

## Philadelphia College of Osteopathic Medicine DigitalCommons@PCOM

---

PCOM Psychology Dissertations

Student Dissertations, Theses and Papers

---

2018

# Examining How Cardiologists Address Alcohol and Substance Use in Their Adolescent and Young Adult Patients Diagnosed with Cardiac Rhythm Disorders

Nicole Stewart

*Philadelphia College of Osteopathic Medicine*

Follow this and additional works at: [https://digitalcommons.pcom.edu/psychology\\_dissertations](https://digitalcommons.pcom.edu/psychology_dissertations)

 Part of the [Psychology Commons](#)

---

### Recommended Citation

Stewart, Nicole, "Examining How Cardiologists Address Alcohol and Substance Use in Their Adolescent and Young Adult Patients Diagnosed with Cardiac Rhythm Disorders" (2018). *PCOM Psychology Dissertations*. 466.

[https://digitalcommons.pcom.edu/psychology\\_dissertations/466](https://digitalcommons.pcom.edu/psychology_dissertations/466)

This Dissertation is brought to you for free and open access by the Student Dissertations, Theses and Papers at DigitalCommons@PCOM. It has been accepted for inclusion in PCOM Psychology Dissertations by an authorized administrator of DigitalCommons@PCOM. For more information, please contact [library@pcom.edu](mailto:library@pcom.edu).

Philadelphia College of Osteopathic Medicine

Department of Psychology

Examining How Cardiologists Address Alcohol and Substance Use in Their Adolescent  
and Young Adult Patients Diagnosed with Cardiac Rhythm Disorders

By Nicole Stewart

Submitted in Partial Fulfillment of the Requirements of the Degree of

Doctor of Psychology

June 2018

PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE  
DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by \_\_\_\_\_  
on the \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_, in partial fulfillment of the  
requirements for the degree of Doctor of Psychology, has been examined and is  
acceptable in both scholarship and literary quality.

Committee Members' Signatures:

\_\_\_\_\_, Chairperson

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_, Chair, Department of Psychology

## **Dedication**

This dissertation is dedicated to the physicians who volunteered their time to participate in this research. Without your openness and insights, this study would not have been possible. It is because of your willingness to speak about your experiences and perspectives that your patients—and other patients—will benefit in the future. This dissertation is also dedicated to all of children, adolescents, and young adults who are diagnosed with cardiac rhythm disorders. You were the inspiration for this study, and you are an inspiration to many, even if you are not aware of it. Lastly, this is dedicated to the memories of my grandparents, Reta and Martin Prince, and Ellen Stewart, who I miss dearly. I hope I am making you proud!

## Acknowledgements

This dissertation represents the culmination of a journey that would not have been possible without some incredible individuals. I would like to express my sincere gratitude to my dissertation committee for all of their support and guidance. I would especially like to thank Dr. Stephanie Felgoise, without whom this study would not have been possible. Dr. Felgoise's mentorship over the past 5 years has made a lasting impact on my journey throughout this program, and I will be forever grateful for her contributions to my academic, professional, and personal development. Her vast knowledge of all things psychology, her enthusiasm for her work and her life, and her unwavering support have truly inspired and motivated me during my pursuit of a doctoral degree. I can only aim to possess such amazing qualities as she does. I would also like to thank my other committee members, Drs. David Festinger and David Kuo, who have been wonderfully supportive of my dissertation throughout the entire process.

It is important to me to thank the faculty and staff at the Philadelphia College of Osteopathic Medicine. It was through the close-knit, collaborative, supportive atmosphere at PCOM that I was able to complete this research and this doctoral program. I would like to thank my fellow cohort members for their friendship and support over the years. In particular, I would like to thank my friends Alexandria Muench and Christina Zebrowski. Without your love, laughter, and words of wisdom, I could not have made it through. I would also like to express my sincere appreciation to Kimberley Desir and Alexandra Pappas, who dedicated their time and energy as members of my coding team.

None of this would have even been possible without the love and support of my family and friends. To my friends: I love you all so much. Thank you for always

supporting me, making me laugh, handling my stress, and simply being a phone call away. You are incredibly important to me. To my parents, Mark and Felicia: thank you for always instilling in me the values of hard work, dedication, persistence, and love. I am forever grateful that I have had you both standing behind me in order to offer words of encouragement and to remind me that I am capable of anything when I put my mind to it. I love you. To my brother and sister, Matthew and Rebecca: thank you both for supporting me and putting up with me over these last several years. I know it could not have been easy, but you both have continuously inspired me to keep moving forward. You are the lights of my life and I love you dearly.

Lastly, to my love, Erin: I am not sure how I got so lucky to have such a supportive, incredibly loving, amazing partner. Thank you for calming my nerves and telling me that everything would work out, even when I was not sure that it would. Hank and I do not deserve you, but we are certainly grateful to have you in our lives. I love you so much.

## **Abstract**

An arrhythmia, or cardiac rhythm disorder, is characterized by a change in the normal pattern of electrical impulses that occur in the heart. Cardiac arrhythmias can be life-threatening. Adolescents and young adults who have arrhythmias experience challenges of youth coupled with the medical challenges associated with their diagnoses.

Cardiologists who treat these patients are faced with an ongoing need for decision-making surrounding addressing alcohol and substance use, which can be prevalent in adolescent and young adult populations. This qualitative study explored what guides physicians' decision-making, as well as physicians' beliefs and practices regarding how they address alcohol and substance use in their cardiac rhythm disorder patients.

## Table of Contents

List of Tables .....	x
Chapter 1: Introduction.....	1
Statement of the Problem.....	1
Purpose of the Study .....	5
Research Question .....	5
Definitions of Terms .....	5
Chapter 2: Literature Review.....	6
Heart Rhythm Disorders .....	6
Long QT Syndrome .....	7
Types of LQTS .....	8
Diagnosis.....	9
Treatment .....	10
Gender.....	13
Other Arrhythmias .....	14
Adolescence .....	14
Adolescent decision-making, recklessness, and risk-taking.....	16
Peer pressure .....	21
Alcohol and Substance Use .....	23
Caffeine and nicotine .....	26
Alcohol and substance use screeners .....	27
Physicians and Stigma .....	28
Physicians and substance use disorders .....	31



Chapter 3: Method .....	33
Overview .....	33
Design and Justification.....	34
Data Analysis.....	35
Participants.....	38
Inclusion criteria .....	39
Exclusion criteria .....	39
Recruitment.....	39
Demographic characteristics.....	39
Measures .....	41
Procedure .....	41
Chapter 4: Results.....	43
Patient Presentation.....	44
Patient symptoms .....	44
Patient age/developmental level .....	45
Parental Presence .....	47
External Influences .....	49
Data or Statistics .....	50
Clinical Experience.....	52
Communication Factors.....	53
Overview.....	53
Realistic approach.....	54

Passive approach.....	55
Viewing the “Big Picture” .....	57
Guilt- or Shame-Inducing .....	58
Relating to/Aligning with the Patient .....	61
Informing of Risks .....	62
Responsibility .....	62
Other providers .....	63
Patient and/or parent .....	64
Integrative Model of Shared Decision-Making .....	65
Essential elements.....	66
Ideal elements .....	69
Interprofessionalism and Shared Decision-Making.....	70
Chapter 5: Discussion .....	74
Overall Findings.....	74
Clinical Implications.....	75
Study Limitations.....	77
Future Research .....	80
References.....	82
Appendix A: Letter Used for Cardiologist Recruitment via Standard Mail, E-Mail, and Social Media Announcement.....	94
Appendix B: List of Questions Used in Cardiologist Interviews .....	95

**List of Tables**

Table 1. Summary of Participant Demographic Characteristics.....40

## Chapter 1: Introduction

### Statement of the Problem

Cardiac rhythm disorders, also known as arrhythmias, are characterized by a change in the heart's normal pattern of electrical impulses (McPherson & Rosenfeld, 1992). Heart rhythm disorders are relatively common and many diagnosed with these disorders live with disturbances in their daily lives and the constant threat of fatality. There are potential accompanying consequences of living with a diagnosis of arrhythmia, ranging from implementing necessary behavioral changes to experiencing involuntary psychological distress (Priori et al., 2014). In order to diagnose an arrhythmia, an electrocardiogram (ECG) is typically used. An ECG is a tool used to monitor and record the electrical signals of the heart as blood pumps through it (McPherson & Rosenfeld, 1992). Many people will occasionally experience an extra heartbeat or two throughout their lives and are generally unaffected; however, an unknown, untreated arrhythmia may lead to sudden cardiac arrest (McPherson & Rosenfeld, 1992).

Long QT syndrome (LQTS), a hereditary or drug-induced arrhythmia, is characterized by a prolonged QT interval on an ECG (Go et al., 2013). Patients diagnosed with LQTS are susceptible to sudden cardiac death, with a diagnosis prevalence of roughly 1 in 2,500 for individuals of European and other ancestries. When untreated, 6% to 13% of those individuals will sustain cardiac arrest or sudden cardiac death (Andersen, Øyen, Bjorvatn, & Gjengedal, 2008; Kaltman, Evans, & Fu, 2018). There are currently 15 defined subtypes, but the majority of genetically-confirmed cases are associated with mutations in three genes, KCNQ1, KCNH2, and SCN5A (Kaltman et al., 2018). Other varieties of arrhythmia have been identified and are in the same

category as LQTS, including short QT syndrome, supraventricular tachycardia, hypertrophic cardiomyopathy (HCM), atrial fibrillation, and Brugada syndrome (Go et al., 2013).

Although these disorders generally present with varying ages of onset and can have differing symptoms, each poses the risk of sudden cardiac arrest and sudden cardiac death (Go et al., 2013). Moreover, this risk is made greater when heart rhythm disorder patients engage in certain behaviors or experience various emotions (McPherson & Rosenfeld, 1992). These behaviors include but are not limited to sleeping or resting, engaging in strenuous or competitive exercise, and ingesting substances that can impact one's heart rhythm (Barsheshet, Dotsenko, & Goldenberg, 2014). Due to the potential impact of these behaviors on a patient's cardiac rhythm, it is imperative that they are addressed by physicians when interacting with patients of all ages.

Research has shown consistently that, across cultures, the developmental stage of adolescence is a period in which risky or reckless behaviors take place (Arnett, 1992). The same elevated level of high-risk behaviors exists in young adults (McCabe, Knight, Teter, & Wechsler, 2005). One of the more common reckless behaviors exhibited is the use of alcohol and/or other substances (Arnett, 1992). For the purposes of the current study, the definition of "substances" will include illicit drugs, prescribed medications, caffeine, and nicotine. Much of the theory discussed will involve vulnerability to engaging in reckless behaviors that could include illegal substance use; however, in the operational definition of "substances," there will also be mention of legal substances, including caffeine, nicotine, and drugs prescribed for various medical purposes. This is

because all of the aforementioned substances can impact heart rhythm and, accordingly, are equally as important in a discussion between a patient and his or her physician.

Drinking alcohol to excess and using other substances have been associated with cardiac arrhythmia (O'Keefe, Bhatti, Bajwa, DiNicolantonio, & Lavie, 2014).

Substances associated with sudden death from cardiac dysfunction include anabolic steroids, amphetamines, methamphetamine, cocaine, and propylhexedrine (Adgey, Johnston, & McMechan, 1995). Commonly prescribed medications for ADHD, such as Ritalin and Adderall, are categorized as stimulants due to the activation of the sympathetic nervous system associated with their use (Rohatgi, Bos, & Ackerman, 2015). Although stimulants are legal if they are prescribed and used appropriately, they are often used for nonmedical purposes, particularly in college-age young adults in the United States (McCabe et al., 2005).

Cardiologists treating adolescent and young adult patients with heart rhythm disorders must be more cognizant of alcohol and substance use. Research has shown unfailingly that alcohol and substance use pose a greater risk in young people who have the disorders (O'Keefe et al., 2014). There is an array of research that has contributed to literature on alcohol and substance use, within the general population and within the cardiac population. Many studies have been organized to illustrate the effects of alcohol and other substances on the heart in a general sense, with both short- and long-term findings. Nevertheless, there is less research available regarding the use of alcohol and substances by individuals with heart rhythm disorders. Adolescents and young adults with heart rhythm disorders constitute a specific subset of cardiac patients and are at greater risk of having cardiac events based on their propensity to engage in riskier

behaviors. Thus, this subset of patients would benefit from closer attention from their doctors.

The average 4-year medical school dedicates only 12 total hours of curricular time to alcohol and drug-related disorders (Miller, Sheppard, Colenda, & Magen, 2001). Additionally, physicians generally have negative views about these disorders and do not regularly evaluate their patients for them in general practice (Miller et al., 2001). Largely, physicians feel incompetent in treating the disorders and do not find treating them gratifying (Miller et al., 2001). Despite potentially negative physician attitudes, there are accessible tools used to screen for and evaluate alcohol and substance use in medical patients, as well as treatment options for patients experiencing psychological difficulty associated with abuse (Barbosa, Cowell, Bray, & Aldridge, 2015). Moreover, although research exists that focuses on the effects of alcohol and substance use in a general sense within the cardiac population, there are some gaps that could use more consideration. Namely, how the effects are addressed by cardiologists with patients in the adolescent and young adult developmental phases.

The current study addressed the gap in the literature regarding how cardiologists approach alcohol and substance use by adolescents and young adults with heart rhythm disorders. Given this population, it was considered advantageous to examine several factors, including the context of a possible discussion, the frequency with which physicians engage in this type of discussion, whether the patient's parent is present when a discussion takes place, the specific recommendations for use made by the cardiologists, and the perception of cardiologists about who is generally responsible for addressing these issues. This study aimed to collect more information about the aforementioned

aspects of patient care. It also aimed to increase awareness about heart rhythm disorders and how affected patients and their families should be educated about the disorder. This could, in turn, support medical professionals in their approach toward young patients with cardiac rhythm disorders. Ultimately, more information on this topic may further improve the treatment of these individuals, both from medical and psychological standpoints.

### **Purpose of the Study**

The purpose of this study was to examine how cardiologists address alcohol and substance use by patients ages 13 to 24 with heart rhythm disorders, including LQTS, and what the content of those discussions may be. The study examined how often and under what circumstances cardiologists address these issues with patients and examined their perceptions of responsibility, importance, and risk for this population of patients. The study also examined the resources used by physicians in order to assist in how they address these issues, and their practices within the scope of integrated healthcare.

### **Research Question**

What are the beliefs and practices of cardiologists regarding adolescent and young adult alcohol and substance use assessment, psychosocial education, and intervention?

What resources do they use and what are their practices in integrative/collaborative care?



## Chapter 2: Literature Review

### Heart Rhythm Disorders

According to the American Heart Association, 7.2% of Americans suffer from some type of cardiovascular disease, including 3.2% with coronary heart disease, 2.7% with stroke, and 2.0% with congestive heart failure (Go et al., 2013). A specific subset of cardiovascular problems is characterized by malfunctions of the heart rhythm, known as arrhythmias (McPherson & Rosenfeld, 1992). Arrhythmias are defined as any type of abnormal heart rhythm and can be separated into two categories: excessively slow heart rates (bradycardias) and excessively fast heart rates (tachycardias; McPherson & Rosenfeld, 1992). The underlying problem with an arrhythmia is the result of a dysfunction within the heart's electrical system, which is responsible for pumping blood throughout the entire body (McPherson & Rosenfeld, 1992). The electrical functioning of the heart is dependent upon an individual brain's ability to receive signals, including hormonal and reflex signals (McPherson & Rosenfeld, 1992). Many factors can lead to a disturbance of these signals, including physical exertion, emotional arousal, and even events occurring in everyday life (McPherson & Rosenfeld, 1992).

In the United States and Europe, approximately 40% of deaths have been reported to be due to life-threatening arrhythmias (Suyama-Chishaki et al., 2007).

Disconcertingly, when an individual is revived successfully from a life-threatening arrhythmic episode, he or she is at 50% risk for having another episode within five years (Suyama-Chishaki et al., 2007). Abnormal heart rates or rhythms are caused by a variety of factors and have variable consequences. The severity of a person's symptoms alone does not necessarily indicate the seriousness of an underlying disorder he or she may

have (McPherson & Rosenfeld, 1992). Symptoms of heart arrhythmias can include dizziness, syncope (fainting), chest pain, and shortness of breath (McPherson & Rosenfeld, 1992). Individuals may experience palpitations as missed beats, or single or multiple beats, which are reported to be felt anywhere from the stomach to the head (McPherson & Rosenfeld, 1992).

### **Long QT Syndrome**

LQTS is a disorder that prolongs the QT interval on an ECG, and can be either inherited or acquired (Moss, 2003). The QT interval, a time interval represented on the ECG, illustrates the time from the electrical impulse (depolarization) of the heart's working chambers (ventricles) to the end of the recharging of the electrical system of the heart (repolarization; Schwartz et al., 2009). The QT interval is measured in milliseconds; it closely approximates the time from the onset of the ventricles' contraction until the end of relaxation (Schwartz et al., 2009). A prolonged QT interval is associated with an increased risk of syncope and can lead to sudden cardiac death caused by ventricular fibrillation (Barsheshet et al., 2014). Despite the fact that patients with very prolonged repolarization times appear to be at a higher risk for having cardiac events, sudden cardiac death can occur in those who present with normal repolarization as well (Knoche, Orland, January, & Maginot, 2012).

