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Adolescence and Cardiac Channelopathies: Predicting Engagement in High-Risk Behavior

By Lauren Lucente

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Psychology

May 2018

**PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY**

Dissertation Approval

This is to certify that the thesis presented to us by Lauren Lucente
on the 2nd day of May, 2018, 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

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Abstract

The purpose of the current study was to explore the type and frequency of engagement in low to high-risk behaviors in adolescents with cardiac channelopathies. Additionally, predictive factors of engagement in developmentally typical behaviors were explored. Individuals ages 13-22 (female = 84.6%; average age = 19.53) with cardiac channelopathies (n = 10) and without any chronic health conditions (n = 4) completed a series of questionnaires examining self-reported quality of life, illness perceptions, problem solving, and risk-taking behaviors. Findings demonstrated that adolescents with cardiac conditions believe that their conditions are controllable, and they experience a moderate amount of medically-related symptoms. Adolescents with and without cardiac channelopathies self-reported similar levels of quality of life. Adolescents with cardiac channelopathies had significantly better overall social problem solving skills than the control condition; in addition, they had better problem identification, solution evaluation, and reorganization skills than participants without cardiac channelopathies. Whether certain factors are predictive of engagement in risk-taking behaviors was unable to be examined, due to small sample size. There were no differences in risk-taking behaviors between participants with and those without cardiac channelopathies. However, participants with cardiac channelopathies self-reported engagement in behaviors that can impact their health. Future studies should continue to examine risk-taking within this medical population and identify variables that are predictive of risk-taking.

Keywords: Risk-taking, adolescents, cardiac channelopathies, social problem solving, quality of life, illness representations

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ADOLESCENCE AND CARDIAC CHANNELOPATHY

Chapter 1: Introduction

Statement of the Problem

Adolescents with chronic conditions have to navigate challenging developmental tasks in addition to adjusting to their medical conditions (Caleshu et al., 2016; Christie & Viner, 2005; Gortmaker, Walker, Weitzman, Sobol, & Arthur 1990; Michaud, Suris, & Viner, 2004; Williams, Holmbeck, & Greenley, 2002). Not only do chronically ill adolescents have to tolerate their own emotional distress related to their conditions, they must also simultaneously cope with medical concerns and emotional reactions of their family members and friends (Caleshu et al., 2016; Gortmaker et al., 1990). The compounding impact of having to cope with psychosocial and physiological factors associated with chronic illness, while also navigating developmental tasks, can result in increased distress and difficulty with daily functioning (Christie & Viner, 2005; Gortmaker et al., 1990; Michaud et al., 204). Typical developmental tasks during adolescence focus on establishing peer relationships and developing a sense of self (Christie & Viner, 2005; Gortmaker et al., 1990; Michaud et al., 2004).

Adolescents may engage in a range of low to high risk behaviors to help them achieve autonomy, determine their personal values, and obtain social acceptance (Christie & Viner, 2005; Gortmaker et al., 1990; Michaud et al., 2004). According to Gullone and colleagues (2000), developmentally-expected behaviors can range from lower risk (e.g., bungee jumping) to higher risk (e.g., illicit drug use, driving above the speed limit, and engaging in unsafe sexual encounters) (Gullone et al., 2000). Although lower risk behaviors tend to be associated with positive outcomes (e.g., pleasant feelings and social

connectedness), any risk-taking behavior can result in negative consequences (Britto et al., 1998; Dobbels, Decorte, Roskams, & Damme-Lombaerts, 2010; Donovan, Jessor, & Costa, 1991; Gullone & Moore, 2000; Gullone, Moore, Moss, & Boyd, 2000; Moore & Gullone, 1996; Nylander, Seidel, & Tindberg, 2014; Simons, McCormick, Mee, & Blount, 2009). Even though engagement in a range of low to high-risk behaviors is commonplace during adolescence, adolescents with chronic conditions who engage in any variety of these behaviors present unique treatment considerations for health care providers (Christie & Viner, 2005; Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005; Gortmaker et al., 1990; Nylander et al., 2014; Simons et al., 2009; Williams et al., 2002). Specifically, healthcare providers need to assess, monitor, and concurrently manage patients' medical conditions and their engagement in developmentally typical behaviors that range in associated risk (Gortmaker et al., 1990; Simons et al., 2009). If these multiple factors are not considered, patients' health may be compromised and result in negative outcomes ranging from slower recovery time to death (Gortmaker et al., 1990; Simons et al., 2009; Williams et al., 2002).

Adolescents with cardiac channelopathies, occurring in 1 to every 2,000 to 3,000 persons, are a particularly high-risk medical population because the consequences that can occur as a result of engagement in developmentally typical behaviors can interact negatively with the pathology of these conditions, further inflating the already high-risk nature of this disorder (Modell & Lehmann, 2006; Schwartz et al., 2009). Patients with channelopathies are considered to be a high-risk medical population because these patients have a type of genetic cardiac condition (e.g., Long QT Syndrome, Brugada

Syndromes, Short QT Syndrome, and Catecholaminergic Polymorphic Ventricular Tachycardia) that results in dysfunctional ion channels in the heart, causing abnormal life-threatening cardiac arrhythmias (Behere & Weindling, 2015). Thus, these patients are vulnerable to sudden cardiac arrest and death (Linder et al., 2013; Modell & Lehmann, 2006). Further, cardiac channelopathies are particularly insidious because many individuals are asymptomatic prior to their first sudden cardiac arrest (Modell & Lehmann, 2006). As with other chronically ill patients, adolescents with cardiac channelopathies are prescribed complex medical regimens that impose many restrictions upon the types of activities in which they can participate (Harvard Health Letter, 2008; Zeigler & Decker-Walters, 2010). Consequently, these patients are faced with the dilemma of following their restrictions and resisting engagement in behaviors and activities with their peers or of ignoring their restrictions and participating in activities that could potentially result in dire consequences (Harvard Health Letter, 2008; Linder et al., 2013; Modell & Lehmann, 2006; Zeigler & Decker-Walters, 2010).

Medical adherence or following treatment recommendations prescribed by one's medical provider (e.g., refraining from engaging in restricted behaviors or taking medication as prescribed) is quite difficult for adults, and likely even more difficult for adolescents who view these restrictions or medical recommendations as impeding their social acceptance and independence (Andersen, Oyen, Bjorvatn, & Gjengedal, 2008; Caleshu et al., 2016; Czosek et al., 2015; Haynes, 1979; Sears, Amant, & Zeigler, 2009; Sears, Burns, Handberg, Sotile, & Conti, 2001). For medical populations, the risk of not following medical regimens provided by healthcare providers poses substantial risk; thus,

medical non-adherence is considered an extremely high-risk behavior comparable to substance use, risky sexual behaviors, and delinquent actions (Rapoff, 2009; Rapoff, 2006; Rapoff, 1998). Unlike other chronically ill adolescents, adolescents with cardiac channelopathies often have additional restrictions that require them to refrain from engaging in many benign activities because participation in activities that pose little risk of detrimental consequences in healthy individuals can trigger lethal arrhythmias or compromise the integrity of life saving medical devices in these patients (Andersen et al., 2008; Harvard Health Letter, 2008; Zareba & Cygankiewicz, 2008; Zeigler & Decker-Walters, 2010). For example, some patients are not allowed to engage in any competitive sports, in activities that include bodily contact, or in watersports (Aleong, Milan, & Ellinor, 2007; Behere & Welding, 2015; Goldenberg, Zareba, & Moss, 2008; Zareba & Cygankiewicz, 2008). Despite the high risk that adolescents with cardiac channelopathies will engage in medical non-adherence, and subsequently increase their propensity for poor treatment efficacy and detrimental physiological effects, the rate of medical non-adherence within the population is currently unknown.

Adolescents with cardiac channelopathies will likely face the dilemma of deciding whether or not to engage in low and high-risk developmentally typical behaviors (Hollis & Morgan, 2001; Michaud et al., 2004; Reaman et al., 1993; Suris, Michaud, Akre, & Sawyer, 2008). Deciding to refrain from engaging in these behaviors may be viewed by patients as impeding their progress through this developmental stage and may, therefore, tempt some of these patients to participate in behaviors that can negatively interact with the pathology of their cardiac channelopathy (Harvard Health Letter, 2008). For example,

adolescent patients who experiment with substances are at risk for experiencing life-threatening consequences because many drugs alter the normal electrical rhythm of the heart and induce an atypical heart rhythm (Harvard Health Letter, 2008; Koskinen & Kupari, 1992; O'Connor et al., 2005; Wannamethee & Shaper, 1992). Despite the likelihood of some of these patients engaging in behaviors that pose a threat to their well-being, the types of behaviors and the frequency with which these individuals engage in them has yet to be determined (Hollis & Morgan, 2001; Michaud et al., 2004; Reaman et al., 1993; Suris et al., 2008).

Similar to other chronically ill adolescents, those with cardiac channelopathies will likely be tempted to engage in medically restricted and low and high-risk behaviors during their progression through this developmental stage (Bender, 2006; Bucks et al., 2009; Eatock & Baker, 2007; Frauenknecht & Black, 1995; Reynolds, Broadbent, Ellis, Gamble, & Petrie, 2007; Sawyer et al., 2001). Consequently, they may increase their risks of negative health outcomes because their actions may compromise the efficacy of their treatments (Beery, Smith, Kudel, & Knilans, 2011; Beresford & Sloper, 2003). To help prevent derailment of medical treatment in adolescents with chronic conditions, research studies have examined and identified specific variables that influence adolescents' engagement in risk taking behaviors and medical non-adherence (Beery et al., 2011; Beresford & Sloper, 2003). Patients' quality of life, social problem solving abilities, and beliefs about the chronicity, severity, and duration of illness (e.g. illness representations) are variables that can either be protective or can increase patients' risk of engaging in risk behaviors (Bender, 2006; Bucks et al., 2009; Eatock & Baker, 2007;

Frauenknecht & Black, 1995; Reynolds et al., 2007; Sawyer et al., 2001). Although these factors have been examined in adolescents with various chronic illnesses, there is a paucity of research examining how the identified factors impact non-adherence and risk taking behaviors that pose a risk to the health of adolescents with cardiac channelopathies.

Research Question

1. How often and to what extent do adolescents with cardiac channelopathies, compared with their healthy peers, engage in developmentally typical behaviors that could potentially pose a threat to their well-being, (e.g., substance use, sexual risk taking, delinquent behaviors, and medical non-adherence)?
2. What factors (e.g. illness representations, quality of life, and social problem solving) are predictive of engagement in problematic health behaviors in adolescents with cardiac channelopathies?

Literature Review

Overview of chronic conditions in adolescents. Health in adolescents is typically defined as those individuals having adequate physiologic energy to maintain satisfactory physical and psychosocial functioning so that they can participate in developmentally typical activities, such as school, acting classes, and soccer practice (Pantell & Lewis, 1987; Perrin et al., 1993). Chronic illness or a chronic medical condition is often defined as the presence of an illness persisting for three or more

months; this condition typically does not resolve and requires frequent medical observation, treatment, and behavioral management interventions (Compass, Jaser, Dunn, & Rodriguez, 2012; Mokkink, Van der Lee, Grootenhuis, Offringa, & Heymans, 2008; Perrin et al., 1993; Stanton, Revenson, & Tennen, 2007; Williams et al., 2002).

Approximately 20-31% of children and adolescents in the United States are diagnosed with a chronic condition (Blumberg et al., 2012; Sexson & Madan-Swain, 1995). Many adolescents with chronic medical conditions are at risk for experiencing acute and long-term consequences attributable to their illnesses, potentially impacting their day-to-day living (Blumberg et al., 2012; Compass et al., 2012; Mokkink et al. 2008; Nylander et al., 2014; Perrin et al., 1993; Schmidt, Petersen, & Bullinger, 2003; Stanton et al., 2007; Stein & Silver, 2002; Van Cleave, Gortmaker, & Perrin, 2010; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007; Williams et al., 2002). However, it is important to note that the extent to which patients' chronic conditions impact their daily life varies because some patients' medical conditions result in the experience of little to no daily symptoms, yet other conditions trigger many severe, constant symptoms (Caleshu et al., 2016; Gortmaker et al., 1990; Varni et al., 2007). Although individuals with cardiac channelopathies tend to experience few or minor symptoms associated with their disorders, they still meet the criteria for a chronic illness (Caleshu et al., 2016; Mokkink et al., 2008). Therefore, the term chronically ill will be utilized throughout the manuscript.

General declines in physical and psychosocial functioning in adolescents with chronic conditions. Although functional impairment can vary greatly across medical disorders, there are physiological and psychosocial declines common across all chronic medical conditions, such as type 1 diabetes and asthma (Gortmaker et al., 1990; Pless, Power, & Peckham, 1993; Varni, Limbers, & Burkwickle, 2007; Yeo & Sawyer, 2005). Some individuals with chronic conditions experience a reduction in their physical functioning attributable to physiological symptoms, such as pain and fatigue, associated with their medical conditions (Gortmaker et al., 1990; Varni et al., 2007). In addition, chronically ill adolescents commonly report unsatisfactory social relationships because their conditions or associated symptoms often prevent them from interacting with and participating in activities and events with their same aged peers (Gortmaker et al., 1990; Kashikar-Zuck et al., 2007; Kendall et al., 2001; Varni et al., 2007; Zeigler & Decker-Walters, 2010). Adolescents with chronic medical conditions typically experience a decline in their academic performances, which is often attributable to numerous illness-related school absences that impede learning by reducing exposure to and opportunities for acquisition of the subject matter (Compass et al., 2012; Gortmaker et al., 1990; Sexon & Madan-Swain, 1995; Varni et al., 2007).

Emotional impairment in adolescents with chronic health conditions. Many studies have established that adolescents with chronic medical conditions often self-report decreased quality of life (Compass et al., 2012; Gortmaker et al., 1990; Nylander et al., 2014; Stuber & Shemesh, 2006; Varni et al., 2007). A study examining 2500 adolescent patients with a variety of chronic health conditions (e.g., asthma, type 1

diabetes, cardiac conditions, and abdominal pain) concluded that chronically ill adolescents have not only an increased risk of reduced overall quality of life, but also of reduced emotional, school, and social functioning (Varni et al., 2007). Specific to emotional functioning, symptoms associated with depression and anxiety are commonly self-reported mental health concerns in adolescents with chronic medical conditions (Compass et al., 2012; Gortmaker et al., 1990; Nylander et al., 2014; Stuber & Shemesh, 2006; Varni et al., 2007). Adolescents with chronic conditions self-reported rates of depression higher than that of their peers without these chronic conditions (Gortmaker et al., 1990). In fact, Erickson and colleagues (2005) identified that adolescents with chronic conditions, defined as having a physical/health condition that makes it hard for an adolescent to do the same things as their peers (e.g., activities, school, and eating), are 1.8 times more likely to experience suicidal ideation and 3.7 times more likely to attempt suicide than adolescents without a chronic condition (Erickson, Patterson, Wall, & Neumark-Sztainer, 2005). Similar to adolescents with other chronic medical conditions, adolescents with cardiac channelopathies may also be vulnerable to reduced physical, psychosocial, and behavioral functioning because they experience unwanted side effects associated with their medical conditions (e.g., fear associated with how their conditions with influence their futures) and treatment (e.g., fatigue associated with medication) (Gortmaker et al., 1990; Varni et al., 2007).

Behavioral impairment in adolescents with chronic medical conditions. Similarly, adolescents with chronic health conditions tend to have a greater propensity for engaging in problematic or unhealthy behaviors, such as not following parental requests or having arguments with peers (Dickinson & O'Reilly, 2004; Erikson et al., 2005; Gortmaker et al., 1990; Nylander et al., 2014; Piquart & Shen, 2011; Suris & Parera, 2005; Zeigler & Decker-Walters, 2010). In fact, Gortmaker and colleagues (1990), who surveyed the impact of chronic conditions on risk behavior among 11,699 adolescents, found that the presence of a chronic condition during adolescence (e.g., congenital cardiac conditions, asthma, diabetes, epilepsy, and arthritis) is a significant risk factor for participation in problematic and high-risk behaviors independent from socioeconomic status, demographic variables, and characteristics of their household (Gortmaker et al., 1990). In fact, rates for problematic behaviors were 1.4 times higher for adolescents with chronic medical conditions (Gortmaker et al., 1990).

Whether or not adolescents with cardiac channelopathies are also at increased risk for engagement in problematic health behaviors is uncertain. Although Gortmaker and colleagues (1990) determined that this increased risk includes children and adolescents with congenital heart conditions, the number of participants with congenital cardiac conditions included in this study was small ($n = 8$) (Gortmaker et al., 1990). Further, Karsdorp and colleagues (2007) explored this association in individuals with congenital heart conditions and found confounding results, suggesting that having a congenital heart condition is not directly associated with an increased risk for behavior problems (Karsdorp, Everaerd, Kindt, & Mulder, 2007). Thus, whether or not this notion applies to

adolescents with cardiac channelopathies needs to be explored further .

Overview of cardiac channelopathies. Cardiac channelopathies are a group of cardiac disorders, both genetic and acquired, that increase individuals' risk for experiencing sudden death as a result of occurrences of lethal arrhythmias or cardiac disturbances attributable to dysfunctional ion channels within the heart (Abriel & Zaklyaminsaya, 2013; Chockalingam & Wilde, 2012; Goldenberg et al., 2008; Krahn, Sanatani, Gardner, & Arbour, 2013; Marban, 2002; Sanatani, Gardner, & Arbour, 2013). The prevalence of these disorders ranges from 1 in every 2,000 to 1 in every 3,000 persons (Schwartz et al., 2009). However, these rates may be an underestimate because many individuals are misdiagnosed, most commonly as suffering from epilepsy, or are undiagnosed prior to death from sudden cardiac arrest (Abriel & Zaklyaminsaya, 2013; Krahn et al., 2013).

Cardiac channelopathies account for approximately one-third of unexplained sudden cardiac death (SCD) cases (Behere & Weindling, 2015; Chockalingam & Wilde, 2012). SCD is defined as death occurring acutely after the onset of cardiac symptoms (Chockalingam & Wilde, 2012; Ellison, 2015). Commonly, children and adolescents experience SCD within minutes of the onset of cardiac symptoms (Ellison, 2015). Approximately two-thirds of survivors of sudden cardiac arrest are subsequently diagnosed with a channelopathy condition (Behere & Weindling, 2015). Sudden cardiac arrest (SCA) is defined as an aborted SCD episode due to successful resuscitation of a patient with the use of an external defibrillation device or other emergency medical interventions (Chockalingam & Wilde, 2012).

Common features of cardiac channelopathies. Although each cardiac channelopathy has distinct features, these disorders have similar clinical presentations and modalities of treatment (Abriel & Zaklyaminsaya, 2013; Behere & Weindling, 2015; Chockalingam & Wilde, 2012; Perez et al., 2005). Presenting symptoms common across cardiac channelopathies include syncope or loss of consciousness, SCA, and SCD (Chockalingam & Wilde, 2012). Less commonly reported presenting symptoms associated with this group of disorders include palpitations, breath-holding spells, and seizure-like episodes (Chockalingam & Wilde, 2012). The most prevalent cardiac channelopathies are Long QT Syndrome, Brugada Syndrome, Catecholaminergic Polymorphic Ventricular Tachycardia, and Short QT Syndrome (Abriel & Zaklyaminsaya, 2013; Behere & Weindling, 2015; Chockalingam & Wilde, 2012; Perez et al., 2005).

Aspects of treatment common across all cardiac channelopathies. Although specific aspects of treatment recommendations may vary within each channelopathy, there are global treatment recommendations that are common across all of the channelopathy disorders (Abriel & Zaklyaminsaya, 2013; Behere & Weindling, 2015; Chockalingam & Wilde, 2012; Perez et al., 2005; Zipes et al., 2005). Most adolescents with channelopathies receive extensive medical restrictions from their cardiologists that stipulate specific behaviors or activities that must be avoided to reduce the risk of lethal arrhythmias (Ackerman et al., 2015; Andersen et al., 2008; Zipes et al., 2015; Zipes et al., 2005). The specific restrictions for each patient may vary because these recommendations are generally based on various factors, including provider preferences, the pathology of

the specific disorder, patients' active and past symptoms, and individuals' histories of SCA (Andersen et al., 2008). Generally, all channelopathy patients are restricted from taking medications that can interact with the heart's electrical rhythm, such as antihistamines, stimulants, and some antibiotics (Harvard Health Letter, 2008). In addition, patients are told to refrain from using illegal substances (e.g. cocaine) and legal substances (e.g., energy drinks) that can disrupt the normal rhythm of the heart (Harvard Health Letter, 2008).

General restrictions for physical activities and sports. General recommendations for physical activities and sports for all individuals with cardiac channelopathies are listed in the Task Force 10 paper published by The American Heart Association and the American College of Cardiology. The following recommendations for physical activities and sports are suggested for anyone with a suspected or diagnosed cardiac channelopathy: 1) the individual receives a comprehensive evaluation that should be completed by a physician who specializes in heart rhythm disorders or genetic cardiology; 2) restriction from all competitive sports until a full evaluation has been completed; the family has a well-developed understanding of the cardiac condition and risks; a treatment regimen has been enacted, and the individual has had no symptoms for a three-month time period; 3) individuals with asymptomatic cardiac channelopathies with a genotype-positive/phenotype-negative disorder are permitted to participate in competitive sports if they avoid medications that interfere with the individual's heart rhythm, avoid dehydration and training induced heat exhaustion/stroke, carry an AED as part of their sports gear, and have an established emergency action plan in place

(Ackerman et al., 2015).

General Recommendations for adolescent patients with ICDs. General recommendations for physical activities in individuals with ICDs have been outlined in the Task Force 9 paper, published by the American Heart Association and American College of Cardiology (Zipes et al., 2015). Outlined recommendations include: 1) individuals with ICDs can participate in the same types of physical activities and sports as individuals without ICDs if they have been properly diagnosed and clinically profiled; 2) the potential risk/benefits associated with participation in physical activity and sports are discussed with the individual; 3) individuals can participate in any IA class competitive sports (billiards, bowling, cricket, curling, golf, and riflery) if they have not needed their device to correct their heart rhythm in the past 3 months; 4) individuals may be eligible to participate in competitive sports classified outside of the IA category if their device has not needed to correct the heart rhythm in the past 3 months and 5) consideration of participation in sports outside of the IA category should include risk/benefit discussions with the individuals, specific to the likelihood of experiencing either an inappropriate or appropriate shock, as well as the likelihood of the ICD being damaged during a physical activity or sport (Zipes et al., 2015).

Additionally, some patients with ICDs/pacemakers must avoid certain medical procedures because some medical equipment can cause device malfunction (Navaratnam & Dublin, 2011). In fact, some medical procedures can cause patients' ICDs to inappropriately shock a patient's heart even when it is in a normal rhythm (Navaratnam & Dublin, 2011). For example, some patients need to avoid MRIs because the magnetic

field produced by the machine can cause their devices to misfire (Navartnam, & Dublin, 2011; Stone & Apinis, 2009). Inappropriate shocks are highly painful and can be lethal (Andersen et al., 2008). Other recommendations enacted to protect the integrity of patients' ICDs/pacemakers include regular follow-up appointments for device interrogation, annually for ICDs and every three months for pacemakers (Cohen et al., 2001; Navaratnam & Dublin, 2011; Stone & Apinis, 2009). Patients who do not have their devices inspected regularly are at higher risk for negative health consequences attributable to technical problems, such as a dead battery (Navaratnam & Dublin, 2011).

Characteristics and treatment recommendations specific to long QT

syndrome. Long QT syndrome (LQTS) is a cardiac disorder characterized by ion channel malfunction that leads to an increased propensity for ventricular tachycardia which can subsequently result in sudden death (Aleong et al., 2007; Algarra et al., 2011; Andersen et al., 2008; Brugada, 2011; Brugada, Brugada, & Brugada, 1998; Goldenberg et al., 2008; Modell & Lehmann, 2006). Genetic forms of LQTS are rare and occur in 1 in every 2500 children (Brugada, 2011; Harvard Health Letter, 2008). Currently there are 14 types of LQTS with the most common types being LQTS 1, LQTS 2, and LQTS 3 (Aleong et al., 2007; Behere & Weindling, 2015; Goldenberg et al., 2008). Occurrences of dangerous cardiac arrhythmias can be triggered by emotional excitement in individuals with all types of LQTS. Individuals with LQTS have additional triggers for lethal arrhythmias; these include exercise, with most episodes occurring when patients are swimming, diving, or are suddenly immersed in water (Aleong et al., 2007; Behere & Weindling, 2015; Goldenberg et al., 2008; Zareba & Cygankiewicz, 2008). In LQTS 2,

potentially lethal arrhythmias are frequently triggered by loud noises (e.g., alarm clocks or ringing telephones) or by the individual being otherwise startled, and in LQTS type 3, episodes commonly occur during rest or sleep (Aleong et al., 2007; Behere & Weindling, 2015; Goldenberg et al., 2008).

The course of treatment for LQTS varies and often depends on patients' current symptoms and histories of SCA (Aleong et al., 2007; Behere & Weindling, 2015).

Patients who have not experienced arrhythmias or SCA, or who are asymptomatic at the time of treatment, begin a prophylactic medication regimen consisting of daily doses of beta-blockers (Aleong et al., 2007; Behere & Weindling, 2015). Patients who are symptomatic at the time of treatment or have survived SCA often undergo surgery to have ICD/pacemakers surgically placed into their chests (Behere & Weindling, 2015). ICDs/pacemakers correct lethal arrhythmias by pacing the heart rhythm or shocking the heart back into a normal rhythm through leads surgically inserted into the heart's chambers (Aleong et al., 2007; Behere & Weindling, 2015). Some patients with ICDs/pacemakers will be required to take daily doses of beta-blockers in addition to having their implanted ICD/pacemaker (Aleong et al., 2007; Algarra et al., 2011). Most patients receive a list of medical restrictions that indicate physical activities (e.g., competitive sports) and medications (e.g., antibiotics and stimulants) that need to be avoided to reduce the risk of inducing prolonged QT waves (Aleong et al., 2007; Chockalingam & Wilde, 2012; Ellison, 2015; Zareba & Cygankiewicz, 2008).

Specific physical activity restrictions, in addition to those specified previously for individuals with LQTS, are listed in the Task Force 10 paper published by The American

Heart Association and the American College of Cardiology (Ackerman et al., 2015). The specific guidelines include: 1) individuals with symptomatic or electrocardiographically manifest LQTS, having a QT interval of >470ms (for males) and >480ms (for females), may be eligible to participate in competitive sports if the individuals have been asymptomatic for at least 3 months, and 2) individuals with previously symptomatic LQTS should avoid competitive swimming activities (Ackerman et al., 2015).

Characteristics and treatment recommendations specific to catecholaminergic polymorphic ventricular tachycardia. Catecholaminergic polymorphic ventricular tachycardia (CPVT) is a rare genetic cardiac channelopathy characterized by sudden episodes of lethal ventricular tachycardia in individuals with normal heart structures (Abriel & Zaklyazminsaya, 2013; Behere & Weindling, 2015; Brugada, 2011). The prevalence rate of this condition is estimated as being 1 in every 10,000 persons (Liu, Ruan, & Priori, 2008). Patients with this disorder are at particularly high risk for SCD, with approximately 30-50% of untreated cases resulting in loss of life (Behere & Weindling, 2015; Brugada, 2011; Leenhardt et al., 1995; Zipes et al., 2005).

