

Experiences of adolescents and their families in the short-term after scoliosis surgery

Experiências de adolescentes e suas famílias a curto prazo após cirurgia para correção de escoliose

Experiencias de adolescentes y sus familias a corto plazo después de cirugía para corrección de escoliosis

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Abstract

Objective: The study was performed to reveal experiences of adolescents and their families in the short-term after scoliosis surgery.

Methods: This study had a qualitative descriptive design, and data were collected from adolescents with scoliosis surgery (n=17) and their family members (n=9) at in-depth interviews. Obtained data were analysed with content analysis.

Results: Five main themes emerged: physical complaints, unfamiliar environment (operating room and intensive care unit), emotional changes, wanting their parents to stay with them and worries about future. Both the adolescents and their families reported that the adolescents experienced not only physical and emotional problems but also worries about their future after surgery.

Conclusion: Nurses should meet the adolescents and their families and allow them to express their feelings before surgery. Informing them before surgery is important in terms of relieving their anxiety and enhancing their adaptation. Creating an appropriate environment in recovery rooms and intensive care units where the adolescents can frequently see their parents may help them have better psychology. In addition, education programs that will be offered at discharge should be designed and interactive methods should be used to allow them to share their thoughts about their future.

Resumo

Objetivo: O estudo foi realizado para revelar vivências de adolescentes e suas famílias a curto prazo após a cirurgia para correção de escoliose.

Métodos: Este estudo teve um delineamento descritivo qualitativo, e os dados foram coletados de adolescentes com história de cirurgia para correção de escoliose (n=17) e seus familiares (n=9), através de entrevistas em profundidade. Os dados assim obtidos foram analisados usando análise de conteúdo.

Resultados: Surgiram cinco temas principais: queixas físicas, ambiente desconhecido (centro cirúrgico e unidade de terapia intensiva), mudanças emocionais, querendo que seus pais fiquem com eles e preocupações com o futuro. Tanto os adolescentes como seus familiares relataram que os adolescentes experimentaram não só problemas físicos e emocionais mas também preocupações com o futuro após a cirurgia.

Conclusão: Os enfermeiros devem ficar junto com os adolescentes e suas famílias e permitir que eles expressem seus sentimentos antes da cirurgia. É importante informá-los antes da cirurgia para aliviar sua ansiedade e melhorar a adaptação. Criar um ambiente adequado em salas de recuperação e unidades de terapia intensiva, onde os adolescentes podem frequentemente ver seus pais, pode ajudá-los a ter um psiquismo melhor. Além disso, programas educacionais devem ser propostos para serem oferecidos no momento da alta e métodos interativos devem ser usados para permitir que eles compartilhem seus pensamentos sobre o futuro.

Resumen

Objetivo: Este estudio se realizó para revelar experiencias de adolescentes y sus familias a corto plazo después de la cirugía para la corrección de escoliosis.

Métodos: Este estudio tuvo un delineamiento descriptivo cualitativo y se recogieron datos de adolescentes con histórico de cirugía para la corrección de escoliosis (n = 17) y sus familiares (n = 9), a través de entrevistas en profundidad. Los datos obtenidos se analizaron utilizando el análisis de contenido.

Resultados: Surgieron cinco temas principales: quejas físicas, entorno desconocido (la sala de operaciones y la unidad de terapia intensiva), cambios emocionales, queriendo que sus padres se queden con ellos y preocupaciones por el futuro. Tanto los adolescentes como sus familiares relataron que los adolescentes experimentaron no solo problemas físicos y emocionales como también preocupaciones con el futuro después de la cirugía.

Conclusión: Los enfermeros deben acompañar a los adolescentes y sus familias y permitirles que expresen sus sentimientos antes de la cirugía. Es importante mantenerlos informados antes de la cirugía para aliviar su ansiedad y mejorar la adaptación. Crear un ambiente adecuado en salas de recuperación y unidades de terapia intensiva, donde los adolescentes puedan ver a sus padres a menudo, puede ayudarlos a tener una psique mejor. Además, los programas educativos deben ser propuestos para ser ofrecidos en el momento del alta y los métodos interactivos se deben utilizar para permitir que compartan sus pensamientos sobre el futuro.

