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Acceptance and Commitment Therapy as an Intervention for Adolescent Chronic Pain


Related to Pectus Excavatum: A Case Study

A DOCTORAL PAPER
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BY
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Acceptance and Commitment Therapy as an Intervention for Adolescent Chronic Pain Related to Pectus Excavatum: A Case Study

The most common chest wall deformity, Pectus Excavatum (PE), is a congenital deformity in which the sternum and adjoining chest wall cave inwards toward the spine (Lawson et al., 2003). While corrective surgical procedures have been shown to have positive effects on the physical and psychosocial well-being of patients with PE (Krasopoulos, Dusmet, Ladas, & Goldstraw, 2006), often surgical procedures, such as those done to correct PE, can result in what is known as Chronic Post-Surgical Pain (CPSP). CPSP has been shown to have great bearing on the patient's overall well-being (Weinrib et al., 2017), meaning that while the corrective surgery for PE may positively alter the aesthetic of the chest-wall deformity, there is a lot of physical and emotional recovery to be expected post-surgery. This case study begins by briefly reviewing chronic pain, PE, and the related surgical experiences. Then it focuses on the psychological aspects of an adolescent male's chronic pain treatment during his recovery from PE corrective surgery and his progress towards a more fulfilling life using an Acceptance and Commitment Therapy approach.

Chronic Pain

Chronic pain (CP) is recurrent or persistent pain that continues past the anticipated healing period of approximately three months (Lioffi & Howard, 2016). CP has been identified as a prevalent problem in child and adolescent populations, ranging from 6% to 57% of the population dependent on the type of pain (King et al., 2011). It can be the result of chronic disease, an injury, or surgery; however, frequently the cause is unidentifiable (Lioffi & Howard, 2016). CP results from a dynamic integration of the patient's biology, psychology, sociocultural environment, and developmental and familial dynamics, and therefore, has often been associated with social, academic, and emotional struggles (Weisman, 2008). While CP is a complex problem to assess

and treat, evidence supporting the benefits of an integrative biopsychosocial approach is quickly growing (Liossi & Howard, 2016).

A biopsychosocial approach to treatment calls for the integration of biological, psychological, and social processes to help create a deeper understanding of the patient and allow for a more robust explanation of behavior. Therefore, creating teams of healthcare providers with expertise in each of these areas allows for a multidisciplinary approach to pain that permits each professional to more fully understand the various factors of the illness by observing how these three processes interact and influence the individual's personal experience. These professionals are then able to address the maladaptive automatic physical and behavioral responses to the stress that are at the center of the patient's pain. A multidisciplinary pain management team's focus is to help restore functioning and improve the patient's quality of life by managing his/her pain more effectively (Crawford & Campo, 2016). Multidisciplinary approaches that include a psychological component have been shown to have both positive short-term and long-term effects on pain and functionality (Hoffman, Papas, Chatkoff, & Kerns, 2007).

In this paper, I will focus on CP related to PE, a musculoskeletal deformity that has been shown to have biological, psychological, and social effects on the patient.

Pectus Excavatum

Pectus Excavatum (PE) occurs in approximately 1 out of 500 people worldwide (1 in 1000 in the United States) and is found four times more frequently in males than in females, making it one of the most common genetic deformities in the United States (Dean et al., 2012; Kelly et al., 2008; Luo, Xu, Wang, Tan, & Zhao, 2017). In PE, also known as "funnel chest," the ribs are longer and steeper than those without PE, meaning that the ribcage forms in a way that decreases the distance between the sternum and spinal column, resulting in a caved-in or funneled chest and frequently, an asymmetric sternum (Dean et al., 2012; Roberts, Hayashi, Anderson, Martin, &

Maxwell, 2003). PE is usually present at birth and continues to progress as the child grows, with the defect increasing dramatically during the growth spurts associated with puberty (Roberts et al., 2003). Many patients do not undergo surgical repair during childhood and subsequently experience progressive worsening of physical symptoms and cardiopulmonary functioning as they age, which could be related to either worsening of the defect or an increase in physical activity (Jaroszewski, Notrica, McMahon, Steidley, & Deschamps, 2010). Some of the most common physical symptoms include dyspnea (abnormally labored breathing) with exercise, fatigue, chest pain, lower levels of endurance, and perceived inability to exercise (Dean et al., 2012; Jaroszewski et al., 2010).

While some studies show contradictory results of the effect of PE on cardiopulmonary function, its effects on the mental state of PE patients have been noted (Luo et al., 2017). Due to the physical symptomology and obvious aesthetic differences of PE, patients often display higher prevalence of psychosocial problems than children in healthy control groups, including body-image issues, inferiority, shame, depression, social problems, and overall reduced quality of life (Einsiedel & Clausner, 1999; Krille et al., 2012; Luo et al., 2017). In response to these psychosocial struggles, PE patients will often turn to avoidance behaviors such as defensive camouflaging (poor posture with crossed arms), abstaining from shirtless events or activities, and even refraining from hugging and intimate relationships (Roberts et al., 2003).

With an increase of research attention on both the physiologic and psychologic effects of PE, attempts at reversing the longstanding misconception that PE is simply a cosmetic deformity have increased in favor of performing corrective surgeries (Dean et al., 2012; Jaroszewski et al., 2010; Kelly et al., 2008).