Adolescent patients with CPVT are at an increased risk for episodes of lethal arrhythmias when they engage in physical activities or exercise (Behere & Weindling, 2015). In fact, this condition is identified as being a main cause of SCD in adolescent athletes (Brugada, 2011). The first line treatment for this disorder is the use of beta-blockers and antiarrhythmic drugs (Algarra et al., 2011; Biernacka & Hoffman, 2011; Kaufman, 2009; Leenhardt et al., 1995; Pott et al., 2011). However, many patients need an ICD to further protect them against SCD (Abriel & Zaklyazminsaya, 2013; Algarra et

al., 2011; Zipes et al., 2005). Specific to individuals with CPVT, the following additional physical activity and sports recommendations are outlined in the Task Force 10 paper published by the American Heart association and American College of Cardiology: individuals who have been previously symptomatic or are asymptomatic are restricted from all competitive sports except those listed in the class IA category (golf, riflmg, curling, bowling, cricket, and billiards) if they have experienced exercise induced premature ventricular contractions, couplets, or nonsustained ventricular tachycardia (Ackerman et al., 2015).

Characteristics and treatment recommendations specific to Brugada

Syndrome. Brugada Syndrome (BrS), a genetic cardiac arrhythmic disorder, occurs in less than 1% of the population; this disorder increases patients' risk of SCD due to elevations in the ST-segment, t-wave inversion, and episodes of polymorphic ventricular tachycardia (Aleong et al., 2007; Algarra et al., 2011; Abriel & Zaklyazminsaya, 2013; Gussak, Antzelevitch, Bjerregaard, Towbin, & Chaitman, 1999). BrS accounts for approximately 4-12% of sudden deaths and occurs in approximately 5 in every 10,000 individuals (Nademanee et al., 1997). These patients are at highest risk for SCD when they are resting, sleeping, or experiencing a fever (Abriel & Zaklyazminsaya, 2013; Aleong et al., 2007; Behere & Weindling, 2015). Further, it has been noted that hyperthermia and heat exhaustion may trigger lethal arrhythmias in some patients (Abriel & Zaklyazminsaya, 2013; Barajas-Martinez et al., 2008; Keller et al., 2005). Currently, ICDs are the only medical intervention utilized for this population (Abriel & Zaklyazminsaya, 2013; Aleong et al., 2007; Algarra et al., 2011; Benito, Brugada,

Brugada, & Brugada, 2008; Brugada et al., 1998; Sacher et al., 2006). There is one additional physical activity recommendation specific to BrS, in addition to those noted previously, outlined in the Task Force 10 paper, published by the American Heart Association and American College of Cardiology (Ackerman et al., 2015). Specifically, individuals with previously symptomatic BrS or electrocardiographically evident BrS may be permitted to participate in IIB competitive sports (American football, figure skating, rodeoing, rugby, sprinting, surfing, synchronized swimming, and field events) in addition to IA sports, if the individual has been without any symptoms for 3 months and has a specified treatment plan and precautionary measures in place (Ackerman et al., 2015).

Characteristics and treatment recommendations specific to short QT

syndrome. Short QT Syndrome (SQTS) is a novel cardiac condition that was discovered in 2000 and confirmed as a cardiac condition in 2003 (Crotti, Taravelli, Girardengo, & Schwartz, 2010; Funada et al., 2008; Giustetto et al., 2011; Gussak, & Bjerregarrd, 2005; Patel & Parvi, 2009; Perez et al., 2005). SQTS, an extremely rare condition occurring in approximately 50 individuals worldwide, is characterized by shortened QT waves that result in occurrences of ventricular fibrillation and, subsequently, SCD (Brugada, 2011; Kaufman, 2009; Rautaharju, Warren, & Callhoun, 1990; Patel & Parvi, 2009). In fact, SCA is the most common presenting symptom in individuals with this disorder (Brugada, 2011; Kaufman, 2009; Rautaharju et al., 1990; Patel & Parvi, 2009). Individuals are at highest risk for experiencing a lethal arrhythmia during sleep, rest, and physical exertion (Behere & Weindling, 2015; Brugada, 2011; Kaufman, 2009). ICDs are the gold standard

treatment for this disorder, but some individuals receive medications such as quinidine, as adjunctive therapy (Brugada, 2011; Kaufman, 2009). There is one additional physical activity recommendation specific to SQTS, in addition to those noted previously, outlined in the Task Force 10 paper, published by the American Heart Association and American College of Cardiology (Ackerman et al., 2015). Specifically, individuals with SQTS may be eligible to participate in IIB competitive sports (American football, figure skating, rodeoing, rugby, sprinting, surfing, synchronized swimming, and field events) in addition to IA sports, if the individual has been without any symptoms for 3 months, and has a specified treatment plan and precautionary measures in place (Ackerman et al., 2015).

The physical and psychosocial impact associated with cardiac channelopathies and treatment recommendations in adolescents. Similar to other individuals with chronic medical conditions, those with cardiac channelopathies report unwanted physical consequences (e.g., fatigue, heart palpitations, and headaches) associated with their disorders (Andersen et al., 2008; Czosek et al., 2015; Gortmaker et al., 1990; Harvard Health Letter, 2008; Varni et al., 2007). Knowledge regarding the extent to which the unwanted physical consequences associated with having these disorders impacts patients' physical functioning and quality of life is limited (Longmuir et al., 2017). Longmuir and colleagues (2017) conducted a study that aimed to review articles that assessed the physical and psychosocial functioning of adolescents with cardiac channelopathies (Longmuir et al., 2017). Their review of the literature revealed that there are only nine relevant research articles, three by the same author and six, which have small sample sizes (n = 4-33), that examine these areas in adolescents with these

conditions (Longmuir et al., 2017). Findings related to physical functioning revealed that these patients experience decreased physical functioning, which is attributed to physical activity restrictions, and limited participation in certain activities due to fear (Longmuir et al., 2017). Because there is limited research examining the impact of physical consequences of being diagnosed with a cardiac channelopathy, the extent to which having a cardiac channelopathy impacts physical functioning within pediatric patients needs to be explored further.

Psychosocial impact of cardiac channelopathies in patients with cardiac channelopathies. Cardiac channelopathy patients often self-report psychosocial concerns such as fear, worry, and reduced and difficult social interactions (Andersen et al., 2008; Harvard Health Letter, 2008; Longmuir et al., 2017; Nylander et al., 2014; Michaud et al., 2004). Adolescents with these disorders indicated that factors which reduced their psychosocial functioning included feeling different from peers, feeling as if they were not normal, and having difficult social relationships (Longmuir et al., 2017; Rahman et al., 2012). Adults with cardiac conditions reported additional fears and worries that impacted their psychosocial functioning, including fears and worries associated with how their medical conditions will impact their futures, episodes of anxiety associated with the onset of cardiac symptoms, such as palpitations and sweating; they worry that these symptoms will lead to more serious symptoms or SCA, and fear associated with the onset of emotions because strong emotional experiences in some patients can trigger SCA (Andersen et al., 2008). Similar to research regarding the physical functioning of adolescents with these conditions, the unique psychosocial concerns for adolescents

living with a cardiac channelopathy need to be examined further (Longmuir et al., 2017). The unique impact of treatment on adolescents with these conditions has been explored in pediatric patients, and it appears that for some patients, their treatment regimens may negatively impact patients' physical and psychosocial functioning (Luiten et al., 2016; Padeletti et al., 2011; Sears et al., 2001).

The psychosocial impact of treatment in adolescents with cardiac channelopathies. Many patients experience unwanted treatment side effects such as fatigue and headaches; these disrupt their daily routines and abilities to function (Andersen et al., 2008; Padeletti et al., 2011; Sears et al., 2001). Additionally, many patients experience social and emotional consequences associated with their treatment regimens (Andersen et al., 2008; Longmuir et al., 2017). Similar to other chronically ill individuals, these patients may worry that their peers and friends may view them as being different if they find out that they must take medication or are not allowed to engage in certain physical activities (Andersen et al., 2008; Longmuir et al., 2017). For example, adolescent patients may avoid sleeping at friends' houses because their peers would see them taking their medication the first thing in the morning.

Similarly, adolescents who frequently engaged in exercise or who played sports, often have to reduce or change the types of physical activities in which they formerly participated (Ackerman et al., 2015; Luiten et al., 2016). This change to one's exercise or sports routine is highly associated with reduced emotional functioning and appears to be particularly impactful for individuals who identify themselves as athletes or competitive sportsmen (Luiten et al., 2016). Patients who were told to limit their physical activity to

protect against an unwanted cardiac event reported unwanted side effects, including fear about how to exercise safely, increased sadness, feeling restricted, losing muscle strength, being in denial of their medical condition, and gaining weight (Luiten et al., 2016). The reduction in psychological well being associated with physical activity restrictions appears to be associated with these activities being viewed as a main medium for maintaining peer relationships as well as for mitigating daily stress (Luiten et al., 2016).

The unique impact of ICDs on adolescent patients' emotional and psychosocial well-being. In addition to consequences associated with physical activity recommendations, adolescents with ICDs self-report more severe emotional consequences, post device implantation than patients who take medication to manage their cardiac conditions (Andersen et al., 2008; Longmuir et al., 2017). A few studies, with sample sizes ranging from 9 to 450, examining the psychosocial impact of ICDS on patient functioning indicated that some patients with ICDs report reduced psychosocial well-being. Specifically, some patients may experience worries associated with body image, physical exertion, sexual activity, and appearance of the ICD under their clothes (Dublin et al., 1996). In addition, some patients report social isolation and fear of shock and death, post device implantation (Vitale & Funk, 1995). Two larger studies, conducted by Luderitz et al. (1993) (n = 57) and Sears et al., 1999 (n = 450), indicated that younger patients, less than 50 years of age, tended to experience greater reduction in psychosocial functioning than older patients with ICDs (Luderitz et al., 1993; Sears et al., 1999). Specifically, younger patients reported more fear and anxiety, more depression, and difficulty mitigating stress than older patients (Luderitz et al., 1993;

Sears et al).

Half of ICD recipients self-report depressive symptoms post surgery (Sears et al., 2001). Depressive symptoms are likely attributable to the reduction in opportunities to experience pleasure from activities that patients engaged in prior to receiving their post ICD activity restrictions (Czosek et al., 2015; Zeigler & Decker-Walters, 2010; Zeigler & Tilley, 2010). In addition to depression, symptoms of anxiety are prevalent among patients with ICDs (Linder et al., 20013). Patients who experience anxiety, post implantation often worry about the efficacy of their devices; many patients feel uncertain about whether or not their ICDs would truly protect them from SCD (Andersen et al., 2008). Further, many patients report worrying and ruminating over the amount of pain they will experience if their devices deliver a shock (Andersen et al., 2008; Linder et al., 2013).

Although more research needs to be conducted to examine the unique impact of ICDS on pediatric patients, few research studies document concerns specific to pediatric patients, post ICD implantation (Alexander et al., 2004; Gradaus et al., 2004; Navaratnam & Dubin, 2011; Sears et al. 2009; Silka, Kron, Dunningan, & Dick, 1993). Sears and colleagues examined the quality of life in 60 pediatric patients with ICDs (Sears et al., 2011). The results of the study indicated that when compared with normative samples, individuals with ICDs reported lower psychosocial and physical quality of life, but when compared with other samples of pediatric patients with chronic conditions, only physical quality of life was lower (Sears et al., 2011). In addition, the findings determined that 84.7% of the sample displayed avoidance behaviors, avoiding certain places, things or

activities, since the implantation of their devices (Sears et al., 2011).

The increased propensity for shocks from ICDs in pediatric samples is a unique treatment side effect that may further impact the emotional functioning in pediatric patients (Sears et al., 2009). Pediatric patients with ICDs, compared with adult patients with ICDs, are at greater risk for experiencing inappropriate shocks because rapid growth during this age group often results in dislodged and damaged device leads (Alexander et al., 2004; Navaratnam & Dubin, 2011; Sears et al. 2009; Silka et al., 1993). In fact, approximately 13% of adolescent patients with ICDs experience an ICD shock, and, of those, 38% are determined to be unnecessary and are a result of device malfunction (Gradaus et al., 2004; Sears et al., 2009; Sears et al., 2001). Sear et al. (2009) reviewed research studies examining ICD shocks in pediatric and adult patients with ICDs, and the findings suggested that patients who have received shocks are more likely to experience symptoms of anxiety (Sears et al., 2009). Further, a review of research literature examining the impact of implantable devices in patients revealed that patients who have received an ICD shock tend to experience additional negative consequences, such as long lasting negative sensations and fear of future ICD firing and misfiring incidents (Padeletti et al., 2011).

As with other adolescents with chronic conditions, adolescents with cardiac channelopathies experience physical and psychosocial consequences that can impact aspects of their daily functioning (Sears et al., 2009; Sears et al., 2001). Healthcare providers who treat adolescents with a variety of medical conditions have reported that treating adolescents presents unique treatment considerations exclusive to this age group

(Christine & Viner, 2005; Gortmaker et al., 1990). Providers have indicated that developmental tasks specific to this stage have the propensity not only to interfere with patients' health outcomes, but also with efficacy of treatment (Christine & Viner, 2005; Gortmaker et al., 1990). Thus, providers must assess, monitor, and treat incidents in which patients' developmental tasks interfere with treatment and jeopardize or negatively impact patients' health (Christine & Viner, 2005; Gortmaker et al., 1990).

Developmental tasks of adolescence. Although all adolescents may experience some challenges as they progress through adolescence, those with chronic medical conditions may face additional challenges, attributable to managing their illnesses; these can inhibit their progression through this stage (Christine & Viner, 2005; Gortmaker et al., 1990). Adolescence is a stage of development with the highest rate of physical and cognitive changes, post infancy (Arnett, 1992; Christie & Viner, 2005; Dovey-Pearce, 2005; Roisman, Masten, Coatsworth, & Tellegen, 2004; Tynan, 2010; Williams et al., 2002). Adolescence is a developmental stage during which individuals begin to develop their personal identities and establish personal values (Dovey-Pearce, 2005; Roisman et al., 2004; Waterman, 1982). Additionally, adolescents are intensely focused on forming and maintaining friendships and romantic relationships, as well as gaining social acceptance from peers (Dovey-Pearce, 2005; Roisman et al., 2004). In fact, it is not uncommon for adolescents to engage in new or exploratory behaviors (e.g., drinking alcohol) in an attempt to fit in with their peers (Arnett, 1992; Christie & Viner, 2005; Dovey-Pearce, 2005; Gullone et al., 2000; Roisman et al., 2004; Tynan, 2010; Williams et al., 2002). In addition to engaging in atypical or new behaviors to fit in with peers, it is

often common for adolescents to engage in behavioral exploration as a means to establish autonomy, identity, and independence (Arnett, 1992; Christie & Viner, 2005; Dovey-Pearce, 2005; Gullone et al., 2000; Roisman et al., 2004; Tynan, 2010; Williams et al., 2002).

Developmental tasks and risk-taking behavior. The specified developmental tasks and neurocognitive changes during this stage increase instances of risk-taking behaviors among this cohort, compared with children, middle adults, and older adults (Arnett, 1992; Christie & Viner, 2005; Dovey-Pearce, 2005; Engles & ter Bogt, 2001; Gullone et al., 2000; Roisman et al., 2004; Tynan, 2010; Williams et al., 2002). The need to establish close peer relationships and avoid social rejection seems to motivate peers to engage in a range of low to higher risk behaviors (Arnett, 1992; Christie & Viner, 2005; Dovey-Pearce, 2005; Engles & ter Bogt, 2001; Gullone et al., 2000; Prinstein, Boergers, & Spirito, 2001; Roisman et al., 2004; Tynan, 2010; Williams et al., 2002). Thus, it is very common for adolescents to engage in the same types of behaviors as their friends (Prinstein et al., 2001). In fact, the types of high-risk behaviors in which an adolescent's friend group engages is highly predictive of the types of behaviors in which he or she engages (Prinstein et al., 2001). For example, adolescents whose friends engage in substance use or delinquent behavior, such as physical fighting, are more likely to engage in these high-risk behaviors than adolescents whose friend group abstains from participation in these high-risk behaviors (Prinstein et al., 2001).

Adolescents often see risk taking behaviors (e.g., drinking alcohol) as having a social benefit (Engles, Knibbe, & Drop, 1999; Engles & ter Bogt, 2001). In fact,

adolescents who use substances (e.g., drink alcohol and smoke marijuana) feel more closely attached to and supported by their friend group, develop more intimate relationships, and perceive themselves as being more socially competent than those who abstain from substance use (Engles & ter Bogt, 2001; Engles et al., 1999; Leifman et al., 1995). Adolescents who have a few close relationships may be more likely to engage in high-risk behaviors because having a few close friends predicts greater engagement in high-risk behaviors than the extent to which one feels attached to their friends, accepted by classmates, and competent in their friendships (Engels & ter Bogt, 2001). Regarding romantic relationships, adolescents may view substance use as a means of reducing anxiety associated with approaching potential partners (Engles & ter Bogt, 2001). Overall, engagement in high-risk behaviors is often highly associated with and predictive of the types of behaviors in which the adolescent's friends group engages (Prinstein et al., 2001).

Neurocognitive-development in adolescence and risk-taking. Similarly, changes in the neurological systems in the brains of adolescents seem to influence their propensity for risk-taking behaviors during this developmental stage, compared with their behavior during childhood and adulthood (Braams, van Duijvenvoorde, Peper, & Crone, 2015; Figner, Mackinlay, Wilkening, & Weber, 2009; Crone, van Duijvenvoorde, & Peper, 2016; Lutz, McClure & Armstrong, 2017). Specifically, changes occurring in the prefrontal cortex, which controls planning, impulsivity, and forethought, and subcortical structures of the brain appear to attribute to this increased risk (Crone et al., 2016; Lutz et al., 2017; Johnston, O'Malley, Miech, Bachman, & Schulenberg, 2014). During mid-

adolescence, there is heightened neuronal activity in the ventral medial prefrontal cortex and ventral striatum, which can lead to an enhanced focus on reward and pleasure (Braams et al., 2015; Crone et al., 2016; Crone & Dahl, 2012; Figner et al., 2009).

Subsequently, this drive for reward is likely to result in increased sensation seeking and risk-taking behaviors, such as alcohol use (Braams et al., 2015; Crone et al., 2016; Crone & Dahl, 2012; Figner et al., 2009). Toward the end of adolescence and into early adulthood, the connectivity between the striatum, dorsal medial, and lateral prefrontal cortex increase and the connections between the striatum and the ventral medial prefrontal cortex decrease, which results in decreased impulsivity (Crone et al., 2016). Overall, the developmental tasks and neurological changes of adolescence, compared with childhood and adulthood, appear to increase this cohorts' vulnerability for risk-taking behavior and elevate the propensity for adolescents to experience a range of consequences associated with risk-taking behaviors (Arnett, 1992; Crone et al., 2016; Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996) .

Types of risk-taking behavior in adolescence. Adolescents' risk-taking actions span a wide range of behaviors that are associated with varying levels of risk for positive and detrimental outcomes (Arnett, 1992; Christie & Viner, 2005; Gullone et al., 2000; Gullone & Moore, 2000; Williams et al., 2002). Risk-taking behaviors are classified into one of four broad hierarchical categories, each of which is defined by the amount of risk for acute and long-term negative outcomes (Arnett, 1992; Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996). Behaviors classified as “thrill or sensation seeking risks” are considered to be of lowest risk because consequences associated with

these actions tend to be socially acceptable and negatively correlated with harm or serious impairment (Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996). In fact, these behaviors often result in personal reward, such as pleasure, increased physiological arousal, material gain, and feelings of accomplishment (Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996). Common thrill or sensation seeking behaviors include parachuting, bungee jumping, snow skiing, flying a plane, and leaving school without permission (Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996).

Actions classified as “rebellious risks” and “antisocial risks” are highly associated with negative outcomes (Arnett, 1992; Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996). Specifically, these behaviors often result in serious physical or emotional injuries that greatly influence the actor’s physical and psychosocial well-being (Gullone et al., 2000; Gullone & Moore, 2000; Hawkins, Catalano, & Miller, 1992; Moore & Gullone, 1996). Thus, these actions are considered to be of greater risk than “thrill seeking” actions (Arnett, 1992; Gullone et al., 2000; Gullone & Moore, 2000). Typical rebellious risk actions are considered to be rites of passage that occur when adolescents are attempting to seek independence; these include underage drinking, smoking, staying out past curfew, getting drunk, and experimenting with substances (Arnett, 1992; Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996). Antisocial risk behaviors are considered to be socially unacceptable for persons of any age; they include cheating, bullying peers, overeating, sniffing gas or glue, and talking to strangers (Gullone & Moore, 2000; Moore & Gullone, 1996).

Behaviors categorized as “reckless risks” are associated with the most serious consequences and include behaviors such as drinking and driving, stealing cars and going on joy rides, speeding, having unprotected sex, and driving without a license (Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996). In fact, consequences attributable to these actions are often life-threatening (Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996). Therefore, actions within this category, compared to thrill seeking, rebellious, and antisocial behaviors, are considered to be the most dangerous and of highest risk (Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996). Even though reckless, rebellious, and antisocial risk-taking are highly associated with negative outcomes, adolescents do engage in these behaviors (Gullone et al., 2000; Moore & Gullone, 1996).

High prevalence rates of risk behaviors during adolescence. Engagement in health-risk behaviors during adolescence has been commonly reported in surveys examining these behaviors in adolescent participant samples (Arnett, 1992; Bender, 2006; Bonomo & Proimos, 2005; Braverman, 2001; Brener et al., 2013; de Winter, Visser, Verhulst, Vollebergh, & Reijneveld, 2015; Gullone et al., 2000; Kann et al., 2016). Findings from a few research studies have suggested that the onset and highest prevalence of substance use (e.g., tobacco, alcohol, and illicit drug use) occurs during this stage (Arnett, 1992; Bono & Proimas, 2005; Gullone et al., 2000; Quadrel, Fischhoff, & Davis, 1993; Scheier, Botvin, Diaz, & Griffin, 1999). National averages for engagement in high-risk behaviors are assessed and published by the Center for Disease Control every few years through the utilization of the Youth Risk Behavior Surveillance System

(YRBSS), which is a school-based self-administered survey that measures engagement in a variety of health-risk behaviors, including substance use and alcohol, sexual activity, violent behavior, tobacco use, unhealthy dietary behaviors, and physical inactivity (Brener et al., 2013).

The YRBSS is administered biennially to participating public and private schools, to students in grades 9-12, across the United States of America (Brener et al., 2013; Kann et al., 2016). The most recent data collection regarding health-risk behaviors was conducted in 2015 (Kann et al., 2016). With regard to alcohol use, the survey revealed the following: 63.2 % of adolescents indicated that they drank alcohol at least 1 day during their lives; 17.2 % indicated that they drank alcohol before the age of 13; 32.8% currently drink alcohol; and 17.7% drank alcohol 30 days prior to taking the YRBSS study (Kann et al., 2016). With regard to substance use, the survey revealed the following: 7% reported using inhalants; 2.1% reported using heroin; 3.0% reported using methamphetamines; 16.8% endorsed taking prescriptions drugs without a prescription; 3.5% reported taking steroids without a prescription; 1.8% injected an illegal drug one or more times, and 21.7% were offered, sold, or given an illegal drug on school property (Kann et al., 2016). With regard to sexual activity the survey indicated the following: 41% reported having sexual intercourse; 4% had sexual intercourse before the age of 13; 12% had four or more sexual partners during their lifespan, and 43% did not use a condom during their last sexual intercourse encounter (Kann et al., 2016).

High-risk behaviors in adolescents with chronic health conditions.

Adolescents with chronic conditions appear to engage in similar types of developmentally typical, high-risk behaviors as their healthy peers (Bender, 2006; Berquist et al., 2008; Kongkaew, Jampachaisri, Chaturongkul, & Scholfield, 2014; Neinstein, 2001; Rapoff, 2009; Rapoff, 2006; Rapoff, 1998; Scaeamuzza et al., 2010; Suris & Parera, 2005; Valencia & Cromer, 2000). With regard to substance use, Suris and Parera (2005) surveyed the health behaviors of 6,952 Spanish adolescents aged 14-19. Of those adolescents, 665 self-reported having a chronic condition, although the specific chronic conditions endorsed by participants were not provided (Suris & Parera, 2005). The results of this study indicated that female adolescents with chronic health conditions self-reported higher rates of drug use than their healthy counterparts (Suris & Parera, 2005). There were no differences in alcohol consumption; the adolescents with and without chronic conditions reported similar rates of this behavior (Suris & Parera, 2005).

Similarly, Suris and colleagues (2008) surveyed health behaviors of 7,548 Swedish adolescents aged 16-20, with 760 of those adolescents self-reporting the presence of a chronic condition (Suris et al., 2008). The findings of this study indicated that individuals with chronic conditions were more likely than their healthy peers to smoke tobacco on a regular basis and to use cannabis daily (Suris et al., 2008). There were no differences in self-reported rates of alcohol consumption between adolescents with and without a chronic condition (Suris et al., 2008). Nylander and colleagues (2013) conducted a population-based survey of 7,262 Swedish students aged 15-17, with 459 of the participants indicating that they had a chronic condition (Nylander et al., 2013). The

findings of this study indicated that male and female participants with a chronic condition were more likely than male and female participants without a chronic condition to have tried drugs (Nylander et al., 2013).

Similar to substance use, chronically ill adolescents report engaging in the similar types and frequencies of sexual activities as their healthy peers (Choquet, Fediaevsky, & Manfredi, 1997; Klosky et al., 2014; Nylander et al., 2014; Suris et al., 2008; Valencia et al., 2000). Carroll and colleagues (1983) surveyed the sexual practices of 61 adolescents, aged 14-18, who self-reported having a chronic illness. The results of the survey indicated that adolescents with chronic illnesses are sexually active, with 26% of those surveyed reporting engagement in sexual behavior (Carroll et al., 1983). Similarly, Suris and colleagues (1996) surveyed health behaviors of 36,284 adolescents living in Minnesota; 460 and 1068 of the total number of participants had a visible chronic condition (e.g., cerebral palsy) and non-visible chronic condition (e.g., asthma), respectively (Suris et al., 1996). The findings of the research study indicated that chronically ill adolescents and their healthy counterparts were engaging in similar sexual behaviors. In fact, the age of first sexual encounter, 14, was similar across groups, as was the frequency in which both groups were engaging in sexual activity (Suris et al., 1996).

Findings from a few research studies have suggested that chronically ill adolescents may engage in sexual activity at a younger age, engage in sexual activity more frequently, and are more likely to self-report a history of pregnancy and sexually transmitted infections than their peers who do not have a chronic condition (Adlerman, Lauby, & Coupey, 1995; Choquet, Pasquier Fediaevsky, & Manfredi, 1996; Suris et al.,

1996; Suris & Parera, 2005). Findings from Suris and colleagues (1996), which was reviewed previously, suggested that chronically ill adolescents reported a greater number of sexually transmitted diseases than their healthy counterparts (Suris et al., 1996). As presented, Suris and Parera (2008) surveyed 6,952 adolescents ages 14-19; 665 of these adolescents self-reported having a chronic condition (Suris & Parera, 2005). The results of this study indicated that males with chronic health conditions were slightly more likely than adolescent participants without a chronic condition to have their first sexual interaction at an earlier age (Suris & Parera, 2005). With regard to female adolescents, the findings suggest that chronically ill adolescent females were significantly more likely to be sexually active and to have a history of being pregnant than their healthy peers (Suris & Parera, 2005).

Similarly, Adlerman and colleagues (1995) surveyed health behaviors of 338 inner-city minority children aged 14-17; of these 217 self-reported having a chronic condition (Adlerman et al., 1995). The findings of this survey indicated that female adolescents with a chronic medical condition were more likely to have initiated sexual activity at a younger age than adolescent participants without a chronic condition (Adlerman et al., 1995). Unlike the female participants, the results of this survey indicated that male adolescent participants with chronic conditions were more likely to initiate sexual activity at an older age than male adolescent participants without a chronic condition (Adlerman et al., 1995). Choquet and colleagues (1996) studied health risk behaviors in 7,963 French adolescents ranging in age from 12-25 years old, with 706 self-reporting the presence of a chronic condition such as cancer, arthritis, epilepsy, diabetes,

and cardiopathy (Choquet et al., 1996). The results of this survey indicated that adolescent female participants with chronic health conditions were more likely to change sexual partners and to report pregnancy than adolescent participants without a chronic health condition (Choquet et al., 1996).