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Introduction

Scoliosis is a serious structural disorder presenting with lateral curving and rotation and leading to anatomical malformation in the chest over time. The prevalence of scoliosis varies between 0,13% and 13,6% depending on ethnic and geographical features.⁽¹⁾ Regional studies performed in our country revealed that the prevalence of idiopathic scoliosis ranges from 0,2% and 1%.⁽²⁾ Scoliosis surgery is one of the most frequent surgeries carried out in adolescents.^(3,4) Although the disorder is diagnosed earlier, surgery is performed between the ages of 12-16 years.⁽⁵⁾ Surgery can stop progression of curving of the spine, improve trunk deformity and prevent respiratory complications. However, the patients experience severe pain, nausea, vomiting, difficulty in mobilization and psychological problems after surgery. Adolescents can have more traumatic experiences due to features of the developmental stage they go through.⁽⁶⁾ These experiences may cause their parents to face some problems. Offering information to adolescent patients and their families and helping them to get prepared before surgery can allow them to feel more comfortable and experience postsurgical period without being traumatized.⁽⁷⁾ Therefore, there is a need to reveal what adolescent patients and their families experience in the early postsurgical period.

Problems frequently appearing after scoliosis surgery like pain, tiredness, lack of appetite, nausea, vomiting, depression and malnutrition have negative effects on mobilization and healing in adolescents.^(6,8) Pain is one of the most important factors reducing patient comfort after surgery.⁽⁶⁾ It has been noted that postsurgical pain is also associated with preoperative fears of the patients, which lead them to feel helpless. In addition, posttraumatic stress experienced after surgery increases the severity of pain.^(9,10) In fact, hospitalization alone causes anxiety in adolescents. They can give different reactions to what they experience after surgery because adolescence is a complex period during which young people want to have freedom, have conflicts with their parents to acquire their autonomy, experience quick changes in their bodies and make future plans.⁽¹¹⁾

Staying in hospital and all perioperative processes have a negative impact on adolescents. They may think control over their body is in the hands of their families and health professionals. They depend on their families and health staff not only in medical interventions but also in their hygiene needs and some activities like mobilization.⁽¹²⁾ Besides, scoliosis certainly affects physical image and self-respect in adolescents.^(13,14) Therefore, evaluations of expectations from surgery and worries in adolescents should be part of health care.

It is important that nurses understand what patients undergoing scoliosis surgery experience in the early postoperative period so that they can provide care based on the whole person approach. There have been retrospective studies evaluating pain and nausea in adolescents after scoliosis surgery⁽⁶⁾ and experiences of these patients after their discharge.⁽¹³⁾ However, there have not been any studies evaluating experiences of adolescents and their families in the early post-surgical period. Therefore, the purpose of this study was to describe experiences of adolescents and their families in the short-term after scoliosis surgery.

Methods

Design and participants

The study had a descriptive qualitative design and focused on experiences of the adolescents undergoing scoliosis surgery and their families.^(15,16)

Participants were recruited from an orthopaedic unit of a university hospital in western Turkey. Purposive sampling was used. Inclusion criteria for adolescents were as follows: a) to be at the age of 12-18 years b) to have undergone scoliosis surgery c) to be willing to be interviewed on the 2nd and 10th postoperative days d) to be able to understand Turkish and express their own experiences verbally. Exclusion criteria were severe concentration problems and functional disabilities (e.g. cerebral palsy). Eligibility criteria required for family members were as in the following a) to be a member of an adolescent's family (mothers, sisters or fathers) b) to be willing to be interviewed c) to be able to understand Turkish and express their own experiences verbally.

