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Relationship Satisfaction and Family Functioning: Mothers of Children with LQTS Versus a Control Group

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RELATIONSHIP SATISFACTION AND FAMILY FUNCTIONING: MOTHERS OF CHILDREN WITH LQTS VERSUS A CONTROL GROUP

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Dissertation Approval

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Abstract

Long QT syndrome is a condition that occurs as a result of a disturbance in the electrical function of the heart, and is a chronic illness that carries a high risk of sudden death. It is estimated that close to 1 in 2,000 individuals in the general population will be diagnosed with LQTS. Given the potential lethality of LQTS, and the numerous restrictions and life changes that individuals diagnosed with LQTS and their families must make, it is surprising that few studies have been conducted to evaluate psychosocial needs of people who have LQTS. Research has examined how children diagnosed with a chronic illness have impacted both family functioning and relationship satisfaction. However, there have been inconsistent findings. The variability of these findings are believed to be attributed to the severity and broad range of the illness researched, the daily demands of the illness, and the age range of the children diagnosed. The purpose of the present study is to examine whether there are differences between perceptions of relationship satisfaction and family functioning when comparing mothers of children with Long QT Syndrome with mothers who do not have a child with a chronic or life threatening physical condition or psychological condition requiring school accommodations, while controlling for variability in social problem solving skills. The study predicted that when controlling for variability in social problem solving skills, mothers with children diagnosed with Long QT syndrome will report lower relationship satisfaction when compared to the reports of mothers that do not have children diagnosed with Long QT or any chronic or life threatening physical condition or psychological condition requiring school. The study also predicted that when controlling for variability in social problem solving skills, mothers with children diagnosed with Long QT syndrome will report lower family functioning when compared to the reports of mothers that do not have children diagnosed with Long QT or any chronic or life threatening physical condition or psychological condition requiring school accommodations. Results found that there was not a significant difference when examining reports of relationship satisfaction and family functioning when comparing the LQTS group participants with the control group participants. Slight distress was indicated in the LQTS group on the satisfaction, cohesion, and total score subscale of the Revised Dyadic Adjustment Scale; however, it was not clinically significant. In examining family functioning both the LQTS group and Control group scored within the “healthy functioning” range on all subscales of the Family Assessment Device.

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Relationship Satisfaction and Family Functioning: Mothers of Children with LQTS versus a Control Group

Chapter 1

Statement of the Problem

Long QT syndrome, which is a condition that occurs as a result of a disturbance in the electrical function of the heart, is a chronic illness that carries a high risk of sudden death (SADS Foundation, 2012). It is estimated that close to 1 in 2,000 individuals in the general population will be diagnosed with LQTS (Schwartz, Stramba-Badiale, Crotti, Pedrazzini, Besana, Bosi…. Spazzolini, 2009; SADS Foundation, 2012). It is important to raise awareness and learn more about the impact of this condition because of its lethality. Many individuals go undiagnosed until they experience their first cardiac event. Often, these events are so severe, they result in death. In researching the potential lethality of LQTS, and the numerous restrictions and life changes that individuals diagnosed with LQTS and their families must make, it is surprising that few studies have been conducted to evaluate psychosocial needs of people who have LQTS (Lane, Reis, Peterson, Zareba, & Arthur, 2009; Chattha & Zelenietz, 2011).

A family can be defined and structured in a variety of ways. One consistent way of viewing a family is as a human system made up of interactions among its members (Becvar & Becvar, 1999). Within the family system, there are separate subsystems which can be defined as the relationships between and among family members. One important subsystem within the family system is the marital dyad. This dyad can be made up of a married, unmarried, homosexual, or heterosexual couple (Becvar & Becvar, 1999). The marital dyad is an important subsystem to examine because it helps to structure the entire

family system. In families in which a child is diagnosed with a chronic illness, the family system, as well as the marital dyad is impacted by the illness.

Research has examined how children diagnosed with a chronic illness have impacted both family functioning and relationship satisfaction. However, there have been inconsistent findings. Some studies reported that chronic illnesses in children negatively impact relationship satisfaction, by increasing emotional distress, yet other studies have shown a positive effect on relationship satisfaction by bringing couples closer together (Quittner, Espelage, Opipari, Carter, Eid & Eigen, 1998). The variability of these findings are believed to be attributed to the severity and broad range of the illness researched, the daily demands of the illness, and the age range of the children diagnosed (Quittner, 1998). Another contributing factor to these inconsistent results may be the generalized nature of the instruments used to measure family impact and relationship satisfaction (Quittner et al., 1998). When further examining the negative effects that a chronic illness in a child has on relationship satisfaction, findings have shown that couples report increased marital role strain (Quittner et al., 1998). The increase in marital role strain is specific with regard to greater role frustration, higher levels of conflict over child rearing issues, performing more child care tasks daily, and reporting fewer positive daily interactions with their partner, when compared with couples that have a child without a chronic illness (Quittner et al., 1998). In researching the family system as a whole, with regard to chronic illness, it has been found that chronic illnesses severely strain not only the person who is ill, but also the family (Dobbie & Mellor, 2008). These stresses may be financial, social, or role related (Dobbie & Mellor, 2008).

In examining a patient's ability to cope with his or her illness, there appears to be a positive correlation between the family's health and ability to cope, and the patient's ability to cope with the chronic illness (Dobbie & Mellor, 2008). Given this relationship, it is important to identify areas that the family identifies as being impacted by the illness; it is also important to control for ways in which this variability in coping may affect how one reports his or her marital satisfaction and family functioning. Problem solving is a rational and systematic approach to coping with life's problems (D'Zurilla & Nezu, 1999a). Because of this, problem solving is examined as a coping style in this current study. It is important to investigate specifically the marital dyad, with regard to relationship satisfaction because parents are commonly the primary caretakers of the child with a chronic illness.

Investigations of the impact that chronic illness in a child has on the family and on marital relationship focus primarily on chronic health issues such as spina bifida, cancer, asthma and arthritis (Barlow & Ellard, 2006). Findings regarding the impact of chronic health conditions on psychosocial factors in families and on couple relationship satisfaction have been mixed; some families and couples report an increase in emotional and psychosocial distress, but others report no significant changes in these areas (Barlow & Ellard, 2006). These discrepant findings, suggest that research from one chronic health condition may not generalize to others (Barlow & Ellard, 2006; Taylor, Fuggle & Charman, 2001). These various findings may be due to the fact that illnesses present differently, with regard to daily maintenance, severity of symptoms, and care taking demands. The unpredictability in the findings of the research suggests that it is important to examine specific illnesses individually in order to identify areas within the marital

dyad and the family that are specifically affected by the illness. Identifying these specific needs can facilitate health care provider's efforts to tailor treatment and provide services that address these critical areas.

Purpose of the Study

The purpose of the present study is to examine whether or not there are differences between perceptions of relationship satisfaction and family functioning when comparing mothers of children with Long QT Syndrome with mothers who do not have child with a chronic or life threatening physical condition or psychological condition requiring school accommodations, while controlling for variability in social problem solving skills. The following research hypotheses are tested: when controlling for variability in social problem solving skills (SPSI-R total score), mothers with children diagnosed with Long QT syndrome will report lower relationship satisfaction, (as defined by the following subscales on the Dyadic Adjustment Scale: dyadic satisfaction, dyadic cohesion, and consensus on matters of importance to dyadic functioning) when compared with the reports of mothers that do not have children diagnosed with Long QT or any chronic or life threatening physical condition or psychological condition requiring school accommodations. The second hypothesis is that when controlling for variability in social problem solving skills (SPSI-R total score), mothers with children diagnosed with Long QT syndrome will report lower family functioning (as defined by problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control), when compared with the reports of mothers that do not have children diagnosed with Long QT or any chronic or life threatening physical condition or psychological condition requiring school accommodations. This study aimed to increase the

understanding of how living with the condition of LQTS, which is life-threatening but often asymptomatic, may or may not affect the marital dyad.

Literature Review

Overview

The focus of this research is to explore how family systems react in terms of marital satisfaction and family functioning, when living with a diagnosis of Long QT Syndrome. There are several useful theories relating to family systems broadly, and to the impact of chronic illness on family systems, specifically, that highlight the need for this type of research. A more recent LQTS-specific model of how families cope with this illness is also considered. According to these theories families, will respond differently, depending on the structure, boundaries, dynamics and rules that govern the system. These characteristics will shape how the system adapts to the new changes that have entered the system. Consideration to family members' problem solving ability suggests there will be variability in relationship satisfaction and family functioning. The theoretical underpinnings and related research to this study follows.

Long QT Syndrome

Long QT syndrome is a condition that occurs as a result of a disturbance in the electrical function of the heart (SADS Foundation, 2012). Long QT syndrome (LQTS) is caused by mutations that affect the cardiac ion channels, which are cell structures in the heart muscle (Liu et al., 2011). These mutations cause a delay in ventricular repolarization, which leads to a prolonged QT interval. A prolonged QT interval refers to the time it takes for depolarization and repolarization of the heart to occur. This prolonged interval, which is identified as a period of time lasting longer than .46-.48 second, can be seen on an electrocardiogram (Friedman, Mull, Sharieff & Tsarouhas, 2003; Garson et al., 1993). LQTS is a condition that can be either inheritable or acquired

(Friedman et al., 2003); this being the case, when one person is diagnosed in the family, it could lead to multiple diagnoses.

There are a variety of phenotypes of LQTS; however, three of these are more commonly known. The first of the most common phenotype is LQTS1 (Anderson, Oyen, Bjorvatn & Gjengedal, 2008). An individual with LQTS1 is at greater risk of experiencing a cardiac event during exercise or emotional arousal (Anderson et al., 2008). The second phenotype is LQTS2. Individuals who are diagnosed with LQTS2 may be at greatest risk for experiencing a cardiac event due to sudden, startling noises, to emotions, or to exercise (Anderson et al., 2008). The third phenotype is LQTS3. Individuals with this diagnosis have a greater likelihood of experiencing a cardiac event while sleeping or resting (Anderson et al., 2008). All types of LQTS are at risk for an event by any of these triggers, but the greatest risks are as indicated.

In considering the three most common phenotypes of LQTS, it is apparent how a diagnosis of LQTS may affect not only the children who are diagnosed but also the families, specifically the spousal dyads who are responsible for the well-being of the children (Chattha & Zelenietz, 2011). For example, LQTS1, the families must be aware of and make appropriate adjustments to the activities in which their children participate. One activity that is typically restricted is swimming. Children with LQTS have an increased risk of a cardiac event while in the water (Modell & Lehmann, 2006; Choi, Porter, & Ackerman, 2004).

New recommendations have been established for athletes with suspected/diagnosed cardiac channelopathy (Ackerman, Zipes, Kovacs, & Maron, 2015). Recommendations with regard to individuals diagnosed with LQTS specifically include

the following: it is considered reasonable for an asymptomatic athlete with genotype-positive/phenotype negative to participate in all competitive sports; however, he or she must take appropriate precautionary measures (Ackerman et al., 2015). These measures include steps such as avoiding QT-prolonging drugs, electrolyte/hydration replenishment and avoidance of dehydration, avoidance or treatment of hyperthermia from febrile illnesses and avoidance of training-related heat exhaustion or heat strokes. The individual should acquire a personal automatic external defibrillator as part of his or her safety gear, or an AED should be present at practice, games/meets and there should be an established emergency action plan with appropriate school or team officials. For an athlete with symptomatic LQTS or with electrocardiographically manifests LQTS, which is considered a corrected QT interval >470 ms in males or >480 ms in females. Competitive sports participation may be considered after institution of treatment and appropriate precautionary measures, assuming the athlete has been asymptomatic on treatment for at least 3 months (Ackerman et al., 2015). If treatment includes an ICD, the individual must be sure to follow recommendations regarding restrictions after the procedure, lead replacements, and so forth

Persons with LQTS2 may have to avoid things that startle, such as alarm clocks, which most people use every day (Zipes et al., 2005). In fact, the whole household may choose not to use these devices in order to decrease the risk that the noise would startle the children with LQTS. These are some every day, “typical” activities that are affected when someone is diagnosed with LQTS. The challenge that these families face is to make these accommodations in the family without having a major impact on the quality of life of the children diagnosed and for those family members who do not have an LQTS

diagnosis. The parents may work to highlight the positive activities in which the children can engage so the children do not feel "different" or as if they are "missing out".

In the general population, it is estimated that close to 1 in 2,000 individuals will be diagnosed with LQTS (Schwartz et al., 2009). Although it is not as common as some other chronic illnesses, it is important to raise awareness for this condition because of the potential lethality. Many individuals go undiagnosed until they experience their first cardiac event. Often, these events result in death. Three common cardiac events or symptoms that may occur with LQTS are fainting (syncope), seizures, and cardiac arrest (Garson et al., 1993). Less severe symptoms include feelings of lightheadedness, muscular weakness, and feeling faint (pre-syncope). Individuals could also experience heart palpitations (Garson et al., 1993). Ventricular arrhythmias lead to these "cardiac" events. Although it is not always the case, these dysrhythmic episodes can turn into ventricular fibrillation (quivering of the heart) and sudden death (Friedman et al., 2003). Males with LQTS are more likely to experience their first cardiac events in childhood, whereas females are more likely to experience their first events in adolescence (Locati et al., 1998). There does not seem to be a significant difference in sex among individuals who are LQTS gene carriers (Locati et al., 1998). In addition, although LQTS affects all races, little research has been done to evaluate the prevalence rate among the different races. One study that has been done included 3479 subjects, 41 of whom were African American and the rest were Caucasian (Fugate et al., 2010). The findings from this study indicated that QTc intervals in African American individuals were 29ms longer than those of Caucasians. This increase in severity may speak more to referral bias related, in part, to socioeconomic and medical care issues, as opposed to meaning that LQTS

appears more severe in African American individuals (Fugate et al., 2010). More research has to be done to identify whether or not there is a difference between races for the incidence and prevalence rate of LQTS.

Treatment. Treatment for LQTS depends largely on the genotype with which the individuals are diagnosed (Garson et al., 1993). Common treatment of LQTS includes the use of beta blockers, pacemakers, and implantable cardiac defibrillators (Friedman et al., 2003). Another treatment that is sometimes used is called left cardiac sympathetic denervation (Goldenberg, Zareba, & Moss, 2008). This surgical procedure was introduced as a treatment for LQTS before beta-blockers were available. It is typically used now for individuals who are still experiencing syncope while using beta-blockers, or for individuals who experience arrhythmia storms and shocks with an implantable cardiac defibrillator; this will be discussed in further detail later (Goldenberg et al., 2008).

Beta blockers are typically considered first line prophylactic therapy (Goldenberg et al., 2008). A common beta blocker that is used is propranolol (Shah & Rao, 2006). The functions of beta blockers are to prevent ventricular tachycardia, which is a rapid heartbeat that starts in the ventricles, from occurring or from escalating to ventricular fibrillation, which leads to sudden death (Shah & Rao, 2006). Beta blockers also work to block the heart rate response to exercise. Typically, this type of medication therapy is continued throughout the individual's life. Beta-blockers should be considered for all intermediate and high-risk patients and can also be considered on a case-to-case basis for low-risk patients (Shah & Rao, 2006), although the risk stratification may not be universally accepted by cardiologists. The negative aspect of beta-blockers is that they may cause some undesirable side effects (Farnsworth, Fosyth, Haglund & Ackerman,

2006). These side effects may include mood swings, depression, and fatigue which are uncommon in children. These side effects may increase the likelihood of non-compliance, especially in the adolescent population (Farnsworth et al., 2006).

