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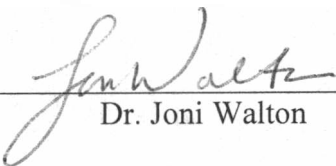
Living with Pediatric Chest Wall Deformities

Nicole Donisthorpe

Carroll College

Signature Page

This thesis for honors recognition has been approved for the Department of Nursing by:



Dr. Joni Walton

4-14-10
Date



Dr. Jennifer Elison

4/14/10
Date



Dr. Lauri Fahlberg

4/14/10
Date

Abstract

The most prevalent congenital chest wall abnormality in children, pectus excavatum and pectus carinatum, effects a child growing up in an appearance focused society. This thesis explored living with a pediatric pectus excavatum, surgery and recovery process. The participants in this study included two individuals, one male and female, between the ages of 17 and 21 years old from Montana. Both of the participants had his and her pectus excavatum deformities corrected by the Nuss procedure at the Mayo Clinic in Rochester, Minnesota. This research was qualitative and was based on the phenomenological method which emphasized the everyday lived experiences of a pediatric chest wall deformity. The research was analyzed using Giorgi's steps of analysis. The themes that emerged from this study include the following: (a) being different, (b) facing limitations, (c) coping with fear, (d) receiving quality nursing care, (e) experiencing pain, and (f) moving forward. The findings of this study can help nurses gain a better understanding of the psychological effect of living with a chest wall deformity as well as how to provide the best patient care during the surgical repair process. The participants in this particular study recommended that nurses show genuine compassion towards patients by taking a personal interest in the patients, effectively communicating with the patient, and encouraging an optimistic outlook on recovery.

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Dedication

To my parents Scott and Vickie and my youngest brother Nolan for your continued love and support. To my brother Logan for being an inspiration for this study.

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Chapter I

Living with Pediatric Chest Wall Deformities

Growing up with a pediatric chest wall deformity such as pectus excavatum or pectus carinatum can be extremely difficult in a society that places great importance on the ideal of physical appearance. Once thought of as simply a cosmetic defect, these deformities have been found to be potentially detrimental to overall heart and lung health and can have a direct effect on body image, self-concept, and perceived role within society (UCSF, 2009). As a healthcare professional, it is imperative to understand all facets of these deformities in order to holistically provide care for these unique individuals, especially when coping with pain management, decreased exercise tolerance, surgical procedures, and the psychological effect of appearance. The purpose of this phenomenological research study is to gain an understanding of what it is like to live with pectus excavatum or pectus carinatum.

Pectus excavatum, also known as funnel chest, is the most prevalent congenital chest wall abnormality in children (UCSF, 2009) occurring in one in 500-1000 children (Cincinnati Children's Hospital, 2007a). Another closely related condition is pectus carinatum or pigeon chest (UCSF, 2009). According to Lewis (2009), both of these conditions are caused by an increased growth of connective tissue that joins the ribs to the sternum creating a malformation of a depression or protrusion which usually appears at birth. These abnormalities increase with age and often worsen during the growth spurts that occur during late childhood and adolescence years (Cincinnati Children's Hospital 2007b). They vary in severity from a minimal presence that can be corrected with nonsurgical methods to extremely severe deformities which cause compression of the

heart and lungs. These cases ultimately alter the function of the heart and lungs, especially during strenuous exercise, and may need to be corrected with surgery (Huddleston, 2009).

Pectus excavatum and pectus carinatum transcend the lines of race and culture as these congenital deformities are found throughout the world; however, a link to gender exists in that it arises three times more frequently in males than females (UCSF, 2009). These deformities are also often accompanied by other muscular and skeletal system problems as one in five patients with pectus excavatum or pectus carinatum has scoliosis as well (Acton & Saltzman, 2009). Science has not found an answer to why there is an increase of connective tissue growth during pregnancy (Cincinnati Children's Hospital, 2007a), but because these deformities frequently occur throughout a family, researchers speculate that there may be the possibility of genetic inheritance (Acton & Saltzman, 2009). With an unknown etiology, identifying risk factors becomes a difficult task. This leaves modern medicine to continue searching for an origin, using the best evidence-based practice related to surgical and nonsurgical treatment of these deformities and finally offering a standard quality of care for the patient during the recovery process.

Impact of Deformity on the Individual

Living with a pediatric chest wall deformity such as pectus excavatum or pectus carinatum constructed a multi-dimensioned problem involving issues related to the body, mind, and soul. This study explored the lived experience of children with chest wall deformities in order to gain a greater understanding of their lives. This study also involved what it would be like to have the deformity treated and return to being a physically normal member of society.

As the sternum awkwardly pushes inward or outward, numerous symptoms develop that directly impinge on the well-being of the individual with a chest wall deformity. The most common symptoms are generally categorized into three issues including pain, decreased exercise tolerance, and an obvious change in appearance (Huddleston, 2009). Cardiac arrhythmias, tachycardia, and heart murmurs may also be present in increased activity levels due to amplified pressure on the respiratory and circulation systems (Acton & Saltzman, 2009). In addition, patients with pectus excavatum and carinatum experience a higher frequency rate of respiratory infections, chest pain, and asthma (Fonkalsord, 2000).

Self image. Besides the physical symptoms, a deformity such as pectus excavatum or pectus carinatum can have a profound effect on a child's self-image. While not present in every case, negative self-image and low self-confidence are attributed to those with these deformities (Anderson, 1982). In a study done by Einsiedel and Clausner (1999) surveying patients eleven years and older with pectus excavatum, 94% expressed a high degree of self-observation when compared to peers, 72% reported a disturbed body image, 74% felt timidity on social contact, and 78% expressed feelings of stigmatization. However, depending on what values parents and society stress as a child grows up, such as intelligence, personality, or relationships instead of physical beauty, the child could have a greater or less likely chance at psychologically coping with the disability (Anderson, 1982). Parental attitudes play a significant role in shaping the self-concept of a child with pectus excavatum or carinatum as the parents set the standard on how the child will potentially look at the deformity (Anderson, 1982).

Treatment. Often, the family and child decide that the best way to resolve the physical and psychological symptoms is by eliminating the deformity with treatment. Although there are non-surgical methods to repair pectus excavatum and carinatum, if the condition is moderate to severe, therapies such as posture improvement programs, Vacuum Bell therapy, which is the use of suction cap to try to re-shape the chest, and bracing will not be effective in reversing these deformities (Huddleston, 2009). If the deformity does not meet the criteria for non-surgical corrective procedures, the family may consider surgical alternatives. Ethically, there could be a discrepancy in what is believed to be the appropriate action of treatment between the parents and doctors or the child and doctors. Also, the surgery is quite costly especially for those who are uninsured.

The two most common types of surgery are the Ravitch Procedure and the Nuss Procedure; however both of these surgeries are expensive. The Ravitch Procedure average hospital stay of 4.0 days, an operating room charge of \$8,325, and a hospital charge of \$4,137; the Nuss Procedure had an average hospital stay of 4.8 days, an operating room charge of \$9,480, and a hospital charge of \$4,137 (Engum, 2001). This economic dilemma puts the extra pressure on the family, others within the same insurance company as cost of surgery will cause general rates to increase, and the hospitals by paying the price in order to correct the deformity.

Ultimately, pectus excavatum and pectus carinatum surpass the simple diagnosis of a chest wall deformity. The deformity itself and the correction of the deformity impact the mind, body, and soul of an individual. The deformity may also directly affect the individual's family as it may alter the way a child grows up, change family dynamics between siblings and cause financial burdens. Society's guidelines regarding physical

beauty and peer acceptance are also tested by the diagnosis of pectus excavatum and pectus carinatum.

