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Philadelphia College of Osteopathic Medicine

Department of Psychology

A FEASIBILITY STUDY OF A LQTS-SPECIFIC WORKSHOP: CHILDRENS'
PROBLEM-SOLVING SKILLS, COPING, SELF-EFFICACY, AND LOCUS OF
CONTROL

By Katherine L. Corvi, M.A., Ed.S., M.S.

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Psychology

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PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by Katherine Corvi on the 23rd day of November, 2015, 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.

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Abstract

Living with a chronic medical condition in childhood and adolescence requires many critical lifestyle changes and restrictions, which may compromise psychosocial development. Social problem-solving skills have been shown to enhance the ability to cope with both minor and major daily stressors and to minimize psychological problems associated with physical health problems. The research is part of a larger study with children with long QT syndrome (LQTS) and their parents; the present study focuses on the children. This study was developed to examine the feasibility and efficacy of a problem-solving workshop to increase problem solving, self-efficacy, coping, and locus of control in children with LQTS. Participants were two parent-child dyads. Parents participated to learn problem-solving skills and coach their children in learning these skills. There was very good agreement ($\kappa = 0.986$) among the independent raters regarding the extent to which the protocol was implemented as intended. Overall evaluations of the workshop by participants were positive, and the workshop was deemed both feasible and effective. Child participants had overall increases in problem-solving skills and maintained these improvements throughout follow-up. They also had increases in coping abilities at 1-month follow-up, but scores returned to baseline at the 3-month follow-up. Although there was a slight increase in locus of control, self-efficacy scores fluctuated from baseline to the 3-month follow-up. The inclusion of parents in the workshop is believed to have helped facilitate children's short-term gains on outcome measures. Continual support and review of problem-solving skills may be necessary to facilitate long-term gains in problem-solving, coping, and adaptive skills in children.

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Chapter 1

Introduction

Statement of the problem.

Long QT syndrome (LQTS) is an inherited cardiac condition that is the result of mutations on certain genes (Liu et al., 2011; Wedekind et al., 2009). This condition predisposes affected individuals to cardiac arrhythmias (Ellis et al., 2003). The clinical manifestations disorder include syncope, ventricular tachycardia, and sudden death (Goldenberg & Moss, 2008; Murray et al., 2002). Although the incidence of LQTS is difficult to estimate, researchers suggest 1 in 2,000 people have LQTS (Schwartz et al., 2009).

A diagnosis of a chronic illness in childhood or adolescence may complicate opportunities to develop peer relationships in areas such as friendships, athletics, and other school functions. Specifically, a diagnosis of LQTS at this time requires many critical lifestyle changes and restrictions (Giuffre, Gupta, Crawford, & Leung, 2008) that may negatively impact a social development.

The literature suggests that individuals with chronic illnesses experience stressful outcomes such as adjustment, depression, or anxiety disorders secondary to their diagnoses (Turner & Kelly, 2000). For example, adolescents may perceive themselves differently from their healthy peers and have problems coping with daily stressors related to the diagnosis (Feinberg, 2010). Adolescents diagnosed with LQTS may experience anxiety and depression due to the inherent uncertainty and risk of sudden death associated with LQTS. This increased anxiety may in turn compromise their sense of control over their illness. Finally, adolescents with LQTS may feel isolated from their

peer group, increasing the likelihood of depression, anxiety, and/or lowered self-esteem. It is therefore important to examine problem solving, self-efficacy, coping, and locus of control in this population.

Purpose of study.

Chronic illnesses interfere with social developmental processes in childhood and adolescence, making youth more vulnerable to compromised psychosocial development (Meijer, Sinnema, Bijlstra, Mellenbergh, & Wolters, 2002). Consequently, the purpose of this study was to provide problem-solving strategies to help children and adolescents with LQTS cope with normative age-related challenges that may be further complicated by having a chronic medical condition. Social problem-solving skills have been shown to enhance the ability to cope with both minor and major daily stressors and to minimize psychological problems associated with physical health problems (Nezu & Nezu, 2012). Additionally, the literature suggests that adolescents who experience anxiety and/or depression due to lifestyle changes associated with chronic illnesses benefit from problem-solving therapy (Meijer et al., 2002; Schmidt, Petersen, & Bullinger, 2003). Though there is little research on coping, locus of control, and self-efficacy in adolescents with LQTS, the efficacy of cognitive behavioral interventions such as problem solving skills training has been demonstrated in individuals with chronic illnesses such as diabetes, asthma, and pediatric cancer patients (Barlow & Ellard, 2004; Nezu, Nezu, Felgoise, McClure, & Houts, 2003). The present intervention was developed to increase problem solving, self-efficacy, coping, and locus of control in children and adolescents with LQTS by means of a problem-solving workshop. This study utilized a social problem-solving manualized treatment that was adapted for use

with children and adolescents diagnosed with LQTS. The workshop provided participants with opportunities to acquire and enhance problem-solving skills to better cope with stressors associated with their illness.

Chapter 2

Literature Review

Chronic illness.

Chronic illnesses affect 15% of youth (van der Lee, Mookink, Grootenhuis, Heymans, & Offringa, 2007). A chronic illness is defined as an illness with symptoms that involve one or more major organ systems (Brown & Macias, 2001). The chronic illnesses most often diagnosed in childhood and adolescence include asthma, cerebral palsy, congenital heart disease, diabetes, and leukemia (Miceli, Rowland, & Whitman, 1999).

Individuals with a chronic illness are burdened with managing their disease and symptoms in the absence of a cure; furthermore, those with a chronic illness must maintain a medical regimen throughout their lifetime (Institute for Health and Aging, 1966). Thus, managing a chronic illness requires numerous skills and abilities. Individuals diagnosed with chronic illnesses must recognize the environmental, personal, and social problems that chronic illness presents, in order to implement effective solutions (Hill-Briggs, 2003).

Long QT syndrome.

Some individuals with LQTS become aware of their problem only after the first episode of syncope, whereas others are diagnosed with the condition soon after birth (Giuffre et al., 2008). Those diagnosed with LQTS may experience symptoms during a triggering event, most likely during childhood or adolescence (Wedekind et al., 2009). Many individuals with LQTS experience a symptom by 15 years of age (Wedekind et al.,

2009). LQTS cannot be cured, but must be medically and behaviorally managed throughout the person's lifetime.

History of LQTS.

Possible evidence of LQTS dates back to the 1950s (Goldenberg, Zareba, & Moss, 2008). After an 18-year study, researchers discovered that a prolonged QT interval in the first few days of life is associated with sudden infant death syndrome (SIDS; Arnestad et al., 2007). Mutations of genes that code for the cardiac channels in LQTS were initially discovered in the mid 1990s. Since that time, knowledge of the cause of LQTS has significantly advanced. Romano-Ward syndrome and Jervell Lange-Nielsen syndrome are types of LQTS (Collins & Van Hare, 2006). Romano-Ward syndrome is the most commonly diagnosed among patients with LQTS. Jervell and Lange-Nielsen syndrome is associated with congenital deafness in addition to the prolonged QT interval (Collins & Van Hare, 2006).

Mechanisms of action.

The prolonged QT interval is the primary result of gene mutations in LQTS related genes (Liu et al., 2011). A mutation in a gene incorrectly encodes a critical ion channel that is located within the heart muscle cells (Collins & Van Hare, 2006). There are mutations in 13 genes associated with LQTS (Shimizu & Horie, 2011). There are eight genes that code for specific ion channels (sodium, potassium, or calcium; Bokil Baisden, Radford, & Summers, 2010).

Ion channels play critical roles in LQTS. The mutations characteristic of LQTS are the result of potassium or sodium abnormalities, causing a prolongation in the repolarization phase of the action potential (Collins & Van Hare, 2006; Moss & Kass,

2005). Arnestad et al. (2007) indicated that mutations caused by genetic variations result in a gain of function, loss of function, accelerated inactivation, increased persistent sodium currents, or impaired activation.

The generation of a normal action potential helps describe the mechanism of action in a patient with LQTS. Zimetbaum and Josephson (2012) found that at rest, the sodium-potassium gate pumps potassium into the cell in exchange for sodium, which is then released. A rapid depolarization occurs and is characterized by the opening of voltage-gated sodium channels and entry of sodium into the cell. Subsequently, there are delayed openings of calcium channels and ions. The calcium channels remain open during repolarization. There is an opening of potassium channels and ions, which result in late repolarization. This repolarization is followed by a return to resting potential of the membrane (Zimetbaum & Josephson, 2012). The QT interval is the total duration of the depolarization and repolarization of the action potential (Saenen & Vrints, 2008). The interval is determined by the activity of the calcium and potassium channels when they attempt to repolarize towards a resting potential (Zimetbaum & Josephson, 2012).

Genetic mutations cause complications within the heart, including transportation defects and suboptimal channel currents (Goldenberg & Moss, 2008). The flow of ions affects the action potential, which in turn affects the QT interval. In variations with sodium-channel mutations, the gate never closes, resulting in continued leakage and a prolonged action potential. Different subtypes indicate which channels have mutations (Collins & Van Hare, 2006).

The inherited mutated gene determines the LQT subtypes (Saenen & Vrints, 2008). LQT1, 2, and 3 are the most commonly diagnosed forms of LQTS (Bokil et al.,

2010). The gene KCNQ1 (encoded potassium channel mutation) is the gene responsible for LQT1 (Collins & Van Hare, 2006). The prevalence of individuals diagnosed with LQT1 ranges from 30% to 35% of all diagnosed cases of LQTS. Individuals diagnosed with LQT1 most often experience symptoms that occur during exercise or emotional arousal (Saenen & Vrints, 2008). KCHN2 (encoded potassium channel mutation) is responsible for LQT2, which affects 30% to 35% of individuals diagnosed with LQTS. Individuals diagnosed with LQT2 may experience a cardiac event as a result of an auditory stimulus, such as a loud noise (Saenen & Vrints, 2008). The gene SCN5A (encoded sodium channel mutation) is responsible for LQT3. The estimate of individuals diagnosed with LQT3 ranges from 5% to 10% of all diagnosed cases of LQTS (Collins & Van Hare, 2006). LQT3 arrhythmias are most apt to occur during sleep (Saenen & Vrints, 2008). There are other variants in LQTS (Type 5-10); however, those variants occurs in less than 1% of the population (Collins & Van Hare, 2006).

Inherited and acquired types of LQTS.

The distribution of mutations located on genes encoding ion channels in patients diagnosed with congenital LQTS is not as rare as researchers once thought (Schwartz, Priori, & Napolitano, 2003). Experts in the field identified genetic links throughout the population diagnosed with LQTS. Two forms of inherited LQTS are known: an autosomal dominant form (Romano-Ward syndrome) and an autosomal recessive form (Jervell Lange-Nielsen syndrome; Bokil et al., 2010). At times, family members do not have a genetic mutation. These instances can be attributed to those genetic variants that have not yet been identified (Bokil et al., 2010).

Within families with LQTS, some individuals may carry more than a single mutation (Schwartz et al., 2003). Molecular screening of individuals diagnosed with LQTS demonstrated that they had two mutations of their genes (Schwartz et al., 2003). Schwartz, Priori and Napolitano (2003) found that among 300 participants, family member carriers of a single genetic defect had mild manifestations, and 83% with multiple mutations had symptoms such as syncope or cardiac arrest. An individual could be an asymptomatic gene carrier with a normal QT interval; however, a mutation may produce a defect in the repolarization that could result in a clinical presentation. Electrophysiologists hypothesized that for individuals who inherited a genetically silent mutation on the potassium channel, the presence of a trigger may result in sudden cardiac arrest (Schwartz et al., 2003).

Acquired long-QT syndrome (aLQTS) is caused by a malfunction of ion channels or proteins that results in a delayed prolongation of the QT interval (Kozik & Wung, 2012). Goldenberg and Moss (2008) suggested that aLQTS can result from several causes including but not limited to drug effects, hypothermia, or myocardial ischemia. Kozik and Wung (2012) indicated that environmental stressors and pharmacological effects are two main causes of aLQTS.

Identification and diagnosis.

LQTS is often difficult to identify and diagnose prior to an event. Typically, LQTS is not diagnosed until a person or a family member experiences syncope, aborted cardiac arrest, or sudden cardiac death (SCD; Liu et al., 2011). This syndrome is life-threatening, especially in children and adolescents who have not yet been diagnosed (Giuffre et al., 2008). To diagnose LQTS, cardiologists use criteria that consist of

electrocardiographic findings and a review of clinical and family history (Mancuso, Brady, Harrigan, Pollack, & Chan, 2004).

Treatment of LQTS.

The literature supports several medical treatments for LQTS. Treatment is dependent upon the type of LQTS. Beta blockers, internal cardioverter-defibrillators, pacemakers, and competitive sport restrictions are among the commonly cited treatments for patients with LQTS.

Beta blockers.

Beta-blocker medication is the initial treatment for patients with LQTS1. Beta blockers slow the heart rate (Kubon et al., 2011). Viitasalo et al. (2006) indicated “the effect of beta-blockers is likely to be mediated by decreasing I_{Ca-L} activity as well as by preventing catecholamine from binding to beta-adrenergic receptors” (p. 751). Beta blockers are also moderately effective for LQT2 (Collins & Van Hare, 2006).

Implantable cardioverter-defibrillator (ICD).

An implantable cardioverter-defibrillator (ICD) is often a second treatment used to treat abnormally fast heart rhythms (Collins & Van Hare, 2006). This treatment is recommended for patients who experience recurrent syncope despite pharmacological therapies (Kwon et al., 2012). Research demonstrates that ICDs are highly effective in high-risk patients with LQTS (Goldenberg & Moss, 2008). Those with ventricular fibrillation (abnormal heart rhythm) are treated effectively by electrical defibrillation (Ganz, Olshansky, & Downey, 2012). Defibrillation is an electrical shock administered to convert ventricular fibrillation to a normal rhythm. ICDs have three main components: sensing and pacing electrodes, defibrillation electrodes, and a pulse generator. The

electrodes record heart rhythm and detect any ventricular tachycardia and fibrillation. If an abnormal heart rhythm is detected, the ICD delivers electrical shocks or energy discharge to the heart to restore a normal heartbeat (Ganz et al., 2012).