LQTS was first identified in 1957, when several children in a family experienced QT prolongation on ECGs and recurring episodes of fainting and sudden death (Moss, 2003). In the 1990s, after familial patterns were explored via research, the genetic basis of LQTS was discovered; there are currently identified mutations in 15 LQTS genes (Chaix et al., 2016; Kaltman et al., 2018; Moss, 2003). LQTS is considered an

infrequently occurring disorder in the general public. The prevalence of LQTS has been estimated to be 1 in 2,500, but this number could be considered a low estimate because, in up to 37% of cases where LQTS is genetically inherited, the disorder is concealed or negligible on an ECG (Barsheshet et al., 2014). An interesting aspect of LQTS is the variability in symptom expression; the significant variability suggests that other genetic factors, as well as environmental factors, can be influential components in diagnosis (Moss, 2003).

Individuals affected by LQTS may present with fainting spells, sudden cardiac death, or prolongation of the QT interval on an ECG during a regular check-up or exam (Moss, 2003). Following an episode of syncope, if an individual has an identified QT prolongation on his or her ECG, the diagnosis of LQTS is positive (Moss, 2003). For these individuals, it is vital to obtain ECG readouts on all first-degree family members to determine whether others are affected (Moss, 2003). It is important to note in the discussion of LQTS that several types of drugs can prolong the QT interval; however, there is a distinct difference between drug-induced QT prolongation and the genetically-inherited form of the disorder (Moss, 2003).

**Types of LQTS.** Currently, there are 15 identified genes associated with inherited LQTS, with most being caused by changes in potassium or sodium ion channel functioning (Chaix et al. 2016; Kaltman et al., 2018; Knoche et al., 2012). The most common types of LQTS, accounting for over 95% of gene-specific LQTS and 75% of all patients with LQTS, are LQT1, LQT2, and LQT3 (Barsheshet et al., 2014). An important aspect of distinguishing between the three main types of LQTS is that each has distinctive primary triggers for cardiac events. For example, in LQT1, patients primarily experience

events during exercise, whereas LQT2 patients primarily experience events resulting from acute emotional arousal and LQT3 patients primarily experience events during sleep or while at rest (Moss, 2003).

The course of the disorder presents differently across patients with LQTS and is impacted by genotype, gender, environmental factors, and types of treatment applied (Moss, 2003). For example, the risk of having a cardiac event is significantly higher among patients with LQT1 and LQT2 mutations than in those with LQT3 (Barsheshet et al., 2014). Additionally, LQT1 patients typically present with the youngest age at the time of first clinical onset of the disorder; however, events for persons with LQTS3 are more likely to be fatal (Moss, 2003). In a general sense, across all types of LQTS, sudden death can occur within any age group, but these occurrences have an increased frequency in adolescence (Moss, 2003).

**Diagnosis.** LQTS can be diagnosed from results of an ECG, genetic testing, and/or clinical interviews including family history (Barsheshet et al., 2014). At the most fundamental level, the ECG is used to detect the heart's patterns of electrical currents; they are most effective for accurately diagnosing if the patient is experiencing symptoms at the time of the ECG (McPherson & Rosenfeld, 1992). Nevertheless, this may not always be an option, as in many cases the symptoms present briefly and are inconsistent in frequency (McPherson & Rosenfeld, 1992). An option used in some cases includes having the patient perform an exercise test while wearing ECG equipment, as physical activity can provoke an arrhythmia (McPherson & Rosenfeld, 1992). An additional option utilized in medical settings is a transesophageal ECG, which consists of ECG electrodes being swallowed by the patient or inserted via the patient's mouth (McPherson

& Rosenfeld, 1992). This particular technique is useful in cases that may be difficult to diagnose, as the esophagus is located directly behind the atria in the heart (McPherson & Rosenfeld, 1992).

Difficulty in diagnosing LQTS is due to genetic mutations having what researchers call “variable expressivity,” meaning that a prolonged QT interval on an ECG may not always be present in an affected patient (Behere, Shubkin, & Weindling, 2014). Therefore, there is a specific set of diagnostic criteria that typically include one or more of the following: (a) if a prolonged QT interval on an ECG is detected after an event of syncope when the individual does not have an acquired case, (b) if there is a very prolonged QT interval in repeated ECGs that is not caused by a secondary factor for the prolongation, and (c) if there is an LQTS risk score, based on family history, personal history, symptoms, and ECG, of more than or equal to 3.5 and/or there is a concrete presence of an LQTS gene (Barsheshet et al., 2014).

Diagnostic criteria also include the individual’s history, taking into consideration gender and age for clinical purposes (Barsheshet et al., 2014). LQT1 patients present with the youngest age with the first clinical manifestation of the disease, with 86% showing symptoms before the age of 20 (Barsheshet et al., 2014). Syncope and sudden cardiac death can occur at any age in LQTS patients; however, the overall risk for these events is higher in adolescents (Moss, 2003).

**Treatment.** Despite the fact that electrophysiology has allowed for advancement in the treatment of heart rhythm disorders, the type of treatment a patient receives is decided ultimately by a range of factors, including the patient’s overall physical health, lifestyle, and tolerance of the accompanying symptoms (McPherson & Rosenfeld, 1992).

Generally, LQTS treatment includes lifestyle modification, pharmacological therapy, and device and surgical therapy (Barsheshet et al., 2014). The treatment of a LQTS patient, however, is established based on individual differences.

In terms of medication, LQTS is treated with beta-blockers as a first-line intervention; additional pharmacological treatment options include sodium channel blockers and calcium channel blockers (Behere et al., 2014). Beta-blocking drugs are given to patients with both asymptomatic and symptomatic LQTS (Behere et al., 2014). Interestingly, beta-blocking drugs have little impact on the length of the QT interval and are mostly effective in decreasing the frequency of syncope events (Moss, 2003). When discussing medications for the treatment of LQTS, it is important to note that mexiletine is effective in shortening the QT interval; however, it has proven to be most effective for LQT3 (Sicouri, Antzelevitch, Heilmann, & Antzelevitch, 1997).

Within a discussion of pharmacological treatments for LQTS, it is important to note that the use of beta-blockers in conjunction with certain illicit substances, particularly opiates and amphetamines, can be dangerous (Krishnamoorthy, Lip, & Lane, 2009). Beta-blockers can also cause negative side effects including mood swings, depression, and fatigue that may result in noncompliance, particularly in adolescents (Farnsworth, Fosyth, Haglund, & Ackerman, 2006).

Patients who still present with symptoms despite being treated with appropriate doses of beta-blockers are typically treated in the United States by implantable cardiac defibrillator devices (ICDs; Behere et al., 2014). These devices monitor the individual's heart rhythm and can provide a shock if a potentially life-threatening arrhythmia is detected (Behere et al., 2014).

Because different mutations of the LQTS gene can be characterized by different environmental triggers, there is some understanding on the part of medical professionals about how to take preventative measures to protect the patient. For example, patients with LQT1 who experiences most of their cardiac events while engaging in strenuous physical activities should avoid those activities unless they have adequate supervision or, depending on their risk level, avoid them altogether (Barsheshet et al., 2014). Further, patients with LQT2, who experience cardiac events as the result of intense emotional arousal, should be encouraged to avoid loud noises, including alarm clocks, fireworks, doorbells, and ringing telephones, and patients with LQT3, who experience events during sleep or at rest, may be encouraged to not sleep alone (Barsheshet et al., 2014).

Across all types of LQTS, however, there is one uniform recommendation: all patients should avoid substances that are known to prolong the QT interval, decrease potassium levels, decrease magnesium levels, or contribute to any kind of electrolyte imbalance (Barsheshet et al., 2014). Moreover, for all LQTS patients, but perhaps more importantly for younger patients who may get sick more frequently, it is important to address any electrolyte imbalances that could occur from diarrhea or vomiting. Of course, an individual with a diagnosis of LQTS should avoid these drugs and remain cognizant of drug effects, but someone without a diagnosis may also ingest these types of drugs and acquire the disorder. Some drugs that can prolong the QT interval include types of gastrointestinal prokinetics, antiemetics, antibacterials, general anesthesia agents, opioids, antimigraine agents, antipsychotics, antiasthmatics, antihistamines, and antidepressants (De Ponti et al., 2002).

Within a discussion of pharmacological treatments for LQTS, it is important to note that the use of beta-blockers in conjunction with illicit substances, particularly opiates and amphetamines, can be extremely dangerous (Krishnamoorthy et al., 2009). Unfortunately, research on non-antiarrhythmic drugs that can cause prolongation of the QT interval has caused a level of perplexity for clinicians; one factor contributing to this confusion is the sometimes questionable clinical evidence for certain drugs (Ponti et al., 2002). Nevertheless, there has been a steady effort over the past several years to create a more comprehensive list of these drugs that are backed by strong clinical evidence (De Ponti et al., 2002).

In addition to the research conducted on the impact of non-antiarrhythmic drugs on LQTS, there also have been a number of studies conducted highlighting the epidemiological and clinical impact of the disorder (Andersen et al., 2008). Much of this research has focused on factors such as gender and age.

**Gender.** According to the research, there are some gender differences across age groups in patients with LQTS. In one study of individuals with LQT1, results showed that in an age range between 0 and 13 years, there was a two-fold increased risk for sudden cardiac death in males compared to females, whereas with LQT2, the risk for life-threatening cardiac events during the same age range was similar between males and females (Barsheshet et al., 2014). There are interesting differences between the risk of cardiac events for males and females and these differences occur within the childhood to adolescence phase of development (Go et al., 2013). For example, the risk of having a cardiac event is higher in boys than girls before the age of 12. Conversely, the risk of having a cardiac event during young adulthood is higher among females than males (Go



et al., 2013). The literature has shown, however, that for all three types of LQTS, the likelihood of experiencing a cardiac event increases significantly during adolescence (Moss, 2003).

### **Other Arrhythmias**

Other types of arrhythmias have been identified and have both similarities with and differences from LQTS (Hamang et al., 2010). For example, both LQTS and HCM have a genetically-based risk for potentially life-threatening arrhythmias and sudden death that could apply to children, teenagers, and adults (Hamang et al., 2010).

Nevertheless, the nature of these disorders can be different, which can lead to differences in quality of life, beliefs about health status, and psychological well-being (Hamang et al., 2010). Interestingly, HCM presents with symptoms that are more likely to impact daily physical health, whereas LQTS may be more likely to cause worry and distress due to the uncertain nature of the symptoms, diagnosis, and treatment of the disorder (Hamang et al., 2010).

### **Adolescence**

Throughout human development, diverse characteristics are acquired within the scope of an individual's ever-changing personality; brain functions begin to advance, the person gains valuable, lifelong skills, and influential interpersonal relationships are formed. According to relational developmental systems theory, human development is considered susceptible to change, and healthy development is the direct result of mutually advantageous interactions between an individual and his or her environment that unfold over time (Wray-Lake, Syversten, & Flanagan, 2016). Positive interactions between an individual and his or her environment, however, are only one piece of the developmental

puzzle. There are other components contributing to developmental growth, which typically adjust over time, including social responsibility, executive functioning, and decision-making (Friedman et al., 2016; Wray-Lake et al., 2016).

According to the literature, adolescence is defined as a transitional time period “marked by the onset of puberty and extending through the late teens into the early 20s” (Luna & Wright, 2016, p. 91. Adolescence is a unique time of both transformation and challenges, particularly because adolescents are considered largely to be immature when compared to adults in various respects (Nagel, Guarnera, & Reppucci, 2016). Biologically, cognitively, socially, and emotionally, adolescents are underdeveloped when compared to fully matured adults (Nagel et al., 2016). Adolescence is a particularly crucial time in an individual’s life; it is a developmental period during which an individual begins to establish autonomy from his or her parents, creates close interpersonal bonds, and experiences various major changes within his or her biological state (Ehrlich, Hoyt, Sumner, McDade, & Adam, 2015).

Many of the fundamental changes which occur during the timeframe of adolescence are considered beneficial; however, there are also several risk factors to which adolescent individuals are exposed. Studies have shown that between the ages of 13 and 18, individuals are in a critical period for the onset of depression (Hankin et al., 2015). Additionally, the literature shows that low quality relationships between the adolescent and his or her parents, as well as between the adolescent and his or her peers, are linked to an increased risk for developing a range of both internalizing and externalizing adjustment disorders (Ehrlich et al., 2015).

**Adolescent decision-making, recklessness, and risk-taking.** Individuals in the teenage and young adult phases of development may make decisions differently from those in other developmental phases. The adolescent brain includes underdeveloped areas, such as the basal ganglia and prefrontal cortex, which can contribute to risk-taking behavior (Luna & Wright, 2016). Evidence shows that various specific behaviors exist within adolescence, and some of those behaviors can vary across different geographical locations and time periods (Arnett, 1992). Society in general, and parents in particular, tend to view adolescence as a time of major behavioral changes, some of which can be characterized by defiant behavior or emotional outbursts (Luna & Wright, 2016). One specific trait that has been linked to adolescence much more strongly than any other developmental stage regardless of culture or time period is reckless behavior (Arnett, 1992). Although the reasons behind some of the difficulties adolescents experience vary in the research, it is a stable conclusion that adolescents are more likely to engage in risky, reckless behaviors (Arnett, 1992). The exact nature of how these behaviors are carried out, however, is less clear (Arnett, 1992).

The ways in which adolescent recklessness is expressed depend upon the dynamic of the culture in which the adolescent is living, as well as the particular time period (Arnett, 1992). For example, in the early 19th century, before the invention of the automobile, reckless driving would not have been a problem because driving was not yet part of society, but in today's society, reckless driving certainly presents a potential hazard (Arnett, 1992). When discussing the topic of driving recklessly, Arnett (1992) also points out that adolescents are not only more likely than individuals in other

developmental phases to drive after consuming alcohol, but they are more likely to drive faster, closer to other vehicles on the road, and fail to use seatbelts.

Some researchers argue with the concept of recklessness itself, suggesting that the notion should be defined subjectively rather than categorizing general behavior as such (Jessor, 1991). For example, Jessor (1991) identified the failure to use contraception as a stigmatized “reckless behavior;” however, he asked the following questions: What if the woman in question either did not have access to it, or was not concerned whatsoever about the consequences of not using it? Does that inherently make the behavior of not using contraceptive reckless? Jessor theorized that each behavior should be evaluated as reckless on a case-by-case basis. Similarly, Arnett (1992) attempted to distinguish the difference between danger and risk-taking, stating that danger is typically recognized but purposely minimized, whereas risk-taking occurs when certain precautions could be taken but purposely are not.

Arnett (1992) identified two factors that appear to be integral to an adolescent’s reckless behavior: sensation-seeking and egocentrism. Arnett posited that these two traits emerge in adolescence and decrease gradually throughout adulthood. He explained that sensation-seeking is a component of an individual’s personality that contributes to his or her need to experience novel and varied sensations (Arnett, 1992). Arnett explained that this need implies that the individual is willing to take “physical and social risks,” even searching eagerly for reckless behaviors in which to engage so her or she can feel these varied, complex sensations. Luna and Wright (2016) explained that sensation-seeking is characterized by “the pursuit of thrills, adventure, and experience as well as disinhibition and susceptibility to boredom” (p. 91).

Research has highlighted the Sensation Seeking Scale, which consists of four subscales: Thrill and Adventure Seeking, Disinhibition, Boredom Susceptibility, and Experience Seeking (Zuckerman, 1996). On the Sensation Seeking Scale, scores are highest at age 16 and decrease gradually with age (Zuckerman, 1996). With egocentrism, defined by Piagetian theory as a failure to distinguish between where the self ends and the other begins, research has shown that by the time an individual reaches adolescence, he or she has not overcome this developmental obstacle (Arnett, 1992). The importance behind this lack of overcoming egocentrism lies in the fact that adolescents may think others are preoccupied with their behaviors and appearance in the same way that they are (Arnett, 1992). In turn, this belief may lead to the thought that they are actually invincible to the penalties of reckless behaviors (Arnett, 1992).

It is noteworthy that much of the previous research conducted surrounding risk behavior in adolescence has shown that taking risks serves an important developmental purpose (Jessor, 1991). According to Jessor (1991), adolescent risk-taking behaviors are “functional, purposive, instrumental, and goal-directed” (p. 378), and the goals being achieved are quite typical within the scope of adolescent development. Luna and Wright (2016) stated that it is an adaptive process necessary for gaining skills that support autonomous trajectories as adults. Jessor explained that most of the risk-taking behaviors considered typical in adolescence are, essentially, functional within this time frame. Jessor pointed specifically to these risk-taking behaviors as methods of gaining acceptance and respect from peers, establishing independence from parental figures, rejecting the norms of authority, managing anxiety, frustration, and potential failure, and asserting personal maturity and making a smooth transition out of childhood. Jessor also

stated that there is nothing inherently illogical about attempting to meet these goals as an adolescent; on the contrary, they are representative of conventional development that help to explain why these behaviors may be so difficult to change.

Interestingly, Steinberg (2007) described the process of risk-taking as a competition between the “socioemotional and cognitive-control networks,” stating that, while in the presence of peers, an adolescent’s socioemotional network becomes activated, leading to a weakened regulatory effect of the cognitive-control network. Steinberg also posited that risk-taking may be heightened during adolescence because of the large amount of time an adolescent spends with peers. From a neuroscience perspective, the reward centers of the brain are activated more prominently during risky situations than they are during situations in which individuals receive non-social rewards by themselves (Steinberg, 2007). The competition described between the socioemotional and cognitive-control networks has been examined from a variety of contexts in which decision-making is involved, including drug use, social-decision processing, moral judgments, and the assessment of alternative rewards and costs (Steinberg, 2007). Across all of these contexts, risk-taking is associated with more prominent activation of the socioemotional network; this association is likely due to the fact that immediate rewards are particularly emotionally arousing (Steinberg, 2007).