Pacemakers are also used as a form of treatment for LQTS. These devices are typically employed in situations in which patients are having profound bradycardia - a heart rate of less than 60 beats per minute (Shah & Rao, 2006). Pacemakers consist of battery-powered pulse generators connected to a system of electrical leads. With a permanent pacemaker, the pulse generator is implanted internally under the chest wall, typically below the left clavicle (Awtry, Jeon & Ware, 2006). The leads pass from the pulse generator through the subclavian vein and are anchored into the right atrium and/or the right ventricle. The purpose of the pacemaker is to detect intrinsic cardiac electrical activity (Awtry et al., 2006). If the intrinsic heart rate falls below the desired rate, the device delivers an electrical impulse to the myocardium, which causes it to depolarize.

Another form of treatment, which was introduced previously, is an implantable cardiac defibrillator (ICD). Typically an ICD is considered for individuals who continue to have episodes of syncope despite the use of beta blockers, and who have a history of cardiac arrest (Shah & Rao, 2006). These devices include a pacemaker and consist of an endocardial lead in the right ventricle apex connected to a pulse generator implanted in the chest wall. The primary role of an ICD is to treat ventricular tachy-arrthymias, which could consist of multiple episodes of ventricular tachycardia or ventricular fibrillation or a ventricular storm (Awtry et al., 2006; Goldenberg, 2008). A ventricular tachycardia occurs when the heart rate exceeds normal range, and originates in the ventricle. A ventricular fibrillation occurs when there is an uncoordinated contraction of ventricles

caused by ineffective rapid electrical depolarizations of the heart, causing them to quiver rather than contract normally (Awtry et al., 2006). When the ICD detects one of these arrhythmias, it works to terminate it either by pacing the heart faster than the rate of the arrhythmia or by delivering a high-energy shock to the myocardium (Awtry et al., 2006). Negative aspects of an ICD include having the ICD deliver shocks at inappropriate times, or being shocked multiple times during ventricular tachycardia/ventricular fibrillation storm (Goldenberg, 2008). Other complications of this device might include lead- related issues, such as lead-fracture, with the need for device replacement, or infection, and psychological adjustment due to the device in general (Goldenberg, 2008). It is typically advisable to use beta-blockers in conjunction with the use of an ICD. Given the variety of phenotypes for LQTS, and the variety of triggers of cardiac events that are possible, depending on the type of LQTS, it is common for certain lifestyle changes to be required after a diagnosis of LQTS. These changes may include dietary, physical, and social restriction (Chattha & Zelenietz, 2011); i.e., not travelling alone, not participating in certain recreational sports, and significantly limiting or abstaining from alcohol use), along with following a lifelong medication regimen and possibly receiving an implantable device.

There are also certain medications that individuals with LQTS must avoid because they are known to cause prolongation of the QT interval (Shah & Rao, 2006). These medications include tricyclic antidepressants, phenothiazines, other psychotropic drugs such as risperidone and haloperidol, antihistamines, epinephrine, and antibiotics such as erythromycin, azithromycin, and clarithromycin (Shah & Rao, 2006). These are some of the medications that these individuals have to be cautious about and to avoid

when diagnosed with LQTS. Another adjustment that needs to be made in order to prepare for a cardiac event is that parents and other individuals in the families learn cardiopulmonary resuscitation (CPR) (Shah & Rao, 2006). It is also advisable to purchase and have on hand an automated external defibrillator (AED) which is a portable device that allows the cardiac episode to be treated with electrical therapy in order for the heart to reestablish an effective rhythm.

Although there are multiple demands and restrictions that a diagnosis of LQTS places on the individuals and families, there are few studies on the psychosocial impact of LQTS (Lane et al., 2009). Studies that have been done to identify the psychosocial impact have shown that parents report an increased fear of their child dying and they also have feelings of uncertainty about the future, especially at the time of diagnosis (Farnsworth et al., 2006). Increased emotional distress was reported by parents of carrier children as compared with parents of non-carrier children, not only immediately after the diagnosis, but also18 months following the diagnosis (Hendriks et al., 2005).

Research regarding the psychosocial effects of LQTS is minimal when compared with research about other chronic illnesses. Based on the research that has been done, it appears that negative psychosocial effects are reported in families coping with LQTS. Further research needs to be done in order to identify specific areas of overall family functioning and marital satisfaction affected by this chronic illness, given the illness's psychosocial effects. Identifying specific areas of family functioning and marital satisfaction is important, so that services can be developed to address those areas of need.

Considering the Family System in Treating Psychological Distress

Prior to the 1940s, the individual was regarded as the focus of psychological distress and was the main target for treatment (Nichols, 2009b; Magnavita, 2012). The shift from treating only the individual to considering the individual as being part of a system occurred during the 1940s. Ludwig von Bertalanffy, an Austrian biologist, combined concepts from systems thinking and biology in order to create a universal theory of living systems (Nichols, 2008a, 2009b). This model came to be known as general systems theory (Nichols, 2008a, 2009b). According to general systems theory, the essential parts of a living system are properties of the whole; none of the parts, alone, comprise the whole; instead, the whole arises from the relationships among the parts (Kazak, 1989; Nichols, 2008a, 2009b; Magnavita, 2012). More simply put, the whole is always greater than the sum of its parts (Kazak, 1989; Nichols, 2008a, 2009b; Magnavita, 2012). This was an important shift in conceptualizing psychological distress because it addressed how individuals are interconnected; it also addressed how individuals experiencing distressing events could affect others in the system. In applying this model to therapeutic interactions, the clinician views families as more than a collection of individuals; rather the focus is on the interactions between these individuals (Nichols, 2008a; Magnavita, 2012). In order to understand families as a system, it is important, initially, to understand the underlying assumptions of systems theory.

The system is considered an "open system" because it is continuously interacting with the environment; a system is considered "closed" if no material enters or leaves it (Nichols, 2008a; Bertalanffy, 1950). Another key assumption is that family systems seek to remain stable, yet change when necessary to adapt to new life circumstances; these

processes are referred to as “morphogenesis” and “morphostasis” (Nichols, 2008a; Becvar & Becvar, 1999; Bertalanffy, 1950). Another important characteristic of systems theory is the concept of “equifinality”. This is the idea that a final state can be reached from different initial conditions, in different ways, and yet produce the same final result, which simply means that there are many different paths to the same ending (Becvar & Becvar, 1999; Bertalanffy, 1950). Given these underlying assumptions about a system, it is important to consider how a system reacts when something new enters it.

The Family as a System

Traditional views of the family typically refer to a father, mother, and children; however, a family can be more broadly construed as being whatever one experiences it as being; this can include couples who are married, unmarried, heterosexual, or homosexual, intergenerational or blended families. When families are observed, their actions reveal repetitive interaction patterns among its members; these patterns serve as unspoken rules of interactions which comprise the boundaries of the families and form a stable predictable system (Becvar & Becvar, 1999). The families systems are composed of subsystems; these subsystems are typically determined by generation, gender, common interests, and function (Becvar & Becvar, 1999; Nichols, 2009b; Minuchin & Fishman, 1981). Within a family system there are multiple subsystems. Three subsystems that are particularly important are the spouse, parental, and sibling subsystem (Minuchin & Fishman, 1981). The parental subsystem (parent-child) involves child rearing and socializing functions. The sibling subsystem provides the first peer group for the child. Although the parental and sibling subsystems are important, the spouse subsystem helps to build a foundation for handling life outside of the family and may help to provide

protection from outside stresses (Minuchin & Fishman, 1981). The current study emphasizes the spousal subsystem, and further consideration of this subsystem is, therefore, emphasized.

The Spousal Subsystem. One way to identify the beginning of a family is two individuals coming together in order to create their own family system. The union of these two adult individuals is what makes up the spousal subsystem. The act of two individuals coming together creates a family unit; if these individuals decide to procreate, it expands their family system. As previously mentioned, this does not have to be a married or heterosexual dyad. Each partner has a set of values and expectations that may be conscious or unconscious (Minuchin & Fishman, 1981). When these two individuals come together, they must work with one another to combine their values in order to have a life together; in combining their values, they are forming a new system, thus creating a family unit. One particularly important task of this subsystem is creating boundaries that help to protect the dyad; this sets the tone for the structure of the family (Minuchin & Fishman, 1981). The spouse subsystem is very important for children's growth. It sets an example for intimate relationships as shown through daily interactions. It also sets an example for children, determining how to express affection, how to relate to a partner who is stressed, and how to handle conflicts as equals (Minuchin & Fishman, 1981). The example that is set by the spousal subsystem will make up the children's values and expectations as they come in contact with the outside world (Minuchin & Fishman, 1981).

Chronic Illness and the Family System

Family Systems Illness Model. In conceptualizing families as a system, and adopting the assumptions that system theory presents, it is suggested that when a new variable such as illness is entered into the system, it affects the entire system in some way. This being the case, it can be said that when individuals within families are diagnosed with a chronic illness, all members of the family are affected (Kazak, 1989). In order to conceptualize the chronic illness in a systemic way, it is helpful to define the illness itself in terms of how it manifests and presents itself in individuals. This is important in order to understand the specific demands that the medical condition places on individuals and how that may impact the families. Rolland (1987) presents the Family Systems Illness Model as a framework for assessment and intervention with families that are facing chronic and life threatening conditions. This model presents three dimensions: components of family functioning, time phase, and illness type (Rolland, 2005a, 1987b, 1987c). These three dimensions work to group chronic illnesses by key biological similarities and differences that create specific psychosocial demands on the individuals and families (Rolland, 2005a, 1987b, 1987c). These dimensions also serve as a way to focus on the natural evolution of the illness, and identify family variables such as multigenerational legacies related to illness, belief system, and individual life cycles which may influence how the illness is experienced (Rolland, 2005a, 1987b, 1987c). These dimensions aid in classifying the illness experience in order to provide appropriate interventions for the family system because every illness presents a unique set of demands on families.

Psychosocial Classification of Illness. The psychosocial classifications of chronic illnesses are broken down into four categories: onset of the illness, course of the illness, outcome of the illness, and incapacitation (Rolland, 2005a, 1987b, 1987c; Newby, 1996). Chronic illnesses can be divided into two groups: those which have an acute onset and those which have a gradual onset. A gradual onset provides different stressors to families, as compared with a sudden onset. The amount of change that must take place within the family system , such as readjustment of roles, problem solving, and effective coping may be the same for both illness types; however, when an illness has an acute onset, these changes must be made in a shorter period of time (Rolland, 2005a, 1987b, 1987c; Newby, 1996). Long QT Syndrome can have either an acute or a gradual onset depending on the circumstances surrounding the diagnosis. For example, individuals may be diagnosed after they have experienced their first cardiac event. This would be considered an acute onset because the individuals and families were not aware of the condition before the event. However, LQTS can also have a gradual onset because children could be born into families who have already identified individuals with the diagnosis. Therefore, the children may be diagnosed as a result of a cardiac screening which is conducted because of the known history within the families. In these instances, the families are able to prepare themselves for the possibility of the children being diagnosed, and have more time to adjust to the diagnosis. Long QT Syndrome is not as symptomatic as other illnesses, and individuals do not typically feel sick. To some families, an acute onset may present a larger challenge, but other families may be able to adjust more rapidly to the demands of the illness.

Course of Illness. When categorizing the course of the illness, there are typically three main classifications. An illness can be considered progressive, constant, or relapsing/episodic. A progressive illness is one in which individuals are continually symptomatic and the illness progresses in severity (Rolland, 2005a, 1987b, 1987c; Newby, 1996). In this case, families are challenged by individuals who are constantly experiencing symptoms of the illness, which means that periods of relief are typically minimal. An illness that is considered a constant course is characterized by the occurrence of an initial event, which is followed by a stable biological course (Rolland, 2005a, 1987b, 1987c). Typically the initial event causes some sort of chronic deficit or limitation. With regard to families, there are changes in the systems which remain predictable so the added strain of new role demands over time is not as prevalent in these families, even though the responsibility for taking care of the individuals in their new physical state can be straining (Rolland, 2005a, 1987b, 1987c). Relapsing or episodic illnesses are typically characterized by alternating time periods, consisting of low symptoms and "flare-ups" when the symptoms increase. This pattern affects families in a unique way because they may be able to maintain their normal routines; however, there is always a possibility of a recurrence. This pattern requires flexibility within the family system to alternate between two forms of family organization (Rolland, 2005a, 1987b, 1987c). The uncertainty of the time when an exacerbation of the symptoms will occur is also stressful to families.

Long QT Syndrome (LQTS), can be considered chronic, with a subset of individuals experiencing it as more episodic. It is considered chronic because after a diagnosis is made, there are restrictions placed on the everyday activities of individuals. In addition,

individuals follow a medical regimen in order to decrease the likelihood of a cardiac event occurring. There may also be daily demands that are placed on the families with regard to taking care of the person who is diagnosed. As previously mentioned, there are a subset of individuals whose experience of LQTS may be more episodic in nature; LQTS can also be experienced as episodic based on the cardiac events that some individuals experience.

Outcome of Illness. The outcome of the illness is characterized as the degree to which the condition could be fatal, or the likelihood of the illness considerably shortening one's lifespan (Newby, 1996). The most important factor within this category is the expectation about whether or not the condition is likely to cause death (Rolland, 2005a, 1987b, 1987c). The expectation of loss can create a challenge for the families to maintain a balanced perspective. It may be a struggle for the families to balance the desire for closeness with the diagnosed individuals, yet work towards letting go emotionally in order to prepare for the loss (Rolland, 2005a, 1987b, 1987c). When loss is less imminent or when there is a risk of sudden death, it creates an environment of overprotection by the family members. This is especially the case when a child is ill (Rolland, 2005a, 1987b, 1987c) and with individuals with LQTS where the risk of sudden death is increased.

Incapacitation refers to the impairment that the illness may cause. This may include impairment in cognition, sensation, movement, stamina, disfigurement, and social stigma (Rolland, 2005a, 1987b, 1987c). The impact of stress placed on families varies, depending on the form and degree of incapacitation. Families with LQTS may perceive

varying degrees of incapacitation, depending on the daily restrictions that are placed on the individuals.

Time Phases of Illness. The function of this part of the Family System Illness Model is to guide families and clinicians into conceptualizing the illness in a longitudinal way. In doing this, families can view the illness as an ongoing process with landmarks, transitions, and evolving demands (Rolland, 2005a, 1987b, 1987c). Each phase of an illness places different demands on families. Three typical ways of distinguishing the different time phases of an illness are crisis, chronic, and terminal (Rolland, 2005a, 1987b, 1987c; Newby, 1996). The crisis time phase is made up of the period of time leading up to the diagnosis, the initial adjustment after the diagnosis, and treatment after the diagnosis. During this time, the members of the families must create the meaning of the illness and also mourn the loss of the families' life prior to the illness. Also during this time, the families must work on accepting the fact that the illness is a permanent fixture in the family system (Rolland, 2005a, 1987b, 1987c). The chronic time phase can range in length; it may be long or it may be short. This span of time ranges from after the initial diagnosis and initial adjustment period occurs, until the third phase of the illness occurs, which is the time when the illness becomes terminal, and death seems imminent (Rolland, 2005a, 1987b, 1987c). During the chronic time phase, the goals of the families are to maintain their newly adaptive life, including the chronic illness. In the terminal time phase of the illness, the imminent risk of death becomes the main focus for families. During this time the families are working through issues of separation, mourning, and rebuilding the family system after the loss (Rolland, 2005a, 1987b, 1987c).

An LQTS-specific model was developed, based on qualitative research (Gonzales, 2009) that is consistent with Rolland's Family System Illness Model. The LQTS model suggests incorporating the following five stages. The first stage incorporates the biological assimilation, and the impact of incorporating and comprehending LQTS. During this stage, the families and individuals spend time assimilating and adapting to the biological understanding and consequences of LQTS (Gonzales, 2009). During Stage Two, time is spent examining the families' and individuals' initial psychological and emotional reactions to the diagnosis. The third stage addresses the after effects of the initial reactions to the diagnosis and the evolving psycho-emotional states. In the fourth stage, families and individuals attempt to integrate LQTS into their social milieu (Gonzales, 2009). The final stage addresses the re-emergence of uncertainty within the families as they face the prospect of their child's future (Gonzales, 2009). Gonzales' model may be pertinent because many people with LQTS do not reach a terminal phase. Death is not imminent, although it is always a threat. Gonzales's model is helpful in understanding how people cope with life after a diagnosis of LQTS; however, Rolland's model is useful in understanding how the illness presentation influences the way that it is experienced within the family system.

