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## Treatment Anxiety Education for Pediatric Cardiac Neurodevelopmental Patients, an Evidence Based Project

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**Final Manuscript**

Treatment anxiety education for pediatric Cardiac Neurodevelopmental patients, an

Evidence Based Project

Mary Nagel

University of San Diego

## **Abstract**

### **Background**

Congenital heart disease (CHD) is the most common birth defect and affects almost 1% of all live births. Treatment anxiety is common among children with CHD who undergo multiple procedures early in their lifetime. Dramatically increased life spans for this cardiac population has led to a shift from focusing on survival to their long-term health outcomes.

### **Methods:**

Administration of the Peds QL Cardiac Module 3.0 assesses health related quality of life (HRQOL) during annual visits to a Cardiac Neurodevelopmental (ND) Clinic by evaluating the level of Treatment Anxiety a patient experiences during healthcare appointments. The questionnaire scores are inversely rated, with higher scores correlating to less Treatment Anxiety. Patients and parents/guardians received targeted education on treatment anxiety, its causes, coping tools, and resources. Pre/post measures of treatment anxiety were measured.

### **Findings:**

There were 7 children aged 5-17 years old enrolled over a period of three months. All but one had measurably decreased treatment anxiety after the intervention. Almost every parent endorsed feelings of being heard and gratitude for the education intervention as well.

### **Discussion:**

This project is a simple, yet effective demonstration that proper education can positively influence pediatric patient outcomes. Focusing on mental health and long-term outcomes for patients with CHD is important and achievable during annual ND appointments.

### **Application to Practice:**

Implementing age-appropriate education on treatment anxiety and coping mechanisms during ND visits is feasible and cost-saving, improving improves short- and long-term outcomes for mental health in congenital cardiac patients. More research is needed for longer term outcomes with these interventions.

EBP Project: Treatment anxiety education for pediatric Cardiac  
Neurodevelopmental patients

**Clinical Problem**

Congenital heart disease (CHD) is the most common birth defect, affecting almost 1% of all live births (Kaugers et al., 2017). In the United States alone, over 35,000 infants are born annually with CHD, and more than a third of these infants have complex CHD (Wernovsky et al., 2018). There are a wide range of defects and severity; many children are subject to lifelong treatment and monitoring, which can include surgical intervention in infancy. Fortunately, over the past few decades, mortality in this population has significantly improved, yet not all health outcomes have had such progress (Wilmot et al., 2015). There are currently over one million adults living in the US with many types of CHDs, with an estimated 150,000 adults with complex CHD (Wernovsky et al., 2018).

This increased survival rate and life expectancy has resulted in identification of new comorbidities for this patient population, including mental health disorders and neurodevelopmental delays (Uzark et al., 2008; Wilmot et al., 2015). There are many factors that impact the presence of anxiety, depression, and ADHD in addition to neurodevelopmental delays (NDDs) for children and adolescents through adulthood with CHD. Some of these risk factors include the presence of underlying genetic syndromes, previous surgeries, familial mental health disorders, time on cardiopulmonary bypass, prematurity, and prolonged hospitalization (Gonzalez et al., 2021). According to Gonzalez et al. (2021), 50-75% of children with complex CHD, such as single ventricle physiology, deal with NDDs and a subsequent reduction in quality of life. These mental health comorbidities and developmental issues can lead to significant lifelong problems for this cardiac population.

### **Problem Clarification**

The general population of 2 to 11-year-olds have a national prevalence of anxiety and depression of 3 and 7% respectively (Gonzalez et al., 2021). In contrast, patients with CHD were found to have a much higher prevalence (16%) of anxiety and/or depression diagnosis (Gonzalez et al., 2021). Adolescents with CHD have more than double the likelihood of anxiety and/or depression when compared with other adolescents without CHD (Gonzalez et al., 2021). Anxiety prevalence is important because the presence of anxiety is directly related to reduced Pediatric Cardiac Quality of Life Inventory scores (Marino et al., 2012).

Treatment anxiety or procedural anxiety is common among pediatric patients and especially for children with special health care needs like CHD who have experienced multiple surgeries or procedures (Goldman-Luthy, 2019). Treatment anxiety can be defined as “the fear or worry related to any medical procedure that can interfere with your ability to receive appropriate medical care” (“Procedural anxiety,” n.d.). Procedural anxiety stems from fear of pain, which may be perceived or real, or from the memory of previous negative experiences (Goldman-Luthy, 2019). The scope of procedures that induce anxiety can greatly vary, anything from a routine diaper change to invasive interventional procedures (Goldman-Luthy, 2019). This matter is important because it affects not only the patient but the whole family unit.