Surgical treatment of Pectus Excavatum. PE surgical repair has been an evolving process for almost 60 years, resulting in two common methods: the Ravitch and Nuss procedures. The Ravitch procedure is an open approach (Jaroszewski et al., 2010), in which the surgeon cuts through the body layers to expose the surgical site (Barta, 2009). The Nuss procedure is a minimally invasive approach that includes smaller skin incisions and shorter operative time. In this procedure, a substernal concave bar is passed behind the sternum and rotated into a convex position to raise the sternum outward. The pectus bar is then left in place as the anterior chest wall remodels for two to three years (Jaroszewski et al., 2010; Metzelder, Kuebler, Leonhardt, Ure, & Petersen, 2007). The modern version of the Nuss procedure has gained wide-standing popularity and acceptance as the new standard technique for PE repair (Metzelder et al., 2007), due to its ability to offer highly acceptable results without the need for a large incision across the chest, resulting in smaller and less-visible scars (Roberts et al., 2003).

While the corrective surgeries for PE can be completed at any age, it is recommended that the repair be done when the patient has nearly reached skeletal maturity to avoid various complications associated with growth. Additionally, patients who receive the procedure during puberty tend to have lower recurrence of PE; thus, most surgeons elect to wait until early teen years or adolescence before performing the repair (Jaroszewski et al., 2010; Luo et al., 2017).

While the Nuss procedure has gained popularity for its aesthetic results and shorter operative time due to smaller incisions, studies show that the procedure does have complications of its own, including more postsurgical pain and longer hospital stays (Gasior, Weesner, Knott, Poola, & St. Peter, 2013; Jaroszewski et al., 2010). In addition, medical pain management after the pectus bar has been placed is particularly challenging, and the best approach has been heavily debated in the literature. Two contested choices are patient-controlled analgesia (PCA) and thoracic epidural catheter (EPI). While EPI has been shown to result in longer operating times,

more calls to anesthesia, and greater hospital charges, PCA after the Nuss procedure comes with higher levels of mental foginess and a need for more postsurgical analgesics (Gasior et al., 2013; Jaroszewski et al., 2010). Some studies have shown that there are high levels of postsurgical pain in approximately one-third of Nuss procedure patients. The pain, experienced as severe and troublesome during the post-operative period, decreases after the post-operative period, disappearing altogether after the removal of the bar (Krasopoulos et al., 2006; Metzelder et al., 2007). Regardless of the management technique used, patients identify the pain as being sharp and locatable, specifically at the sides of the chest (Gasior et al., 2013). Furthermore, most patients have some degree of physical awareness of the pectus bar and some feel that it impairs their daily life (Metzelder et al., 2007).

Despite the physical impact of the procedure, most patients state that they are satisfied with the results, would undergo the operation again (Metzelder et al., 2007), and do not persevere on their postsurgical pain or continue to harbor anxiety (Gasior et al., 2013). In fact, families of patients describe immediately noticeable results and great satisfaction with the results of the procedure (Roberts et al., 2003). Anecdotally, parents speak of immense improvement in their children's behavior and how much better their children feel about themselves. They also note improvement in both exercise tolerance and sports performance (Lawson et al., 2003). Empirical results confirm that the Nuss procedure has a positive effect on both the physical and psychosocial quality of life of children suffering from the PE deformity (Krasopoulos et al., 2006; Lawson et al., 2003). Physically, results have shown that patients feel stronger, have fewer perceived limitations on exercise, decreased somatization, increased stamina, and higher likelihood of participating in activities (Dean et al., 2012; Luo et al., 2017; Roberts et al., 2003). However, the degree to which these results are related to real physical improvements in cardiovascular and pulmonary functioning versus general psychological improvements remains controversial (Dean et

al., 2012). Psychosocially, surgical repair has been shown to affect various areas of mental health in PE patients (Luo et al., 2017). Specifically, improvements have been noted in body image, emotional functioning, interpersonal struggles, self-esteem, confidence, and general quality of life (Dean et al., 2012; Kelly et al., 2008; Krasopoulos et al., 2006; Krille et al., 2012; Luo et al., 2017; Roberts et al., 2003).

However, regardless of possible improvements after the procedure and the chosen pain-management strategy, it has been postulated that the experience of PE correction is overwhelming (Gasior et al., 2013). While patients get maximum correction immediately, the psychological effect is chronic and warrants extended support (Luo et al., 2017). In addition to the psychosocial struggles related to the expected postsurgical pain and discomfort, patients and families often describe their concerns about the procedure and the complications that may arise between the procedure and the removal of the bar two to three years later (Roberts et al., 2003). Possible complications of the Nuss procedure include pneumothorax and associated pain, pericarditis, pneumonia, infection, and bar displacement, each of which can result in the need for bar removal or additional surgery to introduce stabilizers (Nuss, Croitoru, & Kelly, 2003). Most often, patients expressed concerns around the bar being displaced or dislodged by their movement and activities, especially during sports or exercise (Roberts et al., 2003). Additionally, it cannot be assumed that pre-surgical psychological struggles will simply disappear along with the funnel appearance of their chest. Thus, psychological intervention may be necessary in conjunction with corrective surgery, especially if the patient does not experience the expected positive results of the procedure. For example, Metzelder et al. (2007) found that many patients noted overall improvement after the procedure; however, there were a few that did not experience the improvement and, in fact, expressed feeling impaired until the bar was removed. Studies have even shown that some PE patients who have had successful physical treatment of their deformity, but whose psychological

treatment was ignored, later developed more serious psychosocial reactions such as overdependence on parental home, suicidal tendencies, hypochondria, and psychosomatic symptom displacement (Einsiedel & Clausner, 1999).