Chapter II

Review of Literature

Although pectus deformities are the most common congenital disorder in children, procedures for repair of this malformation are relatively new and are continuing to evolve with technology. Researchers have evaluated the long term effects of pectus correction, psychological changes and life style limitations as well as the effectiveness of nonsurgical and surgical procedures. Studies have also highlighted the nurse's role within care which stresses the management of post-operative pain. In addition, this Review of Literature will include guidelines, evidence-based practice, pharmacological treatment of pain, and diagnostic procedures.

Guidelines and Evidence-Based Practice

National guidelines for care and interventions have yet to be defined as there is limited research pertaining to the topics of pectus excavatum and pectus carinatum. Additionally, Micromedix data bases do not supply any references related standards of care for individuals with to pectus excavatum and pectus carinatum, which raises concern as to where healthcare providers can obtain accurate information for patients and parents. Not only will the families be lacking a reliable knowledge source, but healthcare providers will be as well, whether it is in an outpatient setting or in a hospital after surgery.

Without clearly defined national guidelines or standards, it is the obligation of healthcare staff to explore and provide best practice relating to the treatment and care of pectus excavatum and carinatum. Through research studies completed at Cincinnati Children's Hospital, Washington University School of Medicine, and University of

California-San Francisco, it is clear that there are several evidence-based practices currently in use. One such practice is surgical correction in childhood and adolescence to treat complications of pectus deformities including pain, decreased exercise tolerance, and impaired lung and heart functioning. Psychological and psychosocial implications may also arise in the form of mild to severe self-conscious behavior, loss of motivation, anxiety, and other social problems such as disturbed body image. Lastly, there are several different surgical correction techniques available with the most widely used being the Ravitch and Nuss procedures.

Pharmacological Treatment

The three most common symptoms that plague pectus deformity patients are pain, decreased exercise tolerance, and appearance (Huddleston, 2009). Although appearance can only be corrected by surgery, pain and decreased exercise tolerance can be minimized through pharmacological treatment. The etiology of where pain originates is not exactly known; however, it is believed that it has to do with the way the pectoral muscles cross the chest to attach to the ribs and breastbone (Huddleston, 2009). This pain varies from minimal to severe and occurs over short periods of time and is treated with medication such as acetaminophen, morphine, and hydrocodone.

Pain medications. Acetaminophen, a non opioid analgesic and antipyretic, is used to treat mild pain and fever by inhibiting the synthesis of prostaglandins that may serve as mediators of pain and fever in the CNS. It is contraindicated in previous hypersensitivity to products containing alcohol, aspartame, sugar, or tartrazine. The various side effects consist of hepatic failure, hepatotoxicity, neutropenia, rash, and urticaria. Individuals

taking this drug should be sure to take the correct dosing and avoid alcohol (Deglin & Vallerand, 2008).

Morphine, an opioid analgesic is used for the management of severe pain post surgical procedures. Its mechanism of action is defined through the binding of opiate receptors in the central nervous system. It alters the perception of and response to painful stimuli while producing generalized central nervous system depression. It is contraindicated in hypersensitivity and used cautiously in head trauma, increased intracranial pressure, severe renal, hepatic, or pulmonary disease, hypothyroidism, adrenal insufficiency and history of substance abuse. A few of the common side effects include: confusion, sedation, dizziness, headache, hallucinations, blurred vision, respiratory depression, hypotension, and constipation. While using this medication, the individual needs to be aware that drowsiness and dizziness may occur, orthostatic hypotension may result when changing positions, and to avoid concurrent use of alcohol or other central nervous system depressants (Deglin & Vallerand, 2008).

Hydrocodone, an opioid analgesic, is used in combination with non opioid analgesics such as acetaminophen, aspirin, or ibuprofen in the management of moderate to severe pain. Its mechanism of action is defined through the binding to opiate receptors in the central nervous system or CNS in order to alter the perception of and response to painful stimuli with generalized CNS depression. It is contraindicated in hypersensitivity to hydrocodone and acetaminophen, aspirin, and ibuprofen. Common side effects are confusion, dizziness, sedation, hypotension, dyspepsia, and nausea. While using this medication, the individual needs to be aware of orthostatic hypotension when changing

positions, the need to avoid using alcohol or other CNS depressants, and practicing good oral hygiene to decrease dry mouth (Deglin & Vallerand, 2008).

Exercise intolerance. Besides pain, decreased exercise tolerance is a particularly important outcome of pectus excavatum and carinatum as the function of the heart and lungs may be impaired and thus distance these children from the daily activities of childhood. Breathing becomes difficult during exertion as the lung air capacity decreases causing ventilator restriction, and the filling capacity of the heart chambers is constrained due to amplified compression from the sternum and a diminished stroke volume (Cincinnati Children's Hospital 2007b). The combination of respiratory and cardiac involvement leads to exertion dyspnea, or difficulty breathing on exertion.

Asthma. As the child grows older and starts competitive athletics, the symptoms of more rapid fatigue, decreased stamina, and decreased endurance become more problematic (Acton & Saltzman, 2009). To make matters worse, asthma often accompanies pectus deformities. Asthma symptoms, include wheezing, shortness of breath, and a cough which can be treated with bronchodilators such as albuterol and ipratropium in the form of a meter-dose inhaler or MDI. Albuterol is used to control and prevent reversible airway obstruction by binding to beta 2-adrenergic receptors in airway smooth muscle. It is contraindicated in hypersensitivity to adrenergic amines and fluorocarbons in some inhalers with the most common side effects being nervousness, restlessness, tremor, chest pain, and palpitations. It is important that the individual knows how to properly use the inhaler, understand that albuterol may cause an unusual or bad taste, and advise the patient to rinse the mouth with water after each inhalation dose to minimize dry mouth and prevent mold growth (Deglin & Vallerand, 2008).

Ipratropium or Atrovent (MDI) is used to reverse airway obstruction by inhibiting cholinergic receptors in bronchial smooth muscles. It is contraindicated in hypersensitivity to ipratropium, atropine, belladonna alkaloids, or bromide and is not to be used during acute bronchospasm. The few side effects of Atrovent include dizziness, headache, blurred vision, bronchospasm, cough, rash through allergic reactions, and nausea. Individuals should not exceed twelve doses within a twenty-four hour period and should notify a health care professional if symptoms do not improve within thirty minutes after administration (Deglin & Vallerand, 2008).

Diagnostic workup. If the pectus deformity has progressed in severity and these medications do not properly treat the symptoms, an option is surgical correction. The two most common surgical procedures for correction are the Ravitch and Nuss procedures. Before surgery, there are several tests, procedures, and standard diagnostic workups that need to be completed. The most common diagnostic tests include chest x-rays, pulmonary function testing, and echocardiography (Kosloske et al., 2000).

Chest radiography is utilized in order to gain a greater understanding of the pulmonary, cardiac, and skeletal systems. The healthcare providers and surgeons will be able to properly assess the extent of internal and external damage inflicted through the pectus deformity. The chest x-ray usually includes a posteroanterior view and a lateral view. Factors that may impair the results of the examination include metallic objects within the field and improper positioning of the patient (Kosloske et al., 2000).

A pulmonary function test assesses the lungs and respiratory system by providing information about the volume, pattern, rates of airflow, and diffusing capabilities of the lungs. A complete study profile includes determination of all lung volumes, spirometry,

diffusing capacity, maximum voluntary ventilation, flow volume loop, and maximum expiratory and inspiratory pressures. The pulmonary function test allows the doctors and surgeons to identify the degree of lung functioning (Kosloske et al., 2000).