Substantial progress in medical and surgical care has drastically extended the life expectancy for children born with CHD; now almost 90% of children with CHD end up surviving to adulthood (Uzark et al., 2008). With these exciting advances, the focus of care needs to shift beyond just survival and to long term health outcomes in this developing population. Quality of Life and health related measures have become the emphasis for healthcare promotion in cardiac patients (Uzark et al., 2008). Pediatric mental health has also

been highlighted greatly recently, in the context of the past few years and as a result of the Covid-19 pandemic. According to the American Heart Association, “periodic developmental surveillance, screening, evaluation, and reevaluation throughout childhood may enhance identification of significant deficits, allowing for appropriate therapies and education to enhance later academic, behavioral, psychosocial, and adaptive functioning” (Marino et al., 2012, p. 1143).

Utilizing specific management protocols, such as family education or proper referrals, can improve the efficacy of Health-related quality of life (HRQOL) surveillance and better patient health (Varni et al., 2005). The PedsQL 3.0 Cardiac Module consists of a 27-item questionnaire that has 6 themes: Heart problems and treatment, Treatment II, Perceived physical appearance, treatment anxiety, cognitive problems, and communication. This project’s focus was the Treatment Anxiety questionnaire and subsequent scores which consisted of 4 questions rated on a 5-point Likert scale. These scores are inversely rated, with higher scores correlating to less Treatment Anxiety. This survey is a HRQOL measuring tool and suited to this pediatric cardiac population.

### **Summary of Evidence**

In searching for evidence related to the treatment anxiety and HRQOL measures, clinical databases such as CINAHL, Cochrane, and PubMed were utilized. Keywords such as “treatment anxiety”, “Health Related Quality of Life”, “pediatric”, and “congenital heart disease” were used in the search. In total, 13 articles were selected and reviewed, including clinical practice guidelines, cross sectional surveys and prospective studies. Two articles described treatment anxiety, its prevalence in children, and its implications for receiving medical care. Four of the articles recognized the significance of the clinical problem in addition to identifying current gaps

in the literature. Another two studies discussed outcomes related to pediatric mental health, and a third detailed the annual costs of anxiety and depression in children with special health needs.

A comparative cross-sectional study of over 1100 patients found that a significant number of youth with CHD have higher rates of mental health disorders and that screening this population for anxiety and depression disorders is indicated (Gonzalez et al., 2021). Two studies found the Peds QL Cardiac Module 3.0 to be feasible, reliable, and valid in assessing HRQOL in pediatric patients with CHD (Uzark et al., 2003; Varni et al., 2005). According to Uzark et al. (2008), children with CHD report lower quality of life than healthy children in all age groups.

### **Strengths and Limitations:**

In reviewing the current literature for management of treatment anxiety, there are both strengths and limitations present. In recent decades, growing attention has turned to the mental health crisis in youth, with much more time and research devoted. Due to the burden associated with anxiety and depression and their added morbidity throughout life, managing mental health has become an increasing priority in primary care (Pella et al., 2020). The existing depth and breadth of research on the impact of anxiety and depression on HRQOL, costs, and solutions is substantial. This evidence is wide-ranging and integral to creating this EBP project on treatment anxiety.

Unfortunately, there are also limitations associated with the research on mental health illness and HRQOL indicators. There is no meta-analysis or systematic review included in my literature review of this subject. The lack of a comprehensive article such as a systematic review suggests that there is a solid foundation of research for this clinical problem, but there is insufficient data and evidence thus far on interventions and clinical outcomes for mental health disorders in this specific population. Multiple articles also cite limitations due to

small populations and lack of diversity in their participants (Kaugers et al., 2017; Pella et al., 2020; Uzark et al., 2008). Many of the studies only focused on patients with one or two specific cardiac defects such as single ventricle physiology; in reality, there is a wide range of CHDs that affect this cardiac population (Gonzalez et al., 2021; Kaugers et al., 2017). Research in the future should focus on youth of all backgrounds, income classes, and with a range of cardiac defects.