When discussing risk, it is important to characterize differences between biological and behavioral risk. For example, with general cardiovascular disease, high serum cholesterol and hypertension have been identified as biological risks (Jessor, 1991). In contrast, behavioral risk includes engaging in behaviors likely to lead to negative consequences (Jessor, 1991). Biological risk can also be associated with

behavioral risk (Jessor, 1991). For example, certain illnesses, including HIV, cancer, and liver disease, can be associated with behavioral patterns (Jessor, 1991).

A notable paradigm exists when examining risk-taking in cardiac rhythm patients and the use of alcohol and other substances. An individual with a genetic predisposition to developing a cardiac rhythm disorder is inherently at greater biological risk than an individual without the genetic component. Knowing this information, however, could lead to behavioral risk. A teenager or young adult who is aware of his or her potential to be diagnosed with a heart rhythm disorder may feel ostracized or worried, leading him or her to engage in unhealthy behaviors to cope with these emotions. Undoubtedly, the knowledge of a genetic predisposition to a heart rhythm disorder does not always lead to engaging in risky behavioral patterns, but it is feasible and should be taken into account.

On the contrary, engaging in such risky behavioral patterns *without* a genetic predisposition to these disorders may actually lead to a greater biological risk of developing symptoms of one. Research has shown conclusively that, whether short- or long-term, heavy alcohol use can bring on an arrhythmia and, in rare cases, sudden cardiac death (O'Keefe et al., 2014). In addition, withdrawal from alcohol increases cardiac sympathetic activity and heart rate variability, which are both fundamentally linked to arrhythmias (O'Keefe et al., 2014). When discussing risk, it is also important to note that some risky behaviors engaged in commonly by adolescents and young adults can have major impacts on cardiac status. For example, risky sexual behaviors, those that can lead to sexually-transmitted diseases or pregnancy, are common in adolescence (Gupta, 2014). Some research has shown that adolescents with congenital heart disease are less likely to be sexually active at a young age due to psychosocial developmental

delay or uncertainties regarding their diagnosis; however, of those 16- to 18-year-olds with congenital heart disease who are sexually active, up to 75% are likely to engage in risky sexual behavior, including having more than two partners in a 3-month period, using drugs or alcohol before having sex, and failing to use contraception (Gupta, 2014).

A heavily studied topic within research on adolescence is social responsibility, which is identified as a fundamental display of psychosocial maturity, an indicator of general well-being, and an aftereffect of positive youth development (Wray-Lake et al., 2016). Decision-making also plays an integral role in human development. Making the “right” choices is often emphasized throughout all stages of life; however, deciding to engage in healthy behaviors is often dependent upon the individual’s goals (Reyna & Farley, 2006). In adolescence, and often in young adulthood, goals are more likely to be based on achieving immediate pleasure rather than long-term results (Reyna & Farley, 2006). For this reason, it is plausible that certain types of unhealthy behaviors, including alcohol and substance use, may seem like the best option for an adolescent (Reyna & Farley, 2006). The emphasis on maximizing immediate pleasure through potentially unhealthy behaviors, in addition to a heart rhythm disorder diagnosis, can lead to detrimental outcomes.

**Peer pressure.** In the United States, teenagers and adolescents in the general population are particularly vulnerable to social pressures. Peer pressure, in particular, occurs for a variety of reasons, including the desire to be associated with a certain group of same-aged individuals (Lewis & Lewis, 1984). Peer pressure often presents itself in the form of “dares,” many of which are comprised of using alcohol and illicit substances



(Lewis & Lewis, 1984). Substance use is one example of a “problem behavior” as described by Jessor (1991)

Jessor (1991) focused on identifying and describing the trajectory of what he termed “problem behaviors,” which occur during adolescence and are related to adolescent risk-taking. Jessor identified “drug and alcohol use, permissive sexuality, and other actions associated with deviance such as aggression, lying, and stealing” (p. 380) as part of the greater category of problem behaviors, in addition to any actions which may place the individual at personal risk of injury. Jessor’s theory suggested that problem behaviors are the result of three factors: personality, environment, and other behaviors. Moreover, he found that these problem behaviors occur more often among individuals who place higher value on autonomy, have low expectations for their own academic achievement, generally accept deviant behaviors, and have low levels of religiosity (Jessor, 1991). Most importantly, however, was his finding that the environmental factors contributing to problem behaviors included “the existence of peers who model these behaviors, a low degree of support or control from adult significant others, friends exceeding parents as sources of influence, and social pressure from peers who model a problem behavior” (Jessor, 1991, p. 342).

When examining adolescence from an Ericksonian perspective, one may conclude that this stage of development is geared mostly toward gaining a sense of identity (Jessor, 1991). During this stage of development, parental figures have lost their positions as “essential supports” and are replaced, in a sense, by the individual’s peer group (Jessor, 1991). Erickson posited that “dares” and role playing, as well as verbal exaggerations of dares, are normal components of social play, and Jessor (1991) expanded upon this idea.

Jessor believed that role models and the sources of pressure individuals experience act on their vulnerability for developing problem behaviors and channel the vulnerability into particular actions. One study conducted with school-age children showed that with increasing age and grade level, dares connected to peer pressure occurred with more frequency; in fact, they occurred twice as much in junior high school than in elementary school (Jessor, 1991). The content of the dares also changed: Among eighth graders in particular, dares began to include challenges to smoke marijuana, vandalize, and commit acts of violence toward others (Jessor, 1991).

### **Alcohol and Substance Use**

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* states that, in order for a person to be diagnosed with a substance use disorder, he or she must demonstrate at least 2 of 11 possible symptoms (American Psychiatric Association [APA], 2013). Examples of these symptoms include but are not limited to continuing to use past what was originally planned, continuing to use despite experiencing adverse consequences, and building a tolerance to the substance (APA, 2013). In the United States, individuals can drink legally at age 21. Before this age, drinking alcohol in any capacity could be considered reckless; over the age of 21, driving while intoxicated is considered reckless (Arnett, 1992). This varies significantly across cultures. Some countries have a lower legal drinking age, which brings forth the risk of drunk driving at a younger age (Arnett, 1992).

The misuse of alcohol consists of risky and harmful drinking, alcohol abuse, and alcohol dependence (Whitlock, Polen, Green, Orleans, Klein, 2004). In Americans ages 12 and older, 23% have reported “unhealthy” use of alcohol on at least one occasion

during the past 30 days, 8% reported using illicit drugs (including nonmedical use of prescription drugs) within the past 30 days and 2.8% showed evidence for drug abuse or dependence (Holt et al., 2013). One study found that the typical age of a child's first use of alcohol that is described as "more than a few sips" occurs between the ages of 13 and 15 (Grant, Stinson, & Harford, 2001). Another study indicated that 40% of adult alcoholics reported an onset of alcoholism symptoms between the ages of 15 and 19 (Reyna & Farley, 2006). It is important to note that, according to the literature, the earlier in life an individual begins drinking, the more likely he or she is to develop "problem drinking."

Many years ago, the phrase "holiday heart" began being used to describe the instances of acute atrial fibrillation (AF) that were seen frequently in those drinking heavily during celebratory occasions (O'Keefe et al., 2014). Research has shown that the first time an individual is exposed to alcohol, which is typically in the context of a family gathering or religious event, occurs before the age of 15 (Grant et al., 2001). This association between religious or family gatherings and heavy alcohol use is something that is entrenched in American culture and can have a negative impact on adolescents, who are already prone to more risk-taking and reckless behaviors (Arnett, 1992).

Substance use is a common problem in the United States and results in interpersonal and financial costs. Although alcohol use is generally socially acceptable in many cultures, including American culture, illicit substance use is viewed as much more of a public health problem (van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). When coupled with alcohol use, illicit drug use constitutes 4% of worldwide causes of death and accounts for 5.4% of the global burden of disease (van Boekel et al., 2013).

Substance use problems also pose the risk of creating further societal difficulties, including accidents, absenteeism at places of employment, and loss of productivity (van Boekel et al., 2013). One 2009 study found that only 14.7% of individuals with substance dependence received professional assistance in the previous year (Grella, Karno, Warda, Moore, & Niv, 2009). Furthermore, although it has been shown that treatment increases the likelihood of recovery, only 24.1% of those with lifetime alcohol dependence ever seek treatment (van Boekel et al., 2013).

Research has shown that there are several factors involved with individuals choosing to receive treatment for these disorders. First, the utilization of treatment is higher among those who have problems with more than one type of substance, as well as those with co-occurring mental illness (Grella et al., 2009). Second, another factor associated with the use of services is the individual's perception of need and willingness to seek help. The populations afflicted most by unmet needs for treatment are the elderly, those from racial/ethnic minority groups, those with low incomes, those without insurance, and those living in rural areas (Grella et al., 2009).

Young adults between the ages of 18 and 24 encompass a specific subset of individuals who are central in the discussion of risk-taking and reckless behavior: college students. Research has shown that the mere presence of peers increases the likelihood of risk-taking. This likelihood is especially high for teenagers, but also moderately high for college-age individuals (Steinberg, 2007). In one study, results showed that the presence of peers increased the level of risk-taking in college undergraduates by 50% (Steinberg, 2007). College-age individuals are at a particularly high risk for both alcohol and substance use. Studies have shown that the population in the United States most likely to

engage in binge drinking is college undergraduates. Furthermore, many studies have been conducted in recent years highlighting a rising trend among college students: the nonmedical use of stimulant medications (McCabe et al., 2005).

Drugs such as methylphenidate, dextroamphetamine, and mixed-salts amphetamine are considered pharmacological treatment for attention deficit hyperactivity disorder (ADHD; McCabe et al., 2005). In the United States, not only is the prevalence of ADHD diagnoses higher than in other countries, but the use of prescription stimulants is also higher (McCabe et al., 2005). Use of these drugs for legitimate diagnoses of ADHD has been shown to be extremely efficacious; however, the increased frequency of use of these medications in the United States has caused public health concern for several reasons (McCabe et al., 2005). The main source of concern with the use of these medications is the potential for abuse and, disturbingly, college students in particular are among the group of individuals using the medications for nonmedical purposes the most (McCabe et al., 2005). Knowing that college-age individuals are more likely to succumb to the influence of peers and engage in high-risk behaviors, these data are particularly important.

**Caffeine and nicotine.** More than 50% of Americans drink coffee on a daily basis, and more consume caffeine in either coffee or another form, such as tea, soda, and chocolate (Pelchovitz & Goldberger, 2011). Generally, research conducted with both human and animal subjects regarding the effects of caffeine on the heart's rhythm has been somewhat inconsistent (Klatsky et al., 2011). Despite this, it has been found conclusively that caffeine increases individuals' resting energy expenditure, sleeping

metabolic rate, and resting awake metabolic rate by increasing activity in the sympathetic nervous system (Glade, 2010).

**Alcohol and substance use screeners.** Within the scope of medical settings, there are members of a particular population that should be paid close attention by physicians: cardiac patients. Patients suffering from cardiovascular problems represent a large portion of the American population and, unfortunately, many of those patients experience potentially fatal heart arrhythmias (Go et al., 2013). As the research has shown, many types of illicit drugs and medications can impact the heart's rhythm significantly. This highlights the need for increased awareness surrounding the use of both illicit and prescribed or over-the-counter medications and the potential effects they can have on an individual's heart rhythm (Moss, 2003).

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) encourages doctors to identify individuals who are at risk for alcohol problems or currently have them; they are also encouraged to provide brief interventions or referrals to outside sources if needed (Whitlock et al., 2004). Studies have yielded variable results when looking at the success of screening and brief intervention (SBI) for alcohol and substance use (Broderick, Kaplan, Martini, & Caruso, 2015; Haller et al., 2014). In primary care settings, SBI has been indicated to be successful (Barbosa et al., 2015). Research has shown that SBI can decrease weekly alcohol consumption by 13% to 34% (Le et al., 2015). There are barriers to implementing SBI, including physicians' lack of confidence in assessing use and providing brief recommendations or feedback (Le et al., 2015). This has been connected to a lack of training and low levels of physician self-efficacy;

however, variables impacting physician confidence levels are undetermined (Le et al., 2015).

### **Physicians and Stigma**

One aspect of alcohol and substance use disorders that is distinctly different from other types of disorders is the associated shame and stigma. Many patients will simply choose not to disclose to their physicians that they think they have a problem. Mental health stigma consists of four “social-cognitive processes,” including cues, stereotypes, prejudice, and discrimination (Bulanda, Bruhn, Byro-Johnson, & Zentmyer, 2014). Cues are described as the way members of the general public identify an individual with mental illness, including the individual’s external appearance, any deficits in social skills, or psychiatric symptoms (Bulanda et al., 2014). When examining stigma associated with mental illness, common stereotypes could include the idea that the individual suffering is weak, incompetent, or even dangerous (Bulanda et al., 2014). These stereotypes could lead to prejudice, the belief that the stereotype is true and that one should make decisions based on it, which, in turn, could lead to discriminatory behaviors against the identified group (Bulanda et al., 2014). Discriminatory behaviors can be exhibited in many forms, including bullying or social ostracism, both common in adolescent populations (Bulanda et al., 2014). In a 1999 report by the Surgeon General, stigma was identified as the most salient obstacle to receiving mental health treatment (Bulanda et al., 2014).

Stigma is a concept that is acquired early in life, as young people develop stigmatizing analyses of their peers, especially peers with mental health issues. Self-stigma is something that can be affected by a number of factors, including the self-stigma of a child’s parent regarding having a child with a mental health issue (Bulanda et al.,

2014). Justifiably, self-stigma has been associated through research with lack of seeking treatment, decreased self-esteem and self-efficacy, and decreased quality of life (Luoma et al., 2007). A major factor contributing to a substance abusing individual not seeking treatment is the fear of stigma, which often leads to avoidance of treatment and failure to seek medical help (Luoma et al., 2007). Furthermore, research has shown that school-age children who have either restricted or inaccurate knowledge about mental illness have more stigmatizing views toward those afflicted with mental health disorders (Bulanda et al., 2014).

It has been indicated through various studies over the years that stigma is an important factor when engaging a patient in alcohol and substance use treatment, and there are several types of stigma that require understanding when treating young patients in particular (Luoma et al., 2007). Enacted stigma includes straightforward discrimination, including social rejection, difficulty finding a job, or ostracism (Luoma et al., 2007). Perceived stigma, the beliefs an individual within a stigmatized group may hold about the prevalence of stigma in society, could be accurate or inaccurate based on the individual's opinions (Luoma et al., 2007). Lastly, self-stigma is the self-imposed negative beliefs an individual holds about his or her inclusion in a stigmatized group; these negative views could result in shame, guilt, or fear (Luoma et al., 2007).

Patients with alcohol and substance use problems are typically considered problematic to manage and treat due to their dependence, and they are often labeled as "difficult patients" (Lindberg, Vergara, Wild-Wesley, & Gruman, 2006). Research has shown that physicians generally have negative attitudes toward these disorders. Studies have indicated they do not feel confident in treating them and their attitudes toward these



disorders become progressively worse as their training continues (Miller et al., 2001). Additionally, the literature has also demonstrated that medical doctors and students have higher levels of stigmatizing mental illness than do nurses and even the patients themselves (Sickel, Seacat, & Nabors, 2014). One study also found that participants reported 40% less willingness to pay for mental illness treatment versus medical illness treatment, despite an equal perceived societal burden with both illnesses (Sickel et al., 2014).

There has been research conducted on the specific topic of healthcare providers' stigmatizing views toward individuals with substance use problems, which is not surprising given the information about physicians' generally negative beliefs about these patients (van Boekel et al., 2013). One study examining the attitudes of nurses toward these patients showed that, overall, they felt greater acceptance toward them, but a minority of the participants still believed these patients were "immoral" and would not likely recover from the substance use disorders from which they were suffering (van Boekel et al., 2013).

Generally, a healthcare professional holding stigmatizing beliefs toward those with substance use problems can negatively impact delivery of treatment and could eventually lead to treatment avoidance or interruption (van Boekel et al., 2013). Additionally, negative attitudes held by professionals toward patients with these disorders can result in poor communication between the professional and the patient and a damaged therapeutic alliance, and can lead the professional to wrongly attribute physical symptoms to the patient's substance use (van Boekel et al., 2013). Though stigma may

not be remedied easily, physicians' awareness of stigmatized views that are sometimes held may lead to better treatment approaches.

**Physicians and substance use disorders.** According to the literature, 25% to 50% of hospital emergency department visits in urban settings are in some way related to alcohol or substance abuse (Lindberg et al., 2006). With such a large number of emergency room visits being related to these disorders, it should come as no surprise that individuals with such disorders also present to physicians in nearly all specialties and all training levels (Lindberg et al., 2006). Nevertheless, alcohol and substance use disorders are often identified and diagnosed as the result of a patient seeking treatment for another problem, such as headache or pain (van Boekel et al., 2013). Practicing doctors, medical students, and residents spend significant time working with these patients, as they constitute a large percentage of the medical population (Lindberg et al., 2006). Accordingly, healthcare providers are nothing short of essential when considering identifying and providing access to treatment options.