The study was conducted between January 2015 and August 2016. In-depth interviews were used to collect data. The interviews continued until a point at which no new information was obtained. A total of 26 participants, of whom 17 were adolescents undergoing scoliosis surgery and nine were their family members (mothers, sisters or fathers), were enrolled in the study.

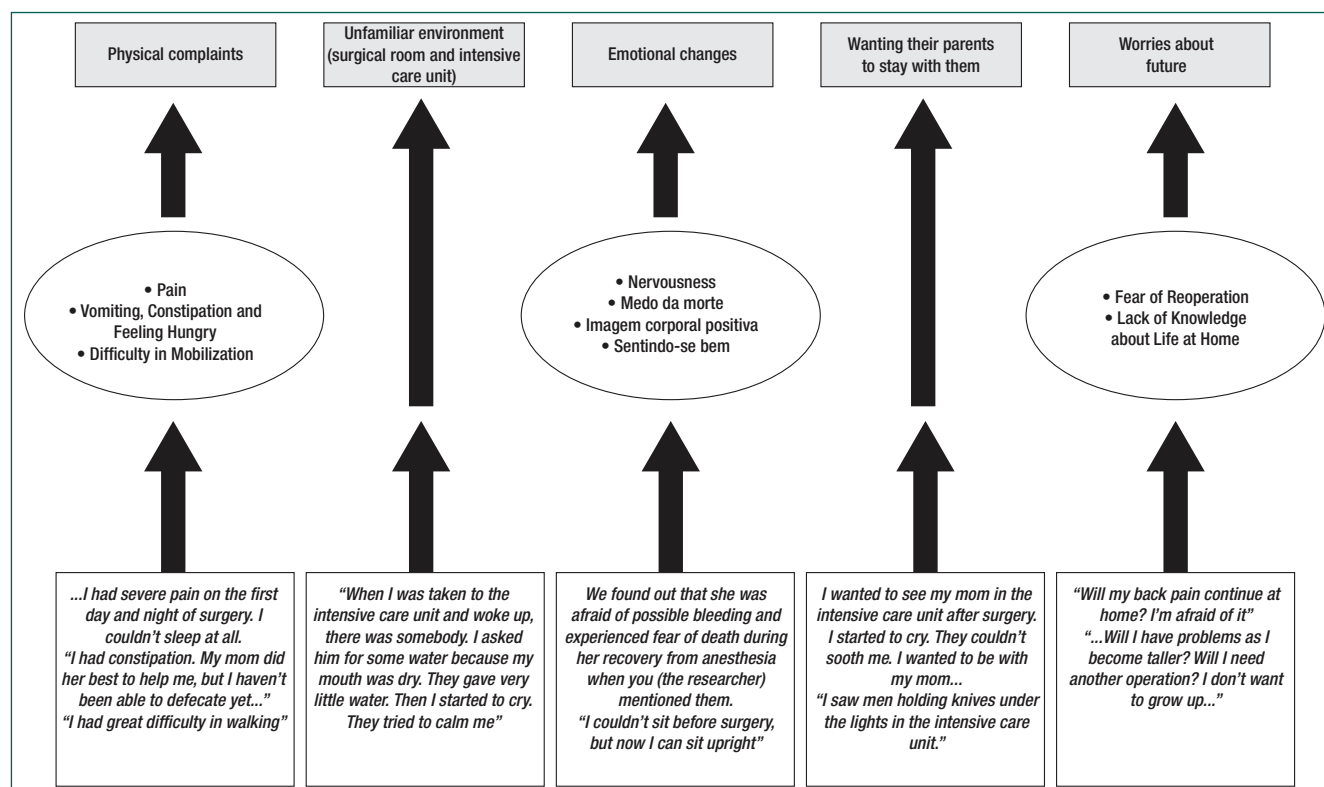
Data Collection

The adolescents and the members of their families were interviewed separately in a quiet, well-lit and well-air-conditioned room to provide an opportunity for them to respond to questions comfortably. The interviews were in-depth in nature and were tape recorded. All data were collected by two researchers using a demographic and clinical data form and an interview form. The demographic form included questions about sociodemographic features of the adolescents and their family members. The interviews began with the question “*What kind of experiences have you had after scoliosis surgery?*” and then continued with the question “*What do you*

think about your future after surgery?”. Exploratory questions were also used when necessary during the interviews. The researchers took field notes during the interviews. Each interview took approximately 20 minutes.