Medical non-adherence is classified as a high-risk health behavior in chronically ill populations. In addition to substance use and sexual activity, medical non-adherence is a health behavior that is also positively correlated with serious consequences and should be classified as a risk-taking behavior (Berquist et al., 2008; Kongkaew et al., 2014; Nylander et al., 2014; Rapoff, 2006; Rapoff, 1998). Medical non-adherence occurs when a patient does not follow his or her medical protocol outlined by medical professionals and includes behaviors such as not taking medication, not completing medical tests, and not attending scheduled appointments (Berquist et al., 2008; Ho, Bryson, & Rumsfeld, 2009; Michaud et al., 2004; Rapoff, 2009). The level of risk associated with non-adherence is considered equal with that of substance use, sexual risk-taking, and delinquent behaviors (Valencia & Cromer, 2000).

In fact, adolescent patients who do not follow medical recommendations are at risk for detrimental consequences, such as death (Berquist et al., 2008; Bullington et al., 2007; Ho et al., 2009; Kongkaew et al., 2014; Nylander et al., 2014; Rapoff, 2006; Rapoff, 1998). Despite the risk associated with this behavior, adolescent patients have a higher rate of medical non-adherence than any other age group (Berquist et al., 2008; Michaud et al., 2004; Rapoff, 2006; Rapoff, 1998). Although the exact reported rates for medical non-adherence ranges, some samples report non-adherence rates upwards of 30%

(Berquist et al., 2008; Gabr & Shams, 2014). For example, Berquist et al. (2008) examined medical non-adherence in 111 adolescent patients, post liver transplantation, and the findings suggested that 45% of the sample was non-adherent to their medical regimen (Berquist et al., 2008). Similarly, Gabr and Shams (2014) examined medical adherence in 116 adolescent patients with epilepsy, and findings suggested that 38.3% were non-adherent to their medical regimen (Gabr & Shams, 2014).

Medical-non adherence in adolescents with cardiac channelopathies. Similar to adolescents with other chronic medical conditions, adolescents with cardiac channelopathies may be vulnerable to engaging in medical non-adherence (Caleshu et al., 2016; Luiten et al., 2016). Many patients with cardiac channelopathies do not experience severe or daily symptoms and for individuals who do experience symptoms, patients often described the nature of these experiences as being mild (Caleshu et al., 2016). Despite their lack of symptoms or minimal symptoms, patients are often provided with medical regimens that greatly restrict their ability to engage in a range of activities in order to prevent possible occurrences of sudden death (Calesgu et al., 2016). Subsequently, patients may feel that following their strict medical regimens is unimportant and not needed (Calesgu et al., 2016). Further, the perceived consequences, which include the loss of peer relationships, distress, the loss of identity of self as an athlete associated with common treatment recommendations, having to take medications and restricting physical activity and engagement in competitive sports, may further increase the likelihood of these patients not following their medical regimens (Luiten et al., 2016). For example, many patients, with cardiac conditions, who were told to restrict

their engagement in competitive sports and physical exercise indicated that they had difficulty reducing the frequency of their engagement in physical activity (Luiten et al., 2016).

The unique impact of high-risk behaviors for chronically ill versus healthy adolescents. The frequency with which chronically ill adolescents participate in high-risk behaviors, compared with their peers is uncertain (Nylander et al., 2014). Research studies have presented conflicting findings that have suggested that this population engages in less, equivalent, or more of these behaviors than healthy adolescents (Nylander et al., 2014). Regardless of the specific frequency or the number of high-risk behaviors in which chronically ill adolescents participate, any engagement in these behaviors could be extremely detrimental for this medical population (Berquist et al., 2008; Choquet et al., 1997; Kongkaew et al., 2014; Nylander et al., 2014; Rapoff, 2006; Rapoff, 1998; Topolski et al., 2001). Specifically, high-risk behaviors have the potential to interfere with the pathology of patients' disorders as well as the efficacy of patients' medical treatment regimens (Berquist et al., 2008; Chocquet et al., 1997; Kongkaew et al., 2014; Nylander et al., 2014; Rapoff, 2006; Rapoff, 1998). Consequently, adolescents with chronic illnesses are vulnerable to acquiring additional acute and long-term physical and psychosocial consequences that can further reduce their already poor health status (Choquet et al., 1997; Topolski et al., 2001). Thus, adolescents with chronic medical conditions should be considered a vulnerable medical population in need of frequent monitoring and behavioral management (Gortmaker et al., 1990; Neinstein, 2001).

High-risk behaviors likely occur and impact the health outcomes of adolescents with cardiac channelopathies. Similar to other chronically ill adolescents, those with cardiac channelopathies may experience detrimental consequences if their behaviors associated with the developmental tasks of adolescence interfere with their health status or treatment regimens (Gortmaker et al., 1990; Neinstein, 2001). Compared with adolescents with non-life-threatening conditions, those with life-threatening illnesses, including cardiac channelopathies, may be a sub-group of patients with the greatest vulnerability for negative consequences resulting from engagement in high-risk behaviors (Andersen et al., 2008; Harvard Health Letter, 2008). The risk is particularly elevated in adolescents with cardiac channelopathies because they are at great risk for life-threatening consequences if they engage in a wide range of developmentally expected behaviors typically classified as being benign or of little risk, such as resting, exercise, and playing competitive sports (Andersen et al., 2008; Harvard Health Letter, 2008). Thus, the life-threatening and unpredictable nature of cardiac channelopathies likely interacts with the typical developmental tasks of adolescents and escalates the vulnerability of this population above that of chronically ill adolescents with non-life-threatening illnesses and that of their healthy peers. Therefore, it is imperative that research examines and determines specific factors that will either increase or decrease patients' risks of engaging in behaviors considered to be of high risk for this medical population (Gortmaker et al., 1990).

Factors that predict engagement in high-risk behaviors in chronically ill adolescents. Researchers have examined many factors that are associated either with increasing or with decreasing the likelihood of chronically ill adolescents engaging in high-risk behaviors (Nylander et al., 2014). A variable that increases the likelihood of an individual engaging in dangerous behaviors is categorized as a risk factor (Fergus & Zimmerman, 2005; Nylander et al., 2014). Contrarily, factors that reduce the likelihood of an individual engaging in behaviors associated with harmful consequences are labeled protective factors (Fergus & Zimmerman, 2005; Nylander et al., 2014). However, factors often function both as a protective and as a risk factor (Fergus & Zimmerman, 2005; Nylander et al., 2014). For example, socioeconomic status can function either as a risk or as a protective factor, with adolescents from low socioeconomic backgrounds more likely to engage in high-risk behaviors than those from higher socioeconomic backgrounds (Fergus & Zimmerman, 2005; Nylander et al., 2014; Topolski et al., 2001).

Models for evaluating risk and protective factors. There are many different models that aim to explain how an individual's unique set of protective factors and risk factors interact and influence his or her likelihood of experiencing negative outcomes (Fergus & Zimmerman, 2005). A protective factor model suggests that one's protective factors or resources moderate or reduce the influence of risk factors (Fergus & Zimmerman, 2005). For example, individuals who have a risk factor, such as a life-threatening illness, and also a protective factor, such as adaptive coping skills, likely have a reduced risk of negative health outcomes because their effective coping attenuates the likelihood of experiencing unwanted consequences associated with having a chronic

illness (Fergus & Zimmerman, 2005). How factors, such as social problem solving, illness representations, and quality of life influence patients' participations in high-risk behaviors has been examined in adolescents who have a variety of chronic illnesses (Nylander et al., 2014; Topolski et al., 2001). However, how these factors influence engagement in high-risk behaviors among adolescents with cardiac channelopathies has yet to be determined.

Risk/protective factors for risk taking in adolescents with and without chronic medical conditions. Similar to other chronically ill adolescents, individuals with cardiac channelopathies are more vulnerable to experiencing negative outcomes if they maintain risk factors associated with risk-taking (Bender, 2006; Nylander et al., 2014; Topolski et al., 2001). Quality of life, social problem solving, and illness representations are associated with engagement in high-risk behaviors among those adolescents with and without chronic medical conditions (Grey, Boland, Davidson, & Tamborlane, 2014; Topolski et al., 2001). Thus, these variables may also be associated with engagement in risk-taking behaviors in adolescents with cardiac channelopathies.

Quality of life. According to the World Health Organization (WHO), quality of life is defined as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment" (World Health Organization, 1995, p.1). Research studies have examined the association between

self-reported quality of life and risk-taking behaviors, and findings have determined that there seems to be an association between the two variables (Felce & Perry, 1995; Topolski et al., 2001). For example, Topolski and colleagues (2001) conducted a survey of quality of life and health risk behaviors among 2,801 high school students. The findings indicated that adolescents who used tobacco, alcohol, or illicit drugs and engaged in risky sexual behavior reported poorer quality of life than adolescents who refrained from engaging in those behaviors (Topolski et al., 2001).

Specific to adolescents with chronic illnesses, poor quality of life has been associated with high-risk health behaviors, substance use and medical non-adherence (Fredricks et al., 2008). With regard to substance use, Sawyer and colleagues (2001) examined health risk behaviors in 4,509 Australian adolescents, with 14% being diagnosed with a chronic mental health condition, including attention-deficit hyperactivity disorder, conduct disorder, and depressive disorders (Sawyer et al., 2001). The findings of the study indicated that adolescents with an identified chronic condition had lower quality of life and self-reported more frequent use of marijuana and tobacco (Sawyer et al., 2001). However, there were no differences in self-reported alcohol consumption in those adolescents with or those without chronic mental health conditions (Sawyer et al., 2001).

With regard to medical adherence, the findings from the following studies demonstrate the association between quality of life and this health risk behavior (Fredricks et al, 2008; Hovinga et al., 2008). Fredricks et al. (2008) examined quality of life and adherence in 25 adolescent patients who had a liver transplant (Fredricks et al.,

2008). The findings suggested that patients with poorer quality of life were also less adherent to their medical regimens (Fredricks et al, 2008). Similarly, Hovinga and colleagues (2008) examined the association between medical non-adherence and quality of life in 408 patients with epilepsy (Hovinga et al., 2008). The findings suggested that poor quality of life was positively associated with medical non-adherence (Hovinga et al., 2008).

Quality of life and risk-taking behavior in patients with cardiac channelopathies. It has been well established in the research literature that patients with chronic medical conditions tend to self-report reduced quality of life (Hwee-Wee et al., 2005; Varni et al., 2007). Unlike other chronic medical populations, the quality of life of individuals with cardiac channelopathies has been rarely studied. In fact, there appears to be only one study, conducted by Czosek and colleagues (2008), that examined quality of life in individuals with cardiac channelopathies. However, this study, which examined quality of life in 288 pediatric patients with a variety of electrophysiologic diseases, included participants with only one subtype of cardiac channelopathies, LQTS (Czosek et al., 2015). The findings indicated that pediatric patients with LQTS self-reported poorer quality of life than cardiac patients with congenital complete heart block (CCHB) and bicuspid aortic valve (BAV) (Czosek et al., 2015). LQTS patients' quality of life was not compared with a normative sample, thus how their quality of life compares with adolescents without LQTS is not known (Czosek et al., 2015). Although the quality of life in patients with these medical conditions is unknown, if some adolescents with cardiac channelopathies experience reduced quality of life they, as with other adolescents

with and without chronic medical conditions, may be at risk for engagement in high-risk behaviors such as substance use and medical-non-adherence (Felce & Perry, 1995; Hwee-Wee et al., 2005; Topolski et al., 2001; Varni et al., 2007).

Engagement in high-risk behaviors is associated with illness

beliefs/representations in individuals with chronic medical conditions. Similar to quality of life, patients' illness beliefs or representations are associated with engagement in high-risk behaviors and adaptive coping behaviors (Arran, Craufurd, & Simpson, 2014; Fredericks et al., 2008; Gould, Brown, & Bramwell, 2010; Law, Kelly, Huey, & Summerbell, 2002; Reynolds et al., 2007). According to the self-regulation model (SRM) and Common Sense Model (CSM,) proposed by Leventhal and colleagues (1980), illness representations are defined as patients' affective and cognitive representations of their illnesses (Arran et al., 2014; Leventhal, Leventhal, & Cameron, 2001; Leventhal, Meyer, & Nerenz, 1980; Lowe, Porter, Snooks, Buttons, & Evans, 2011; Petrie, Cameron, Ellis, Buick, & Weinman, 2002, Petrie, Jago, & Devcich, 2007; Sharpe & Curran, 2006). These beliefs are established through an individual's cultural context, personal experiences, and knowledge (Hagger & Orbell, 2003). The development of illness representations are guided by the following sources of information: base knowledge of the illness; individual's cultural beliefs about the illness; information from authoritative individuals (e.g., physicians); information about illness provided by significant persons in the individual's life (e.g., parent or partner); information gained from one's emotional and physiological experiences associated with one's illness (Hagger & Orbell, 2003).

Patients' illness representations tend to fit within five specific categories,

including identity, cause, severity and consequences, control, and timeline (Arran et al., 2014; Broadbent, Petrie, Main, & Weinman, 2006; Cameron, 2008; Hagger & Orbell, 2003; Petrie et al., 2007; Petrie et al., 2002; Scharloo et al., 1998; Sharpe & Curran, 2006). Identity representations include the patient's label for his or her disorder and the severity and type of the symptoms he or she perceives as being attributable to the illness (Edgar & Skinner, 2003). Consequence beliefs are often associated with the amount of functional impairment and quality of life one attributes to his or her illness (Hagger & Orbell, 2003). Further, these beliefs are associated with how much one feels his or her illness has impacted one's economic resources (Edgar & Skinner, 2003).

Cause representations are beliefs related to what the patient believes caused him or her to develop the particular illness, e.g., stress, genetics, or biological factors (Hagger & Orbell, 2003). Timeline representations consist of beliefs related to how long their conditions (e.g., acute, cyclical, or chronic) and symptoms will persist (Edgar & Skinner, 2003; Hagger & Orbell, 2003). Control representations are patients' beliefs related to the extent to which they feel that either they, their medical provider, or medical treatment can effectively manage their conditions (Edgar & Skinner, 2003). Thus, these beliefs are associated with how empowered one feels in his or her ability to utilize coping behaviors to control one's illness (Hagger & Orbell, 2003).

Illness representations and coping behavior. Research has suggested that patients' individual illness beliefs or profile of beliefs, influence their ability to adjust to their illnesses because they are predictive of the types of coping behaviors patients use to manage their conditions (Hagger & Orbell, 2003). Hagger and Orbell (2003) conducted a meta-analysis of 45 empirical studies, with sample sizes ranging from 24 to 2,056. The findings of this meta-analysis indicated that certain illness beliefs may be predictive of coping behaviors and maladaptive health-behaviors, such as medical non-adherence (Hagger & Orbell, 2003).

Common illness representation profiles related to maladaptive coping include: timeline, identity, consequences and control (Hagger & Orbell, 2003). Specifically, patients who believed that they had control over their illnesses and believed that their symptoms were less severe and controllable were more likely to seek out social supports and utilize problem-focused and active coping strategies (Hagger & Orbell, 2003). Conversely, patients who believed that their illnesses had serious consequences, were unable to be controlled, and were chronic in nature were more likely to engage in denial, ineffective emotional expressions, avoidance of problems, and passive coping behaviors (Hagger & Orbell, 2003). Although there is not currently any information regarding the association between illness representations and coping behaviors in adolescents with cardiac channelopathies, individuals with these conditions may follow a pattern that is similar to individuals with other chronic health conditions. Therefore, timeline, identity, consequences and control illness beliefs in individuals with these conditions may also be linked with the utilization of adaptive and maladaptive coping behaviors.

Illness beliefs and medical adherence. Illness beliefs related to control and illness identity appear to influence patients' adherence to their treatment regimens (Griva, Myers, & Newman, 2000; Hagger & Orbell, 2003; Nouwen, Law, Hussain, McGovern, & Napier, 2009; Zugelj et al., 2010). Specific to control beliefs, patients appear to be more likely to engage in behaviors that will mitigate their symptoms if they believe that their illnesses are able to be controlled (Hagger & Orbell, 2003; Nouwen et al., 2009). The association between control beliefs and non-adherence has been examined in a few studies exploring these factors in patients with diabetes.

Specifically, Nouwen and colleagues (2009) surveyed illness beliefs and dietary management behaviors in 151 adolescents with type 1 diabetes, and the findings of this study suggested that adolescents with type 1 diabetes had better dietary management if they believed that following this treatment regimen would control their illness (Nouwen et al., 2009). Griva et al. (2000) surveyed illness beliefs and self-management behaviors in 64 adolescents with type 1 diabetes (Griva et al., 2000). The findings suggested that control beliefs, thinking one has control over his or her illness, predicted better medical adherence (Griva et al., 2000). Broadbent et al. (2006) studied illness beliefs and various health outcomes in patients with a variety of illnesses, including 309 asthma patients, 132 renal patients, and 119 diabetes patients. Of the patients with type 1 diabetes, the findings of this study indicated that individuals who thought that their treatments could control their conditions had better metabolic control, as measured by lower A1C blood markers (Broadbent et al., 2006).

Similar outcomes were found in studies examining this association in patients

with conditions other than diabetes (Broadbent et al., 2006; Zugelj et al., 2010). For example, Zugelj and colleagues (2010) surveyed 97 hypertensive adolescent patients to determine if their beliefs about treatment effectiveness were predictive of medical adherence to their treatment regimens (Zugelj et al., 2010). The findings of this study indicated that perceptions of treatment being effective was predictive of medical adherence to prescribed treatment regimens (Zugelj et al., 2010). Perhaps patients who view their illnesses as being unable to be controlled have less motivation to engage in adaptive coping or medical adherence because they do not believe that it will result in change or positive outcome.

Similar to control beliefs, identity beliefs are associated with medical non-adherence because patients who have strong illness identity or experience many symptoms associated with their illnesses are less adherent to their medical regimens (Hagger & Orbell, 2003; Kemp, Morely, & Anderson, 1999). For example, Griva et al. (2000), who surveyed 64 adolescents with Type 1 diabetes, suggested that illness identity is associated with adherence because their findings indicated that adolescents who self-reported having many symptoms associated with their illnesses were less adherent to their treatment regimens (Griva et al., 2000). Horne and Weinman (2002) surveyed 100 patients with asthma and explored the association between illness beliefs and medical adherence (Horne & Weinman, 2002). The findings of the study indicated that patients who perceived their illnesses as having many negative consequences were less likely to be adherent to their medical regimens (Horne & Weinman, 2002). Perhaps, patients who maintain that their symptoms are severe are less likely to be adherent to their medical

regimens because they do not believe that adaptive coping or their medical regimens will effectively reduce their symptoms (Hagger & Orbell, 2003).

Illness representations and life-threatening illnesses. Similar to patients with other chronic conditions, it is control, identity, consequences, and timeline illness representations that predict engagement in maladaptive coping and health behaviors such as medical non-adherence, in those diagnosed with life-threatening illnesses (Arran et al., 2014; Bucks et al., 2009; Hopman & Rijken, 2015; Michaud et al., 2004; Reynolds et al., 2007; Rolland & Walsh, 2006). For example, Hopman and Rijken (2013) examined the relationship between illness beliefs and coping in 325 terminal cancer patients (Hopman & Rijken, 2013). The results indicated that patients who felt that their conditions resulted in numerous unwanted consequences tended to engage in passive coping behaviors, such as avoidance, more than patients who perceived their illnesses as resulting in few consequences (Hopman & Rijken, 2013). Perhaps patients with life-threatening conditions who perceive themselves as having many symptoms and unwanted consequences engage in ineffective health behaviors because they do not believe that adaptive coping will change their diseases (Broadbent et al., 2006). In addition, it is possible that they already feel miserable and do not believe that engaging in maladaptive behaviors could make them feel any worse (Broadbent et al., 2006).

Similar to beliefs about consequences, duration of illness and treatment control beliefs predicted coping behaviors in patients with life-threatening illnesses (Bucks et al., 2009; Edgar & Skinner, 2003; Griva et al., 2000; Nouwen et al., 2009; O'Connor, Jardine, & Millar, 2008; Reynolds et al., 2007; Rolland & Walsh, 2006). Reynolds et

al.(2007) examined the relationship between self-care behaviors and illness representations in 1,217 patients with HIV (Reynolds et al., 2007). Patients who perceived their illnesses as being of short duration and more dire, or short term illness, engaged in significantly less self-care, self-management, and adaptive health behaviors (Reynolds et al., 2007). O'Connor, Jardine, and Millar (2008) examined illness beliefs and coping behaviors in 73 patients with end stage renal disease (O'Connor et al., 2008). The findings suggested that patients in end stage renal disease who believed that their illnesses were of short duration were less adherent to medical restrictions than those who perceived their illnesses to be of long duration (O'Connor et al., 2008). Perhaps these patients were not motivated to engage in adaptive coping because they believed that their illnesses were going to result in death in a short time anyway.

Patients who believed that their conditions could not be adequately controlled either by themselves or by their treatment engaged in significantly fewer self-management behaviors and more maladaptive coping behaviors (Edgar & Skinner, 2003; Griva et al., 2000; Nouwen et al., 2009; Reynolds et al., 2007; Rolland & Walsh, 2006; Zugelj et al., 2010). For example, Reynolds and colleagues (2009) examined illness beliefs in 1,217 international patients with HIV (Reynolds et al., 2009). Findings suggested that beliefs about one's illness being unable to be controlled were predictive of engagement in fewer self-management behaviors (Reynolds et al., 2009). Similarly, Bucks et al. (2009) surveyed illness and treatment beliefs in relationship to medical adherence in 38 adolescents with cystic fibrosis (Bucks et al., 2009). The findings of this study indicated that believing that one's illness was amenable to treatment was predictive

of adherence to treatment regimens (e.g. taking antibiotics) (Bucks et al., 2009). As presented, Broadbent and colleagues (2006) explored illness beliefs and health behaviors in patients with a variety of medical conditions. Specific to asthma patients (n = 309), those patients who perceived their treatment as being effective had lower morbidity rates (Broadbent et al., 2006).

Potential for an association between illness representations and health behaviors in adolescents with cardiac channelopathies. Although studies have not been done, it seems likely that adolescents with cardiac channelopathies will develop some beliefs or cognitive representations about their chronic medical conditions (Leventhal et al., 2001; Leventhal et al., 1980). The types of beliefs that they develop may range and may or may not be similar to individuals with other chronic and medical conditions. If some patients in this medical population develop illness beliefs regarding control, identity, and timeline that are similar to those of other patients with chronic and life-threatening illnesses, their beliefs may also be associated with maladaptive coping and health behaviors such as medical non-adherence (Hagger & Orbell, 2003).

With regard to control, cardiac channelopathy patients who believe they have control over the illness may be more likely than those who believe that they do not have control over the illness to utilize adaptive coping (e.g., problem focused strategies) and follow their treatment regimens (Hagger & Orbell, 2003). Related to illness identity, channelopathy patients who view their conditions as causing them to experience many unwanted consequences and symptoms may be more likely to utilize maladaptive coping strategies (e.g., avoidance) and be medically non-adherent (Hagger & Orbell, 2003);

Hopman & Rijken, 2013; Kemp et al., 1999). In terms of illness duration, patients with cardiac channelopathies who perceive their illnesses as being terminal or life-threatening may be less likely to engage in positive health behaviors, medical adherence and self-care, than those who view their illnesses as being of long duration but not terminal. The types of illness beliefs maintained by individuals with cardiac channelopathies and whether or not there is an association between these beliefs and health behaviors needs to be explored further because both are currently unknown.

Social problem solving is associated with engagement in high-risk behavior among adolescents. Similar to quality of life and illness representations, social problem solving is associated with engagement in high-risk behaviors in individuals with and without chronic medical conditions (Eskin, Savk, Uslu, & Kucukaydogam, 2014; Frauenknecht & Black, 1995; Hill-Briggs, 2003). Social problem solving, according to D’Zurilla and Nezu (2000), is a self-directed process in which one engages to cope, manage, and address effectively a variety of acute (e.g., forgetting one’s homework at home) and long-term problems (e.g. chronic illness) (D’Zurilla & Nezu, 2000; D’Zurilla, Nezu, & Maydeu-Olivares, 2004; Eskin et al., 2014; Frauenknecht & Black, 2003; Nezu, Nezu, & D’Zurilla, 2012). Frauenknecht and Black’s (2003) problem solving model for adolescents suggests that the social problem solving process is multidimensional and consists of two processes, automatic and evaluative (Frauenknecht & Black, 2003).

The automatic and evaluative processes are utilized individually to manage and attenuate effectively any stress associated with acute and long term problems (Frauenknecht & Black, 2003; Frauenknecht & Black, 1995). The automatic process is

defined as a simplistic, habitual approach in which one implements a learned response derived from one's past experiences, rules, and beliefs that have been identified as effective solutions (Frauenknecht & Black, 2003; Frauenknecht & Black, 1995). One will continue to utilize this automatic process until it is determined that the habitual response will not successfully solve the problem or when one must solve a novel problem (Frauenknecht & Black, 2003). When the automatic process is determined to be no longer effective, one will then enact the evaluative process, which is a multifaceted formal procedure comprising problem orientation and skills (Frauenknecht & Black, 2003).

The problem solving orientation component is the motivational and cognitive-affective aspect of the social problem solving process (D'Zurilla & Nezu, 2000; D'Zurilla & Goldfried, 1971; Frauenknecht & Black, 2003; Frauenknecht & Black, 1995). The cognitive aspects of this process include an individual's beliefs about his or her knowledge and ability to engage effectively in the evaluation process (D'Zurilla et al., 2004; Eskin et al., 2014; Frauenknecht & Black, 2003; Hill-Briggs, 2003; Nezu et al., 2012). The emotional or affect component is associated with an individual's feelings that result when he or she tries to solve problems (Frauenknecht & Black, 2003). Individuals' problem solving orientations co-occur on their own continuums and are not, globally, either positive or negative; rather, individuals can utilize both orientations, so that they may maintain a positive orientation for solving one type of problem and a negative orientation for another set of problems (D'Zurilla et al., 2004; Nezu et al., 2012). For example, an individual may utilize a positive orientation when he or she has interpersonal conflicts, but utilize a negative orientation when he or she has medical difficulties

(D’Zurilla et al., 2004; Eskin et al., 2014; Nezu et al., 2012).

A positive orientation is defined as one’s tendency to view his or her problems as achievable challenges and one’s belief in his or her ability to solve problems successfully (D’Zurilla et al., 2004; Eskin et al., 2014; Jaffee & D’Zurilla, 2009; Nezu et al., 2012). Individuals with a positive orientation acknowledge that effectively addressing their problems will require them to exert a certain amount of effort, and they recognize that negative emotions are a normal aspect of the problem solving process (D’Zurilla et al., 2004; Jaffee & D’Zurilla, 2009; Nezu et al., 2012). Thus, these aspects of the problem solving process do not decrease their motivation for addressing difficulties (D’Zurilla et al., 2004; Jaffee & D’Zurilla, 2009; Nezu et al., 2012). A negative orientation is a tendency to view problems as an unsolvable threat to one’s well-being (D’Zurilla et al., 2004; Eskin et al., 2014; Hill-Briggs, 2003; Jaffee & D’Zurilla, 2009; Nezu et al., 2012). Individuals who maintain this perspective believe that they are incapable of effectively resolving their problems (D’Zurilla et al., 2004; Jaffee & D’Zurilla, 2009; Nezu et al., 2012). Consequently, these individuals often become dysregulated and frustrated when problems arise, which decreases their motivation to address their difficulties (D’Zurilla et al., 2004; Nezu et al., 2012).