The final assessment techniques is the echocardiography which is a Doppler echo or an ultrasound of the heart. This procedure uses high frequency sound waves of different intensities to diagnose cardiovascular disorders. Possible cardiovascular disorders could include mitral valve prolapse, in which one or both leaflets of the heart valve are too large, or cardiac chamber compression or displacement, in which the heart chambers undergo an increase in pressure (Kosloske et al., 2000). These disorders have a low occurrence rate, but individuals with a pectus deformity require screening (Kosloske et al., 2000). After these diagnostic tests have been completed, nonsurgical or surgical correction of the deformity can be determined.

Nonsurgical Procedures

Nonsurgical techniques such as physiotherapies, chest wall bracing, vacuum suction, and patient counseling are particularly effective when treating moderate to minimal pectus deformities (University of Rochester Medical Center, 2009). These techniques are not as aggressive as surgical techniques and will require more time in order to achieve the desired results. In most moderate to severe cases, these techniques will not provide permanent correction and, therefore, surgical techniques will then be needed (University of Rochester Medical Center, 2009).

Postural improvement. The two most common types of postural improvement for pectus deformities are in the form of physiotherapy and chest wall bracing.

Physiotherapies encompass posture improvement and building physical exercise

endurance and stamina (University of Rochester Medical Center, 2009). By exhibiting proper spinal alignment and correcting posture stances such as rounded shoulders and slouching, the appearance of the heart and lung performance may improve as well as decrease the protrusion or intrusion of the septum (University of Rochester Medical Center, 2009). This process can take an extended duration of time, months to years, for correction, so patients and family members need to be committed and exhibit patience while waiting for results. Also, patient and parents need to be involved in setting a therapeutic time line so that if the therapy is not working properly other options can be considered.

Chest wall bracing, or the compressing and remolding of the chest, is another form of postural alignment which may benefit pectus deformity patients (Robert Wood Johnson University Hospital, 2009). The brace needs to be individually fitted by an orthotist and the brace must be worn for a majority of each day for several months, time varying from model to model (Robert Wood Johnson University Hospital, 2009). Within one year, significant improvement can be seen in most cases; however, this is only plausible in moderate to minimal chest wall deformities. There is also a component of social isolation, impaired body image, and loss of self confidence that accompany the bracing system, especially if the desired outcomes are not achieved (Robert Wood Johnson University Hospital, 2009).

Vacuum chest wall lifter. The innovative idea of a vacuum chest wall lifter is a reasonable nonsurgical way to manage pectus excavatum by using a suction cup to pull the patient's chest wall outward. This is done by using a patient-activated hand pump to reduce pressure 15% below atmospheric pressure (Bahr et al., 2005). This device was

used in a quantitative study by sixty patients, fifty-six being males and four being female, from the age of six to thirty-four years old (Bahr et al., 2005). The vacuum chest wall lifter was applied for a minimum of 30 minutes, twice a day, up to 5 hours per day (Bahr et al., 2005). The patient progress was documented between two and eighteen months using photography, radiography, and plaster casts of the defect (Bahr et al., 2005).

The results of the vacuum chest wall lifter showed considerable improvement as “after one month, an elevation of 1 cm was noted in 85% of the patients and after five months, the sternum was lifted to a normal level in twelve patients (20%) when evaluated immediately after using the suction cup” (Bahr et al., 2005, Abstract). Unfortunately, all patients who participated in the study exhibited moderate subcutaneous hematoma, or significant bruising (Bahr et al., 2005). Other complications included transient paresthesia in the right arm and leg and orthostatic disturbances during the first application of the suction cup (Bahr et al., 2005). Although the primary results show dramatic improvement to the pectus deformities, this study did not cover a large enough time frame to accurately assess the long-term results of this correction. Despite this flaw, the vacuum chest wall lifter serves as a relatively simple adjunct treatment for the correction of pectus excavatum (Bahr et al., 2005).

Counseling therapies. Pectus deformities not only impact the physical features of the body, but also impact the individual psychologically as well. Issues such as impaired body image, loss of confidence, social isolation, and stigmatization can occur. Through counseling therapies, a trained professional can help the child develop coping strategies, establish a healthy self image, and defer or eliminate surgery as an option if that is desired (“Pectus Deformities,” 2009). Therapy may also help the individual improve his

or her attitude towards the pectus deformity which plays an important role in a individual's well-being and the adjustment to the pectus deformity ("Pectus Deformities," 2009). Regrettably, the impact of pectus deformities is so immense for some that the use of counseling may not be enough to overcome it ("Pectus Deformities," 2009). If the first line of treatment including medications, postural improvement programs, vacuum chest wall lifter, and counseling fails, the next treatment step is surgical repair of the pectus deformity.

Surgical Procedures

Ravitch and Nuss procedures. Although the Ravitch and Nuss procedures vary greatly, both surgical procedures have shown to significantly improve and repair pectus excavatum and carinatum. The Ravitch procedure "involves [an] incision and removal of deformed cartilages, sterna mobilization, transverse osteotomy" as well as forms of internal bracing (Hight et al., 2001, p. 421). However, the complications of the Ravitch technique include development into restrictive lung disease caused by chest wall hypertrophy and impaired rib growth (Hight et al., 2001). The Nuss procedure on the other hand, "involves the placement of a transthoracic retrosternal stainless steel bar to correct the chest wall defect and avoid the need for cartilage incision or resection" (Hight et al., 2001, p. 419).

Through a tertiary pediatric referral center, the forty-two patients in this study were comparable in terms of age, weight, and severity of chest wall defects (Hight et al., 2001). All of these patients' deformities were labeled as purely cosmetic as none of the deformities involved cardiopulmonary symptoms. Thirty-six of the patients underwent the NUSS procedure, and six patients underwent the Ravitch procedure. After the

surgeries were completed, the outcomes were measured in a quantitative form in order to compare the two surgical techniques.

The MIR or Nuss procedure had a “mean operative time of 1.6 hours, a mean blood loss of 22 ml . . . no intensive care unit admissions, and a mean length of hospital stay of 5.5 days” (Hight et al., 2001, Abstract). The Ravitch procedure had a “mean operative time of 5.2 hours, a mean blood loss of 222mL . . . 2 patients admitted to the intensive care unit and a mean length of hospital stay of 4.5 days” (Hight et al., 2001, Abstract). These results led the researchers to believe that the Nuss procedure was a “less invasive, less morbid, and a better tolerated” surgery than the use of the Ravitch procedure (Hight et al., 2001, Abstract). Although these findings are valuable in the sense that the numerical data support the researchers’ conclusion, more prospective studies are needed to investigate into the outcomes of this study and “assess patient age limitations, associated connective tissue disorders, and long-term complications” (Hight et al., 2001, p. 422). These studies would have also been more valuable if both the Ravitch and Nuss procedures used the same number of children, instead of six compared to thirty-six.

Even though this study focused strictly on the surgical procedures, nursing implication regarding treatment option education can be enhanced. The nurse would also be able to anticipate possible complications based on which surgical procedure was to be performed. If the patient is undergoing a Ravitch procedure, a nurse would want to be aware of significant blood loss, intake and outputs, and signs and symptoms of infections.