Pacemakers.

Pacemakers are yet another treatment for LQTS. Pacing is a treatment used in infants who may be too small for ICD implantation (Saenen & Vrints, 2008).

Pacemakers are devices that are implanted under the skin and used to treat abnormal heart rhythms. Pacemakers are different from ICDs because they are typically used to treat individuals with slow heartbeats. The pacemaker sends electrical impulses to the heart and causes the heart to beat at a normal rate. Pacemakers have hardware similar to that of the ICD. Pulse generators and leads connected to the heart generate information about how the heart is functioning and deliver an electrical impulse to the heart to prevent low rates (Martin & Villalba, 2012).

Activity restrictions.

Individuals diagnosed with LQTS are often restricted from physical activities. Collins and Van Hare (2006) indicated that published guidelines for physical activities and recreational sports in young patients are available. These restrictions were created based on concern that an accelerated heartbeat that can lead to ventricular fibrillation and possibly sudden death (Collins & van Hare, 2006). However, new recommendations have eased restrictions for some individuals, allowing those who are asymptomatic or symptomatic and treatment compliant to participate in more physical activities than previously allowed (Ackerman, Zipes, Kovacs, & Maron, 2015). Patients with LQT3 may not have these restrictions because they are more likely to have cardiac events at

rest. However, persons with LQTS may be more likely to have a pacemaker and may therefore be restricted from activities to avoid impact to the device.

LQTS is a life-threatening cardiac arrhythmia disorder caused by genetic mutations, with subtypes LQTS1, 2, and LQTS3 being the most common. LQTS is often underdiagnosed, perhaps because persons with LQTS are often asymptomatic. Once diagnosed, treatment of LQTS is dependent upon identifying the genetic subtype and family history. With treatment, persons with LQTS can live active lives. However, the psychosocial sequelae are significant because the threat of fainting, or having seizures or cardiac arrest without warning is always present. Additionally, cardiologists require individuals diagnosed with LQTS to make significant lifestyle changes in order to increase the likelihood of avoiding such events. Thus, persons with LQTS experience significant daily challenges in living with the condition.

Children and adolescents with LQTS.

A diagnosis of LQTS in childhood may involve physical limitations and psychosocial factors such as anxiety or worry (Anderson, Oyen, Bjorvatn, & Gjengedal, 2008). Compared to children with other chronic illnesses who experience worry and medical fears, those with LQTS may have greater difficulty navigating socially, as they may feel overwhelmed by their illness or fear social rejection (Giuffre, Gupta, Crawford, & Leung, 2008). Holen, Lervåg, Waaktaar, and Ystgaard (2012) found that children who employ active coping strategies, have fewer psychosocial difficulties. Furthermore, children with less passive avoidance coping tended to have more situation-specific coping with social and school-related stressors (Hampel, Rudolph, Stachow, Lab-Lentzsch, & Petermann, 2005).

Difficulty in coping with LQTS in adolescence may be exacerbated by hormonal and physical changes (Radico, 2013). Adolescence is also period when youth form values, self-efficacy, and identities (Boice, 1998). Adolescents with a cardiac condition may face even greater social difficulties than their peers (Uzark, VonBargen-Mazza, & Messiter, 1989). For example, LQTS treatment may require unexpected absences from school for doctor appointments. These absences may impact adolescents' social development and ability to form peer relationships because of less contact with their peers (La Greca, 1990). Physicians may recommend that parents and guardians monitor adolescents' daily activities and participation in sports (Giuffre et al., 2008). Adolescents diagnosed with LQTS who wish to play team sports in high school, college, and beyond are often suspended indefinitely from these types of activities, thus impacting their peer relations and even identities (Asif et al., 2014). Additionally, individuals with LQTS may be restricted from activities that can trigger cardiac events, such as those that involve loud and sudden noises, high-risk/thrill-seeking activities, or those that may cause a sudden increase in heart rate (Feinberg, 2010). Overall, a diagnosis of LQTS in adolescence can cause a series of daily problems and stressful experiences (Nezu, Nezu, Friedman, Faddis, & Houts, 1998).

Children and adolescents diagnosed with LQTS may appear healthy, but the restrictions and lifestyle modifications associated with LQTS are often challenging and can impact their social development. For example, one modification may be drinking a prescribed amount of water every day. The challenge may include explaining to an adult at school that they must drink more so than is typical for their age group and

subsequently need to use the restroom more often. Other challenges and lifestyle modifications include fatigue and dietary restrictions.

Children and adolescents may have difficulty attaining peer acceptance as a result of their condition (Feinberg, 2010). These students often receive school-based accommodations and are often required to seek medical treatment regularly. Feinberg (2010) suggested that limited participation and stigmatization in school may hinder social relationships because others may fear or misunderstand LQTS. For instance, others may question why adults carry an automated external defibrillator with the person with LQTS. Thus, adolescents diagnosed with LQTS may feel isolated or different from their peer group.

Research has identified the relationship between maladaptive psychological functioning and chronic illness in adolescents (Pless & Roghmann, 1971). Those who respond adaptively to chronic illness learn to adjust and cope well (Thompson & Raezer, 1998). In contrast, adolescents with chronic illness who do not adapt well to or engage in lifestyle changes associated with chronic illness are at risk for low self-efficacy (Clay & Telfair, 2007). Adolescents with chronic illness therefore tend to be more at risk for mood disorders because of feeling isolated due to restrictions necessitated by their illness (Feinberg, 2010).

The effects of LQTS on quality of life (QoL) in children were found to be greater than the effects of other electrophysiologic diseases, such as congenital complete heart block, bicuspid aortic valve, supraventricular tachycardia, and ventricular tachycardia (Czosek et al., 2015). Children with LQTS and with a cardiac implantable device rated their QoL as lower than those with other cardiac conditions. This research explored the

possibility of easing activity restrictions to promote improved QoL (Johnson & Ackerman, 2013; Lampert et al., 2013).

Social problem solving therapy (SPS), a form of cognitive behavioral therapy, has been used successfully with patients diagnosed with chronic illness. It has been shown to positively impact health behaviors and emotional well-being and decrease symptomatology (Martire & Schulz, 2007). However, few evidence-based interventions have specifically addressed LQTS in adolescents (Anderson & Davis, 2011), therefore, SPS may be a useful intervention to consider for this population.

Social problem solving.

SPS is the process of solving problems within the natural environment (D’Zurilla & Nezu, 1982). Interventions that include SPS techniques attempt to teach individuals to examine their thinking about problems in daily living, identify a problem, identify solutions to the particular problem, choose the best solution, and determine ways to implement the solution (D’Zurilla & Nezu, 1982).

SPS is a multidimensional theory consisting of two different but related concepts, problem orientation and problem-solving style. Problem orientation is the set of stable cognitive schemas that reflect individuals’ beliefs, appraisals, and feelings about problems in their everyday lives and their ability to solve problems (D’Zurilla, Nezu, & Maydeu-Olivares, 2004). The two different types of problem orientation in SPS are positive problem orientation (PPO) and negative problem orientation (NPO; D’Zurilla et al., 2004). PPO is the belief in one’s ability to assess and solve a problem. With an NPO, problems are perceived as threats to well-being, and individuals often doubt their ability to solve problems. Individuals with a NPO often become frustrated when faced

with problems (D’Zurilla et al., 2004). SPS is focused on attempting to move individuals from an NPO to a PPO, which allows them to better solve problems, believe in their ability to solve problems, and feel less threatened when confronted with difficult problems.

The cognitive and behavioral activities through which an individual attempts to understand problems and find effective solutions to cope with the problem are an individual’s problem-solving style (D’Zurilla et al., 2004). Problem-solving style can be effective or ineffective, adaptive or maladaptive (D’Zurilla & Nezu, 2007). When individuals employ an ineffective problem solving style, they may experience increased frustration, stress, negative mood, and maladaptive psychological and physical states (Nezu, Nezu, Friedman, Faddis, & Houts, 1998). Individuals who utilize more adaptive problem solving styles are more likely to experience less stress, anxiety, and other psychosocial consequences associated with the chronic condition (Nezu, Nezu, Felgoise, McClure, & Houts, 2003). SPS plays a critical role in the coping strategy to reduce or minimize psychological distress (D’Zurilla & Nezu, 1990). The three problem-solving styles are: rational problem solving, impulsivity/carelessness style, and avoidance style. Rational problem solving is a constructive and adaptive problem-solving style in which the individual’s problem solving skills are deliberate and systematic. The impulsivity/carelessness style is maladaptive and characterized by attempts to solve problems actively, but a tendency to be limited in the ability to generate solutions. Individuals with an impulsivity/carelessness style of problem solving tend to have impulsive and careless attitudes and behaviors towards solving a problem. Another maladaptive problem-solving style, the avoidant style, is characterized by procrastination

and withdrawal features in the face of difficulties. An individual with an avoidant style may become dependent upon someone else to address and cope with the problem (D’Zurilla et al., 2004).

The three major concepts within the SPS model are problem solving, problem, and solution. These concepts are important in understanding the SPS model and to be able to distinguish between the ideas of problem solving and solution implementation. Problem solving is an individual’s attempt to discover or identify a solution when faced with a problem in daily living (D’Zurilla et al., 2004). Furthermore, problem solving is an effortful approach that individuals use to discover effective ways to cope with daily problems (D’Zurilla & Nezu, 2007). SPS is a conscious approach with goals to change problematic situations for the better, thus reducing stressful situations (D’Zurilla et al., 2004).

D’Zurilla et al. (2004) defined a problem as “any life situation or task (present or anticipated) that demands a response for adaptive functioning but no effective response is immediately apparent or available to the person or people confronted with the situation because of the presence of one or more obstacles” (p. 12). The demands of the problems may be based within the individual or in the environment. One problem might be a chronic, ongoing event (e.g., repeated symptomatic events or depression), a single event (e.g., forgot homework, forgot uniform for game, or missed the bus), or a series of similar events (e.g., repeated unreasonable demands from teacher). Another problem may be interpersonal conflict when expectations vary between two individuals (Jacobson & Margolin, 1979). When individuals are faced with a problem, they call upon their habitual problem-solving skills and decide if the problem is predictable, unpredictable, an

obstacle, a threat, or an opportunity (McKendree, 2011). Furthermore, individuals are likely to examine the obstacles and determine if they are novel or ambiguous. The individuals will also determine whether they have adequate resources or skill deficits (D’Zurilla et al. 2004). Essentially, when LQTS is first diagnosed, as an example, the information, the risks, expectations, and challenges may all be new and perceived as a threat.

Theoretically, after a problem is assessed, a solution is identified. D’Zurilla et al. (2004) described the solution as a *coping response* or *response pattern* that is utilized to achieve the problem-solving goal whereby individuals maximize the positive and minimize the negative consequences. Those who are effective problem-solvers, who identify adaptive solutions, appear to have positive orientations and effective application of problem-solving skills. In contrast, those who tend to avoid a solution or possess negative attitudes towards problem solving tend to have negative problem-solving orientations and to experience stress, depression, and even anxiety (Bell & D’Zurilla, 2009; Siu & Shek, 2005).

There is varied research on SPS with adolescents supporting its use. Siu and Shek (2010) examined SPS in adolescents related to anxiety and depression. The investigators recruited young adults aged 18 to 30 from Hong Kong and investigated the participants’ self-efficacy in handling stressful social situations. Siu and Shek (2010) used an open-ended questionnaire to identify social situations perceived as stressful by the participants. Content analysis revealed 36 stressful social situations. Factor analysis of the categories uncovered two factors, basic social skills and advanced social skills. A 36-item questionnaire of situations was created for an online survey questionnaire in the second

part of the study. A convenience sample of 179 young Hong Kong adults completed the questionnaire, which examined self-efficacy in handling different social skills and social situations (e.g., maintaining a conversation with others, having appropriate topics to discuss with others, expressing one's feelings freely). The results demonstrated that young adults had higher self-efficacy in handling relationships with friends and were generally confident in their basic social skills, but lower self-efficacy in relating to family members (Siu & Shek, 2010).

In a third study, Siu and Shek (2010) recruited a convenience sample of 235 adolescents ranging in age from 11 to 15 years old. Part one of the study explored social problem solving and depression (Chinese version of the Beck Depression Inventory). Results suggested that the negative subscales of the Chinese version of the Social Problem-Solving Inventory–Revised (Impulsiveness/Carelessness Style, Avoidance Style, and Negative Problem Orientation) were significantly positively correlated with depression, and the PPO subscale negatively correlated with depression. In the second part of the study, 235 participants completed the State Trait Anxiety Inventory (STAI) and the Chinese version of the Social Problem-Solving Inventory–Revised (C–SPSI–R). The trait scales of the STAI had higher correlations with the C–SPSI–R subscales than the state scale. Siu and Shek (2010) found a moderate correlation between anxiety, problem orientation, and avoidance style. In sum, individuals' problem orientations were correlated with their levels of depression and/or anxiety (Siu & Shek, 2010). Anxiety and depression were significantly related to aspects of SPS in expected directions and expected strength; those with PPOs had lower depression ratings (Siu & Shek, 2010).

SPS interventions have also demonstrated effects when used with individuals in distress. In a study of college students, problem solving served as a moderator between depressive symptoms and stressful life events (Nezu, 1986a). Results indicated that problem-solving dimensions were predictors of depression. A multiple regression analysis demonstrated that under high levels of stress, effective problem solvers had significantly lower depression scores than their ineffective problem-solving peers. Furthermore, D’Zurilla and Sheedy (1991) examined the relationship between SPS ability and stress in college students. A multiple regression analysis found that problem orientation (PPO or NPO) is a stronger predictor of stress than individuals’ rational problem-solving skills (D’Zurilla & Sheedy, 1991).