Clinical Implications of the Model. Rolland's Family System Illness model is useful in assessing illnesses in order to shape clinical interventions. It aids families in defining the chronic illness in psychosocial terms. The timeline of the illness helps to structure the psychosocial stage of an illness and helps families to focus on the specific adjustment that each phase of the illness requires (Rolland, 2005a, 1987b, 1987c). The framework that this model provides is helpful in preparing families for psychosocial

changes that coincide with the transition points in the illness life cycle (Rolland, 2005a, 1987b, 1987c).

Family Functioning

Family systems theory and Rolland's (1987) family systems illness model support the fact that an illness entering a system impacts the family system as a whole; however, these models do not delineate exactly how the system is impacted. Another system theory model, The McMaster Approach to Families, provides a heuristic by which family functioning can be understood; it also aids in conceptualizing how illness may impact the family system. This model makes the assumption that family functioning cannot be fully understood by understanding each individual family member or subgroup (Miller, Ryan, Keitner, Bishop & Epstein, 2000b). It is also suggested that family structure and organization influence the behavior of the family members and that the patterns of interactions strongly shape the behavior of family members (Miller et al., 2000b). The McMaster Model focuses on six dimensions of family function which include problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control (Epstein, Lawrence, & Bishop, 1983; Miller et al., 2000a, 1994b).

Dimensions of Family Functioning-Problem Solving. According to the McMaster model, problem solving is defined as the family's ability to resolve problems in a way that maintains effective family functioning (Epstein et al., 1983; Miller et al., 2000a, 1994b). In this instance, a family problem is considered to be an issue for which the family has a difficult time finding a solution. Another characteristic of a problem according to this model is that it threatens the integrity and functional capacity of the family. Therefore, not everything is considered a problem. If the family is able to

maintain its typical functioning, then the issue that has risen is not identified as a problem (Epstein et al., 1983; Miller et al., 2000a, 1994b). Within the model, problems are further broken down into two groups: instrumental or affective. Instrumental problems are considered mechanical problems of everyday life; this may include such things as finances, employment, and housing. This is applicable to families who have children with LQTS because, for example, there may be more financial strain due to increased medical expenses. In addition, the parent of a child with LQTS may feel the need to be present during sporting and athletic activities away from or at school, as well as on field trips; this can create a difficulty for other children in the family and for the parents, relative to their employment. Affective problems are situations that arise and are related to feelings and emotional experiences (Epstein et al., 1983; Miller et al., 2000a, 1994b). With regard to LQTS, affective problems could apply both to the families and to the individuals diagnosed. There may be problems that arise, related to feelings and emotional experiences in processing the diagnosis within the families. Also, the daily restrictions that are placed on the children diagnosed may trigger more emotional situations for the children, if they feel "left out" or "different" from other children. There may also be increased feelings of anxiety or fear about experiencing a cardiac event, which would be considered an affective problem.

Communication. Communication is another dimension that is observed in the McMaster model. Communication is defined as the way information within the system is exchanged (Epstein et al., 1983; Miller et al., 2000a, 1994b). This dimension specifically focuses on verbal communication because it is difficult to interpret nonverbal communication without running the risk of misinterpretation (Epstein et al., 1983; Miller

et al., 2000a, 1994b). As with the problem solving dimension, communication is also divided in two groups: instrumental and affective (Epstein et al., 1983; Miller et al., 2000a, 1994b). Another area of communication that is assessed in this model is whether the communication is clear or vague and whether the communication is direct or indirect. When assessing if the communication is clear or if it is vague, the model determines how clearly the content of the message is being expressed. The directness or indirectness of the communication refers to whether or not the message is clearly directed to the person for whom it is intended (Epstein et al., 1983; Miller et al., 2000a, 1994b). This dimension is especially important when taking into consideration the decisions and changes that have to be made when children are diagnosed with LQTS. It is important that communication is effective among the couple subsystem and within the families in order to make the adjustments within the system more fluid. For example, if the children diagnosed are more symptomatic or have more restrictions, it is important for the couple to be able to communicate how they will follow the medical regimen and implement the restrictions so that it is consistent. For example, one parent may be comfortable allowing the child with LQTS1 to swim, as long as there is someone with the child and there is an AED close by; however, the significant other does not feel comfortable with this, and would rather the child engage in a different activity. The couple has to be able to communicate their concerns effectively and be able to compromise. It is also important for the families to be able to communicate openly and effectively with one another about the concerns or questions about LQTS, and how they experience or adjust to the medical condition.

Family Roles. Another dimension that is assessed in the McMaster model is family roles. Family roles are defined as the recurrent pattern of behavior within the family by which family members fulfill family functions (Epstein et al., 1983; Miller et al., 2000a, 1994b). These tasks can include routine activities such as cleaning, cooking, and taking out the garbage. This dimension is again divided into instrumental and affective areas, and then subdivided in two groups: necessary family functions and other family functions. Necessary family functions are considered tasks that the family must be repeatedly concerned with because it is crucial so their family system can function well (Epstein et al., 1983; Miller et al., 2000a, 1994b). These tasks can be instrumental, affective, or a combination of both. Other family functions are considered tasks that are not required for the family system to function well, but they are somehow part of the family system. Family roles can be greatly affected when a child has a medical condition. More responsibility could be placed on other members of the family to complete routine activities, or more responsibility may be placed on other members of the family to care for the individual who is diagnosed. For instance, if parents of a child with LQTS perceive the child as weak, fatigued, or limited in some ways (whether it is accurate or not), the child may have less responsibility than other siblings in taking out the garbage, doing outside yard work, or even walking the dog alone. In terms of LQTS-needs, a child may not need special day-to-day care, but there may be more tasks that are added to the day with regard to the medication regimen, or more responsibility to help that individual avoid specific triggers, communicate LQTS-related precautions or needs to child care providers or friends' families. In terms of the couple, family roles may be altered, depending on how the couple adjusts to a medical condition and who takes on the

role of the primary caretaker for the day-to-day changes that have to be made for the child.

Affective Responsiveness. The dimension of affective responsiveness refers to the ability of the family to respond to a range of stimuli with the appropriate quality and amount of feeling. Two main, quality areas that the model examines involve whether or not family members respond with a full range of feelings and whether or not the emotion experienced is appropriate for the stimulus and situational context (Epstein et al., 1983; Miller et al., 2000a, 1994b). In regard to the amount or quantity of feelings, the model considers the degree of response and whether it is considered non-responsive, under-responsive, or over-responsive, given the situation (Epstein et al., 1983; Miller et al., 2000a, 1994b). For example, parents may be overly cautious about upsetting a child with LQTS if they enforce consequences for not doing chores, or may protect the child with LQTS from physical chores more than they do for siblings.

Affective Involvement. Affective involvement is the dimension that focuses on the degree to which families as a whole show interest in and support the activities and interests of other members of the family. Within this area, close attention is paid to how much time family members spend supporting one another in these activities, including how much interest each one shows to other family members (Epstein et al., 1983; Miller et al., 2000a, 1994b). There is also a focus on how family members show this support and interest to one another. The quantity is not necessarily important in this case, but rather the degree of involvement, and how invested they are. This dimension may be affected negatively by an illness entering the system because time may be taken away

from these activities because of health-related restrictions, so the family may need to find other ways to show support.

Behavioral Control. The last dimension of this model is behavioral control. Behavioral control is defined as the pattern that families use for handling behavior in three types of situations: physically dangerous, situations that involve meeting and expressing psychological needs or drives, and situations that involve interpersonal socializing behavior (Epstein et al., 1983; Miller et al., 2000a, 1994b). In a physically dangerous situation, families would be needed to monitor and control the behavior that is occurring. For families with children diagnosed with LQTS, physically dangerous behaviors include anything that is restricted for their particular type of LQTS. One way to make these behaviors less dangerous is for families to have AEDs with them. For example, children with LQTS1 should not swim or hike alone, or engage in activities that may cause an adrenaline rush. Situations that meet psychological needs or drives refer to situations such as eating, drinking, sleeping, and sexual activity (Epstein et al., 1983; Miller et al., 2000a, 1994b). Again, for children with LQTS, some of these areas may be affected. Individuals are given dietary restrictions, such as avoiding chocolate due to the caffeine content, which could increase their heart rates (Rottlaender, Motloch, Reda, Larbig & Hoppe, 2012). Others are required to drink a certain amount of liquid a day in order to stay hydrated and maintain adequate blood pressure. It is particularly dangerous for children with LQTS to have low levels of electrolytes (Fitzgerald & Ackerman, 2005). Sleeping may be interrupted, depending on the children's medication regimen. The third situation regarding interpersonal socializing behavior includes behaviors

among family members and behaviors when interacting with individuals outside of the family system (Epstein et al., 1983; Miller et al., 2000a, 1994b).

Dysfunctional Transactional Patterns. The McMaster Model also addresses dysfunctional transactional patterns, in addition to the six dimensions that the model presents as key aspects to family functioning (Miller et al., 2000a). Dysfunctional transactional pattern refers to common interactions among family members that are related to impaired functioning within the family system (Miller et al., 2000a). Typically there is a function to these maladaptive interactions; one function may be to decrease anxiety within a subsystem at the expense of the family system as a whole. Maladaptive transactional patterns are not necessarily the direct cause of family dysfunction; however, there is an association between them. Typically for an improvement in family functioning, there must be a change in the dysfunctional interaction (Miller et al., 2000a). This is important to keep in mind when working with families with LQTS, because it could help to identify useful interventions to help the family work through and adjust to the diagnosis. For example, as mentioned previously, there may be different expectation within the home for the children diagnosed with LQTS. Some of these may be to reduce the risk of cardiac events, but some may be simply to reduce the anxiety within the families (families may restrict or be overly protective, beyond what is medically recommended, towards children with LQTS, out of fear, which could be detrimental to the children). It is important to study if demands of specific illnesses, such as LQTS, impact family functioning and couple satisfaction because illnesses present so differently, and these variables can be measured in so many different ways; therefore, results are hard to generalize.

Literature on Chronic Illness and Family Functioning. Previous research reports demonstrated varied results with regard to ways in which having children with a chronic illness impact family functioning; some of the variability may be due to the difference of the illnesses being studied. Variability may also be accounted for by the various measures and models that are used to assess family functioning. One study examined parental reports of family functioning across several different chronic pediatric conditions, as compared with parental reports from parents of healthy children, when controlling for statistically significant family variables (Herzer et al., 2010). The five illnesses that were examined in this study included cystic fibrosis, obesity, irritable bowel syndrome, epilepsy, and sickle cell disease. Results of the study indicated that group means on all Family Assessment Device dimensions fell below established cut offs for "unhealthy" functioning, meaning overall scores did not meet the "unhealthy" cut off. There were high percentages of families meeting clinical criteria for "unhealthy" family functioning on specific subscales (Herzer et al., 2010). Across all five chronic conditions 13% to 36% of families endorsed "unhealthy" levels of functioning, 36% falling within the roles dimension and the affective involvement dimension (Herzer et al., 2010). Also, 28% of families with chronic conditions perceived "unhealthy" family functioning in terms of communication. These results suggest that chronic illness alone may not affect overall generic family functioning. When looking at specific areas that make up family functioning, there was a subgroup of families that reported "unhealthy" functioning on certain dimensions, when compared with "healthy" controls (Herzer et al., 2010; Spieth et al., 2001).

Another study looked specifically at families that had children diagnosed with cancer (Streisand, Kazak, & Tercyak, 2003). Findings from this study showed that there were no differences reported with regard to family functioning when examining respondents' gender, age, race, marital status, education level, and household income. There were, however, differences when looking at whether or not the child was currently undergoing treatment (Streisand et al., 2003). Families whose children were still undergoing treatment reported more difficulty in all subscales of the Family Assessment Device except communication (Streisand et al., 2003). Both of these studies utilized the Family Assessment Device in order to measure family functioning, which is what will be used in the current study as well.

As stated previously, results on whether or not chronic illness impacts family functioning are varied, based on the many measures used to define family functioning and the illnesses that are being observed. One study evaluated 64 families who had children with juvenile rheumatoid arthritis, using the Family Environment Scale; they reported no significant differences when compared with 64 healthy family controls in levels of family functioning (Gerhart et al., 2003). The ages of the children ranged from 8 years old to 14 years old (Gerhart et al., 2003). Another study compared 24 families who had children with hemophilia with 12 healthy control families, using the Family Assessment Measure parent report to assess family functioning (Evans, Cottrell, & Shiach, 2000). All of the children in this study were male, and their ages ranged from 4 years old to 15 years old. Findings from this study did not show a difference in parent-reported levels of family functioning (Evans et al., 2000).

Measuring Couple Satisfaction

Revised Dyadic Adjustment Scale. There are various measures that examine couple satisfaction. The measure that the current study will be using is the Revised Dyadic Adjustment Scale (Busby, Christensen, Crane & Larson, 1995). This measure is based on the Dyadic Adjustment Scale which was created by Spanier (1976). The Revised Dyadic Adjustment Scale (Busby et al., 1995) is different from the Dyadic Adjustment Scale because it removes some of the homogenous and heterogeneous items that were on some of the subscales. In doing this, 7 first order scales were created; these were combined to create 3 second order concepts: consensus, satisfaction, and cohesion.

As with family functioning, it is important to examine if specific illnesses have an impact on couple satisfaction because findings from previous research vary. Again, this difference in results may be accounted for by examining the various constructs that define marital satisfaction and the demands of the illness that is being studied. One study explored the association between parents' perception of the negative impact of their child's chronic health condition and relative changes in marital satisfaction and depressive symptoms (Berge, Patterson, & Rueter, 2006). In this study, marital satisfaction was measured by the Locke-Wallace scale, which is a 16-item assessment that measures each partner's perception of marital satisfaction. Findings from this study showed that mothers' marital satisfaction at time 1 was associated with mothers' perceptions of the negative impact of their children's conditions and predicted relative decreases in their marital satisfaction over time (Berge et al., 2006). In comparison, the fathers' relative increases in marital dissatisfaction were not influenced over time by their perceptions of the negative impact of their children's conditions. This is consistent with

other research that has shown that fathers are less distressed by their children's conditions and are less likely to report adverse marital effects (Berge et al, 2006). This study suggests that the way the medical condition is perceived by the couple impacts marital satisfaction, particularly for mothers. With regard to LQTS, the increased risk of sudden death may contribute to a greater negative outlook of the medical condition, which the study suggests may negatively impact marital satisfaction.

Another study examined 66 married couples, half of whom had a child diagnosed with cystic fibrosis, and the other half who did not (Quittner, Espelage, Opipari, Carter, Eid, & Eigen, 1998). These families were assessed in terms of role strain, parenting stress, couples frustration with role expectation, a card sort looking at the division of tasks, a daily phone diary to monitor differences in division of household and child-care tasks, the Conflict over Child Rearing scale of the Marital Satisfaction Inventory, the Personal Assessment of Intimacy in Relationships questionnaire (PAIR), the Dyadic Adjustment Scale (DAS), and the Center for Epidemiological Studies Depression Scale (CES-D) (Quittner et al., 1998). Findings from this study revealed no group differences on the DAS, PAIR, CES-D, or the daily phone diary mood rating (Quittner et al., 1998). However, there were differences in regard to gender. Women in both groups reported higher intimacy than men on the PAIR and more symptoms of depression on the CES-D. The couples in the group with children that were diagnosed with cystic fibrosis reported higher role strain, as compared with the control group, but this did not seem to impact their marital satisfaction rating as measured by the DAS and PAIR (Quittner et al., 1998). This varies from what is expected to be found in the current study due to the constant uncertainty that parents of children with Long QT Syndrome face regarding symptoms

and prognosis. The current study is expecting to find a difference between groups because the mothers with children diagnosed with LQTS will report decreased marital satisfaction due to the increased demands placed on them when caring for a child with a chronic medical condition.

