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

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Background: Adolescent Idiopathic Scoliosis (AIS) affects 1 – 3% of all children and adolescents. Scoliosis surgery is an extensive surgical procedure, and is known to cause severe pain that requires advanced pain management.

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

Methods: In study I and II the participants underwent surgery in the period from 2004 to 2007. In study I a cohort of 87 adolescents and young adults with different types of scoliosis were invited together with their parents/caregivers. They completed a questionnaire with questions about experienced pain, nausea and satisfaction with hospital stay. In Study II six of the participants with AIS from the cohort in study I, were interviewed regarding their experiences of undergoing scoliosis surgery. Study III was a quantitative study with 37 consecutive included participants from four spine centres in Sweden. They completed two psychometric instruments and a structured interview before surgery and six months after. They also self-reported pain on the third postoperative day. In study IV the participants belonged to the same cohort as in study III. In this Mixed Methods study the participants self-reported pain before surgery, the first five postoperative days and once a day the first two weeks after discharge. They kept a diary during the first two weeks after discharge and were interviewed after six months.

Results: Study I showed that the patients experienced severe pain and nausea during the hospital stay. The parents/caregivers felt helpless and lacked in confidence in the nurses. Study II showed that the adolescents experienced nervousness and fear before surgery, severe pain and postoperative nausea during the hospital stay and had traumatic memories up to two years after surgery. In study III ratings of stress were higher before than after surgery. Levels of preoperative stress correlated with postoperative pain and postoperative pain correlated with stress symptoms after six months. Study IV there was a substantial variation in levels of self-reported pain, and occasionally pain was severe. Described experiences of hovering between suffering and control and a strive towards normality emerged. The adolescents described supportive factors that helped alleviate difficulties.

Keywords
Adolescent, scoliosis surgery, pain, perioperative, nursing, assessment, adaptation, recovery

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