Long term effect of pectus correction. Although there is a debate among healthcare professionals whether pectus excavatum deformities are a cosmetic or physiological issue and the implications that occur with the corrective process, UCLA

Medical Center took one step forward towards ending this argument. The researchers reviewed the surgical hospital records of 375 individuals who had pectus excavatum deformities repaired between the years of 1969 and 1999 (Atkinson et al., 2000). This vast study covered three decades of surgeries and also examined a diverse age group that ranged from 2.5 years old to 53 years old (Atkinson et al., 200, p. 444). The surgical technique used for all the 375 individuals was a modification of the Ravitch procedure, also known as a Welch procedure, which included the “subperiosteal resection of the abnormal cartilages, transverse wedge osteotomy of the anterior sternum, and internal support with a steel strut for six months” (Atkinson et al., 2000, Abstract). All the individuals involved in this study reported a pre operative decrease in stamina and endurance, occurrence of frequent respiratory infections, chest pain, and asthma as well as a cardiac deviation into the left chest (Atkinson et al., 2000). These symptoms strongly supported the notion that pectus excavatum is not just a cosmetic defect. Yet, surgical correction still remains controversial as it is reported that only fifteen percent of patients with pectus excavatum undergo corrective surgery (Atkinson et al., 2000). This is a staggering number as the results of this study reported that the “mean hospital stay was 3.1 days . . . all patients with preoperative respiratory symptoms, exercise limitations and chest pain experienced improvement . . . and there were no deaths” (Atkinson et al., 2000, Abstract). There were also minimal complications as “more than 97% had a very good or excellent result” (Atkinson et al., 2000, Abstract) with a mean follow-up time of 12.6 years.

This study disproved that surgical repair of pectus excavatum is “dangerous, minimally effective and unnecessary” and that “repair based on a large clinical

experience with long-term follow-up” had extremely successful results (Atkinson et al., 2000, pp. 446-447). These deformities can be repaired with low rates of complications, a short hospital stay, and excellent long term physiologic and cosmetic results (Atkinson et al., 2000, Abstract). It portrayed pectus excavatum as not only a cosmetic defect, but as a physiological and psychological issue that can be corrected with surgery. This is particularly important with nursing implication as it is partially the nurse’s responsibility to inform and teach patients and parents the options in order to treat and correct pectus excavatum and other chest wall deformities.

Through the clinical review of 664 patients followed for one to forty years, 95% of individuals had excellent long-term results and only 5% had mild recurrences after the repair of pectus excavatum through the Ravitch technique. The operating technique of Ravitch consists of the “removal of three to four overgrown costal cartilages, repositioning of the sternum with a transverse osteotomy, and internal support using the child’s lowest normal ribs” (Colombani et al., 1989, p. 578). The results of the Ravitch techniques were gained by reviewing the medical records and charts of patients as well as gaining information about the diagnosis, operation, and type of surgical repair (Colombani et al., 1989). Often this pectus deformity is repaired in the teenage years; however, this longitudinal study also emphasized the importance of correcting pectus excavatum during childhood to “relieve structural compression of the chest and allow normal growth of the thorax, prevent pulmonary and cardiac dysfunction in teenagers and adults and obviate the cosmetic impact that may cause a child to avoid sports and gymnastics” (Colombani et al., 1989, p. 578). The recommended elective age for repair

of the defect was ages four to six years, before the child entered elementary school (Colombani et al., 1989).

With a total of 664 pediatric patients, boys were more common at 498 patients compared to girls at 166 patients with a mean hospital stay of seven to five days. The morbidity rate was 5% and had a higher incidence of complications which included superficial wound infections, pneumothorax, subcutaneous fluid collection, a shift in substernal strut, and pneumonitis (Colombani et al., 1989). The individuals were examined at “two weeks after surgery to monitor healing, 7-8 weeks to allow them to resume full physical activity . . . [and then at] 2 years after the first postoperative year until they had full growth of the chest wall” (Colombani et al., 1989, p. 578).

This particular study had significant findings related to the Ravitch procedure as it offered a successful surgery technique that had excellent long-term results. Although this study was conducted in 1989, it allowed researchers to longitudinally examine the true post operative cosmetic results and physiological changes.

Vertical midline approach. The results of a qualitative prospective cohort study, provide excellent results regarding the repair of pectus excavatum and carinatum through a vertical midline approach. Those who underwent surgery with a temporary sternal bar had an outcome that was superior to those without the sternal support bar (Backer et al., 1999). The vertical midline approach uses an incision over the deformity at midline as the skin flaps are elevated off the cartilage by skin hooks. A subperichondrial resection is then performed to resect the deformed cartilage, perichondrial sheaths, intercostals muscle bundles, and anterior triangular wedge of the sternum. In some cases, a substernal bar was added laterally to the sternum for extra support and finally the surgery was

completed by suturing the muscle flaps together at midline (Backer et al., 1999). The sternal support bar stays in place for six to twelve months and can be removed in an outpatient procedure.

Out of the 120 children and families contacted, 89% of patients reported good or excellent results, and only 3% of patients reported poor results with the vertical midline approach (Backer et al., 1999). In order to assess the outcomes of the vertical midline approach, 120 pediatric repair cases were reviewed, and then the individuals were asked to evaluate the results of the operation as poor, fair, good, or excellent. There were 111 cases of pectus excavatum and nine cases of pectus carinatum (Backer et al., 1999). For those individuals who acquired the sternal support bar, 86% had excellent outcomes versus 52% who obtained excellent outcomes without the bar (Backer et al., 1999). There were thirty-five individuals who used the sternal support bar and eighty-five who underwent repair without the bar (Backer et al., 1999). The procedure proved to be relatively safe as there were no early or late deaths, and minimal instances of the following complications: atelectasis, pleural effusion, postoperative bleeding, pneumothorax, wound infection, seroma, arrhythmia, and sterna bar migrations were reported (Backer et al., 1999).

This study had significant findings that strongly supported the use of a sternal support bar which increased the overall patient satisfaction with good to excellent long-term results. The vertical midline approach with sternal support bar maintains the long-term outcome of the improved pectus contour and supports the use of this bar in routine pectus deformities repair surgeries. The drawbacks to this method of research included the use of a patient satisfaction scale as the categories of poor, fair, good or excellent are

not clearly defined in the study and may be subject to differences in opinions on the quality of outcomes.

Psychological changes. After a pectus deformity corrective surgery, not only are there physical improvements, but psychosocial changes that radically improve patient quality of life. By using a quantitative tool known as the Pectus Excavatum Evaluation Questionnaire, a study was performed using parents and patients, ages eight to twenty-one years old before, and one year after surgery, to evaluate the psychosocial and physical changes in the body (Azizkhan et al., 2008). From 2001 to 2006, 264 patients and 291 parents completed the initial questionnaire, and 247 patients and 274 parents completed the postoperative questionnaire (Azizkhan, 2008). The respondents used a Likert-type scale of 1 to 4 to evaluate the responses. Individuals and their parents reported significant positive postoperative changes with considerable improvements in social, physical, and psychosocial functioning (Azizkhan et al., 2008). Individuals reported being less social self-consciousness and having a more favorable body image with 97% of patients reporting an extreme improvement in how their chest looked (Azizkhan et al., 2008). These results support the idea that surgical repair of pectus deformities can help improve the physiological and psychological implications of these deformities and help the patient live with a better quality of life.

Nurses Role in Patient Care

Management of post operative pain. One of the most significant post-operation complications after a Nuss or Ravitch technique is pain. It is the nurse's role to effectively manage this pain, yet often a knowledge deficit and poor communication skills with parents contribute to obstacles in effective pain management (Bernaix et al.,

2007). A phenomenological study including the interviews of twenty parents and twenty nurses was completed in order to focus and analyze the gaps between knowledge and communication to gain a greater awareness and understanding of treating pain in children (Bernaix et al., 2007).