Problem solving styles, or the behavioral component of the evaluation process, comprise an individual’s coping mechanisms or behavioral approaches to solving problems and include both cognitions and behavioral actions (D’Zurilla et al., 2004; Eskin et al., 2014; Frauenknecht & Black, 2003; Hill-Briggs, 2003). Individuals who utilize a rational problem solving style (RPS) intentionally utilize their problem solving

skill set, which often results in their effectively remediating their problems or concerns (D’Zurilla et al., 2004; Eskin et al., 2014; Jaffee & D’Zurilla, 2009; Hill-Briggs, 2003; Nezu et al., 2012). This approach to problem solving is considered to be an adaptive coping mechanism that is employed to decrease one’s stress associated with his or her circumstances (D’Zurilla et al., 2004; Eskin et al., 2014; Jaffee & D’Zurilla, 2009; Hill-Briggs, 2003; Nezu et al., 2012). Impulsive/careless and avoidant styles of problem solving are considered to be maladaptive coping mechanisms that result from deficits within individuals’ problem solving skill sets (D’Zurilla et al., 2004; Eskin et al., 2014; Jaffee & D’Zurilla, 2009; Hill-Briggs, 2003; Nezu et al., 2012).

One utilizes an impulsive/careless style (ICS) when he or she attempts to solve his or her problem without considering other options or evaluating the effectiveness of alternatives (D’Zurilla et al., 2004; Eskin et al., 2014; Jaffee & D’Zurilla, 2009; Hill-Briggs, 2003; Nezu et al., 2012). Often the individual’s attempts to solve his or her problems are incomplete and hurried (D’Zurilla et al., 2004; Eskin et al., 2014).

Individuals with an avoidant style tend to procrastinate, or they do not even attempt to solve their problems (D’Zurilla et al., 2004; Eskin et al., 2014; Jaffee & D’Zurilla, 2009; Hill-Briggs, 2003; Nezu et al., 2012). In fact, they often rely on others to solve problems for them, and they frequently do not take responsibility for their problems or failed solutions (Eskin et al., 2014; Jaffee & D’Zurilla, 2009; Nezu et al., 2012).

The problem solving steps that comprise the evaluation process include general problem identification, specific problem identification, decision making (problem selection, alternative generation, consequences prediction), alternative selection, strategic

plan implementation, progress evaluation, and reorganization (Frauenknecht & Black, 2003). General problem identification is an individual's ability to utilize cues, such as emotional responses or physiological sensations, to identify that he or she is experiencing a problem (Frauenknecht & Black, 2003). After one recognizes that there is a general problem he or she must engage the next two steps of the process and identify and choose the specific problem by utilizing a series of cognitive skills such as self-monitoring and Socratic questioning (Frauenknecht & Black, 2003). In addition, this step occurs when the individual must determine to what extent he or she has control over the problem (Frauenknecht & Black, 2003).

After determining the problem, the individual must next engage the decision making steps, which consist of alternative generation, consequence prediction, and alternative selection (Frauenknecht & Black, 2003). The alternative generation step requires the individual to brainstorm a variety of possible as well as implausible solutions to his or her problem (Frauenknecht & Black, 2003; Nezu et al., 2012). Brainstorming implausible solutions helps to increase cognitive flexibility; this consequently increases the likelihood of determining a solution that may effectively solve one's concern (Frauenknecht & Black, 2003). After a list of solutions has been generated, the individual must engage in consequence prediction, in which he or she creates a list of advantages and disadvantages to implementing each identified solution (Frauenknecht & Black, 2003). Then the individual utilizes alternatives selection and chooses the solution that he or she feels will be most effective at mitigating his or her problem (Frauenknecht & Black, 2003).

Following decision making, the individual must apply the solution implementation step by creating a strategic plan (Frauenknecht & Black, 2003). When creating this plan, the adolescent must consider the five following components: the behavioral action needed to implement the solution; who is going to be involved in enacting the solution; when will one implement the behavioral actions associated with the solution; where will one implement the behavioral actions of the solution; and how will one determine if he or she has successfully solved his or her problem (Frauenknecht & Black, 2003). Following the implementation step, the individual must engage in the process evaluation and reorganization steps (Frauenknecht & Black, 2003). One engages the process evaluation component by self-reflecting on whether or not his or her strategic plan has adequately answered the behavioral objective set during the solution implementation step (Frauenknecht & Black, 2003).

If the behavioral objective has been met, then the problem is considered to be resolved, but if the behavioral objective has not been met, then the adolescent must implement the final step, reorganization (Frauenknecht & Black, 2003). During this step, the person tries to determine what prevented him or her from meeting his or her objective by considering the following: did the strategic plan include all of the five identified areas to consider; did he/she consider all of the pros/cons of each possible solutions; did he/she generate novel solutions when brainstorming; did he/she choose a solution impulsively/prematurely; did he/she identify the correct problem (Frauenknecht & Black, 2003). After answering these questions, the individual must correct any errors and reimplement a corrected strategic plan (Frauenknecht & Black, 2003). This step

continues to occur until the behavioral objective is met (Frauenknecht & Black, 2003).

Social problem solving and risk-taking behaviors. Numerous research studies have examined the relationship between high-risk behaviors and problem solving abilities; the findings of these studies suggest that there is a relationship between these two variables (Frauenknecht & Brylinsky, 1996; Godshall & Elliott, 1997; Heppner et al., 1982; Nezu et al., 2013; Williams & Kleinfeiler, 1989). Specifically, under developed problem solving skills and a negative problem orientation and/or impulsive or avoidant style of social problem solving are associated with utilizing maladaptive coping strategies (e.g., substance use and self-injury) instead of adaptive coping behaviors (Douglas et al., 1997; D’Zurilla et al., 2004; Frauenknecht & Black, 2003; Frauenknecht & Brylinsky, 1996; Godshall & Elliott, 1997; Heppner, Hibbel, Neal, Weinstein, & Rabinowitz, 1982; Jaffee & D’Zurilla, 2009; Nezu et al., 2013; Williams & Kleinfeiler, 1989). For example, Heppner et al. (1982), Williams and Kleinfeiler (1989), Frauenknecht and Brylinsky (1996) examined social problem solving skills and risk behaviors in college students (Frauenknecht & Brylinsky, 1996; Heppner et al., 1982; Williams & Kleinfeiler, 1989). The sample sizes of these studies ranged from 192 to 568, and the findings suggest that individuals classified as ineffective problem solvers were more likely to engage in risk taking behaviors, such as drinking alcohol and using illicit substances (Frauenknecht & Brylinsky, 1996; Heppner et al., 1982; Williams & Kleinfeiler, 1989). Contrarily, better developed problem solving abilities are associated with less frequent engagement in high-risk behaviors, such as substance use and physical violence (Frauenknecht & Brylinsky, 1996). For example, Jaffee and D’Zurilla (2009)

examined the relationship between problem solving and a variety of adaptive and maladaptive coping behaviors in 307 adolescents; the findings suggested that effective problem solving skills were associated with less lifetime alcohol and marijuana use (Jaffee & D’Zurilla, 2009).

In addition to overall problem solving abilities, problem solving style has been associated with engagement in risk-taking behavior (Jaffee & D’Zurilla, 2009; Godshall & Elliott, 1997; Frauenknecht and Brylinsky, 1996). For example, Godshall and Elliott (1997) identified that adolescents ($n = 307$) who had a more avoidant problem solving style drank more alcohol than adolescents who had a less avoidant problem solving style (Godshall & Elliott, 1997). Frauenknecht and Brylinsky (1996), surveyed 568 college students, and findings suggested that students with a more rational problem solving style reported drinking and driving, physical violence, and not wearing a seatbelt less often than individuals with more avoidant or impulsive styles of problem solving (Frauenknecht & Brylinsky, 1996).

The connection between problem solving and maladaptive coping appears to be related to problem solving orientation and style (Nezu et al., 2012; Suso-Ribera et al., 2016). Specifically, individuals with more negative problem solving orientations appear to rely on and continue to utilize maladaptive coping strategies to solve their problems because they do not believe that they are capable of solving their problems and experience intense emotional distress in response to challenges and decreased motivation to address problems (Nezu et al., 2012). Consequently, these individuals may continue to utilize ineffective coping mechanisms instead of expending the energy necessary for

determining and implementing more effective and adaptive solutions (Nezu et al., 2012). With regard to problem solving styles, patients with an impulsive/careless style of social problem solving appear to lack cognitive flexibility and experience a decreased capacity to utilize and integrate information from the present moment into their problem solving process, which prevents individuals from being able to determine effective solutions to their problems (Suso-Ribera et al., 2016). Individuals who utilize an avoidant style of problem solving tend to engage in avoidance behaviors, which prevents them from effectively solving their problems (Suso-Ribera et al., 2016).

Social problem solving and adolescents with chronic medical conditions. All adolescents face daily problems that require them to utilize social problem solving abilities to attenuate stress and resolve their daily problems effectively (Eskin et al., 2014; Frauenknecht & Black, 1995; Hill-Briggs, 2003; Nezu et al., 2012). Adolescents with chronic conditions may face problems related solely to their medical condition in addition to typical daily problems (Frauenknecht & Black, 1995; Hill-Briggs, 2003; Nezu et al., 2012). Thus, it may be beneficial for chronically ill adolescents to have strong problem solving abilities because being an effective problem solver is predictive of one having a better ability to utilize adaptive behaviors to solve daily problems and mitigate stress (Nezu & Ronan, 1988; Nezu et al., 2013; Nock & Mendes, 2008).

In addition to adaptive coping, effective problem solving and a rational problem solving style is associated with engagement in more adaptive health behaviors (e.g., medical adherence) that can be important predictors of positive health outcomes (Hill-Briggs, 2003; Nezu et al., 2012; Suso-Ribera, Camacho-Guerrero, McCracken, Maydeu-

Olivarest, & Gullardo-Pujol, 2016). For example, Hills-Briggs (2003) reviewed empirical literature, which analyzed 12 empirical studies (with sample sizes ranging from 21 to 151) examining problem solving and self-management behaviors in adult and adolescent patients with type 1 diabetes (Hill-Briggs, 2003). Patients who endorsed a negative problem solving orientation seemed to have greater difficulty adhering to their medical regimens than patients who maintained a positive problem solving orientation (Hill-Briggs, 2003).

Social problem solving may predict risk taking behavior in some adolescents with cardiac channelopathies. Similar to adolescents without chronic medical conditions, adolescents with cardiac channelopathies may be more likely to engage in high-risk behaviors as coping strategies or solutions to their problems if they have reduced problem solving abilities, a more negative problem orientation, or an impulsive or careless problem solving style (Douglas et al., 1997; D’Zurilla et al., 2004; Frauenknecht & Black, 2003; Frauenknecht & Brylinsky, 1996; Godshall & Elliott, 1997; Heppner, Hibell, Neal, Weinstein, & Rabinowitz, 1982; Jaffee & D’Zurilla, 2009; Nezu et al., 2013; Williams & Kleinfelter, 1989). As with other individuals with chronic illnesses, adolescents with cardiac channelopathies who have reduced problem solving abilities may have an increased propensity to engage in health risk behaviors, such as medical non-adherence (Hill-Briggs, 2003). However, the problem solving abilities in adolescents with cardiac channelopathies have yet to be explored. Whether or not some patients self-report deficits in their problem solving abilities needs to be examined further. Similarly, whether or not poor problem solving abilities and problem orientation and style are

associated and predictive of engagement in high-risk behaviors needs to be examined.

The theory behind examining quality of life, illness representations, and social problem solving, independently and combined, as predictors of high-risk behavior. Quality of life, illness representations, and social problem solving likely increase individuals' vulnerabilities for high-risk behaviors both separately and when combined (Gartland, Bond, Olsson, Buzwell, & Sawyer, 2011; Greeff, Vansteenwegen, & Geldhof, 2014; Jaffee & D'Zurilla, 2009; Mandleco & Peery, 2000; Reynolds et al., 2007; Rolland & Walsh, 2006). All three variables are key components of resiliency, which is a multifaceted process comprising an individual's unique personal predispositions that interact and influence an individual's ability to overcome the negative effect associated with being exposed to a risk factor (Fergus & Zimmerman, 2005; Gartland et al., 2011; Greeff et al., 2014; Mandleco & Peery, 2000; Rolland & Walsh, 2006).

In addition to being associated with resiliency, each of these variables is individually predictive of adjustment to illness and engagement in risk-taking behaviors among individuals with chronic illnesses, so that chronically ill adolescents who maintain poor quality of life, ineffective social problem solving skills and negative illness representations are less able to adjust to living with an illness and more likely to engage in ineffective coping and high-risk behaviors, such as smoking marijuana, in an attempt to manage their stress (Denz-Penhey & Murdoch, 2008; Denz-Penhey & Murdoch, 1993; Gartland et al., 2011; Mandleco & Peery, 2000).

These variables are so influential in adjustment to chronic illness, many treatment

programs that aim to help adolescents adjust to living with a chronic illness aim to improve patients' quality of life and social problems solving skills and to reframe patients' negative illness representations (Fergus & Zimmerman, 2005; Haase, Heiney, Ruccione, & Stutzer, 1999; Mandleco & Peery, 2000). Because these factors independently influence the types of coping behaviors, maladaptive or adaptive, utilized by adolescent patients, perhaps they are more influential when combined (Denz-Penhey & Murdoch, 2008; Denz-Penhey & Murdoch, 1993; Gartland et al., 2011; Mandleco & Peery, 2000). Perhaps patients who maintain two or all three of these factors are more vulnerable to engaging in high-risk and maladaptive coping skills (e.g., substance use and medical non-adherence) to reduce or manage stress than adolescent patients with only one of the specified factors (Denz-Penhey & Murdoch, 2008; Denz-Penhey & Murdoch, 1993; Gartland et al., 2011; Mandleco & Peery, 2000).

The interaction between the high-risk nature of cardiac channelopathies and developmentally typical, low to high-risk behaviors in adolescents with cardiac channelopathies. The insidious, life-threatening nature of cardiac channelopathies, myriad treatment difficulties and obstacles, and common occurrences of developmentally typical, low to high-risk behaviors interact, and, when combined, appear to elevate further the level of risk associated with this medical population. Adolescents with cardiac channelopathy disorders are considered to have a high-risk medical disorder because a prominent feature of these disorders is episodes of potentially malignant arrhythmias, which can result in SCA (Kaufman, 2009). The risky nature of these disorders is further increased because of the many challenges associated with diagnosis and treatment of

them (Andersen et al., 2008; Kaufman, 2009; Krahn et al., 2013; Modell & Lehmann, 2006; Schwartz, 2009). Without proper diagnosis and medical interventions, these patients will likely succumb to their conditions (Abriel & Zaklyazminskaya, 2013).

Challenges in treating cardiac channelopathies. Providers who care for patients with cardiac channelopathies base their treatment recommendations on patients' ages, severity of the disease, current symptoms, history of SCA, and their responses to treatment (Algarra et al., 2011; Kahn, 2002; Napolitano, Bloise, Monteforte, & Priori, 2012). Even though taking antiarrhythmic medications, having an ICD/pacemaker surgically implanted, and making lifestyle changes can reduce occurrences of lethal arrhythmias, often these measures do not fully protect patients against SCA (Moss et al., 2000; Kahn, 2002; Zareba & Cygankiewicz, 2008). As already presented, the first line treatment for many cardiac channelopathies is daily doses of beta-blockers (Moss et al., 2000; Schwartz & Locati, 1985). However, the sole use of medications to manage patients' channelopathies is typically ineffective in individuals who have had an episode of SCA prior to their diagnoses or the onset of treatment (Moss et al., 2000).

Approximately 14% of patients who have had an episode of SCA prior to starting beta-blockers experienced another SCA within five years of beginning the medication regimen (Moss et al., 2000). Further, 50% of those individuals had SCA within 6 months of beginning their medication regimens (Moss et al., 2000). Approximately 32% of individuals who reported cardiac symptoms prior to beginning a beta-blocker regimen experienced continued cardiac symptoms or SCA within five years of beginning their medication regimens (Moss et al., 2000). Therefore, patients with active symptoms or a

past history of SCA typically require a pacemaker/ICD to reduce occurrences of SCA (Kahn, 2002). Even though these devices are meant to protect against episodes of SCA, they may be less effective in young patients, compared with adult patients (Kuhl, Sears, & Conti, 2006; Sears et al., 2009).

Treatment difficulties exacerbated by developmental tasks of adolescence. Many aspects of adolescence exacerbate difficulties associated with providing effective treatment to individuals with cardiac channelopathies. Rapid physical development that occurs during this stage can compromise the integrity of implanted devices used to correct instances of lethal cardiac rhythms (Sears et al., 2009). In fact, approximately 24% of adolescent patients experience lead complications due to physical growth (Alexander et al., 2004). In addition, adolescents typically have higher resting heart rates and quicker fluctuations in their heart rates than their adult counterparts, which makes this population more vulnerable to experiencing inappropriate device discharges and shocks (Chun, 2008; Navaratnam & Dublin, 2011). Further, adolescent changes that occur with rapid growth appear to shorten device longevity (Chun, 2008; Navaratnam & Dublin, 2011). Taken together, adolescent patients, compared with adults, are more likely to experience device malfunction and reduced device life which subsequently increases their vulnerability to occurrences of SCA (Modell & Lehmann, 2006).

In addition to physical growth, low to high-risk behaviors that typically coincide with the desire to be independent, gain social acceptance, and develop a sense of self have the potential to compromise adolescent patients' health by interfering with the efficacy of treatment. Although these behaviors increase the risk for negative health

outcomes in all ill adolescents, engagement in these behaviors is likely more detrimental to this population because of the increased risk for devastating and life-threatening consequences (Christie & Viner, 2005; Modell & Lehmann, 2006; Navaratnam & Dublin, 2011; Zeigler & Decker-Walters, 2010). Specific to this medical population, medical non-adherence (e.g., not taking their medications as prescribed, engaging in restricted activities, not attending regular appointments, and ignoring recommendations for regular device monitoring) can elevate patients' risk for experiencing treatment complications, dysfunction or failure of devices, and ultimately SCA (Christie & Viner, 2005; Lampert, 2013; Modell & Lehmann, 2006; Navaratnam & Dublin, 2011; Zeigler & Decker-Walters, 2010).

In addition to non-adherence, many other developmentally typical behaviors can greatly interfere with and sacrifice adolescent patients' health outcomes (Christie & Viner, 2005; Fanone, Hvidt, Ege, & Jensen, 2007; O'Connor, Rusyniak, & Bruno, 2005; Zeigler & Decker-Walters, 2010). Substance use and experimentation is a high-risk behavior, commonly occurring during adolescence, that can result in life-threatening consequences if used by adolescents with cardiac channelopathies (Christie & Viner, 2005; Fanone et al., 2007; O'Connor et al., 2005; Wannamethee & Shaper, 1992; Zeigler & Decker-Walters, 2010). Alcohol misuse in healthy people or individuals with normal functioning hearts has been associated with cardiac arrhythmias; those who consume the largest amounts of alcohol are at highest risk for heart rhythm irregularities (Koskinen & Kupari, 1992; O'Connor et al., 2005; Wannamethee & Shaper, 1992). If healthy individuals can experience cardiac irregularities from alcohol misuse, it seems probable

that adolescents with irregularly functioning hearts, prone to arrhythmias, may be particularly vulnerable to the effects of this substance. Because many chronically ill adolescents self-report alcohol use and a small subset admit to binge drinking, adolescents with cardiac channelopathies may also use this substance; thus, they are at risk for SCA associated with arrhythmias triggered by the alcohol (Choquet et al., 1997; Koskinen & Kupari, 1992; Nylander et al., 2014; Suris et al., 2008; Suris et al., 2005).

Similar to the use of alcohol, healthy and chronically ill individuals who use cocaine, amphetamines, or pain medications are more vulnerable to SCD (O'Connor et al., 2005; Witchel, Hancox, & Nutt, 2003). In healthy individuals, cocaine use has been highly associated with cardiac arrhythmias (O'Connor et al., 2005). This substance is thought to disrupt electrical functioning in the heart by inhibiting sodium channels and reducing vagal tone (O'Connor et al., 2005). Similarly, amphetamine and methadone use has been associated with ventricular arrhythmias and disrupted electrical conduction in the heart in individuals without any known cardiac condition (Baranchuk, Simpson, Methot, Gibson, & Strum, 2008a; Fanone et al., 2007; O'Connor et al., 2005). Because these substances can result in life-threatening arrhythmias in healthy individuals, cardiac channelopathy patients who experiment with or regularly use these substances are likely even more vulnerable to SCD because they already have a propensity for abnormal and lethal arrhythmias (Fanone et al., 2007; O'Connor et al., 2005).

The use of substances often considered to be benign and unlikely to result in arrhythmias in healthy individuals can result in dangerous and life-threatening cardiac events in individuals with cardiac conditions (Baranchuk et al., 2008a; Baranchuk, Johri,

Simpson, Methot, & Redfearn, 2008b). For example, marijuana has not been associated with cardiac arrhythmias in healthy users, but it is associated with an increased risk for SCD in patients with cardiac conditions and ICDs (Baranchuk et al., 2008a). Similarly, caffeine use in healthy individuals may cause an individual to experience cardiac symptoms, such as racing heart, but it does not appear to trigger cardiac events (Goldfarb, Teller, & Thanassoulis, 2014). However, caffeine consumption in patients with channelopathies has been associated with an increased risk for ventricular arrhythmias (Goldfarb et al., 2014). Because this population is physiologically predisposed to episodes of arrhythmias, and their developmental stage increases the probability that they will participate in a variety of low and high risk developmentally typical behaviors, it is imperative that research examine the extent to which these patients are engaging in behaviors that will interfere with the efficacy of their treatment and, subsequently, their well-being (Dovey-Pearce et al., 2005; Zeigler & Decker-Walters, 2005).

The need for research examining how developmentally typical high-risk behaviors interact and elevate the risk associated with treating this medical population. Because the developmental tasks of adolescence appear to be capable of interfering with the efficacy of treatment for chronically ill adolescent patients, health care providers have requested that researchers begin to examine this phenomenon to improve health outcomes for these patients (Dovey-Pearce et al., 2005; Zeigler & Decker-Walters, 2010). Therefore, researchers have begun to examine how adolescence interferes with the implementation of effective treatment interventions in adolescents with a variety of chronic illnesses (Dovey-Pearce et al., 2005; Zeigler & Decker-Walters,

2010). However, there is a paucity of research examining this phenomenon in adolescents with cardiac channelopathies. This lack of research is of particular concern for this population because the interaction between this developmental stage and this particular class of medical disorders appears to increase patients' risk for life-threatening consequences. Without knowing the types and frequency with which this population typically engages in high-risk behaviors, providers may be unable to determine appropriately the extent to which adolescence interferes with their patients' treatments and functioning. Further, they may be unable to develop tools to help assess and monitor for engagement in behaviors that reduce efficacy of treatment.

Additionally, there is a lack of research exploring risk and protective factors associated with and predictive of engagement in or refraining from high-risk behaviors among adolescents with cardiac channelopathies. Access to this information may help providers identify patients at greatest risk for engaging in the behaviors with the most devastating consequences, and, thus, in need of greater services such as behavioral health intervention and monitoring, more frequent appointments, substance use treatment, and family interventions. Although this information may not eliminate the risks associated with treating this population, research findings may be able to help isolate high-risk subgroups within this medical population and decrease some risk associated with treating them. Specifically, findings would inform treatment by enhancing physicians' knowledge regarding how to assess and individualize treatment to reduce occurrences of high-risk behaviors that could derail treatment (Neinstein, 2001).

Purpose of the Study

How the unique developmental behaviors of adolescence interact with the management of adolescents with cardiac channelopathies is poorly understood (Dovey-Pearce et al., 2005). Even though many physicians have requested more research assessing how adolescence interferes with treatment, there is no available information regarding this interaction for adolescents with cardiac channelopathies (Dovey-Pearce et al., 2005). Thus, little is known about how often adolescent cardiac channelopathy patients engage in low to high-risk developmentally typical behaviors that can compromise their treatment (Dovey-Pearce et al., 2005; Zeigler & Decker-Walters, 2010). This particular medical population must be cautious of and navigate many potential triggers to reduce the probability of SCA; therefore, non-adherence to medical recommendations is considered to be a high-risk behavior within this adolescent medical population (Berquist et al., 2008; Kongkaew et al., 2014; Nylander et al., 2014; Rapoff, 2007; Rapoff, 1998). Thus, it is important to determine the extent to which this population adheres to the limits and restrictions placed on them by their physicians. Acknowledging that low and high-risk developmentally typical behaviors can negatively impact treatment and cardiac channelopathy patients' health, the frequency and duration of substance use (e.g., tobacco, amphetamines, pain medications, marijuana, and alcohol) and rates of delinquent, impulsive, and risky sexual behaviors need to be examined (Zeigler & Decker-Walters, 2010). Therefore, the purpose of the current study is to examine the types of behaviors and the frequency with which adolescents with cardiac

channelopathies engage in normal, developmentally expected low and high-risk behaviors that could pose greater than normal risks for this population. Additionally, this study will aim to identify specific factors or a combination of factors that predict the likelihood of this population engaging in these specified problematic health behaviors.

Chapter 2: Hypotheses

Hypothesis 1

It is hypothesized that adolescents with cardiac channelopathies will self-report poorer quality of life than adolescents without a diagnosed chronic illness, as measured by lower total scores on the *Pediatric Quality of Life Inventory-IV (PedsQL-IV)*. This hypothesis is supported by numerous research findings that have demonstrated chronically ill adolescents, with a variety of conditions, have poorer self-reported quality of life than their healthy peers (Compass et al., 2012; Gortmaker et al., 1990; Varni, 1998; Williams et al., 2002).

Hypothesis 2

Within the cardiac condition, it is hypothesized that poorer quality of life, as measured by lower total scores on the *PedsQL-IV*, less well-developed social problem skills, as measured by lower mean scores on the *Problem Solving Skills* subscale of the *SPSI-A*, and greater negative illness representations, as measured by higher total scores on the *Brief Illness Perceptions Questionnaire*, will be predictive of engagement in high-risk behaviors, as measured by higher total scores on the *ARQ*, above and beyond age and socioeconomic status, as measured by information reported on the demographic questionnaire. This hypothesis is supported by numerous research studies that suggest that these variables are risk factors associated with engagement in risk behaviors that can increase the likelihood of healthy and chronically ill adolescents engaging in low and high-risk behaviors (Broadbent et al., 2006; Compass et al., 2012; D'Zurilla et al., 2004;

Gortmaker et al., 1990; Gullone et al., 2000; Gullone & Moore, 2000; Kuperminc & Allen, 2001; Scheier et al., 1999; Sharpe & Curran, 2005; Topolski et al., 2001; Varni, 1998; Williams et al., 2002).

Hypothesis 3

Of exploratory nature, the type of behaviors, associated risk category, and frequency of engagement in high-risk behaviors, as measured by the total score and mean scores on subscales of the *ARQ*, will be examined in a group of adolescents with cardiac channelopathies.

Hypothesis 4

Of exploratory nature, whether or not there are mean differences in the frequency, as measured by total scores on the *ARQ*, with which the cardiac and control conditions self-report engagement in high-risk behaviors will be determined.

Chapter 3: Method

Participants. A total of 22 individuals completed the eligibility questionnaire. However, data from only 14 participants were included in the current study, with 10 of the participants having a diagnosed cardiac channelopathy and 4 participants having no chronic illness. Participant data were not included in the current study if participants ($N = 4$) did not meet the study criteria. One participant was outside of the required age range, over the age of 22, and three participants in the control condition indicated that they had a chronic illness. Data from an additional four participants were not included in the analyses because the participants did not complete any questions, post the eligibility questionnaire.

Across both conditions, the majority of the sample was caucasian (92.3%), female (84.6%), and not married (100%). Most of the sample resides in the United States of America (85.7%), with only two participants indicated that they reside outside the United States of America, and the majority identify their religious affiliation as being Christian (92.3%). Regarding participants' current living environments, the majority of the participants endorsed living in the suburbs (61.5%). However, a small number of participants endorsed living on a farm (15.4%) and in a city (23.1%).

