professionals understand and manage patients' school reintegration following spinal surgery and other medical procedures would also be useful. Considering the current study examined participants treated at one tertiary health care center, investigations at additional centers to identify similarities and differences are necessary.

Although a school reintegration framework that involves effective collaboration between school and healthcare systems and planning that is intentional and systematic in nature is advocated in the literature, based on participants' responses in the current study, formal school reintegration plans are not being implemented. Further investigation of how school and healthcare systems can work collaboratively with one another to support students interacting with both systems is critical. The development and evaluation of a school reintegration framework for supporting adolescents return to school following spinal surgery is one proposed way of assisting school and healthcare systems to collaborate effectively and therefore, would be a significant contribution to the literature.

Conclusion

The current examination provides a preliminary understanding of adolescents' experience returning to school following surgery. To our knowledge, the current study is the first to discuss surgical outcomes following SFI surgery in specific relation to the school context. Overall, challenges adolescents faced during their recovery extended into the return to school period.

Despite these challenges, adolescents were motivated to return to school and developed a variety of coping strategies to ensure their successful reintegration. Although it was difficult, adolescents demonstrated determination and resourcefulness throughout the school reintegration process. Healthcare and school teams expressed openness to supporting adolescents throughout their return to school; however, they did not drive the process, leaving adolescents and their parents as the primary facilitators of school reintegration. Students returning to school from spinal surgery are at the intersection of health and education systems, which traditionally operate in separate realms with different approaches and policies. As a reflection of this separation, adolescents' health and education needs at school are often not well integrated. In the future, active preparation meetings about school re-entry should take place at the outset of the treatment process and include the youth, parents, school personnel and healthcare professionals. Continued monitoring and follow-up once the student returns to school is critical. To achieve this, it is essential that collaboration between healthcare and school systems be optimized during this time. By increasing dialogue and collaboration between systems, it will be possible to facilitate the school reintegration process for adolescents who have had SFI surgery, leading to more positive academic and social outcomes for this group of patients.

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Table 1

Demographic Statistics for the Total Sample

Alias	Age at Participation (years)	Grade at Participation (grade)	Age at Surgery (years)	Grade at Surgery (grade)	Hospital Stay (days)	School Missed (weeks)
Kate	13	8	12	7	5	0
Courtney	17	12	15	9	7	0
Taylor	14	9	12	7	6	3
Sara	15	10	14	9	7	4
Emily	15	9	14	8	8	9
Julia	15	9	14	9	5	6
Kelly	13	8	12	7	7	4
Lisa	15	9	14	9	7	4
Mean	14.6	9.3	13.4	8.1	6.5	3.8
Median	15	9	14	8.5	7.5	4.0
Mode	15	9	14	9	7	4