A more recent study examined aspects of coping with family crisis and individual states of distress in couples with a child diagnosed with multiple sclerosis, compared with couples of healthy children (Uccelli, Traversa, Trojano, Viterbo, Ghezzi, & Signori, 2013). This study included 15 couples with a child who had multiple sclerosis and 29 couples with healthy children. The couples were asked to complete the Maternal Worry Scale, the Four ENRICH Couple scales which assess couple satisfaction, couple communication, conflict resolution, and idealistic distortions, the Family Crisis Oriented Personal Evaluation scales (F-COPES), the Parenting Sense of Competence (PSOC) scale, the Hospital Anxiety and Depression Scale (HADS), the WHO-Five Well-being index, and the Multiple Sclerosis Knowledge Questionnaire (Uccelli et al., 2013). In regard to couple satisfaction, findings did not reveal a difference between groups, which suggests that the couples were able to maintain their relationship despite the diagnosis of multiple sclerosis.

Again, this varies from what is expected to be found in this study because it is expected that there will be a difference between groups. These differences may be accounted for by the difference in presentation of these two chronic conditions. For example, although Multiple Sclerosis is a progressive disease, the threat of sudden death is not present, which may contribute to findings of this study that show no difference in marital satisfaction. Also with MS there are not as many daily restrictions placed on an

individual at the time of diagnosis, such as the diet, exercise, and activity restrictions that are placed on individuals with LQTS. Another factor which may have impacted this study was that parents in both groups reported being together over 12 years; this suggests that having time to solidify the relationship before the diagnosis may have facilitated handling the challenge of parenting a chronically ill child (Uccelli et al., 2013). Examining whether or not couple satisfaction and family functioning are affected when a child is diagnosed with LQTS, research suggests that it is important to take into consideration how problem solving skills could influence how the family handles the illness because problem solving and coping have been found to be predictive of stress in populations in which outcome is uncertain, such as parenting oncology patients (Nezu, Nezu, Friedman, Faddis, & Houts, 1998). For the purpose of this study, the model set forth by D'Zurrilla, Nezu, and Olivares (2004) will be used to explain the aspects of social problem solving that are characteristics of coping.

Social Problem Solving

The way individuals and families solve problems in daily living is important to life satisfaction, and marital satisfaction. The families' and individuals' reactions to the stress and the coping mechanisms that are implemented impact the way the stressor is addressed and worked through, according to the relational model of stress. The social problem solving model acknowledges that life is filled with major and minor life stressors. A diagnosis of LQTS may be considered a major life stressor. The life modifications and management of the emotional aspects of living with a chronic medical condition can be considered minor problems (Nezu et al., 1998). How one handles them (adaptively or mal-adaptively, using adaptive problem solving skills or ineffective

problem solving skills) will greatly impact their overall level of distress, and thus, their marital distress or satisfaction (Nezu et al., 1998). For example, some individuals may have an avoidant problem solving style, which involves an individual reacting to a problem in a passive, dependent manner, or simply procrastinating in addressing the problem (D'Zurilla et al., 2004). These individuals have a tendency to wait for the problem to resolve itself or try to shift the responsibility of the problem to someone else (D'Zurilla et al., 2004). When looking at families with children diagnosed with LQTS, the child may be asymptomatic; this factor paired with a parent with an avoidant problem solving style, may put the child at an increased risk of engaging in activities that may be detrimental to his or her health because the parents are more passive.

Social problem solving refers to the process that takes place when an individual implements effective strategies for coping with problematic day-to-day living situations (D'Zurilla & Nezu, 1999a, 1982b). Within this model, a problem is defined as a life situation that demands a response for adaptive functioning, but an effective response is unknown to the individual or is not available to the individual because of one or more obstacles (D'Zurilla, Nezu & Maydeu-Olivares, 2004). The problem may be occurring presently or it may be an anticipated problem. The problem might occur in the environment or within the person; obstacles in resolving the problem may include ambiguity, performance skill deficits, and lack of resources (D'Zurilla et al., 2004; D'Zurilla & Nezu, 1999a). A problem could be a single time-limited event, a series of similar events, or an ongoing situation (D'Zurilla et al., 2004). A solution is defined as a situation-specific response pattern or a coping response that is the outcome of the problem solving process during a specific problematic situation (D'Zurilla et al., 2004;

D'Zurilla & Nezu, 1999a). An effective solution is one that changes the situation for the better, and resolves the conflict so that all parties are happy with the result (D'Zurilla et al., 2004; D'Zurilla & Nezu, 1999a).

Another important distinction that should be made when discussing social problem solving is the difference between problem solving and solution implementation. Problem solving is the behavior of finding solutions to specific problems. Solution implementation is the process of carrying out those solutions when the problematic situation is occurring (D'Zurilla et al., 2004; D'Zurilla & Nezu, 1999a). Another difference between these two concepts is that problem solving skills are considered general skills, whereas solution implementations typically vary, depending on the type of problem, and the type of solution (D'Zurilla et al., 2004; D'Zurilla & Nezu, 1999a).

Problem Orientation and Problem Solving Styles. When assessing the social problem solving process, there are two typical problem orientations that most individuals exhibit. These two approaches are referred to as a positive problem orientation, and a negative problem orientation (D'Zurilla et al., 2004). When an individual exhibits a positive problem solving orientation, he or she is more apt to view a problem as an opportunity for benefit or gain. These individuals are optimistic in their view of the problem and see it as something that can be solved, and believe in their ability to solve the problem. These individuals also have an understanding that solving a problem successfully takes time and effort, and are committed to the process of working through the problem, as opposed to avoiding the problem (D'Zurilla et al., 2004). In contrast, another problem orientation that an individual could have is a negative one. A negative problem orientation is typically viewed as a dysfunctional cognitive emotional outlook

that generally increases the likelihood that an individual will view the problem as a significant psychological, social, or economic threat to his or her well-being. These individuals would also be more likely to doubt their ability to solve the problem successfully, and may have the tendency to become frustrated when a problem arises (D'Zurilla et al., 2004).

In addition to having a positive or negative problem orientation, individuals also have a unique problem solving style. Three problem solving styles that are discussed in this model are rational problem solving, impulsivity-carelessness style, and avoidance style (D'Zurilla et al., 2004). An individual who exhibits a rational problem solving style is deliberate and systematic in implementing problem solving skills. The impulsivity-carelessness style of problem solving is an example of a dysfunctional problem solving pattern that is made up of an individual making impulsive, rushed, and careless attempts to apply problem solving strategies to the problems that are being experienced (D'Zurilla et al., 2004). These individuals often do not consider a large array of solutions and do not assess the solution or solution outcomes in an adequate manner (D'Zurilla et al., 2004). Another dysfunctional problem solving style is the avoidance style. This style of problem solving involves in an individual reacting to a problem in a passive, dependent manner, or simply in procrastinating in addressing the problem (D'Zurilla et al., 2004). These individuals have a tendency to wait for the problem to resolve itself or to try to shift the responsibility of the problem to someone else (D'Zurilla et al., 2004).

Dimensions of Social Problem Solving Ability. Social Problem Solving Theory is considered a multidimensional construct made up of several different stages (D'Zurilla et al., 2004). These stages represent a different skill or procedure which has a

specific function in the overall social problem solving process (D'Zurilla et al., 2004). The five dimensions of this model are problem orientation, problem definition and formulation, generation of alternatives, decision making, and solution implementation and verification (D'Zurilla et al., 2004; D'Zurilla Nezu, 1999a). The first dimension, problem orientation, is focused on reducing negative emotional states and negative thoughts that may hinder social problem solving thinking (D'Zurilla & Nezu, 1982b; D'Zurilla & Goldfried, 1971). During this stage the focus is also on identifying self-statements that will help facilitate effective problem solving (D'Zurilla & Nezu, 1982b). In order to begin effective problem solving, the individual must adopt a problem solving set which is made up of four components: identifying a problematic situation when it occurs, accepting the view that encountering problems is an inevitable part of life and that problem solving is a way of coping with them, the perception that the individual is capable of solving the problem, and the importance for the individual to "stop and think" instead of responding automatically to the problem (D'Zurilla & Nezu, 1982b).

The next stage of the model is problem definition and formulation. In this stage an individual assesses the problem, and identifies a realistic goal for problem solving (D'Zurilla & Nezu, 1982b). This is an important stage with regard to social problem solving because the better defined a problem is the more likely it is that relevant solutions can be generated, and that decision making will be improved (D'Zurilla & Nezu, 1982b; D'Zurilla & Goldfried, 1971). Within this stage, there are four main steps that take place. The first step is to gather all the information about the problem and to try to define the problem in concrete terms. The next step is to differentiate between relevant information and information that does not pertain to the situation or that is not verified to be factual

(D'Zurilla & Nezu, 1982b; D'Zurilla & Goldfried, 1971). Next the individual has to identify the factors that are causing the event to be problematic. After this, the individual should identify a realistic goal and identify the desired outcome. The second aspect of this dimension is the formulation of the problem. This step is designed to help the individual to understand the problem so that relevant solutions can be formulated. Although there are many types of problematic situations, there are four common categories into which most situations can be placed: aversive, loss of reinforcement, frustration, and conflict (D'Zurilla & Nezu, 1982b). Aversive problematic situations are defined as situations that are characterized by a threat or punishment. A situation that is considered a loss of reinforcement involves a change in environment, which creates an absence of an expected reinforcement. Problematic situations that are considered frustrating are characterized by the situation involving some sort of obstacle which prevents the individual or group from achieving the desired goal (D'Zurilla & Nezu, 1982b). Last, there are problematic situations that are classified as a conflict. Within this group there are interpersonal conflicts or personal conflict. An interpersonal conflict occurs when one person's behavioral expectations do not match another person's behavioral expectations. A personal conflict occurs when an individual has conflicting internal messages or conflicting demands from the environment which cause distress (D'Zurilla & Nezu, 1982b). Formulation of the problem leads to the specification of a problem solving goal.

The third dimension of the social problem solving model is the generation of alternatives. The purpose of this stage is to create as many solution alternatives as possible. In creating many alternatives, the likelihood that the best solution is within

those choices is increased (D'Zurilla & Nezu, 1982b; D'Zurilla & Goldfried, 1971). In order to accomplish this, it is important for individual to use two techniques: brainstorming and strategy-tactics procedures. When brainstorming, it is important for individuals to defer judgment and to adopt the thinking that quantity breeds quality (D'Zurilla & Nezu, 1982b; D'Zurilla & Goldfried, 1971). The idea behind this is that an individual is able to generate more high quality solutions if he or she postpones evaluating the response until later in the problem solving sequence (D'Zurilla & Nezu, 1982b; D'Zurilla & Goldfried, 1971). The concept behind the strategy-tactic approach is that an individual will increase the probability of finding the best solution when he or she considers a variety of approaches in handling the problem. Strategy refers to the overall course of action; tactic refers to the steps that describe how the plan is implemented (D'Zurilla & Nezu, 1982b; D'Zurilla & Goldfried, 1971).

The fourth dimension of this model is decision making. The goal of this stage is to evaluate the solution alternatives and identify the most effective one (D'Zurilla & Nezu, 1982b; D'Zurilla & Goldfried, 1971). The concept of decision making utilizes the model of human choice; it is believed that effectiveness of an alternative is based upon how likely it is that the alternative will produce the desired outcome (D'Zurilla & Nezu, 1982b; D'Zurilla & Goldfried, 1971). In considering the consequences of the solution, there are four general dimensions that are evaluated: short term, long term, personal, and social impacts.

The final dimension of this model is solution implementation and verification. The goal of this stage is to verify the real life usefulness of the chosen solution. At this stage, the problem is considered to be solved, but the effectiveness of the solution in

dealing with the real-life problematic situation has not been proven (D'Zurilla & Nezu, 1982b). In order to evaluate the solution, it must be implemented and the outcome must be analyzed in a function similar to that done in a behavioral analysis. This process is broken down into four steps: performance, observation, evaluation, and reinforcement (D'Zurilla & Nezu, 1982b). The performance step is focused on implementing the chosen solution in the real-life problem situation. The observation step requires the individual to attend to and measure the solution outcome as well as the consequence. In the evaluation step, the individual compares the observed outcome with the desired outcome; if the results are satisfactory the individual can proceed to the final step, which is reinforcement. During the reinforcement stage, the individual rewards himself or herself for completing the process and finding an effective solution (D'Zurilla & Nezu, 1982b).

The theory of social problem solving, suggests that people with more effective problem solving skills are generally better at coping with major life events and daily problems (Nezu et al., 1998). Mothers' perceptions of marital satisfaction and family functioning may vary, based on effectiveness of social problem solving. Research has shown that there is a positive correlation between individuals who have a higher level of social problem solving skills and how they rank their satisfaction in these two areas. One study specifically examined the relationship between dysfunctional relationships beliefs, problem solving responses, and satisfaction in close relationships (Metts & Cupach, 1990). Findings demonstrated that the problem solving responses of exit and neglect, which were identified as dysfunctional, were negatively associated with relational satisfaction. Along with this, voice, which was defined as discussing problems and using

problem solving techniques, was positively associated with relational satisfaction (Metts & Cupach, 1990). Numerous studies have confirmed that better social problem solving skills, which include characteristics such as open communication and positive interactions, as well as some of the skills presented in the social problem solving theory, are positively related to marital satisfaction (Markman, 1981; Johnson et al., 2005).

In addition to social problem solving skills influencing an individual's perception of marital satisfaction, they also affect the perception of family functioning. Research that measures reports of family functioning are limited; however, studies have indicated that increased social problem solving skills decrease negative affectivity. One study specifically compared the reports of negative affectivity of mothers whose children were recently diagnosed with cancer, who were given eight sessions of problem solving training with those mothers who received usual psychosocial care (Sahler et al., 2005). This study revealed the effectiveness of social problem solving skills on decreasing negative affect with regard to a child's illness. Another study examined a family member's social problem skills in relation to depression and life satisfaction in individuals diagnosed with congestive heart failure (Kurylo, Elliot, DeVivo, & Dreer, 2004). Findings of this study indicate that family caregivers' problem solving abilities are important factors in adjustment following congestive heart failure (Kurylo et al., 2004). Specifically, these findings showed that a negative problem solving orientation was saliently related to reports of depression (Kurylo et al., 2004). Overall, results from numerous studies have established that adaptive coping causes less stress and those individuals with better social problem solving skills are better able to cope, overall, when compared with individuals that lack social problem solving skills.

Conclusion

Long QT syndrome, which is a condition that occurs as a result of a disturbance in the electrical function of the heart, is a chronic illness that carries a high risk of sudden death (SADS Foundation, 2012). It is important to raise awareness and learn more about the impact of this condition because of its lethality. The current research suggests that the impact a chronic illness has on reports of marital satisfaction and family functioning is varied. This variation can be due to the differences in symptom presentation from one medical condition to another; results from one medical condition cannot be generalized to another medical condition (Barlow & Ellard, 2006; Taylor, Fuggle & Charman, 2001). Few studies to date have examined family functioning in individuals with LQTS. The social problem solving model suggests that the way individuals and families solve problems in daily living impacts their ability to cope, which is important to life satisfaction and marital satisfaction (Nezu et al., 1998). Studies of family functioning and marital satisfaction need to control for this variable. Further research needs to be done in order to identify specific areas of overall family functioning and marital satisfaction affected by this chronic illness because it is expected to have psychosocial effect on individuals, due to the numerous restrictions that are placed on individuals who are diagnosed (Lane, Reis, Peterson, Zareba, & Arthur, 2009). This is important research to conduct in order to identify specific areas within families that are impacted by the illness so that services can be developed to address those areas of concern.

