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The Experience of Grief and Loss in Persons Affected by Long QT Syndrome

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THE EXPERIENCE OF GRIEF AND LOSS IN PERSONS AFFECTED BY LONG QT SYNDROME

By David Haynes-Weller

Submitted in Partial Fulfillment of the Requirements of the Degree of Doctor of Psychology

April 2011
GRIEF AND LOSS

PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by David Haynes-Weller on the 26th day of April, 2011, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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Abstract

Long QT syndrome (LQTS) is a life-threatening genetic arrhythmia syndrome. LQTS is caused by mutations in the ion channel of the heart resulting in ventricular arrhythmias that predispose individuals to syncope and cardiac arrest. The risk of sudden death is heightened in undiagnosed children and adolescents. Effective treatments for controlling LQTS are available, although they often impose significance lifestyle limits. Limited psychosocial resources are available to help families cope with the losses related to LQTS. This qualitative research study focuses on affected individual’s experiences of loss and grief related to LQTS. The study used archival data obtained from an internet message board dedicated to LQTS. The primary objective of this study was to describe the individual’s experiences of loss and grief as a means of assisting health care professionals to (a) identify potential issues related to loss that result from a diagnosis of LQTS, (b) recognize potential chronic grief reactions that families may result, (c) and recognize the need for resources to help families cope with loss.
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STATEMENT OF THE PROBLEM

Statement of the Problem

Long QT Syndrome (LQTS) is a life-threatening genetic arrhythmia syndrome that has the potential to cause sudden death (Goldenberg & Moss, 2008). LQTS is caused by genetic mutations in the ion channels of the heart (Sudden Arrhythmia Death Syndromes (SADS) Foundation, 2002); these channels produce the ongoing electrical activity that maintains the beating of the heart. Sodium and potassium channels are most commonly affected (Vetter, 2007). The mutated channels extend the QT interval which then predisposes affected persons to syncope and cardiac arrest (Sudden Arrhythmia Death Syndromes (SADS) Foundation, 2002). The first manifestations of LQTS normally occur between early childhood and adolescence (Vetter, 2007). Symptoms of LQTS include heart palpitations, lightheadedness, and syncope.

The prevalence of LQTS in the United States has been estimated at 1:5,000 to 1:7,000 (Vincent, 2005). The risk of sudden death is heightened in undiagnosed children and adolescents. Undiagnosed individuals with LQTS are at risk for syncope and sudden cardiac death due to ventricular tachyarrhythmia. Although syncope may occur as a result of physical exertion, fear or emotions, 10-30% of individuals experience a sudden cardiac arrest as the first manifestation of LQTS (Vetter, 2007). Although there is no cure, effective treatments for controlling this syndrome are available. Therefore, prompt and accurate diagnosis of the syndrome can be life-saving. Diagnosis of LQTS occurs through the evaluation of the
individual’s electrocardiogram and the individual’s and family’s medical history (Vetter, 2007). When these factors do not allow for a clear diagnosis, genetic testing for specific gene mutations is indicated (Goldenberg & Moss, 2008). Treatment for LQTS includes beta blocker medication, lifestyle modifications and, for select individuals, implantable cardiac defibrillators (ICD).

The physical and psychological implications of LQTS can mean devastation for those affected. In the United States, it is estimated that as many as 3,000 children and adolescents die from LQTS each year (Sudden Arrhythmia Death Syndromes (SADS) Foundation, 2002). Early detection and treatment may be effective in reducing the number of deaths associated with LQTS. The probability for sudden death is higher for LQTS boys (5%) than for LQTS girls (1%) (Goldenberg et al., 2008). Symptoms of this syndrome can often be unexpressed until the child is struck with a sudden, and often fatal, cardiac event. Even when the cardiac event is not fatal, medical personnel may need to perform invasive procedures to resuscitate the person. Therefore, the sudden and unexpected nature of this event can have traumatic psychological implications for family members of the person affected by LQTS (i.e., chronic anxiety, posttraumatic stress disorder, etc.). Once diagnosed, even though the risk for a cardiac event decreases dramatically (Goldenberg et al., 2008), the person is faced with treatment requirements which often include significant lifestyle changes (i.e., restriction of physical activity, strict medication regimen, etc.) (Vetter, 2007). The patient and family members are faced with adjusting to the losses that inevitably result from the reality of dealing with a chronic illness. Similar to other chronic illnesses, family caregivers may have the potential to experience symptoms of chronic sorrow related to the losses associated with these limitations and restrictions (Roos, 2002).