Chronic Postsurgical Pain

In addition to the pain and discomfort that is expected during the four to six-week post-operative period (Roberts et al., 2003), there is yet another concern for postsurgical PE patients: chronic postsurgical pain (CPSP). Like other types of chronic pain, CPSP is not always associated with identified nerve injury and appears to be neuropathic (Wooden, 2017). CPSP has six primary characteristics: (1) the pain develops after a surgical procedure, (2) it lasts at least two months, (3) it creates interference with the patient's health-related quality of life, (4) it is a continuation of the expected postsurgical pain, or redevelops after a period with no symptoms, (5) it is localized to the surgical area, and (6) it cannot be attributed to other factors (Weinrib et al., 2017). Furthermore, the surgical procedures that most commonly cause CPSP are those involving the abdomen, pelvis, and thorax. Nearly a quarter of patients undergoing thoracic surgery develop CPSP. There is controversy over the factors related to CPSP, with some saying that it is functional and others attributing it to psychological factors (Wooden, 2017). Psychological risk factors that have been linked to CPSP include pre-surgical instances of anxiety, depression, and general psychological distress. Overall, CPSP places a considerable amount of physical and psychological stress on those hoping to ameliorate a physical condition and recover from major surgery (Weinrib et al., 2017). These findings suggest that individuals who are diagnosed with PE and choose to undergo the Nuss procedure can anticipate an overwhelming physical and psychological journey towards the promised post-bar-removal results.

Psychological Approach

The psychosocial portion of CP treatment has a well-documented record of success using behavioral therapies (Hoffman et al., 2007; Vowles & McCracken, 2008; Vowles, McCracken, & O'Brien, 2011; Wicksell, Melin, Lekander, & Olsson, 2009). A meta-analysis of various psychological interventions for CP found cognitive-behavioral therapy to be efficacious (Hoffman et al., 2007). In recent years, there has been a new emphasis on what is known as 'third wave behaviorism', including an approach called Acceptance and Commitment Therapy (ACT; Ferguson & O'Donohue, 2015). Key aspects of ACT that differ from other behavioral models are its focus on Acceptance, a willingness to experience and sit with pain rather than alter thoughts about one's pain; Values, which are personally meaningful purposes; and Committed Action, or making a values-based decision to persist with activity regardless of the presence or absence of the pain (Harris, 2009). ACT focuses not on the reduction of symptoms, but on improving values-based living. When applied to CP, that ideology refers to decreased pain-related distress and more engagement in daily valued activities, rather than a focus on the reduction of pain sensations (Bach, 2008). Studies have shown that ACT-based treatment results greater short-term improvements than pain-control approaches for adults with CP (Vowles & McCracken, 2008). Other studies have shown that ACT also results in long-term improvements in depression, pain-related anxiety, and psychosocial disability; and fewer pain-related healthcare visits for CP patients (Vowles et al., 2011). These improvements in academic, physical, and emotional functioning have been demonstrated within adolescent CP groups being treated with the ACT model (Vowles & McCracken, 2008). For example, in a controlled study by Wicksell et al. (2009) the ACT group showed "substantial and sustained improvements" (p. 53), including significantly better results than other groups on self-reported functionality and pain intensity. Additionally, the

treatment group had significantly better post-treatment changes in fear of reinjury and kinesiophobia (the fear of pain related to movement), and quality of life.

Unfortunately, while some studies suggest that the mere presence of the PE deformity can cause psychosocial difficulties for the patient (Kelly et al., 2008), there is a paucity of research on the effects of PE, associated procedures, and resultant chronic postsurgical pain on psychosocial functioning, as well as the related psychosocial treatment. Given the preliminary data suggesting that ACT is beneficial for adolescents with chronic pain, an ACT-based psychological intervention as part of a multidisciplinary approach should be useful to children and adolescents struggling with chronic pain due to a medical procedure such as the Nuss procedure. Therefore, the purpose of this case study was to explore the use of an ACT-based model of psychotherapy within a multidisciplinary treatment team for an adolescent with chronic pain related to PE medical procedures. Specifically, the research questions addressed in this study were as follows:

1. How does the implementation of an ACT-based intervention affect the pectus excavatum patient's recovery (defined as a return to normal functioning)?
2. In what way does an ACT-based intervention support a shift in perspective for the patient away from pain-focused experience and behavior towards an increase in values-based committed action?

Method

Case studies allow researchers and health professionals to assess new approaches for evidence-based practices in clinical settings. They can also be an effective way to highlight the role of psychological treatment within a multidisciplinary pediatric medical team (Ernst, Bierenbaum, Piazza-Waggoner, & Carter, 2013). The adolescent male featured in this case study presented with complaints of chest wall pain due to PE procedures and had attended nine months of individual ACT-based psychotherapy as a part of a multidisciplinary chronic pain team.

Case Description

Participant. This study's participant was a 17-year old male, "Kyle"¹, living with his biological family, including parents, older brother, and younger sister. Both parents work from home, his mother as an artist and his father as a project manager for a well-known technology company. Kyle and his mother reported at the initial intake that they have good family support locally; no legal issues or social service involvement; no financial stressors; and stable housing, transportation, and food.