Despite the high frequency with which patients with substance use disorders present to all specialties of medicine, there are several issues that can arise when these patients and doctors interact. Miller and colleagues (2001) identified several reasons why physicians are underprepared to treat patients who have alcohol and substance use disorders. As mentioned previously, stigma exists among healthcare professionals when treating patients with alcohol and substance use disorders. To make matters more complex, research has shown that there are deficiencies in the amount of time spent on these disorders in United States medical schools, especially when considering how common the disorders are in the general population (Miller et al., 2001). Other barriers

when considering changing the attitudes and practices of physicians in regard to treating alcohol and substance use disorders include physician denial that addiction is a “brain disease” and not a moral choice one makes, a lack of political support and physician advocacy in response to public concern, and physicians having a personal and/or family history of drug or alcohol problems (Miller et al., 2001).

Interestingly, research has shown that physicians and medical students can feel intimidated by attempts to be educated and trained about these disorders (Miller et al., 2001). A potential reason for these feelings may be any alcohol or substance use issues experienced by the practitioners themselves. One 2016 study found that nearly one third of medical student participants met criteria for either alcohol abuse or alcohol dependence (Jackson, Shanafelt, Hasan, Satele, and Dyrbye, 2016). Literature suggests that physicians having to learn about, diagnose, and treat substance use disorders may bring to the surface denial of their own disorders. Consequently, for similar reasons, physicians may be resistant to diagnosing and treating the disorders in their patients (Jackson et al., 2016). Recommendations from one study included addressing the attitudes of medical professionals toward substance abuse in order to create change in substance abuse within the greater population (Jackson et al., 2016). Therefore, it can be presumed that, in order to treat patients diagnosed with alcohol or substance use disorders effectively, a physician must address his or her own attitudes toward the disorders.

### **Chapter 3: Method**

#### **Overview**

There has been relatively little research conducted on how cardiologists address alcohol and substance use with adolescents and young adults who have heart rhythm disorders. The goal of the current study was to increase understanding about the clinical practice of cardiologists treating adolescent and young adult patients. To evaluate the perspectives of the cardiologists, an interview format was used.

The current study focused on cardiologists and their beliefs and practices regarding alcohol and substance use among their adolescent and young adult patients with LQTS and other heart rhythm disorders. The study aimed to explore the degree to which they address alcohol and substance use with their patients, and the cardiologists' perspectives regarding who holds responsibility for addressing this topic. Also examined was whether the child's parent is present during such discussions, what the cardiologist recommends, and any themes occurring throughout participant answers. Additionally, methods of assessment and intervention used by the cardiologist, as well as the preference for and level of integrative care used by the cardiologist were explored.

Generally, qualitative research focuses less on an event specifically, and more on how it occurs, the facets that comprise it, and the effects it has (Tetnowski & D'Amico, 2001). According to Baxter and Jack (2008), multiple sources of data allow the researcher to study the phenomenon through a variety of lenses while also ensuring that many aspects of the occurrence are revealed and understood.

### **Design and Justification**

The study utilized a qualitative research methodology, which led to the development of themes that explain the phenomena of interest (Kazdin, 2003). A qualitative design was used to understand the perspectives of the cardiologists treating this particular population of patients; the purpose of this type of study design was to examine participants' experiences without restrictions and assumptions (Kazdin, 2003). Cardiologists completed an interview with the investigator by telephone. Participants openly discussed their experiences treating patients with heart arrhythmias and the manner in which they have approached the topic of alcohol and substance use in the past, or how they believe the topic should be approached. Additionally, their views on collaborative care were explored.

Grounded theory, a method of qualitative research analysis, aims to create hypotheses rather than to test previously established ones (Auerbach & Silverstein, 2003). Grounded theory allowed the investigator to utilize concepts and ideas coming from the cardiologist interviews in order to glean a better overall image of their experiences. The study utilized a semi-structured interview method to examine and describe the experiences of cardiologists who treat heart rhythm disorders. After certain themes and ideas were derived from the data analysis, an applicable theory emerged that allowed the experiences of the population at hand to become more evident. The grounded theory method employs a data analysis protocol termed theoretical coding, which is used to create hypotheses based on what the participants of the study indicate (Auerbach & Silverstein, 2003). An integral component of grounded theory is the relevance of the theory created to the experiences of those who are in situations similar to

the participants of the study; this relevance leads to credibility of the research and is vital to qualitative analysis (Wagner, Lukassen, & Mahlendorf, 2009).

Despite the significant literature addressing the medical impact that heart arrhythmias can have on a person, there is less research addressing potential developmentally-specific lifestyle modifications a patient may need to make. Additionally, there is a void in the literature surrounding the manner in which physicians approach discussing these potential modifications with their patients, as well as physicians' perceptions of this discussion in a more general sense. The limited range of psychosocial research on how alcohol and substance use are addressed within this specified population may broaden based on the results of the current study.

The questions comprising the interview included open-ended questions and additional prompts assessing demographic and background information and cardiologist experiences. The study explored various aspects of how cardiologists address alcohol and substance use with this population, including (a) whether the cardiologist addresses the topic in general, (b) the context and nature of a potential conversation he or she may have, (c) whether the patient's parent is present during this conversation, (d) the cardiologist's belief about who should be addressing these issues with the patient, and (e) what the cardiologist recommends for the patient (i.e., abstinence versus moderated use, type of treatment plan implemented, etc.). The questions also aimed to explore participants' general views and attitudes about alcohol and substance use.

### **Data Analysis**

The methodology chosen for the current study was grounded theory, which was created by sociologists Glaser and Strauss (1967, as cited in Glaser & Holton, 2004).

When compared to previously established analysis techniques, grounded theorists believed that theories should be rooted in data coming from the field, including in the actions, interactions, and social processes of human beings (Corbin & Strauss, 2008). Grounded theory allows researchers to construct theory by analyzing data collected from participants in a study; these data could include participants' observations, experiences, and various processes (Creswell, Hanson, Clark Plano, & Morales, 2007). Grounded theory allows the researcher to gather information from the participants in the study in order to create a hypothesis relevant to the information; this process is called hypothesis-generating research (Auerbach & Silverstein, 2003).

Grounded theory employs a process of hypothesis generation called theoretical coding, which follows a multi-step process to draw from data and highlight ideas and themes, which are then used to produce and develop a hypothesis considered crucial to the research question and phenomena being examined (Auerbach & Silverstein, 2003). The coding team for this study included the investigator and two other advanced graduate students, all of whom were supervised by a licensed psychologist with experience in qualitative methodology.

The initial review of the participant responses consisted of each coder engaging in process note-taking, or memoing, from which he or she gained insight into developing ideas and generated initial hypotheses about the participants' experiences and beliefs in regard to addressing alcohol and substance use in their patient population. According to Glaser and Holton (2007), memoing will "present hypotheses about connections between categories and/or their properties and begin to integrate these connections with clusters of other categories to generate the theory" (p. 63). Memoing was used in this study in order

to assist the coders in making connections between the raw data and the phenomenon being explored (Birks, 2008). The initial review of the participant responses enabled the coders to understand experiences from the perspectives of those being interviewed (Corbin & Strauss, 2008). By coding the data and exploring information garnered from it, research questions and insights were able to be generated (Auerbach & Silverstein).

Coding strategies utilized included open coding, axial coding, and selective coding. Beginning with the open coding technique, researchers examined the data and coded them for major themes. From this step, researchers implemented axial coding, in which the researchers identified at least one of the open coding categories, called the core phenomena (Creswell et al., 2007). Lastly, in selective coding, the researchers took the created model and developed hypotheses based on connecting the categories in the model, describing the relationship between the categories (Creswell et al., 2007).

These steps were implemented by the investigator and two additional individuals, in order to achieve triangulation. Each coder reviewed participant responses, exploring and highlighting relevant ideas and, ultimately, generating an initial theory (Auerbach & Silverstein, 2003). Within the scope of grounded methodology, sample size is unknown initially because the researcher needs to continuously add new information to the theory by gathering more data from participants (Auerbach & Silverstein, 2003). Theoretical saturation, which indicates that the sample size is sufficient and appropriate, was reached when new information was no longer recognized and information began to repeat itself (Auerbach & Silverstein, 2003). Ultimately, the coding team agreed upon the evaluation of the themes and interpretations of the data in order to produce accurate results.



## **Participants**

The participants in this study consisted of five cardiologists who provide medical treatment to individuals with LQTS and/or other arrhythmias. Participants included cardiologists with varying ranges of experience in treating patients with LQTS or other cardiac rhythm disorders. Additionally, the participants either currently work or have previously worked in various states in the United States. The study data were collected via telephone. The interviews were scheduled at times convenient for both the researcher and the study participants. The interview was conducted by both parties in quiet spaces in which interruptions were unlikely.

Due to the small sample size in this study, variability in the participants' experiences and backgrounds was pursued and appears to have been achieved. In addition, saturation of the data was sought, to ensure a reliable basis for identifying themes. Theoretical saturation is the point in analysis when all categories are well developed in terms of properties, variations, and dimensions (Corbin & Strauss, 2008). This requirement for qualitative research was met, as several themes were developed from the interviews.

**Inclusion criteria.** Participants in this study were required to be cardiologists within the United States, including those from within specialized fields, such as interventional cardiologists, noninvasive cardiologists, electrophysiologists, pediatric cardiologists, and cardiac and vascular surgeons. As the patient population of interest included adolescents and young adults (individuals ages 13 to 24), general cardiologists were appropriate participants for the study. Additionally, the cardiologists must have

self-identified as having recent experience treating adolescents and young adults with rhythm disorders (within the last two years).

**Exclusion criteria.** Individuals were excluded from this study if they did not treat heart rhythm disorders. They were also excluded from the study if they had not treated a patient with a heart rhythm disorder within the last two years.

**Recruitment.** A sample of cardiologists was recruited to participate in this research study. Information about the study was sent in the form of a recruitment letter to prospective candidates via mail and e-mail (Appendix A). Physicians were recruited via networking, word-of-mouth, and snowball sampling, which provided the investigator with contact information of cardiologist colleagues. Physicians were also recruited via a social media announcement posted to sites such as Facebook and LinkedIn. Recruitment letters were sent to pediatric cardiologists based on contact information listed on the Pediatric & Congenital Electrophysiology Society (PACES) website. According to the PACES website, this international group of doctors aims to improve the care of children and young adults with heart rhythm disorders. The group is nonprofit and has a mission of exchanging information and ideas about arrhythmias, particularly in young individuals, through collaboration and research. A similar organization, Sudden Arrhythmia Death Syndrome (SADS) Foundation, also provides patients and families with a yearly updated list of physicians nationwide; the SADS Foundation website was also of use to the current study in seeking potential eligible participants.

**Demographic characteristics.** Various demographic questions were answered by each participant at the onset of the interview. The participants were five cardiologists including four males and one female. Additionally, each participant worked in a different

state in the United States, varying from the Pacific West Coast to the Midwest to the Northeast. None of the participants had family members diagnosed with LQTS; however, two of the five participants identified having family members with arrhythmias (one cardiologist's mother, now deceased, had atrial fibrillation, and another cardiologist's wife has atrial tachycardia). The table below provides demographic information for participants.

Table 1

*Summary of Participant Demographic Characteristics*

Characteristic	Participants				
	Dr. Alex	Dr. Barbara	Dr. Charlie	Dr. David	Dr. Evan
<b>Gender</b>	Male	Female	Male	Male	Male
<b>Board Certified</b>	Yes	Yes	Yes	Yes	Yes
<b>Type of Medical School</b>	Allopathic	Allopathic	Allopathic	Allopathic	Allopathic
<b>Years of Experience</b>	16	27	15	12	22
<b>Any Outside Mental Health Training</b>	No	No	No	No	No
<b>Practice Setting</b>	Academic Children's Hospital	Outpatient Outreach Clinic	Office & Inpatient	Office & Inpatient	Academic Hospital
<b>U.S. State Location</b>	WV	MI	NJ	NY	CA
<b>Adolescent/Young Adult Children</b>	Yes	Yes	No	No	Yes
<b>Family Member with Arrhythmia</b>	No	Yes	No	No	Yes
<b>Family Member/Friend with SUD</b>	No	Yes	No	Yes	No

**Measures**

A list of interview questions was developed by the investigator as the result of a comprehensive literature review and collaboration with colleagues and mentors. The list of questions was reviewed carefully by individuals with expertise in the areas being examined and only necessary and relevant questions were included (Appendix B). The semi-structured interview consisted of specific questions, open-ended questions, and background and demographic questions. It also included additional prompts used by the investigator. The questions were not always asked in order; however, each participant was asked the same core questions. The interview consisted of questions related to each cardiologist's approach to addressing alcohol and substance use with his or her adolescent and young adult patients. The interviewer also gathered personal information about the participants, such as their gender, number of years of experience with the population of interest, whether they have family histories of LQTS, and whether they have had additional psychological training.

### **Procedure**

The population of interest was solicited through the PACES and SADS Foundation. Participants were also solicited by e-mail with a letter gauging interest in participating in the study. Potential participants were presented with a brief description of the purpose of the study in the e-mail they received. Members of PACES and SADS Foundation were also able to read a brief description of the purpose of the study in an e-mail, which was sent to each member. By reading the brief introduction and agreeing to participate, participants provided informed consent. All interviews were recorded on a digital recorder. After each interview was complete, the investigator transcribed all recordings. Transcribing each interview allowed information to be extracted via a

functional form for analysis of the data, and ensured that the information gathered from the interviews was accurate and consistent. Pseudonyms were created and used during the coding process to maintain the participants' anonymity. All collected data were password protected and remained confidential; no identifying information was retained from participants. After each interview was recorded and transcribed, it was deleted completely.

After the interviews were transcribed, the coding team reviewed the transcripts for common themes. A coding scheme was created to define themes that emerged from the information collected during the interviews. The coding team met on multiple occasions to discuss impressions of the data and reach agreement on the topics identified. The investigator then interpreted the themes generated from the transcripts and, subsequently, developed a theory relating to those themes. The themes were explored and linked to existing research. Specific quotations from the participants were utilized in order to best demonstrate the meaning of the common themes that emerged, and to provide a voice for cardiologists who work with the population of interest. All participants were given a \$10 gift card toward Starbucks Coffee.

### Chapter 4: Results

In the current study, the experiences and beliefs of cardiologists treating adolescent and young adult arrhythmia patients were examined. Analysis of the data collected resulted in emergent themes: patient presentation, parental presence, external influences, communication factors, and responsibility.

According to the literature, physicians are guided by their own individual set of heuristics; therefore, even if two physicians emphasize the same component of a medical problem, one may perceive it as more important than the other (Mancuso & Rose, 1987). Participants in this study were asked about their decision-making process in regard to addressing alcohol and substance use with their patients; specifically, they were asked about what may trigger them to approach the topic with a patient, and what influences their approach.

Participant responses varied significantly in this context. Although all five participants stated that they address alcohol and substance use with their patients, the frequency with which such a discussion occurs varied across participants. Some participants shared that they address the topic with their patients routinely, eliminating the need to utilize any decision-making process. For example, one cardiologist explained that he follows a standardized procedure for addressing alcohol and substance use with his patients, which begins before he even enters the exam room with the patient. His medical assistants collect information from the patient about alcohol and substance use along with other information, such as vital signs, and enters it into the electronic medical record so it can be reviewed prior to meeting with the patient.

Other cardiologists referenced using a standard form or questionnaire that is given to patients at the onset of each visit. One participant stated that he addresses alcohol and substance use with a new patient on the first visit, but infrequently addresses it in following visits. Overall, participants acknowledged several factors they are influenced by in regard to addressing the subject of alcohol and substance use with patients.

### **Patient Presentation**

**Patient symptoms.** Patient symptoms led to physicians addressing high-risk behaviors thoroughly. One cardiologist cited heart palpitations, shortness of breath, or chest pain as symptom “triggers” that would lead him to address the topic. Several participants explained that they “dig deeper” and inquire more thoroughly about alcohol or substance use if it is apparent that the use is contributing to the reason the patient is being seen. For example, one cardiologist explained the circumstances of a former patient who would present with cardiac symptoms several times per year following episodes of heavy drinking.