The use of internet message boards to communicate information and provide a supportive community for individuals coping with chronic illness has been growing at a dramatic rate.
recently. Many individuals find a strong sense of community support through message boards. A few empirical studies have found evidence that online support groups provide social support for cancer patients in various stages of treatment (Beaudoin & Tao, 2007). Unlike other chronic illnesses, there are few physical support groups available for persons and family caregivers affected by LQTS. Therefore, many individuals depend upon LQTS internet message boards for information concerning the disorder and social support in coping with the problems arising from the disorder.

**Purpose of the Present Study**

LQTS is a genetic disorder that affects the heart’s electrical system (Sudden Arrhythmia Death Syndromes (SADS) Foundation, 2002). The first diagnosed case of LQTS was identified in 1957 but discovery of the specific LQTS gene mutations began only in 1991 (Vetter, 2007). Although a great deal of research has been conducted into the genetic and physiological factors related to LQTS, very little research has been done to identify and understand the psychosocial factors that impact families affected by this syndrome. Because of the sudden and traumatic nature of syncopal events or cardiac arrest, there is the potential for complicated and debilitating symptoms of grief and loss over a long period of time. The need to identify the factors related to grief and loss is important in order for professional caregivers to be able to respond quickly to the families’ needs following the event. Even when cardiac events are not present, individuals diagnosed with a chronic illness such as LQTS will encounter inevitable lifestyle changes; because of these changes, both the individuals and their families may experience debilitating cognitive, affective, and behavioral changes related to grief and loss. These experiences of grief
and sorrow have the potential to interfere with the normal functioning of the affected individual and the ongoing care of the child affected with chronic illness. Using a qualitative design, the present study will explore, describe, and explain the experiences of grief and loss in individuals affected by LQTS as communicated via internet user groups.

At the present, there have been very few studies that examined the psychosocial concerns of individuals affected by LQTS (Farnsworth, Fosyth, Haglund, & Ackerman, 2006; Giuffre, Gupta, Crawford, & Leung, 2008; Hendriks, Grosfeld et al., 2005; Hendriks, Hendriks et al., 2008; Hendriks et al., 2005). This study is part of a larger research project examining the psychosocial experiences of this population. When taken together with the findings of this larger study, knowledge gained from this qualitative study will help to inform the medical community and other health providers who serve individuals affected, directly or indirectly, by this disorder. Information gained from this study will be used to develop resources for persons affected by LQTS; these resources would be valuable for persons affected by LQTS to have, at their disposal, better information concerning their condition and quality of life factors. The goal would be that these resources would eventually be available directly through the medical community or online. Knowledge of the potential psychosocial and quality of life implications of the disorder on persons living with LQTS, parents of children with LQTS, or persons who have other family members affected by LQTS will have important ramifications both for the management of the disorder and for healthcare costs.
Relevance to the Goals of the Program

The current study is relevant in helping produce an appreciation and comprehension of the general knowledge base concerning the psychosocial concerns that persons have who are affected by chronic illness. The biopsychosocial model of illness has been a strong focus of this program. It is, therefore, important for a psychologist to have an understanding of the interactions of biological, psychological, and social processes that inform disorders such as LQTS. The current study, which required the researcher to grasp the basic genetic and biological foundations of LQTS, also empowered him to learn a broad range of theories concerning grief and loss specifically as they impact individuals affected by chronic illness. Finally, the researcher developed an appreciation and understanding of a new mode of communication (i.e., internet user groups) and its growing use for the support of persons dealing with chronic illness.