Kyle was in the 12th grade at a local high school, and although would occasionally miss school for various medical reasons, was generally doing well academically. His plans were to graduate at the end of the academic year and attend a local art school. He also stated that he hoped to pursue a career in boxing; however, had not been participating in physical activities because of his chest pain.

Medical history. Kyle was born with PE at 39 weeks and weighed 9 pounds, 4 ounces. Except for pneumonia as an infant and a history of headaches, he was a healthy child. At intake his growth and development, physical exam, and exercise tolerance were within normal limits. He presented with exercise-induced migraines and PE-related shortness of breath with various levels of activity. During his physical therapy intake, he presented with impairments in posture, excessive recruitment of accessory musculature during inhalation (using muscles other than the diaphragm to aid in breathing), decreased range of motion and strength in his neck and trunk, increased muscle tension, and decreased scar mobility.

¹ Name changed to protect patient's privacy.

At 15 years and 6 months, Kyle underwent the Nuss procedure to have his initial bar placed. Two months later, he had to undergo another procedure to adjust the bar after it became dislodged. About a year after the initial procedure, a second bar had to be placed for stabilization, and nine months later he required yet another readjustment and stabilization surgery. After each surgery, he recovered and resumed normal activities; however, soon the bar would move and prompt further surgeries to add stabilizers, additional bars, or repositioning. He experienced the usual postsurgical pain after his initial pectus repair, and then continued to have chronic chest wall pain for the next two and a half years. Around the two-year mark, he went caving with his friends for three to four hours, after which his pain worsened dramatically and did not improve.

Kyle described his pain as aching, sharp, shooting, and as though it were coming in “jolts.” He explained that sometimes the pain was so severe that he would lose concentration and discontinue his activities. He stated that his pain lasted all day and was constant – without worsening or improving at any specific time. He explained that there were some treatments and activities that affected his experience of pain. For example, Kyle stated that it was worsened by any type of exercise, such as walking long distances; lifting items; twisting his body; doing chores; or yawning, sneezing, and coughing. Icing, heating, soaking, and medication made the pain better. Kyle also reported that he would try to use calming music and meditation to distract him from his pain and the associated anxiety. Various medical workups for his pain included lab tests, X-rays, MRI, and orthopedic/general surgery consultations.

Kyle asked his surgeon to perform the removal surgery after two years and three months because he believed it would relieve his pain. However, he was also worried that if the bars were removed prematurely his chest would again cave in and the previous surgeries would have been for naught. His surgeon expressed to him that, ideally, she wanted to wait the full three years before removal as suggested by the literature on the procedure. However, in discussing it with

him, she was willing to schedule the removal surgery for the two-year, 6-month mark, and simultaneously referred him to the pain clinic for support with pain management until that time.

Mental health history. Kyle had not had any prior formal mental health treatment at the time of intake with the pain clinic. However, he expressed that he was open to a psychotherapy referral to learn coping skills as part of his pain treatment. He and his family expressed anxiety over his medical appointments, and Kyle endorsed PE-related mild anxiety, stress, and depressive symptoms. He reported having an overarching sense of disappointment that the procedure had not gone as planned and required numerous additional surgeries. He explained that having prior notice of his initial surgery gave him time to prepare and cope with his feelings; however, the following surgeries were unexpected and left him feeling shocked. While he wanted the bar removal to occur “sooner rather than later” because of the pain he was experiencing, he reported that he also worried that the earlier removal procedure would not turn out as he hoped and would lead to further disappointment.

Kyle had an extensive history of involvement with various sports and exercise, with boxing being his most recent interest. However, since his last surgery, his pain had worsened, and he no longer participated in any sports or exercise because physical activity caused him to breathe heavier and triggered anxiety around pain. To avoid the pain, he engaged in shallow breathing, which would often lead to shortness of breath.

Kyle reported the use of personal coping skills, including support from friends, relaxation (listening to nature sounds and meditation), and drawing to manage his anxiety symptoms, help himself relax, and express himself.

Setting. This case study was conducted at a local children’s hospital that serves the psychological and medical needs of infants, children, adolescents, and young adults. Specifically, the treatment for this study was provided by the Pain Management Services team housed within

the anesthesiology department. The psychotherapy treatment was provided in a private clinic room on an individual basis. Physical therapy (PT) treatment was done individually in the PT gym. Other pediatric PT patients and family members were frequently working with their own therapists in the same area. Medical check-ups were provided in private medical rooms.

Measures

The following measures were administered at various points throughout treatment during visits to the multidisciplinary chronic pain team. For this case study, those data are used as a descriptive reference of Kyle's functioning. Assessment focuses on the experience of pain and patient-specific functioning goals.

Numeric Pain Rating Scale. This pain measure was conducted during each visit to the pain clinic. Kyle was asked to rate his current pain intensity according the Numeric Pain Rating Scale (NPRS; McCaffery & Beebe, 1989), an 11-point scale where 0 indicates "no pain" and 10 indicates "worst imaginable pain." On occasion, Kyle was asked to identify his *average* pain rating according to the same scale.

Patient-Specific Functional Scale. This measure was completed during PT appointments. The Patient-Specific Functional Scale (PSFS; Stratford, Gill, Westaway, & Binkley, 1995) is a self-report, patient-specific measure aimed at assessing functional change in patients with musculoskeletal disorders. Kyle was asked to identify three activities that he was unable to perform or was having difficulty with because of his chronic chest pain at the beginning of treatment. On follow-up appointments, he was asked to rate his current level of difficulty with each activity on an 11-point scale where 0 indicates "unable to perform activity" and 10 indicates "able to perform activity at preinjury level."