Data Analysis

Inductive content analysis, in which obtained data were continuously compared by two researchers, was used to analyse the data. To perform this analysis, first recorded interviews were transcribed verbatim, and subthemes and main themes were determined independently by two researchers. The two researchers subsequently compared their coding and reached consensus on them. The themes were next analysed and confirmed by another researcher (investigator triangulation).^(15,16) To determine themes, first concepts were derived from the coding. They revealed subthemes and the subthemes were combined to create themes (Figure 1).⁽¹⁶⁾ The field notes taken by the researchers during the interviews were also taken into consideration in the analysis process. In order to maintain anonymity, participants were



Source: Yildirim A, Şimzek H. Qualitative research methods in the Social Sciences. 8th ed. Ankara, Turkey: Seckin Publishing; 2011.⁽¹⁶⁾

Figure 1. Essential Themes and Subthemes

identified with their years, postoperative days, and relationship.

The adolescents and their family members included in the study were informed about the aim of the study, and both oral and written informed consent was obtained from all the participants. This study was approved by the Ethics Committee of the Dokuz Eylul University (protocol no=1869-GOA, 2015/09-31) and was conducted according to the ethical guidelines of the Declaration of Helsinki.

Results

The mean age of the adolescents and their family members was 15.41±3.05 years and 44.14±5.03 years respectively. Of 17 adolescents included in the study, 14 were female and three were male. Of all the family members included in the study, five were mothers, one was a sister and three were fathers. Five main themes and ten subthemes emerged from the experiences of the adolescents and their family members after scoliosis surgery (Figure 1).

Physical Complaints

The adolescents having scoliosis surgery reported that they had pain, nausea, vomiting, constipation and difficulty in mobilization and felt hungry after anaesthesia and surgery. The majority of the adolescents added that the physical complaints they had in the early postsurgical period were surprising.

Pain: All the adolescents commented that they experienced pain after surgery. They explained that severe pain caused sleep problems and nervousness. A mother noted that they did not think her child would experience such severe pain.

“I started to cry due to the pain I had after surgery” (15-year-old, postoperative third day).

“I had severe pain on the first day and night of surgery. I couldn’t sleep at all” (18-year-old adolescent, Postoperative second day).

Vomiting, Constipation and Feeling Hungry:

One adolescent and his mother said that he had fast-

ing for two days due to postponement of surgery and that the feeling of hunger was severe after surgery.

“I was very hungry since I was left hungry for two days in the recovery room” (14-year-old adolescent, postoperative seventh day).

“He was left hungry for two days since his operation was postponed two times ... He said he was hungry while sleeping” (45-year-old father).

The adolescents reported to vomit and have constipation after surgery.

“I had severe vomiting for two days after surgery” (18-year-old adolescent, postoperative fifth day).

Difficulty in Mobilization: Although the adolescents wanted to move, walk and perform their daily routines after surgery, they had difficulty in doing them. The adolescents and their family members reported difficulties in mobilization and problems with standing up after surgery.

“I had great difficulty in moving. I think it is because I’ve lain continuously” (17-year-old adolescent, Postoperative fifth day).

“When they first walked me, I couldn’t raise my head since I was still under the influence of anaesthesia. I had great difficulty in walking” (15-year-old adolescent, Postoperative third day).

“We didn’t know surgery would cause so much difficulty for him. He even didn’t want to move” (48-year-old father).