Communication between parents and nurses resulted in the common topic of the need for information, not only for the parents of children in pain but for the nurses as well (Bernaix et al., 2007). A hospital stay for a parent of a sick child can be stressful, so it is the responsibility of a nurse to answer all parent questions in comprehensible terms and show patience when parents ask the same question more than once. Nurses need to be both knowledgeable and accountable to pain management and each medical and nursing intervention performed. Nurses also need to take the time to acknowledge parental concerns. Although many parents are attuned to their child's behavior, the nurse may need to inform the parents on how to interpret their child's pain and how to appropriately use a pain scale (Bernaix et al., 2007).

Last, another common obstacle of pain management is parents' misunderstanding or knowledge deficit of the use of morphine, a common pain medication used for post operative pain. This is particularly true when the child has a patient control analgesia pump (PCA). The parents have difficulty understanding how to use the machine including which buttons to push. The parents also struggle with understanding and remembering the potential side effects of morphine. Therefore, it is the nurse's duty to explain the medication to the parents and the children so that a greater level of understanding of medication is obtained and the child's pain is controlled. By using these nursing interventions listed above, lack of knowledge and effective pain management

practices, as well as parents' frustrations and lack of confidence, will be an occurrence of the past replaced by evidence based care related to pain management in pediatrics (Bernaix et al., 2007).

Postoperative nursing care. After the Ravitch and NUSS procedures, infection control and pain management are essential. Interventions for the nursing diagnosis, risk for infection, include the following: monitoring temperature for greater than 100.8° F, assess the wound site every 24 hours, document any abnormal findings, evaluate all abnormal lab findings especially complete blood count (CBC), administer all prophylactic antibiotics, use aseptic technique during dressing changes, and instruct client and the family on appropriate aseptic practice (Carpenito-Moyet, 2008). Nursing interventions for acute pain consist of eliminating lack of knowledge, fear, and fatigue, prescribed analgesics, use of heat and cold applications, the use of distractions such as music, video games, books, etc, and relaxation techniques (Carpenito-Moyet, 2008). Other common nursing diagnoses include activity intolerance, ineffective coping, fear, anxiety, disturbed body image, disturbed self-esteem, readiness for enhanced decision-making, readiness for enhanced knowledge, and readiness for enhanced hope (Carpenito-Moyet, 2008).

Children's perceptions of nurses. With over three million children in the United States staying in the hospital each year, the experience of a hospital stay varies from child to child; however, the common theme reoccurring throughout each stay is vulnerability (Roberson & Simons, 2002). There are diverse reasons that contribute to this state such as the illness, change of environment, limited control of the circumstance, separation from family or familiar faces, pain, intrusive procedures, and a generalized fear (Roberson &

Simons, 2002). This fear and anxiety also interfere with the healing and recovery process, which is why it is important for the nurses taking care of hospitalized children to take every intervention seriously in order to promote a positive, comfortable, and therapeutic environment.

In a naturalistic inquiry approach, researchers utilized a semi-structured interview process to discover seven important themes that emerge when assessing hospitalized children's perceptions of nurses and nurse behaviors (Roberson & Simons, 2002). Data were obtained by interviewing younger children and giving older children a chance for written responses. The data were then analyzed using a reductionistic and constructionistic approach in order to identify common themes. These seven themes were identified as most important in treating pediatric patients: positive affect or attitude, physical comfort, the use of entertainment and humor, advocacy, meeting the child's basic needs, acknowledgement, and finally, reassurance (Roberson & Simons, 2002).

The most common theme, positive affect or attitude, reflects a positive outlook of care which included being happy, helpful, smiling, and nurturing. Since pain is a large part of most pediatric hospital experiences, especially when related to pectus deformities, physical comfort and pain management were particularly important to patients as well as avoiding other interventions which inflict more pain such as extra needle sticks through shots and IV insertions (Roberson & Simons, 2002). By using entertainment and humor, a nurse may provide distraction in order to lighten the mood and help children escape from the scary experience of a hospital stay. This may be in the form of stickers, toys, movies, or video games; nevertheless, these distractions need to be age appropriate in order to be successful (Roberson & Simons, 2002). Providing advocacy is also vital as it

creates a sense of security and protection which may be in the form of explaining situations in terms that a child may understand, respecting privacy of the individual, answering questions, and by providing honesty (Roberson & Simons, 2002).

Providing basic needs of individual such as hygiene, food, and the affect of therapeutic touch create the basis of a therapeutic relationship which can be extremely helpful when parents are not able to be at the bedside at all times. Acknowledgment of the child as an individual with his or her own needs is also imperative as children feel that the nurse truly does care and conversely feel as though they have a personal supporter within the hospital. The environment best suited for pectus deformity patients would be one of understanding, acceptance and a caring attitude (Kosloske et al, 2000).

Support groups. After taking care of children with pectus deformity before or after corrective surgery, it is also vital that healthcare providers can refer them to specific organizations which may be beneficial to their healing. Although there are a very limited number of pectus deformities organizations and groups available, the use of shared experience can be a source of support and comfort for pectus deformity patients and family. In the minimal number of organizations, one nonprofit group is increasingly gain popularity. The Pectus Deformities Support Group (PDSG) which centered on promoting awareness of pectus deformities, exchanging information with regard to disorder etiology, treatment and care, and giving mutual support ("Pectus Deformities," 2008). Other websites such as www.meetup.com allow children and parents with pectus deformities to set up their own groups within their residential area by connecting them to others with pectus deformities. Through groups like this, more pleasant treatment

experience can be gained while uniting families and healthcare teams with other sources of information, support, and peace of mind.

Lifestyle Limitations.

There are no specific diets, activities, or restrictions listed for pectus deformities patients as the individuals are able to participate in various activities as tolerated.

However, after correction surgery has been completed, this may vary as activity limitations and restrictions may be put into place in order to maintain the patency and cleanness of the surgical site. Patients who have undergone surgery should be aware of the signs and symptoms of infection and report those immediately to a healthcare provider. Weight lifting or body building exercises are often discouraged before or after surgery due to the enlargement of the pectoral muscles which could amplify the chest wall deformity or damage the tissues around the surgical site (“Pectus Deformities,” 2009).

Chapter III

Methodology

A qualitative methodology was used to explore the impact of pectus excavatum and pectus carinatum on the life of an individual in order to gain a greater understanding of the experience of living with chest wall deformities. This study was particularly beneficial to the individual as it gave the participant a way to tell his or her story as well as create a greater physical, psychological, emotional, and spiritual understanding of patients with pectus deformities. It also helped health care providers find best evidence-based practice related to surgical and nonsurgical treatment of these deformities and finally, offered a standard quality of holistic nursing care.

In order to elicit meaningful data, interviews allocate more control of the atmosphere by “allowing [the] probing of subject’s responses and decreases the possibility of vague answers” (Fain, 2004, p. 222). An interviewer may also ask open-ended questions which permit the participant to create a free-form response and enrich the pertinent data as compared to closed-ended questions. The interview questions covered multi-facets with an emphasis on coping with pain management, decreased exercise tolerance, surgical procedures, and the psychological effect of appearance.

Phenomenology

A phenomenological approach is “a descriptive, retrospective, in-depth analysis of a conscious lived experience” (Fain, 2004, p. 221). It uses intrinsic traits or the essences of the lived experience to gain the true meaning of something in order to form a greater understanding of this phenomenon. Through a semi-structured interview process,

open-ended questions were continuously asked until a clear picture of the lived experience was created with a full description of all valuable data.