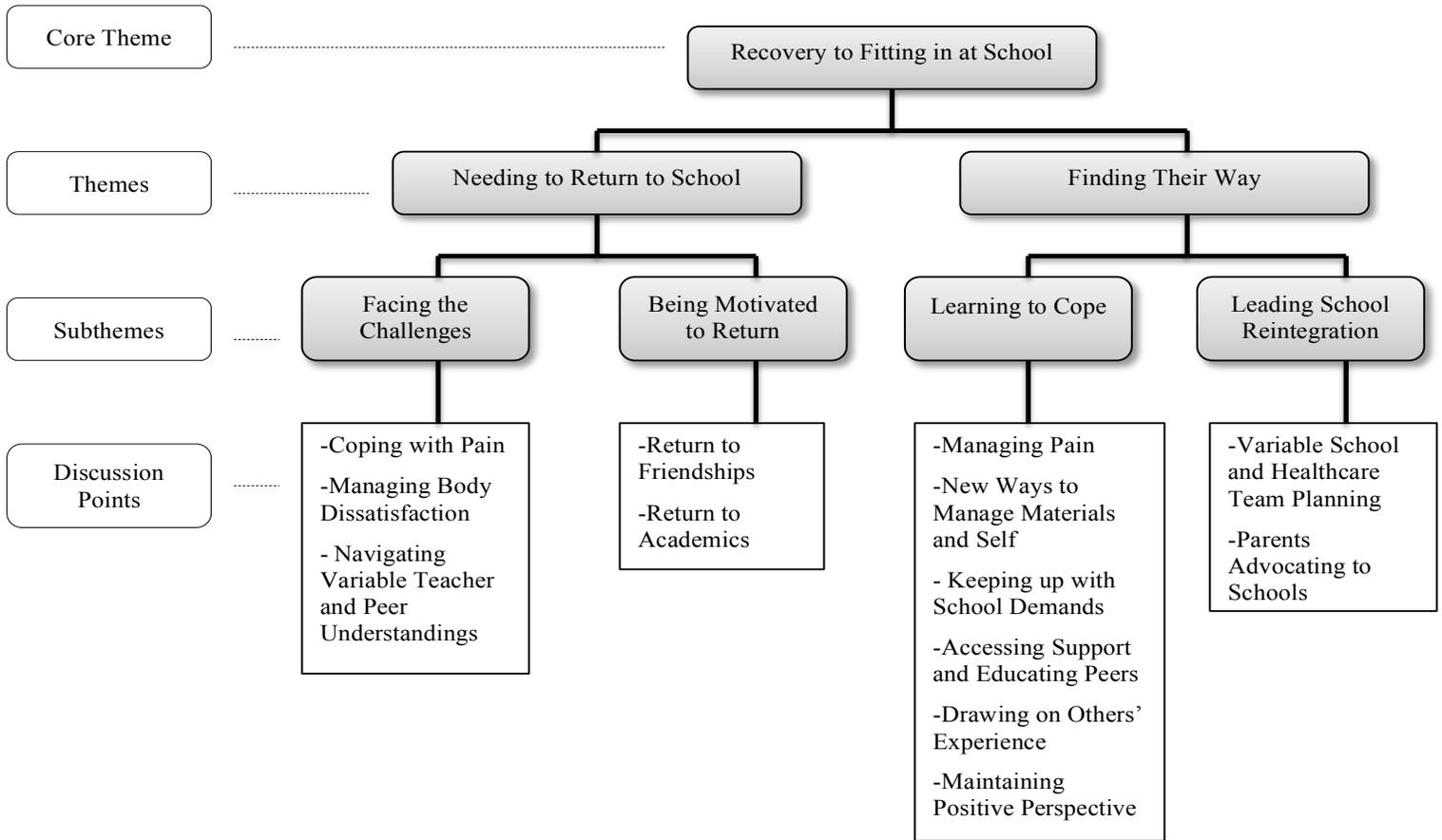


Figure 1. Overview of themes and subthemes that offer a concise retelling of participant experiences in their return to school following surgery.

Appendix A
Demographics Questionnaire

This questionnaire collects some information about you. This information is used to help us describe the group of adolescents we talked to about their return to school following surgery. Your name is not connected to this information in any way. If you do not want to answer any question, it's okay to leave it blank.

1. How old are you right now? _____ Years
2. How old were you when you had surgery? _____ Years
3. What grade are you in right now? _____ Grade
4. What grade were you in when you had surgery? _____ Grade
5. How long were you in the hospital following your surgery? _____ Days
6. How many weeks of school did you miss as a result of your surgery? ____ Weeks
7. Did you go back to school for any half days following your surgery?
 Yes No
If yes, how many days? _____
8. Did you go back to school for a period of time and then have to miss more school because being back at school was too difficult?
 Yes No
If yes, how many days? _____
9. Do you think your marks changed after your surgery?
 Yes No
If yes, how did your marks change:
10. At any of your doctor's appointments before surgery did you talk about missing school?
 Yes No
If yes, what kinds of things did you talk about:
11. Did you talk to anyone at school (e.g. teachers) about your surgery?
 Yes No
If yes, when did you talk to them:
If yes, what kinds of things did you talk about:
If yes, who did you talk to:

Appendix B Interview Guide

Return to School Following SFI Surgery: Interview Guide

Thank you for agreeing to participate in this study about adolescents and their return to school following SFI surgery. This interview will last about one hour and we will be audio recorded. If there are any questions that you do not want to answer, or if you want to stop the interview at anytime that is okay. Although this is being recorded and will later be typed up, your name and that of anyone else you mention will be removed before sharing any of the findings with others. If you are unsure what I am asking in a question, please just tell me and I will reword the question. Are you ready to get started?

1. Can you tell me about your school?

Probes:

- What grade are you in?
- Can you tell me about some of the things you like about school?
- Can you tell me about some of the things you dislike about school?

2. I know you had surgery for scoliosis. What was it like living with scoliosis before your surgery?

Probes:

- Was there anything you wanted to do but could not because of your condition?
- Was there any thing that was difficult for you to do?
- Did you find people understood about your condition?
- Did you experience pain before your surgery? How often? What was this like?
- Did it affect your school attendance in anyway before your surgery? How?

3. So, you had spinal surgery, what was that like?

Probes:

- Can you tell me what a typical day in the hospital was like for you after your surgery?
- Did you work on schoolwork while you were in the hospital?
- Did you talk to your doctor about going back to school?

I would like to know more about what it was like to go back to school after your surgery.

4. What was it like to miss school for your surgery?

Probes:

- How much school did you miss?
- What did you miss while you were away from school?
- How did it feel to miss school?

- Did you talk about the fact that you would be missing school with your teachers or doctors? What was this like?
5. What was it like to go back to school after your surgery?

Probes:

- Were you surprised by anything when you went back to school?
 - How did your teachers treat you when you went back to school? Were they any different than before? Can you tell me how they were different?
 - How did your friends treat you when you went back to school? Were they any different than before? Can you tell me how they were different?
6. Did you experience pain after your surgery?

Only for children who experienced pain

Probes:

- What was it like to have pain after your surgery?
 - How long did it last?
- Did you experience pain when you went back to school after surgery?
 - What was it like to have pain at school?
 - Did the pain stop you from doing things that you wanted to do? How did that make you feel?
- Do you still have pain?
 - How much does it stop you from attending school?
 - Does it stop you from doing things that you want to do?

Many people find that there are times when others can be helpful and other times when people can be unhelpful.

7. When you were returning back to school after your surgery can you tell me about something that someone did that was helpful?

Probes:

- What was easy when you went back to school?
 - How did this make you feel?
 - Was there anyone or anything else that helped?
8. When you were returning back to school after your surgery can you tell me about something that someone did that was unhelpful?

Probes:

- What was difficult when you went back to school?
 - How did this make you feel?
 - Was there anyone or anything else that was not helpful?
9. What do you think schools need to know about students coming back to school after having surgery?

Probes:

- Is there anything that you wish was different about your return to school?
 - Is there anything you think might be helpful for other students to know about going back to school after having their surgery?
10. Is there anything that we didn't discuss about going back to school after your surgery that is important to you?