SPS interventions are commonly used in individuals with chronic health conditions (Hill-Briggs, 2003; Schmied & Tully, 2009). In a study that assessed self-esteem and social adjustment in adolescents with chronic health conditions, researchers found that preventive interventions are helpful for this population (Meijer et al., 2002). Data were collected on the psychosocial functioning of children and adolescents with a chronic illness. Participants, who included parents, adolescents, and children, completed a series of questionnaires. Predictor variables included coping styles and locus of control. Psychosocial adjustment variables included social activities, self-esteem, social anxiety, behavioral problems, and social skills. The researchers studied depressive reactions, social support, avoidance, and locus of control to predict adjustment. The researchers found that adolescents who discussed their daily problems tended to have better social and assertive skills than those who were less likely to seek social support. Meijer et al. (2002) found that coping style characterized by active problem-solving was

the most important determinant for positive psychosocial functioning. Adolescents who react to daily problems with depressive behavior reported low overall self-esteem and high social anxiety (Meijer et al., 2002). Thus, an intervention focused on adaptive coping and problem-solving techniques may provide adolescents with tools to cope with LQTS and solve everyday problems and those related to the chronic illness.

In a study using SPS to reduce psychological distress, patients with cancer and their significant others reported decreased levels of distress at both a 6-month and 1-year posttreatment follow-up (Nezu et al., 2003). In a study of SPS in adolescents with diabetes, Mulvaney et al. (2011) found that barriers to disease management can be addressed by teaching problem solving. Nezu, Nezu, and Jain (2008) evaluated SPS among individuals with noncardiac chest pain and found that NPO and rational problem solving are significant mediators of stress. Nezu et al. (2008) concluded that SPS is a useful intervention for treating individuals with noncardiac chest pain. Thus, it may be appropriate for the LQTS population.

Finally, an investigation of SPS in individuals with chronic fatigue syndrome demonstrated that those with elevated levels of affect dysregulation had high NPO, with either avoidance or impulsive problem-solving styles, thus impacting positive problem resolution (Christopher & Thomas, 2008). The findings suggest that SPS deficits likely increase distress in this population (Christopher & Thomas, 2008).

There are many different constructs that are evaluated when examining health-related behavior. In summary, general investigations using SPS suggest that there is a relationship between problem-solving ability and the predisposition to develop psychological sequelae. Research on SPS in populations with chronic illness suggests

SPS deficits increase psychological distress and decrease disease management and coping. To date, there has been no outcome research conducted with LQTS and SPS, but people with LQTS who went to the emergency room had poorer problem orientation, working alliance, and overall care than healthy adults (Felgoise, Lawrence, & Vetter, 2013).

Social problem solving, coping, locus of control, and self-efficacy.

Chronic illnesses interfere with social developmental periods, making affected adolescents more vulnerable to difficulties than their peers (Meijer et al., 2002). For instance, those with chronic illness are more likely to miss school to undergo medical procedures, make lifestyle changes to adhere to treatment recommendations, and experience social isolation as a result of school absences (Vance & Eiser, 2002; Williams, 2000). Coping, locus of control, and self-efficacy are variables often studied in adolescents because adolescence is a time of further development of these skills and one's identity.

Coping.

Coping is a highly complex process that is sensitive to the demands of the environment, personality characteristics, and the appraisal of an individual's resources (Folkman & Moskowitz, 2004). Lazarus (1991) postulated that coping is what a person thinks or does to try to deal with a stressful situation. Folkman and Moskowitz (2004) indicated that an individual's characteristics influence the outcome of coping. For example, the way in which an individual responds to a stressful situation calls upon his or her coping ability (de Boo & Wicherts, 2009). People cope in many different ways. Skinner, Edge, Altman, and Sherwood (2003) suggested that people cope by seeking the

help of others, ruminating, problem solving, denying, or even changing their thoughts. Compas, Connor-Smith, Saltzman, Thomsen, and Wadsworth (2001) reviewed empirical studies of the association between coping and psychological outcomes and found that problem-focused coping was associated with better adjustment, while disengagement coping was associated with poorer psychological adjustment. Overall, coping can be thought of as strategies, cognitions, or behaviors that assist an individual in dealing with diverse person-environment transactions (Schwarzer & Schwarzer, 1996). When faced with a problem, an individual appraises the situation, or evaluates what might be thought or done in that situation, and then identifies how to manage the problem (Lazarus, 1991) in an effort to cope with it.

Social problem solving is integrally related to coping and has been defined as a set of coping skills (Nezu et al., 1989). Individuals who perceive that they have the ability to solve problems are likely to do so because of their coping ability (Bandura, 1982). The appraisal of a situation, akin to problem identification, is a prerequisite for coping (Schwarzer & Schwarzer, 1996). D’Zurilla and Chang (1995) examined the relationship between problem solving and coping. They found that PPO and rational problem solving are associated with the uses of adaptive coping strategies and that three dysfunctional problem-solving dimensions are related to a tendency to avoid coping. Therefore, when individuals have acquired adequate problem-solving skills, they are more easily able to cope with daily stressors (Goodman, Gravitt, & Kaslow, 1995). Those with deficits in social problem-solving skills tend to receive less positive reinforcement in social situations and tend to develop cognitive and affective symptoms

associated with depression (Lewinsohn, 1974), thus further illustrating that those with lesser problem-solving skills are likely to have deficits in their coping abilities.

Coping with cardiac diagnoses involves many cognitive and behavioral strategies that include active efforts and avoidance strategies (Scherck, 1992). For instance, an active approach to coping is positively related to quality of life among individuals with cardiac surgery (Scheier et al., 1989). However, passive or poor approaches to coping resulted in different outcomes. D’Zurilla and Goldfried (1971) indicated that when faced with problematic situations in daily life, those with poor coping abilities, such as avoidance, are more likely to experience emotional and behavioral disorders that require psychological intervention. Similarly, Holahan, Moos, Holahan, and Brennan (1995) tested a 1-year predictive model of depressive symptoms in patients reporting cardiac illness. When compared to healthy individuals, those with chronic cardiac illness were more depressed. Additionally, structural equation models demonstrated that for those with cardiac illness, social support and adaptive coping strategies predicted fewer depressive symptoms (Holahan et al., 1995).

Adolescents with chronic health conditions must cope with the tasks commensurate with this developmental stage, along with the treatment regimens, medical procedures, and possibly social rejection associated with their medical condition (Boekaerts, 1999; Roder, 1999). Researchers agree that the way individuals cope with stress likely predicts their psychological adjustment (Holen et al., 2012). The literature in this area reveals that adolescents with chronic health conditions have a greater likelihood of depression and social withdrawal than their healthy peers (Gizynski & Shapiro, 1990). Moreover, fear and uncertainty are common among patients with chronic cardiac

conditions (Forrester et al., 1992). However, for individuals with adequate coping skills, daily stressors may not increase vulnerability to difficulties. In a study that investigated coping among adolescents with chronic illness, researchers found that those who tended to utilize coping strategies were better adjusted than their passive avoidant peers (Hampel, Rudolph, Stachow, Laß-Lentzsch, & Petermann, 2005).

Locus of control.

In addition to coping, adolescents' perceptions of their control over their illness have an impact on health outcomes. Therefore, locus of control is another construct that is typically assessed when examining health behaviors. Locus of control, or perceived control over an individual's environment, tends to mediate psychological risk factors and adjustment (Meijer et al., 2002). Locus of control, a component of social learning theory originally developed by Rotter (1954), is a construct that suggests that an individual's behavior is determined by the nature or significance of reinforcements within the environment and by the expectation that these reinforcements will occur. An individual's ability to accurately identify the antecedents and consequences of reinforcement increases the likelihood of engaging in a behavior. Rotter then further developed the idea of internal versus external control of reinforcement (Carton & Nowicki, 1994).

Rotter (1990) defined internal versus external locus of control as:

The degree to which persons expect that a reinforcement or an outcome of their behavior is contingent upon their own behavior or personal characteristic versus the degree to which persons expect the reinforcement is a function of chance, luck or fate, is under the control of powerful others, or is simply unpredictable (p. 489).

Rotter and Hochreich (1975) demonstrated that an individual with more internal expectancies is more likely to:

(a) be more alert to those aspects of the environment which provide useful information for his future behavior; (b) take steps to improve his environmental condition; (c) place greater value on skill or achievement reinforcements and be generally more concerned with his ability, particularly his failures; and (d) be resistive to subtle attempts to influence him (p. 212).

Studies have found that individuals with a high internal locus of control are more likely to have better cognitive processing abilities, academic and vocational performance, emotional adjustment, and socialization skills than their peers with an external locus of control (Crandall & Crandall, 1983). This is likely because those individuals believe they have control over outcomes in those particular areas of life. Past researchers dichotomized these constructs, and more recently, researchers have begun to conceptualize locus of control perceptions on a continuum (Nunn, 1988). Nunn (1988) indicated that individuals with a high internal locus of control style are more likely to view success or failure as a result of their own actions or efforts, and individuals with high external locus of control patterns are more likely to believe that outcomes are the result of fate, luck, or circumstances.

The relationship among health behavior, illness prevention, and locus of control has been extensively studied over the years (Meijer et al., 2002; Sorlie & Sexton, 2004; Wallston & Wallston, 1978). Wallston and Wallston (1978) identified that individuals with high internal locus of control were more likely than those with low internal locus of control to seek and retain information about their medical conditions, make and keep

their appointments, and adhere to medication regimens. More recently, however, researchers have found that locus of control is not associated with psychosocial adjustment; rather, coping styles were related to social adjustment in adolescents with chronic illness (Meijer et al., 2002).

Though research is limited on health locus of control in adolescents, a few studies have examined locus of control in adolescents with chronic illnesses (Burkhart & Rayens, 2005; Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980; Ozolins & Stenström, 2002). Psychological effects of illness, specifically locus of control during adolescence, have been studied. Researchers examined healthy adolescents compared to adolescents with chronic diseases on measures of anxiety, self-esteem, and health locus of control. Though no differences in anxiety or self-esteem were found, patients with chronic illness, such as renal, cardiac, and rheumatologic disorders, perceived significantly less control over their health than their healthy peers (Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980). This finding was further supported in a study of Swedish adolescents. Those adolescents who reported higher self-esteem had an internal locus of control of health. Lower self-esteem was evident when there was the belief that others determined their health and that health, i.e., a high external locus of control of health (Ozolins & Stenström, 2002).

Another study examined the relationship among self-concept, health locus of control, and medication adherence in 42 children with daily asthma treatment (Burkhart & Ravels, 2005). The participants completed a self-concept and locus of control measure at the beginning and end of a 5-week asthma self-management training program at an outpatient clinic. Adherence was measured at the end of the intervention program by

recording the number of days that the children used the treatment at least once. The authors found that adherence was positively correlated with a high self-concept and high internal locus of control. They also found that scores on the self-concept scale and the locus of control scale increased over the course of the intervention program. Over the course of the treatment program, the children had gradually changed from external to internal locus of control (Burkhart & Ravens, 2005).

Locus of control has been found to relate to SPS. Wege and Möller (1995) investigated the effectiveness of a problem-solving training program in relation to problem-solving efficiency and measures of self-efficacy and locus of control. The researchers recruited and assigned 29 participants to either an effective or an ineffective problem-solving group. One group of participants was exposed to a problem-solving training program over the course of 8 weeks, with each session 50 minutes in duration, while the second group did not receive the intervention. Results indicated that ineffective problem-solvers appraised problem-solving skills more negatively and reported low self-efficacy and an external locus of control orientation. Those who underwent the problem-solving training reported improved self-efficacy and confidence in problem solving and increased internal locus of control immediately following the intervention and on follow-up measures (Wege & Möller, 1995). Similarly, in a study that measured problem-solving treatment and locus of control in individuals with unipolar depression, Nezu (1986b) found that increased problem-solving skills were associated with changes in locus of control orientation immediately after the intervention and on follow-up measures. Participants reported moving from an external locus of control to an internal locus of control during the problem-solving treatment (Nezu, 1986b).

Self-efficacy.

Just as coping and locus of control are related to chronic illnesses, self-efficacy is another construct that is typically assessed when examining health behaviors. Self-efficacy, as defined by Bandura (1994), is an individual's belief in his or her ability to produce a desired outcome. Self-efficacy is an individual's persistent attempts to attain a goal, despite obstacles that hinder success. Self-efficacy can be developed through mastery experiences, vicarious experiences, social persuasion, or physical states (Bandura, 1986). Mastery experiences, or success, provide an individual with the strongest belief in self-efficacy (Bandura, 1994). Self-efficacy beliefs are task-specific judgments about one's ability and are subject to change over time (Bandura, 1986).

Self-efficacy relates directly to D'Zurilla's model of social problem solving. An individual's belief that he or she can solve problems effectively is otherwise known as his or her problem solving self-efficacy (D'Zurilla et al., 2004). Bandura (1993, 1997) proposed that perception of self-efficacy affects problem-solving skills. According to his theory, individuals with high self-efficacy are more likely than those with low self-efficacy to use more effective ways to solve problems because they have self-confidence about their ability to handle situations (Bandura, 1993, 1997).

Erozkan (2013) examined the relationships among communication skills, problem solving skills, and social self-efficacy in 494 randomly selected high school students using surveys. The results suggested that communication skills and problem solving abilities were significantly correlated with social self-efficacy. Furthermore, communication skills and interpersonal problem-solving skills were important predictors

of self-efficacy. Self-efficacy was positively related to cognitive, affective, and behavioral communication and to constructive problem solving (Erozkan, 2013).

Bandura's social cognitive theory proposes that an individual's sense of control over his or her environment and behavior impacts health-related goals and is a significant predictor of health-related behavior and maintenance (Bandura, 1997). Self-efficacy has been assessed in chronic conditions, including arthritis, diabetes, sickle cell disease, and cystic fibrosis (Barlow, Williams, & Wright, 1996; Bartholomew, Parcel, Swank, & Czyzewski, 1993; Cashaw, 2013; Griva, Meyers, & Newton, 2000). These studies found increased levels of self-efficacy with knowledge about conditions and management. Self-efficacy is enhanced when individuals with chronic illness succeed in solving problems related to their illness (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Other studies examined beliefs and the ability to perform behaviors related to chronic illness (Bond, 2002; Pinto et al., 2002). Bond (2002) and Pinto et al. (2002) found that diet and exercise were related to self-efficacy and health behavior compliance.