Physicians mentioned that they tend to generally address various factors that could induce symptoms. For example, one cardiologist explained that he will address “things that could trigger an arrhythmia,” which not only includes drugs and alcohol, but physical activity such as competitive sports. A common theme emerged that cardiologists feel either more comfortable addressing alcohol and substance use, or more likely to address it, if they believe that a patient’s use could be contributing to his or her current cardiac issues. Interestingly, one participant noted that he typically will broach the subject on the first visit with a patient and only bring it up in the future “if it’s a recurring issue:”

If I saw that there might be, you know, something that is contributing to why they're seeing me, or their symptoms or whatever. So, you know, I'll ask about caffeine and alcohol most commonly with people with arrhythmias or palpitations. Otherwise I don't dig too deep if I'm not concerned about it sort of from a cardiac standpoint. (Dr. Charlie)

**Patient age/developmental level.** All participants in the current study were cardiologists who either currently work with or have worked recently with patients between the ages of 13 and 24. Several of the participants acknowledged their awareness of how the patient's age and/or developmental level typically inform their approach of the topic of alcohol and substance use. For instance, participants referenced the prevalence of binge drinking and caffeine use within college-age students:

So with alcohol, questioning in an adolescent or college age students, if they said they didn't smoke cigarettes 6 months ago, but now they're coming and/or they didn't drink alcohol 6 months ago, if they're coming to see me 6 months later, I might re-address: "Oh, just out of curiosity, are you drinking wine now or beer or something? Even though you said you weren't 6 months ago?" Because in that patient population, you know, it's more likely that something has changed, or at least statistically, binge drinking is very common in college-age students. Or in some cases with caffeine, I may have students who don't normally drink caffeine, but when midterms come they'll say, "Oh, I have midterms," and when I hear someone's studying for exams I think, "Well I wonder, are you now drinking a lot of coffee while studying for your exams?" which is sort of



episodic, once every 6 months, “and is that causing you to have chest pain or insomnia or palpitations?” (Dr. David)

Generally, participants demonstrated knowledge and awareness of developmental level when considering their approach to addressing the topic of alcohol and substance use with their patients. The prominence of binge drinking habits, caffeine consumption, and recreational use of stimulant medication was acknowledged in many of the cardiologist interviews. Dr. David explained that, with a patient who is in his or her 60s, he likely will not address the topic of alcohol use or cigarette smoking continuously. In contrast, for a college-age patient, he will continue to address the topic, as “it’s more likely that something has changed” with a college-age patient versus an older patient who has longstanding habits.

Physicians also acknowledged patient developmental age by speaking about peer pressure and social situations. The presence of peer pressure, pressure to “fit in,” and the occurrence of potentially difficult social situations in an adolescent or young adult’s life appears to heavily impact the decision of the physician to address the subject of alcohol and substance use. Dr. Alex detailed what he might say to a young patient: “I would say, ‘It’s okay if you want to fit in and you want to grab a beer or whatever, that’s fine, but for you to get sloshed and blackout drunk is not a good idea.’” Later in the same interview, Dr. Alex said in regard to college-age patients: “You have enough pressure fitting in and you don’t want to add another problem.”

Dr. Evan spoke of the idea that adolescents tend to view themselves as immortal or invincible. Although this is a widely held belief, some of the literature disputes it. The terms “optimistic bias” and “perceived vulnerability” are often mentioned in these

data and refer to the concept that adolescents' perceptions of risk are skewed (Reyna & Farley, 2006). Research shows that, when compared to adults, children and adolescents have less ability to delay gratification, inhibit their behaviors, anticipate the future, think of consequences spontaneously, or learn from negative consequences (Reyna & Farley, 2006). Additionally, they tend to view consequences as being less harmful than adults do (Reyna & Farley, 2006). Nevertheless, it has been shown that adolescents do not perceive themselves to be invincible, and perceived vulnerability declines with age (Reyna & Farley, 2006).

### **Parental Presence**

Studies have shown that, within patient-parent-physician encounters, parents tend to interfere and offer themselves as the "leaders" of these encounters (Nova, Vegni, & Moja, 2005). This is true for parents regardless of their children's ages; however, physicians are more likely to involve older child patients in these encounters (Tates, Elbers, Meeuwesen, & Bensing, 2002). Moreover, in the patient-parent-physician scenario, the physician tends to ask the child directly for information, but excludes the child in the discussion regarding the diagnosis or treatment (Nova et al., 2005). Some studies have argued that parents may be to blame for inhibiting their children's participation in medical encounters (Stivers, 2012). Others have shown that, regardless of parent presence, outpatient healthcare providers do not spend an adequate amount of time interacting with their young patients (Stivers, 2012).

Responses varied significantly when participants were asked about whether their approach is impacted by the presence of a patient's parent. Dr. Alex stated that he will "always" discuss alcohol and substance use with his patients, but that he is "less likely"

to address illicit drugs if the patient's parent is in the room. A 2002 study suggested that there are two types of adult behaviors in the context of these types of medical interactions: supportive and non-supportive (Tates et al., 2002). Supportive adult behavior refers to the parent and the physician being verbally and nonverbally encouraging toward the child, enabling him or her to take an active role in the encounter, whereas non-supportive behavior refers to both parties directing the interaction and treating the child as a bystander (Tates et al., 2002).

Two of the five cardiologist participants said that their approach to addressing alcohol and substance use is not impacted at all by the patients' parents being present in the room. Dr. Evan said, "It doesn't really impact how I say it, depending on the whether the parent's there, because I've chosen to do it in a way that, to me, is acceptable to do in front of the parents." Dr. Evan went on to describe how he believes that his approach does not necessarily elicit an "admission" of use from the patient, and that it is more focused on educating the patient instead of lecturing or shaming him or her. Dr. David said that his approach is not affected by the presence of the patient's parent "because it's so important to the clinical perspective" to get the information from the patient, regardless of whether the parent is in the room.

Dr. Charlie stated that he would likely ask the patient's parent to step out of the room "if there's a high-risk situation." Although he did not elaborate on this response, it can be inferred that he would use clinical judgment in order to assess whether the parent's presence would have a negative impact on the patient's treatment. Dr. Barbara indicated that she sometimes feels conflicted when it comes to parental presence. She explained that she is less likely to bring up alcohol or substance use if the patient's parent

is present, but then stated that the parent “could have useful information” or “provide a reality-check” if the patient is not being truthful or completely honest about his or her use of substances.

### **External Influences**

Data suggest that external influence of mass media is extremely powerful in creating societal views and perceptions of drugs and drug use. In fact, some data acknowledge that media is involved in creating “moral panics” and “strong societal reactions against certain drugs and drug users” (Montagne, 2011, p. 849). Research has identified “collective social knowledge” as influential in the development and communication of perceptions about drugs; social knowledge is defined as the cumulative knowing of something, based mostly on available information and past experiences (Montagne, 2011).

From 2000 to 2016, the rate of deaths from drug overdoses increased 137%, with a 200% increase in the rate of overdose fatalities from opioids (Rudd, Aleshire, Zibbell, & Matthew Gladden, 2016). In present-day society, the frequent use of the word “epidemic” has been associated with the rising rates of the use of opioids, including heroin. The opioid epidemic in the United States has been identified as an “urgent public health and public safety crisis;” in 2014, there were 1.9 million Americans abusing prescription opioids (Knopf, 2016; Thornton, Lyvers, Scott, & Dwibedi, 2017).

Additionally, recent legislation legalizing or decriminalizing the medical and recreational use of marijuana in some states has been widespread in the media. Both of these contemporary issues were mentioned in the participant interviews and seemed to

impact cardiologists' approaches and decision-making. Dr. Barbara referenced the opioid crisis specifically, and her thought process in regard to her patient population:

I guess it's more the media and, you know, you read about all the numbers of things. And you know, you hear about people that are overdosing on opioids, or just the impact of marijuana, or that kind of thing, and then you think "If these numbers are so high," and I have thought about this, you know, "I'm seeing this many patients this week, chances are, especially in that age group, that some of those people walking in are dealing with these issues," is the most statistical standpoint. (Dr. Barbara)

### **Data or Statistics**

Four of the five participants in the current study shared that their approach is driven by data or statistics. The statistical information the cardiologists mentioned seems to be used to either inform patients about potential risks or to decrease worry in patients or their parents. Research shows that having children with congenital heart diseases can be associated with such outcomes in parents as adaptation problems, distress, guilt, and reduced quality of life (Lawoko & Soares, 2003). Learning about various statistical information may minimize worry in parents of patients, particularly of those who have children with arrhythmias associated with sudden death. Dr. Alex addressed this and described how he often tells his young patients and their parents about statistics regarding the risk of dying from having an arrhythmia such as LQTS:

We're so afraid, and I get it. It's in the newspaper and on the news. It's devastating, right? A little 8-year-old kid dies playing soccer, and the whole world goes upside down, and it's very, very sad. Don't get me

wrong, it's very, very sad. But the chances of that happening . . . there's about 500 deaths per year in America from unrecognized things, like long QT, in athletes. So 500 kids a year, that's a boatload, but not when you consider how many millions of baseball games, basketball games, soccer games, or whatever, are played per year in America. Five hundred is pretty low, right? But we make a huge deal out of that, yet 15,000 teenagers die a year in cars. It's actually higher than 15,000. But there's a much, much greater risk of your kid dying when they get into a car and they're a teenager, than your kid with long QT ever dying. (Dr. Alex)

Dr. Alex also described informing the patient and the patient's parent about how the knowledge of the patient's diagnosis can decrease statistical risk of dying from sudden death. For example, he will tell a patient with LQT1 and his or her parent that there is a 10% chance of sudden death with that particular disorder, and that the risk of sudden death decreases to 1% once a diagnosis is made and the patient is put on medication. When managing an illness that carries high levels of uncertainty, being informed of statistical information may be tremendously comforting to a patient and his or her family.

Other cardiologists insinuated that they feel more comfortable addressing alcohol and substance use with patients and their families if they are well-informed about statistics and data regarding the particular substance. Dr. Barbara said, "There's a lot of data about cigarette smoking, so I'm pretty comfortable saying 'Cigarettes hurt your lungs, but they also hurt your heart and make you at risk for future heart problems.'" Dr. Evan explained, "I do tell [patients] how concerned I am about binge drinking, and not

even because binge drinking is bad, it's because binge drinking is certainly associated with some arrhythmias.”

In the context of data and statistics, it is noteworthy to discuss the opioid epidemic and its impact on how physicians approach the topic of alcohol and substance use with their patients. Of particular interest is the state of West Virginia, where Dr. Alex practices, which had the most deaths from drug overdoses in 2015 out of all 13 states considered part of the cultural area of Appalachia (Thornton et al., 2017). The year prior, West Virginia had the highest rate of overdose deaths in the entire United States (Rudd et al., 2016). Dr. Alex acknowledged the high frequency of opioid use in West Virginia and insinuated that this knowledge impacts the way he approaches patient drug use. Dr. Alex said, “Unless I have something that triggers me, I don't have a routine conversation about cocaine. And really, in this state, it's opioids.”

### **Clinical Experience**

Several cardiologist participants recognized that their approach is informed by clinical experience, which varied in years across participants, with a range of 12 to 27. It seems as though clinical experience is a generally positive influence on a cardiologist's approach; it allows the physician to go through somewhat of a “trial and error” experience, enabling him or her to learn about which approaches are most efficacious. Dr. Charlie noted the trial and error process, saying, “I think that it takes time, and some of it is experience, and just taking what works and doesn't work.”

Dr. Evan, who works primarily with adolescent patients, shared that his clinical experience has led to a better understanding of teenagers in general. He mentioned fellows and residents with less experience, explaining that the less-experienced doctors

will remark on his approach and its efficacy, and that they learn from him. Dr. Evan also spoke about his observation that residents are often hesitant to address alcohol and substance use on each visit, saying, “Well, we’ve talked to [the patient] about that,” and Dr. Evan will respond by saying, “No, you have to talk about it every visit.” This was another aspect of clinical experience that seemingly impacts an approach taken with patients.

### **Communication Factors**

**Overview.** The way in which a doctor communicates with his or her patient can impact many factors, including physiological measurements, adherence to treatment recommendations, and general satisfaction with medical care (Pantell, Stewart, Dias, Wells, & Ross, 1982). Research has shown that physicians tend to underestimate their patients’ desire for information, overestimate how much information they give to their patients, and give variable amounts of information based on a patient’s level of education, income, gender, and age (Street, 1991). Research has also found that patients who are more seriously ill will generally receive more information from doctors than those who are not as seriously ill (Street, 1991). Communication between patient and physician is critical, especially when addressing chronic illnesses.

When considering physician-patient encounters with younger individuals, direct communication is of particular importance. It builds trust and rapport and is highly valued by young patients (Stivers, 2012). Furthermore, studies have shown that children are interested in clinical information and can actually retain some information better than their adult counterparts (Pantell et al., 1982). One study suggested that the physician talking more extensively with the young patient led to better parent satisfaction and



adherence to treatment by the patient's parent (Pantell et al., 1982). Patient-physician communication was a commonly referenced theme throughout the interviews in this study. Physicians were asked about specifics regarding their communication with patients and parents, including the language they tend to use and their preferred communication styles.

**Realistic approach.** Three of the five participants in the study acknowledged that they take a "realistic" approach when addressing the topic of alcohol and substance use with patients. Dr. Evan explained, when discussing what he recommends to his adolescent and young adult patients in regard to alcohol and substance use, "I certainly don't talk to them about abstinence because that's kind of ridiculous. I just try to get them to understand what my concerns are." Regarding abstinence, Dr. Alex said, "[it] is just not realistic."

Several of the participants spoke about the concept of moderation and how strongly they believe in encouraging the patient to practice moderation rather than complete abstinence when using alcohol or substances; however, the suggestion of practicing moderation did not always apply to every substance. For example, Dr. Alex explained that he recommends to patients to *never* drink energy drinks with high levels of caffeine, such as Red Bull, Monster, or 5-Hour Energy, but that he believes it is acceptable for the patient to drink caffeinated beverages, such as sweet tea or soda, if it is consumed in moderation. Dr. Alex recommends that while at home, the patient drink only decaffeinated beverages, but if the patient is out with family at a restaurant, he or she can have a caffeinated beverage. He does not tell his patients explicitly how many caffeinated beverages they should limit themselves to.

Cardiologists also seemed to integrate their knowledge of the patient's developmental phase into striving toward a realistic approach of the subject of alcohol and substance use. Several cardiologists referred to putting an adolescent or young adult "in a bubble" and how doing so can be detrimental. Participants also often used the word "normal" and seemed to strive to take not only a realistic approach with patients, but an approach that will minimize patients' feelings of being different or "other." Dr. Alex said, "I've seen kids put in bubbles, and I have to tell you, when they come in, they're just not right." He explained his belief that if a young patient is restricted excessively, he or she will not be capable of functioning properly in society.

**Passive approach.** Two of the five cardiologists described their somewhat passive approaches. When asked about a specific patient who had been struggling with alcohol use issues, one cardiologist said that she is "not in the habit of quantifying [patient alcohol consumption]" and insinuated that she typically becomes aware of a how much of a substance a patient is consuming only if he or she is forthcoming or volunteer the information.

When Dr. Charlie was asked about how he would approach a patient who was vehemently denying using despite the patient's use being quite blatant, he described how he may say, "Are you sure you're not drinking?" or "Are you sure you haven't used cocaine in the last week?" He said, "and if they say no, then, you know, it is what it is." The passive nature of the cardiologist's approach and using the phrase "it is what it is" could be due to several factors, including feeling underprepared or ill-equipped to address the issue further. The passivity could also be due to fear of confrontation which, in some

cases, could result in a strained patient-physician relationship, or even cessation of treatment with that provider.

Within the context of taking a more passive approach with patients, the issue of documentation was introduced during the participant interviews. More specifically, one cardiologist expressed her reticence to address certain aspects of patient alcohol or drug use because of the need to subsequently document them in the patient's electronic medical record:

I think the documentation piece is also a bit of a potential problem. In the old days there were records that people rarely saw, but nowadays, if people are in fact looking, and I'm looking at the letter you wrote and see "the person's drinking four days a week," I wouldn't like that to be in my record. They may not want things disclosed. It's one thing to see it in writing. You put something in a record and it just stays on there forever. It's on a problem list, and then it's stuck. (Dr. Barbara)

Dr. Barbara's approach seemed to be guided partially by an avoidance of potential patient pushback or rupture of the patient-physician relationship. Since 2009, the number of hospitals utilizing electronic medical records (EMRs) has tripled, and almost half of all hospitals now use them (Guttmacher & Tiersten, 2014). The utility of an EMR is rooted in the idea that it can become a hub of information for all of the medical providers involved in a patient's care; however, there are some drawbacks. A provider may be fearful of putting some information about a patient into the record that might lead to misunderstandings, or even legal action, if that information is misinterpreted (Guttmacher & Tiersten,

2014). In some cases, including in the case of the aforementioned cardiologist, physicians may refrain from entering information into EMRs due to the potential drawbacks, which can impact patient care negatively (Guttmacher & Tiersten, 2014). Having positive rapport between patient and physician is extremely important; however, it could be argued that purposely omitting information from a patient's EMR is unethical. Furthermore, omitting certain information from a patient's record may actually impede the patient's recovery and, in some cases, create more frustration or stress for other providers.

### **Viewing the “Big Picture”**

Another common theme discussed by participants was the idea of viewing the patient and the patient's life from a “big picture,” holistic perspective. More specifically, several of the participants took into consideration their patients' social lives, education, and quality of life. For example, one cardiologist discussed his approach when working with athletes who have arrhythmias. He described working with a college cheerleader diagnosed with LQTS, who he cleared medically so she could continue to participate in her sport. He explained that part of his treatment approach with her takes into consideration the fact that it is more likely to develop medical comorbidities by being sedentary than by being active. Moreover, he explained, the chances that a patient will develop obesity as a result of inactivity are higher than the chances of a patient dying from a sudden cardiac event while playing sports.

An interesting aspect of the “big picture” approach taken by several of the participants included considering the potential consequences of restricting patients from engaging in certain activities. For example, one cardiologist explained his experience

with a patient who resided in an inner city area and earned a college scholarship to play basketball. He shared about how his thought process included imagining what the patient's life would be like if he were not medically cleared. The cardiologist said, "there's a much, much greater chance of him dying by not going to [X University], or not going to school, than whatever the risk is playing basketball."