The current study is also relevant in the development of practitioner-scholars in the context of an evolving body of scientific knowledge. Research into LQTS is a relatively new endeavor. Genetic and biological understandings of the disorder are evolving and progressing at the present. In the midst of this study, new insights have arisen concerning this disorder which the researcher was required to integrate into the study. Of greater importance, the purpose of this study involves exploring and describing the psychosocial experiences of families affected by a disorder; these have yet to have been studied in depth.
Chapter 2

LITERATURE REVIEW

The experiences of grief and loss in individuals affected by Long QT Syndrome, as communicated via an internet message board, are examined in this study. Literature related to Long QT Syndrome, grief and loss, and chronic illnesses in children and adolescents are examined in order to provide empirical and theoretical grounding for this study. The literature review is divided into two sections. The first describes the diagnosis and treatment of Long QT Syndrome and examines the quality of life issues that are faced by families of children with chronic illnesses. Because there is very little empirical research on the psychological effects of LQTS on the families of patients, empirical research will be examined related to other chronic illness (i.e., childhood cancer, sickle cell disease, spina bifida, etc.) that affect children and adolescents. The second section examines theories of the process of grief with specific emphasis upon anticipatory grief related to individuals and families dealing with chronic illness. Empirical research will be examined as it relates to the experiences of grief and loss in individuals dealing with chronic illnesses.

Long QT Syndrome and Chronic Childhood Illness

The Nature of Long QT Syndrome

Symptoms, course, epidemiology, and etiology. Hereditary long QT Syndrome (LQTS) is a genetic cardiac condition in which affected family members display delayed ventricular
repolarization (Goldenberg & Moss, 2008). The delay in repolarization is represented by a prolonged QT interval on the electrocardiogram (ECG). Genetic LQTS is considered to be a relatively rare condition. The prevalence of LQTS in the United States has been estimated at 1:5,000 to 1:7,000 (Vincent, 2005), although these estimates are not based on empirical data. More recent estimates place the disease prevalence closer to 1:2,500 (Crotti, Celano, Dagradi, & Schwartz, 2008).

Several different types of LQTS have been identified, based on the specific gene mutation that has caused the disorder (Crotti et al., 2008). The most common genotypes of LQTS are LQTS1, LQTS2 and LQTS3 (I. Goldenberg & Moss, 2008). LQT1 and LQT2 are caused by mutations in potassium channels but LQTS3 is caused by a mutation in the sodium channel (Crotti et al., 2008). Treatment protocols vary, depending upon the specific type of LQTS. Therefore, not only is it important to determine a general diagnosis of LQTS but it is also essential to specify the exact type. Treatment will then be tailored to the exact type of the disorder.

LQTS presents itself, clinically, in syncopal episodes, seizures, or sudden cardiac death (Crotti et al., 2008). Cardiac death is “caused by the ventricular tachyarrhythmia torsade de pointes (TdP)” (Vincent, 2005, p. 15). Goldenberg et al. (2008) used a regression modeling to identify risk factors in children for cardiac events. They found that boys had a significantly higher rate of fatal cardiac episodes (5%) than girls (1%). Zareba et al. (1998) found the rate of death for each of the three major genotypes to be 4% over a 40 year period. Although in the majority of cases, the individual recovers from the syncopal episode, there is rarely advanced warning (Vincent, 2005).
Cardiac events may be triggered by various events depending upon the type of LQTS. Strenuous physical activities (e.g. running, swimming, biking) may trigger an event (Goldenberg & Moss, 2008). Because of the variation in symptoms, LQTS may be misdiagnosed during these triggers. Al Jarallah (2005) found, in a case report, that LQTS manifestations can sometimes be misdiagnosed as epileptic seizures in children who are swimming. Other triggers include various types of startle responses (e.g. ringing phone, smoke detector, alarm clock) or emotional responses (e.g. anxiety, anger, stressful situations) (Goldenberg & Moss, 2008). On the other hand, an event may occur simply during sleep or rest.

LQTS is usually diagnosed through the observation of QT prolongation on the ECG (I. Goldenberg & Moss, 2008; Moss & Robinson, 2002; Vincent, 2005). However, a minority of patients with LQTS have normal QT values in the resting ECG (Vincent, 2005). Therefore, serial ECGs and exercise ECGs are used to supplement diagnosis. Genetic testing is also used for diagnosis.