Chapter 2

Research Question

Are there differences in perceptions of relationship satisfaction and family functioning when comparing perceptions of mothers of children with Long QT Syndrome with perceptions of mothers who do not have child with a chronic or life threatening physical condition or psychological condition requiring school accommodations, while controlling for variability in social problem solving skills?

Hypotheses

The following research hypotheses are proposed:

Hypothesis 1: When controlling for variability in social problem solving skills (SPSI-R total score), mothers with children diagnosed with Long QT syndrome will report lower relationship satisfaction (as defined by the following subscales on the Dyadic Adjustment Scale: dyadic satisfaction, dyadic cohesion, and consensus on matters of importance to dyadic functioning), when compared with the reports of mothers that do not have children diagnosed with Long QT or any chronic or life threatening physical condition or psychological condition requiring school accommodations.

Hypothesis 2: When controlling for variability in social problem solving skills (SPSI-R total score), mothers with children diagnosed with Long QT syndrome will report lower family functioning (as defined by problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control), when compared with the reports of mothers that do not have children diagnosed with Long QT or any chronic or life threatening physical condition or psychological condition requiring school accommodations.

Chapter 3

Method

Design and Design Justification

This study employed a between groups cross sectional case control design and is considered observational research. The control group was formed by matching the number of children in the family, including the child with the diagnosis of Long QT Syndrome in order to control for the effects of having multiple children versus just one child, and how that would impact a mother's perception of family functioning and relationship satisfaction. The sample for the control group came from the general population, and was recruited through social media and use of the snowball method.

A case control design was used to examine whether or not there were differences between perceptions of relationship satisfaction and family functioning when comparing mothers of children with Long QT Syndrome with mothers who do not have a child with a chronic or life threatening physical condition or psychological condition requiring school accommodations, while controlling for variability in social problem solving skills. A case control study can provide critical insight into the experience of these two groups (Kazdin, 2003). This particular design was chosen because it was well suited for studying conditions that are relatively infrequent in the population, such as particular diseases (Kazdin, 2003). Another strength of this design was that it was efficient in terms of resources and time because it was a cross sectional assessment (Kazdin, 2003). This design also allowed for matching which equalized the subjects on one or more of the variables assessed. A limitation to this study design was that no timeline was able to be

shown among the variables, so the investigator was unable to establish whether one characteristic preceded the other or if they emerged together (Kazdin, 2003).

Participants

Recruitment. Participants for this study were recruited through multiple venues. There were 48 participants in each group. Postings of the study were placed on the Sudden Arrhythmia Death Syndrome website under their research posting tab (http://www.sads.org/research/Research#.Uu_TIPldVrN). The investigator joined the "Long QT Syndrome Support and Learning Community"; "LQTS Kids & Families for Anyone Affected by Long QT Syndrome"; "Long QT Syndrome 1,007"; "Long QT Strong"; "Living with Long QT Syndrome (support group)"; "LQTS1-Long QT Syndrome Type 1"; "Life with Long QT Syndrome"; "LQTS3-Long QT Syndrome Type 3"; "Long QT Syndrome (& other SADS conditions)"; "Yahoo! Long QT Syndrome Support"; "LQTS5-Long QT Syndrome Type 5", and the "20-something with Long QT Syndrome" Facebook groups in order to gather participants by posting a letter of recruitment on these pages. Participants were also recruited from Yahoo user groups including the Cardiac Rhythm Disorders; Sensitive Hearts LQT Chat; Long QT Syndrome; Long QT and Heart Arrhythmias. Participants from prior LQTS research studies from the current research group were contacted via email with a research study announcement. Finally, individuals were recruited from other social media outlets by posting on websites such as twitter. Recruitment for the control group was open to the general public; participants were recruited through social media and the use of the snowball method. Participants were given the opportunity to be entered in a drawing with a 1 in 10 chance of winning a $10 gift card to Walmart or Target.

Inclusion Criteria. Participants included in this study were mothers of a child under the age of 18 who is diagnosed with Long QT syndrome. They were in a one partnered relationship since before the initial diagnosis of Long QT syndrome and were cohabiting. There was also no physical, emotional, or sexual abuse in the partnered relationship. The participants were English speaking and be able to read and understand English and resided within the United States.

Exclusion Criteria. Those excluded from the study included mothers that were in multiple partnered relationships since the initial diagnosis of Long QT syndrome and were not currently cohabiting with their partners. Individuals in physical, emotional, or sexually abusive relationships also were excluded from participating, as were individuals with cognitive impairments or the inability to read.

In order to screen for the inclusion/exclusion criteria, the requirements to participate in the study were listed on the recruitment announcement. Demographic information was collected from most participants (some did not complete questionnaire). This information included but was not limited to the age and race of the participants, the number of children in the family, the age of the child with Long QT syndrome diagnosis, whether all the children were biologically related, the number of years that the mother had been in the relationship with her partner, whether there was ever any abuse in the relationship, defined as physical, sexual, or emotional harm imposed on the mother by her partner or vice-versa. Information was also collected about whether the parent has also been diagnosed with Long QT syndrome.

Control Group Inclusion. The control group was composed of mothers with the same number of children as the families identified who had a child diagnosed with Long

QT syndrome. The child could not have a chronic or life threatening physical condition or psychological condition requiring school accommodations. The mothers were in a single-partnered relationship and were cohabiting with their partners. The individuals were fluent in spoken and written English, and resided in the United States. The mothers also had to deny current involvement in a physically, emotionally, or sexually abusive relationship.

Control Group Exclusion. Participants not included in the control group were mothers that were in multiple partnered relationships and were not cohabiting with their partners. Individuals in physical, emotional, or sexually abusive relationships are also excluded from participating, as were mothers with cognitive impairments or the inability to read and understand English. Finally, mothers who had a child with any chronic or life threatening physical condition or psychological condition requiring school accommodations were also excluded.

Potential Risks to Participants. A potential risk to the participants was emotional discomfort due to the personal nature of some of the questions on the questionnaire.

Protective Factors. All data were collected anonymously and given a number for organizational purposes.

Measures

Personal Information Questionnaire. This questionnaire was used to collect descriptive information both from the Long QT participants and from the control group participants. This information included the age and race of the participants, general information about region of the country in which participant resides, the age of the child

with Long QT syndrome diagnosis, number of children in the family, general information about the mother's relationship (i.e. length, status of relationship (married, cohabitating etc.), safety within relationship). Medical history with regard to child and parent diagnosed with Long QT Syndrome was also collected (i.e. time of diagnosis, symptomatic vs. asymptomatic, treatment regimen etc.). The questionnaire was originally created by the Long QT Research team at the Philadelphia College of Osteopathic Medicine. The researcher added items to the measure to gather more information and modified the measure by removing questions about Long QT Syndrome for the control group only. The Personal Information Questionnaire included 45 items for participants with children diagnosed with Long QT Syndrome, and who were also diagnosed with Long QT Syndrome. Participants who had only the child diagnosed with Long QT Syndrome had 34 items to answer because the medical questions pertaining to the mother's diagnosis were removed. Control group participants had 21 items included in their Personal Information Questionnaire because medical questions about Long QT Syndrome were not included.

Revised Dyadic Adjustment Scale. The Revised Dyadic Adjustment Scale (RDAS) was used in this study in order to measure adjustment in relationships (Busby et al., 1995). This measure is based on of the Dyadic Adjustment Scale which was created by Spanier (1976). The Dyadic Adjustment Scale is used to assess marital adjustment and evaluates four dimensions of a couple's relationships. The dimensions that are observed are the consensus on matters of importance to marital functioning, dyadic satisfaction, dyadic cohesion, and affectional expression (Busby et al., 1995). Dyadic adjustment is defined as a process whose outcomes are determined by the amount of

troublesome dyadic differences, interpersonal tensions, and personal anxiety (Spanier, 1976). In addition to these factors, dyadic adjustment is also determined by the degree of dyadic satisfaction, dyadic cohesion, and consensus on matters of importance to dyadic functioning (Spanier, 1976). The Revised Dyadic Adjustment Scale (Busby et al., 1995) is different from the Dyadic Adjustment Scale because it removed some of the homogenous and heterogeneous items that were on some of the subscales. The RDAS is a 14-item self-report measure. It is made up of three subscales which include Dyadic Consensus subscale, Dyadic Satisfaction subscale, and Dyadic Cohesion subscale (Busby, Christensen, Crane, & Larson, 1995). The responses of this measure are rated on a 5-point Likert scale, ranging from 0 = Always Disagree to 5 = Always Agree for items 1 through 6. Items 7 through 10 utilize a different Likert scale ranging from 0 = All the Time to 5 = Never. Item 11 has its own Likert scale ranging from 0 = Never to 4 = Every Day. Items 12 through 14 utilize a Likert scale that ranges from 0 = Never to 5 = More Often. Scale scores of 48 and above represent non-distressed dyads and a score of 47 and below indicate distress (Crane, Middleton, & Bean, 2000).

Internal consistency as measured by Cronbach's Alpha was found to be $\alpha = .90$ (Busby et al., 1995). When measuring Guttman split half reliability and Spearman-Brown Split-Half reliability, the RDAS measured .94 for Guttman and r_s=.95 for Spearman Brown (Busby et al., 1995). When examining the criterion validity of this measure, which considers how successful an instrument is at predicting some important outcome such as being a distressed or non-distressed dyadic group, results showed that the RDAS, as compared with the Dyadic Adjustment Scale (DAS) was able to correctly classify 81% of cases (Busby et al., 1995). A discriminant analyses with the subscales of

the RDAS revealed the standardized discriminant coefficients for Consensus, Satisfaction, and Cohesion subscales to be .34, .55, and .32, respectively, meaning that the Satisfaction subscale had a larger influence on the discriminant ability of the RDAS as compared with the other two scales (Busby et al., 1995).

McMaster Family Assessment Device-Version 3. The McMaster Family Assessment Device Version 3 (FAD) is a 60-item self-report instrument developed to assess six dimensions of family functioning (Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990). These six dimensions include Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, and Behavior Control. In addition, the FAD included a General Functioning scale which assessed overall health pathology (Kabacoff et al., 1990). The responses for this measure are rated on a 4-point Likert Scale ranging from Strongly Agree (SA) to Strongly Disagree (SD). The FAD is scored by summing the endorsed items for each subscale and dividing by the number of items in each scale (Miller et al., 2000). Negatively worded items were reversed. The individual scale scores ranged from 1.0 which is considered best functioning to 4.0 which is considered worst functioning (Miller et al., 2000). This measure was tested in large clinical, nonclinical and medical samples; intended for completion by anyone over 12 (Kabacoff et al., 1990; Miller et al., 2000). Completion time for this measure is estimated to be about 20 minutes.

When examining internal consistency as measured by Cronbach's alpha, the General Functioning scale ranged from $\alpha = .83$ to $\alpha = .86$ in non-clinical, psychiatric, and medical families (Kabacoff et al., 1990). The Problem Solving scale ranged from $\alpha = .74$ to $\alpha = .80$; Communication ranged from $\alpha = .70$ to $\alpha = .76$; Roles ranged from $\alpha = .57$ to

α = .69; Affective Responsiveness ranged from α = .73 to α = .70; Affective Involvement ranged from α = .70 to .78, and Behavior Control Ranged from α = .70 to α = .73 (Kabacoff et al., 1990).

Social Problem Solving Inventory –Revised-Short Form. The Social Problem Solving Inventory-Revised-Short Form (SPSI-R-S) is a self-report instrument that assessed individuals' abilities to resolve problems in their everyday lives (D'Zurilla et al., 2002). The measure is made up of 25 items and uses a Likert-type scale format ranging from 0 = Not at all true of me to 4 = Extremely True of Me. Reliability evidence for the SPSI-R was generated using internal consistency and test-retest data. Internal consistency data were collected using four normative samples specifically adolescents, young adults, middle adults, and elderly adults. The alpha coefficients ranged from .60 to .95, with most falling in the .80 or higher range (D'Zurilla et al., 2002). Concurrent validity data were reported, comparing the SPSI-R with the Problem Solving Inventory (Heppner & Peterson, 1982); correlations ranged from .33 to .75 which indicates that the SPSI-R met adequate standards of concurrent validity with an instrument used to measure social problem-solving skills. Scoring for this measure yields five standardized scaled scores. A raw score is calculated for each subscale by adding all the items from that subscale. For the Negative Problem Orientation, Impulsivity/Carelessness Style, and Avoidance Style scales, each raw score is subtracted from 20 and then divided by 5. For the Positive Problem Orientation and Rational Problem Solving scales, each raw score is divided by 5. In order to get the Total SPSI-R: S Raw Score take the sum of the numbers that are derived from each subscale being divided by 5. Higher Total scores indicate more constructive or effective problem solving. Lower scores indicate more defective or

dysfunctional problem solving. Completion time for this measure is estimated to be about 10 minutes.

Procedure

Data Collection. An announcement for recruitment describing the purpose of the study was posted on multiple online sources. These sources included the Sudden Arrhythmia Death Syndrome website; "Long QT Syndrome Support and Learning Community"; "LQTS Kids & Families for Anyone Affected by Long QT Syndrome"; "Long QT Syndrome 1,007"; "Long QT Strong"; "Living with Long QT Syndrome (support group)"; "LQTS1-Long QT Syndrome Type 1"; "Life with Long QT Syndrome"; "LQTS3-Long QT Syndrome Type 3"; "Long QT Syndrome (& other SADS conditions)"; "Yahoo! Long QT Syndrome Support"; "LQTS5-Long QT Syndrome Type 5", and the "20-something with Long QT Syndrome", the Yahoo user groups including the Cardiac Rhythm Disorders, Sensitive Hearts LQT Chat, Long QT Syndrome, Long QT and Heart Arrhythmias, and other social media outlets such as Twitter (Appendix A). Participants of previous LQTS studies were also notified via email with the announcement for recruitment. The control group was recruited from the general public; participants were recruited through social media and the use of the snowball method. The announcement had a link to the Survey Monkey page for the individual to click on if they chose to participate (Appendix A). A consenting screen appeared, which led the participants to screens presenting the inclusion criteria for the study (Appendix A). After consenting and agreeing to participate, the participants began to complete the measures. After the measures were completed, participants were asked to complete the Personal Information Questionnaire (Appendix B) in order to provide the investigator with more

descriptive information. Participants were not specifically recruited based on race and ethnicity, religious affiliation, or other individual characteristics, however, for practical reasons, information on these characteristics was collected and described. It was hoped that internet-based recruitment would allow for recruitment of a heterogeneous sample.

On the internet survey site, the first measure that appeared was the Social Problem Solving Inventory-Revised, followed by the Family Assessment Device, and the Revised Dyadic Adjustment scale. After completing these measures, the participants were asked to fill out the Personal Information Questionnaire. After completing all measures, participants were given the opportunity to be entered in a drawing with a 1 in 10 chance of winning a $10 gift card to Walmart or Target. If the participant wanted to be entered into the drawing, they were asked to email lqtstudies@pcom.edu. On this same page, information regarding LQTS resources was displayed. When data collection was complete, the winners of the drawing were notified. The data collected on Survey Monkey were downloaded into SPSS. Data were collected without identifiers. IP addresses that downloaded into SPSS with the study data were deleted and were not used to obtain participants' identities.