A study in 2007 measured self-efficacy in adolescents diagnosed with sickle cell disease (Clay & Telfair). The measures included a Sickle Cell Self-Efficacy Scale (Edwards, Telfair, Cecil, & Lenoci, 2001) and a review of physical activity, self-reports of disease management (e.g., taking medication, drinking fluids), and psychological symptoms. Results suggested that those adolescents with higher self-efficacy practiced more self-care behaviors and had lower levels of physical and psychological distress than those who did not engage in self-care behaviors (Clay & Telfair, 2007). The investigators included in their discussion the implication that cognitive-behavioral

interventions are necessary to evaluate adjustment to chronic illnesses (Clay & Telfair, 2007).

A recent investigation examined the feasibility of a nutritional program to improve knowledge of dietary habits in adolescents with sickle cell disease (Cashaw, 2013). The study examined self-efficacy and health management while living with complications, such as pain and fatigue, which are associated with sickle cell disease (Cashaw, 2013). While the intervention was found to be feasible, adolescents endorsed moderate self-efficacy beliefs. This finding illustrated adolescents' uncertainties about their ability to prevent symptoms from impacting their engagement in enjoyable activities. Adolescents' self-efficacy improved over the course of the intervention, but at the 1-month follow-up, results suggested that self-efficacy beliefs decreased slightly (Cashaw, 2013). While this finding was dispiriting for the adolescents, this research consistently demonstrates that self-efficacy is not a global judgment, but rather task related and likely to change over time (Bandura, 1986). Although research has been conducted on the previously mentioned chronic illnesses and several others, there is a lack of extensive research on the role of self-efficacy in individuals diagnosed with LQTS.

Many studies conducted in adults with chronic illness and SPS generalize to adolescents. Studies have demonstrated that those with SPS abilities demonstrate an internal locus of control and self-efficacy, or the belief that they can solve problems. Those with a PPO and rational problem solving style have adaptive coping strategies and are more easily able to cope with daily stressors. Though LQTS is a chronic disease, it differs from other chronic diseases because of the risk of sudden cardiac death. Coping,

self-efficacy, and locus of control have been examined in adolescents diagnosed with a chronic illness. The constructs of coping, self-efficacy, and locus of control have been widely found to play important roles in development for adolescents diagnosed with a chronic condition. However, these constructs have not been specifically examined to assess their importance for adolescents diagnosed with LQTS.

Research question.

Is it feasible and effective to implement a social problem-solving (SPS) workshop designed to increase self-efficacy, internal locus of control, and coping in children and adolescents surrounding problems associated with LQTS?

LQTS is a chronic illness often diagnosed in childhood and adolescents that affects psychosocial well-being. The present study evaluated the impact of a group intervention using an SPS approach with two children diagnosed with LQTS. This pilot study examined if there were any long-term (3-month) gains in children's social problem-solving abilities and ability to cope with LQTS and explored locus of control styles and self-efficacy. The feasibility and effectiveness of the 4-hour workshop were evaluated using the satisfaction questionnaire created for the study.

H₁: The participants would have an increase in total SPS abilities, as measured by Social Problem-Solving Inventory for Adolescents (SPSI-A) from baseline to 1-month follow-up, which would be maintained at the 3-month follow-up, after participation in a social problem-solving workshop (Frauenknecht & Black, 1995).

H₂: Participants with better SPS skills would report higher internal locus of control than those with lesser SPS skills from baseline to 1-month follow-up, which

would be maintained at the 3-month follow-up, after participation in a social problem-solving workshop.

H₃: Participation in an SPS workshop would improve participants' ability to engage in active and support seeking coping styles, as measured by the Children's Coping Strategy Checklist (CCSC), from baseline to 1-month follow-up, which would be maintained at the 3-month follow-up, after participation in a social problem-solving workshop (Ayers, Sandler, West, & Roosa, 1996).

H₄: Participants' self-efficacy scores would increase, as measured by the General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995), from baseline to 1-month follow-up, which would be maintained at the 3-month follow-up, after participation in a social problem-solving workshop.

Chapter 3

Method

This was part of a larger research project that assessed the feasibility and effectiveness of a problem-solving skills workshop for children and adolescents accompanied by their parents. The present study focused on involvement and outcomes in children diagnosed with long QT syndrome (LQTS). The purpose of the workshop was to teach problem-solving skills to children diagnosed with LQTS. Parents were included in the group to help increase the child's use of these skills.

Design and design justification.

The study was a single-subject, within-group, repeated measure design. Participating families were contacted by phone at 1 month and 3 months after the workshop to evaluate independent variable outcomes. In order to maximize participation and limit the number of participants per workshop, the same workshop was offered multiple times. This design relates to the research goals, which were to examine the feasibility of a group social problem-solving workshop and to evaluate the effectiveness of the workshop on children's and adolescents' coping, self-efficacy, and locus of control with regards to LQTS-related problems. The repeated measure design provided the necessary conditions to demonstrate whether the social problem solving workshop was effective by measuring potential change over time. The design began with two scheduled groups, with six and two registered participants, respectively. However, six participants dropped out prior to obtaining baseline data and participation in the workshop. Therefore, only one workshop was held, and all baseline and follow-up measures were obtained from the two children who participated in this group.

Participants.

Children and adolescents were recruited for participation in the study if they met the following criteria: between the ages of 8 to 17; diagnosed for at least 6 months with LQTS; capable of giving assent; able to read/write English, as indicated by their ability to read and sign the assent form; and willing to participate in the 4-hour workshop. Only one guardian per child or adolescent was required to participate in the workshop. Siblings who were diagnosed with LQTS were also encouraged to attend the workshop if they met the inclusion criteria, as long as one guardian was present.

For this study, the goal was to recruit five to 10 dyads (parents and their child/children) for participation in the workshop. Eight children and adolescents registered for participation. However, six of the children were unable to participate in the workshop. Recruited dyads did not attend the workshop for the following reasons: child unwilling to attend the workshop, scheduling conflicts, not attending the scheduled workshop, and not responding to investigator contact attempts. The participants, both Caucasian, were 9 and 13 years of age ($M = 11$, $SD = 2.8$), one male and one female. One participant was diagnosed with LQTS at 11 years of age; the other was diagnosed at birth. It was reported that one child did not have any LQTS-related events, whereas the other child had one or two LQTS-related events. One participant had a pacemaker, and the other participant did not. Both children had food restrictions and required rests from physical activity. In school, it was reported that the participants received accommodations such as a bus aide, no timed gym activities, AED present at all times, permission to carry water throughout the day, and frequent bathroom breaks. Both participants completed all baseline, postworkshop, 1-month and 3-month follow-up

measures. Parents/caregivers (ages 40 and 43, 1 male and 1 female) also participated in the workshop to learn problem-solving skills and coach their children to learn these skills.

Manuals.

The protocol for this feasibility study was created from a combination of two manuals, adapted to incorporate material that is specifically related to the experiences of individuals diagnosed with LQTS. The protocol was primarily based on the problem-solving therapy described in *Helping Cancer Patients Cope* (Nezu et al., 1998). The *I Can Problem Solve: An Interpersonal Cognitive Problem-Solving Program* (Shure, 2001) manual was utilized as a model for age-appropriate language and examples within the protocol. Problem-solving skills training has been effective in helping medical patients (Nezu et al., 1998).

The *I Can Problem Solve: An Interpersonal Cognitive Problem-Solving Program* (ICPS) manual provides children and adolescents with skills to think about how to solve problems at a young age to increase their chances of success and social competence in their future (Shure, 2001). An initial study that evaluated the ICPS training at age 10 demonstrated positive changes. Findings showed that prosocial behaviors increased and negative behaviors decreased, thus increasing concentration on task demands in the classroom, which subsequently increased achievement in school (Shure, 2001).

The *Helping Cancer Patients Cope* manual outlines a 10-session social problem-solving therapy program (Nezu et al., 1998). This particular program can be applied and adapted to individual, group, or family settings. The model of social problem solving helps to diminish patients' sense of helplessness and despair, while instilling a sense of control and hope. Included in the manual are numerous case examples, transcripts from

sessions, and sample introductions that are a helpful adjunct to mental health treatments (Nezu et al., 1998).

Measures.

Social Problem-Solving Inventory for Adolescents (SPSI–A). The Social Problem-Solving Inventory for Adolescents (SPSI–A) Short Form measures social problem-solving skills. The SPSI–A is a 30-item valid and reliable measure of social problem-solving skills (Frauenknecht & Black, 1995). Items are rated on a 5-point Likert scale and are designed to assess problem-solving behavior in social or personal contexts (Frauenknecht & Black, 1995). The measure is comprised of three scales that assess the following constructs: automatic process, problem orientation, and problem-solving skills. Alpha coefficients for total scale reliability were above $r = .93$, and coefficients for all three scales were above $.81$ (Frauenknecht & Black, 1995). Test-retest reliability is stable across administrations over a 2-week period. Correlation coefficients for the SPSI–A total scores and the three scales between test administrations were above $r = .67$, $p < .001$ (Frauenknecht & Black, 1995). The SPSI–A does not have normative data for the younger participants selected to be a part of this pilot study. However, the items measure problem-solving behaviors that a typical child might utilize, and the specific responses are therefore helpful in establishing a baseline measure of problem solving in children diagnosed with LQTS.

General Self-Efficacy Scale. The General Self-Efficacy Scale (GSE) is a measure of an individual's general sense of perceived self-efficacy in predicting his/her ability to cope with daily hassles, as well as adaptation after experiencing stressful life events (Schwarzer & Jerusalem, 1995). The self-administered scale was designed and

normed for individuals 12 years of age and older. Responses to the 10 items are made on a 4-point scale: 1, *not at all true*; 2, *barely true*; 3, *moderately true*, and 4, *exactly true*.

Total scores are calculated by summing all responses to yield a final composite score with a range of 10 to 40, with 40 indicating more general self-efficacy. Internal consistency coefficients in a variety of populations have yielded positive ratings, ranging from .75 to .91 (Scholz, Gutierrez Doza, Sud, & Schwarzer, 2002). Chronbach's alpha for the General Self-Efficacy Scale among adolescents (0.87) indicated good internal reliability (Cramm, Strating, Roebroek, & Nieboer, 2013).

Children's Coping Strategies Checklist. The Children's Coping Strategies Checklist (CCSC) is a self-report inventory (Ayers, Sandler, West, & Roosa., 1996). This measure was normed on children aged 9 to 13 years. The CCSC is a general measure of coping styles that includes subscales consistent with the constructs measured by the adolescent and adult instruments, including cognitive decision making, direct problem solving, positive cognitive restructuring, avoidant actions and cognitions, problem-focused support, and emotion-focused support (Ayers et al., 1996).

Children's Health Locus of Control Scale. The Children's Health Locus of Control Scale (CHLOC) is a self-report measure for children ages 7 through 12, with 20 statements about factors influencing health with which subjects either agree or disagree (Parcel & Meyer, 1978). The total scale score is obtained by summing endorsed items, with higher scores (31 to 40) indicating an internal locus of control style and lower scores (20 to 30) indicating an external locus of control (Parcel & Meyer, 1978). Three factors influencing health are assessed by this measure: beliefs regarding internal control, general beliefs regarding the degree to which health and illness are determined by luck or chance,

and beliefs about the degree to which powerful others (e.g., physicians, nurses, and parents) determine health and illness outcomes (Parcel & Meyer, 1978). This measure has demonstrated satisfactory levels of test-retest reliability ($r = 0.62$ to 0.80), internal consistency ($r = 0.75$), and construct and discriminant validity in research with children and measure of locus of control (O'Brien, Bush, & Parcel, 1989; Parcel & Meyer, 1978). The adolescents' scores on this measure were compared to a study completed with a group of adolescents with a chronic illness (Goertzel & Goertzel, 1991).

Satisfaction questionnaire. Participant satisfaction data and qualitative feedback were obtained using a brief satisfaction questionnaire. At the end of the workshop, participants were asked to rate how well the session achieved the designated objective and the usefulness and informativeness of the topics using a 10-point Likert scale (*not at all to definitely*). An average score of 7 or greater was given for each section (workshop information, workshop materials, presenter qualities, topics of workshop, workshop length/location, overall evaluation of workshop, and parents only). Qualitative participant feedback on the most favorable and least favorable components of the workshop was examined and evaluated for further determination of participant satisfaction with the overall workshop, as well as to determine if changes to the protocol were required to make it more feasible.

Workshop evaluation form. A short workshop evaluation survey form was developed for group leaders to complete at the end of the workshop. Group leaders evaluated the ease of following the protocol, time taken to complete each section of the protocol, usefulness of examples, and engagement of the group using a 10-point Likert

scale (1, *not at all*, to 10, *definitely*). Group leaders also answered open-ended questions regarding effective and ineffective elements of the workshop.

Protocol adherence checklist. A protocol adherence checklist was created for three independent raters to utilize in conducting the integrity check. The checklist evaluated group leaders' specific behaviors and specific task completion.

Personal information questionnaire. A personal information questionnaire (PIQ) was constructed to acquire information about the parent and child, including ages, medications, history of sudden cardiac arrest for parents and adolescents, presence of implantable devices, possession of automatic external defibrillator, number of siblings, other medical or psychological illnesses for parents, adolescents, and other family members, and other personal characteristics relevant to the description of the sample and study. Only the parents completed the PIQ.

Procedure.

The study was approved by the Institutional Review Board of Philadelphia College of Osteopathic Medicine (PCOM). Parents signed an informed consent form for themselves and their children as participants, and children signed an assent form. The study was conducted at PCOM.