Unfamiliar Environment (Operating Room and Intensive Care Unit)

The operating room and the intensive care unit were unfamiliar to the adolescents. They said they were cold in the operating room and an electric heater was used to make them warm. Staying in the intensive care unit, being intubated and being alone when recovered from anaesthesia had a negative impact on them. Some family members attracted

attention to the fact that their children were very cold when they were taken to the ward.

“Going to the operating room was like an action film ... When they (health staff) took me to the surgical stretcher, they were talking. Then I slept. They took me to a cold room. I waited there. Then I was operated. When I woke up, my hands were tied. I guess I couldn’t wake up completely and struggled to untie my hand. I was told to be injected a sedative since I threw the thing attached on my finger (pulse oximeter probe). (17-year-old adolescent, postoperative fifth day).”

“I can’t completely remember what happened in the intensive care unit, but I thought I was going to suffocate; there was something in my throat. I couldn’t speak, I slept and then I woke up. Later, they removed it from my throat and I felt quite relaxed” (18-year-old adolescent, Postoperative second day).

“She was freezing when she was brought to the ward. She said she was kept warm with a pipe-like thing, but she was very cold” (45-year-old father).

Emotional Changes

The majority of the adolescents reported their positive and negative feelings about scoliosis surgery. The adolescents felt nervous and were afraid of death due to pain and restricted movements after surgery. Despite these negative experiences, they said they were happy and felt better thanks to positive changes in their bodies.

Nervousness: One adolescent and one parent commented that surgery and physical changes experienced after surgery made the adolescents more nervous.

“It’s very important to be free for me and I know my body is well. I felt my muscles were contracted after surgery and I felt irritated and was moody and bad-tempered” (17-year-old adolescent, Postoperative fifth day).

“In general, she isn’t bad-tempered ... She became really aggressive” (26-year-old, sister).

Fear of Death: One adolescent associated fear of death in the early postoperative period with bleeding in surgery. The father of this adolescent reported that he learned about the fear of death his child experienced during the interviews.

“I might have died of bleeding. If I had died, I would have wanted the last persons I saw were my parents” (15-year-old adolescent, postoperative fifth day).

“We found out that she was afraid of possible bleeding and experienced fear of death during her recovery from anaesthesia when you (the researcher) mentioned them. She did not talk to us about them. In fact, she was really afraid of them (45-year-old father)

Positive Body Image: The adolescents happily reported that they stood upright and were taller after surgery.

“I couldn’t sit before surgery, but now I can sit upright” (15-year-old adolescent, Postoperative fifth day).

“Now I’m taller. I’m surprised with it. I didn’t know that I would be taller” (14-year-old adolescent, Postoperative seventh day).

“Becoming taller made her very happy. When I see her being happy, I say luckily she had surgery” (50-year-old father).

Feeling Good: The participants said they felt good when they recognized positive effects of surgery.

“Undergoing operation benefitted me. If I hadn’t had this operation, the outlook would have been worse. My bones would have stuck into my liver” (14-year-old adolescent, postoperative seventh day).

Wanting Parents’ Accompaniment

Not seeing family members upon waking up in the intensive care unit caused the adolescents to feel helpless. The majority of the adolescents wanted their parents to accompany them.

"I wanted to see my mom in the intensive care unit after surgery. I started to cry. They couldn't soothe me. I wanted to be with my mom ..." (15-year-old adolescent, Postoperative third day).

"I didn't want to be alone (in the recovery room). I wanted to see my parents, not people I don't know. What if I would have died there? The people I last saw could have been those I didn't know, couldn't they?" (15-year-old adolescent, postoperative fifth day).

"The intensive care unit nurse called me. My daughter wanted to see me very much. They couldn't help her and called me. I got surprised when I received that call" (38-year-old mother).