Chapter 4

Statistical Plan

A power analysis was conducted in order to identify how many participants would be needed in the study for adequate power. The effect size was set at .2 which is between a small and medium effect size (Cohen, 1992). It was estimated that 44 participants would be needed in each group to see a difference, if one existed. Descriptive statistics using means, standard deviation, and Pearson-product correlations were provided to describe the participants and their personal characteristics. This information was collected from the Personal Information Questionnaire and the dependent variables. Normative comparative scores obtained from the test manuals are provided for interpretation.

Hypothesis 1: A Multiple Analysis of Covariance (MANCOVA) was used to analyze the data. The independent variable in this study was child diagnosis and there were two levels: a child diagnosed with Long QT Syndrome, and a child not diagnosed with a chronic or life threatening physical condition or psychological condition requiring school accommodations. The dependent variables that were studied included: dyadic satisfaction, dyadic cohesion, and consensus on matters of importance to dyadic functioning. The Bonferroni correction was utilized in order to control for a Type I error. In order to reduce error terms and eliminate the effect that social problem-solving skills may have on reports of Marital Satisfaction, Social Problem Solving was controlled as a covariate. Prior to conducting a MANCOVA, the assumptions were tested and it was determined that they were not violated.

Hypothesis 2: A Multiple Analysis of Covariance (MANCOVA) was used to analyze the data. The independent variable in this study was child diagnosis and there were two levels: a child diagnosed with Long QT Syndrome, and a child not diagnosed with a chronic or life threatening physical condition or psychological condition requiring school accommodations. The dependent variables that were studied included: problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control. The Bonferroni correction was utilized in order to control for a Type I error. To reduce error terms and eliminate the effect that social problem solving skills may have on reports of Family Functioning, Social Problem Solving was controlled as a covariate. Prior to conducting a MANCOVA, the assumptions were tested and were determined not to be violated.

Chapter 5

Results

LQTS Study Population

Data were collected from 342 participants; of those 342 participants, who clicked on the survey link, 155 were in the LQTS group and the remaining 187 were in the control group. Within the LQTS group (N=155), 50 completed the survey in its entirety and provided information regarding number of children in the family, so that they could be matched. Of those 50 participants, 48 were matched with the control group for number of children in the family. The control group had 187 participants click on the survey link; of those 187 participants. 68 completed the survey in its entirety and provided information regarding number of children in the family, so that they could be matched. Of those 68 participants, 48 were matched with the LQTS group for number of children in the family.

Ages of participants in the LQTS group ranged from 25 years old to a maximum age of 51; the mean age for participants was 40 years old with a standard deviation of 5.86. Of the 50 participants, 40 reported their ages. Therefore, ten ages were imputed using series means. It was necessary to impute ages to calculate SPSI-R: S standard scores, which have age-based norms. Interpretations of SPSI-R: S standard scores, therefore, are made with caution. The range for the number of children in a family for the LQTS group was a minimum of 1 child and a maximum number of 7 children. Average number of children living in the home was 2 with a minimum number of 1 child and a maximum number of 4 children with a standard deviation of .912.

Within the LQTS group, of the 39 participants who completed the data, 94.9% of participants identified as female (n=37); 5.1% participants identified as male (n=2). The two participants that identified as male were included in the study because inclusion criteria for the study did not specify that participants who were "mothers" had to be females." When asked how these 39 participants identified with regard to race, they replied as follows: 89.7% Caucasian (n = 35), 2.6% African American (n = 1), 2.6% Hispanic (non-white) (n = 1), 2.6% Native American (n = 1), and 2.6% Multiracial (n = 1). All participants spoke English (n = 39). Refer to Table 1a and Table 1b for information regarding residential area and region of the country in which participants lived.

Table 1a. Residential Area of LQTS Participants

Residential Area	n	Percentage
Farm	1	2.6
City	11	28.2
Rural	3	7.7
Suburban	24	61.5
Total	39	100

Table 1b. Region of the Country where LQTS participants lived

Region of the Country	n	Percentage
Northeast	11	28.2
South	8	20.5
Midwest	11	28.2
West	9	23.1
Total	39	100

Participants in the LQTS group were asked if they had previously participated in any other lqtstudies@pcom.edu research; 20.5% of 39 said yes (n = 8). With regard to relationship status, 92.3% of participants identified as married (n = 36), 2.6% as divorced (n = 1), and 5.1% as cohabitating (n = 2). All participants were heterosexual (n = 39; 100%). Please see Table 2 for information regarding length of participants' current relationships.

Table 2- Length of Current Relationship of LQTS Participants

Length of Relationship	n	Percentage
0-5 years	2	5.13
6-10 years	6	15.38
11-15 years	7	17.95
16-20 years	8	20.51
21-25 years	14	35.91
26-30 years	1	2.56
31-35 years	1	2.56
Total	39	100

Ages of the children in the family ranged from 1 year of age to 25 years of age. The child diagnosed with Long QT syndrome had to fall within a school-age range, which was defined as kindergarten (5 years of age) to 18 years old in order for the individual to be able to participate. Four of the 39 participants reported the family experiencing a loss of a child after birth (10.3%). Circumstances surrounding these deaths include a stillborn baby; the suspected cause of death was a heart defect, an 11 year old died from undetected LQT2; a baby died at birth and the suspected cause of death was LQTS, a 20 week old baby died from hypo plastic left heart syndrome. With regard to other people in the home, other than the 7.7% of participants who reported having grandparents in the home (n = 3), all of the families had a nuclear composition. Thirty-two participants reported that all the children in the family were biologically related (82.1%). The participants who reported that the children were not related stated that the children had different fathers (n = 1); they had a son before they were married and spouse had a son (n = 1), oldest son is adopted by father but biological by mother (n = 1), one child is adopted (n = 1) same mother but different fathers (n = 1). Two participants did not disclose more descriptive information regarding this question.

Table 3 describes length of time since the child/children had been diagnosed with Long QT syndrome. Table 4a shows the type of LQTS with which the child is diagnosed; Table 4b shows how many children are symptomatic, and Table 4c shows how frequently the child/children LQTS symptoms occur.

Table 3. How long ago child/children were diagnosed with Long QT Syndrome

Time from Diagnosis	n	Percentage
0-5 years	21	53.85
6-10 years	12	30.77
11-15 years	6	15.38
Total	39	100

Table 4a. Type of LQTS Child is Diagnosed with

Type of LQTS	n	Percentage
LQTS 1	20	42.55
LQTS 2	12	25.53
LQTS 3	6	12.77
LQTS 4	1	2.13
LQTS 5	1	2.13
LQTS 6	0	0
LQTS 7	0	0
Unidentified Gene	4	8.51
Other	3	6.38
Total	47	100

*Due to multiple children being diagnosed in a single family n is greater

Table 4b How many children are symptomatic

Symptomatic	n	Percentage
Yes	14	35.9
No	19	48.7
I have multiple children with LQTS with varying presentations	6	15.4
Total	39	100

Table 4c. Frequency of LQTS Symptom Occurrence

How Frequently Symptoms Occur	n	Percentage
Multiple Children Are Diagnosed	8	20.5
Never	20	19.4
Weekly	1	1.0
Monthly	4	3.9
Yearly	6	5.8
Total	39	100

The participants, who selected that multiple children in the family are diagnosed, provided information for each child with regard to how often their symptoms occur. These eight participants described symptoms occurring rarely (n = 5), weekly in the past but not at all within the year (n = 1), one child having symptoms multiple times a year but the other has no symptoms (n = 2). Table 5 shows How Many Events in Total Child/Children have had.

Table 5. Total Number of Events

How Many Events in total (fainting, arrest) has your child/children had	n	Percentage
Multiple Children Diagnosed	6	15.4
0	13	33.3
1 or 2	13	33.3
3 or 4	3	7.7
5 or 6	2	5.1
7 or more	2	5.1
Total	39	100

The participants who selected that multiple children in the family had been diagnosed provided information for each child with regard to how many total events the child/children have had. These six participants described 1 fainting for one child and multiple seizures for another child (n = 1); multiple "cardiac effusions" and seizures for one child and one fainting for the other (n = 1); one child having more symptoms in the morning if getting out of bed quickly (n = 1); over 2 dozen events for one child and no events for the other (n = 1); multiple events for one child and none for the other (n = 2). Please see Table 6a for information relative to whether or not the child/children have a pacemaker or implantable cardioverter defibrillator (ICD) and Table 6b for information on whether or not the child/children are on medication.

Table 6a. Do your child/children have a pacemaker or ICD?

Do child/children have pacemaker or ICD?	n	Percent
Multiple Children Diagnosed	9	23.1
ICD	3	7.7
Both	3	7.7
Neither	24	61.5
Total	39	100

Table 6b. Do your child/children take medication?

Do child/children take medication for LQTS?	n	Percent
Multiple children diagnosed	10	25.6
Yes	26	66.7
No	3	7.7
Total	39	100

Participants who indicated that multiple children in the family were diagnosed with LQTS (n = 9) relative to whether the child/children had a pacemaker or ICD provided the following information. One child had a pacemaker and the other child did not have a device at all (n = 2); both have ICD's (n = 2); both children have no devices (n = 2); one child has both devices and the other child has nothing (n = 1); one child has an ICD; the other had the device removed (n = 1), and one responded that the child used to have a device but had it removed (n = 1). Participants who responded that there are multiple children with LQTS with regards to medication (n = 10) provided information about the specific medication children were taking; of the ten participants who had multiple children diagnosed, eight responded that all children were on medication and specified which medications and two participants responded that one child was and one child was not on medication.

When asked how many of the participants themselves were diagnosed with LQTS, 21 of the participants replied in the affirmative, saying that they also were diagnosed with LQTS (53.8%), and 18 stated that they were not diagnosed with LQTS (46.2%). Please see Table 7a for information regarding how long participant has been diagnosed with LQTS; Table 7b for information regarding the type of LQTS that participant was diagnosed with; Table 7c for information regarding whether or not they are symptomatic, and Table 7d for information regarding how frequently cardiac events occur.

Table 7a. How long participant has been diagnosed with LQTS

Time from Diagnosis	n	Percentage
0-5 years	8	38.1
6-10 years	7	33.33
11-15 years	5	23.81
16-20 years	1	4.76
Total	21	100

Table 7b. Type of LQTS Participant is diagnosed with

Type of LQTS	n	Percentage
LQTS 1	13	61.90
LQTS 2	4	19.05
LQTS 3	3	14.29
LQTS 4	0	0
LQTS 5	0	0
LQTS 6	0	0
LQTS 7	0	0
Unidentified Gene	1	4.76
Other	0	0
Total	21	100

Table 7c. Is participant symptomatic?

Symptomatic	n	Percentage
Yes	7	33.3
No	14	66.7
Total	21	100

Table 7d. How frequently cardiac events occur

How Frequently Symptoms Occur	n	Percentage
Never	12	57.1
Weekly	1	4.8
Monthly	4	19.0
Yearly	4	19.0
Total	21	100

Table 8a shows how many participants have a pacemaker or ICD, and Table 8b shows how many take medication for their LQTS.

Table 8a. Do you have a pacemaker or ICD?

Do you have pacemaker or ICD?	n	Percent
Both	6	28.6
Neither	15	71.4
Total	21	100

Table 8b. Do you take medication for LQTS?

Do you take medication for LQTS?	n	Percent
Yes	12	57.1
No	9	42.9
Total	21	100

Please see Table 9 for information regarding household income range for participants.

Table 9. Household Income Range LQTS Participants.

Household Income Range	n	Percent
$5,000-$20,000	2	5.13
$21,000-$40,000	6	15.38
$41,000-$60,000	4	10.26
$61,000-$80,000	4	10.26
$81,000-$100,000	4	10.26
Above $100,000	19	48.71
Total	39	100

Control Study Population

Ages of participants in the control group ranged from 25 years old to a maximum age of 56; (M = 38 years; SD = 8.004). Forty-seven of 48 participants reported their ages; one age was imputed using series means. It was necessary to impute this age to calculate SPSI-R: S standard scores, which have age-based norms. Interpretations of SPSI-R: S standard scores, therefore, are made with caution. The Range for the number of children in a family for the Control group was a minimum number of 1 child and a maximum number of children as (n = 66). Average number of children living in the home was 2 with a minimum number of 1 child and a maximum number of 7 children and a standard deviation of 1.196.

Within the Control group, of the 48 participants who completed the data, 100% of participants identified as female (n = 48). When asked how these 48 participants identified with regard to race, 91.7% were Caucasian (n = 44); 6.3% were Hispanic (non-white) (n = 3), and 2.1% were Multiracial (n = 1). All participants reported being English

speaking 100% (n = 48). Refer to Table 10a for information regarding residential area and Table 10b for information regarding region of the country in which participants lived.

Table 10a. Residential Area of Control Group Participants

Residential Area	n	Percentage
Farm	1	2.1
City	9	18.8
Rural	6	12.5
Suburban	31	64.6
Other (specified beach)	1	2.1
Total	48	100

Table 10b. Region of the Country where Control Group participants lived

Region of the Country	n	Percentage
Northeast	38	79.2
South	3	6.3
Midwest	3	6.3
West	4	8.3
Total	48	100

With regard to relationship status, 75.0% of participants identified as married; 2.1% were divorced; 2.1% were widowed, and 20.8% were cohabitating. The two participants who identified as widowed and divorced were included because they can identify in that way, but continue to be in a current single partnered cohabitating relationship, which would mean they would meet inclusion criteria to participate. In terms of sexual orientation, 95.8% of participants identified as heterosexual, and 4.2% bi-

sexual. Please see Table 11 for information regarding length of participant's current relationship.

Table 11- Length of Current Relationship Control Group

Length of Relationship	n	Percentage
0-5 years	9	18.75
6-10 years	11	22.92
11-15 years	8	16.67
16-20 years	5	10.41
21-25 years	8	16.67
26-30 years	5	10.41
31-36 years	2	4.17
Total	48	100

Ages of the children in the family ranged from 3 months of age to 23 years of age. Participant was matched as long as one child fell within a school-age range which was defined as kindergarten (5 years of age) to 18 years old. None of the participants reported the family experiencing the loss of a child after birth. With regard to other people in the home, 2.1% of participants reported having grandparents and their daughter's boyfriend in the home (n = 1); 97.9% reported no people other than their children in the home (n = 47). Forty-four participants reported that all the children in the family were biologically related (91.7%). The participants who reported that the children were not related stated that the children were either step-sibling (n = 2), half-sibling (n = 1), or the children were adopted (n = 1). Three participants reported that their child has been diagnosed with a chronic or life threatening physical condition or psychological condition requiring school

accommodations (n = 3; 6.3%); the remainder of the participants replied " No" to this question (n=45; 93.8%). Two of these participants referred to these diagnoses in past tense and identified them as lung disease from having been born prematurely, and as Asperger's Syndrome. The other participant stated that one child has ADHD. These participants were included in the study because they referred to diagnosis in past tense and they had previously answered "no" to this question as part of the criteria to participate. Please refer to table 12 with information regarding Yearly Household Income Range for the control group.

Table 12. Yearly Household Income Range Control Group

Household Income Range Control Group	n	Percent
$5,000-$20,000	1	2.1
$21,000-$40,000	1	2.1
$41,000-$60,000	4	8.3
$61,000-$80,000	12	25.0
$81,000-$100,000	13	27.1
Above $100,000	17	35.4
Total	48	100

Dependent Variables

The Revised Dyadic Adjustment Scale was completed by 127 participants; of those participants, 48 were matched in each group. Please see Table 13 for information regarding the LQTS group, and control group, mean, and standard deviations of the scores on the subscales of this measure and the total scores, compared with clinical and non-clinical samples. Lower scores on this measure indicate greater distress. Scores on

the Consensus subscale of the Revised Dyadic Adjustment scale ranged from a 5.0 to 30.0, which show variability in the sample. Average scores in the LQTS Group and Control group fell either right at the cutoff of 22 or just above, indicating non-distress (Crane et al., 2000). Please refer to table 13 for score information. Scores on the Satisfaction subscale ranged from a .00 to 20.0. Average scores in the Control Group fell above the cutoff of 14, indicating non-distress. Average scores in the LQTS Group fell just under the cut-off indicating slight distress (Crane et al., 2000). Please refer to table 13 for further information. Scores on the Cohesion Subscale ranged from 1.0 to 19.0, showing variability in responses within the sample. Average scores for the Control Group were slightly over the cut-off, 11, indicating non-distress. Average scores in the LQTS Group on this subscale, on average, were just under an 11, indicating slight distress (Crane et al., 2000). Please refer to table 13 for further score information. For the Revised Dyadic Adjustment Total, scores ranged from 8.0 to 64.0, showing variability in responses. On average, the Control group scores fell slightly above the cutoff of 48, which indicates non-distress in the total sample and Control Group. On average, the LQTS Group fell just slightly below the cut-off of 48, which may indicate slight distress. Please refer to table 13 for score information.