A number of recruitment methods were utilized to attempt to reach as many interested potential participants as possible for the 4-hour workshop. Information about the Living Life With LQTS workshop was disseminated to a list of potential subjects obtained through a hospital in the Mid-Atlantic region, mailings to cardiac centers at local hospitals, and Internet announcements posted on LQTS related social media such as Facebook groups, Twitter, Craigslist, and Sudden Arrhythmia Death Syndromes (SADS).

Participants were recruited from hospitals that serve a diverse population of genders and races/ethnicities. Families who responded were contacted and given further information regarding the workshop. Families who registered for the workshop were contacted twice prior to the workshop by phone and e-mail to remind them of the date and time and answer any questions.

The workshop was conducted by two clinical psychology doctoral candidates under the supervision of a licensed, board certified clinical psychologist. The steps of the social problem-solving model (Nezu et al., 1998) were introduced and taught to the children and their parents. Practice and implementation of the social problem solving model were accomplished using vignettes of typical LQTS-related problems. Children and parents then discussed the vignettes and the problem using the steps of the Social Problem-Solving model. The instructors then facilitated group discussion time. Further explanation and practice time were provided for areas in which participants experienced difficulty. Finally, each child attempted to use the model to solve a personal LQTS-related problem they experienced, with the help of the parent. A list of resources, including psychology referrals, online support groups, and informational websites, was provided to each family at the conclusion of the workshop.

Participants were asked at the completion of the workshop if any of the study material made them upset or uncomfortable. None of the participants disclosed such problems. If participants had experienced discomfort, they would have been given a referral to a qualified professional to discuss their concerns. In addition, formal procedural guidelines were established in advance in case a participant experienced extreme emotional discomfort.

The psychologist and two doctoral candidates discussed the workshop following its completion. Each of the group leaders also completed the workshop evaluation survey, evaluating the ease of following the protocol, pacing of sessions, usefulness of examples, and engagement of the group.

Three independent raters, doctoral students who were trained in social problem-solving, conducted integrity checks utilizing the videotapes of the workshop. They made qualitative observations and followed a checklist of the protocol to verify that techniques were used in the workshop and evaluate the extent to which the group leaders followed the protocol.

The investigator contacted each participant for a 5- to 10-minute phone call 1 month after the workshop. This phone call was utilized to maintain contact with the participant, assess workshop effectiveness, and to address any concerns in applying problem-solving strategies. Participants were assigned an identification number and asked to complete the SPSI-A, a short quiz on the social problem solving model, the CCSC, the CHLOC, and the GSE via SurveyMonkey. An e-mail reminder was sent if questionnaires were not completed within 1 week. Participants received a \$10 gift card to a nationwide retailer after the 1-month follow-up questionnaires were completed. Another brief phone call was made to participants 3 months after the workshop. A SurveyMonkey link was e-mailed to them to complete the SPSI-A, CCSC, CHLOC, and GSE. All participants completed the measures at the 3-month follow-up and received a \$10 gift card to a nationwide retailer.

Chapter 4

Results

Two children participated in the Living Life With LQTS workshop, and data were examined and analyzed within and between participants. The preworkshop, postworkshop, and 1- and 3-month follow-up measures were analyzed to evaluate change in each participant's social problem-solving ability, locus of control, coping, and self-efficacy. The feasibility and effectiveness of the Living Life With LQTS Workshop were examined and described.

Social problem-solving ability.

The results of the SPSI–A total score, comprised of the Automatic Process, Problem-Solving Skills, and Problem Orientation scales, indicated an overall increase of these skills from baseline to 1 month and a slight decrease from 1-month to 3-month follow-up (baseline $M = 2.89$, $SD = 0.07$; 1-month $M = 3.26$, $SD = 0.2$; 3-month $M = 3.04$, $SD = 0.17$; see Figure 1). Overall SPSI–A total scores for both participants were at least one standard deviation greater when compared to those of the normative group across all time periods (Frauenknecht & Black, 1995).

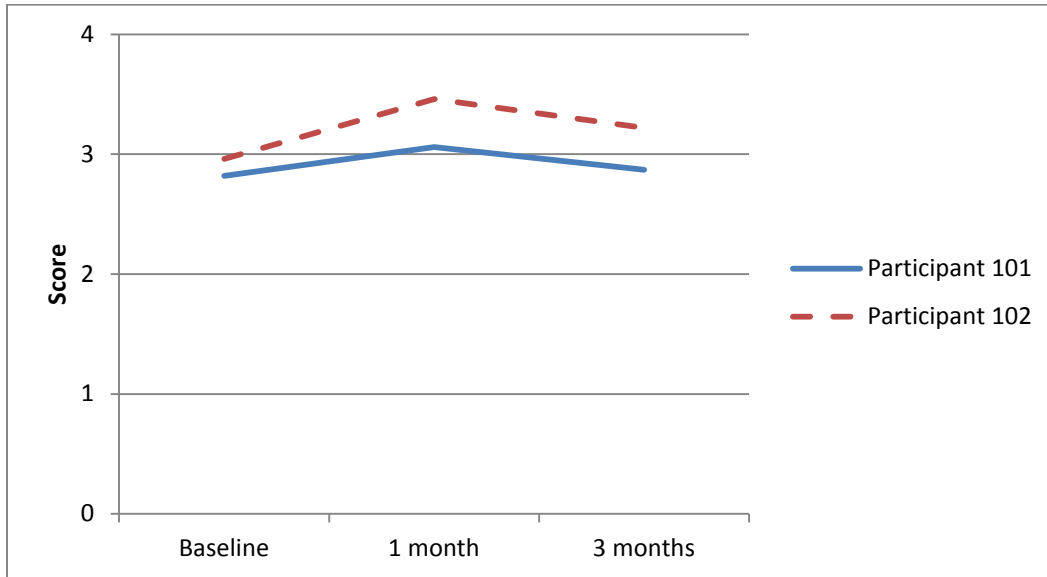


Figure 1. Change in Total Score on SPSS-A.

The Problem-Solving Skills Subtest (PSSS), which is comprised of the Problem Identification, Alternative Generation, Consequence Prediction, Implementation, Evaluation, and Reorganization subscales, also had a similar pattern in both participants in that these skills increased from baseline to 1 month and decreased from 1-month to 3-month follow-up (see Figure 2; Baseline $M = 2.89$, $SD = 0.33$; 1-month $M = 3.22$, $SD = 0.5$; 3-months $M = 2.69$, $SD = 0.30$). The PSSS scores for both participants were significantly greater than those of the normative group at baseline and 1- and 3-month follow-ups (Frauenknecht & Black, 1995).

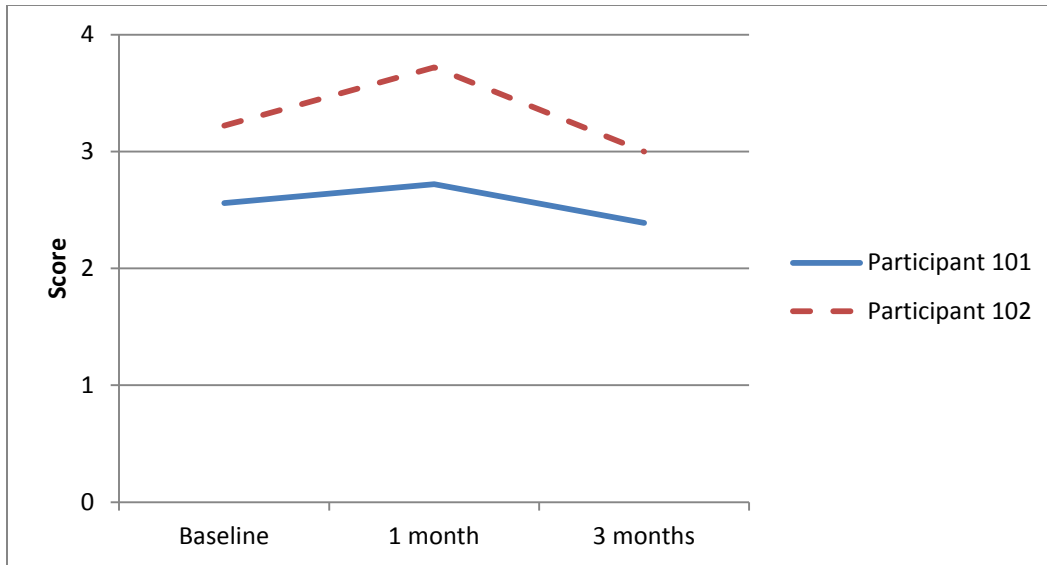


Figure 2. Change in PSSS Score on SPSI-A.

The Problem Orientation subtest (POS), comprised of the Cognitive, Emotion, and Behavior subscales, differed between Participant 101 and Participant 102. This scale measures individuals' beliefs, attitudes, and values regarding the use of the problem-solving process for actually solving the problem. Participant 102's problem orientation remained unchanged from baseline through the 3-month follow-up, whereas Participant 101 had an increase in positive problem orientation from baseline to 1 month. Participant 101's orientation score returned to baseline levels at the 3-month follow-up (see Figure 3). The increase in POS was statistically greater than that of the normative group, with the increase at 1-month follow-up reaching a statistically significant difference in comparison to the scores of the normative group (Frauenknecht & Black, 1995). Participant 102's scores at baseline, 1-, and 3-month follow-up were statistically significant and greater than two standard deviations greater than the scores of the normative group ($M = 4.00$, $SD = 0.00$)

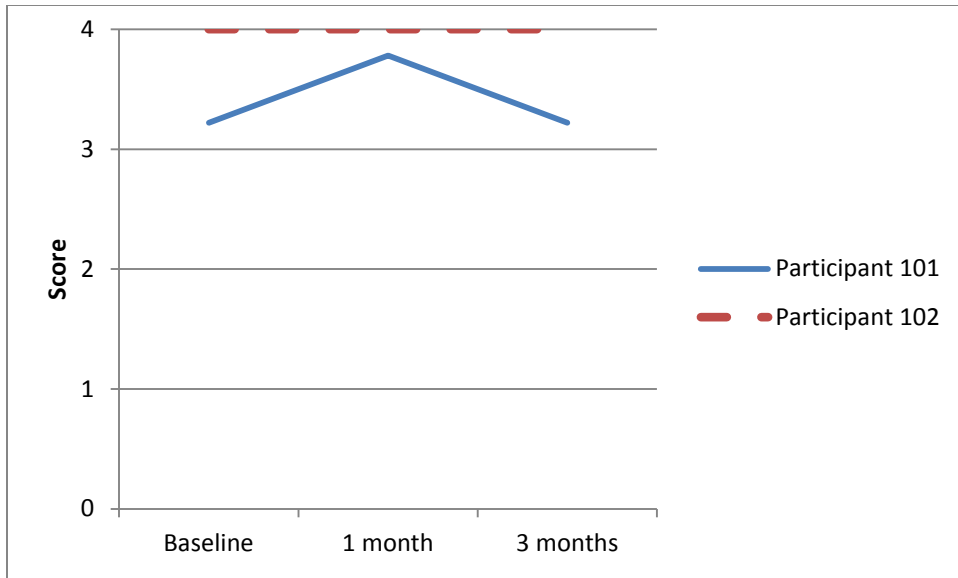


Figure 3. Change in POS Score on SPSI-A.

The Automatic Process subtest (APS) on the SPSI-A represents the child's ability to apply strategies that previously had been effective in solving problematic conflicts, typically derived from facts, rules, and techniques. Results suggest that both participants applied a learned response that had been effective in solving other problematic situations (see Figure 4). Participant 102 relied on strategies that previously had been effective in solving problematic conflicts from baseline to 1-month and maintained the automatic process of problem-solving strategies from 1-month to 3-month follow-up. Participant 101 adequately implemented problem-solving skills, rules, and techniques from baseline to 1-month and then applied an increase in strategies from 1-month to 3-month follow-up. Both participants appeared to employ similar automatic processes at the 1-month follow-up. The differences in APS across periods measured ($M = 2.55$, $SD = 0.4$) was not statistically significant when compared to that of the normative group ($M = 2.51$, $SD = 0.63$); however, Participant 101 demonstrated a statistically significant difference at 3-

month follow-up ($X = 3$) when compared to the APS of the normative group ($M = 2.23$, $SD = 0.70$).

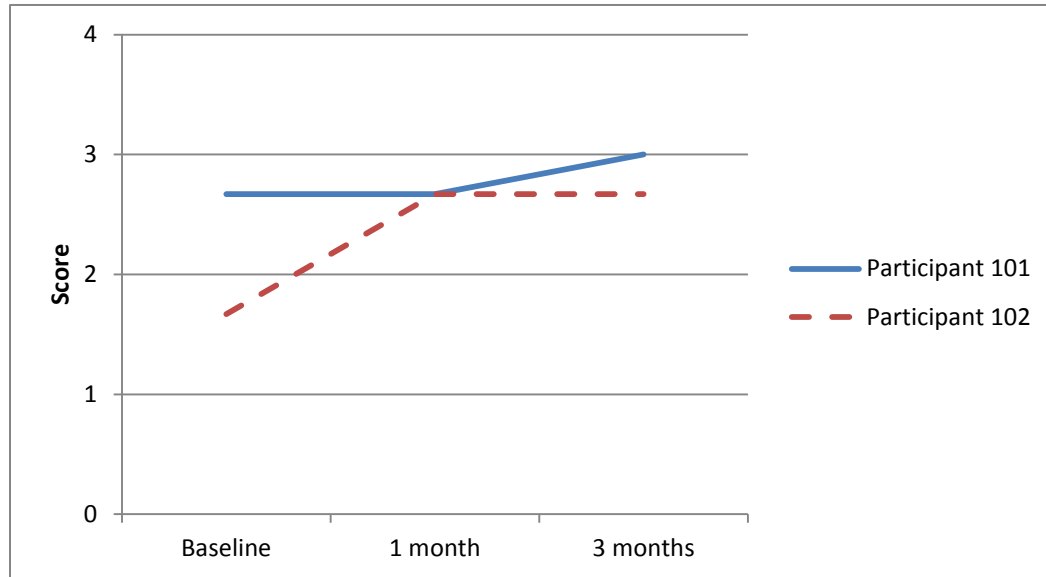


Figure 4. Change in APS Score on SPSI-A.