Taking this type of empathic, patient-centered approach may indicate to patients that their physicians truly care about their overall well-being, rather than only their symptoms or diagnoses. The literature shows that this type of empathic expression can be beneficial for patients and, in turn, society, in many ways. The effective implementation of empathic communication can improve patient adherence to treatment, which leads to improvement in patient health and can lead ultimately to reduction in the economic costs often caused by frequent changing of doctors and malpractice lawsuits (Kim, Kaplowitz, & Johnston, 2004).

### **Guilt- or Shame-Inducing**

Participants were asked to describe exactly what they may say to patients who admit to using alcohol and/or substances. Several of the participants explained that they tend to take a nonjudgmental approach or an approach that is driven by wanting to educate patients rather than "lecture" them. Some research has shown that an approach focusing on patient empowerment, one in which the physician is viewed as a resource, is most successful in assisting patients in making decisions. In particular, one study supported this approach when sharing negative information with adolescents and their families in regard to chronic illness (Karnieli-Miller & Eisikovits, 2009). Others have

shown that a more directive approach is more successful with some patients (Cohen & Britten, 2003).

Although participant responses in this domain varied, a common theme emerged indicating that physicians sometimes feel unequipped to handle situations in which their patients admit to using drugs or alcohol despite being aware of the potential risks. One cardiologist said, “Other than sort of telling them [the patient] the risk of continuing, I don’t really feel equipped.” Research suggests that training within medical school curricula is often inadequate and, at times, nonexistent. Thus, it is unsurprising that medical students and doctors often lack competency in assessing and managing alcohol and drug health problems effectively (Cape, Hannah, & Sellman, 2006).

Research has shown that physician interactions often result in patient shame (Harris & Darby, 2009). Individuals who experience shame in a medical context can attribute extremely adverse consequences to the interaction, including distress, cessation of treatment, and lying to the physician in future encounters to avoid feeling embarrassed (Harris & Darby, 2009). On the other hand, some patients interpret shame-inducing remarks by their physician to be helpful (Harris & Darby, 2009). Interestingly, one study suggested that participants identifying smoking, alcohol use, or drug use as the source of feelings of shame tended to think physicians were helpful and even admirable, but were also more likely to lie to physicians during future visits (Harris & Darby, 2009). One participant described taking an approach that could be considered guilt or shame-inducing.

I tell them, “You’re lucky enough to be alive, you’re lucky enough to know what your diagnosis is, you’re lucky enough to receive treatment for

that diagnosis . . . do you really want to add another issue on top of it like lung cancer or COPD?” And if it were congenital heart disease . . . I have an adult who is 34 and they survived the transposition of arteries or something like that . . . tetralogy of Fallot . . . into adulthood. “You’re here, right? You’re 34 . . . you’re lucky to be here and you survived tetralogy of Fallot. Do you really want to have to deal with lung cancer?” . . . for example. Or in the case of obesity, I do the same thing for obesity, right? I’ll say, “You’re alive. Do you really want to have diabetes, coronary artery disease, stroke . . . on top of what you’ve already survived?” So that’s the approach that I use. (Dr. Alex)

Although this type of message could induce guilt or shame, it appears that the impetus behind it is to support the patient and let the patient know that he or she is cared for. One cardiologist participant, who appeared to take a similar approach, said that he says to patients, “You just don’t want to have to deal with the additional issues” of using substances. This indicates a level of empathy from the physician that may be interpreted positively by the patient. Additionally, it seems as though a guilt- or shame-inducing approach was connected to cardiologists’ desire for their patients to feel as “normal” as possible. While discussing his approach to patients who admit to using substances, one cardiologist said, “I don’t want to deprive the kid . . . a significant part of my practice is helping children and, more, honestly, families and parents . . . treat their kids like a normal kid.”

**Relating to/Aligning with the Patient**

Cardiologist participants often referenced the fact that they have experienced adolescence and young adulthood, along with the factors that impact individuals in those age ranges, and used it as a part of their approaches. Cardiologists used statements such as “I’ve been there,” “I’ve gone to college too,” or “I can understand” while speaking to patients. Additionally, three of the five cardiologist participants disclosed that they have adolescent or young adult children. This additional form of connection between physician and patient could result in the physician approaching the subject in a more personal manner. One participant disclosed during the interview that he has a congenital heart defect. He shared his belief that he would be “hypocritical” if he were to tell a patient not to do something that he has done.

Cardiologist participants referred to using age-appropriate language when discussing alcohol and substance use with their patients. Data suggest that children and young people dislike when providers use high-pitched vocalization, also known as “singsong” (Howells & Lopez, 2008). One participant described how he uses age-appropriate, casual language with his patients without trying to “sound like a teenager.”

Another common theme throughout the cardiologist interviews was relating to patients by referring to things familiar to them. This was particularly evident in one cardiologist interview while discussing patient recommendations for consuming energy drinks. Dr. Alex said, “nothing good comes from Red Bull, you know, nothing good comes from Red Bull or Full Throttle or Monster. So I do pick on those, I do name them by brand, because that’s what they know.”



**Informing of Risks**

Participants spoke about risk frequently when discussing their approaches to addressing the topic of interest with their patients. Information exchange signifies the type and amount of information that is exchanged between the physician and the patient, and whether the information flows one way or both ways (Charles, Gafni, & Whelan, 1999). The types of information that the physician may impart to the patient include the benefits and risks of various treatment alternatives (Charles et al., 1999). Three of the five participants in the study said that they inform their patients of the potential risks, outcomes, or consequences of alcohol and substance use, particularly in relation to their cardiac status. One participant specified that he not only informs the patient of the potential risks of using, but also the potential impact using will have on the medications he or she is taking (e.g., a blood thinner such as Coumadin). Risk was also discussed when cardiologists spoke about connecting with their patients' other providers. For example, one cardiologist said that he will be in contact with a mental health provider if their shared patient's psychiatric medication could have a potential impact on his or her cardiac status.

**Responsibility**

Participant responses varied when discussing responsibility of informing, addressing, and following up with patients regarding alcohol and substance use. Participants were asked various questions surrounding responsibility based on their previous responses to interview questions. Overall, participants identified multiple sources when discussing who is responsible for addressing alcohol and substance use

with patients. Also in the context of responsibility, a theme that emerged was responsibility in relation to advocating for patients and patient education and knowledge.

**Other providers.** The most commonly referenced source when cardiologists were asked about responsibility was the primary care physician (PCP). Even one cardiologist, who tended to put more emphasis on the patient having responsibility, acknowledged that the patient mostly needs to be responsible so he or she can inform other providers of his or her illness or symptoms if necessary. Although many of the participants identified that part of their own responsibility includes addressing alcohol and substance use, they also frequently spoke of referring to patients' PCPs.

One cardiologist seemed to have conflicting thoughts regarding this subject; she acknowledged that although she feels partially responsible for addressing the topic, she tends to refer patients to their PCPs to address the issue more thoroughly. She stated, "It's a bit of a black hole," because she is aware of how irregularly patients visit their PCPs. Another cardiologist suggested that he places responsibility on the patient's "pediatrician or PCP" to address psychological issues, such as depression or anxiety.

A common theme that emerged throughout the interviews included an emphasis on referring the patient to his or her PCP if it is believed that the patient is struggling with more serious alcohol or substance issues, or with serious psychological issues, that may be beyond the cardiologist's scope of competency. Cardiologists were asked during the interviews whether they have ever had a patient who was seeing an outside provider for an issue related to alcohol or substance use, and whether they had contact with the outside provider. One cardiologist described recently treating two siblings who both struggle with mental health issues.

I mean, my approach is usually, I ask the patient about the diagnosis and I ask them who they're seeing, what meds they're on, and what the follow-up plan is. Yeah, that certainly happened yesterday . . . where the kids are on Zoloft, and I know one of them has problems with depression and anxiety, the other one has problems with anxiety and, and you know, we just acknowledge that and make sure that they were taking their meds, and I ask them how often they're seeing them [the outside provider]. I mean, my responsibility there is just to make sure that they're plugged in. So once that's recognized, I can feel confident that things are being addressed. (Dr. Evan)

**Patient and/or parent.** Some participants referred to the patient or the patient's parent holding the responsibility when it comes to remaining informed about the cardiac effects of alcohol and substance use. Also related, some participants placed responsibility on patients by questioning them about what they have done in terms of finding resources:

I guess one thing I might say is, "You need to talk to your primary care physician about, you know, the resources that might help you with this problem," I guess is what we do. Or I guess you can ask them, "So what are you doing about this problem?" and, you know, turn it around as well. (Dr. Barbara)

In terms of responsibility, cardiologists also spoke about how parents are responsible for various aspects of their children's care. As the patient population in this study included children under 18, many of the participants' patients live at home with

their parents, consume food and beverages purchased by their parents, and rely on their parents to transport them to destinations, purchase their medications, and finance their leisure activities.

As discussed previously, cardiologists referred to “overly restrictive” parents when taking a realistic approach. In terms of discussing responsibility, participants also shared about how parents are also partially responsible for making their children’s lives as “normal” as possible. One cardiologist explained that he believes parents “play a huge role in all of it:”

All the kids are great. But it seems like when the kid gets diagnosed with a cardiac issue, even something like a heart murmur or something that can be easily managed with medications or lifestyle changes, the parent almost makes it so the kid can’t be normal or do things with their friends. Not to say that binge drinking or using drugs is a normal, good thing, but there’s some things that kids just need to experience for themselves, you know?

(Dr. Evan)

### **Integrative Model of Shared Decision-Making**

Treatment decision-making processes and treatment approaches for children, adolescents, and young adults with arrhythmias are multifaceted and involve numerous factors. Several themes emerged from this research that provide information about the considerations and processes cardiologists implement in their approaches to addressing alcohol and substance use with patients. The themes included patient presentation, parental presence, external influences, styles of communication, and responsibility. Due to the fact that treatment decision-making occurs within the framework of the physician-

patient relationship, many models of decision-making have been recommended based on the rights and roles of both parties in gathering and exchanging information, and in making treatment decisions (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2012). Some of these models include behavioral decision-making, conflict theory, family-centered, and paternalistic models (Tariman et al., 2012). Although the patient-physician relationship has shifted internationally from a physician-centered, paternalistic relationship to a more patient-centered one, more work needs to be done in order to continue to strengthen patient care (Lee & Lin, 2010).

Makoul and Clayman (2006) proposed what they labeled an integrative model of shared decision-making (SDM), which was designed to build upon the existing SDM literature. They pointed out that existing models do not share a cohesive definition of SDM; thus, their aim was to create a definition of SDM that was “conceptually sound, useful for future research, and applicable to clinical practice” (Makoul & Clayman, 2006, p. 305). In order to achieve this, the researchers extricated specific observable behaviors, or elements, and relatively general characteristics, or qualities, and separated them into two groups. The two groups, essential elements and ideal elements, comprise their proposed model. The authors explained, however, that only the essential elements need to be present in order to engage in integrative SDM, and the ideal elements are not necessary, but helpful in the process (Makoul & Clayman, 2006). In order to examine the current research more closely, it was perceived through a lens of an integrative SDM model.

**Essential elements.** Makoul and Clayman (2006) identified numerous factors when outlining the essential elements of integrative SDM, several of which were

discussed throughout the cardiologist interviews. First, the patient and physician must define and/or explain the problem that needs to be addressed (Makoul & Clayman, 2006). Next, the physician should review options and patients should bring up options of which he or she is aware (Makoul & Clayman, 2006). All five participants in this study acknowledged the problem being addressed, alcohol and substance use, and also acknowledged options in some form. Within a framework of integrative SDM, physicians and patients should discuss the benefits and drawbacks of the options; this discussion is integral because the patient and physician may have different opinions on the relative significance of benefits, risks, and costs (Makoul & Clayman, 2006). This was made evident throughout the cardiologist interviews, particularly in the context of patient age and/or developmental level. As mentioned previously, adolescents have underdeveloped cognitive maturation, which can lead to skewed perception of benefits, risks, and costs. Many of the participants acknowledged this and seemed to incorporate it into their approaches with patients.

Cardiologists in this study generally presented options in regard to alcohol and substance use. They were asked about what their recommendations are in regard to consumption by their patients and, despite variable specifics, participants all seemed to integrate options into their patient approaches. For example, recommending that the patient completely abstain from highly-caffeinated energy drinks while also being able to drink caffeinated soda in moderation. In terms of providing options to patients, cardiologists also seem to use fact-based knowledge in order to make those options known. For example, pointing out that the patient has the option to drink alcohol or to

abstain, but that the patient should be aware of his or her symptoms when drinking socially with friends who do not have cardiac conditions.

Another essential element within an integrative SDM framework is self-efficacy, referring to patients' ability to follow through with plans or to execute a specified behavior or set of behaviors (Makoul & Clayman, 2006). Although patient self-efficacy was not addressed specifically during the cardiologist interviews, cardiologists seemingly took into consideration their patients' abilities when acknowledging their developmental levels and ages. They also referred indirectly to patients' self-efficacy when pointing out the restrictions sometimes put onto them by parents. Cardiologists appeared to want to help their patients strive to achieve self-efficacy by providing them with as much educational information as possible. Furthermore, they promoted self-efficacy by making known their desires for each patient to live as "normal" a life as possible.

In order to assess decision outcomes, it is imperative that physicians and patients arrange follow-up appointments (Makoul & Clayman, 2006). The objective of follow-up appointments from an integrative SDM perspective is to check in with the patient and his or her family regarding final decisions made after an initial meeting (Makoul & Clayman, 2006). In the current study, follow-up was addressed throughout the interviews. In regard to addressing the topic of alcohol and substance use, each of the five participants stated that they address it, at minimum, on the first visit with the patient. One could consider the first visit to be a period during which both parties, the doctor and the patient, exchange information and, ultimately, the patient can either make a decision or defer a decision until a later time (Makoul & Clayman, 2006). Participants did not state uniformly that they continuously address the topic during future visits; however, the

initial appointment seems to act as a marker by which the patient and family can decide how they would like to proceed.

Patient values and preferences, another essential element of an integrative model, was addressed throughout the cardiologist interviews. Taking into consideration a “big picture” perspective and looking at a patient’s life holistically was a common theme in the interviews. Cardiologists tended to view patients and their lives when considering their cardiac symptoms. As arrhythmias are associated with some lifestyle choices, this was not surprising; however, it also introduced a sense of empathy on the part of the physicians. The physicians not only considered other aspects of their patients’ lives when approaching the subject of alcohol and substance use, but their patients’ quality of life.

**Ideal elements.** Makoul and Clayman (2006) considered some elements of their integrative model “ideal” because, although they may enrich the process of SDM, they are more pertinent to some encounters than others. Ideal elements of integrative SDM include unbiased information, definitive roles, presenting of evidence, and mutual agreement (Makoul & Clayman, 2006). In the current study, presenting evidence was discussed commonly in the cardiologist interviews. Cardiologists seemed to favor taking a data- or statistics-driven approach when addressing alcohol and substance use with their patients. This could be due to physicians’ level of comfort with addressing less-familiar topics, their perceived competency in this realm, or simply their preference for concrete, empirically-supported facts.

In terms of unbiased information, Makoul and Clayman (2006) indicated that delivering it may only be appropriate if the patient does not want the physician’s perspective (2006). The cardiologists in this study seemed to be biased in a way that was



ultimately beneficial for their patients. For example, when relating to or aligning with the patient, one cardiologist shared that he would explain that he has been through college and can, therefore, understand the struggles associated with stressful social situations. Interestingly, one cardiologist used his biased perspective as an advantage in order to provide hope and decrease worry in patients and their families. He explained that he has had a heart condition since childhood, and that it would be hypocritical for him to inhibit a patient from doing something he has done. When considering unbiased information, it is important to note that three of the five cardiologists have children who are of adolescent or young adult age. It could be argued that, because those participants have children in the same age range as their patients, it is unlikely that they could deliver fully unbiased information.

### **Interprofessionalism and Shared Decision-Making**

Building upon an integrative model of shared decision-making in medical settings, Légaré and colleagues (2013) proposed an interdisciplinary model called the interprofessional model for primary care (IP-SDM). Their model consists of three levels: an individual (micro) level, and two healthcare system levels (meso and macro; Légaré et al., 2013). The model is based on the premise that at least two healthcare professionals from different disciplines are in collaboration to achieve shared decision-making with the patient, either at the same time or one after the other (Légaré et al., 2013). In order to achieve IP-SDM, there is a stepwise process involved on the individual (micro) level. Overall, the steps include (a) a decision endpoint being acknowledged with various options, potential risks and benefits being acknowledged, and professionals offering their knowledge and understanding with the patient, (b) an “exchange of information”

regarding the options, (c) a “values clarification” process by which the patient acknowledge his or her values and how those values may impact a decision made, (d) consideration of the practicality of the options, (e) making a decision with help from different individuals, and (f) supporting the patient so the option has a positive impact on the health outcomes the patient values most (Légaré et al., 2013).

Within the healthcare system, the “meso” level includes healthcare teams and organizations, and the “macro” level consists of healthcare policies, social context, and professional organization (Légaré et al., 2013). The healthcare team must develop “collaborative communication that is authentic, constructive, and open, so as to foster mutual trust and respect among team members as well as between the team and the patient” (Légaré et al., 2013, p. 21). For the macro level of the model to be achieved, there must be understanding on the part of healthcare professionals that their roles are either cultivated or inhibited by organizational routines (Légaré et al., 2013). The basic underpinnings of this model emphasize the importance of fostering communication between individuals throughout the decision-making process in order to share knowledge and arrive at a common understanding of the concerns at hand (Légaré et al., 2013).