Table 13. Revised Dyadic Adjustment Scale Scoring Means & Standard Deviations LQTS Group, Control Group Compared to Clinical and Non-Clinical Sample Mean Scores & Standard Deviations

	LQTS Group (n = 49)		Control Group (n = 48)		Non-Clinical Population (Non-Distressed) (n = 240)		Clinical Population (Distressed) (n = 114)	
	X	SD	X	SD	X	SD	X	SD
RDAS Total Score	47.0612	9.80520	50.5625	7.50576	52.3	6.5	41.6	8.2
RDAS Consensus Subscale	22.3878	4.21217	23.6809	3.53936	24.2	3.1	20.1	3.9
RDAS Satisfaction Subscale	13.8571	3.94757	15.4894	2.70163	15.7	2.2	12.2	3.1
RDAS Cohesion Subscale	10.8163	3.71749	11.3617	3.20615	12.4	2.8	9.3	3.3

The Family Assessment Device was completed by 132 participants; of those participants, 48 were matched in each group. Please see Table 14 for information regarding the LQTS Group and Control Group mean, and standard deviations of the scores on the subscales of this measure and the total scores. On this measure, a score of 1 is considered healthy and a score of 4 is considered unhealthy. Scores greater than or equal to the cut-off score means unhealthy functioning in the dimension. Scores on the FAD Problem Solving Subscale ranged from a 1.17 to a 4. Average scores in the LQTS Group, and Control Group were below the cutoff score of 2.20, which means that, on average, healthy functioning was reported (Ryan, Epstein, Keitner, Miller, & Bishop,

2005). Scores on the FAD Communication Subscale ranged from a 1.00 to a 4. Average scores in the LQTS Group, and Control Group were below the cutoff score of 2.20, which means, on average, healthy functioning was reported (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). Scores on the FAD Roles Subscale ranged from a 1.36 to a 3.45. Average scores in the LQTS Group, and Control Group were below the cutoff score of 2.30, which means on average healthy functioning was reported (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). Scores on the FAD Affective Responsiveness Subscale ranged from a 1.00 to a 3.83. Average scores in the LQTS Group, and Control Group were below the cutoff score of 2.20, which means, on average, that healthy functioning was reported (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). Scores on the FAD Affective Involvement Subscale ranged from a 1.00 to a 4. Average scores in the LQTS Group, and Control Group were below the cutoff score of 2.10, which means that, on average, healthy functioning was reported (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). Scores on the FAD Behavior Control Subscale ranged from a 1.00 to a 3.44. Average scores in the LQTS Group and Control Group were below the cutoff score of 1.90, which means that, on average, healthy functioning was reported (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). Scores on the FAD General Functioning Scale ranged from a 1.00 to a 3.83. Average scores in the LQTS Group, and Control Group were below the cutoff score of 2.00, which means that, on average, healthy functioning was reported (Ryan, Epstein, Keitner, Miller, & Bishop, 2005).

Table 14. Family Assessment Device Scoring Means & Standard Deviations LQTS Group, Control Group, Comparative Scores

	LQTS Group (n = 49)		Control Group (n = 47)		Non-Clinical Population (N = 627)		Medical Population (N = 298)	
	X	SD	X	SD	X	SD	X	SD
FAD Problem Solving	1.9150	.48007	1.8830	.37897	1.91	.40	1.95	.45
FAD Communication	2.0363	.40022	1.9551	.37477	2.09	.40	2.13	.43
FAD Roles	2.1391	.42886	2.0754	.32630	2.16	.34	2.22	.39
FAD Affective Responsiveness	1.9252	.47515	1.7979	.46617	2.08	.53	2.08	.53
FAD Affective Involvement	1.8857	.44907	1.7617	.47847	2.00	.50	2.02	.47
FAD Behavior Control	1.6077	.44334	1.4965	.32753	1.94	.44	1.84	.42
FAD General Functioning	1.7857	.46802	(n= 48) 1.6181	.39644	1.84	.43	1.89	.45

The Social Problem Solving Inventory - Revised Short Form was completed by 144 participants; of those participants, 48 were matched in each group. Please see table 15 for information regarding LQTS group and control group mean, and standard deviations of the scores on the subscales of this measure, and the total scores. When interpreting standard scores for this measure, scores ranging from 55 or lower are considered “Extremely Below Norm Group”; 56-70 is considered “Very Much Below Norm Group Average”,; 71-85 is considered “Below Norm Group Average”; 86-114 is

considered to be the “Norm Group Average”; 115-129 is considered “Above Norm Group Average”; 130-144 is considered “Very Much Above Norm Group Average”, and 145 and above is considered “Extremely Above Norm Group Average (D’Zurilla et al., 2002). Average standard scores on all subscales for the LQTS Group and Control Group fell within the Norm Group Average Range.

Table 15. SPSI-R Short Form Scoring Means, Standard Deviations, and Ranges LQTS Group & Control Group

	LQTS Group (n = 49)				Control Group (n = 48)			
	Min	Max	X	SD	Min	Max	X	SD
SPSI-R:S Total Standard	70	135	102.8163	14.88382	77	128	(n = 47) 104.9787	11.96824
PPO Standard Score	47	131	101.2653	15.92270	58	127	100.9375	13.33593
NPO Standard Score	77	145	100.5510	16.80161	80	135	97.0208	12.54183
RPS Standard Score	58	132	101.8980	13.50346	72	136	102.1042	13.72409
ICS Standard Score	73	158	94.6939	18.73967	73	119	92.7292	13.07058
AS Standard Score	78	145	98.7959	15.74799	78	131	95.2708	11.74143

A T-test using 2 groups and the SPSI-R: S Total Score was run in order to identify if there was a significant difference between groups on social problem solving because the study was controlling for this. The main effect of the covariate, which for this study was social problem solving, according to Pillai’s trace was not significant between the LQTS group and the Control Group. (*F (1, 95) = .457, p = .807).*

Hypotheses

To determine if the dependent variables are correlated, a Pearson product-moment correlation coefficient was calculated. When looking at correlations, a larger number value indicates a stronger correlation. A positive correlation indicates that both variables increase on their respective scales together. A negative correlation indicates that as one variable increases, the other variable decreases. There was a positive correlation between the two variables RDAS Consensus and SPSI-R: S Total Standard r = .217, n = 96, p = .033. A negative correlation was found between the RDAS Satisfaction variable and the FAD Affective Involvement variable r = -.252, n = 97, p = .013. A negative correlation was also found between the RDAS Cohesion scale and the FAD Behavior Control scale r = -.251, n = 97, p = .013. All of these correlations were significant at the .05 level. A positive correlation was found between RDAS Satisfaction scale and the SPSI-R: S Total Standard Score r = .334, n = 96, p = .001. A positive correlation was also found between the RDAS Cohesion scale and the SPSI-R: S Total Standard r = .250, n = 96, p = .008. Both of these correlations were significant at the .01 level. A negative correlation at the .01 level was found between all the subscales of the Family Assessment Device and the SPSI-R:S Total Standard Score the correlations were as follows : FAD Problem Solving r = -.358, n = 96, p = .000, FAD Communication r = -.416, n = 96, p = .000; FAD Roles r = -.406, n = 96, p = .000; FAD Affective Responsiveness r = -.334, n = 96, p = .001; FAD Affective Involvement r = -.435, n = 96, p = .000; FAD Behavior Control r = -.591, n = 96, p = .000.

A Multiple Analysis of Covariance (MANCOVA) was conducted to assess if there were differences in reports of dyadic satisfaction, dyadic cohesion, and consensus

on matters of importance to dyadic functioning when controlling for social problem solving between the LQTS Group and the Control Group participants. None of the assumptions for the MANCOVA was violated. A significant effect was found when evaluating the contribution of Social Problem Solving on the dependent variables, Pillai's Trace = .133, F (3, 91) = 4.664, p = .004. However, there was not a significant difference on RDAS subscales of cohesion, satisfaction, and consensus between groups when social problem solving was controlled for, Pillai's Trace = .050, F (3, 91) = 1.609, p = .193. Further analysis of the between subjects effects showed that Social Problem Solving has a significant effect on all RDAS subscales: RDAS Cohesion F = 4.186, p = .044,; RDAS Satisfaction F = 10.968, p = .001; RDAS Cohesion F = 7.004, p = .010. Please see Table 16 for information regarding group means and standard deviations on each of the RDAS subscales.

Table 16. Group Means and Standard Deviations on RDAS Subscales Compared to Norm Group

	LQTS Group (n = 49)		Control Group (n = 47)		Non-Clinical Population (Non-Distressed) (n = 240)		Clinical Population (Distressed) (n = 114)	
	M	SD	M	SD	X	SD	X	SD
RDAS Total Score	47.0612	9.80520	50.5625	7.50576	52.3	6.5	41.6	8.2
RDAS Consensus	22.3878	4.21217	23.6809	3.53936	24.2	3.1	20.1	3.9
RDAS Satisfaction	13.8571	3.94757	15.4894	2.70163	15.7	2.2	12.2	3.1
RDAS Cohesion	10.8163	3.71749	11.3617	3.20615	12.4	2.8	9.3	3.3

A Multiple Analysis of Covariance (MANCOVA) was conducted to assess if there were differences in reports of family functioning on problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control when controlling for Social Problem Solving between the LQTS Group and the Control Group participants. None of the assumptions for the MANCOVA was violated. A significant effect was found when examining the contribution of Social Problem Solving (Total Standard Score) to the dependent variables, Pillai's Trace = .376, F (6, 88) = 8.836, p = .000. There was not a significant difference between groups on the FAD problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control between groups when social problem solving was controlled for: Pillai's Trace = .026, F (6,88) = .395, p = .880. Please see Table 17 for information regarding group means and standard deviations on each of the FAD subscales. Further analysis of the between subject effects showed that Social Problem Solving had a significant effect on all FAD subscales: FAD Problem Solving F = 13.524, p = .000; FAD Communication F = 18.940, p = .000; FAD Roles F = 17.894, p = .000; FAD Affective Responsiveness F = 11.178, p = .001; FAD Affective Involvement F = 21.010, p = .000, and FAD Behavior Control F = 49.016, p = .000.

Table 17. Group Means and Standard Deviations for FAD Subscales Compared to Norm Groups

	LQTS Group (n = 49)		Control Group (n = 47)		Non-Clinical Population (N = 627)		Medical Population (N = 298)	
	X	SD	X	SD	X	SD	X	SD
FAD Problem Solving	1.9150	.48007	1.8830	.37897	1.91	.40	1.95	.45
FAD Communication	2.0363	.40022	1.9551	.37477	2.09	.40	2.13	.43
FAD Roles	2.1391	.42886	2.0754	.32630	2.16	.34	2.22	.39
FAD Affective Responsiveness	1.9252	.47515	1.7979	.46617	2.08	.53	2.08	.53
FAD Affective Involvement	1.8857	.44907	1.7617	.47847	2.00	.50	2.02	.47
FAD Behavior Control	1.6077	.44334	1.4965	.32753	1.94	.44	1.84	.42
FAD General Functioning	1.7857	.46802	1.6181	.39644	1.84	.43	1.89	.45

Chapter 6

Discussion

Clinical Implications. When comparing mean scores on the Social Problem Solving Inventory Revised Short Form with the normative population, both the LQTS group and the Control group fell within average group norm range for all subscales. This means that the sample has average problem solving skills, and on average, can identify problems and generate solutions. As previously discussed, the way individuals and families solve problems in daily living is important to life satisfaction, and marital satisfaction. Every family experiences major and minor life stressors; how adaptively or mal-adaptively they approach the problem and work through it using problem solving skills will greatly affect their overall level of distress, and thus, their marital distress or satisfaction as well (Nezu et al., 1998). Therefore, average problem solving skills in this population may have contributed to participants not identifying as distressed because most participants had adequate problem solving skills to navigate through what they may identify as problematic situations.

Consensus scores on the Revised Dyadic Adjustment in the LQTS Group and Control group indicated non-distress. Scores on the Satisfaction subscale for the Control Group indicated non-distress; however, in the LQTS group, average scores indicated slight distress according to the criteria offered by the standardized measure. The LQTS group scores were not significantly different from the control group. The Cohesion scale scores of the Control Group indicated non-distress; however, the LQTS Group indicated slight distress. The mean score of the LQTS group was higher, as compared with the mean score of the normative clinical sample, indicating less distress than the normative

clinical sample. According to scores of the Revised Dyadic Adjustment Total, the Control group scores on average indicated non-distress. On average, the LQTS Group fell just below the cut-off, indicating slight distress. Overall, there were no significant differences between groups on the RDAS subscales.

The FAD Problem Solving Subscale, FAD Communication Subscale, FAD Roles Subscale, FAD Affective Responsiveness, FAD Affective Involvement Subscale, and the FAD Behavior Control Subscale indicated average healthy functioning in the LQTS Group, and Control Group. Similarly, the total FAD General Functioning Scale the LQTS Group and Control Group indicated on average healthy functioning across groups.

The hypotheses for this study, that mothers with children who are diagnosed with LQTS would report lower relationship satisfaction and lower family functioning , as compared with mothers of children who are not diagnosed with any chronic or life threatening physical condition or psychological condition requiring school accommodations, were not supported.

There were no significant differences found between groups on mothers' perception of relationship satisfaction or family functioning when controlling for variability in social problem solving skills (SPSI-R: S total score). This may be the case because often, the challenges that parents of children with LQTS face are the same as those that other parents face; parenting is the daily stressor; LQTS acts as an added stressor rather than its being the sole stressor. Therefore, every family may have different added stressors, which may be the reason why there were no significant differences found between the groups. Parenting on its own may be stressful, regardless of other compounding variables such as an illness.

The data gathered were helpful in supporting the fact that differences in problem solving contribute to perceptions of relationship satisfaction and family functioning, not the diagnosis of LQTS. It was understood that individuals with different problem solving approaches may cope differently when a chronic illness enters the family system, which is the reason why that factor was controlled. Coping is frequently defined as the way one responds to stress (D'Zurilla & Chang, 1995). As previously discussed, problem solving is a self-directed cognitive behavioral process through which an individual tries to identify effective and adaptive ways of coping with a difficult situation. It is a way to systematically approach and respond to problems (D'Zurilla & Chang, 1995). It appears that coping with a situation includes the use of problem solving (D'Zurilla & Chang, 1995). Decreased problem solving ability is related to the use of maladaptive coping strategies (D'Zurilla & Chang, 1995). For example, investigations of the impact that problem solving may have on coping with a medical illness found that individuals who scored higher on the impulsivity/carelessness style reported decreased control of their asthma and decreased quality of life (McCormick, Nezu, Nezu, Sherman, Davey, Collins, 2014). This correlation could be due to the fact that often health related behaviors and decision making may require systematic planning in order to implement and follow appropriate steps. Individuals who react impulsively to a situation or are careless in how they respond may have difficulties following through with many of the demands of a chronic illness. In regard to other medical conditions, individuals receiving rehabilitation after a stroke, and those who reported higher depression scores, also reported lower values on health related quality of life; however, these individuals reported higher use of

emotion-oriented coping, negative problem orientation, and avoidance style (Visser, Jeijenbrok-Kal, Spijker, Oostra, Busschbach, Ribbers, 2015).