Coping style.

The Children's Coping Strategies Checklist (CCSC) is divided into four major factors: active coping, distraction, avoidance, and support seeking. The Active Coping factor is comprised of an individual's ability to plan or think about ways to solve a problem, his or her efforts to improve the problem situation, and efforts to find meaning in a problem. Results suggest that both participants demonstrated a slight increase from baseline to 1 month in employing active coping strategies. From 1- to 3-month follow-up, Participant 101 continued to employ active coping strategies, whereas Participant 102 implemented fewer active coping strategies for problems (see Figure 5). The scores of Participants 101 and 102 at all time points were within the average range, in comparison to those of the normative sample (Ayers, 1991).

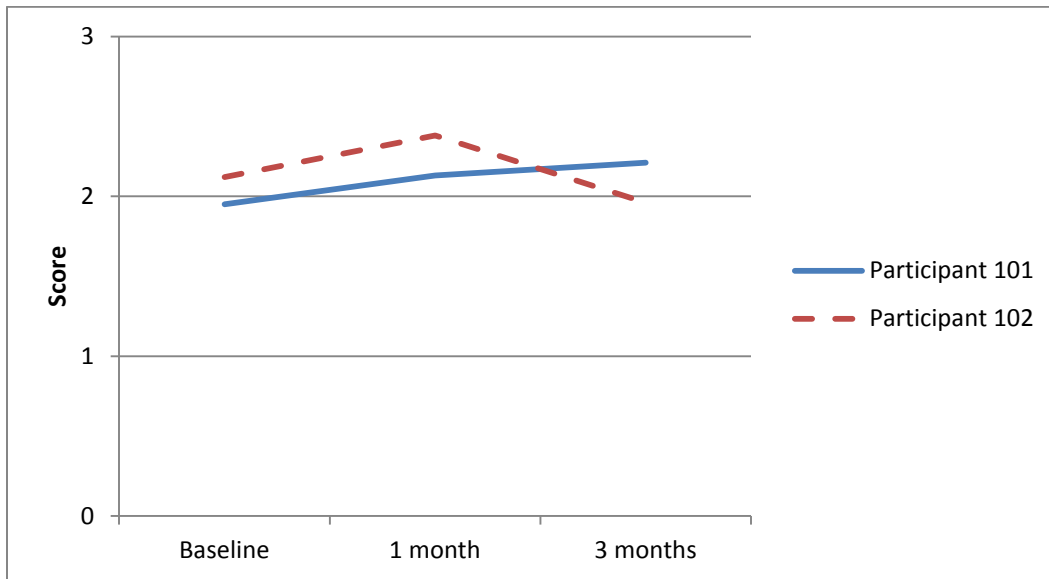


Figure 5. Change in Active Coping Factor Score.

The Problem-Focused Coping subtest is comprised of direct problem solving, cognitive decision making, and seeking understanding. The results from this subdimension suggest that Participant 101 demonstrated a steady increase through baseline, 1-month, and 3-month periods. Conversely, Participant 102 demonstrated an initial increase in problem-focused coping from baseline to 1 month, then a decrease from 1- to 3-month follow-ups (see Figure 6). The participants' scores at each time point were within the average range, in comparison to the scores of normative sample (Ayers, 1991).

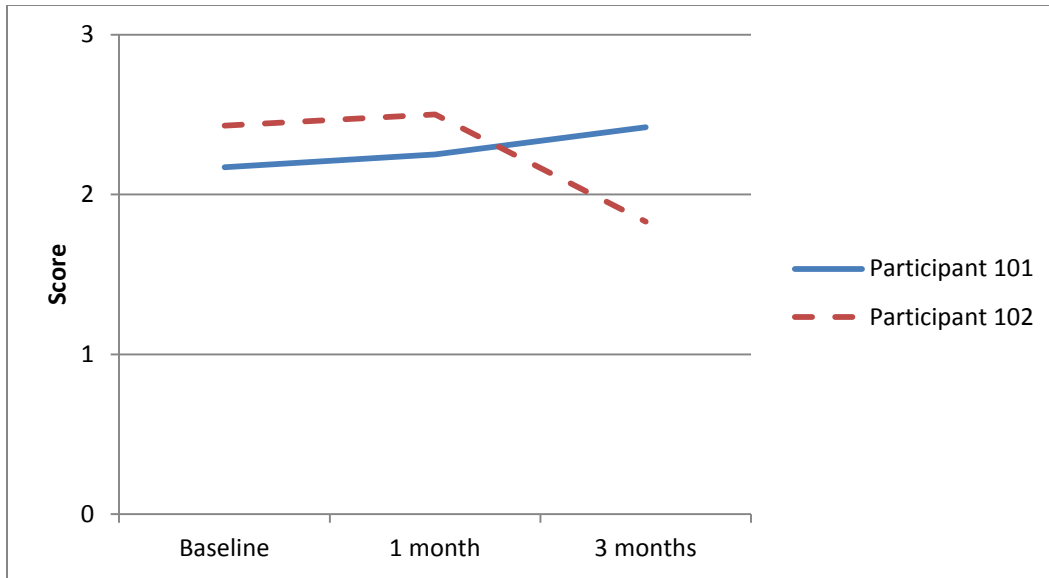


Figure 6. Change in Problem-Focused Coping Score.

The Positive Reframing/Restructuring Coping subtest measures ability to think about the good, think about the future with an optimistic attitude, and think that one can handle or deal with a problem. This coping also reflects one's ability to minimize the problem or consequences of the problems. Results suggest that both participants had increased positive reframing coping from baseline to the 1-month follow-up. After the 1-month follow-up, Participant 101 reported a slight decrease and Participant 102 maintained positive reframing coping skills (see Figure 7). Participants' scores on the Positive Reframing/Restructuring Coping scale were within the average range, in comparison to those of the normative sample (Ayers, 1991).

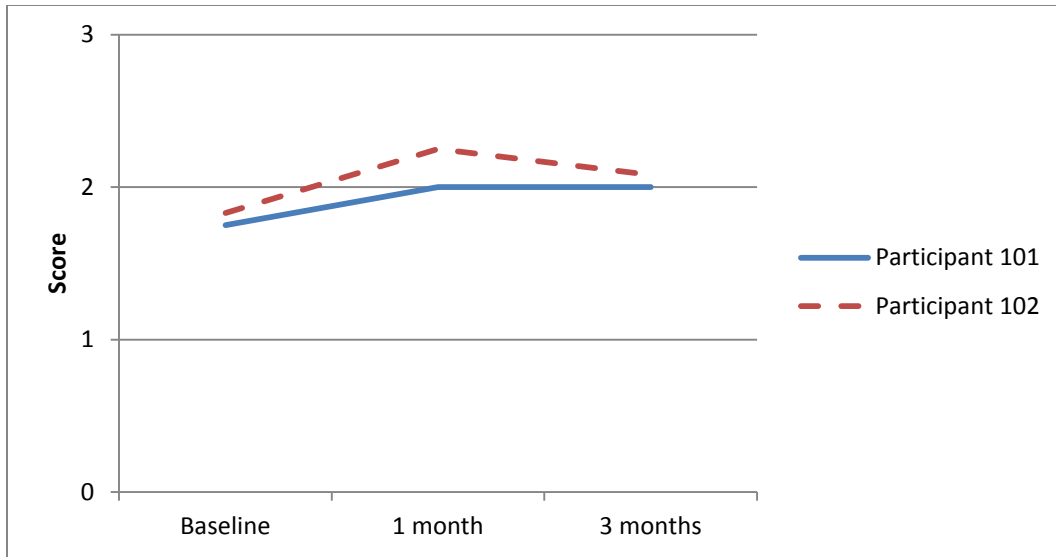


Figure 7. Change in Positive Reframing Coping Score.

The Distraction Strategies factor is comprised of the Distracting Actions and Physical Release of Emotions subscales. This factor includes examples of efforts to avoid thinking about the problem situation by using distracting stimuli, entertainment, or other distracting activity. This factor also includes efforts to physically work off feelings with exercise, play, or relaxation. Results suggest a similar trend in that both participants employed these strategies from baseline to 1-month follow-up and then employed fewer distracting strategies from 1- to 3-month follow-up (see Figure 8; baseline $M = 1.83$, $SD = 0.1$; 1 month $M = 2.34$, $SD = 0.01$; 3 months $M = 2.05$, $SD = 0.07$). Participants' scores were within the average range, in comparison to those of the normative sample ($M = 1.94$, $SD = 0.67$; Ayers, 1991).

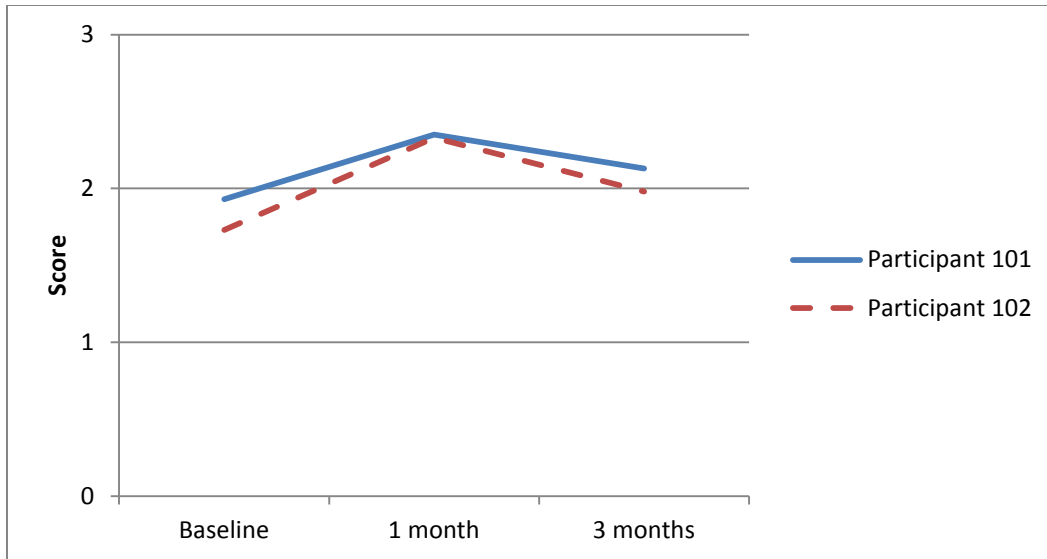


Figure 8. Change in Distraction Strategies Factor Score.

The Avoidance Strategies factor consists of Avoidant Actions, Repression, and Wishful Thinking subscales. This factor includes behavioral efforts to avoid a stressful situation by staying away from it or leaving it. This factor also includes efforts to avoid thinking about the problem and the use of fantasy or wishful thinking or imagining that the situation was better. Results suggest that Participant 101 reported a general increase in avoidant strategies across all points measured. In contrast, Participant 102 reported an increase in avoidant behaviors from baseline to 1-month follow-up and a decrease from 1-month to 3-month follow-up (see Figure 9). Results for both participants' overall Avoidance factor ($M = 2.02$, $SD = 0.23$) were below those of the normative group ($M = 2.47$, $SD = 0.75$), suggesting less overall engagement in avoidant behaviors.

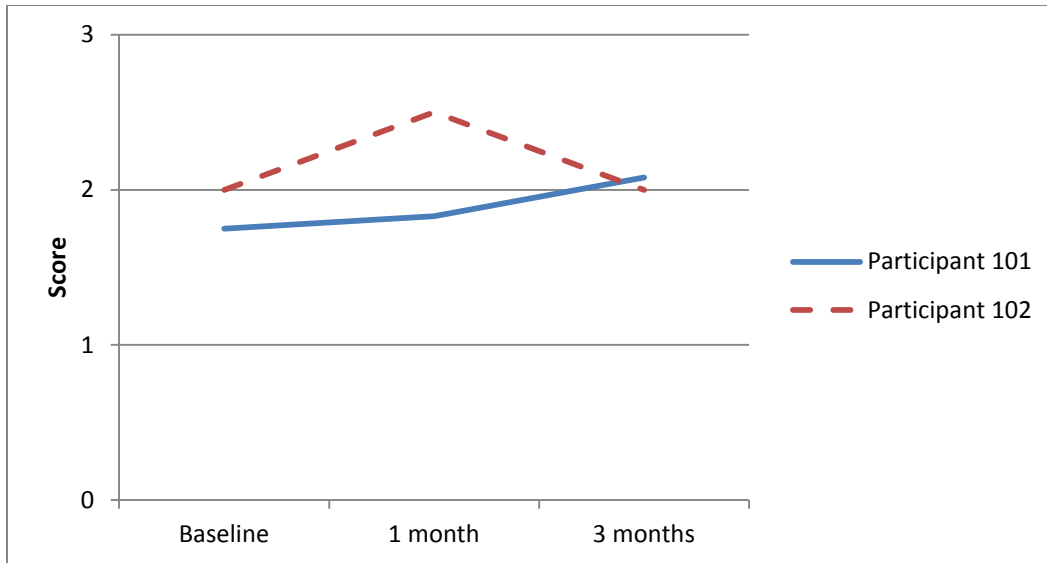


Figure 9. Change in Avoidance Strategies Factor Score.

The Support Seeking Strategies factor score consists of subscales that evaluate the ability to use other people as resources to assist in seeking solutions to problem situations. Additionally, this factor is comprised of a subscale that examines ability to seek out others who will listen to feelings or provide empathy to help the person become less upset. Participant 101 reported a general increase in support-seeking strategies across all points measured. In contrast, Participant 102 reported an increase in support seeking behaviors from baseline to 1-month follow-up and a decrease from 1-month to 3-month follow-up (see Figure 10). The scores of Participant 101 at all time periods were within the average range, compared to the normative sample, whereas the scores of Participant 102 were statistically significantly higher at the 1-month follow-up, but similar to the normative group at baseline and 3-month follow-up (Ayers, 1991).