The age of the sample ranged from 13 to 22 ($M = 19.92$, $SD = 2.64$). Most of the sample indicated that they had graduated from high school (64.3%). Regarding school performance, 76.9% of the participants identified their school performances as being either somewhat above or above average. Approximately 38.5% of the sample reported

having academic accommodations, including “extra time or double time on tests,” “salty snacks and water breaks in class,” and “notes.”

Table 1. *Demographic Questionnaire Descriptive Information*

Characteristics	<i>n</i>	%
Age		
13	1	
15	1	
17	1	
19	1	
20	3	
21	2	
22	4	
Year in School		
Eighth grade (High school)	1	
Tenth Grade (High school)	1	
Twelfth Grade (High school)	1	
Sophomore in college	2	
Junior in college	4	
Senior in college	2	
College Graduate	1	
N/A	1	
Number of Individuals in household		
Live alone	1	7.7%
2	3	23.1%
3	6	46.2%
4	1	7.7%
6	1	7.7%
7 or more	1	7.7%
Relationship Status		
Single	5	38.5%
I have a boyfriend/girlfriend	7	53.8%
Other:		
Dating	1	4.5%
Performance in School		
Above Average	7	53.8%
Somewhat Above Average	3	23.1%
Average	1	7.7%
Not in school	1	7.7%
Other:		
Above Average		
until the last year	1	7.7%
Therapist for mental health concerns		
Yes	5	38.5%
No	8	61.5%

Health status descriptive statistics for the cardiac condition. Participants in the cardiac condition endorsed having the following cardiac channelopathies: BrS (11.1%), LQTS (33.3%), and CPVT (55.6%). No participants with SQTS participated in the current study. All participants indicated that they see a cardiologist; however, the frequency with which they attend their cardiology appointments ranges from every 3 months to every 2 years, with most participants indicating that they see their practitioner every 3 months (44.4%).

Although not directly assessed by the health status questionnaire, the age of diagnosis was provided by three participants and included diagnosis at birth and diagnosis at ages 7 and 9. The type of first symptoms felt by participants varied and included fainting (44.4%), sudden cardiac arrest (33.3%), low blood pressure (11.1%), and dizziness (11.1%). One participant indicated that he or she did not have an identifiable first symptom (11.1%). The age at which participants experienced their first symptoms ranged from birth to age 18. The sample identified fainting (77.8%) and having a seizure (11.1%) as symptoms they have experienced that are attributable to their cardiac channelopathies. Some participants endorsed having a cardiac emergency that required medical attention, including receiving a shock from an AED (22.2%), going to the emergency room (66.7%), and receiving a shock from their ICD (33.3%). Some participants indicated that they prepare for future cardiac emergencies by having a specific emergency plan in place at school, at work, or at a friend's house (66.7%) and wearing medical alert jewelry (55.6%).

Medical regimen and non-adherence. All participants indicated that they take medication for their cardiac conditions. In regard to medication adherence, only one participant indicated that he or she does not take his or her medication as prescribed. In addition to medication management, 3 participants indicated that they have an implantable device (33.3%). Regarding restrictions, 44.4% of participants indicated that there are certain foods that they are not allowed to consume. However, 22.2% of participants indicated that they eat foods that they have been told to avoid. Approximately 33.3% of individuals in the cardiac condition indicated that they were given specific recommendations regarding how much water they should consume. However, there was no uniform response regarding the recommended daily water intake because individuals' requirements varied greatly (e.g., "enough to stay hydrated" and "half my bodyweight in water"). Approximately 88.9% of individuals indicated that there are activities and sports in which they are not allowed to participate due to their cardiac conditions. Despite the medical recommendations, 44.4% of participants indicated that they participate in restricted activities.

Other medical conditions. Approximately 77.8% of participants indicated that they have been diagnosed with another medical condition; the identified conditions included attention deficit hyperactivity disorder, anxiety, depression, asthma, migraines, polycystic ovary syndrome, gastrointestinal symptoms, irritable bowel syndrome, autism, posttraumatic stress disorder, gastrointestinal reflux, and a "curved back." In regard to supports utilized to assist with adjusting to living with a cardiac channelopathy, two participants indicated that they see a therapist to help them cope with their cardiac

conditions, and one indicated that he or she attends a support group for people with his or her similar cardiac condition.

Table 2. *Health Status Questionnaire Descriptive Information*

Health Status Questionnaire		
Characteristics	<i>n</i>	%
Total Number of Implantable Devices		
Pacemakers only		
Two	1	11.1%
ICD with/without Pacemaker		
One	2	22.2%
Cardiology Appointments		
Every 3 months	4	44.4%
Every 6 months	2	22.2%
Once a year	2	22.2%
Once every two years	1	11.1%
Age when experienced first symptom		
At Birth -7	3	33.3%
11-15	4	44.4%
17 and older	2	22.2%
Other Medical Conditions		
ADD	1	
Anxiety	4	
Depression	3	
Asthma	2	
Migraines	1	
Irritable Bowel Syndrome	1	
Polycystic Ovary Syndrome	2	
Autism	1	
Posttraumatic Stress Disorder	1	
Gastrointestinal Symptoms	1	
Curved Back	1	
None	2	
Participate in Gym Class	4	44.4%

Inclusion/Exclusion Criteria

Cardiac condition. Participants were eligible to participate in the current study as part of the cardiac condition if they: 1) have been diagnosed with a cardiac channelopathy such as long QT syndrome (LQTS), Brugada syndrome (BrS), short QT syndrome (SQTS), and catecholaminergic polymorphic ventricular tachycardia (CPVT); 2) were actively prescribed medication or had an ICD/pacemaker; 3) were between the ages of 13 and 22; 4) completed high school/GED or were actively enrolled in school above a fifth-grade level. Participants were considered to be actively enrolled in school if they attended any private, public, online, medical day, or home schooling programs. Any adolescents who were on a medical absence from school had to be receiving in-home tutoring from a professional in their districts to be eligible for the study. Further, adolescents who attended only half day sessions due to an active 504 plan were able to participate in the current study. Participants with more than one chronic condition, such as seasonal allergies or anxiety, were eligible for the current study if they were willing to disclose information related to the status and current treatment regimen for any other non-cardiac conditions. Prospective participants who were not actively enrolled in an academic program or who did not meet the other listed criteria regarding exceptions, as listed previously, were not eligible for participation.

Control condition. Participants were eligible for the current study as part of the control condition if they: 1) had never received a diagnosis of a chronic medical or psychiatric condition such as diabetes, depression, thyroid disorders, or asthma; 2) took daily contraceptive medication, allergy medication, or multivitamins; 3) were between

the ages of 13 and 22; and 4) had completed high school/GED or were actively enrolled in school above a fifth-grade level. Participants had to be attending private, public, online, or a homeschooling program to be considered actively enrolled in school.

Participants who did not obtain their high school diplomas/GEDs or were not actively enrolled in an education program were not be eligible for the current study. Participants were ineligible for participation if they had been diagnosed with a chronic condition in the past, or if their disorders were considered to be in remission or resolved.

Measures

Demographic questionnaire. The participants completed a demographic questionnaire that assesses various data, including age, gender, sex, socioeconomic status, ethnicity, year in school, and race.

Health status questionnaire. Participants in the cardiac condition completed a health status questionnaire that assessed a variety of health information, including name of diagnosed cardiac channelopathy, names of other diagnosed medical conditions, names of providers who had diagnosed their cardiac channelopathy, their providers' specialties, the current medical regimens for their cardiac channelopathy, current treatment regimens for other diagnosed medical or psychiatric conditions, and information about their past medical histories.

Pediatric Quality of Life Inventory-IV (PedsQL-IV; Varni, 1998). The adolescent version of this questionnaire, developed for individuals ranging in age from 13-18, was utilized to assess participants' physical and psychosocial functioning over the past month (Varni, Burwinkle, Seid, & Skarr, 2003). These areas were assessed through four subscales: *Physical Functioning* (8 items), *Emotional Functioning* (5 items), *Social Functioning* (5 items), and *School Functioning* (5 items) (Varni et al., 2003). This measure consists of 23 items (e.g. problems with "paying attention in class") measured on a 5 point Likert-type scale, ranging from 0 (Never) to 4 (Almost Always) (Varni et al., 2003). To score this inventory, all items are transformed linearly onto a 0 to 100 scale (0 = 100, 1 = 75, 3 = 25, and 4 = 0) (Varni et al., 2003). Missing data for items on subscales were imputed using the mean of the subscale from which data were missing.

Individuals' overall quality of life was determined by finding the mean of all subscales; higher scores indicated better overall quality of life (Varni et al., 2003). Individuals' physical quality of life was determined by finding the mean of the items designated as composing this particular subscale; higher scores indicated better physical functioning (Varni et al., 2003). Individuals' psychosocial quality of life was determined by finding the mean of scores on the *Emotional Functioning*, *Social Functioning*, and *School Functioning* subscales; higher scores indicated better psychosocial functioning (Varni et al., 2003). Participants' emotional, school, and social functioning were determined by finding the mean of the items designated as composing each individual subscale; higher scores indicated better functioning (Varni et al., 2003). This measure has high internal consistency with a Cronbach's alpha of .89 and is considered to be a valid

measure of various aspects of functioning so that it is highly correlated with other questionnaires that measure physical and psychological functioning (Varni et al., 2003). In addition, it has high divergent validity to the degree that it can distinguish between children with and children without chronic health conditions (Varni et al., 2003).

Social Problem Solving Inventory for Adolescents (SPSI-A; Fraeunkecht & Black, 2003). This self-report inventory was utilized to measure participants' attitudes and beliefs regarding everyday problems, the problem solving process, and their abilities to solve their own problems (Fraeunkecht & Black, 2003; Fraeunkecht & Black, 1995). In addition, this inventory was used to measure individuals' problem solving abilities (Fraeunkecht & Black, 2003; Fraeunkecht & Black, 1995). These areas are assessed by three scales: *Automatic Process scale* (APS: 3 items), *Problem Orientation scale* (POS: 9 items), *Problem Solving Skills Scale* (PSSS: 18 items) (Fraeunkecht & Black, 1995). The *Problem Orientation Scale* comprises 3 subscales: *Cognitive* (COG), *Emotion* (EMO), and *Behavior* (BEH) (Fraeunkecht & Black, 1995). The *Problem Solving Skills Scale* comprises 6 subscales: *Problem Identification* (PID), *Alternative Generations* (ALT), *Consequence Prediction* (CON), *Implementation* (IMP), *Evaluation* (EVL) and *Reorganization* (REO) (Fraeunkecht & Black, 2003). This questionnaire consists of 30 items (e.g., "I try to see a problem as a challenge rather than a threat.") measured on a 5 point Likert-type scale, ranging from 0 (not true at all of me) to 4 (extremely true of me) (Fraeunkecht & Black, 1995).

A total scale score, which measures social problem solving proficiency, was determined by summing the three main scales (APS, POS, and PSSS) and then dividing

the total score by three (Fraeunkecht & Black, 1995). To determine participants' problem solving skill knowledge and abilities, the mean of the *Problem Solving Skills Scale* was determined, by summing the six subscales of which it is composed (PID, ALT, CON, IMP, EVL, and REO) and dividing that total score by six (Fraeunkecht & Black, 1995). Higher scores indicated better problem solving abilities (Fraeunkecht & Black, 2003). Participants' problem solving orientations were determined by calculating the mean score of the *Problem Orientation Scale*, by adding the total scores of the three subscale scales of which this scale is composed (COG, EMO, and BEH) and then dividing that number by three (Fraeunkecht & Black, 2003). Lower mean scores indicated more negative problem solving orientations and irrational/avoidant styles (D'Zurilla et al., 1999; Fraeunkecht & Black, 1995). Participants' specific strengths and weaknesses, both in their problem solving orientations as well as the six individual problem solving skills were determined by comparing total, scale, and subscale scores within each condition (Fraeunkecht & Black, 1995).

When scoring this measure, missing items were given a score of 2 (D'Zurilla et al., 1999; Fraeunkecht & Black, 1995). This inventory has high internal consistency with Cronbach's alphas, ranging from .77 to .95 across the three main scales and with Cronbach's alphas, ranging from .76 to .90 across all eight subscales (Fraeunkecht & Black, 2003). In addition, this inventory is considered to be a valid measure of social problem solving abilities to the degree that it is highly correlated with Heppner's Problem Solving Inventory (1988) ($r = .82$) (Fraeunkecht & Black, 1995).

The Brief Perception of Illness Questionnaire (Broadbent et al., 2006). This questionnaire was utilized to assess participants' emotional and cognitive representations or beliefs about their illnesses across many domains, including consequences, timeline, personal control, treatment control, identity, coherence, concern, emotional response, and causes (Broadbent et al., 2006). This questionnaire consists of 9 items, with each item measuring one specific illness representation, measured on an 11 point Likert-type scale (e.g. "How concerned are you about your illness?"), ranging from 0 (not at all) to 10 (extremely concerned).

The sum of all nine items was utilized to determine the extent to which one maintains a more threatening view of one's illness, with higher scores indicating more threatening views (Broadbent et al., 2006). Individual items can indicate the types of illness representations that the sample or individual maintains, with higher mean scores across each item indicating higher beliefs in the associated representation. Thus, the types of illness beliefs endorsed by the current sample was determined by reviewing mean scores on each individual item. This measure has high reliability to the degree that the questionnaires test-retest ranged from .45 to .70 over three weeks and .42 to .73 over six weeks (Broadbent et al., 2006). In addition, this measure has high concurrent validity to the degree that it is highly correlated with other measures assessing patients' perceptions of their illnesses (Broadbent et al., 2006).

Adolescent Risk-Taking Questionnaire (ARQ; Gullone et al., 2000). This questionnaire was utilized to assess the types of behaviors, associated risk categories, and frequency with which participants engaged in a variety of high-risk behaviors (Gullone et al., 2000). These aspects are assessed across 4 subscales: *Thrill-Seeking Behaviors* (7 items), *Rebellious Behaviors* (5 items) *Reckless Behavior* (5 items), and *Antisocial Behavior* (5 items) (Gullone et al., 2000). The scale consists of 22 items (e.g., “racing cars”) measured on a 5 point Likert-type scale with questions pertaining to engagement in behaviors ranging from 0 (never) to 4 (very often) (Gullone et al., 2000).

The frequency of overall risk-taking was determined by summing all scores across the four subscales, with higher scores indicating greater risk-taking behavior. Frequency of engagement in each of the risk categories was determined by finding the mean of each individual subscale. This questionnaire has high internal consistency, with Cronbach's alphas ranging from .70 to .80 across all 4 subscales (Gullone et al., 2000).

Procedure

Recruitment. Participants, both in the cardiac and control conditions, were recruited through condition-specific postings on social media websites, such as Facebook and Twitter. In addition, potential participants for the cardiac condition were recruited by postings on online patient forums, such as the Inspire Community and the SADS Foundation website. Posting on social media and patient forums occurred one time per week for the duration of the study. To ensure that participants, eligible for both conditions, who do not utilize social media or patient forums had the opportunity to participate in the current study, condition-specific flyers, requesting participation were

posted in pediatrician, adolescent medicine, and cardiology offices in a variety of South Jersey and Philadelphia medical practices and clinics. In addition, flyers were sent to cardiac camps for children with these conditions, as well as to cardiac rehab programs and physical and occupational therapy offices. To ensure that individuals from many different cultural backgrounds had the opportunity to participate in the current study, medical clinics that provided services to patients who vary in socioeconomic status, ethnicity, and culture were selected.

Participants ages 18-22. Participants who were over the age of 18 and were interested in participating in the study contacted the student researcher and expressed their interest in participating via email to the email address provided in the recruitment posting. Then, the prospective participant received an email containing the informed consent form and instructions regarding how to provide consent using an e-signer program. Next, the participant signed the consent form by utilizing the secure e-signer program. After signing the informed consent form, the participant emailed the student researcher indicating that the consent form had been signed. After the student researcher verified that the consent form was signed by the participant, she signed the document and sent an email to the participant with instructions, including the link for the online survey, hosted by Survey Monkey, and a reminder to save a copy of the signed consent form to his or her computer for future reference. Participants read the email and clicked the survey link, embedded in the email, to access the online survey.

Participants ages 13-17. Participants under the age of 18 who were interested in participating in the current study had his or her parent or guardian send the student researcher an email to the address provided in the flyer, indicating his or her dependent's interest in being a participant in the study. After the student researcher received the request, the participant's parent or guardian received an email containing the informed consent form and instructions regarding how to provide consent, using an e-signer program. The parent or guardian then signed the consent form by utilizing the secure e-signer program.

After the informed consent document was signed, the parent or guardian emailed the student researcher to indicate that the consent form was completed. The student researcher then verified that the consent form was signed and utilized the e-signer to sign the consent form. The parent or guardian then received an email with a reminder to save a signed copy of the consent form to his or her computer for future reference, as well as the link to the online survey, and instructions, which directed the parent to have his or her child click on the link, embedded in the email, to access the online survey. In addition, the instructions asked the parent or guardian to allow the participant to take the survey alone in order to increase the likelihood that the participant would respond accurately and not in a socially desirable manner. Also attached to the email was a document that listed a variety of resources offering educational information about healthy coping behaviors, alcohol and substance use, and chronic conditions. After the child clicked on the link, he or she was required to provide assent by reading the assent consent form and clicking the designated agree button.

After providing consent or assent, all participants were directed to a screen that ensured participant eligibility by having participants check off all requirements they were required to meet; these requirements were designated in the recruitment flyer. If they did not meet the inclusion criteria either for the cardiac or for control conditions, they were directed to a “thank you” page. After completing the eligibility questionnaire, participants were directed to a condition. All participants under the age of 18 had to provide consent prior to being directed to the condition-specific survey.

Cardiac condition specific survey. After having been deemed eligible for the current study and having provided assent (for those under age 18 only), participants in the cardiac condition completed the health status questionnaire, *PedsQL-IV*, *SPSI-A*, the *Brief Perception of Illness Questionnaire*, the *ARQ*, and the demographic questionnaire. After completing the survey, participants were directed to the “thank you” page.

Control condition specific survey. After having been deemed eligible for the current study and having provided assent (for those under age 18 only), individuals in the control condition completed the *PedsQL-4*, *SPSI-A*, *ARQ*, and the demographic questionnaire. After completing these questionnaires, the participants were directed to the “thank you” page.

“Thank you” page for both conditions. The “thank you” page thanked participants for their time and provided them with information regarding whom they could contact should they have questions about the materials or findings of the study, or if they needed to discuss an unwanted reaction resulting from their participation. Further, the “thank you” page provided a variety of resources that offered educational information about healthy

coping behaviors, alcohol and substance use, and chronic conditions. Further, the resources provided information regarding places where adolescents can seek professional services if they were engaging in high-risk behaviors, having difficulty adjusting to adolescence, or experiencing psychiatric symptoms, such as anxiety or depression that were interfering with their functioning. The resource document also contained information specific to cardiac conditions, including associations and not-for-profit foundations that provide supportive services for the cardiac community and information regarding evidence-based therapies designed to help patients adjust to their conditions. As noted, all participants or parents/guardians who signed the consent form received a pdf of these resources that could be saved to their computer for future reference.

Chapter 4: Results

Illness beliefs

Overall, individuals in the cardiac condition appeared to maintain neutral beliefs about how threatening they believed to be the nature of their conditions ($M = 43.50$, $SD = 10.71$). However, this may not accurately represent the entire sample because there was some variability in how the overall threatening nature of the illness was viewed by individual participants. Specifically, 5 participants appeared to maintain a less threatening view of their conditions, with their mean scores ranging from 22 to 43. However, 5 participants appeared to hold a more threatening view of their illnesses, with their mean scores ranging from 44 to 57.

A review of specific illness beliefs maintained by the cardiac group indicated that overall, the sample viewed their conditions as being lifelong ($M = 10.80$, $SD = .63$, range 0-10) and as having a somewhat negative impact on their lives ($M = 7.50$, $SD = 2.59$, range 0-10). In addition, the sample endorsed the severity of their symptoms as being moderate ($M = 5.20$, $SD = 3.79$, range 0-10). Participants perceived themselves as having a moderate amount of personal control over their illnesses ($M = 5.90$, $SD = 2.73$, range 0-10). In addition, they perceived their treatment as being helpful in controlling their medical conditions ($M = 8.00$; $SD = 2.26$, range 0-10).

The sample endorsed having moderate cognitive concerns about their conditions ($M = 6.8$; $SD = 3.16$, range 0-10), and they believed that their illnesses had a moderate impact on their emotional well-being ($M = 6.50$, $SD = 3.53$, range 0-10). Participants perceived themselves as having a very well developed and clear understanding of their illnesses (M

= 10.20, SD = 1.62, range 0-10). Regarding the cause of their illnesses, all of the respondents, with the exception of one, attributed the development of their conditions to genetics. However, 5 participants identified additional contributing factors, other than genetics that likely led to the development of their conditions, including “exercise and fate,” “unlucky and wrong life to be lived,” and “stress and medication.” The participant who did not list genetics as a contributing factor indicated that she was unsure about the reason why her condition developed.

Quality of life

Psychosocial and physical health quality of life for the cardiac condition. The cardiac conditions’ overall mean score for their psychosocial (M = 62.59, SD = 21.89) and physical (M = 61.81, SD = 21.07) functioning or quality of life suggests that these domains are functioning equally. However, examining mean scores for these scales may not accurately depict all individuals psychosocial and physical functioning due to variability among the individual scores. Participants’ psychosocial scores ranged from 25.00 to 91.67, with two participants’ individual mean scores measuring 1 standard deviation below the mean. In regard to individual aspects of psychosocial functioning, participants rated their social (M = 68.89, SD = 24.21) and school (M = 62.22, SD = 24.76) functioning as being slightly higher than their emotional functioning (M = 56.67, SD = 25.86). Participants’ physical functioning scores ranged from 34.38 to 93.75, with 3 participants’ individual scores falling 1 standard deviation below the mean. Therefore, some participants in this group do appear to have diminished psychosocial and/or physical functioning.

Psychosocial and physical health quality of life for the control condition.

Psychosocial (M = 73.33, SD = 8.05) and physical (M = 79.69, SD = 5.98) overall mean scores for participants in the control condition appeared to indicate that neither one of these domains is better functioning than the other. Unlike the cardiac condition, the overall mean score on these scales appears to be a more accurate depiction of all individual participants' functioning because all individuals scores, on both scales, were within one standard deviation of the group mean for each scale. With regard to the individual domain of psychosocial functioning, participants' social (M = 86.25, SD = 7.50) and school (M = 78.75, SD = 11.81) functioning were higher than their emotional functioning (M = 55.00, SD = 12.25).

Table 3.
Quality of Life for Cardiac and Control Conditions

Scale/Subscale	M	SD
Cardiac Condition		
Psychosocial Functioning	62.59	21.89
Emotional Functioning	56.67	25.86
Social Functioning	68.89	24.21
School Functioning	62.22	24.76
Physical Functioning	61.81	21.07
Control Condition		
Psychosocial Functioning	73.33	8.05
Emotional Functioning	55.00	12.25
Social Functioning	86.25	7.50
School Functioning	78.75	11.81
Physical Functioning	79.69	5.98

*Note: M = Mean. SD = Standard Deviation

Comparison of Quality of Life in Adolescents With and Without a Cardiac Condition

Comparison of overall and psychosocial and physical functioning. To examine hypothesis 1, which stated that adolescents with cardiac channelopathies would have poorer quality of life than their healthy peers, a Mann-Whitney U Test was conducted to determine if there is a significant difference between the self-reported quality of life between adolescents with a cardiac condition and adolescents without a cardiac condition. A Mann-Whitney U test indicated that there are no significant differences in overall quality of life. Post hoc analyses were conducted to determine if there were significant differences in physical and psychosocial functioning between participants in the cardiac and control conditions. A Mann-Whitney U test indicated that there were no significant differences in physical and psychosocial functioning between individuals in the two conditions.

Table 4.
Differences in Individual Psychosocial and Physical Functioning among Cardiac and Control Conditions

	Cardiac	Control			
Subscale	Mdn	Mdn	U	Z	r
Overall Quality of life	71.74	73.37	12.50	-8.51	-.24
Physical Functioning	65.63	78.13	28.50	-1.63	-.45
Psychosocial Functioning	71.67	70.83	20.50	-.39	-.11

Note: Mdn = median, higher medians indicate better functioning.

*p<.05

Comparison of individual psychosocial functioning domains. Post hoc analyses were conducted to determine if there were any significant differences in the individual aspects of psychosocial functioning between adolescents in the cardiac and in the control condition. A Mann-Whitney U test was conducted and indicated that there were no significant differences in self-reported emotional, social, and school functioning between the cardiac and control conditions.

Table 5.
Differences in Individual Psychosocial Components of Functioning among Cardiac and Control Conditions

	Cardiac	Control			
Subscale	Mdn	Mdn	U	Z	r
Emotional Functioning	50.00	56.67	17.00	-.16	-.04
Social Functioning	80.00	85.00	24.50	-1.01	-.28
School Functioning	60.00	75.00	26.50	-1.32	-.37

Note: Mdn = median, higher medians indicate better functioning.
*p<.05

Predicting Engagement in High-Risk Behavior.

Hypothesis 2 aimed to examine whether or not poorer quality of life, as measured by lower total scores on the *PedsQL-IV*, less well-developed social problem skills, as measured by lower mean scores on the *Problem Solving Skills* subscale of the *SPSI-A*, and greater negative illness representations, as measured by higher total scores on the *Brief Illness Perceptions Questionnaire*, would be predictive of engagement in high-risk behaviors, as measured by higher total scores on the *ARQ*, above and beyond age and

socioeconomic status, as measured by information reported on the demographic questionnaire. Unfortunately, the statistical analysis needed to examine this hypothesis could not be conducted due to lack of adequate power, which resulted from small sample size.

Social Problem Solving Descriptive Information

Social problem solving strengths and weaknesses for cardiac and control condition.

Cardiac condition problem solving relative strengths and weaknesses. The cardiac condition appears to have relative problem solving strengths and weaknesses in problem orientation and individual problem solving skills. With regard to their problem solving orientation, the group has a relative strength in their problem orientation cognitions or beliefs about their intellectual ability to solve their own problems ($M = 3.19$, $SD = .67$) and a relative weakness in their problem orientation emotions or the feelings they experience when they have a problem ($M = 2.70$, $SD = 1.09$). Therefore, the individuals believe they have the cognitive capacity to solve their problems, but they may face some emotional concern when they actually experience a problem. With regard to individual problem solving skills, the group has a relative strength in their ability to determine the consequences of potential solutions to their problems ($M = 3.22$, $SD = .75$) and a relative weakness in their ability to implement the solutions to their problems ($M = 2.63$, $SD = .68$).

Control condition problem solving relative strengths and weaknesses. The control condition appears to have relative strengths and weaknesses in their problem solving orientation and in the individual problem solving skills. With regard to their problem solving orientation, the control group appears to have a relative strength in their problem orientation behaviors or their willingness to approach their problems ($M = 2.56$, $SD = .69$), but they have a relative weakness in their problem orientation emotions or the feelings they experience when they have a problem that needs to be solved ($M = 2.25$, $SD = 1.29$). Thus, the group may feel motivation to approach their problems, but they may experience some emotional concerns when they face problems. With regard to the individual problem solving skills, the group has a relative strength in the ability to identify possible consequences to each potential solution to their problems ($M = 2.33$, $SD = 1.66$) and a relative weakness in the ability to reorganize other potential solutions that may be more effective in solving their problems when the solution they implemented did not solve their problems ($M = 1.17$, $SD = .69$).