### **Evidence Based Intervention**

This project focused on screening for treatment anxiety in pediatric patients with cardiac defects being seen at the Cardiac Neurodevelopmental Clinic of a large, regional, pediatric referral hospital. The purpose of this outpatient clinic is to evaluate the growth and development of infants and young children with congenital heart disease. Risk reduction through early identification and treatment of multisystem problems is important for successful development and improved quality of life. Since quality of life cannot be exactly gathered from clinical or laboratory results, optimizing health related interventions and outcomes depends on proven measures for evaluating quality of life (Uzark et al., 2003). The literature, as previously stated, supports the validity and reliability of the Peds QL Cardiac Module 3.0 for this patient population. This is a valid and reliable measuring tool for HRQOL in this population.

The capability of an instrument to impact both clinical practice and patient outcomes derives from the measuring tool's effect on clinical decisions (Uzark et al., 2003). Screening this group of patients for treatment anxiety is one of the evidence-based interventions in this project. Regardless of the treatment anxiety score, all patients and families were given an informative handout and educated on treatment anxiety background, coping mechanisms, and symptoms during a detailed discussion. The patient education is the project's second and more significant

intervention. The primary outcome from this project is the treatment anxiety score from the Peds QL Module; the project's overall objective is to improve these scores after a short, uniform education piece.

### **Gap Analysis**

This Cardiac Neurodevelopmental Clinic was started in February 2020 as a transition for patients from the High Risk Infant Follow-up Clinic. The focus of this new clinic is to evaluate and monitor the neurodevelopmental outcomes of cardiac patients annually from childhood through adolescence. The Peds QL Cardiac Module 3.0 was already being administered during these appointments prior to this DNP Project. A considerable gap was present, due to the novelty of this clinic. An experienced Nurse Practitioner identified an opportunity for this EBP Project regarding treatment anxiety. On the Peds QL assessment, the treatment anxiety section regularly scored low for these patients. Additionally, parents were voicing concerns over patient anxiety during medical procedures and regular appointments. This project capitalizes on the intersection of the movements towards neurodevelopmental outcomes in cardiac patients, mental health, and patient centered care.

### **PICOT Clinical Question**

At a Cardiac Neurodevelopmental clinic in the patient population ages 5-18 years old, does administering the Peds QL Cardiac Module 3.0 improve education and support for treatment anxiety in a 6-month period?

### **Nursing Theory and EBP Model**

For this project, Virginia Henderson's Nursing Need Theory applies comprehensively. This nursing theory emphasizes the significance of supporting the patient to their utmost health and independence (Ahtisham & Jacoline, 2015). Fourteen vital activities were composed for the

nurse to help carry out, all based on basic human needs. Henderson's approach is holistic and includes components such as physiological, psychological, spiritual, and social ("Henderson's Nursing Need," 2019). The ultimate goal utilizing these nursing activities is to help the person reach their full independence. This theory fits well with this project because it encourages nurses to promote health and illness prevention. Giving patients and families the tools to manage treatment anxiety applies the essential components of communicating with others in expressing emotions, needs, fears or opinions. As a Pediatric Nurse Practitioner, assisting patients with their growth and eventual functional independence in their own healthcare is the core of meeting the patient's needs for this Need Theory.

The Stetler Model of Evidence-Based Practice served as the framework for the implementation of EBP into this project. Advanced Practice RNs (APRNs) utilize this model when creating new protocols and in innovative nursing led programs that originate from research and the most up to date practice evidence (Melnik & Fineout-Overholt, 2015). The Stetler Model is frequently employed in advancing current practices and interventions to improve patient outcomes in many settings such as primary care clinics. The five steps of this model are both straightforward and user friendly for a wide range of clinical uses. These steps outlined as Preparation, Validation, Comparative Evaluation or decision making, Translation or application, and Evaluation. The Stetler Model optimized this project through the use of its key features of simplicity and practitioner focus. The most current evidence of treatment anxiety screening and education was collected and validated through the literature review.