Intervention

Kyle's treatment was provided by a multidisciplinary team consisting of PTs, nurses, medical doctors, and psychotherapists. He attended a multidisciplinary intake and was then expected to see his nurse and medical doctors monthly and his PT and psychotherapist weekly. The focus of this study was on the psychotherapeutic intervention from the values-based behaviorism approach known as ACT.

In the early stages of pain psychotherapy, psychoeducation is provided to reduce pain-related anxiety and to encourage an increase in activity. During the initial psychotherapy appointment, Kyle discussed his history with pain, the specifics of his Nuss treatment that gave rise to his pain, and how the pain had affected his life. He was then given a brief overview of the mechanisms and benign character of pain – meaning that pain, in and of itself, is not directly harmful to his health. His psychotherapist explained the difference between acute and chronic pain and how they are affected by the mind-body connection, more specifically, the bidirectional relationship between mind and body sensations and their influence on pain. Psychoeducation was also provided on how his genetics, body mechanics, behaviors, and emotions affected his experience of pain. Emphasis was placed on the understanding that pain can cause stress and anxiety symptoms in both the patient and his family – and, in turn, that stress can cause pain.

Acceptance and Commitment Therapy

According to Harris (2009), Acceptance and Commitment Therapy's three core concepts can be encapsulated by the modality's acronym: ACT. The letter A represents acceptance of your thoughts and feelings; C stands for choosing what is important to you, a valued direction; and T denotes taking action. The aim of these concepts is to increase one's psychological flexibility, i.e., the ability to approach each present moment with openness to one's experience and to choose to take action guided by one's values rather than a focus on attempts to avoid or control unwanted

physical and psychological sensations. Psychological Flexibility was identified as the main emphasis for Kyle's treatment in order to initiate a shift in perspective away from pain-focused experience and behavior and to spur an increase in values-based committed action.

A: Acceptance vs. Avoidance. Acceptance refers to allowing our thoughts and feelings to be as they are, whether they are pleasant or painful, rather than struggling with them. Instead, allowing them to come and go as they do naturally (Harris, 2009). Since acceptance of what cannot be controlled or changed (thoughts, emotions, pain) was identified as a first step towards choosing values-based behaviors, Kyle was instructed to notice and accept (as opposed to try to control, suppress, or avoid) his internal experiences without acting on them. Thoughts, emotions, physical reactions, and urges to act that were aimed at reducing pain or the risk of pain, rather than the engagement in valued behaviors, were identified and understood as avoidance. Kyle was encouraged to perform values-based exposure aimed at accepting his internal experiences (both physical and emotional) and increasing behaviors that aligned with his identified values. The values-based exposure focused on expanding and increasing his behavioral range in pain-related situations. Fear related to pain, never getting better, failure, etc. were targeted as main components of the exposure process. It should be noted that acceptance does not mean resignation or tolerance but signifies a willingness to grant those experiences permission to be there as they are.

C: Choose a Valued Direction. Values are statements about what gives our life meaning or purpose, what we want to stand for or strive towards (Harris, 2009). They are meant as a compass that guides our life in a direction that is important to us. As a core feature of ACT, the process of pinpointing aspects of life (activities, situations, etc.) that were valuable to Kyle was used to create goals, work towards pain exposure, create motivation, and facilitate a shift in perspective away from symptom alleviation and towards values-congruent living

T: Take Action. Committed action means choosing to take effective action that is guided by one's values. It also refers to flexible action – readily responding to the challenges of the human experience and persisting with or altering behavior as necessary to live according to our values (Harris, 2009). For Kyle, this referred to choosing to engage in activities and situations that were important to him rather than focusing on fear or avoidance-driven behaviors.

Results

Response to ACT Intervention

A: Acceptance vs Avoidance. During the initial stages of his treatment, Kyle would speak about his frustration with his procedures and the associated pain and how those things limited his ability to train “effectively” and delayed his dream of becoming a professional boxer. While he understood the logical importance of keeping his pectus bars in place for as long as possible, his anger and frustration focused on what he felt he was missing out on because of his belief that he could no longer box. He would often hide his pain from others, including his medical professionals, because he believed that pain is weakness, and being weak mean that “you’re pathetic.” Kyle’s fear of being “pathetic” or weak resulted in avoidant behavior – pretending that he was not experiencing any pain and continuing to suppress it internally, resulting in increased pain-related anxiety. Using a metaphor of a child falling off a bicycle, Kyle’s psychotherapist asked how he would treat a child that fell, scraped his knee, and was crying. He stated that he would treat the scrape, acknowledge the child’s hurt, and encourage him to get back on the bicycle. The psychotherapist asked, “You wouldn’t tell him he’s pathetic and weak and should just stop crying?” to which Kyle responded that doing so would not decrease the child’s pain. Using his own response to that metaphor, Kyle was able to identify the importance of acknowledging and accepting pain, treating it, and not letting it hold you back from doing what is important to you.