Differences in Problem Solving Abilities among Cardiac and Control Conditions

Post hoc analysis examining differences in overall problem solving abilities between the cardiac and healthy conditions. A post hoc analysis was conducted to determine if there were significant mean differences in overall problem solving abilities between the cardiac and control conditions. A Mann-Whitney U Test was conducted, and the result indicated that there was a significant difference, with individuals with cardiac conditions having better overall problem solving abilities than individuals in the control condition.

Table 6.
Differences in Overall Problem Solving Abilities Among Cardiac and Control Conditions

	Cardiac	Control			
Subscale	Mdn	Mdn	U	Z	r
Problem Solving Abilities	3.00	2.22	3.00	-2.32*	-.64

Note: Mdn = median, higher medians indicate better overall problem solving abilities
 *p<.05

Post hoc analysis examining differences in automatic processing and problem orientation between the cardiac and control conditions. A post hoc analysis was conducted to determine if there were significant mean differences in automatic processing and problem orientation between the cardiac and control conditions. There were significant differences in automatic processing between cardiac and control conditions, with the cardiac condition having significantly better automatic processing than the control condition. Thus, the cardiac condition appears to be better able to apply strategies that have successfully mitigated problems in the past than individuals in the control condition. There were no significant differences in overall problem orientation between the two groups. Similarly, there were no significant differences in cognitive, emotional, and behavioral aspects of problem orientation between the two groups.

Table 7.
Differences in Problem Orientation Among Cardiac and Control Conditions

Scale/Subscale	Cardiac	Control	U	Z	r
	Mdn	Mdn			
Automatic Process	3.33	2.33	4.50	-2.12	-.59*
Problem Orientation	2.78	2.39	13.50	-.696	-.19
Cognitive Orientation	3.33	2.50	10.00	-1.26	-.35
Emotion Orientation	2.67	2.17	14.50	-.55	-.15
Behavior Orientation	3.00	2.67	15.00	-.47	-.13

Note: Mdn = median, higher medians indicate better abilities within each domain.

* $p < .05$

Post hoc analysis examining differences in overall problem solving skills

between the cardiac and control conditions. A post hoc analysis was conducted to explore whether or not there were significant differences in participants' overall problem solving skill knowledge, as well as within each of the six individual skills. A Mann-Whitney U test indicated that there were no significant differences in overall problem solving skills knowledge and application among individuals in the cardiac and control conditions.

Table 8.
Differences in Overall Problem Solving Skills Knowledge/Application Between Cardiac and Control Conditions

	Cardiac	Control			
Subscale	Mdn	Mdn	U	Z	r
Problem Solving Skills	3.11	1.94	5.50	-1.93	-.54

Note: Mdn = median, higher medians indicate better skills knowledge and application.
 *p<.05

Post hoc analysis examining differences in individual problem solving skills between the cardiac and control conditions. A Mann-Whitney U test indicated that the cardiac condition, compared with the control condition, had significantly better knowledge and application abilities in the domains of problem identification, reorganization, and evaluation. Thus, the cardiac group appears to have better developed abilities than the control condition in identifying the fact that a problem exists through noticing discomfort in one’s physiological, emotional, and behavioral domains; evaluating and reflecting about whether or not, a solution adequately solved one’s problem, and recycling and determining a new solution to the problem if the previous solution did not adequately solve the problem. Both conditions equally developed abilities in brainstorming potential solutions to a proble, in predicting the consequences, advantages and disadvantages of each potential solution, and in implementing the solution which was determined to be the best solution to his or her problem.

Table 9.
Differences in Individual Problem Solving Skills Knowledge/Application Between Cardiac and Control Conditions

Subscale	Cardiac	Control	U	Z	r
	Mdn	Mdn			
Reorganization	3.33	1.17	1.00	-2.65***	-.74
Problem Identification	3.00	1.33	1.50	-2.62***	-.73
Evaluation	2.67	1.67	2.00	-2.55**	-.71
Consequences	3.33	2.50	13.00	-.78	-.22
Alternative Generation	3.33	2.67	12.00	-.93	-.26
Implementation	2.67	2.00	7.50	-1.64	-.45

Note: Mdn = median, higher medians indicate better skills knowledge and application.
 *p<.05. **p = .01. *** p<.01

Risk-Taking

To examine hypothesis 3, which aimed to examine the type, associated risk category, and frequency of high-risk behaviors within the cardiac condition, descriptive statistics of the *ARQ* were conducted. Overall, participants in the cardiac condition endorsed items that suggest they engage in thrill-seeking (M = 4.22, SD = 1.92) and anti-social (M = 4.56, SD = 2.07) risk behaviors more often than behaviors classified as reckless (M = 2.0, SD = 1.80) and rebellious risks (M = 1.07, SD = .75).

Endorsed thrill-seeking risks. The most commonly reported actions classified as thrill seeking were entering a competition; six participants endorsed engagement in this behavior with a frequency of done “sometimes”, to done “very often,”; rollerblading was also endorsed, and five individuals reported that they rollerblade with a frequency

ranging from done “hardly ever” to done “sometimes.” Leaving school was endorsed by four participants, who indicated that they engage in this behavior with a frequency ranging from “hardly ever” to “sometimes.” Three participants indicated that they “sometimes” snow ski, and one participant indicated that he or she parachutes “sometimes.” No participants endorsed flying a plane or engaging in Taekwondo.

Endorsed antisocial risks. The most commonly endorsed behaviors classified as anti-social risks included talking to strangers and overeating. Specifically, eight participants indicate that they talk to strangers and seven indicated that they overeat; the reported frequency of both behaviors ranged from “hardly ever” done to done “often.” Three participants reported that they cheat, and two participants endorsed teasing other individuals; the frequency with which both behaviors occur ranged from “hardly ever” to “sometimes.” No participants indicated that they sniff glue or gas.

Endorsed rebellious risks. With regard to rebellious risks, the most commonly endorsed behavior was staying out late, with seven participants indicating that they engaged in this behavior with a frequency ranging from done “sometimes” to done “often.” Four participants indicated that they drink alcohol until they feel drunk, with a frequency of this behavior ranging from “hardly ever” done to “sometimes” done. No participants endorsed smoking or taking drugs.

Endorsed reckless risks. In the reckless risks category, the only behaviors that were endorsed by participants were speeding and having unprotected sex. Specifically, six participants indicated that they engage in speeding with a frequency ranging from “hardly ever” done to done “often.” Three participants indicated that they have

unprotected sex, with the frequency ranging from “hardly ever” to “sometimes.” No participants indicated that they have stolen cars to go for a joy ride, have driven without a license, or engaged in drinking and driving.

Table 10.
Frequency of Engagement in High-risk Behavior in Cardiac Condition

Risk Taking Behavior Categories/Behavior	<i>n</i>	%
Thrill-Seeking Risks		
Entering a competition	6	66.7%
Rollerblading	5	55.6%
Leaving school	4	44.4%
Snow Skiing	3	33.3%
Parachuting	1	11.1%
Flying a plane	0	0.0%
Taekwondo	0	0.0%
Rebellious Risks		
Staying out late	7	77.8%
Get drunk	4	44.4%
Smoking or taking drugs	0	0.0%
Reckless Risks		
Speeding	6	66.7%
Unprotected sex	3	33.3%
Stolen car for joy ride	0	0.0%
Drive without a license	0	0.0%
Drink and Drive	0	0.0%
Anti-Social Risks		
Talking to strangers	8	88.9%
Over eat	7	77.8%
Cheat	3	33.3%
Teasing others	2	22.2%
Sniff glue or gas	0	0.00%

Comparison of Risk-Taking among Cardiac and Control Conditions.

To examine hypothesis 4, which aimed to explore whether or not there are mean differences in the frequency of risk-taking behaviors among the cardiac and control conditions, as measured by total subscale scores on the *ARQ*, a Mann-Whitney U Test was conducted, and the results indicated that there were no significant differences in frequency of engagement in risk-taking behavior. Thus, the cardiac and healthy conditions are engaging in risk-taking behaviors at a similar frequency. Post hoc analyses were conducted to see if there were differences in the frequency of engagement in behaviors across risk categories. A Mann-Whitney-U test was conducted and revealed that there were no significant differences, between the cardiac and control conditions, in the frequency of engagement in behaviors across the four risk categories.

Table 11.

Differences in Risk Taking Behavior Between Cardiac and Control Conditions

	Cardiac	Control			
Subscale	Mdn	Mdn	U	Z	r
Total ARQ Score	13.00	14.00	12.50	-.85	-.24
Thrill-seeking Risks	4.00	2.50	9.50	-1.33	-.37
Rebellious Risks	1.20	2.60	29.00	-1.72	-.48
Reckless Risks	2.00	4.50	27.00	-1.40	-.39
Anti-social Risks	5.00	5.00	25.00	-.55	-.15

Note: Mdn = median, higher medians indicate greater risk taking
 *p<.05. **p = .01. *** p<.01

Chapter 5: Discussion

General Findings

Illness beliefs. Overall, the cardiac condition had a neutral view regarding how threatening they perceive the nature of their illness to be. With regard to individual beliefs about their illness, the cardiac condition viewed their illness as being lifelong, as having a somewhat negative impact on their lives and as causing them to experience a moderate number of symptoms. Participants self-reported believing that they themselves maintain a moderate amount of control over their illness; they appear to believe that their treatment regimens are helpful in controlling their condition. In addition, participants indicated that they are moderately concerned about their illness and have a well-developed understanding of their illness. The report of this cohort experiencing a moderate number of symptoms is similar to another research study, suggesting that some patients with inherited cardiovascular diseases, such as CPVT, typically experience few symptoms (Caleshu et al., 2016). It is possible that this cohort understands the nature and timeline of their conditions because they have been educated about these factors during regular cardiac appointments. However, this information is not known and is in need of further exploration. Whether this profile of illness beliefs or representations is unique to this sample or is consistent with other individuals with cardiac channelopathies needs to be further explored.

Quality of life. Hypothesis 1, which stated that the cardiac group would have poorer quality of life than the healthy condition, was not supported because there were no significant differences between the cardiac and control conditions in overall quality of life, or across the psychosocial and physical domains of functioning. This finding is different from other research findings which suggest that individuals with chronic illnesses have reduced quality of life, when compared with their healthy peers (Blumberg et al., 2012; Compass et al., 2012; Mokkink et al., 2008; Nylander et al., 2014; Perrin et al., 1993; Schmidt et al., 2003; Stanton et al., 2007; Varni et al., 2007). The cardiac sample may have rated their quality of life as being similar to participants in the control condition for a variety of reasons, including experience of symptoms, lack of implantable devices, illness beliefs, and social problem solving abilities.

Symptoms and quality of life. Past research has suggested that patients with cardiac channelopathies self-report experiencing mild symptoms associated with their medical condition (Caleshu et al., 2016). This notion was consistent with the current study; most patients reported experiencing few to moderate symptoms associated with their condition. Some research findings have demonstrated a link between severity of symptoms and quality of life because individuals with chronic conditions who experience more mild symptoms tend to have a higher self-reported quality of life (Paschalides et al., 2004; Timmers et al., 2008). Because the cardiac group for the current study reported few to moderate symptoms, it is possible that their lack of symptoms attributed to their self-reporting a quality of life being equivalent to that of their same aged healthy peers.

Implantable devices and quality of life. In addition to the severity of symptoms experienced, having an implantable device has also been associated with quality of life (Andersen et al., 2008). In fact, having an implantable device is highly associated with decreased quality of life (Andersen et al., 2008; Czosek et al., 2015; Linder et al., 2013; Sears et al., 2009; Sears et al., 2001). Some individuals report a decline in their quality of life post device implantation (Andersen et al., 2008; Czosek et al., 2015; Linder et al., 2013; Sears et al., 2009; Sears et al., 2001). The decline in quality of life is theorized to be attributable to patients' self-report of increased emotional distress and decreased social interactions, post device implantation (Andersen et al., 2008; Linder et al., 2013; Padeletti et al., 2011). The majority of the current sample do not have an implantable device and manage their cardiac channelopathy with medication only; therefore, self-reported quality of life may be higher because the participants may not have experienced the decline in quality of life typically associated with having an implantable device. Perhaps the quality of life of the current sample may have been different if more participants had implantable devices.

Illness beliefs and quality of life. Another possible reason that the cardiac condition had self-reported quality of life similar to the control condition may be related to their self-reported illness beliefs. Specifically, the cardiac condition reported viewing their illnesses as being highly controlled by medication. In addition, they reported believing that they, individually, had a moderate amount of control of their illness. Research findings have suggested that individuals who believe that their conditions can be controlled have higher self-reported quality of life than individuals who believe that

their illnesses cannot be controlled (Paschalides et al., 2004; Timmers et al., 2008). Thus, the cardiac conditions' illness beliefs may have resulted in their having a higher quality of life than a sample which may consist of individuals who view themselves as having less control over their specific illnesses.

Social problem solving and quality of life. The problem solving abilities of the cardiac condition may point to another reason related to reasons why the cardiac group reported having a quality of life that was similar to their same aged healthy peers. Individuals with well-developed problem solving skills are better able to reduce distress effectively and are less likely to develop mental health disorders such as depression, anxiety, and adjustment disorders (Frauenknecht et al., 1996; Palermo et al., 2016). Having well-developed problem solving abilities may have functioned as a protective factor for the cardiac condition, and consequently, reduced the likelihood that this group would experience reduced quality of life. Whether or not the identified factor functioned as a protective factor, improving self-reported quality of life for the current sample, needs to be examined further.

Social Problem Solving

Problem solving strengths and weaknesses. Individual strength and weakness profiles for both the cardiac and for the control conditions were reviewed. Participants in the cardiac group appear to have relative strengths in the cognitive component of problem orientation, as well as in the consequences step of the evaluation process. Therefore, the cardiac condition appears to have more self-efficacious beliefs about their intellectual capability to solve problems comparative with their beliefs about their emotional

reactions to a problem and willingness to approach their problems. In addition, their ability to determine consequences of potential solutions to their problems is better developed than the other problem solving steps in the evaluation process. The cardiac group has a relative weakness in the emotion component of problem orientation, as well as in the implementation step of the evaluation process. Therefore, the cardiac group may feel less self-efficacious about their emotional experiences when faced with a problem comparative with their beliefs about their cognitive capabilities to solve problems and willingness to approach problems. In addition, their ability to implement solutions is likely less well developed than the other skills in the evaluation process.

The control condition appears to have relative strengths in the behavioral component of problem orientation, as well as in the identifying consequences step in the evaluation process. This may indicate that the control group has strong self-efficacious beliefs about their willingness to approach and solve their problems. In comparison with their beliefs about their cognitive capability to solve problems and in their emotional reactions in response to the presence of a problem. In addition, their ability to determine the consequences of potential solutions to problems is the most well-developed skill of the evaluation process. The control condition appears to have a relative weakness in the emotional component of problem orientation, as well as in the reorganization step of the evaluation process. Thus, the participants in the control condition may have less well developed self-efficacious beliefs about their emotional reactions to problems, comparative with their beliefs about their cognitive capabilities related to solving problems and their willingness to take behavioral actions needed to solve problems. In

addition, their ability to reorganize other potential solutions to their problems when their original solution did not successfully solve their problems is likely their least well-developed skill of the evaluation process. The reason why these differences exist should be further explored in future research.

Comparison of automatic processing and problem solving orientation among cardiac and healthy conditions. Post hoc analyses were conducted to see if there were significant differences in automatic processing and problem orientation between the cardiac and healthy conditions. With regard to automatic processing, the cardiac condition appears to be significantly better able to apply the automatic process of social problem solving than the control condition. This suggests that individuals in the cardiac condition are better able to apply previously successful strategies to current problems than the individuals in the control condition. The reasons for the significance between the two conditions should be explored further to determine if this pattern is unique to this particular sample.

With regard to problem orientation, there were no significant differences noted in the cardiac or in the control condition's problem orientation, which suggests that both conditions maintain a more positive problem solving orientation. Thus, both groups believe that they have the cognitive capability to solve their problems, feel capable of solving them, and approach and take action toward solving their problems. Whether or not this finding was unique to the current samples of individuals needs to be further explored.

Comparison of overall problem solving abilities among cardiac and control conditions. With regard to overall problem solving abilities, the current study determined that the cardiac group had significantly better overall problem solving abilities than the control condition. Having significantly better social problem solving abilities than a normative control group is inconsistent with some research that has suggested that medical populations tend to have more deficits in their problem solving abilities than individuals without chronic conditions (Nezu et al., 2012). The exact reason why this particular cohort had better problem solving abilities than their healthy peers is unknown and is in need of further exploration. It may be hypothesized that the cardiac condition self-reported well developed problem solving skills because they also reported maintaining a more positive problem solving orientation and utilizing a more rational approach to solving difficulties because individuals with a more positive orientation and rational style tend to more effective problem solvers (Nezu et al., 2012). However, this theory would likely not explain the reasons why the cardiac group had significantly better self-reported problem solving abilities because there were no significant differences in self-reported positive problem solving orientation or problem solving style among the cardiac condition and control condition. Whether or not this finding is unique to this particular sample needs to be further explored.

Comparison of abilities and knowledge of individual problem solving skills. In regard to participants' overall knowledge and application of the individual problem solving skills, there were no significant differences noted between the two conditions. However, there were significant differences noted among knowledge of each individual skill. Specifically, the cardiac group appears to have better developed abilities in the following skills: problem identification or identifying that a problem exists through noticing discomfort in one's physiological, emotional, and behavioral domains; progress evaluation or evaluating and reflecting about whether or not a solution adequately solved one's problem; and reorganization or recycling and determining a new solution to the problem if the previous solution did not adequately solve one's problem. The cardiac and control conditions appear to have equally developed abilities in the following skills: alternative generation or brainstorming potential solutions to one's problem; predicting the consequences and advantages and disadvantages of each potential solution; and implementing the solution which was determined to be the best solution to his or her problem. Whether or not these exist in other samples of adolescents with and without cardiac channelopathies needs to be examined further.

High-Risk Behavior

Due unfortunately to small sample size, the current study was unable to examine whether or not poorer quality of life, less well-developed social problem skills, and greater negative illness representations predicted engagement in high-risk behaviors above and beyond age and socioeconomic status. However, the frequency and type of high risk behaviors in which the cardiac group engaged was able to be examined. In

addition, the current study was able to explore whether or not there were differences in risk-taking behavior between the cardiac and control condition.

Type and frequency of high-risk behaviors. Hypothesis 3 aimed to explore the type, associated risk category, and frequency of high-risk behaviors within the cardiac condition. Participants in the cardiac condition appear to engage in more behaviors classified as thrill-seeking and anti-social risks than in reckless and rebellious risks. Thrill-seeking risks are often associated with the least negative outcomes and are typically associated with a positive outcome (Arnett, 1992; Gullone et al., 2000; Gullone & Moore, 2000; Hawkins et al., 1992; Moore & Gullone, 1996). The cardiac group endorsed engagement in the following thrill-seeking behaviors: entering a competition, rollerblading, leaving school, and snow skiing. Anti-social risks are behaviors associated with negative outcomes that can result in physical or emotional injury (Arnett, 1992; Gullone et al., 2000; Gullone & Moore, 2000; Hawkins et al., 1992; Moore & Gullone, 1996). Endorsed risks associated with this risk category included talking to strangers, overeating, cheating, and teasing others.

Although endorsed to a lesser degree, the cardiac group endorsed engagement in behaviors classified as rebellious and reckless risks. Rebellious risks are behaviors that are often considered rites of passage (Arnett, 1992; Gullone et al., 2000; Gullone & Moore, 2000; Hawkins et al., 1992; Moore & Gullone, 1996). However, these actions are associated with negative consequences, such as physical or emotional injuries (Arnett, 1992; Gullone et al., 2000; Gullone & Moore, 2000; Hawkins et al., 1992; Moore & Gullone, 1996). Endorsed behaviors associated with this category included staying out

late and getting drunk. Rebellious risks are behaviors with the highest propensity for negative life-threatening consequences (Arnett, 1992; Gullone et al., 2000; Gullone & Moore, 2000; Hawkins et al., 1992; Moore & Gullone, 1996). The cardiac group endorsed engagement in the following behaviors that are classified within this risk category: speeding and having unprotected sex. Overall, the cardiac condition did endorse engagement in behaviors that can result in negative health outcomes. Of the endorsed behaviors, the cardiac group endorsed engagement in two behaviors that may be particularly detrimental to this medical population, i.e., alcohol consumption and having unprotected sexual encounters (Christie & Viner, 2005; Fanone et al., 2007; Kaufman, 2009; Zeigler & Deck-Walters, 2010).

Alcohol consumption. It is recommended that individuals with cardiac channelopathies refrain from drinking alcohol (Priori et al., 2013). Even in healthy individuals, alcohol has been associated with an increased risk for arrhythmias (Koskinen & Kupari, 1992; O’Conner et al., 2005; Priori et al., 2013; Wannamethee and Sharper, 1992). Thus, the risk for arrhythmias in individuals who already have a high propensity for these symptoms is higher and greatly increases their risk for negative health outcomes and potentially life-threatening arrhythmias (Koskinen & Kupari, 1992; O’Conner et al., 2005; Priori et al., 2013; Wannamethee & Sharper, 1992). In addition to increasing the risk for life-threatening arrhythmias, alcohol consumption is contraindicated with the use of beta-blockers because alcohol reduces the half-life of beta blockers and ultimately the efficacy of the medication (Lopez-Sendo et al., 2004). In addition, alcohol use should be avoided in individuals with these conditions because it

can result in dehydration, which consequently, can increase their risk for cardiac symptoms, such as syncope and arrhythmias (Johnson & Ackerman, 2012; Priori et al., 2013). Because beta-blockers are the first line treatment to control occurrences of life-threatening arrhythmias in individuals with these conditions, patients who take these medications must abstain from alcoholic substances to avoid negative health outcomes (Lopez-Sendo et al., 2004; Priori et al., 2013). Thus, four of the ten participants in the cardiac condition may be increasing their risks for negative health consequences because they reported drinking until intoxicated.

Sexual risk-taking. In adolescents with and without chronic medical conditions, engaging in sexual risk taking behaviors has been associated with serious negative outcomes (Choquet et al., 1997; Nylander et al., 2013; Suris et al., 2008; Suris & Parera, 2005). Individuals with cardiac channelopathies who engage in unsafe sex practices are at an increased risk for negative consequences such as unwanted pregnancy and sexually transmitted infections (Carlos et al., 2016; DiMatteo et al., 2007; World Health Organization, 2007). The consequences associated with sexual risk taking could result in these individuals having to adjust to and manage the physical (e.g., acute and chronic infections) and psychosocial (e.g., emotional distress) consequences associated with their sexual risk taking, in addition to having to manage treatment, psychosocial, and physical concerns related to their cardiac channelopathy (Choquet et al., 1997; Nylander et al., 2014; Suris et al., 2008; Suris & Parera, 2005). Overall, three of the ten participants are at an increased risk for consequences associated with this high-risk behavior because these participants reported having unprotected sex.

Drinking alcohol until intoxicated and utilizing unsafe sex practices is not unique to this sample; past research findings have determined that adolescents with chronic conditions report participation in these two behaviors (Britto et al., 1998; Choquet et al., 1997; Klosky et al., 2014; Neinstein, 2001; Nylander et al., 2014; Reid et al., 2008; Valencia & Cromer, 2000). However, it is important to note that the current study's findings regarding abstinence from smoking cigarettes, sniffing glue and gas, drinking and driving, and doing drugs differs from previous research findings, which suggest that adolescents with chronic conditions endorse using substances (e.g., illicit drugs, marijuana, and tobacco) and operating a motor vehicle under the influence of substances (Miauton et al., 2003; Nylander et al., 2014; Valencia & Cromer, 2000). Regarding drinking and driving, it should be noted that seven of the nine participants in cardiac condition were of legal driving age. However, whether or not participants were currently driving was not assessed. It is possible that some participants in our sample were unable to drive because some ICD recipients receive driving restrictions (Conti et al., 1997). If many of the individuals in the cardiac condition were not currently driving, this may be one reason why drinking and driving was not reported. Whether or not abstinence from drug use and drinking and driving occurs in other samples of adolescents with cardiac channelopathies needs to be explored.

Medical non-adherence as high-risk behavior. Although not assessed by the adolescent risk-taking questionnaire as a high-risk behavior, whether or not the cardiac group engaged in medical non-adherence was important to consider. Not following medical recommendations is considered a high-risk behavior for individuals with chronic conditions because this behavior is highly associated with poor health outcomes (Berquist et al., 2008; Bulington et al., 2007; Ho et al., 2009; Kongkaew et al., 2014; Nylander et al., 2014; Rapoff, 2006; Rapoff, 1998). This high-risk behavior is quite common in chronically ill adolescents; more than 30% of adolescents have self-reported non-adherence to medical recommendations (Berquist et al., 2008; Michaud et al., 2004; Rapoff, 2006; Rapoff, 1998). Individuals with cardiac channelopathies who do not adhere to their medical regimen are likely at an increased risk for treatment complications and sudden cardiac arrest (Christie & Viner, 2005; Fanone et al., 2007; O'Conner et al., 2005; Priori et al., 2013; Wanamethee & Shaper, 1992; Zeigler & Deckle-Walters, 2010). A review of the health status questionnaire revealed that some participants are non-adherent to all of their medical regimens. Specifically, 44.4% of participants (n = 4) reported engaging in restricted activities; 11.1% of participants indicated that they do not take their medication as prescribed (n = 1), and 22.2% indicated that they eat restricted foods (n = 2). Thus, individuals from the current sample who report non-adherence to medical recommendations may be at increased risk for negative consequences.

Physical activity restrictions. Restrictions for individuals with cardiac channelopathies vary and depend on an individual's specific condition and medical provider (Priori et al., 2013). The physical activity guidelines on which physicians base their recommendations for patients are outlined in the Task Force 10 and 9 papers, published by the American Heart Association and American College of Cardiology (Ackerman et al., 2015; Zipes et al., 2015). The outlined recommendations were created to reduce the risk of physical activities triggering life-threatening arrhythmias. Therefore, patients whose physicians recommend that they avoid certain activities should follow those treatment recommendations carefully because their physicians likely have made treatment decisions based on their concerns that engagement in these behaviors may be detrimental to their health. Because some of the participants in the cardiac condition indicated that they chose to engage in restricted activities, they are likely at an increased risk for negative health outcomes. More research should be conducted to see if these results generalize to other individuals with cardiac channelopathies.

Medication non-adherence. Most individuals with cardiac channelopathies are prescribed beta-blockers as a first line of treatment (Priori et al., 2013). Beta blockers are utilized because they reduce occurrences of sudden cardiac arrest by preventing occurrences of life-threatening arrhythmias (Chockalingam et al., 2012; Lopez-Sendo et al., 2004; Priori et al., 2013). Thus, individuals with these conditions who do not take their medication as prescribed are increasing their risks for serious negative health outcomes, such as life-threatening arrhythmias and death (Chockalingam et al., 2012; Lopez-Sendo et al., 2004). Only one participant in the current study indicated that he or

she does not take medication as prescribed. Considering the fact that medication adherence appears to be high for this particular population, future research may want to examine whether or not this is consistent across more individuals with cardiac channelopathies or specific to the current study or current participant. It would also be of interest for future research to examine what factors individuals with cardiac channelopathies consider before they choose to be non-adherent to their medical regimens, and if individuals with cardiac channelopathies have any specific decision making protocols they follow prior to engaging in restricted behaviors or medication non-adherence.

Comparison of Engagement in High-Risk Behaviors In the Healthy and Cardiac Conditions.

Whether or not the cardiac group would engage in more, less, or equivalent frequencies of risk taking behaviors was examined by hypothesis 4. Whether or not individuals with cardiac channelopathies would engage in more or in less high-risk behaviors than the control condition was not predicted because findings for whether individuals with chronic conditions engage in more or less risky behaviors than their healthy peers is mixed (Nylander et al., 2014). The findings of this study showed no significant differences in overall risk-taking behavior between the cardiac and control conditions. In addition, post hoc analyses demonstrated that the cardiac condition and control condition engage in similar frequencies of high-risk behaviors across all of the risk taking categories.