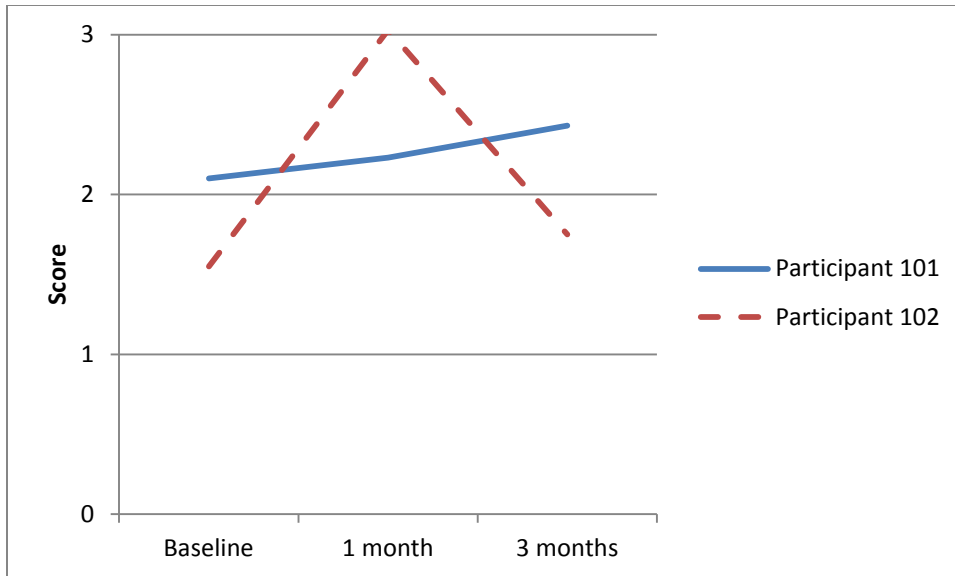


Figure 10. Change in Support Seeking Strategies Factor Score.

Locus of control.

The impact of cognitive appraisals was measured by the Children's Health Locus of Control (CHLOC) questionnaire. The CHLOC has a minimum score of 20 and a maximum score of 40, with lower scores (20 to 30) indicating an external locus of control style and higher scores (31 to 40) indicating an internal locus of control style.

Participants' locus of control was measured at baseline, immediately postworkshop, and at 1- and 3-month follow-ups. Results suggest that both participants reported an internal locus of control style, with an average score of 37.5 at baseline. As expected, both participants' locus of control increased immediately following the workshop (see Figure 11). When compared to the normative group, which was similar in age, gender, grade, and having chronic illness, Participants 101 and 102 demonstrated a significantly greater internal locus of control scores at all measured time points (Goertzel & Goertzel, 1991; Parcel & Meyer, 1978). Given the higher locus of control for the two participants at the

beginning of the study, it is not possible to determine the effect of the workshop on locus of control.

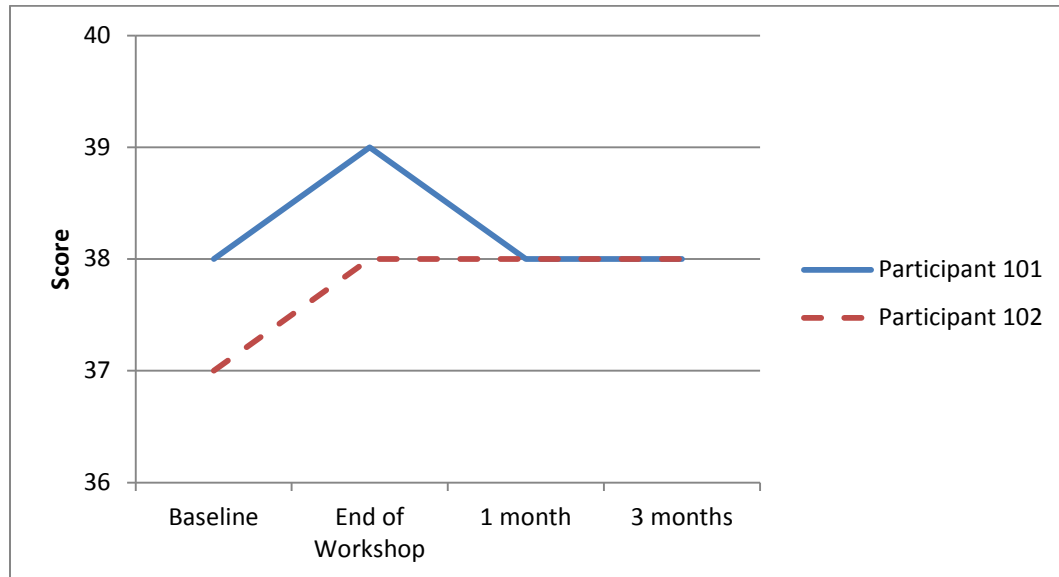


Figure 11. Change in CHLOC score.

Self-efficacy.

Both participants completed the General Self-Efficacy (GSE) scale at baseline and 1- and 3-month follow-ups. The GSE measured participants' beliefs in their competence to cope with a challenging task (Luszczynska, Scholz, & Schwarzer, 2005). Results indicated an overall increase in participants' beliefs in their ability to cope with a challenging task from baseline to 1-month follow-up and a slight decrease from 1-month to 3-month follow-up (baseline $M = 3.20$, $SD = .20$; 1-month $M = 3.56$, $SD = .30$; 3-month $M = 3.2$, $SD = .30$) (see Figure 12). When compared to children in the normative sample ($M = 2.9$, $SD = .40$), the general self-efficacy of Participant 101 was within the average range. Participant 102 reported similar levels of self-efficacy at baseline and

statistically significantly lower scores at 1- and 3-month follow-ups (Cramm, Strating, Roebroek, & Nieboer, 2013).

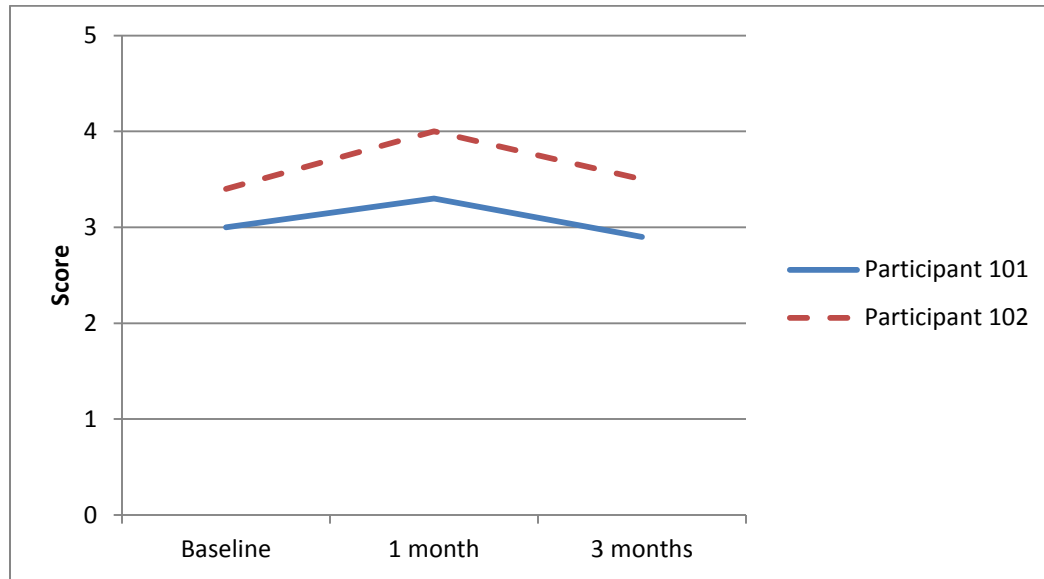


Figure 12. Change in Total GSE Score.

Integrity checks.

Interrater reliability ratings ($\kappa = 0.986$) indicated very good agreement among the raters of the extent to which the protocol was implemented as intended. All of the raters identified that each of the steps of the Social Problem-Solving model was explained in detail, and that utilization of the worksheets and handouts for the participants facilitated the participants' learning. One rater indicated that identification of "what makes a particular situation a problem" was not discussed, and noted that the group leaders did not summarize the problem in the terms given by the child before moving on to the goal-setting portion of the manual. Two of the raters noted that problem orientation was discussed at a later time during the workshop than was established in the manual. One

rater questioned whether the children understood some of the terms that were utilized in the manual, such as *quality of life* and *assumptions*. Qualitatively, it was noted that there was considerable participation by the parents, especially at the beginning of the workshop, which may have overshadowed some of the children's participation or internalization of the concepts being presented in the workshop.

Leader evaluations of overall satisfaction with the workshop indicated very good agreement ($\kappa = 0.969$). Specifically, the leaders had mutual agreement that the topics covered during the workshop were definitely useful to and informative for the participants, the workshop was well planned and executed, it incorporated participants' LQTS-specific problems in the workshop materials, and that participants were actively engaged in the workshop. Furthermore, leaders believed that participants acquired specific strategies to use when faced with LQTS-related problems, define problems, investigate the details of a problem, generate new alternatives to solving problems, evaluate the pros and cons of a solution alternative to the problem, and implement a solution and evaluate the outcome. There was slight disagreement between the leaders in regarding acceptability of the duration of the workshop, whether too much information was presented to the participants, and how well the workshop was paced for the participants.

Feasibility and effectiveness.

The feasibility and effectiveness of the Living Life With LQTS workshop was measured using the Satisfaction Questionnaire. Overall, participants' evaluations suggested that the workshop was feasible and effective. Participants rated the question, "All and all, I am glad that I attended the workshop" as a 9 or 10 (*definitely*). Participants

reported that they most liked the workshop's in-depth focus on the problems faced by those with LQTS and on problem solving for those with LQTS. Both children indicated that they would recommend this workshop to others.

Overall, participants reported a 96% satisfaction rating for the Living Life With LQTS workshop. Participants reported a 95% satisfaction rating for the information presented during the workshop. This indicates that the participants found the topics covered during the workshop useful and informative and that enough information was presented during the workshop. A discrepancy occurred in the ratings for the amount of new material presented to the participants; one child indicated that 25% was new, and the second child indicated that 76% was new. This participant may not have had exposure to these skills generally in her daily life.

Participants reported a 93% satisfaction rating for workshop materials, suggesting that the handouts were useful, the workshop was well planned, and the participants understood the materials presented during the workshop.

The participants also reported on presenter qualities, indicating a 97% satisfaction rating. This result suggests that the participants felt respected, believed that the presenters understood the material they were teaching and explained the material in an understandable manner, and believed that the workshop was interesting.

Regarding the information covered in the workshop, the participants indicated that they were 95% satisfied with the topics. Specifically, the participants reported that the workshop increased their understanding of how to deal with LQTS-related problems effectively and provided specific strategies that can be used when faced with LQTS-related problems. Furthermore, participants learned how thoughts and feelings affect the

way they understand problems. Participants learned how to define a problem, investigate the details of a problem, and generate new alternatives to a problem. Participants reported satisfaction in learning how to generate the pros and cons of each alternative to solving a problem and how to implement and evaluate solutions when problem solving. These results suggest that by the end of the workshop, the children had increased their knowledge of problem-solving skills.

Participants reported 100% satisfaction with the duration, location, and setting of the workshop. Additionally, both participants indicated that they felt comfortable asking questions and giving their opinions during the workshop.

Chapter 5

Discussion

This study presents the findings from a pilot project aimed at assessing the feasibility and acceptability of a problem-solving workshop for children diagnosed with LQTS and their parents. The primary purpose of the Living Life With LQTS workshop was to teach children and their parents problem-solving skills. Previous research has indicated that teaching problem-solving skills to individuals diagnosed with chronic illnesses results in disease-related improvements (Hill-Briggs, 2003; Schmied & Tully, 2009). The workshop provided participants with opportunities to practice problem-solving skills with general LQTS-related problems and with an LQTS problem they currently faced. The results of this study generally supported the hypotheses. Though there was a small sample, the findings indicate that the workshop was possibly feasible and effective for the children diagnosed with LQTS who participated in the workshop. The participants reported an overall satisfaction rating of 96% following participation in the workshop. Participants provided positive feedback regarding the content, instructional materials, group leaders, and skills taught during the course of the one-time workshop.

Although the outcomes are preliminary, the data suggest that there are benefits of teaching problem-solving skills to children with LQTS in helping to navigate LQTS-related problems. The workshop was designed to increase problem-solving skills, self-efficacy, internal locus of control, and coping in children and adolescents regarding problems associated with LQTS. However, results should be interpreted with caution, given the small sample size. Possible factors that may have influenced the results include

a possible selection bias. The parents were motivated to help facilitate their child's participation on the day of the workshop and at each follow-up. Perhaps this bias was because of their commitment to research, which thus reinforced problem-solving skills that would be otherwise unknown in a larger sample. Also, because of the lack of anonymity, participants may have felt compelled to respond positively.

Problem solving.

Few evidence-based interventions have specifically addressed LQTS in children and adolescents (Anderson & Davis, 2011). Mulvaney et al. (2011) found that difficulties related to disease management can be addressed by teaching problem solving. The participants in this problem-solving workshop identified LQTS-related problems and generated solutions to help them work through these daily problems. The children also examined their thinking about problems in daily living, chose the best solution, and determined ways to implement the solution (D'Zurilla & Nezu, 1982). The follow-ups targeted skill retention and served as cues to remember the skills taught in the workshop.

Similar to Nezu et al. (2008), the Living Life With LQTS workshop to teach problem-solving skills to children with LQTS and their parents was found to be a useful intervention. D'Zurilla and Chang (1995) examined the relationship between problem solving and coping. The researchers found that an individual's orientation and his or her active and rational strategies for solving that problem are associated with the uses of adaptive coping strategies. Both participants had statistically significantly better problem orientations than their peers from norm scores. This finding suggests that the children who participated in the workshop had developed beliefs, attitudes, and values about their abilities when they encountered problems. Similar to the adequate problem-solving skills

in participants in Goodman et al. (1995), both participants acquired adequate problem-solving skills and therefore were more easily able to cope with daily stressors, specifically those related to LQTS.