With the support of his PT, Kyle noticed his attempts to control or avoid his pain, such as by not breathing deeply or using his diaphragm; and avoiding running, training, or activity of most kinds. While initially those behaviors had been a reaction to pain, they soon became his *modus operandi* in response to his anxiety that he MIGHT feel pain if he were to breathe deeply and correctly or engage in activities. At the beginning of treatment, he would completely avoid activities that might cause pain; later, he began to engage in activity but restricted his breathing and chest movement, and at various times during his treatment, he would not disclose new or worsening pain to his medical team to avoid what “might” be wrong.

During psychotherapy sessions, Kyle would qualify most areas of his life as “pretty good” (whether the topic was school, activities, social life, or pain, etc.), in hopes that by not acknowledging his struggle, it might disappear. However, he continued to struggle with his frustration about his perceived limitations due to his procedure. He expressed anger that his procedure had “taken away” boxing from him. In addition, with his focus on his pain and treatment, he had taken college application exams later than his peers, and he was sure it was “too late” for him to apply to the animation art program he wanted to attend. Consequently, he was suddenly fighting a fear that his future in every desired direction had been “taken away” by his PE. A discussion about his tendency to label his feelings as “good” or “bad” followed. His psychotherapist asked him what it might be like to simply look at all his emotions as signs of what is going on in his life, rather than “good” or “bad” experiences that he needed to control or react to. He responded with a metaphor of his own. He related his emotional stressors to an opponent in boxing. He stated that “it’s good to be afraid of your opponent, because then you respect them.” He realized that he was seeing his stress about his future, his procedure, and his pain as “bad” but was beginning to understand that perhaps his fear, frustration, and stress were present because he respected (valued) his future – his opponent. He shifted his perspective from naming his emotions

as “good” or “bad” to understanding them as experiences that come and go naturally; and that can help him more fully understand his experience if allowed to be present instead of fought or controlled.

Near the end of his treatment, Kyle discussed the possibility of the procedure (now set for the full three-year mark) not being successful. He reported that he was slightly scared, very nervous, and fully aware that he would be in incredible pain post-surgery and filled with disappointment if the procedure failed. He did not say this sheepishly or with embarrassment, but matter-of-factly. When asked why, he stated it was because he no longer viewed pain as a weakness or something that made him “pathetic,” and how acknowledging it and accepting it rather than trying to ignore or fight it had diminished its effect on him. It was no longer an invincible opponent, but a sparring partner.

During his final psychotherapy appointment, a few weeks before his procedure, Kyle stated that he was experiencing pain again for the first time in a while. When he was asked how he was coping with it, he listed the skills he had learned (such as diaphragmatic breathing, imagery, and exercises), in addition to acceptance of the pain and its related emotions. He stated that, when looking back at his experience in psychotherapy, he realized how much he had internalized acceptance of his experiences. This acceptance was not only specifically implemented in regard to his pain, but in each area of his life where his unwillingness to have uncomfortable experiences became the focus rather than engaging in the things that were important to him.

C: Choose a Valued Direction. During Kyle’s treatment, he expressed a sense of his and others’ expectations or “shoulds.” He “should” be happier (self), or he “should” do his at-home PT exercises (parents), or he “should” avoid thorax contact during sparring (pain treatment team), or he “should” wait longer for removal of the Nuss bars (surgeon). He exclaimed that if he didn’t have doctors and parents telling him what he “should be doing” then he would just be boxing

anyway and would get the bars removed to rid himself of the pain. His psychotherapist responded by saying “Well, you can.” He smirked in response; it hadn’t occurred to him that he had a say in the matter. They discussed values-directed choices, such as making decisions that are important or fulfilling to him in some way. He explained that he chose not to box or get the bars removed immediately because he did not want to make all of his previous surgeries and struggles “a waste of time.” They then spoke about the difference between values-based choices and fear-driven choices. For example, his academic choices were often aimed at avoiding failure, such as not completing assignments because he was afraid he would fail (and then failing anyway due to missing assignments), or not engaging in physical activities because of his fear of pain (resulting in overworking other muscles or increasing muscle tension, leading to more pain). He then identified areas of his life, such as athletics, where he tended to face his fears, challenging himself to work harder. This was not always because of fear of failure, although that was sometimes the case, but because of a desire to improve – to be a better athlete, a better boxer. However, when asked directly what he wanted, what was important to him, he explained that he wasn’t sure.

In order to help Kyle identify and name his personal values, he completed a values card sort, the Life Compass Cards (Steinwachs, 2011), which asked him to sort 108 values cards into piles indicating *very important to me*, *somewhat important*, and *not important*. He then took the *very important* pile and removed values that he chose because they solve a problem, e.g., Health because he was struggling with pain, or because he thought he *should* choose it, e.g., Patience because it is considered a virtue. Then, he re-sorted the remaining cards into three piles – *very important*, *somewhat important*, *of little importance* – until seven cards remained. At this point, Kyle was asked to look at the remaining values and ask himself if anything was missing. He was allowed to recall or add cards if desired. Then, he was asked to choose his top three values, and

finally his overall top value. This process is focused not on devaluing or giving up anything, but on prioritizing values in that moment.

Kyle was thoughtful and engaged throughout the card sort process. His top value was “personal nature,” or being true to himself; boxing, represented by the “athleticism” card and “connection” rounded out his top three values. He spoke about how his dream of becoming a professional boxer had been affected by several years of surgical procedures and pain. He then spoke about how the boxers he admires have “heart” (part of their “personal nature”) that helped them overcome their obstacles to achieve their height in the boxing world. He explained that “heart” is also something he values and looks for in friends.