Sample

The subject population was one 21 year old female and one seventeen year old male who have had their pectus deformity corrected by either the NUSS or Ravitch technique. There was no specific ethnicity or race, although the participants did need to be English speaking. The subjects chosen were healthy volunteers who were physically stable and willing to contribute valuable information related to his or her experience with a pectus deformity.

The subjects for this study were recruited from a pectus deformity support group website called Pectus Deformity Support Group at www.pectusinfo.com. This website connects individuals and family members with pectus deformities to one another. The recruiting was done by creating an account on the website, and posting a notice explaining the study, which asked if individuals would be interested in participating in an interview. These prospective participants were asked to contact the researcher and told that all personal information gained through the recruitment process would remain confidential. The participants also needed to present significant evidence such as a medical record in order to prove that the individual did in fact have a pectus deformity.

The risk for participating in this study was minimum as it did not cause any physical, economic, social, and legal jeopardy. The likelihood of psychosocial harm, emotional distress, or embarrassment did vary from participant to participant depending on the individual's personal experience with pectus deformities. All measures were taken to ensure comfort to the participants during the interview, and the participant was

informed before the interview that he or she had the option to decline answering a specific question if uncomfortable. There was no cost to the subject other than time required to participate in the study. The researcher obtained institutional review board (IRB) approval prior to the start of the study.

Setting

The interview setting took place at a location that was most convenient for the participant with a quiet and personal space for communication. All possible distractions were eliminated so that the participant could focus solely on the interview questions. If the participant was too far away for a personal interview, a phone conversation was the other option, and a secure telephone line was used. To avoid the individual feel as though he or she was being studied, the study focused more on recalling the experience of living with pectus deformities.

Data Collection

Each interview lasted approximately one to two hours. The participants were also willing to answer any follow-up questions during the following weeks as questions arose during the final process of analyzing the data. The participant had two to three possible contacts with the researcher, with the first being to discuss the study purpose and confirm his or her participation in the study, as well as sign a consent form before the interview. At that time, the researcher and participant set up an interview time and place that was most convenient for the participant.

Confidentiality

To maintain confidentiality for the participants of this study, the complete interview was not shared with anyone other than the faculty director. The participant also

had the option of choosing not to use his or her full name in the honors thesis as well. A secure network was used that was password protected and each participant signed an informed consent form.

The informed consent form included the title of the study, phone number of the investigator, invitation, purpose, description, risk and benefits, economic cost to participant, confidentiality measures, and most importantly, the freedom to quit the study without penalty. If the female or male was under the age of eighteen, a consent form was obtained from his or her parents. There were also no inducements for participation in this study. The participant reward for the interview was gained by sharing his or her life experience with pectus excavatum with others so that a greater understanding of the deformities would be gained.

Risks for Participant

The risk for participating in this study was minimum as it did not cause any physical, economic, social, and legal jeopardy. The likelihood of psychosocial harm, emotional distress, or embarrassment varied from participant to participant depending on the individual's personal experience with pectus deformities. There was a possibility of emotional costs, including nervousness and fear related to the interview process, and stress and anxiety related to the subject's personal experience with pectus deformities. Various measures were taken to ensure comfort to the participants during the interview, and the participants were informed before the interview that the participant had the option to decline answering a specific question if uncomfortable. If the participant was a minor, he or she also had the option of having a parent or guardian accompany him or her through the interview process. The parent or guardian was informed that he or she was

there solely for support of the subject and was not to answer any of the interview questions or prompt the subject to answer a question a certain way. The parent was also aware that if he or she answered any of the questions or the researcher felt that he or she was prompting the subject, the interview would be ended and the subject would not be eligible to participate in the study.

Analysis

The qualitative data gained through the interview process was then analyzed through Edmund Husserl's phenomenology focusing on inter subjectivity and life world or the world of lived experience which is real and true to the participant. The sample size of two individuals was adequate in this particular study as the interview gave sufficient qualitative data with two different perspectives of lived experience. The researcher was able to compare and contrast these experiences in order to justify the findings of the study. Common themes, essences, or meaning structures of the lived experience were identified as the research was reviewed over and over again.

Chapter IV

Results

The purpose of this study was to gain an understanding of what it is like to live with pectus excavatum or pectus carinatum. The two participants interviewed were between the ages of 17-21 years old. One was female and one was male and they both were born and raised in Montana. For confidentiality reasons, the male will be referred to as Edward and the female will be referred to as Alice. Both participants were born with a pectus excavatum deformity and elected to have corrective surgery, the Nuss technique, completed during his or her sixth grade year. The corrective surgery took place at the Mayo Clinic in Rochester, Minnesota. Both of these adolescents overcame a long emotional and physical journey related to the correction of his or her deformity. They both described their experiences of living with a chest wall deformity through these themes: being different, facing limitations, coping with fear, receiving quality nursing care, experiencing pain, and finally moving forward.

Being Different

At early ages, both Edward and Alice realized they were physically different than their peers. Edward described his chest wall deformity as “almost like a cereal bowl” and found himself joking with elementary school friends about the depth of his “bowl.” Alice also described her similar experience:

When I was way young, I always thought it was fun because when I was taking a bath or something I could put water in it and have fun with it because it was a pretty deep inversion. When I started getting older and went to the swimming suit I always had the problem that my swimming suit would get wet and suction into

my inversion. I started to realize then that it was very different and it looked very different.

As the participants grew older, Edward and Alice's deformities became less of a joke and more of a harsh and cold reality. Alice recalls how the presence of her deformity and being physically different affected her both socially and psychologically.

Socially, I remember, especially going through puberty and being a girl, just noticing that I was different. I started to realize then that it looked very different. It was very weird having to go through puberty having something that looked completely different than someone else. And that was the time that I really wanted to do something about it. I was at the point where it was something that I didn't feel comfortable with anymore.

Being different only affected Edward in certain situations, he stated:

Pectus excavatum psychologically affected me was when I was in a public setting like a public pool. I always felt as though people were looking at me because of my indentation in my chest. I never knew if people were, but it always felt like people were staring and that always bothered me.

Besides looking different, Edward and Alice both struggled with the physical consequences of being born with pectus excavatum.

Facing Limitations

The physical limitations experienced by both participants significantly impacted their ability to perform in sports related activities. Alice shared her swimming experience:

Physically, I started swimming at a young age and so pectus excavatum definitely had an effect on my swimming abilities because of the breathing issues. And I kind of noticed it at the beginning as I wasn't able to breathe as easy as the others [sic] kids. My swim coach would try to get us to breathe every four strokes and I would never be able to do that. I would always struggle with every other stroke.

Edward also struggled in the arena of sports:

I could not physically run for long periods of time, just short bursts, because I would get short winded and wouldn't be able to breathe very well. It kind of dampened being able to do random normal kid things like playing football, baseball, or just running around with my friends.

The physical limitations also continued after the NUSS procedure for Edward. He shared setbacks after the surgery:

After the surgery, the doctors said that they really didn't want me to participate in any sports that required direct contact like football or rugby, but I used to play football before the surgery and I wanted to play after. We finally got it approved from the doctor and I wore an extra chest protector under my normal football pads in order to protect my sternum. When I moved to high school, I recognized the kids were bigger, tougher, and hit harder. I also realized I didn't have a future in football and it wasn't worth risking my health. I then switched over to the safer alternative- golf. Sometimes after long days of golf, my sides ache and get sore along the incisions; however, if you swing properly this shouldn't happen.