**Treatment of LQTS.** There are several effective therapeutic options for the control of the symptoms of this disorder. Close medical supervision is an important part of treating the disorder. The first line of therapy for both LQT1 and LQT2 has been the use of beta-blockers (Patel & Antzelevitch, 2008; Shimizu, 2005). Given the risk of sudden death when LQTS symptoms initially occur, Crotti et al. (2008) considers beta-blocker therapy essential even for asymptomatic patients. Priori et al. (2004) studied 335 LQTS patients treated with beta-blockers over a 5 year period. They collected data on the patients and found a high rate of cardiac events on those treated with beta-blockers. Therefore, a significant percentage of symptomatic LQTS patients treated with beta-blockers are recommended for additional, more invasive treatment (Goldenberg & Moss, 2008).
Implantable cardiac defibrillators (ICD) are often implanted in high risk candidates including those who continue to present with symptoms while on beta-blockers (Goldenberg & Moss, 2008; Moss & Robinson, 2002; Vincent, 2005). Crotti et al. (2008) believe that ICD implantation should be considered only when specific episodes of cardiac arrest have occurred. Although beta-blockers and ICDs represent the most common therapeutic interventions for LQTS, occasionally pacemakers and left cervicothoracic sympathetic denervation (LCSD) have been utilized but remain less effective options (Goldenberg & Moss, 2008). Because of the relatively rare prevalence of LQTS, randomized trials of specific therapies are not able to be conducted.

Although therapeutic interventions can be very effective in controlling the symptoms of LQTS, patient nonadherence to prescribed medication can lead to drug failure (Vincent, Timothy, Fox, & Zhang, 1999). Children and adolescents may be especially resistant to following a routine of daily medication usage. Most cases of cardiac arrest following diagnosis and treatment of LQTS have been associated with medicine nonadherence. Chatrath, Bell, and Ackerman (2004) in a retrospective cohort study, found that although there were differences in the effectiveness of various beta-blockers in controlling LQTS symptoms, medicine noncompliance played an important role in symptom occurrences.

Important lifestyle restrictions are usually recommended following the diagnosis of LQTS. Vigorous exercise has been a common precipitator of syncope and sudden death in patients with LQTS (Vincent et al., 1999). Therefore, restricting competitive sports and other vigorous physical activity are normal parts of the treatment of LQTS.

**Potential psychological effects of LQTS.** Because LQTS is usually diagnosed in childhood and early adolescence, therapeutic lifestyle restrictions have the potential to have
serious negative psychological consequences for patients and parents. The potential risk for sudden cardiac event may produce hypervigilance to risk factors in their surroundings in children and in their parents. Potential limitations in activities and social involvement for fear of triggering a cardiac event may negatively affect the child’s mood. Regular avoidance of triggers (e.g. school bells, gym class) may create feelings of being set apart from the rest of their peers. These feelings may negatively impact their social connections to their peers and to their self-worth.

LQTS can have devastating effects upon an individual who experiences a sudden cardiac arrest, and in some instances can be fatal. The losses experienced in the death of the individual or in associated losses (i.e., loss of hopes and dreams) that loved ones experience may be equally devastating. The psychological effects upon an individual diagnosed with LQTS and upon his or her family has the potential for high levels of distress.

Although traumatic events associated with LQTS may produce obvious psychological distress, the long term lifestyle changes associated with caring for a young person with LQTS have the potential for underlying psychological problems. The uncertainty surrounding the long term outcome of the disorder may produce symptoms of chronic anxiety. Parents’ expectations and dreams for their child have been disrupted and they may have difficulty adjusting to the new reality.