To help him understand the difference between a value and a goal, his psychotherapist asked him if the act of boxing would be enough, regardless of whether he could become a professional boxer. She explained that goals are achievements that we strive for, with their importance lying within the act of achieving them; while values are a direction, a compass, for the choices we make or the goals we create that are important in and of themselves. One is not more important than the other. In fact, to work toward our values, it is imperative that we set goals that move us in the valued direction.

After reviewing his values, the way Kyle spoke about and approached his progress in other areas of the multidisciplinary team shifted. For example, his PT explained a shift in his activity goals. Previously, he had set specific objectives for himself, such as running five miles with only two 30-second breaks. His PT shared that he would become frustrated with himself if he did not meet his specific goals or would avoid running altogether if he did not think he would be able to achieve them. However, that began to change. For example, Kyle reported going on a few runs simply because he wanted to and because it was part of his recovery; he did not record distance or time. Once, he joked about being “lazy,” but then revealed that his decision to not engage in an

activity was not based on an attempt to avoid feeling “pathetic” or having pain. In psychotherapy, he was able to describe a shift in the way he viewed his approach to activities or challenges. Prior to the discussion about values he felt that if he was doing something he had to give 100% regardless of the consequences; afterwards, he saw that he could avoid “over-doing it” with activities and still enjoy and value them. During his final session, he explained that he now found enjoyment in the *doing* of activities, rather than needing them to have a specific outcome - boxing, itself, was enough.

T: Take Action. After the initial appointment that focused on psychoeducation around pain and the importance of physical activity for the improvement of pain, Kyle increased his engagement in activities. He began doing diaphragmatic breathing, weightlifting, and taking walks. However, the decision to do so was because he had been told that he “should” by the pain team. Once he began having discussions about acceptance and values, his perspective on his decisions and his choices about his behavior began to change. For example, after telling his psychotherapist that he wanted to have his pectus bar removed, he met with his pain nurse and medical doctor and let them know that he had decided that he was “in it for the long haul” and was going to wait the full three-years to have the bars removed, as his surgeon had recommended. When asked about this change of mind by his psychotherapist, he stated that he finally realized that he had a choice in the matter. He had a new understanding of his ability to choose to do what mattered to him instead of trying to control the things he *didn't* want. In that moment, he saw that repairing his PE was important to him, the journey he had endured to get that far was important to him, and he was not going to give up on either: he was going to make a committed choice.

In addition, he began to take committed action in other areas of his life where he felt frustration and anger. For instance, he was angry and worried about delayed college entrance exams and missed animation art school applications; however, once he faced and accepted those

emotions, he realized that attending an animation program was important to him and decided to take action. He contacted the school, spoke to them about his circumstances and their applications, and then completed and submitted an application. He was accepted for admission the following semester. Kyle had been so focused on his worry that his desired future had been “taken away” from him, that he had stopped working towards it; however, when he began taking committed steps towards it, he was able to reach a values-directed goal that he had set for himself.

Toward the end of his treatment, he began experiencing increased pain due to sparring with a friend at his boxing gym; however, this time he was not distressed by the pain because he was still choosing to engage in his PT exercises and his valued activities. He stated that he planned to continue sparring despite the pain because he and his friend “take it easy” and because there was no medical damage. They discussed the difference between pushing himself in a beneficial way (committed action) rather than pushing himself too far (fear-driven avoidance because he feared getting left behind or trying to ignore the distress of being in pain, etc.). He reported that his health and recovery were important to him and that he was choosing to do all that he could to “ensure” a successful outcome for the final surgery the next month.

Kyle was also able to identify how mindful commitment to values-directed behavior in one area of his life allowed him to engage in values-directed behaviors in other areas of his life. For example, he spoke about how accepting and facing his pain and choosing to engage in boxing spilled over into a positive change in his relationships with his family, friends, and himself (his reflected his value of “connection”).

During his final psychotherapy session, Kyle was asked how he might know whether he needs to seek psychotherapeutic support in the future. He responded by saying, “If I am not doing the things that are most important to me, which, for now are relationships, boxing, art, and

spending time outdoors, then it is time.” Specifically, he will seek support when he is no longer taking committed action towards the things that he values.

Empirical Measure Results

As mentioned previously, the empirical measures administered as a part of this case study are merely for a description of Kyle’s functioning. These results are represented in Figure 1. The results from the NPRS show an overall decrease in his experience of both current pain (represented by the line graph) and pain average (represented by the plotted points) with occasional upsurges towards the middle of treatment. The PSFS, represented by the bar graph, shows an increase in his perceived ability to complete activities at the level of pre-pain performance (namely: running, boxing, and weightlifting).