Coping with Fear

The theme of being scared and fearful surfaced with both Edward and Alice during the interviews. For Alice, it began when her parents realized something was physically wrong and took her to the doctor.

It was a scary experience for me as a child and they wanted to see how the inversion was advancing. I remember getting tests done when I was like eight and I thought it was fun kind of like a game and then when I was about ten I started to realize that it was a little bit of more serious situation.

The serious medical situation lead Alice to corrective surgery as she underwent the Nuss procedure. For her, it was the scariest part of the corrective process. She stated:

I have the most distinct memory of waking up from the anesthesia and starting to cry because I couldn't see my mom and dad and I was so scared. I had forgotten where I was and didn't know why I was there. But the care there was really great and the nurse that was there immediately comforted me, rehashed what had happened, and reassured me that my mom was about to come through the room, things like that. Being that young and having to do that was definitely scary.

Alice also shared information about the experience of being in children's hospital as she stated:

I don't know if a lot of it was nerves. I guess I was just frightened and just scared to be a young kid in the children's ward. You are surrounded by a lot of kids who are really sick and so you start to think and feel really sick, not that I wasn't. You start to realize how serious surgery is.

Edward also experienced the same emotion of being scared and fearful as he underwent surgery. He shared his story:

I have to admit, I was pretty calm and trusting throughout the whole surgery process, but there was one time that I really became scared. It was right before I was put under anesthesia. The doctors and nurses explained everything that was going to happen beforehand, but it was way different to experience it firsthand. My vision got blurry, I couldn't think properly, and I was completely confused and scared. I truly didn't know what was in store for me.

Although the surgical experience was frightening for both Edward and Alice, as they were both in sixth grade and 12 or 13 years of age, they both recalled the genuine compassionate care they received from their nurses.

Receiving Quality Nursing Care

Edward and Alice explained that the nurses truly made a difference in their hospital stay and that they will never forget the care the nurses provided. Alice shared the impact of nursing care:

I thought that the nurses were phenomenal. They had a great sense of humor which was really necessary because I had my surgery right around Christmas time and I could see snow outside my window. I was so delusional due to the fact that I was sitting in a hospital bed. If I would get a card, flowers, or a stuffed animal, they would all come in and be very excited for me. All the good nurses made you feel like they were motherly or sisterly person that really genuinely cared about you especially when you were in such a vulnerable state. It meant a lot for the nurses to take a personal interest and not be afraid to find out what I liked in

school, what I was going to do when I got back to Montana or anything that helped keep my mind off the fact of where I was and that I was missing ski season.

Edward agreed with the importance of nurse's taking a personal interest in each patient and being able to effectively communicate as he stated:

I really appreciated all the nurses. Each one showed kindness and compassion towards my situation. They acted as though they genuinely cared about me by simply talking to me and making conversation comfortable. They also pushed me to get better by encouraging me to get up and walk and have a positive and optimistic outlook on my recovery. They were truly there to help me in my moments of helplessness. The care was great and I didn't have any complaints.

He also offered a few suggestions of what a Children's Hospital wing should include as he said:

The other thing related to nursing care was the atmosphere of the Children's ward. I loved the Children's ward. Everyone was so friendly, loving, and family oriented. It was nice to see other kids in my same boat and be able to encourage each other the get better.

Experiencing Pain

While the support of the nursing care helped ease the recovery process, the intense pain of the post surgery period was inevitable. Alice shared her difficult recovery story:

I had a couple complications in the surgery. They broke a couple ribs getting the bar in and that complicated my ability to walk upright and breathe comfortably

for a while. I also had a collapsed lung during surgery and I think that the mental and physical aspects combined made my recovery tough and painful. Then to make matters worse, the pain medication, Morphine, just knocked me off of my feet. It would make me throw up and it physically hurt so much to throw up because of my ribs. I remember the pain the most when trying to get up to walk, it would feel awful and it would take several people to help me get up. I felt so helpless and I didn't like feeling helpless.

Likewise Edward talked about his recovery from surgery:

My post surgical experience was kind of a rough one. It was very hard to move to the left or right as both sides of my body were so sore from the surgery. Sitting up was really hard because it took strengthen [sic] from the upper abs which were pretty sore from the surgery. Walking was the hardest part for a while because it was so painful. The pain was pretty severe for about the first two weeks after surgery. The first two days were the roughest and progressively the pain lessened and the pain progressed into a general soreness.

Despite all the pain, struggles, self doubt, and physical problems caused by growing up with a pectus deformity, both participants were happy with the end result of the corrective surgery.

Moving Forward

Both Edward and Alice reported coping with positive and negative experiences as they progressed through childhood with a chest wall deformity, underwent corrective surgery, and finally pressed onward towards the future without the stigmatism of pectus excavatum. When asked if they would complete the corrective surgery all over again,

both Edward and Alice stated “yes, without a doubt.” Alice summed up her surgical outcome by saying:

I am glad that I got it done because I feel much less nervous about having more problems related to pectus excavatum. Athletics were huge for me, I wanted to be sure I was able to swim and ski. I took the pulmonary function tests after the surgery and it was vastly improved which was really encouraging. I was able to swim throughout high school. I remember swimming and feeling a difference in my ability to breathe. It definitely made a difference in my life.

She continued by stating:

My body has improved since the surgery and if I wouldn't have had the surgery I know I would have struggled with it. People would have asked more questions and I wouldn't have wanted to date people and it would have been a really difficult situation to navigate in the awkward stage.

Edward shared this same point of view as he shared his recovery process by stating:

After the surgery my self esteem was a lot higher than it used to be because I looked like everyone else and pectus excavatum became just a part of the past. I've never really looked back since. I think that I would definitely have the surgery again because it helped me breath a lot better and really helped my self confidence level.

Conclusion

The experience of living with chest wall deformities and surgical correction was described by the following themes (a) being different, (b) facing limitations, (c) coping with fear, (d) receiving quality nursing care, (e) experiencing pain, and (f) moving

forward emerged while the participants explained the lived experience of pectus excavatum.

Chapter V

Discussion

Throughout the semi-structured interview and the analysis process, a greater understanding of what living with a pediatric chest wall deformity was gained. The participants, Edward and Alice, were affected both psychologically and physically as indicated by the identified themes of being different, facing limitations, coping with fear, receiving quality nursing care, experiencing pain, and finally moving forward. The themes that emerged from the study are similar to issues faced by other adolescents during the surgical experience (Bergh et al, 2008). It also provided a learning opportunity for nurses in order to improve quality of care and positively develop the overall experience of an adolescent hospital stay.

Being Different

Throughout childhood, Edward and Alice observed that they were physically different from their peers. The participants' perception and attitude towards the chest inversion of pectus excavatum shifted from positive to negative as they both grew older. The indentation transformed from being a bath time trick in childhood to creating a self-conscious body issue when at the public pool during adolescence. Both participants expressed concerns about body images worsening when entering the teenage years. The parents of both participants selected to have the pectus excavatum deformity corrected through the NUSS procedure at the Mayo Clinic in Rochester, Minnesota. By choosing to have corrective surgery, both participants were making an effort to become normal again.