A magnitude of possible reasons exist, explaining why adolescents with cardiac

channelopathies may engage in similar frequencies and types of risk-taking behaviors as adolescents without chronic conditions. Perhaps these adolescents, similar to those with and without medical conditions engage in risk-taking; they do not want to be viewed as being different from their peers because establishing social groups is a major concern during this developmental stage (Andersen et al., 2008; Dovey-Pearce, 2005; Longmuir et al., 2017; Roisman et al., 2004). In addition, the majority of these patients may feel less severe symptoms on a daily basis, so they do not feel ill (Caleshu et al., 2016). Perhaps feeling well and not as if they have a chronic illness results in their being more willing to engage in restricted activities and developmentally typical risk-taking behavior (Caleshu et al., 2016). Last, perhaps some patients feel protected by their medical regimen (medication or ICD/pacemakers), which results in their being more comfortable with engaging in restricted or developmentally typical low and higher risk behaviors because they believe that their treatment will prevent life-threatening consequences that might otherwise result from these actions (Rahman et al., 2011). In fact, Rohman and colleagues (2011) interviewed adolescents with ICDs, and some of the participants reported viewing their device as a form of protection (Rahman et al., 2011). However, viewing an ICD as protective does not automatically result in patients' being more prone to engage in low and high-risk behavior. In fact, past research suggests that having an ICD is associated with avoidance of activities (physical activity) that could place the heart in a dangerous rhythm and trigger the implanted device to fire a shock (Dublin et al., 1996; Sears et al., 2011). As indicated, all of these explanations are simply theories, and much more research is needed to explore this area in other cohorts of adolescents

with cardiac channelopathies to determine reasons supported by research findings.

Overall, the findings of this study seem to suggest that for this particular sample having a chronic illness does not alone increase one's risk of engaging in more high-risk behaviors.

Limitations

The current study had a few limitations, including small sample size, inclusion of international participants, and use of self-report forms.

Small sample size. A major limitation of the current study was the small sample size. The current study experienced difficulty recruiting participants, both with and without cardiac conditions. Having a small sample size prevented the examination of one of the four hypotheses. In addition, it prevented the use of parametric statistical analyses because adequate power needed to conduct the analyses was not achieved. In addition, the small sample size may prevent the results from being able to be generalized to other samples of individuals with cardiac channelopathies because the findings may be specific to this small cohort of individuals. Related to generalizability, it is important to note that participants in the current study rated their academic abilities as being above or somewhat above average. Perhaps having above average academic abilities influenced these participants to complete the survey questionnaires. How these results generalize to other samples of individuals with various academic abilities is unknown.

Factors contributing to small sample size. One factor that may have contributed to the small sample size was the consent procedure that participants needed to complete in order to participate in the current study. Specifically, participants who were over the age of 18 needed to contact the student researcher, receive a consent form, read, review, and sign the consent form, and receive an email with the Survey Monkey link to complete the study, and then finally complete the battery of questionnaires. There were additional steps that needed to be fulfilled for adolescents under the age of 18 to participate in the current study. Specifically, participants under the age of 18 needed to have a parent or guardian contact the student researcher and complete the consent form. Next, the parent had to provide the underage participant with the link to the survey. Then the underage participant needed to provide assent and complete the questionnaires.

Perhaps participants and parents and guardians found the consent procedure to be cumbersome and inconvenient; as a result, potential participants may have decided against participation in the current study. Had participants been able to complete the study without having to go through a consent process, perhaps more participants would have chosen to participate. The current study did attempt to reduce the likelihood of parents/guardians and participants feeling inconvenienced by the consent procedures by utilizing an e-signer program, which allowed participants and parents/guardians to provide consent easily and conveniently by legally signing the consent document via email.

Another explanation related to difficulty with participant recruitment, specific to minor participants, could be related to parents'/guardians' concerns regarding what their

child might experience when completing the survey. Specifically, the child's parent or guardian was made aware of the types of questions his or her child would have to complete. It is possible that parents or guardians may have been concerned that having to answer questions about engagement in high-risk behaviors would result in their dependent child feeling uncomfortable or experience negative emotions. In addition, they may have been concerned that their child would think about or "get the idea to" engage in the high-risk behaviors after reading about them.

Attempts to increase sample size. There were many attempts made to increase sample size, including the use of incentives and expanding recruitment methods.

Incentives. Participants were provided with an incentive, a chance to win a 10-dollar gift card, in exchange for participation in the current study. However, this incentive may have not been attractive enough because only 1 in 10 participants would win a giftcard. Perhaps participants would have been more willing to participate if everyone would have received a gift card after completing the survey. Thus, future studies may want to consider increasing the incentives to make participation more attractive to potential participants. However, future studies may really want to consider how much money they offer participants because it would be imperative to avoid coercion. For example, providing a significant amount of money in exchange for completing the survey could result in parents pressuring their children to complete the study as a means to obtain the incentive.

Expanding recruitment. Originally, the current study aimed to recruit participants by posting on Facebook groups and having organizations for individuals with these conditions and cardiologists share flyers with potential participants. In an attempt to reach more participants, the current study obtained additional IRB approval to expand recruitment procedures by sending out the study flyer to cardiac rehabs and physical therapists. In addition, the current study obtained approval to expand the eligibility criteria to include participants who resided outside the United States. Despite these changes to the recruitment procedures, the current study was able to recruit only a small number of additional participants.

International participants. Although the current study attempted to increase the sample size of the current study by including international participants, inclusion of individuals who live outside of the United States may be an additional limitation of the current study. There is some research suggesting that the frequency of drinking varies within and outside the United States (Simons-Morton, Pickett, Boyce, ter Bogt, & Vollebergh, 2010). Specifically, countries such as the United States that have more strict drinking laws tend to have lower drinking rates for adolescents and adults than countries with less strict drinking laws, such as Canada and the Netherlands (Gilligan, Kunstsche, & Gmel, & 2012; Simons-Morton et al., 2010). Despite stricter drinking laws being associated with lower frequency of drinking in adolescents and young adults, some research findings suggests that strict drinking laws may actually influence young individuals to drink more (Gilligan et al., 2012). For example, adolescents and young adults, both in the United States and Europe may choose to binge drink as a way to rebel

against the strict drinking laws (Bellis et al., 2009; Gilligan et al., 2012; Russell-Bennett, Hogan, & Perks, 2010).

Similar to drinking laws, some research findings suggest that higher alcohol prices deter alcohol consumption, particularly for adolescents (Gilligan et al., 2012). However, research findings have also suggested that although higher prices of alcohol decrease the frequency of alcohol consumption for adolescents, higher prices may influence adolescents to engage in risky drinking behavior (e.g., binge drinking) when they do have access to alcohol (Gilligan et al., 2012). In addition to drinking laws and alcohol prices, countries that produce wine or maintain wine consumption as a cultural norm (e.g., Germany) tend to have higher rates of alcohol consumption than countries that are not wine producers or have ambivalence or negative beliefs about alcohol consumption, such as the United States (Bloomfield, Greenfield, Kraus, & Augustin, 2002).

Although there may be some differences in the frequency of alcohol consumption among individuals from different countries, it seems that adolescents, regardless of their residence, consistently continue to report engagement in risky binge drinking behaviors (Gilligan et al., 2012). Thus, engagement in this high-risk behavior may not have been influenced by recruitment of participants from countries around the world. Further, for adolescents with cardiac channelopathies, variances in cultural norms, prices, and laws may be less relevant because these adolescents are at risk for negative health consequences even when the frequency and quantity with which they consume alcohol is low (Koskinen & Kupari, 1992; O'Conner et al., 2005; Priori et al., 2013; Wannamethee

& Sharper, 1992).

Use of self-report measures and social desirability. The current study utilized a self-report measure to determine the types of behaviors and associated risks and the frequency of engagement in high-risk behaviors among chronically ill and healthy adolescents (Gullone et al., 2000). Relying on self-report measures may have influenced the type of information provided by participants, to the degree that some adolescents may have felt as if they needed to respond in a socially desirable manner (Brener, Billy, & Grady, 2003; Steinberg, 2005). Some participants may have underreported their engagement in high-risk behaviors to prevent them from being viewed negatively by the researcher or by individuals who may have been in the room with them while they completed the survey (Brener et al., 2003). Consequently, the current study's findings may be an underestimate of the frequency and intensity with which this population engages in high-risk behaviors.

The current study attempted to reduce the influence of this limitation by ensuring that the participants knew the study was anonymous and that the student researcher would not be able to pair their answers with their identities. When adolescents feel as if their answers cannot be linked to their identities, they tend to be more comfortable answering honestly (Brener et al., 2003). Additionally, the current study asked parents and guardians to allow their dependents to complete the survey independently to help ensure that participants felt that their responses were truly anonymous. Further, this study was completed online, which may have led to participants feeling more comfortable answering survey questions openly (Brener et al., 2003). In fact, adolescents tend to

answer online surveys more honestly because they feel as if their identities are better protected (Brener et al., 2003).

Another concern with utilizing self-report measures with an adolescent population is that, developmentally, these participants may have reduced self-reflection capabilities (Brener et al., 2003; Steinberg, 2005). Thus, they may report information less accurately than patients from older medical populations who are better able to self-reflect (Brener et al., 2003). The current study aimed to reduce the impact of this limitation by using developmentally appropriate questionnaires that have been normed on an adolescent population. Further, the current study utilized a valid and reliable measure of engagement in high-risk behaviors in adolescents (Gullone et al., 2000).

Implications

The current study did determine that individuals with cardiac channelopathies are engaging in behaviors associated with an increased risk in negative health outcomes. Although the sample size of the current study was small, the information provided is of value because it highlighted the fact that despite the associated risks, pediatric patients with these conditions continue to choose to engage in behaviors that can result in life-threatening consequences. Thus, the current findings do present information that may be of value to both cardiologists/physicians who work with individuals with cardiac channelopathies, as well as to parents/guardians who have children with these medical conditions.

Recommendations for clinicians working with children with cardiac

channelopathies. Although there is much research examining engagement in high-risk behaviors in adolescents with various types of chronic health conditions, there is a paucity of research examining these behaviors in adolescents with cardiac channelopathies (Dovey-Pearce et al., 2005; Zeigler & Decker-Walters, 2010). Before healthcare providers can determine how to counteract negative consequences that can result from participation in high-risk behaviors, they need to first determine to what extent their patients are engaging in risky behaviors. Therefore, a major aim of the current study was to provide information regarding the types of behaviors, category of risk, and frequency of developmentally typical low to high-risk behaviors in which adolescent cardiac channelopathy patients participate. The findings of the current study determined that this cohort of adolescents with cardiac channelopathies are engaging in behaviors that can result in negative health outcomes, including drinking alcohol until drunk, engaging in restricted activities, not taking medication as prescribed, eating restricted foods, and sexual risky behavior. Thus, this information may encourage providers to monitor and assess for these behaviors in their adolescent patients.

Current and future findings may inform assessment of engagement in risk-taking behavior through discussion and the development of a screening tool.

Unfortunately, the current study was unable to predict what specific factors increase the likelihood of a patient engaging in high-risk behaviors. However, providers can continue to utilize the findings of the current study to inform their assessment of risk-taking behavior. One way of informing assessment is through discussions of risk-taking

behaviors with patients. Because providers know that some patients with these conditions, such as this small cohort, are reporting engagement in high-risk behaviors, it may benefit the providers to assess whether or not their own patients are engaging in these behaviors. In fact, discussing engagement in high-risk behaviors with patients often results in patients feeling open to discussing their behaviors and a decrease in unwanted health behaviors (Kreuter, Chheda, & Bull, 2000). Patients who discussed changing high-risk and negative health behaviors with their physicians, prior to their receiving any form of clinical intervention to reduce these behaviors, were more likely to attempt to reduce their engagement in negative health behaviors (Kreuter et al., 2000).

In addition to discussing engagement in these behaviors with patients, another way to determine which individual patients are at risk for negative health outcomes associated with risk-taking behavior would be to have access to a screening tool that assesses for this information. It was an aim of the current study to identify and provide information regarding predictive factors associated with an increased engagement in risk-taking within this medical population. Unfortunately, the current study was unable to complete this goal. However, future studies should continue to examine and identify predictive factors for engagement in risk-taking because utilization of screening tools has been found to increase positive health outcomes in other chronically ill adolescents who engage in a variety of high-risk behaviors, such as suicide attempts (Horowitz et al., 2001).

Specific to this medical population, developing a screening tool that can identify patients at risk for engagement in high-risk behaviors, such as medical non-adherence

and substance use, could improve health outcomes. Identifying these patients could help physicians determine a modality for monitoring and intervention, which could in turn reduce the likelihood of risk taking and, consequently, unwanted health outcomes (Neinstein, 2001; Yeo, Bond, & Sawyer, 2005). For example, providers could utilize the tool to identify an individual or subgroup of patients who do not take their medication as prescribed, engage in restricted sports, and drink alcohol. Once these patients have been identified, physicians could determine a plan for mitigating the risk, such as meeting with the higher risk patients more frequently or consulting with a behavioral health practitioner to help these patients better adjust to their illnesses and reduce their participation in high-risk behaviors (Neinstein, 2001).

Future and current findings could inform treatment protocols. In addition to informing discussions with patients and the development of a screening tool, determining the predictive nature of risk factors could help to inform treatment protocols that would be designed specifically to treat adolescents with cardiac channelopathies who are engaging in high-risk behaviors. Even though the current study was unable to determine the predictive factor of quality of life, illness representations, and social problem solving, these factors are integral components of treatment protocols for adolescents with other chronic conditions who engage in risk taking behaviors (de Winter et al., 2015; Fergus & Zimmerman, 2005; Fischer et al., 2013; Grey & Berry, 2004; Grey et al., 2000; Haase et al., 2004; Harris et al., 2013; Mandleco & Perry, 2000; Osborn, Demoncada, & Feuerstein, 2006; Mandleco & Peery, 2000; Spivack, Platt, Shure, 1976). If future research findings determine that these three variables are predictive of engagement in

high-risk behaviors in adolescents with cardiac channelopathies, then these variables should be included in intervention programs focused on reducing risk taking and increasing adaptive coping skills in this specific medical population (Brener et al., 2003; Neinstein, 2001).

Recommendations can inform parental supervision and discussion of risk-taking behavior. The findings of the current study are not only informative for medical providers, but the results appear also to be relevant for parents/guardians/caregivers of children with these conditions; research findings have recommended that discussions regarding risk-taking behaviors should not occur solely during visits with an individual's health care provider (DiClemente et al., 2001; Dishion & Andrews, 1995; LaBrie et al., 2015; Napper et al., 2016; Stanton et al., 2004). Rather, parents of children with cardiac channelopathies should coordinate with their children's healthcare provider to reduce the risks associated with engagement in high-risk behaviors (DiClemente et al., 2001; Dishion & Andrews, 1995; LaBrie, Boyle, & Napper, 2015; Napper et al., 2016; Stanton et al., 2004). Much research has determined that parents' behavior influences their adolescents' actions and that specifically parent-child communication about risk-taking and parental monitoring can protect against engagement in high-risk behaviors (DiClemente et al., 2001; LaBrie et al., 2015; Napper et al., 2016; Stanton et al., 2004). In fact, parental influence on behavior appears to be longer lasting and more influential than peer influence; peer-to-peer relationships tend to be less stable and permanent, compared with parent-child relationships (Stanton et al., 2004; Stanton, Fang, Feigelman, Galbraith, & Ricardo, 1997). Thus, parents are more likely to be able to intervene and reduce, both

acutely and longer term, the frequency of engagement in high risk behaviors by their children (Stanton et al., 2004).

Communication strategies as means for reducing engagement in risk-taking.

Similar to parents of healthy adolescents, parents of adolescents with cardiac channelopathies may want to examine how they communicate about substance use in their homes because parental discussion of these behaviors is associated with child substance use (Bahr et al., 2005; Calhoun, Maggs, & Loken, 2018; LaBrie et al., 2015; Napper et al., 2016; Reimuller, Hussong, & Ennett, 2011). Adolescents whose parents communicate a zero tolerance policy for substance use have a reduced risk for alcohol consumption and drug use by their children (Bahr et al., 2005; Calhoun et al., 2018; LaBrie et al., 2015; Napper et al., 2016). When parents do not communicate that alcohol and substance use is unacceptable, children may interpret parental conversation as permission for engagement in these behaviors (LaBrie et al., 2015; Napper et al., 2016; Reimuller et al., 2011).

Research findings have recommended that parents refrain from discussing their own history of substance use with their children, even if they discuss the harmful consequences of their behavior because children may interpret these discussions as permission or approval to engage in substance use (LaBrie et al., 2015; Napper et al., 2016). In addition to refraining from discussions about their own experiences with substance use, it is recommended that parents refrain from providing their children with information about how they can engage in high-risk behaviors in a safe manner because children whose parents have utilized these methods of communication engage in more

substance use than those whose parents communicated abstinence (Calhoun et al., 2018; LaBrie et al., 2015; Napper et al., 2016). Rather, it is recommended that parents have frequent open discussion about the risk and serious consequences associated with substance use (Napper et al., 2016; Ritchwood et al., 2017; Widman, Choukas-Bradley, Noar, Nesi, & Garrett, 2016).

The same recommendation applies to sexual risk taking; research findings suggest that parental discussions about sexual behavior and activities and the associated consequences are highly associated with engagement in these behaviors (Napper et al., 2016; Ritchwood et al., 2017; Widman et al., 2016). In fact, open and frequent conversation with children about sex and dating is associated with reduced engagement in sexual risk taking (Napper et al., 2016; Ritchwood et al., 2017; Widman et al., 2016). With regard to children with chronic illnesses, such as cardiac channelopathies, parents may want to include information about how the child's medical condition increases his or her risk for specific negative consequences if they engage in high risk behaviors such as high-risk sexual activity (Napper et al., 2016).

It is recommended that parents begin to have the frequent and open conversations about high-risk behaviors (e.g., substance use and unsafe sex practices), prior to the onset of these behaviors (Napper et al., 2016). Research has shown that talking about risk is highly effective prior to the child engaging in substance use or risky sexual practices (Napper et al., 2016). For example, Atienzo et al. (2009) conducted a study which examined sexual behaviors in 5952 adolescents (Atienzo et al., 2009). The findings suggested that discussion about risk and prevention prior to sexual encounters was related

to greater use of contraceptives during the first sexual encounter, as well as having the first sexual at a later age (Atienzo et al., 2009). If the parent waits to have these discussions until after the child has already engaged in these behaviors, he or she may be less likely to believe his or her parent and view the risks associated with the sexual activity as being inaccurate (Atienzo, Walker, Campero, Lamadrid-Figueroa, & Gutierrez, 2009; Ritchwood et al., 2017; Napper et al., 2016).

Parental-monitoring as means for reducing engagement in risk-taking. In addition to the specified communication strategies, parental monitoring or parental supervision of their children's behavior is a proposed effective modality for risk reduction (Bahr, Hoffman, & Yang, 2005; Stanton et al., 2004). Knowing where and with whom one's child is reduces the child's risk of engaging in high-risk behavior (DiClemente et al., 2001; Huebner & Howell, 2003; Napper et al., 2016). Not only does parental supervision reduce the risk for engagement in high-risk behaviors during adolescence, but it also protects young adults from engagement in risky behaviors when they no longer live in their parents' homes (Napper et al., 2016).

As with parents of children without chronic medical conditions, it is recommended that parents of children with cardiac channelopathies also develop and implement effective parental monitoring strategies. Specifically, parents may want to ensure that they know their children's whereabouts and with whom their children spend their time outside of school hours (Atienzo et al., 2009; DiClemente et al., 2001; Huebner & Howell, 2003; Napper et al., 2016). In addition, it is recommended that parents communicate to their children that they are aware of and are keeping track of this

information; adolescents who believed that their parents did not monitor them, compared with those who thought that their parents did monitor them, were more likely to use illicit drugs, drink alcohol, and use marijuana (Bahr et al., 2005; DiClemente et al., 2001; Lac & Crano, 2009; Napper et al., 2016). For example, Bahr and colleagues (2005) examined the influence of parental monitoring on risk-taking behavior in 522 adolescents, aged 14-18 years (Bahr et al., 2005). The findings indicated that less parental monitoring was associated with sexual risk taking (e.g., more positive STI testing and less contraceptive use), as well as greater marijuana use and alcohol consumption (Bahr et al., 2005). Overall, parents of healthy children, as well as parents of children with cardiac channelopathies may help to protect against risk-taking behavior by implementing the identified communication and monitoring strategies.

Future Research

This study appears to be the first one examining how adolescence and the physiology of cardiac channelopathies interact to increase the risk of negative health outcomes for adolescents with these conditions. Specifically, there do not appear to be any studies that discuss the type, frequency, duration, and intensity of participation in low to higher risk developmentally typical behaviors among adolescents with cardiac channelopathies. The findings of the current study indicate that more systematic studies need to be conducted to determine if other cohorts of adolescents with cardiac channelopathies are engaging in the same type of behaviors with the same frequency as the current participants. In addition, future studies should aim to examine the predictive utility of quality of life, illness beliefs, and social problem solving on engagement in

high-risk behaviors in adolescents with cardiac channelopathies. Further, future studies may want to examine other variables (e.g., provider characteristics and parent characteristics) that may predict engagement in high-risk behaviors for this medical population.

Difficulty recruiting adolescent research participants is not limited to the current study (Bassett, Beagan, Ristovski-Slijepcevic, & Chapman, 2008; Clark & Marion, 2001; Heinrichs, Betram, Kuschel, & Hahlweg, 2005; Hinshaw et al., 2004; Moolchan & Mermelstein, 2002; Nguyen et al., 2012; Steinbeck, Baur, Cowell, & Pietrobelli, 2009). Past research findings have recommended techniques to improve recruitment; these include 1. clearly communicating research risks and benefits and procedures to parents of potential adolescent participants; 2. increasing incentives for participation to increase recruitment of minority participants; 3. increasing parental trust, and 4. utilizing the internet, peer relations and public relations when recruiting potential participants (Bassett et al., 2008; Hinshaw et al., 2004; Moolchan & Mermelstein, 2002; Nguyen et al., 2012). Because the current study did utilize the majority of these recommendations, additional steps may need to be taken to determine what other factors interfere with recruitment of underage participants.

Future studies may want to explore variables that increase both parent and adolescent interest and motivation for engagement in research studies. Because parents need to be involved in research aiming to recruit minor participants, it is particularly important to gain information pertaining to parental/guardian motivation in addition to adolescent motivation. One way in which this could be achieved would be to hold focus

groups for adolescents and parents/guardians (Basch, 1987; Clark & Marion, 2001).

Focus groups would be an effective modality to explore this topic because the utilization of these groups helps to gain information about the perspectives of the individuals being interviewed (Clark & Marion, 2001). Hopefully, the information gained from the focus groups with the goal of increasing adolescent/parental participation would be of value and reduce barriers to recruiting minor research participants.

Future studies may also want to examine whether or not social learning theory, perceptions of risk taking, and individual beliefs are important factors to consider when developing treatment protocols for adolescents with cardiac channelopathies. Social learning theory consists of expectations, about the consequences of one's own action, one's ability to perform a behavior, and beliefs about how events are connected (Rosenstock, Strecher, & Becker, 1988). In addition to expectancies, this theory indicates that the consequences one believes are associated with their behaviors influence behavioral choices (Rosenstock et al., 1988) Whether or not these individuals, i.e., adolescents with cardiac channelopathies decide to engage in particular behaviors, especially those that are protective against, or further increase risk for negative health outcomes, may be attributable to social learning (Rosenstock et al., 1988). For example, an adolescent who believes that his or her cardiac channelopathy is not life-threatening, who feels as if he or she does not know how to decline invitations to engage in risk taking behaviors from peers, and believe that risk taking may increase his or her ability to make social connections, may be more likely to engage in high risk behaviors. Therefore, future research may want to determine if utilizing cognitive behavior therapy to reframe

inaccurate expectations is protective against risk taking in adolescents with cardiac channelopathies.

Similarly, future research may want to consider whether or not treatment protocols may benefit from targeting and reframing maladaptive perceptions of risk and individual illness beliefs. For example, Cohn and colleagues (1995) examined the perception of risk taking in adolescents and their parents. The results of this study indicated that adolescents often viewed risky health behaviors, such as drinking, as having little likelihood of resulting in negative outcomes (Cohn, Macfarlane, Yanez, & Imai, 1995). Whether or not this pattern is also applicable to adolescents with cardiac channelopathies should be explored. If it is determined that adolescents with cardiac channelopathies minimize the impact of engaging in risk taking behaviors on their health outcomes, treatment protocols may want to include strategies for helping adolescents develop more accurate perceptions of the types of negative outcomes that could occur if they engage in risk taking behaviors, such as drinking.

In addition, future researchers may want to consider the interaction between risk taking beliefs and perceptions of illness when treating adolescents with cardiac channelopathies. For example, the majority of the current sample did not believe their illnesses to be threatening in nature, despite its being associated with potential for life-threatening cardiac events. Thus, whether or not individuals' perceptions of their illnesses as being non-threatening interacts with risk perceptions needs to be explored further. If it is determined that perceptions of risk and having a less-threatening view of one's illness interact and increase incidents of risk taking, treatment protocols can strive to help

adolescents develop a better understand of the relationship between their illnesses and risk taking behaviors.

Cultural considerations for future research findings. Future research could aid in the development of culturally informed parental and provider recommendations and treatments by examining and determining efficacious interventions for this specific medical population. Ensuring that specific medical populations receive culturally relevant interventions has been found to be imperative to obtaining positive health outcomes (Flores, Abreu, Schwartz, & Hill, 2000). Adolescents with cardiac channelopathies are a unique group that differs from adolescents with other types of cardiac conditions. In addition, this group may be different even from other age cohorts, young pediatric patients and older adults, with cardiac channelopathies. For example, young children's vulnerability for engagement in high-risk behaviors may be more closely related to environmental factors such as family social problem solving skills, whereas adolescent factors may be related more closely to their own internal problem solving abilities (Hawkins et al., 1999; Harris et al., 2013). Compared with adults, adolescents' developmental stage may uniquely influence their actual ability to engage in high-risk behaviors (Hawkins et al., 1992). For example, adolescents may be less likely than adults to drink alcohol or smoke cigarettes because they are unable to purchase these products legally. Therefore, research exploring factors predictive of engagement in high-risk behaviors in adolescents with these disorders may be more beneficial if conducted separately from research examining adolescents with other cardiac conditions and other age cohorts with cardiac channelopathy conditions.

If the findings of future studies do not identify quality of life, illness representations, and social problem solving as being risk factors for risk taking in adolescents with cardiac channelopathies, perhaps there is something unique about this medical population that causes these factors to be non predictive of participation in high-risk behaviors. Therefore, future research should examine other variables that may be more predictive of engagement in high-risk behaviors in this specific population. One way to accomplish this task would be to conduct focus groups and collect qualitative data from patients and their parents to determine what factors may be most likely to influence their choices to engage in high-risk behaviors (Basch, 1987; Patton, 2005).

Advocacy Through Prevention for Adolescents with Cardiac Channelopathies

Preventive interventions are considered to be vehicles for advocacy, because these interventions fulfill the objectives of advocacy; these aim to improve collective and personal emotional and physical well-being, in addition to improving the environments or communities in which people live and work through the modality of social and political change (Romano & Hage, 2000; Hage et al., 2007). Advocating through prevention is particularly important for pediatric medical populations; focusing on this factor has been associated with a reduced likelihood of difficulties with adjustment in individuals identified as being at increased risk for negative health outcomes (Catalano, Berglund, Ryan, Lonczak, & Hawkins, 2002; Hage et al., 2007). Advocacy for individuals with cardiac channelopathies can include multiple contexts including providers, patients, and caregivers (Hage et al., 2007).