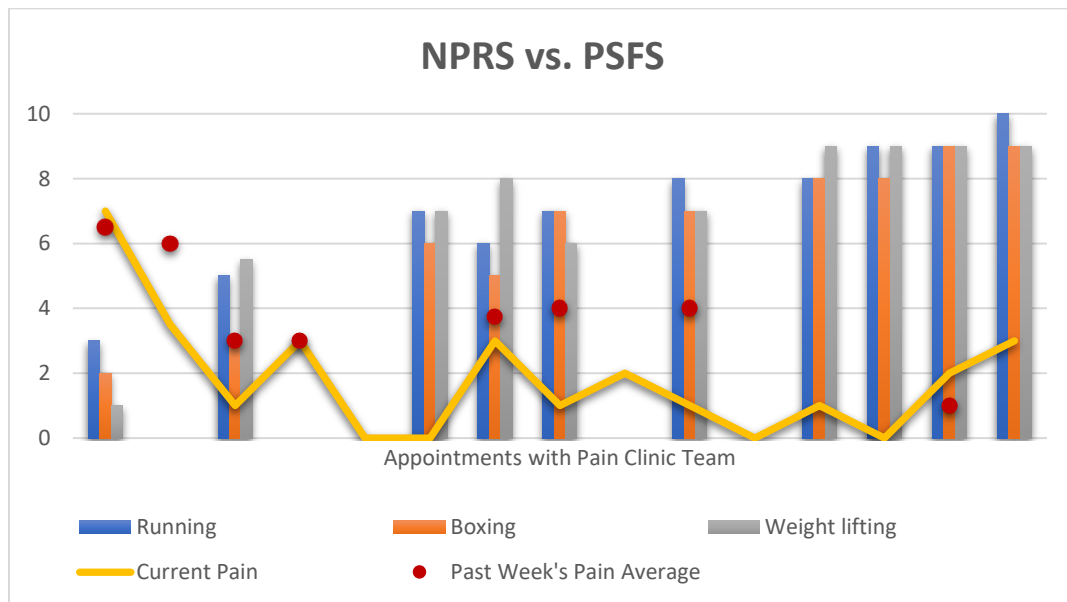


Figure 1. Perceived ability (for Running, Boxing, and Weightlifting) ratings collected from the Patient Specific Functioning Scale compared with pain ratings as collected from the Numeric Pain Rating Scale

Discussion

The purpose of this case study was to illustrate how an ACT-based intervention can be incorporated into the treatment and recovery of an adolescent with chronic pain related to PE surgeries. The intervention aimed to identify and shift the patient’s perspective away from pain-

focused experience and behaviors towards an increase in values-based committed action.

Specifically, how could ACT support the patient's behaviors away from avoidance of physical and emotional pain towards a life filled with activities that he found meaningful and fulfilling? Kyle demonstrated improvements in valued choices, activity and treatment engagement, and acceptance of internal struggle during the course of treatment. Simultaneously, an overall decrease in rating of pain and disability was seen even though decreasing pain intensity was not the focus of the psychological aspect of treatment. Kyle's overall pain experience decreased throughout his work with the multidisciplinary treatment team. It should be noted that towards the middle of treatment when his pain increased, his perceived ability to do activities decreased; however, after the concepts of acceptance, values, and committed action had been covered and reportedly internalized, his perceived ability to engage in chosen activities increased or remained stable even when his reported pain increased.

Although the Nuss procedure is usually successful in repairing the aesthetic nature of PE, studies have shown that PE patients whose psychological needs were not addressed often developed serious psychosocial reactions, such as overdependence on parental home, suicidal tendencies, hypochondria, and psychosomatic symptom displacement (Einsiedel & Clausner, 1999). These results suggest that, although the mental health struggles may have begun as a result of an individual's funneled chest, simply removing the cause may not be enough to repair the psychological damage that has developed over time. For that reason, it is important to include psychotherapy as a part of a PE patient's reparative journey. Prior to the procedure, some PE patients have dealt with a lifetime of embarrassment, low self-esteem, and engagement in avoidance behaviors. These patterns cannot be expected to simply disappear with the removal of the Nuss bar. Therefore, it is important to help patients shift their focus away from restrictive, avoidance behaviors towards behaviors that are important to them. This is an outlook that can

continue long after the bars have been removed. Fortunately, that is something that ACT can do for them that surgery simply cannot.

ACT is not a linear, manualized approach. The areas of Acceptance, Values, and Committed Action are broached individually and together throughout the course of treatment. Kyle realized that acceptance of his unwanted experiences allowed him to make space in his life for different areas of focus. That is, if he stopped focusing on his experience of pain and the associated stress, he could begin to look at what was important to him and the steps needed to move in that valued direction. However, the conversation around acceptance needed to be approached again later in the treatment when topics related to fear-based action compared to values-based action arose. In the same way, while discussion about committed action remained constant over the course of treatment, it evolved as his perspective shifted. Initially, Kyle's decision to engage in activities, such as exercise and treatment, was seen as a commitment to his treatment; however, after discussing acceptance and values, he took committed action to move in a valued direction, with little to no focus on the role that pain played. Furthermore, before Kyle focused on acceptance, he lacked the psychological flexibility to think carefully about what was important to him: what he wanted to work *toward* rather than what he wanted to get *away* from. However, once he accepted the reality that he would continue to experience pain, he was able to let go of the focus on avoidance and instead concentrate on what was important to him and what behaviors would lead him in that direction. The non-linearity of the ACT model allows for flexibility to approach the client wherever he currently is situated within his ever-changing human experience.

This case study shows how the implementation of ACT-based procedures helped shift the perspective of an adolescent PE patient *away* from avoidance and *toward* a fulfilling approach to life. However, given the methodological nature of case studies, caution should be taken when

making interpretations or attempting to draw any extensive conclusions beyond the information presented for this patient. Nevertheless, due to the limited research on this difficult group of patients, there is a critical need for empirical studies on effective treatments for PE adolescents with chronic pain-related struggles. The promising outcome of this specific intervention merits supplementary empirical studies to assess the role of ACT-based interventions for children and adolescents who struggle with chronic pain due to surgical procedures.

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