In regard to interprofessionalism, cardiologists in the current study responded to interview questions addressing their healthcare teams, the typical procedures they follow when referring patients to other professionals, and their perspectives on referring patients to mental healthcare providers. Generally, cardiologist responses varied significantly when asked about who comprises their healthcare teams and what their referral procedures have involved.

In the context of cardiologists' healthcare teams, responses varied due to cardiologists practicing at multiple sites throughout the work week. For example, Dr. Alex's healthcare team consists of himself, a pediatric nurse practitioner, and a registered nurse when working in an outpatient setting, and while in the inpatient setting, the team consists of himself, other attending physicians, physician assistants, residents, social workers, and psychologists. Dr. Barbara, who works full-time in an outpatient office setting, explained that her healthcare team consists of herself and another cardiologist, a licensed nurse practitioner, and a sonographer.

To attain successful collaborative communication between healthcare workers, professionals need to be familiar with each other's expertise, roles, and responsibilities (Légaré et al., 2013). When elaborating further about their healthcare teams, several cardiologists exhibited confusion about whether mental healthcare providers are a part of their teams and, if so, what the mental healthcare providers' roles and expertise are:

So as part of my team, when the kids are in my clinic here, I have a psychologist—she's not a psychiatrist, she's a psychologist—I don't . . . she might have her master's in child psychology. I can call her, like if I know I have a new kid with long QT, or she'll come to my clinic and do [an evaluation] right after I'm done. Then she'll decide if she needs to continue to follow them as an outpatient. (Dr. Alex)

Dr. Alex's hesitation when describing his fellow healthcare team member indicates a level of misunderstanding that may be impeding his ability to engage in successful interprofessional collaboration. On the other hand, Dr. Alex stated that he routinely refers patients to mental healthcare providers, particularly those

who have been newly diagnosed with an illness carrying the risk of sudden death. Interestingly, Dr. Charlie was the only cardiologist to bring up the issue of accessibility of mental health services due to insurance barriers. He also explained that he has only referred patients to other providers for mental health issues “once or twice” in his career. Dr. Evan, when asked about referral sources for mental health issues in patients, said “I would ask the social worker to help with that.”

## Chapter 5: Discussion

### Overall Findings

Overall, the study's results indicate that the five cardiologists who treat adolescent and young adult patients with arrhythmias address alcohol and substance use. The frequency with which cardiologists address the topic varies, in addition to whether parental presence impacts their approaches. Generally, cardiologists seem to be influenced most by their patients' presentations, parental presence, and external factors. When speaking about mental health issues, including alcohol and substance use disorders, cardiologist participants tended to take a somewhat self-deprecating stance, indicating that they do not address those issues "as much as they should." This is an area in which a clinical psychologist, or other qualified mental health professional, could collaborate with cardiologists to improve coordination of care.

Research suggests that establishing an effective level of collaboration with other disciplines requires skilled judgment by physicians (Peek, Baird, & Coleman, 2009). Data from the current study indicated that physicians would be more likely to refer a patient for psychological services if resources were more readily available, or if they had psychology staff on their healthcare teams. Physicians feeling "ill-equipped" or underprepared to deal with mental health issues was a common pattern amongst participants. One cardiologist said that he requires all patients who receive a diagnosis "that carries the risk of sudden cardiac death" to have at least one individual and one family therapy session; however, this was not the norm.

One participant referenced stigmatizing beliefs when asked about this issue, saying, "I certainly wish there were more resources in general. Easier access to referrals,

less of a stigma for people that need the help.” Later in the interview, he said, “I’m sure there is a stigma. Personally, I’m happy for people to get the help if they need it. I try not to really judge when people are actually mentally ill.” Interestingly, the participant with the highest number of years of experience, who also has a family member with an alcohol or substance use disorder, seemed to have different views. She offered her opinion in regard to reasons people use despite knowing it is bad for them:

I think some people have addictive personalities too, and if you don’t have that, then you kind of wonder, you kind of scratch your head somewhat. I would want to know, why would anybody do that to themselves? It’s a little bit of a lack of understanding, I think, trying to figure out why. (Dr. Barbara)

Research suggests that taking a “big picture” perspective, or treating the patient in a holistic manner, can lead to greater collaboration between mental health providers and physicians when caring for patients (Peek et al., 2009).

### **Clinical Implications**

The findings from this study have several implications for patients, parents, and physicians in regard to decision-making and communication. In ideal circumstances of shared decision-making in medical contexts, the roles and rights of both patients and physicians should be defined clearly (Makoul & Clayman, 2006). Thus, physicians should consistently define their roles with their young patients in order to increase transparency in the decision-making process. In the same vein, it is vital for physicians and parents to include young patients in the decision-making process. This can lead to cultivating the patients’ sense of self-efficacy and, ultimately, impact their adherence to

treatment, satisfaction with treatment, and overall investment in treatment (Tariman et al., 2012). It is also essential for physicians to continue to consider their patients holistically when making decisions and treatment recommendations, and to include consideration of quality of life.

Due to cardiologists referencing their desire to have easier access to referrals, or to have mental health professionals as part of their healthcare teams, it is recommended that physicians consult regularly with colleagues in order to embrace the concept of collaboration and to create opportunities to receive interpersonal and professional support with difficult treatment decisions, especially decisions they feel underprepared to make as physicians. Furthermore, given the importance of effective communication between cardiologists, patients, and parents, it is important to integrate enhanced training on alcohol and substance use, as well as other mental health issues, early in their careers.

This study is relevant to the theory and practice of psychology due to the information it provides regarding stressors, challenges, and areas of difficulty in existence with triadic parent-patient-physician relationships. When mental health professionals including psychologists are present on healthcare teams, they can utilize their positions to improve patient adherence to treatment and to improve communication between patients and physicians. Additionally, they can use their positions to provide modeling opportunities for problem-solving, advocacy, and shared decision-making skills.

Given the significance of interdisciplinary collaboration, it is of the utmost importance that clinicians remain aware of several components of their care with patients. Providers must be cognizant of their involvement in macro-level healthcare systems, how

to provide support to patients during decision-making processes, and the roles and responsibilities of other providers. Specifically, it would be beneficial for physicians within an interprofessional model to maintain awareness of the expertise of mental healthcare providers in order to accommodate patient needs.

### **Study Limitations**

Based on the nature of the research design, there are several study limitations. Some of the limitations of the current study relate to external validity, which assesses the confines of the results and how the results will generalize to other settings.

The sample size for this study was small and homogenous; none of the five cardiologists are people of color, and only one of the five is female. Thus, the generalizability of the findings from the study is very limited due to a lack of diverse representation. The specific sample that was used in this study were recruited from the PACES and SADS Foundation databases, from hospital and medical centers' public websites, and by word-of-mouth and snowball sampling techniques. Despite the fact that PACES includes a sizeable number of pediatric electrophysiologists, it does not include all physicians who treat individuals with LQTS, including adults. Although many cardiologists belong to this society and the SADS Foundation database, the findings from the current study may not generalize to cardiologists who vary in region, background, and experience.

Additionally, the small sample size in this study was partly due to a lack of responses from potential participants during the recruitment phase. Letters were sent via e-mail and standard mail to over 100 cardiologists over a 1.5-year period and only three responded. The other two cardiologists were recruited by word-of-mouth. Recruitment



announcements were also posted to social media websites including Facebook, LinkedIn, and Twitter, which yielded no cardiologist participant responses. Cardiologists who responded to the recruitment attempts may be more passionate about the topic of alcohol and substance use. Therefore, they may feel a sense of personal investment in research on the topic, leading them to respond to the recruitment letters. One such example was Dr. Alex, who spoke about a week-long “heart camp” that he oversees each year for individuals aged 8 to 17 with LQTS and other arrhythmias. During the heart camp, children and adolescents engage in informational talks, including one called “Sex, Drugs, and Rock and Roll,” during which the topics of alcohol and substance use are discussed. During the interview with Dr. Alex, he laughed and said, “Well that’s why [I’m] an exception. If you pick any cardiologist, not everyone may do that.”

Another limitation of the current study includes the reliability of the measure used to obtain the data. As the measure was a newly created list of interview questions that had not been tested previously, there was no history or evidence to support the reliability or validity of the questions asked. Additionally, a common issue with self-report is that responses may not accurately reflect participants’ true behaviors, but rather the participants’ perceptions of the manner in which they treat their patients (Kazdin, 2003). Another potential limit is that respondents were aware that the study was being conducted as a psychology dissertation and, thus, this awareness may have primed participants to respond more favorably toward psychological screening, the need for psychological referrals, and the likelihood of referring a patient to an on-staff psychologist. In the same vein, this awareness may have led respondents to respond more favorably toward practice they perceive as psychologically-sound.

Kazdin (2003) indicated that qualitative research is not meant to describe all people; rather, it is meant to expand on the meaning and understanding of experiences held by individuals within a specific context. Additionally, all interviews were conducted by telephone, and the population of participants came from a very specific subset of physicians. These factors limit the generalizability of the findings. Further, participants' states of mind during the time they answered the interview questions cannot be determined; for example, their moods, whether they were tired, or the level of distraction they experienced while answering the interview questions were unclear.

Social desirability leading to response bias may have also played a role in the limitations of the current study. For example, participants may have been more inclined to maximize the positive aspects of their behaviors and experiences and minimize negative aspects. There may have also been variability in the motivation of participants, which could have led to additional response bias, as some participants may have included more information than others in their responses.

Lastly, another limitation associated with qualitative research is related to credibility, also described as the internal consistency of the results (Morrow, 2005). Credibility is known as the believability of the findings; there should be consistency of interpretations made in order to improve understanding of the phenomenon being studied (Kazdin, 2003). Because of the presence of experimenter bias in qualitative research, it is vital to consult with other investigators to identify the level to which the data reflect the key concepts and overall themes identified by the researcher (Kazdin, 2003). Thus, multiple coders were used in order to increase interrater reliability, or dependability of the findings (Morrow, 2005). Nevertheless, it must be noted that each coder has his or

her own perspectives, attitudes, beliefs, and experiences, which could have led to coder bias within interpretation of the data.

### **Future Research**

Future research is necessary in order to further explore the ambiguity associated with LQTS and other arrhythmias, and how this ambiguity impacts treatment of patients affected. With this in mind, and based on the results of the current study, implications for new areas of research include determining whether a uniform protocol for addressing alcohol and substance use in these patients would be efficacious. Cardiologists in this study seemed to express uncertainty about who holds the responsibility in regard to addressing alcohol and substance use issues with patients; future research could address whether an implemented protocol for cardiologists would be beneficial in assisting with distinguishing responsibility. Moreover, a training component for early career cardiologists including clear guidelines may be helpful in establishing roles. This could also be an area of further exploration.

Future research could explore whether physician decision-making is impacted by such factors as number of years of experience. This may be beneficial in implementing psychoeducation protocols for physicians, with level of experience being a factor. Additionally, it would be of interest to explore whether specific personality characteristics of physicians impact their communication styles or perspectives in regard to alcohol and substance use issues. Future research could also investigate the perspectives of children and adolescents and their families regarding physicians' approaches to alcohol and substance use. Patients can be queried about whether they

receive conflicting information from their doctors, what doctors' various recommendations are, and whether they follow their doctors' advice.

Additional research could be done incorporating the more recent national issue of opioid use. It would be of value to examine how physicians' approaches to addressing ] substance use may have changed since the onset of the opioid epidemic in this country, and how the onset of the epidemic may impact opioid use by children and adolescents with arrhythmias. Moreover, future research could incorporate asking physicians whether they have lost patients to drug or alcohol abuse and whether such losses have impacted their approaches to the subject.

A follow-up study might incorporate several changes. First, the researcher should aim to conduct in-person interviews with participants in order to more clearly understand their experiences and to facilitate a more open interview atmosphere. Additionally, after reviewing the interview transcripts, missed opportunities to engage in more in-depth questioning and obtain more information were identified. In future studies, researchers should be prepared to ask follow-up questions in order to increase insight into and deeper understanding of the physician experience, as well as the patient and parent experience from the perspective of the physician.

### References

- Adgey, A. J., Johnston, P. W., & McMechan, S. (1995). Sudden cardiac death and substance abuse. *Resuscitation, 29*(3), 219-221.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*. Washington, DC: Author.
- Andersen, J., Øyen, N., Bjorvatn, C., & Gjengedal, E. (2008). Living with long QT syndrome: A qualitative study of coping with increased risk of sudden cardiac death. *Journal of Genetic Counseling, 17*(5), 489-498.
- Anderson, K., Anderson, L. E., & Glanze, W. D. (2002). *Mosby's medical dictionary*. St. Louis, MO: Mosby.
- Arnett, J. (1992). Reckless behavior in adolescence: A developmental perspective. *Developmental Review, 12*(4), 339-373.
- Auerbach, C., & Silverstein, L. B. (2003). *Qualitative data: An introduction to coding and analysis*. New York, NY: NYU Press.
- Barbosa, C., Cowell, A., Bray, J., & Aldridge, A. (2015). The cost-effectiveness of alcohol screening, brief intervention, and referral to treatment (SBIRT) in emergency and outpatient medical settings. *Journal of Substance Abuse Treatment, 53*, 1-8.
- Barsheshet, A., Dotsenko, O., & Goldenberg, I. (2014). Congenital long QT syndromes: Prevalence, pathophysiology, and management. *Pediatric Drugs, 16*(6), 447-456.
- Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *Qualitative Report, 13*, 544-559.

- Behere, S. P., Shubkin, C. D., & Weindling, S. N. (2014). Recent advances in the understanding and management of long QT syndrome. *Current Opinion in Pediatrics*, 26(6), 727-733.
- Birks, M. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, 13, 68-75.
- Broderick, K. B., Kaplan, B., Martini, D., & Caruso, E. (2015). Emergency physician utilization of alcohol/substance screening, brief advice and discharge: A 10-year comparison. *The Journal of Emergency Medicine*, 49(4), 400-407.
- Bulanda, J. J., Bruhn, C., Byro-Johnson, T., & Zentmyer, M. (2014). Addressing mental health stigma among young adolescents: Evaluation of a youth-led approach. *Health & Social Work*, 73-80. doi:10.1093/hlu008
- Cape, G., Hannah, A., & Sellman, D. (2006). A longitudinal evaluation of medical student knowledge, skills and attitudes to alcohol and drugs. *Addiction*, 101(6), 841-849.
- Chaix, M. A., Koopmann, T. T., Goyette, P., Alikashani, A., Latour, F., Fatah, M., ... & Rioux, J. D. (2016). Novel CALM3 mutations in pediatric long QT syndrome patients support a CALM3-specific calmodulinopathy. *HeartRhythm case reports*, 2(3), 250-254.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician–patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49(5), 651-661.
- Cohen, H., & Britten, N. (2003). Who decides about prostate cancer treatment? A qualitative study. *Family Practice*, 20(6), 724-729.

- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Creswell, J. W., Hanson, W. E., Clark Plano, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The Counseling Psychologist, 35*(2), 236-264.
- De Ponti, F., Poluzzi, E., Cavalli, A., Recanatini, M., & Montanaro, N. (2002). Safety of non-antiarrhythmic drugs that prolong the QT interval or induce torsade de pointes. *Drug safety, 25*(4), 263-286.
- Ehrlich, K. B., Hoyt, L. T., Sumner, J. A., McDade, T. W., & Adam, E. K. (2015). Quality of relationships with parents and friends in adolescence predicts metabolic risk in young adulthood. *Health Psychology, 34*(9), 896.
- Farnsworth, M., Fosyth, D., Haglund, C., & Ackerman, M. (2006). When I go to wake them . . . I wonder: Parental perceptions about congenital long QT syndrome. *Journal of the American Academy of Nurse Practitioners, 18*, 284-290.
- Friedman, N. P., Miyake, A., Altamirano, L. J., Corley, R. P., Young, S. E., Rhea, S. A., & Hewitt, J. K. (2016). Stability and change in executive function abilities from late adolescence to early adulthood: A longitudinal twin study. *Developmental Psychology, 52*, 326-340. Retrieved from <http://psycnet.apa.org>
- Glaser, B., & Holton, J. (2007). Remodeling grounded theory. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 5*(2). doi:10.17169/fqs-5.2.607
- Go, A. S., Mozaffarian, D., Roger, V. L., Benjamin, E. J., Berry, J. D., Blaha, M. J., . . . Turner, M. B. (2013). Heart disease and stroke statistics—2013 update: A report

from the American Heart Association. *Circulation*, 127, e6-e245.

doi:10.1161/CIR.0b013e31828124ad

Grant, B. F., Stinson, F. S., & Harford, T. C. (2001). Age at onset of alcohol use and DSM-IV alcohol abuse and dependence: A 12-year follow-up. *Journal of Substance Abuse*, 13(4), 493-504.

Grella, C. E., Karno, M. P., Warda, U. S., Moore, A. A., & Niv, N. (2009). Perceptions of need and help received for substance dependence in a national probability survey. *Psychiatric Services*, 60, 1068-1074.

Gupta, P. (2014). Caring for a teen with congenital heart disease. *Pediatric Clinics*, 61(1), 207-228.

Guttmacher, S., & Tiersten, D. (2014). Digital health records: A viewpoint on impact on medical practice and potential implications for both communication and future research. *Journal of Communication in Healthcare*, 7(1), 5-7.