For healthcare providers, advocacy projects, with a focus on prevention, can be

enacted in primary care and cardiology settings and residency training programs (Wright et al., 2005). Integrated teams located in primary care settings and cardiologist offices can work together on preventative interventions for pediatric patients with cardiac channelopathies because these patients likely have regular primary care and cardiology appointments. Physicians and behavioral health consultants can focus on prevention through screenings and discussions with patients, behavioral health treatment, and continued research efforts. Specific to discussions with patients, physicians could choose to utilize the findings of the current study, as well as the findings of previously published literature and future research, to open discussion about engagement in risk-taking behaviors with their patients.

For example, physicians or behavioral health consultants can indicate that other adolescents with cardiac channelopathies report difficulty with adherence to their medical population and that some indicate that they drink alcohol. By having an open discussion about these topics, other adolescents with these conditions may feel supported and be more likely to endorse engaging in or having thoughts about engagement in these activities (Kreuter et al., 2000). Although the current study was unable to determine factors that are predictive of engagement in risk-taking behaviors, future studies will hopefully examine these factors further. Hopefully, once risk factors are identified, screening tools can be created to help identify patients at risk for engagement in these behaviors, as well as those who might benefit from behavioral health interventions that can be specifically designed for this medical population. For example, if problem solving is a construct that is highly predictive of engagement in high-risk behaviors, then

treatment protocols for this population should specifically focus on assessing and improving weaknesses in individuals' problem solving abilities.

With regard to research as presented, physicians and behavioral health consultants who treat this medical population can work towards prevention of negative health outcomes by continuing to conduct relevant research studies utilizing participants with these conditions. Specifically, research aims can focus on identifying factors that increase patients' risks for negative health outcomes. This research appears to be of value because engagement in risk-taking behaviors is highly associated with negative health outcomes for individuals with and without chronic medical conditions (Choquet et al., 1997; Gullone et al., 2000; Gullone & Moore, 2000; Moore & Gullone, 1996). Exploring this topic is likely of great value for adolescents with chronic conditions, because they, compared with their peers without chronic conditions, may experience additional negative outcomes associated with the interaction between their risk-taking behaviors and the etiology of their medical conditions (Choquet et al., 1997).

With regard to pediatric or family medicine residency programs, many directors of these programs highlight the importance of advocacy because the Accreditation Council for Graduate Medical Education (ACGME) has mandated the inclusion of structured experiences that prepare pediatric residents for being community advocates for their pediatric patients (ACGME, 2001; Wright et al., 2005). Thus, residency programs in cardiology, pediatrics or even primary care would offer a great opportunity for advocacy projects focusing on this medical population. The types of advocacy projects could be similar to those outlined for physicians and behavioral health consultants.

In addition to being advocates in medical settings, providers can also advocate for this medical population at the community level (Wright et al., 2005). Specifically, physicians and behavioral health consultants can dedicate time to speak at community events that are aimed at supporting individuals with cardiac channelopathies (e.g., SAD's annual patient conference). Specific to findings presented in this study and others, focusing on risk-taking behaviors, providers can discuss with caregivers (e.g, parents and guardians) the importance of speaking with their children about risk taking. In addition, they can provide information regarding effective communication strategies and highlight the importance of discussing engagement in these behaviors with their providers. Further, they could take this opportunity to discuss options for behavioral health treatment for patients and their families who may experience a variety of unwanted psychosocial consequences, such as difficulty with adjustment, depression, anxiety, and poor quality of life.

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Appendix A

Recruitment Flyers

Flyer for Cardiac Condition

“Examining Habits and Social Activities of Teenagers and Young Adults.”
We are looking for individuals ages 13-22 to complete an online study examining the habits and social activities of adolescents and young adults with and without cardiac rhythm disorders. Participants must have a cardiac rhythm disorder and have an ICD/pacemaker or take medication to be eligible.

Participation in this study is confidential! You can complete the survey in as many sessions as needed. It will take about 60 minutes to complete.

For more specific information about this study, please send an email to LQTStudies@pcom.edu and put “Attention Lauren” in the subject line. If under age 18, please have your parent/guardian email your interest to the email address above.

All participants will be eligible to participate in a raffle for a 10-dollar giftcard to Target. 1 out of every 10 participants will win!

Lauren Lucente, LPC, MA
4th year psychology student in PCOM’s Psy.D. Program in Clinical Psychology

Stephanie H. Felgoise, Ph.D., ABPP
Professor & Vice-Chair, Dept of Psychology
Director, PsyD Program in Clinical Psychology, Philadelphia College of Osteopathic Medicine

This research study is being conducted as a means to fulfilling a psychology student’s dissertation, a requirement of the student’s PsyD. Clinical psychology program. This study has been approved by the Philadelphia College of Osteopathic Medicine Institutional Review Board. For further information on this approval, please contact the Research Compliance Specialist at 215-871-6782.

Flyer for Control Condition

“Examining Habits and Social Activities of Teenagers and Young Adults.” We are looking for individuals ages 13-22 to participate in an online study examining the habits and social activities of adolescents and young adults with and without cardiac rhythm disorders. Participants must not have a chronic medical or mental health condition (thyroid disease, depression, anxiety, or diabetes) to be eligible.

Participation in this study is confidential! You can complete the survey in as many sessions as needed. It will take about 60 minutes to complete. For more specific information about this study, please send an email to LQTStudies@pcom.edu and put "Attention Lauren" in the subject line. If under age 18, please have your parent/guardian email your interest to the email address above.

All participants will be eligible to participate in a raffle for a 10-dollar gift card to Target. 1 out of every 10 participants will win!

Lauren Lucente, LPC, MA
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Appendix B

Demographic Questionnaire

Which group best describes you?

- Native American
- Asian (includes pacific, South, Southeast, and North)
- African American
- Latino/Latina
- Caucasian/White
- Middle Eastern
- Multiracial
- Other (please specify)

What gender were you assigned when you were born?

- Male
- Female

Which gender do you identify now?

- Male
- Female
- Transgender
- Other (please specify)

How old are you?

Which best describes your religious beliefs?

- Buddhist
- Christian
- Hindu
- Jewish
- Muslim
- Agnostic
- Atheist
- Other (please specify)

Which best describes where you live.

- Farm
- City
- Suburbs
- Other (please specify)

What is your current grade/year in school? (Example: Junior in high school)

If you have graduated from high school, please tell us if you work or attend college.

Who lives with you in your home?

How many people live with you?

- 2
- 3
- 4
- 5
- 6
- 7 or more

What is your current relationship status?

- Single
- Married
- I have a boyfriend/girlfriend
- Not interested in having a relationship
- Other (please specify)

Do you take any daily medications?

- Yes
- No

If you take daily medication, please list the name of the medication below.

How do you do in school?

- Above Average
- Somewhat Above Average
- Average
- Somewhat Below Average
- Below Average
- I am not in school
- Other (please specify)

Do you have any problems or difficulties in school or at work?

- Yes
- No

If you have problems at school or work, please describe your problem or difficulties below.

Do you have any special accommodations in school? (For example, you can have extra time on tests)

- Yes
- No

If you get accommodations in school, please list what they are below.

Have you ever seen a therapist for anxiety or depression?

Yes

No

Please list any academic activities you participate in.

Please list any sports you play

Please list any religious activities you participate in.

How often do you see your doctor per year?

Just for a check up and when I have a cold/flu

More than 5 times per year

More than 10 times per year

Appendix C

Health Status Questionnaire

Health Status Questionnaire

What is the name of your heart problem?

Do you take medication for your heart?

Yes

No

If you take medication for your heart, please list the name/names of your medication below.

How old were you when you had your first heart symptom (fainting or cardiac arrest)?

What was your first heart symptom?

Where were you when you had your first heart symptom?

Have you ever fainted?

Yes

No

If you have fainted, please describe how many times you have fainted, where you were, and who was with you when you fainted.

Have you ever had a seizure?

Yes

No

If you have had a seizure, please write how many times you have had seizures, where you were, and who was with you below.

Has anyone ever had to help you by using an AED?

Yes

No

If you have had someone help you with an AED, please describe the situation and your reaction to it below.

Do you have own an AED

Yes

No

Other (please specify)

Do you wear medical alert jewelry?

Yes

No

Do you take medication at school or work?

Yes

No

Are there any foods you cannot eat?

Yes

No

If there are foods you cannot eat, please list them below.

Do you ever eat foods you are not allowed to have?

Yes

No

If you eats foods you are not allowed to have, when do you eat these foods and what makes you want to eat them?

Do you participate in gym class?

- Yes
- No
- I am not in school

If you participate in gym class, what activities do you do?

Do you have to drink a certain amount of water everyday?

- Yes
- No

If you are told to drink a certain amount of water per day, how much are you told to drink and how much do you drink everyday?

Do your teachers or boss know about your heart problem?

- Yes
- No

Do your teachers treat you differently than your classmates because of your heart problem?

- Yes
- No
- I am not in school

If you feel like you are treated differently because of your heart condition, please explain how people treat you differently below.

Do you have a ICD or pacemaker?

- Pacemaker
- ICD
- I don't have an ICD or pacemaker

How many pacemakers have you had?

- None
- One
- Two
- Three
- Four
- More than four

How many ICDs have you had?

- None
- One
- Two
- Three
- Four
- More than four

If your pacemaker/ICD given you any trouble, please describe what problems you have experienced below.

Please write the name of your heart doctor below.

How often do you see your heart doctor?

- Once a year
- Every three months
- Every six months
- Once every two years
- I don't know

Does anyone else in your family have a heart problem?

How old were you when you were told you have a heart problem?

Who explained your heart problem to you?

Do you have any activities or sports you can't do because of your heart problem?

Yes

No

What are the sports or activities you cannot play because of your heart problem?

Do you ever play any activities or sports that you are told to not do?

Yes

No

If you do sports or activities you are not allowed to play, what are those activities and what makes you play or participate in them?

Do you take your medication like your doctor tells you?

Yes

No

If you don't take your medication like you are told, what makes you not take it?

Have you ever had to go to the emergency room for your heart problem?

Yes

No

If you have had to go to the ER for your heart, please write how many times you have gone and why you had to go there below.

If you have an ICD, has it ever shocked your heart?

Yes

No

If you worry about your heart, please write about your worries below.

If you feel sad because of your heart problem, please write about what makes you sad below.

Has anyone else in your family gone to the ER for a heart problem?

Yes

No

I don't know

If you have other health problems, please list them below. (For example: thyroid disorder, diabetes, anxiety)

Do your other health problems keep you from doing things you would like to do?

Do you have a plan in case you have an emergency happen at school?

Yes

No

Do you have a plan in case you have an emergency at a friend's house?

Yes

No

Is there anything you like about having a heart problem?

What do you not like about your heart problem?

Do you attend any support groups?

Yes

No

Do you see a therapist?

Yes

No

Appendix D

Emails to Participants

Series of Emails Sent to Participants 18 Years of Age or Older

Good Morning/Afternoon/Evening <insert participant's first name>:

Thank you so much for your interest in participating in the study entitled "Examining Habits and Social Activities of Teenagers and Young Adults."

Please email the student researcher and confirm that you are interested in participating in the study that is looking for individuals ages 13-22 to complete an online study examining the habits and social activities of adolescents and young adults with and without cardiac rhythm disorders. Also, please indicate in your email if you have a cardiac condition.

Thanks,

Lauren Lucente, LPC, MA
4th year psychology student in PCOM's Psy.D. Program in Clinical Psychology

Stephanie H. Felgoise, Ph.D., ABPP
Professor & Vice-Chair, Dept of Psychology
Director, PsyD Program in Clinical Psychology, Philadelphia College of Osteopathic Medicine

Good Morning/Afternoon/Evening <insert participant's first name>:

Below is a list of criteria you must meet in order to participate in the current study.

<insert condition specific inclusion/exclusion criteria>

If you meet the criteria above, please read and follow the detailed instructions below. This is how you will provide consent for participation in the current study.

1. Use the e-signer program to read the complete informed consent form.

Decide if you

want to be in the study. If you do, sign the informed consent form using the e-

signer
program.

<insert e-signer link here>.

2. Email the researcher after you have completed the informed consent form and let her know that you have signed the document. The student researcher will sign it after you have signed the document.
3. After the student researcher receives your email, she will review the form and use the e-signer program to also sign the document.
4. Save a copy of this document, signed by yourself and the student researcher, for your personal records.

Once you have signed the informed consent form the following will occur:

1. You will receive an email that contains the online survey link.
2. You can use a smartphone/computer to complete the online survey.
3. The online survey can be completed over the course of a week in as many sessions as you would like.
4. If you decide to participate in the study, you will then be asked to answer questions about a variety of topics, such as your social activities and habits.
5. In the follow-up email, you will receive an attachment with resources regarding physical wellness, healthy coping, and strategies for decreasing stress.

Thanks,

Lauren Lucente, LPC, MA
4th year psychology student in PCOM's Psy.D. Program in Clinical Psychology

Stephanie H. Felgoise, Ph.D., ABPP
Professor & Vice-Chair, Dept of Psychology
Director, PsyD Program in Clinical Psychology, Philadelphia College of Osteopathic
Medicine

Good Morning/Afternoon/Evening <insert participant's first name>:

Thank you so much for agreeing to participate in this study. Please make sure you have saved a copy of the informed consent form, signed by both yourself and the study researcher, for your personal records.

Below is the survey link and detailed instructions for you to follow when you are completing the survey.

Remember that all information you provide is **anonymous**. Researchers cannot link the information you provide in the survey or in your emails to your personal identity.

1. You may complete the online survey on your computer/smartphone over the course of a week in as many sessions as you would like.
2. Once you click the link below, you will be directed to the survey.
3. You will first answer questions to determine if you are eligible for the study.
4. If you are eligible, you will then be asked to answer questions about a variety of topics, such as your social activities and habits.
5. Once you have finished, if you would like to be entered into the raffle for a \$10-dollar gift card to Target, please email the researchers at LQTStudies@pcom.edu. **Please put "Attention Lauren" in the subject line.**
6. Also, after you are finished you will be provided you with resources, regarding physical wellness, healthy coping, and strategies for decreasing stress. A copy of those resources is attached to this email for your convenience. Please feel free to save a copy for your records or future reference.

You are still able to participate in the raffle if:

- You agree to participate in the online study but are told you are not eligible.
- You stop participating in the study at any point.
- Please email the researchers at LQTStudies@pcom.edu to be entered into the raffle. Please put "Attention Lauren" in the subject line.

When you are ready to complete the online survey click this link: <insert survey link>.

Again, thank you so much for participating in this study!

Regards,

Lauren Lucente, LPC, MA
4th year psychology student in PCOM's Psy.D. Program in Clinical Psychology

Stephanie H. Felgoise, Ph.D., ABPP
Professor & Vice-Chair, Dept of Psychology
Director, PsyD Program in Clinical Psychology, Philadelphia College of Osteopathic
Medicine

Series of Emails Sent to Parents/Guardians of Participants Under 18 Years of Age

Good Morning/Afternoon/Evening <insert parent/guardian's first name>:

Thank you so much for emailing us to express your child's interest in participating in the study entitled "Examining Habits and Social Activities of Teenagers and Young Adults."

Please email the student researcher a confirmation that your child is interested in participating in the study that is looking for individuals ages 13-22 to complete an online study examining the habits and social activities of adolescents and young adults with and without cardiac rhythm disorders.

Also, please indicate in your email if your child has a cardiac condition.

Thanks,

Lauren Lucente, LPC, MA
4th year psychology student in PCOM's Psy.D. Program in Clinical Psychology

Stephanie H. Felgoise, Ph.D., ABPP
Professor & Vice-Chair, Dept of Psychology
Director, PsyD Program in Clinical Psychology, Philadelphia College of Osteopathic
Medicine

Good Morning/Afternoon/Evening **<insert parent/guardian first name>**:

Below are criteria your child must meet in order to participate in the current study.

<insert condition specific inclusion/exclusion criteria>

If your child meets the criteria above, please read and follow the detailed instructions below. This is how you will provide consent for your child to participate in the current study.

1. Use the e-signer program to read the complete informed consent form. Decide if you will provide your child permission to be in the study. If you will, sign the informed consent form using the e-signer program.
<insert e-signer link here>.
2. Email the researcher and tell her you have signed the consent form. Also, please provide her with your child's first name, so the researcher can address him/her specifically in the follow-up email. The student researcher will sign the consent form after you have signed the document.
3. After the student researcher receives your email, she will review the form and use the e-signer program to also sign the document.
4. Save a copy of this document, signed by yourself and the student researcher, for your personal records.

If you have any problems using the e-signer program please do not hesitate to contact the student researcher at LQTStudies@pcom.edu.

Once you have provided consent for your child, the following will occur:

1. You will receive an email that contains the survey link that your child will need to complete the online survey.
2. He/she can use a smartphone or computer to complete the online survey.
3. The online survey can be completed over a week's time in as many sessions as your child needs.
4. We ask that your child independently complete the online survey because adolescents are more likely to answer honestly if they feel comfortable and are provided privacy.
5. In the follow-up email, you will receive an attachment with resources, which will be provided to your child after they complete the study, regarding physical wellness, healthy coping, and strategies for decreasing stress. Please feel free to print these resources and provide them to your child.

Thanks,

Lauren Lucente, LPC, MA
4th year psychology student in PCOM's Psy.D. Program in Clinical Psychology

Stephanie H. Felgoise, Ph.D., ABPP
Professor & Vice-Chair, Dept of Psychology
Director, PsyD Program in Clinical Psychology, Philadelphia College of Osteopathic
Medicine

Good Morning/Afternoon/Evening <insert parent/guardian's name>:

Thank you so much for allowing your child to participate in the current study! Please make sure you saved a copy of the consent form, signed by the researcher and yourself, for your personal records.

Remember any information your child provides is **anonymous**. We will not be able to link your child's responses with his/her identity. Also, we will not be able to link any information provided in these emails with his/her identity.

As promised, attached is a list of resources regarding physical wellness, healthy coping, and strategies for decreasing stress. Again, please feel free to print a copy for your child. They will receive these resources after completing the study.

Below are instructions and a link that we ask you to share with your child.

Remember: **Please allow your child to complete the survey alone!** We want them to answer honestly. If you have any questions or concerns, please feel free to contact the student researcher at LQTStudies@pcom.edu. **Please put "Attention Lauren" in the subject line.**

Hi -<insert child's name>:

Thank you for taking our survey!

Remember that all information you provide is **anonymous**. Researchers cannot match the your answers on the online survey with your name. No one, including your parents, will be able to get your answers to the questions on the online survey.

1. Complete the online survey on your computer or smartphone over the course of a week when you have time!
2. Click the link, at the bottom of this email, to start the survey.
3. Answer questions to determine if you can participate in the study.
4. Read and sign the assent form.
5. If you agree to be in the study, you will then be asked questions about many topics, such as your social activities and habits.
6. Once you have finished, if you would like to participate in the raffle for a 10-dollar gift card to Target, please have your parent/guardian email the student researcher at LQTStudies@pcom.edu
7. After you have finished, you will be provided with resources about physical wellness, healthy coping, and strategies for decreasing stress.

You are still able to participate in the raffle if:

- You agree to participate in the online study but are told you are not eligible.
- You stop participating in the study at any point.
- Please have your parent/guardian email the researchers at LQTStudies@pcom.edu to be entered into the raffle.

When you are ready to complete the online survey click this link: <insert survey link>.

Again, thank you so much for participating!

Lauren Lucente, LPC, MA
4th year psychology student in PCOM's Psy.D. Program in Clinical Psychology

Stephanie H. Felgoise, Ph.D., ABPP
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Medicine

Appendix E

Adolescent Resources

Resources Provided to Participants and Parent/Guardians**For Fitness and Health:**

<http://www.letsmove.gov> : provides information for living a healthy active lifestyle.

<http://youngwomenshealth.org> : provides information about general health for older teens (16+).

<http://www.girlshealth.gov> : provides information about general health for younger teens (10-16).

Teenshealth.org : provides information for teens on all kinds of health and illness topics.

Chronic Illness/Cardiac Channelopathies:

http://geiselmed.dartmouth.edu/koop/resources/chronic_illness/ : teens share their stories of their experiences.

<http://www.sads.org/living-with-sads/For-Kids/SADSCoach-for-Youth#.WA1ZGWP790s> : This is a youth connection program hosted by the SADS Foundation.

<http://www.aedsuperstore.com/resources/sudden-cardiac-arrest-in-children/> : information about AEDS.

<http://www.hrsonline.org/Patient-Resources/Patient-Information-Sheets> : education and educational information about various heart conditions.

<https://rarediseases.org/rare-diseases/brugada-syndrome/> : provides educational and support information for patients and parents

<https://www.bhf.org.uk/heart-health/conditions/inherited-heart-conditions> : provides information and materials about support for individuals with a variety of

cardiac conditions.

For Bullying:

<http://www.pacer.org/bullying/> : PACER provides digital-based resources for parents, schools, teens and youth to help address and prevent bullying.

<http://westophate.org> : This anti-bullying group is dedicated to raising self-esteem in teens through various social media platforms that engage teens to help each other gain confidence.

For Mental Health:

<http://www.ifred.org> : The International Foundation for Research and Education on Depression shines a positive light on depression and aims to eliminate the stigma associated with the disease through prevention, research, and education

<http://us.reachout.com> : This non-profit organization meets youth where they are to deliver peer support and mental health information in a safe and supportive online space.

<http://www.crisistextline.org> : Make sure teens know about this free, 24/7 text line that provides emotional support to those in crisis.

<https://www.nimh.nih.gov/index.shtml> : A government organization focused on transforming the understanding and treatment of mental illnesses.

<https://twloha.com> : TWLOHA is a non-profit movement dedicated to presenting hope and finding help for people struggling with depression, addiction, self-injury, and suicide.

<http://patient.info/blogs/pro/2016/10/mental-health-in-young-people-the-time-of-their-lives> : Blog about mental health in teenagers and youth people.

National Suicide Hotline: 1-800-SUICIDE (784-2433) or the National Suicide Prevention Lifeline: 1-800-273-TALK (8255) Both toll-free, 24-hour, confidential hotlines which connect you to a trained counselor at the nearest suicide crisis center.

The Jed Foundation: works to reduce the stigma students feel about having or seeking treatment for emotional problems. It provides safe, accessible resources for students to help themselves or a friend.

National Alliance on Mental Illness (NAMI): NAMI on Campus clubs are student-run, student-led organizations that provide mental health support, education, and advocacy in a university or college setting.

DepressedTeens: provides valuable information/educational resources for teenagers, their parents and educators to understand the signs and symptoms of teenage depression and get help when needed.

Positive Coping and Stress Reduction:

Resilience for Teens—Got Bounce? : offers tips from the American Psychological Association (APA) for building skills that can help teens cope in tough times.

<http://mindfulnessforteens.com/> : resources to help teens use mindfulness to handle stress and includes apps to practice meditation and guided meditation

<https://www.psychologytoday.com/blog/the-race-good-health/201501/teens-and-stress-practical-coping-skills> : Provides information about helpful coping strategies

<https://www.apa.org/helpcenter/stress-teens.aspx> : offers ways to reduce stress.

<https://www.healthychildren.org/English/healthy-living/emotional-wellness/Building-Resilience/Pages/For-Teens-Creating-Your-Personal-Stress-Management-Plan.aspx> : provides steps to reducing stress.

<http://www.pamf.org/teen/life/stress/managstress.html> : provides tips for reducing stress.

<http://www.nysyouth.net/leadership/> : provides information regarding how teenagers can become effective leaders within their community.

<http://us.reachout.com> : interactive website is focused on emotional well-being. Designed by and for young people, it includes stories, coping strategies, fact sheets, video clips, and a user forum. Inspire USA.

Smoking/Drug/Substance Use:

<https://teens.drugabuse.gov> : Created for middle and high school students and their teachers, this website provides accurate and timely information about drug prevention that can be used in and out of the classroom.

<https://www.thetruth.com> : This campaign is dedicated to putting an end to teen smoking and provides the facts about tobacco that everyone should know.

<http://www.drugfree.org> : An organization dedicated to reducing substance abuse among adolescents by supporting families and engaging with teens.

<http://patient.info/blogs/sarah-says/alcohol-and-teenagers-why-should-they-care>

<http://patient.info/blogs/sarah-says/2016/08/underage-drinking-what-s-the-big-picture>

Sexual Orientation and Gender Identity:

<https://www.genderspectrum.org/explore-topics/teens/> : provides information regarding gender identity

<http://www.youthproject.ns.ca/resources.php?loc=Resources> :resources and information around sexual orientation and gender identity.

Grief:

<http://toodamnyoung.com>: An online resource and community for grieving teens and young adults to let them know they're not alone. The site features expert articles, personal accounts, fiction, poems, and more.

<http://www.whatsyourgrief.com> : Started by two mental health professionals who each dealt with the loss of a parent, this site's mission is to promote grief education, exploration, and expression in both practical and creative ways.

Healthy Romantic Relationships:

<http://www.loveisrespect.org> : Its mission is to engage, educate, and empower young people to prevent and end abusive relationships. The site provides comprehensive education on healthy, unhealthy and abusive dating relationships and behaviors.

<http://stayteen.org> :The goal of Stay Teen is to encourage youth to enjoy their teen years and avoid the responsibilities that come with too-early pregnancy and parenting. Created by The National Campaign, the site features facts and resources to help teens make informed decisions.

Driving Safely:

<http://www.nrsf.org> :The NRSF created "Teen Lane" as a resource to help tweens and teens learn everything they need to know about driving safety.

<http://teendriving.com> : Safety tips and advice for teen drivers, as well as their parents. Resources include a Teen Driving Contract and an "Are You A Safe Driver?" checklist.

Technology:

<http://www.nsteens.org> : A site dedicated to teaching teens about Internet safety. It includes animated videos, short films, games, and interactive comics, as well as teaching materials for educators.

Resources for Adolescents are provided by the following programs/associations/organizations:

Choices: Their mission is “to help teens think critically about their health, their lives, and their world. We want to arm young people with information so they can make thoughtful, positive decisions.”

Patient Info

C. Everett Koop Institute: Their mission is to “promote the health and well-being of all people.” The Koop Institute works to enhance our understanding of mental and physical health and the prolongation of a high quality of life...”

Cry for Help: Their mission is to help with the “difficult transition from high school to college.”

American Psychological Association

Healthy Children.org: this website is “committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.”

The Palo Alto Medical Foundation for Health Care, Research and Education

(PAMF): a not-for-profit health care organization dedicated to enhancing the health of people in our communities.

The Youth Project: non-profit charitable organization dedicated to providing support and services to youth, 25 and under, around issues of sexual orientation and gender identity. We have a provincial mandate so although we are located in HRM, we travel around the province to meet with youth in other communities. We provide a variety of programs and services including support groups, referrals, supportive counseling, a resource library, educational workshops, social activities.

SADS Foundation (Sudden Arrhythmia Death Syndromes): To save the lives and support the families of children and adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

Heart Rhythm Society

The World Heart Federation: exists to prevent and control these diseases through awareness campaigns and action, promoting the exchange of information, ideas and science among those involved in cardiovascular care, advocating for disease prevention and control by promoting healthy diets, physical activity and tobacco free living at an individual, community and policy maker level. Our work is organized in four programme areas.

National Organization for Rare Diseases (NORD): Every day in America, 30 million people wake up to fight the battle with a rare disease. The vast majority are children. For most, there are no cures and few, if any, proven and effective treatments. NORD provides a unified voice for those courageous individuals, and the parents and other caregivers seeking to help them, so that they won't have to fight that battle alone.

British Heart Foundation: their mission is to win the fight against cardiovascular disease and our vision is a world in which people do not die prematurely or suffer from cardiovascular disease.

Just for parents:

<http://www.med.umich.edu/yourchild/topics/chronic.htm>

"Helping your child through adolescence"

Also see the attached documents:

"Surviving adolescence": <https://www.psychologytoday.com/us/blog/surviving-your-childs-adolescence>