Both participants demonstrated an increase in their abilities to identify problems, generate alternatives, predict consequences, implement solutions, and evaluate from baseline to 1-month follow-up. Similarly, both participants demonstrated statistically significant increases in their automatic process associated with problem solving, their skills, and orientation from baseline to 1-month follow-up. Though these findings support the hypothesis, these gains were not maintained at the 3-month follow-up.

Learning problem-solving skills does not automatically guarantee that those skills will be implemented (Nezu & Perri, 1989). A possible explanation could be related to time between implementation and frequency of practice. Since the group only met one time, participants may not have had the reminders or cues to work through problems regularly and may have forgotten to employ the problem-solving steps. The participants might have benefited from another brief workshop that reviewed the problem-solving steps between the 1- and 3-month follow-ups. Another possible explanation is that the participants may not have experienced problems for which they could have implemented their problem-solving skills. However, results suggested that from the 1- to 3-month period, Participant 101 applied more strategies based on learned problem-solving techniques, whereas Participant 102 maintained the automatic process of problem solving. The individuals who participated in the Living Life With LQTS workshop were similar to those who D’Zurilla et al. (2004) concluded are effective problem solvers who identify adaptive solutions and appear to have positive orientations and effective

application of problem-solving skills. Similar to the current study, Cormier, Otani, and Cormier (1986) found self-report changes following problem-solving training were maintained at a follow-up after 1 month.

Locus of control.

Given the small number of participants and similarly developed SPS skills, the impact of social problem solving on locus of control was not able to be examined; however, locus of control as its own variable was evaluated in this study. The children who participated in the problem-solving workshop reported statistically significantly greater problem-solving skills and internal locus of control from baseline to 1-month follow-up, which were maintained at the 3-month follow-up, than those in the normative group. As previously mentioned, participants demonstrated an increase in their abilities to identify problems, generate alternatives, predict consequences, implement solutions, and evaluate from baseline to 1-month follow-up. Though the participants reported applying fewer of these problem-solving skills at the 3-month follow-up, Participant 101 maintained a consistently high level of internal locus of control both at baseline and at 3-month follow-up. Participant 102 reported an increase in locus of control from baseline to immediately following the workshop, and internal locus of control was maintained at the 1- and 3-month follow-ups. Data suggest that both participants experienced an immediate increase in internal locus of control on the day of the workshop. This finding was also observed in another problem-solving training in which researchers noted an increase in locus of control immediately following intervention (Wege & Möller, 1995).

Problem-solving interventions have shown that an individual's increased problem-solving skills often impact his or her sense of an internal locus of control (Nezu,

1986b). Both participants reported strong problem-solving skills and beliefs regarding internal control. Participants 101 and 102 rejected general beliefs regarding the degree to which their health and LQTS are determined by luck and chance. Lastly, the children who participated in the Living Life With LQTS workshop reported beliefs that they have the ability to determine their health outcomes. Results from this study reflected the similar trend of an increase in internal locus of control immediately following intervention (Nezu, 1986b). This immediate increase in locus of control may be related to chance error or possibly the temporal association of practicing the problem-solving skills and the reinforcement of the leaders, group members, and participation in a group setting (Rosenstock, Strecher, & Becker, 1988).

Coping.

There were mixed results regarding the hypothesis that there would be an improvement in coping style, as measured by the Children's Coping Strategy Checklist (CCSC) from baseline to 1-month follow-up and maintained at the 3-month follow-up (Ayers et al., 1996). Overall, both participants demonstrated an increase in active and support-seeking coping strategies. Changes in Participant 101's active coping seemed to be a result of increases in problem-solving abilities and included skills of planning, problem-focused coping, positive reframing, and support-seeking behaviors or efforts to use other people as resources. At the 3-month follow-up, this participant reported engaging in fewer distracting activities and entertainment as a way to avoid problems, suggesting active engagement in solving problems rather than avoiding them. A possible explanation for the decrease in avoidance may be related to the participant's orientation and confidence in implementing problem-solving skills. Alternatively, internal factors

not related to the participant's participation in the workshop, such as confidence, may also explain these changes in active coping abilities.

Participant 102 had overall increases in active coping, support seeking, distraction, and avoidance behaviors from baseline to the 1-month follow-up. These coping behaviors then decreased between the 1- and 3-month follow-ups. Changes in these coping behaviors over time for this participant may be due to the development of executive functioning skills, attentional abilities, and organization skills in comparison to those of the older participant, who may have been able to retain and incorporate the information more thoroughly. Additionally, reduction in coping behaviors may be the result of the principle of recency effects, suggesting that memory performance declines with the passage of time (Howard & Kahana, 2001). Problem-solving skills were fresh and new from baseline to 1-month follow-up and forgotten by 3-month follow-up. In order to mitigate this in future workshops, participants may benefit from receiving buffer sessions, phone calls focusing on problem-solving skills, or a workshop divided into several sessions rather than a 1-day session. This may help to reinforce practiced skills and provide participants with increased feedback over time.

The findings of this study indicate that both subjects demonstrated active problem solving similar to their same aged peers (Ayers, 1991), as reported in the normative statistics. Meijer et al. (2002) found that coping styles characterized by active problem-solving were the most important determinant of positive psychosocial functioning. Thus, participants in this study demonstrated a developed ability to plan ways to solve a problem, improve a problem situation, and find meaning in problems. Perhaps the participants in the workshop are similar to those children who employed active coping

strategies and responded adaptively to chronic illness and therefore demonstrated fewer psychosocial difficulties (Holen et al., 2012; Thompson & Raezer, 1998).

Self-efficacy.

The self-efficacy measures in this study examined how well the participants could manage their lives with LQTS from baseline through 3-month follow-up. Overall, participants' self-efficacy increased following participation in an SPS workshop from baseline to 1-month follow-up, maintained at 3-month follow-up after participation in a social problem-solving workshop. Contrary to those with chronic illness who do not adapt well to or engage in lifestyle changes (Clay & Telfair, 2007), those who participated in the workshop demonstrated high levels of self-efficacy, suggesting that they adapted well and held the belief that they had the ability to achieve their goals despite obstacles or problems that may hinder their success. The participants endorsed high levels of self-efficacy beliefs, suggesting that the opportunities for performance attainment incorporated into the workshop may have enhanced their beliefs about their abilities. Though self-efficacy beliefs are subject to change over time (Bandura, 1986), this change was not observed among the participants in this workshop. Perhaps the participants' high levels of self-efficacy resulted from their belief in their ability to manage their LQTS and adhere to the treatment recommendations. According to self-efficacy theory (Bandura, 1977), individuals' beliefs in their ability to adequately solve problems determine whether they actually cope well with stressful events (Bandura, 1977). Results suggest that the participants in this workshop had the belief that they could solve problems, and this was further illustrated by their adaptive coping abilities.

Clinical impressions.

An anecdote shared by one of the participants supports the feasibility and effectiveness of the problem-solving workshop with parent-child dyads. One of the children was required to wear a Holter monitor to school. A teacher thought it was a bomb and sent him to the principal's office. This was embarrassing, humiliating and frightening for both the child and parent. The other child validated these feelings, and parents discussed their shared reactions to this experience.

Recruitment issues.

The original goal was to recruit five to 10 adolescents diagnosed with LQTS and their parents. Following difficulty in scheduling adolescents, the investigators decided to lower the age of eligibility to 9 years. After forming a group of six children and four adults and scheduling a workshop, one family dropped out because of the child's fear of feeling different, and a second family with three children did attend, despite confirmatory phone calls and e-mails..

After subsequent recruitment efforts were unsuccessful, the investigators and dissertation committee members explored interest in the workshop topics. The following announcement was posted on the PCOM LQTS Research Team Facebook page:

As many of you have seen our posts, we've been offering studies including a free workshop for children with LQTS offered in the Philadelphia area; however, we have not received high responses. We are trying to brainstorm other ways to reach those who may be interested or understand why our workshop may not be of interest. We greatly appreciate all of your help and feedback! (Post by study investigators on Facebook).

Feedback posted on Facebook users revealed that individuals interested but barriers including time, money, child's age, energy to travel, location (lived outside the tristate area), and fear of feeling different. Recommendations for the future included Google Drive to distribute workshop materials, online workshops, podcasts, and compensation for transportation (plane tickets).

The investigators determined that child's age was the most feasible barrier to eliminate and changed the criterion to 8 years. A second workshop was scheduled with two children (ages 8 and 9 years) and their parents. Unfortunately, unforeseen circumstances among participants prevented this workshop from being held.

Feasibility and effectiveness.

There may be concerns about the feasibility of the workshop, given the small number of participants. Feasibility is defined as "capable of being done or carried out" (Merriam-Webster, 2015); because the workshop was conducted, the workshop can be deemed feasible. Effective is defined as "producing a decided, decisive, or desired effect" (Merriam-Webster, 2015). Changes in participants' scores suggest that the workshop was effective. However, the results are not generalizable to the greater population of children who have been diagnosed with LQTS, given the small sample size.

Limitations.

The generalizability of these findings to the larger population of children diagnosed with LQTS is limited by the small sample size. Future researchers should consider the technological and other suggestions provided on the Facebook page to increase participation.

The changes in score for the participants in the present study suggest that the workshop was informative, worthwhile, and helpful to the participants. The variability in follow-up scores indicates that future problem-solving skills workshops and interventions may need to include reinforcement of skills. For children, this reinforcement could include telephonic coaching at 1 and 3 months after the workshop.

Another limitation is that the results of this study are not generalizable to children who have been diagnosed with other chronic illnesses. This study investigated a specific population. Problem-solving skills, coping, and self-efficacy in children and adolescents diagnosed with LQTS may differ from those with other chronic illnesses.

An additional limitation is that the investigators did not identify whether participants were effective problem solvers. Change in problem-solving skills may be because participants were already effective problem solvers. Therefore, a problem-solving workshop may not have increased their SPS skills to the same extent as those with weaker problem-solving skills or who are experiencing problems related to LQTS. In addition, the researchers were not able to conduct statistical analyses, such as correlations or regressions between the variables of coping, locus of control, social problem solving, and self-efficacy because of the limited sample size.

A further limitation of the current study is that research is limited to a 4-hour skills-based intervention implemented with a population diagnosed with a chronic illness. Problem-solving interventions with adolescents have typically spanned across multiple sessions with opportunities for practice and feedback following implementation and practice over time (Tisdelle & St. Lawrence, 1988). In contrast to prior research with

problem-solving interventions, participants in this pilot study did not have the ability to return to the group to discuss problems related to implementing problem-solving skills.

An additional limitation is that social problem-solving interventions have not been empirically evaluated for children diagnosed with LQTS; there were no evidence-based recommendations in the literature for problem-solving interventions with children diagnosed with LQTS. This may limit the generalizability of the results.

There may have been a selection bias for those who enrolled in the pilot study. Children who participated may have differed from those who did not participate in the workshop. As previously mentioned, the reasons for not participating included fear of feeling different and distance from the workshop location.

A final limitation is that this pilot study had simultaneous participation by parents and children. Although family interventions aim to improve the parent-child relationship, combined participation could impact a child's ability to learn the problem-solving skills (Goldbeck & Babka, 2001; Johnson, Kent, & Leather, 2004). Combined-group factors, such as communication difficulties or boundary setting, may inhibit children from adequately participating, and the current study did not address these components (Hayutin, Blount, Lewis, Simons, & McCormick, 2009).

Future research.

Future research should examine the feasibility and effectiveness of social problem-solving treatment with a larger sample of children and adolescents diagnosed with LQTS in order to determine whether correlations exist between problem-solving skills, coping, locus of control, and self-efficacy following participation in a 1-day workshop. Literature in this area is sparse, and the current study did not include an

adequate number of participants to draw substantial conclusions about these variables. Not all of the variables evaluated in this study have been investigated with this population, and understanding the relationship between these variables would extend the findings from this one-time problem-solving workshop.

Future research should also examine the benefit of social problem-solving skills in adolescents with LQTS who are distressed. For those individuals who have experienced psychosocial factors related to chronic illnesses, problem-solving skills have been shown to decrease levels of distress after a problem-solving intervention (Nezu et al., 2003). Such research may contribute to the generalizability and implications of social problem-solving workshops for children diagnosed with LQTS.

Another important area to consider is the barriers to participation in this workshop. Future researchers may wish to consider providing online workshops and access to workshop materials via Google. Grant funding to reimburse participants for travel to attend the workshops is another possible strategy to increase participation.

Conclusion.

Despite the limitations, the Living Life With LQTS workshop appears to be a worthwhile addition to care for children and adolescents with LQTS. To date, this workshop is the first intervention designed specifically to address problem-solving skills for children and adolescents with LQTS. The participants in this study were taught social problem-solving skills to help manage everyday stressors related to their LQTS.

Problem-solving skills are important for individuals diagnosed with LQTS, as these skills have been found to help individuals diagnosed with other chronic illnesses cope with daily problems (Nezu & Nezu, 2012). Problem-solving skills may help

children and adolescents achieve greater self-efficacy, a sense of control, and the ability to cope with everyday problems associated with LQTS. Implementing these skills may be helpful in dealing with unanticipated events or LQTS problems when they occur.

The limited psychosocial interventions for the specific problems that individuals diagnosed with LQTS encounter, combined with research that has shown that patients with LQTS face psychosocial issues similar to those faced by patients with other cardiac diseases, make the usefulness of this intervention an important contribution for physicians and medical professionals working with adolescents with LQTS (Waldron, Felgoise, Tress, Lawrence, & Vetter, 2013). Physicians should be aware of problem-solving workshops as an alternative recommendation for treatment or support. Problem-solving skills may increase adolescents' coping, self-efficacy, and internal locus of control, especially related to their LQTS. Overall, this study demonstrated the potential usefulness of a problem-solving workshop to increase problem-solving, self-efficacy, coping, and locus of control in children with LQTS.

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