One adolescent told her nightmare she had in the recovery room while recovering from anaesthesia as in the following:

"I saw men holding knives under the lights in the intensive care unit. I asked the woman wearing a surgical cap to call my mom. I asked for it many times, but they didn't allow it" (13-year-old adolescent, postoperative tenth day).

Worry about Future

The adolescents said that they did not know anything about the processes of healing and discharge from hospital and how to perform their daily activities since no sufficient knowledge was offered to them and their families before and after surgery. The participants were worried about return to daily life activities and pain. The adolescents expressed their worries about their life in the future as in the following:

"I wonder whether I will be able to walk as in the past" (18-year-old adolescent, postoperative second day).

"Will my back pain continue at home? I'm afraid of it" (13-year-old adolescent, Postoperative seventh day).

Fear of Reoperation: The adolescents and their mothers commented that they had a fear of reoperation.

"...will I have problems as I become taller? Will I need another operation? I don't want to grow up... I've heard that there were others operated again" (15-year-old adolescent, postoperative fifth day).

"She is afraid of returning home. She thinks we can give harm to her accidentally. Actually, she is afraid of having an operation again" (43-year-old mother).

Lack of Knowledge about Life at Home: The adolescents and their mothers needed to be offered information about life after surgery.

"When will I be able to run? When will I be able to go to school?" (13-year-old adolescent, postoperative seventh day).

"We know nothing about what she will or won't do at home. What kind of exercise will she do?"

Discussion

In the present study, the adolescents having scoliosis surgery experienced pain, vomiting, constipation and difficulty in mobilization and felt hungry in the early postoperative period. The adolescents and their family members reported that they encountered more severe pain on the first day of surgery than they expected. It has also been noted in the literature that severe pain occurs after scoliosis surgery.⁽¹⁷⁾ Sieberg et al. reported that 35% of the children undergoing spinal fusion surgery had moderate to severe pain.⁽¹⁸⁾ In a qualitative study by Rulander, adolescents having scoliosis surgery complained about pain.⁽⁶⁾ An effective pain management following surgery is important.⁽¹⁹⁾ It has been emphasized in the literature that administration of narcotic analgesics through patient controlled analgesia (PCA) after spinal surgery is very beneficial in pain management.^(19,20) PCA, frequently used in vertebrae surgery, has been reported to have advantages like performing activities more comfortably, provision of more effective analgesia at lower doses, having fewer side-effects and reducing stress.⁽²⁰⁾

Nonsteroidal anti-inflammatory drugs and corticosteroids are used in combination with narcotics for pain management.^(19,21) Several studies have shown that multimodal analgesia is more effective in reduction of pain in children.^(22,23) Besides, transcutaneous electrical nerve stimulation (TENS) has been reported to decrease analgesia needs and have few side-effects.^(24,25) In addition, nonpharmacological techniques such as attracting attention to things other than pain and relaxation diminish pain.⁽²⁶⁾ Relaxation training before spinal surgery and postoperative music therapy have also been found to lower pain and anxiety in adolescent patients.⁽²⁷⁾ Consistent with the present study, Rulander et al. (2013) reported that the adolescents complained about vomiting, difficulty in mobilization and hunger. Unlike the participants in the present study, they reported different hip levels and problems with scarring and the urinary catheter.⁽⁶⁾ It may be that the patients were not offered sufficient information about pain management and the postoperative process. In addition, practices related to pain, nausea and vomiting performed in the clinic might have been inadequate.