### **Project Implementation**

This project to screen and educate both patients and families on treatment anxiety administered the Peds QL Cardiac Module 3.0 to patients from 5 to 18 years old. These

recruited patients had pre-existing appointments at the Cardiac Neurodevelopmental (ND) Clinic (in person or via Telehealth) with its Nurse Practitioner. This questionnaire is valid and reliable for this patient population. After a stakeholder meeting, which had representatives from the Cardiology Clinic, Research Team, and the Heart Center at the pediatric hospital, there was collective support from management and staff for project implementation. The intervention consisted of formalized treatment anxiety education and handout during the Cardiac ND appointment or on a follow-up phone call to the family after screening for treatment anxiety. Patient education included a 3-5 minute discussion with an informative handout on treatment anxiety, coping mechanisms, and resources for the patient and family. Once the education was complete, the parents answered the same questions from the Peds QL Cardiac Module 3.0 after any following medical appointment to trend the treatment anxiety scores pre- and post-education. The project's focus is on the treatment anxiety scores of the Peds QL Cardiac Module 3.0. All patients received education and supportive materials on treatment anxiety following completion of the Peds QL Cardiac Module 3.0.

The primary outcome measures are the treatment anxiety scores. Secondary outcome measures include patient and parent satisfaction and HRQOL. There were minimal costs associated with this project. There was no additional staff education necessary beyond the clinic's sole Nurse Practitioner, and the other financial cost was for printing family handouts. At the project's finish, a stakeholder presentation with the same members was held; this meeting discussed the positive effects of treatment anxiety education in pediatric cardiac patients. This education session covered the problem of anxiety in this population, benefits of managing treatment anxiety, and family feedback on feeling heard and having open discussions on this

topic. This education is cost effective due to reduction in anxiety and improved long term neurodevelopmental outcomes for this patient population.

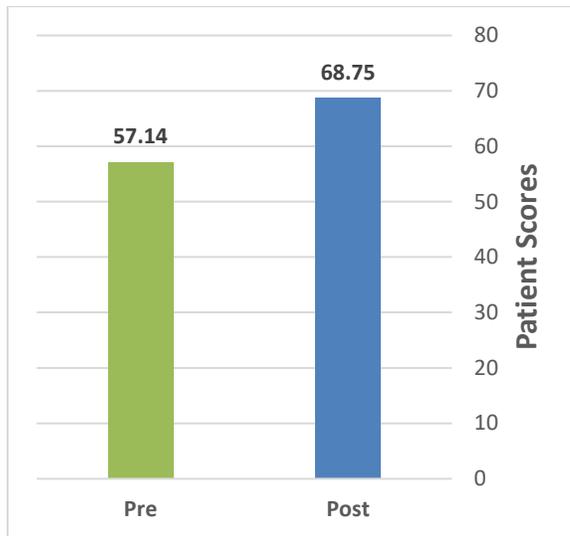
This evidenced based project received IRB approval from the UCSD Human Research Protections Program on December 7<sup>th</sup>, 2020. IRB approval through the USD Hahn School of Nursing for this EBP Project was obtained on December 11, 2020. Once approved, patients were retroactively recruited from an 8-month period and their Treatment Anxiety scores were accessed through EPIC patient charts. The first set of scores was predominantly taken from patient charts. The follow-up period for education, additional appointments and second administration of the scoring was completed over a 3-month period (Dec 2020-Feb 2021). During the follow-up period, a qualitative parental assessment on their feelings of satisfaction and sense of control in care was done as well. Data analysis and evaluation of this project will be discussed in the following section.

### **Evaluation Plan**

Evaluating the outcomes from this project's intervention is one of the utmost important steps. There were 7 patients enrolled in this project, with 4 females and 3 males. The ages ranged from 5-17 years old with an average age of 9. See Figures 1 and 2 for results and patient scores. Overall, the scores from the questions pulled from the Treatment Anxiety section of the Peds QL Cardiac Module 3.0 increased after providing education. The average score from before the appointment was 57.14; after the project intervention, the average score increased to 68.75. Of all the participants, all but one score increased after age-appropriate patient education was administered. Although this project was completed on a small scale, these results are promising that this intervention makes a meaningful difference almost immediately for these patients during their healthcare related appointments.