Facing Limitations

Besides the psychological issues, Edward and Alice both had to acknowledge and adapt to the physical limitations caused by pectus excavatum. It was difficult for both participants to breathe during strenuous exercises and they often fell behind in sporting activities due to decreased exercise tolerance and lack of oxygen supply. Alice had difficulty in the sport of swimming and had to deal with the unrealistic breathing expectations set by her coach. Edward had to adjust to the fact that he could no longer participate in football, even after the corrective surgery. Limitations became a way of life and these limitations were greatly improved after the corrective surgeries allowing Alice to return to swimming and Edward to select a golf, a lesser impact sport. In the end, it was the quickly declining pulmonary function tests that lead Edward and Alice's parents to seek medical treatment for pectus excavatum.

Coping with Fear

Each participant in this study experienced fear in a slightly different form. Alice experienced fear throughout the diagnostic and surgical process, whereas Edward experienced fear immediately before surgery. Researchers have shown that the major stressors for children during hospital stays are the unfamiliar routines and the aesthetic and operation expectations (Bergh et al, 2008). Both participants struggled with induction of surgery and post operative recovery from anesthesia which lead to a generalized fear of undergoing surgery. Due to the underlining fear, the nurse may need to "assess the adolescent's emotional readiness for surgery- knowing that adolescent's understand and fear much more than they verbalize: Silence may indicate terror, not calm" (Carter & Hancock, 2008, p. 49). Following an assessment of the emotional status related to various

issues including previous hospital experiences, the nurse needs to provide a quality education session.

Research suggests that it is best to fight fear with teaching (Carter & Hancock, 2008). When teaching an older child it is better to include more cognitive terms and explain words not common in an adolescent's vocabulary (Carter & Hancock, 2008). Also, choose words that do not have a double meaning and use honesty as the best policy (Carter & Hancock, 2008). One small lie can often destroy the time and effort used to create a strong patient rapport. If the nurse cannot answer the question truthfully then redirect the adolescent and address the question at a later time when adequate time is given to the response (Carter & Hancock, 2008).

Timing is also important as adolescents should discuss operative teaching up to one week before the surgery in order to give the adolescent a proper amount of time to process the information and form coping mechanisms (Carter & Hancock, 2008). For adolescents, the nurse needs to provide as many opportunities as possible for questions and concerns, with and without the presence of the parents or primary care provider (Dearmun & Smith, 2006). This is a different approach than with younger children as teaching should be done the day of surgery to avoid time to become anxious. Both participants expressed that they did receive adequate teaching pre surgery; however, they still did not fully comprehend what was going to happen during surgery and the pain that would occur afterwards.

Receiving Quality Nursing Care

Although going under anesthesia was frightening for both of the participants, Edward and Alice both expressed that the reassurance they felt after seeing a familiar

face of a nurse with the knowledge that they would be reunited with their parents shortly after the immediate post operative period. Continuity of care is an important issue in receiving quality nursing care. The adolescent and parents need to see one or two faces that they recognize throughout the hospital stay (Carter & Hancock, 2008). The faces of the health care provider also need to be seen as competent and caring so that the patient is able to trust and accept care (Carter & Hancock, 2008). In order to build patient rapport, the nurse needs to use effective therapeutic communication. Addressing the adolescent by what he or she likes to be called is the first building block (Carter & Hancock, 2008). Also, finding an interest and being able to comfortably converse with the adolescent is also important. Edward and Alice commented on how the nurses each took a personal interest in them, conversed easily with them about sports and other interest and finally were genuinely happy for them when they made small improvements.

Both participants expressed that being vulnerable was part of the hospital stay during the immediate post operative period as they could not complete simple activities of daily living (ADL's) without assistance. The nurse can play an active role in solving this problem by making sure that the adolescent does not feel as if he or she is being treated like a baby (Carter & Hancock, 2008). The hospital setting already forces adolescents into a situation in which he or she is dependent on the healthcare staff and family support. By giving the adolescent as many choices as possible, within established limits, it will stimulate independences and the process of recovery (Carter & Hancock, 2008).

Experiencing pain

Pain is one issue in surgery that often cannot be avoided. Both of the participants described the severe pain that they felt during the post operative period. In order to assist adolescents through the pain associated with the surgical and post operative time, it is the nurse's responsibility to use an effective pain assessment tool, look for physiological and behavioral indicators, try non-pharmacological methods, administer pharmacological pain relief, and reassess pain promptly (Twycross, 2008). The participants identified that the pain intensified while they participated in daily care activities, as well as physical activity such as walking down the hospital hallways. During periods of activity, it is vital that the nurse properly assess and treat the patient's pain before and after activities (Twycross, 2008). Both participants also expressed the importance of having nursing staff focus on small activity goals, such as walking to the doorway and back on the first time out of bed, in order to mentally tolerate the pain caused by the particular activity. By making small gains, the participants felt motivated by positive encouragement and felt that the healing process was occurring.

Alice also identified issues, such as nausea, that occurred with her pain medication. When giving the pharmacological treatment for pain control, it is the nurses' role to accurately reassess pain levels and look for side effects of the medication (Twycross, 2008). The participants both struggled through the discomfort of the generalized pain and overcame this pain by taking small steps toward a full recovery.

Moving Forward

After examining perioperative dialogues with children who underwent surgery, researchers found that the post-operative period is a time to "breathe a sigh of relief and

regain normality in life again” (Bergth et al, 2008, p. 96). Moving forward was a major theme for both of the participants. The successful correction of the pectus excavatum deformity allowed each participant to be able to physically and psychologically return to being a normal adolescent. After the recovery period, both participants were able to more fully participate in sports again, such as golf and swimming. Both participants expressed the relief that they would not have to deal with body image issues and dating fears associated with chest wall deformities as they progressed into high school and being a teenager. They both also stated that they felt that their self-confidence was increased after the surgical repair of pectus excavatum.

Future Nursing Research

Despite the unique experiences described by the participants, more research is needed to validate the findings and themes of this study. The sample size of the participants was very limited with only two participants and only individuals with chest wall deformities in Montana were represented. More research needs to be conducted with a larger sample of individuals and emphasizing not only the physical aspects and limitations of pectus excavatum, but the psychological issues as well. It would also be beneficial to use a sample size with greater varying ages and sociocultural subgroups to further investigate the relationship of common themes.

Conclusion

The experience of living with a chest wall deformity can be physically and psychologically taxing. Being different than Edward and Alice’s peers and facing limitations were issues that the participants dealt with throughout childhood. It was also a motivating factor in choosing to receive corrective surgery. The process of undergoing

corrective surgery was complicated and brought about several topics of concern. Coping with fear, receiving nursing care and experiencing pain were all part of the hospital experience. Although the pectus excavatum journey brought challenges and obstacles, both of the participants' surgeries yielded successful results. Edward and Alice expressed the importance of remembering their pectus excavatum experience, yet moving forward with living life to the fullest.

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Appendix

Consent to Participate in Pectus Deformity Interview

I have been invited by Nicole Donisthorpe to participate in a voluntary research study. The purpose of this study is to gain understanding of what it is like to live with pectus excavatum or pectus carinatum.

If I choose to participate in this study, my participation will consist of an audiotape recorded interview with Nicole Donisthorpe lasting about 10- 30 minutes. In this interview, I will be asked to discuss my experiences, feelings, and ideas related to simulation. I may withdraw from this study at any time. There are no risks to my participation in this study. Confidentiality will be maintained throughout the study, and at no time will my name or identifying characteristics be used. I am aware that this research will be used to advance the understanding of pectus deformities for both students and faculty and that there may be presentations and publications associated with this study. I am aware that if I have any questions I can call Nicole Donisthorpe at 406-899-5332 or email at ndonisthorpe@carroll.edu and I understand this consent form.

I agree to participate in this study:

Name

Date

Researcher

Date