In the current study, the adolescents were affected by the atmosphere of the operating room and the intensive care unit and the interventions performed there with which they were unfamiliar. Adolescence is a period during which adolescents want to gain their autonomy and make future plans. They also think as if they could do everything and keep away from their families and want to become individuals, which cause conflicts.^(11,28) The intensive care unit environment can be traumatic for patients trying to recover from anaesthesia. Surgery and hospital stay restrict freedom of adolescents. Therefore, their individuality and decisions should be respected. In this process, the participation of the family in the care of the adolescent is important. It has been underlined in the literature that involvement of families is important in reduction of anxiety children experience before surgery and their preparation for surgery in accordance with their age and personal characteristics.^(29,30) It is also recommended that families should stay with their children until anaesthesia induction. Several studies have shown that cooperation with

families are important in effective management of pain after scoliosis surgery and decreases pain.^(30,31) Even if families are involved in care for their children, nurses should talk to adolescents individually; they should give them information about the operating room, the intensive care unit, possible risks of surgery, pain management after surgery and the healing process. Their explanations should be based on the real situations and appropriate terms which adolescents can understand should be used.^(8,13) This can make them feel that they have control over their body. If they have peers in the clinic, they should be introduced to each other. This may allow them to get peer support and help them to cope with their difficulties.

Spinal curvature in patients with scoliosis cause them to feel bad. The angle and the place of the curvature lead to poor body image and a reduction in spinal functions. This restricts their movements and affects their psychology. Inability of adolescents to perform their normal activities with their friends and families and their use of a girdle can decrease the quality of their life.⁽³²⁾ In the present study, disappearance of the spinal curvature and an increase in height helped to restore body image and to be happy in the adolescents. In studies on patients with scoliosis, scores for functions-activities, physical appearance, mental health and satisfaction have been found to increase after surgery. This suggests that patients with scoliosis have a better body image and the quality of life after surgery. Compatible with the literature, the present study showed that improvement of physical functions and physical appearance had positive effects on psychology of the adolescents.

In the current study, the participants reported to worry about healing after surgery and discharge from hospital and daily life. Congruent with this finding, several studies have indicated that the patients had fears about persistence of pain after their discharge from hospital.⁽¹⁷⁾ In a study, 7% of the patients undergoing scoliosis surgery reported to suffer from pain for 12 months after surgery.⁽³³⁾ Persistence of pain after surgery causes a change in mood and anger in individuals.⁽³⁴⁾ Preoperative education can enhance adaptation of children undergoing scoliosis surgery. However, it is quite

difficult to prepare children for surgery in the pre-operative period when intensive anxiety is experienced. Provision of information and development of coping strategies before surgery are important so that adolescents can have real expectations.⁽²⁷⁾ After surgery, the patients' needs for information about healing and discharge from hospital should be determined and fulfilled by nurses. Cooperation with families by taking account of individual characteristics of adolescents can improve their adaptation to surgery and the healing period. Underlying anxiety of children and their families about the healing period and the future is their insufficient knowledge. Therefore, adolescents undergoing scoliosis surgery and their families should be supplied information before discharge about the problems they are likely to encounter. They should be offered information about pain management, girdle use, movements to be avoided, recommended daily exercise, what needs to be taken care of concerning daily life activities and when to return to hobbies and work in particular. In the current study, the adolescents were found to experience fears about bleeding and death before surgery and fears about reoperation after surgery. Several studies have revealed that adolescents have different fears after scoliosis surgery.^(6,10,18) The fact that scoliosis surgery is a major surgery and difficulties in the healing process after surgery result in fears in adolescents.

Conclusion

Adolescents having scoliosis surgery experience conflicting feelings including happiness, aggression and anxiety in addition to physical problems. They have insufficient information and anxiety about the postsurgical period. When combined with poor body image and problems with adolescence, this complex process experienced after surgery complicates the healing process. Therefore, nurses should evaluate adolescents and their families separately and develop a multifaceted care plan. Adolescents planned to have scoliosis surgery and their families should be provided education about the surgery and support for development of coping

skills. Adolescents should certainly be involved in treatment and care processes and allowed to express their feelings. They should be offered detailed information about scoliosis surgery and care before and after surgery. Generating a suitable environment in recovery rooms and intensive care units where the adolescents frequently see their parents can lead them to have better psychology. However, Further studies should be performed to determine effects of using technologies including mobile phones, notebooks and tablets on understanding and putting the information given into practice.

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