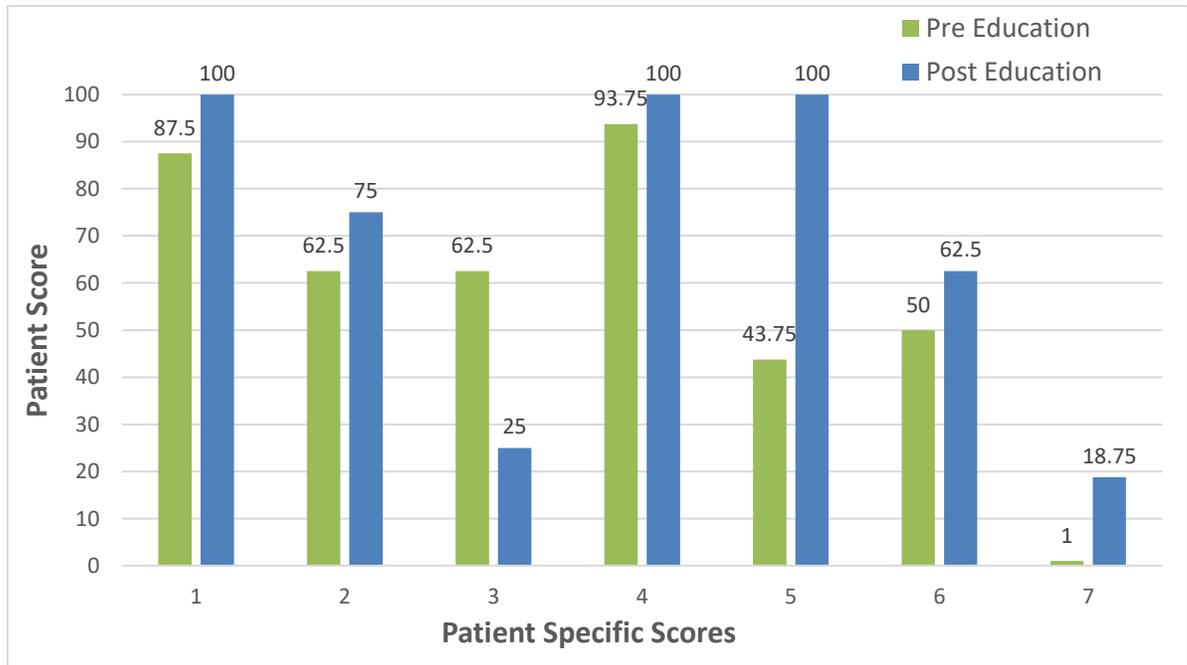
**Figure 1**

*Pre & Post Treatment Anxiety Education Average Scores*



**Figure 2**

*Individual Pre & Post Treatment Anxiety Education Scores*



Another outcome that was followed was parent satisfaction. This secondary outcome was assessed during the follow-up phone call to the parent. Almost all of the parents endorsed

feelings of being heard, gratitude for being given the opportunity to talk about this undervalued topic, and confidence for future appointments based on techniques and resources they learned about through the education intervention. Family satisfaction during visits with providers is an important metric measured frequently in outpatient clinics. This project shows that treatment anxiety is a topic patients and families do value having a discussion about, and it can only improve satisfaction scores.

Because the patient education is already formalized in a handout and the Peds QL Cardiac Module 3.0 is integrated into the patient intake forms, this intervention will be relatively simple to continue moving forward in this clinic. The intervention was easy to implement and management support was not difficult to obtain at the start of the project. Once IRB approval was granted, the project was executed quickly. No major modifications to the intervention are necessary to reimplement in a new cycle for another round of larger data collection. A possible barrier to continued implementation can be provider time during the patient visit. Although this education only takes 3-5 minutes, it can be overlooked at the end of the appointment.

Additionally, these CHD patients are very complex and there may not be time during the visit to properly teach about Treatment Anxiety. Another barrier could be no shows; during the Covid-19 pandemic, many patients have not shown up to appointments or continually push back and reschedule their annual ND visit.

### **Cost Benefit Analysis**

The annual cost of pediatric anxiety disorder in the United States in the school age population is \$6405 (Pella et al., 2020). This cost includes direct and indirect factors such as mental health services utilized, counseling, children's missed school and parents' missed work (Pella et al., 2020). Additionally, the higher average costs were correlated with greater child

anxiety and depression severity (Pella et al., 2020). Analysis of mental health illness financial costs only further demonstrates how important this issue is to screen for and treat. The economic burden of anxiety among other concerns necessitates improved access to mental health services by promoting care in places with fewer barriers such as in primary care (Pella et al., 2020).