Therefore, it may be helpful to offer workshops that provide education about problem solving styles and approaches in order to increase coping and contribute to resilience of families. Studies have shown a relationship between resiliency and problem solving. One study explored the Resiliency Model of Family Stress and Adjustment by McCubbin & McCubbin (1993) (Hall, Neely-Barnes, Graff, Krcek, Roberts, Hankins, 2012). This framework examines how parents experience both the stress and benefits of having a child with a disability (Hall et al., 2012). This model begins with the illness stressor, the impact of the stressor, which is impacted by family's vulnerability. Within this portion of the framework, it is important to identify resistance resources, which include communication, patterns of functioning, and supports (Hall et al., 2012). Another important aspect is the family's appraisal of the illness, which includes a definition of the illness and illness related difficulties, and this works simultaneously with the resistance resources which leads to family problem solving and coping. The next step is to use problem-solving and coping strategies to organize the problem into manageable components and maintain emotional stability (Hall et al., 2012). When examining non-stressed parent profiles, they reported the use of coping and solving problems by educating family members and planning for the future (Hall et al., 2012). It has been found that cognitive factors impact how one experiences emotional disturbances and how people deal with social problems (Rutter, 1993). It is important to recognize this relationship in order to provide resources and interventions designed to enhance social problem solving (Rutter, 1993). Problem solving skills have shown to be effective in

handling stresses and its challenges (Rutter, 1993). This is important to study because the way in which the chronic illness is experienced in the family (the way the family copes and/or problem solves) can affect the overall health of the individual diagnosed.

In examining problem solving therapy it is important to identify the objectives of time of treatment. When working with individuals from a problem solving approach specific treatment objectives include increasing positive problem orientation, decreasing negative problem orientation, facilitating planned problem solving, and minimizing avoidant and impulsive/careless problem solving (Nezu, Nezu & D'Zurilla, 2013). In working with individuals, there are four major components that clinicians focus on teaching. These components are considered the "problem solving tool kits" (Nezu et al, 2013). The first component is Problem-Solving Multitasking. Within this toolkit individuals are taught three strategies which include: externalization, visualization, and simplification. Externalization involves displaying the information that is in your mind (Nezu et al., 2013). For example, this may be done by writing down the information, drawing diagrams, and audio recording the information. This strategy helps to allow the individual to focus to a greater degree on better understanding the problem rather than focusing on remembering all the information pertaining to the problem (Nezu et al., 2013). The second strategy is visualization. This skill emphasizes visual imagery in order to positively impact the problem solving process. This may include such things as problem clarification, imaginal rehearsal, and stress management. The third strategy is simplification. This step focuses on breaking down complex problems in order to make them more manageable (Nezu et al., 2013).

The second component of problem solving therapy is the SSTA Method

With this method, individuals are taught to Stop, Slow Down, Think, and Act (Nezu et al., 2013). Within this tool kit individuals are taught to stop when identifying an emotional reaction that can potentially turn into a negative response. Individuals are also taught various ways that to "slow down". After the individual is able to "slow down" he or she is taught to think more carefully and with specific planning, about how to proceed and then the individual can act (Nezu et al., 2013). The third component focuses on healthy thinking and positive imagery. The final component focuses on planful problem solving. This toolkit teaches individuals the four important skills of planful problem solving which include: problem definition, generation of alternatives, decision making, and solution implementation and verification (Nezu et al, 2013).

The personal information that was collected from the Personal Information Questionnaire was used as a way to address other variables that may explain how the participants answered the questions and also to see if there was more stress in one group versus another. The goal of this study was to begin narrowing down and identifying if families with children with LQTS are reporting lower functioning and relationship satisfaction, and if so where the problems are being reported; however ,this study found that there were no difference between these families.

Limitations. There were several limitations to the current study. For the purpose of this study, only mothers' perception of family functioning was evaluated, which may not give a full depiction of a given family's dynamics. Another limitation pertained to the internal validity of this study. There are many potentially confounding variables that may have accounted for how the individual rated marital satisfaction and family functioning in addition to the constructs assessed in this research. Although

efforts were made to control for some of these confounding variables, it was not possible to account for all of them. For example, research has identified the fact that children of different developmental ages may create different family dynamics; however, it would be difficult to match for age of children and number of children within the household, given the scope of this research. Another limitation to this study was that there was a sample bias; this was due to the fact that we excluded mothers who were in multiple relationships.

Another limitation was this study's reliance on recruitment from the internet. The researchers were unable, therefore, to confirm either the identity of participants, or the validity of a diagnosis of LQTS in the respondent's family. Furthermore, recruiting solely from the internet created a selection bias because only individuals who are able to use the internet and have access to computers were able to participate. In this study, there was a small yield of participants who clicked on the survey link and actually completed the survey in its entirety. In order to increase the number of participants who completed the survey, perhaps participants could be permitted to return to the survey at a later time to complete it. Because of the way in which the survey was designed, participants were not allowed to continue once the window was closed. In addition, the survey could be condensed so that it would require less time and increase the likelihood of having it completed in one sitting. In addition, participants consisted of individuals who belonged to LQTS groups on social media sites or of individuals who search for LQTS information, versus individuals who do not utilize the internet in this way. Participants may have had a stronger LQTS identity and this may have contributed to the fact that they coped better with the diagnosis. New research suggests that individuals that

participate in internet support groups experience increased confidence in knowledge about their health and treatment options (Griffiths, Mackinnon, Crisp, Christensen, Bennett, Farrer, (2012); Rotondi, Anderson, Haas, Eack, Spring, Ganguli et al., (2010)). These individuals also experience an increased feeling of control of their illness, reduced social isolation, and decreased psychological distress (Griffiths et al., (2012); Rotondi et al, (2010)). Because most LQTS participants were recruited through social media groups, their participation in these groups may account for reasons why there was not a significant difference in perception of relationship satisfaction and family functioning. Furthermore, persons experiencing LQTS who are more stressed or have poor coping styles or skills may not participate in a study that takes time away from their efforts to manage their lives otherwise. Therefore, the sample may represent well-functioning LQTS mothers, rather than mothers of children with LQTS, as a whole.

Recruiting solely from the internet may also have created a possible bias against diversity, given the fact that individuals who are of lower socio-economic status may not have computers or access to the internet in their home. That being said, a majority of the participants in the study reported higher socio-economic status which may have contributed to decreased distress. Another limitation was that participants were not specifically selected for variance in individual characteristics, but it was hoped that there was heterogeneity in the sample. Given that the study design is cross sectional and that information is gathered at one point in time, only a snapshot of the families' functioning was obtained; it might be beneficial to view a chronic illness in a longitudinal manner.

Future Research. Future research could examine father's perception of family functioning and marital satisfaction. Also, it would be beneficial for a longitudinal

approach to be taken in order to understand changes over time and measure how adjustments are made. Future research could also be conducted to examine if there is a difference in family functioning and relationship satisfaction in families that have one individual diagnosed with LQTS, as compared with families with multiple LQTS diagnoses. Future studies could also explore how people cope as couples, rather than simply identifying whether or not they do. Additionally, future research could utilize a more specific family functioning measure which could be more useful in identifying distress in families.

Conclusion. Long QT Syndrome is an important chronic illness, worthy of study. Affected families experience numerous life changes. Although findings from this study did not indicate clinically significant difference between the LQTS participants and control group participants, it is important to further explore this topic. Results on the Revised Dyadic Adjustment Scale indicated slight distress in certain areas for the Long QT participants. Further research utilizing more specific measures may be helpful in identifying specific areas related to dyadic coping and also to adjustment for intervention for this population.

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Appendix A

Recruitment Announcement

Relationship Satisfaction & Family Coping

Mothers of children with Long QT Syndrome are needed to participate in a study!

You can help us learn about LQTS if you:

- Live with your child under the age of 18 who has LQTS

- Are in an adult, committed/partnered relationship

- Have 30 minutes to complete online questionnaires about thoughts, feelings, and behaviors relating to relationship satisfaction and family functioning.

- Can read and write English
- Live in the United States

Study participation is ANONYMOUS. After completing the questionnaires participants will be given the opportunity to be placed in a random drawing with a 1 in 10 chance to win a $10 gift certificate to Walmart or Target.

This study is being led by Stephanie Felgoise, Ph.D., ABPP and Karen Gentis, MFT, at the Philadelphia College of Osteopathic Medicine (PCOM) in collaboration with Vicki Vetter, MD, at the Children's Hospital of Philadelphia.

To participate, please click on the following link:
https://www.surveymonkey.com/s/Relationship_Family_Study

To ask questions about the study, please email the study team at lqtstudies@pcom.edu.

Recruitment Announcement for Control Group

Relationship Satisfaction & Family Coping

Mothers of children who are not diagnosed with a chronic or life threatening physical condition or psychological condition requiring school accommodations are needed to participate in a study!

You can help us learn about relationship satisfaction and family coping if you:

- Live with your child under the age of 18 who is not diagnosed with a chronic or life threatening physical condition or psychological condition requiring school accommodations

- Are in an adult, committed/partnered relationship

- Have 30 minutes to complete online questionnaires about thoughts, feelings, and behaviors relating to relationship satisfaction and family functioning.

- Can read and write English
- Live in the United States

Study participation is ANONYMOUS. After completing the questionnaires participants will be given the opportunity to be placed in a random drawing with a 1 in 10 chance to win a $10 gift certificate to Walmart or Target.
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To participate, please click on the following link:
https://www.surveymonkey.com/s/Relationship_Family_Study

To ask questions about the study, please email the study team at lqtstudies@pcom.edu.

Twitter Recruitment Announcement

LQTS Group Post:

Mothers w/child w/LQTS needed for study on relationship satisfaction &family coping

https://www.surveymonkey.com/s/Relationship_Family_Study

Control Group Post:

Mothers w/healthy child needed for study on relationship satisfaction&family coping

https://www.surveymonkey.com/s/Relationship_Family_Study

Twitter posts are required to be 140 characters including spaces

Consent Screen (for Survey Monkey)

By answering the following questions, I am giving my consent to use the information provided for research purposes. I understand the information is ANONYMOUS, and cannot be linked to me in any way, and will be combined with other people's answers. I also have the choice to stop answering questions at any time.

Please Choose One of the following:

□ I am a mother of a school-aged (kindergarten and above) child under the age of 18 who is diagnosed with Long QT Syndrome.

□ I am a mother of a school-aged (kindergarten and above) child under the age of 18 who is not diagnosed with Long QT Syndrome

By clicking on the designated group participant were sent to yes/no questions addressing each inclusion criteria

Appendix B

Personal Information Questionnaire

Age of Participant:

Gender: ☐ Male ☐ Female

Which group best describes how you identify yourself?

☐ Native American

☐ Asian (includes Pacific, South, Southeast, and North)

☐ Black

☐ Hispanic (Nonwhite)

☐ White

☐ Middle Eastern

☐ Multiracial

Primary Language:

Which residential area of the choices below best describe where you live?

☐ Farm

☐ City

☐ Rural

☐ Suburban

☐ Other (please specify) _____

What region of the country do you live in?

☐ Northeast

☐ South

☐ Midwest

☐ West

Have you previously participated in any lqtstudies@pcom.edu research? ☐ Yes

☐ No

Sexual Orientation:

☐ Heterosexual ☐Homosexual ☐Bi-sexual ☐ Questioning ☐C

specify) _____

Relationship status:

☐ Single ☐Married ☐Widowed ☐Divorced ☐Cohabiting

If married, please specify if this is your first marriage_____

How long have you been in your current relationship? _____

With regards to your current relationship: has there ever been any physical, emotional, or sexual abuse in the relationships? If so, please specify

☐Yes_____

_____

_____

_____

☐ No

How many children are in the household?

_____

What are the ages of the children in the household?

_____

Are any of the children diagnosed with any other major life illnesses (not including LQTS)? If so, please specify

☐Yes_____

_____

_____

_____

☐ No

Has the family experienced a loss of a child (after birth)? If so, please briefly explain the circumstances

☐Yes_____

_____

_____

_____

☐ No

Is there anyone else living in your household? If so, please specify

☐Yes_____

_____

_____

_____

☐ No

Are all the children biologically related? If not, please specify

☐Yes

☐No_____

_____

_____

_____

How old is child who is diagnosed with Long QT Syndrome? _____

How long ago was the child diagnosed with Long QT Syndrome? _____ __

What type of LQTS does your child have?

☐ LQTS 1 ☐ LQTS 2 ☐ LQTS 3 ☐LQTS 4 ☐ LQTS 5 ☐ LQTS 6

☐ LQTS 7 ☐ Unidentified gene ☐ Other _____

Is the child with the LQTS diagnosis symptomatic?

☐ Yes ☐ No

When was your child's most recent event? Date _____ (month) _____ (year) ☐

Not Applicable

How many events in total (fainting, arrest) has your child had?

☐ 0 ☐1 or 2 ☐3 or 4 ☐5 or 6 ☐7 or more

How frequently do your child's LQTS symptoms occur?

☐Never ☐Weekly ☐Monthly ☐Yearly

Does your child have a pacemaker or implantable cardioverter defibrillator (ICD)?

☐Pacemaker ☐ICD ☐Both ☐Neither

Does your child take medication for LQTS? ☐ Yes ☐ No

How often does your child take this medication?

☐Once Daily ☐ 2 or 3 times a day ☐Other, please specify ☐Not Applicable

Does your child experience side effects from medication? If so, please specify

☐ Yes

_____

_____

_____

☐ No

Are there multiple children in the home with the diagnosis of Long QT Syndrome?

☐Yes ☐No

If yes please list their ages and the age that they were diagnosed as well as the type of LQTS they have.

_____

_____

_____

_____

_____

Are you diagnosed with Long QT Syndrome? ☐ Yes ☐ No

If Yes, please explain the circumstances surrounding your diagnosis.

_____

How long ago were you diagnosed with Long QT Syndrome?

_____

What type of LQTS do you have?

☐ LQTS 1 ☐ LQTS 2 ☐ LQTS 3 ☐ LQTS 4 ☐ LQTS 5 ☐ LQTS 6

☐ LQTS 7 ☐ Unidentified gene ☐ Other _____

Are you symptomatic?

☐ Yes ☐ No

When was your most recent event? Date _____ (month) _____ (year) ☐ Not Applicable

How many events in total (fainting, arrest) have you had?

☐ 0 ☐ 1 or 2 ☐ 3 or 4 ☐ 5 or 6 ☐ 7 or more

How frequently do your LQTS symptoms occur?

☐ Never ☐ Weekly ☐ Monthly ☐ Yearly

Do you have a pacemaker or implantable cardioverter defibrillator (ICD)?

☐ Pacemaker ☐ ICD ☐ Both ☐ Neither

Do you take medication for LQTS? ☐ Yes ☐ No

How often do you take this medication?

☐Once Daily ☐2 or 3 times aday ☐Other, please specify ☐Not Applicable

Do you experience side effects from medication? If so, please specify

☐ Yes

_____

_____

_____

☐ No

Are you diagnosed with any other chronic or life threatening physical conditions or psychological conditions? ☐ Yes

☐ No

_____

_____

Is your child diagnosed with a chronic or life threatening physical condition (other than LQTS) or psychological condition requiring school accommodations? ☐ Yes

☐ No

(If yes, please explain below)

_____

What is your yearly household income range?

☐$5,000-$20,000

☐$21,000-40,000

☐$41,000-$60,000

☐$61,000-$80,000

☐$81,000-$100,000

☐Above $100,000