Haller, D. M., Meynard, A., Lefebvre, D., Ukoumunne, O. C., Narring, F., & Broers, B. (2014). Effectiveness of training family physicians to deliver a brief intervention to address excessive substance use among young patients: A cluster randomized controlled trial. *Canadian Medical Association Journal*, 186(8), E263-E272.

Hamang, A., Eide, G. E., Nordin, K., Rokne, B., Bjorvatn, C., & Øyen, N. (2010). Health status in patients at risk of inherited arrhythmias and sudden unexpected death compared to the general population. *BMC Medical Genetics*, 11(1), 1.

Hankin, B. L., Young, J. F., Abela, J. R. Z., Smolen, A., Jenness, J. L., Gulley, L. D., . . .

Oppenheimer, C. W. (2015). Depression from childhood into late adolescence:



- Influence of gender, development, genetic susceptibility, and peer stress. *Journal of Abnormal Psychology*, *124*(4), 803-816. Retrieved from <http://psycnet.apa.org>
- Harris, C. R., & Darby, R. S. (2009). Shame in physician–patient interactions: Patient perspectives. *Basic and Applied Social Psychology*, *31*(4), 325-334.
- Holt, S. R., Ramos, J., Harma, M., Cabrera, F., Louis-Ashby, C., Dinh, A., . . . Tetrault, J. M. (2013). Physician detection of unhealthy substance use on inpatient teaching and hospitalist medical services. *The American Journal of Drug and Alcohol Abuse*, *39*(2), 121-129. doi:10.3109/00952990.2012.715703
- Howells, R., & Lopez, T. (2008). Better communication with children and parents. *Paediatrics and Child Health*, *18*(8), 381-385.
- Jackson, E. R., Shanafelt, T. D., Hasan, O., Satele, D. V., & Dyrbye, L. N. (2016). Burnout and alcohol abuse/dependence among U.S. medical students. *Academic Medicine*, *91*(9), 1251-1256.
- Jessor, R. (1991). Risk behavior in adolescence: A psychosocial framework for understanding and action. *Journal of Adolescent Health*, *12*(8), 597-605.
- Kaltman, J. R., Evans, F., & Fu, Y. P. (2018). Re-evaluating pathogenicity of variants associated with the long QT syndrome. *Journal of Cardiovascular Electrophysiology*, *29*(1), 98-104.
- Karnieli-Miller, O., & Eisikovits, Z. (2009). Physician as partner or salesman? Shared decision-making in real-time encounters. *Social Science & Medicine*, *69*(1), 1-8.
- Kazdin, A. E. (2003). *Research design in clinical psychology* (4th ed.). Boston, MA: Allyn & Bacon.

- Kim, S. S., Kaplowitz, S., & Johnston, M. V. (2004). The effects of physician empathy on patient satisfaction and compliance. *Evaluation & the Health Professions, 27*(3), 237-251.
- Klatsky, A. L., Hasan, A. S., Armstrong, M. A., Udaltsova, N., & Morton, C. (2011). Coffee, caffeine, and risk of hospitalization for arrhythmias. *The Permanente Journal, 15*(3), 19.
- Knoche, J. W., Orland, K. M., January, C. T., & Maginot, K. R. (2012). Atrial fibrillation and long QT syndrome presenting in a 12-year-old girl. Case reports in pediatrics, 2012.
- Knopf, A. (2016). Governors unify to recommend opioid crisis strategies. *Alcoholism & Drug Abuse Weekly, 28*(9), 3-4.
- Krishnamoorthy, S., Lip, G. Y., & Lane, D. A. (2009). Alcohol and illicit drug use as precipitants of atrial fibrillation in young adults: A case series and literature review. *The American Journal of Medicine, 122*(9), 851-856.
- Lawoko, S., & Soares, J. J. (2003). Social support among parents of children with congenital heart disease, parents of children with other diseases, and parents of healthy children. *Scandinavian Journal of Occupational Therapy, 10*(4), 177-187.
- Le, K. B., Johnson, J. A., Seale, J. P., Woodall, H., Clark, D. C., Parish, D. C., & Miller, D. P. (2015). Primary care residents lack comfort and experience with alcohol screening and brief intervention: A multi-site survey. *Journal of General Internal Medicine, 30*(6), 790-796.
- Lee, Y. Y., & Lin, J. L. (2010). Do patient autonomy preferences matter? Linking patient-centered care to patient-physician relationships and health outcomes.

*Social Science and Medicine*, 71, 1811-1818.

Légaré, F., Stacey, D., Briere, N., Fraser, K., Desroches, S., Dumont, S., . . . Aubé, D.

(2013). Healthcare providers' intentions to engage in an interprofessional approach to shared decision-making in home care programs: A mixed methods study. *Journal of Interprofessional Care*, 27(3), 214-222.

Lewis, C. E., & Lewis, M. A. (1984). Peer pressure and risk-taking behaviors in children.

*American Journal of Public Health*, 74(6), 580-584.

Lindberg, M., Vergara, C., Wild-Wesley, R., & Gruman, C. (2006). Physicians-in-

training attitudes toward caring for and working with patients with alcohol and drug abuse diagnoses. *Southern Medical Journal*, 99(1), 28-35.

Luna, B., & Wright, C. (2016). Adolescent brain development: Implications for the

juvenile criminal justice system. In K. Heilbrun, D. DeMatteo, & N. E. S. Goldstein (Eds.), *APA handbooks in psychology series: APA handbook of psychology and juvenile justice* (pp. 91-116). Washington, DC: American Psychological Association.

Luoma, J. B., Twohig, M. P., Waltz, T., Hayes, S. C., Roget, N., Padilla, M., & Fisher, G.

(2007). An investigation of stigma in individuals receiving treatment for substance abuse. *Addictive Behaviors*, 32(7), 1331-1346.

doi:10.1016/j.addbeh.2006.09.008

Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making

in medical encounters. *Patient Education and Counseling*, 60(3), 301-312.

- Mancuso, C. A., & Rose, D. N. (1987). A model for physicians' therapeutic decision making. *Archives of Internal Medicine, 147*(7), 1281-1285.  
doi:10.1001/archinte.1987.00370070095014
- McCabe, S. E., Knight, J. R., Teter, C. J., & Wechsler, H. (2005). Non-medical use of prescription stimulants among U.S. college students: Prevalence and correlates from a national survey. *Addiction, 100*(1), 96-106.
- McPherson, C. A., & Rosenfeld, L. E. (1992). Heart rhythm disorders. *Yale University School of Medicine Heart Book, 195*.
- Merriam-Webster, Inc (Ed.). (1993). *Merriam-Webster's medical desk dictionary*. Merriam-Webster.
- Miller, N. S., Sheppard, L. M., Colenda, C. C., & Magen, J. (2001). Why physicians are unprepared to treat patients who have alcohol-and drug-related disorders. *Academic Medicine, 76*(5), 410-418.
- Montagne, M. (2011). Drugs and the media: An introduction. *Substance use & misuse, 46*(7), 849-851.
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52*(2), 250-260.
- Moss, A. J. (2003). Long QT syndrome. *Journal of the American Medical Association, 289*(16), 2041-2044.
- Nagel, A. G., Guarnera, L. A., & Reppucci, N. D. (2016). Adolescent development, mental disorder, and decision making in delinquent youths. In K. Heilbrun, D. DeMatteo, & N. E. S. Goldstein (Eds.), *APA handbooks in psychology series:*

- APA handbook of psychology and juvenile justice* (pp. 117-138). Washington, DC: American Psychological Association. doi:10.1037/14643-006
- Nova, C., Vegni, E., & Moja, E. A. (2005). The physician-patient-parent communication: A qualitative perspective on the child's contribution. *Patient Education and Counseling, 58*(3), 327-333.
- O'Keefe, J. H., Bhatti, S. K., Bajwa, A., DiNicolantonio, J. J., & Lavie, C. J. (2014). Alcohol and cardiovascular health: the dose makes the poison . . . or the remedy. *Mayo Clinic Proceedings, 89*(3), 382-393.
- Pantell, R. H., Stewart, T. J., Dias, J. K., Wells, P., & Ross, A. W. (1982). Physician communication with children and parents. *Pediatrics, 70*(3), 396-402.
- Peek, C. J., Baird, M. A., & Coleman, E. (2009). Primary care for patient complexity, not only disease. *Families, Systems, & Health, 27*(4), 287-302.
- Pelchovitz, D. J., & Goldberger, J. J. (2011). Caffeine and cardiac arrhythmias: A review of the evidence. *The American Journal of Medicine, 124*(284-289).
- Priori, S. G., Wilde, A. A., Horie, M., Cho, Y., Behr, E. R., Berul, C., . . . Tracy, C. (2013). HRS/EHRA/APHRS expert consensus statement on the diagnosis and management of patients with inherited primary arrhythmia syndromes. *Journal of Arrhythmia, 10*(12), 1932-1963.
- Reyna, V. F., & Farley, F. (2006). Risk and rationality in adolescent decision making: Implications for theory, practice, and public policy. *Psychological Science in the Public Interest, 7*(1), 1-44.

- Rohatgi, R. K., Bos, J. M., & Ackerman, M. J. (2015). Stimulant therapy in children with attention-deficit/hyperactivity disorder and concomitant long QT syndrome: A safe combination? *Heart Rhythm*, *12*(8), 1807-1812.
- Rudd, R. A., Aleshire, N., Zibbell, J. E., & Matthew Gladden, R. (2016). Increases in drug and opioid overdose deaths—United States, 2000–2014. *American Journal of Transplantation*, *16*(4), 1323-1327.
- Schwartz, P. J., Stramba-Badiale, M., Crotti, L., Pedrazzini, M., Besana, A., Bosi, G., . . . Spazzolini, C. (2009). Prevalence of the congenital long-QT syndrome. *Circulation*, *120*(18), 1761-1767. doi:10.1161/CIRCULATIONAHA.109.863209
- Sickel, A. E., Seacat, J. D., & Nabors, N. A. (2014). Mental health stigma update: A review of consequences. *Advances in Mental Health*, *12*(3), 202-215.
- Sicouri, S., Antzelevitch, D., Heilmann, C., & Antzelevitch, C. (1997). Effects of sodium channel block with mexiletine to reverse action potential prolongation in in vitro models of the long QT syndrome. *Journal of Cardiovascular Electrophysiology*, *8*(11), 1280-1290.
- Steinberg, L. (2007). Risk taking in adolescence: New perspectives from brain and behavioral science. *Current directions in psychological science*, *16*(2), 55-59.
- Stivers, T. (2012). Physician–child interaction: When children answer physicians’ questions in routine medical encounters. *Patient Education and Counseling*, *87*(1), 3-9.
- Street Jr., R. L. (1991). Information-giving in medical consultations: The influence of patients’ communicative styles and personal characteristics. *Social Science & Medicine*, *32*(5), 541-548.

- Suyama-Chishaki, A., Miyazono, M., Tsuchihashi-Makaya, M., Chishaki, H., Inoue, S., Mukai, Y., . . . Kubo, C. (2007). Quality of life and psychological factors in patients with implantable cardioverter defibrillator. *Journal of Arrhythmia*, 23(4), 269-276. doi:10.1016/S1880-4276(07)80031-7
- Tariman, J. D., Berry, D. L., Cochrane, B., Doorenbos, A., & Schepp, K. (2012). Physician, patient, and contextual factors affecting treatment decisions in older adults with cancer: A literature review. *Oncology Nursing Forum*, 39(1), E70-E83. doi:10.1188/12.ONF.E70-E83
- Tates, K., Elbers, E., Meeuwesen, L., & Bensing, J. (2002). Doctor-parent-child relationships: A 'pas de trois.' *Patient Education and Counseling*, 48(1), 5-14.
- Tetnowski, J. A., & Damico, J. S. (2001). A demonstration of the advantages of qualitative methodologies in stuttering research. *Journal of Fluency Disorders*, 26, 17-42.
- Thornton, J. D., Lyvers, E., Scott, V. G. G., & Dwibedi, N. (2017). Pharmacists' readiness to provide naloxone in community pharmacies in West Virginia. *Journal of the American Pharmacists Association*, 57(2), S12-S18.
- Van Boekel, L. C., Brouwers, E. P., Van Weeghel, J., & Garretsen, H. F. (2013). Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: Systematic review. *Drug and Alcohol Dependence*, 131(1), 23-35.
- Wagner, S. M., Lukassen, P., & Mahlendorf, M. (2009). Misused and missed use: Grounded theory and objective hermeneutics as methods for research in industrial

marketing. *Industrial Marketing Management*, 1-11.

doi:10.1016/j.indmarman.2008.05.007

Whitlock, E. P., Polen, M. R., Green, C. A., Orleans, T., & Klein, J. (2004). Behavioral counseling interventions in primary care to reduce risky/harmful alcohol use by adults: A summary of the evidence for the U.S. Preventive Services Task Force. *Annals of Internal Medicine*, 140(7), 557-568.

Wray-Lake, L., Syvertsen, A. K., & Flanagan, C. A. (2016). Developmental change in social responsibility during adolescence: An ecological perspective. *Developmental Psychology*, 52(1), 130.

Zuckerman, M. (1996). Item revisions in the sensation seeking scale form V (SSS-V). *Personality and Individual Differences*, 20(4), 515. doi:10.1016/0191-8869(95)00195-6



## Appendix A

### Letter Used for Cardiologist Recruitment via Standard Mail, E-Mail, and Social

#### Media Announcement

Dear Dr. XX,

My name is Nicole Stewart and I am a 4<sup>th</sup> year student in the Doctor of Psychology in Clinical Psychology program at Philadelphia College of Osteopathic Medicine, under the mentorship of Stephanie H. Felgoise, Ph.D., ABPP. I am recruiting **licensed cardiologists like yourself who treat adolescents and young adults for heart rhythm disorders to participate in a one-hour or less phone or in-person interview to discuss alcohol and substance use in their patient population.** Your participation will provide a better understanding of the beliefs and practices of cardiologists in regard to their approach and treatment of adolescent and young adult patients with heart rhythm disorders and alcohol and substance use. Your participation and information provided will be held confidential and reported anonymously in aggregate with other cardiologists' data. Upon completion, you will receive a \$10 gift card towards Starbucks Coffee.

If you are interested in participation, please reply to [LOTStudies@pcom.edu](mailto:LOTStudies@pcom.edu) with your contact information and best times for availability. You will be contacted within three days of your reply. Your consideration and assistance is greatly appreciated. If you have any questions about this research, you may contact my dissertation chair, Dr. Stephanie Felgoise, Ph.D., ABPP, [stephanief@pcom.edu](mailto:stephanief@pcom.edu), or myself at (516) 652-6396 or [nicolest@pcom.edu](mailto:nicolest@pcom.edu).

Sincerely,

Nicole Stewart, M.S.W., M.S.

Philadelphia College of Osteopathic Medicine

## Appendix B

### List of Questions Used in Cardiologist Interviews

#### Demographic Questions

- Are you board certified in cardiology?
- Did you attend a homeopathic or osteopathic medical school?
- Where do you practice?
- For how many years have you been practicing medicine?
- Is anyone in your family diagnosed with LQTS or another rhythm disorder?
- Do you have children that are adolescent or young adult?
- Do you have any background of mental health or substance abuse training?
- Do you have any family members or close friends who were diagnosed with an alcohol or substance use disorder?

#### Main Questions

##### General (1)

- a. Do you consider yourself a rhythm specialist?
- b. How many years of experience do you have as a rhythm specialist?
- c. Could you estimate the percentage of patients diagnosed with rhythm disorders that you follow when considering the number of your total patients?
- d. How often do you see patients you follow for LQTS or another rhythm disorder?
- e. Of those who have LQTS or another rhythm disorder, how many patients are adolescent or young adult (13-24)?

##### Alcohol/Substance Use

2. Do you approach the subject of alcohol, drug, caffeine, or nicotine consumption when you discuss an adolescent or young adult patient's diagnosis?
  - a. If yes:
    - i. What may trigger you inquiring about the topic?
    - ii. What screens do you use?
    - iii. Where in the patient's "timeline" do you address it? I.e. at the patient's first appointment, every appointment, every other appointment? How often do you inquire?
    - iv. Is the patient's parent present?
    - v. Is your decision to address this topic impacted by any of the following? The patient's age, whether the parent is present, the subtype of LQTS the patient has?
      1. At what age would you first bring this up to a patient? Why that age range versus another one?
    - vi. What is the conversation like if the patient says they do drink alcohol/use nicotine/drugs/caffeine? If they say they don't?

- vii. What would you say to me if I was your patient and you knew I was using substances, caffeine, or nicotine?
    - viii. Who is part of your healthcare team?
  - b. If no:
    - i. What are the reasons behind this choice?
    - ii. What are the barriers?
    - iii. What makes this process challenging?
- 3. Do you screen for depression, anxiety, or other mental health diagnoses?
  - a. What do you do for these patients?
- 4. By whom else do you expect adolescents will be screened or educated about alcohol and substance abuse?
  - a. If another provider is addressing this, do you check in with the patient about it? How often?
- 5. What has influenced your approach to this topic? I.e. your clinical experience, literature, lawsuits?
- 6. What would you think would be contributing to alcohol or substance use choices in patients who should know it is bad for them?
- 7. What guides your decision-making in regard to addressing this topic with patients?
- 8. How do you view patients who experience alcohol or substance use disorders? How do you view patients who use caffeine and/or nicotine?
- 9. Is there anything else I haven't asked you about this topic that I should have?