The costs associated with this EBP Project include recurring costs of extra time spent during office visit completing the Treatment Anxiety education and funds for printing educational handouts for families. Other costs and contributions in kind consist of support for the project from Cardiology clinic staff, managers, and providers and technology used (telephone, computers, EHR access). Taken as a whole, these costs to carry out the project are minimal. There is significant cost avoidance for patients that have appropriately managed anxiety. Depending on severity of illness, there can be a cost-savings of up to \$6405 per child annually. This project improved the treatment anxiety of 6 children in a 6-month period. The cost savings of 6 children per annum is \$38,430. For every dollar spent for this project, there is a potential \$294.03 cost savings.

Additional positive consequences include reduced risk for co-morbid conditions such as concurrent depression, weight gain, or acquired cognitive deficits. Another advantage is improved service to patients and families with implementation of focused education during appointments. This also leads to increased satisfaction from providers due to connecting with patients and families during visits as well as improved provider communication with patients and families. A last intangible benefit lies in appreciation from both patients and families for relevant information and optimal care.

### **Implications for Clinical Practice**

Implementing age-appropriate education on treatment anxiety and coping mechanisms during ND visits is both feasible and cost-saving. An increase in HRQOL scores improves short- and long-term outcomes for mental health in congenital cardiac patients. Family satisfaction with the pediatric clinic increases due to feeling heard and addressing unrecognized needs. A future opportunity for this project is for the patient education to be translated into Spanish and other languages to reach a wider patient population. In Southern California there is a large Spanish speaking population. There are multiple ways to further this initial project moving forward in Neurodevelopmental Clinics. Overall, proactive steps to identify, screen, and manage treatment anxiety in children with CHD leads to better outcomes for both the patient and family.

### **Conclusion**

Increasing amounts of research show that mental health issues, including treatment anxiety, for pediatric CHD patients are a growing problem in the United States. With Congenital Heart Defects being the number one birth defect, there will be no shortage of future patients in the coming years. As much advancement in mortality outcomes as the medical field has had, it is time to focus on the HRQOL outcomes for these aging children. This project demonstrates that with properly implemented interventions, treatment anxiety can be reduced in the pediatric CHD population.

This project is a simple, yet effective demonstration that proper education can positively influence pediatric patient outcomes. Focusing on mental health and long-term outcomes for patients with CHD is significant and achievable during annual ND appointments. Instituting a standard protocol that includes the Peds QL Cardiac Module 3.0 and formal education during routine outpatient follow-ups could greatly benefit these patients. This intervention could easily be done in any Cardiac Neurodevelopmental Clinic or Cardiology office. Benefits of reducing

treatment anxiety and discussing mental health problems include improved overall health, decreased rates of anxiety and depression, and improved school performance. More research on this topic is needed for longer term outcomes with these interventions.

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## Appendix A

### Treatment Anxiety Education Flyer

# Treatment Anxiety



#### *What is treatment anxiety?*

Treatment anxiety, or Procedural anxiety, is the fear or worry related to any medical procedure; these feelings can interfere with your ability to receive necessary medical care. Unlike general anxiety, which affects how you function every day in life, procedural anxiety happens around medical procedures or doctor's appointments.

People with cardiac defects experience many medical visits and procedures—which can begin as early as infancy. Given the frequency of procedures that occur over the lifetime, having a negative experience that leads to future anxiety is more likely than it is for people without Cardiac disease. Treatment anxiety can impact your life negatively and add stress to common events.

**How to help as a parent:** Manage your own anxiety. If your child has an appointment or procedure he or she may not be the only one feeling anxious. It's natural as a parent to be nervous, but it's important to manage your feelings in an appropriate way. You appearing nervous may rub off on your child and increase their feelings of anxiety. The best way to help your child is to stay calm and model voicing your concerns in a proper way and at the right time during the visit.

#### Symptoms

- ▶ Sweating
- ▶ Feeling of breathlessness
- ▶ Irritability
- ▶ Shaking/trembling
- ▶ Heart palpitations/pounding heart
- ▶ Loss of appetite or nausea
- ▶ Inability to speak or think clearly
- ▶ Fear of fainting or losing control

#### Coping Mechanisms

- ▶ Distraction
- ▶ Deep Breathing
- ▶ Mindfulness
- ▶ Exercise
- ▶ Open Communication
- ▶ Asking Questions

#### RESOURCES:

Child Mind Institute: [childmind.org](http://childmind.org)

Substance Abuse and Mental Health Services Administration: [samhsa.gov/disorders/mental](http://samhsa.gov/disorders/mental)

Mindfulness Apps: Calm, Headspace