Research into the psychological effects in families affected by LQTS is in its infancy. Only a few empirical studies have examined the psychological impact of a positive genetic test on the parents of a child with LQTS. Hendriks et al. (2005) found that, in the short term, at least 50% of parents who received a positive genetic test for LQTS displayed clinically significant high levels of distress. A follow-up study examined the long term psychological impact for
parents whose child had been diagnosed with LQTS (Hendriks, Grosfeld et al., 2005). The study found that, even 18 months following the genetic test results, over half of the parents in the study maintained high levels of distress including disease-related anxiety, worry about their child’s future, and with frustration with accessibility to information concerning LQTS. In a recent study, Hendriks, Hendriks et al. (2008) assessed the levels of distress in parents of children with LQTS. The parents were measured on levels of anxiety and depression 2 weeks prior to consultation, 2 weeks after consultation, and 18 months after DNA results. They compared levels of distress of parents of children who had abnormal ECG along with the genetic mutation for LQTS, those who had uncertain ECG along with the mutation, and children with uncertain ECG without the mutation. They found that the parents whose children had uncertain ECG and the mutation had levels of overall distress that were higher than the other groups. Levels of disease-related anxiety did not significantly decline even after 18 months.

One qualitative study reported that both parents of young children and of adolescences with LQTS described anxiety that their child would die (Farnsworth et al., 2006). Parents also reported frustration over the lack of knowledge about the syndrome by the medical community.

Only one empirical study has examined the levels of psychological distress in children with LQTS (Giuffre et al., 2008). The study compared fear and anxiety in children with LQTS with fear and anxiety in children with asthma. Children with asthma tended to display more medical-related fears and death fears than the LQTS children; however, children with LQTS tended to internalize their true fears and expressed only those fears concerning failure and criticism.
Parental Psychological Experience of Chronic Illness

Because of the lack of empirical research on the psychosocial impact of the diagnosis of LQTS upon the family members, the remainder of this section will focus on the psychosocial impact of other chronic and potentially life-threatening childhood diseases. Childhood cancer can have a devastating impact upon a family. Even with the new advances in treatment, when a child is diagnosed with cancer the biopsychosocial implications can be overwhelming. There may be both similarities and differences in the long-term psychological impact upon parents of children with cancer and parents of children with LQTS. On the one hand, both may experience high degrees of anxiety and depression related to the progression of the child’s disease. Both may experience sorrow related to the loss of hopes and dreams for their child’s future. Both may experience sadness related to the disease-related limitations placed upon the child. On the other hand, the outcome of childhood cancer tends to be much more predictable than the outcome for LQTS. Therefore there may be the potential for high levels of anxiety in parents of LQTS children related to sudden cardiac events. Although there is the potential for a cure or remission for cancer, there is no cure for LQTS. Therefore parents of children with LQTS must cope with the reality that their children will never be “cured” from this syndrome, but parents of children with cancer hold onto this realistic hope.

There seems to be a strong correlation between the psychological adjustment of children with cancer and their mothers. Zebrack, Chesler, Orbuch, and Parry (2002) found that mothers of survivors of childhood cancer worry about their children’s health both physically and psychologically. They reported that mothers worried most often when they thought that their children had high, cancer related worries. Another study found that behavioral problems in the child with cancer were strong predictors of depression in parents (Manne et al., 1995). An
important consideration, therefore, are the relational factors that impact the parent’s overall adjustment to their child’s chronic health problems. In earlier studies, researchers have reported that mothers of childhood cancer survivors are at greater risk for a variety of psychological problems, including anxiety (Koocher & O'Malley, 1981), depression (Magni, Messina, & DeLeo, 1983), and marital problems (Adams-Greenly, 1986). Similarly, there may be the potential for high degrees of worry and anxiety for parents of children with LQTS as they focus on the uncertainty surrounding the child’s long term prognosis. On the other hand, anxiety may manifest itself in very different ways. Parents of children with LQTS may focus their worries on potential unpredictable triggers such as cardiac events.

Most of the quantitative studies have focused on the parent’s affective problems related to coping with their child’s chronic illness (Frank, Brown, Blount, & Bunke, 2001; Gerhardt et al., 2007) including depression and anxiety. Very few quantitative studies have examined grief responses in parents of children with chronic illnesses. In large part the research in this area has been limited to qualitative research.

Beltrao, Vasconcelos, Pontes, and Albuquerque (2007) used qualitative methods to investigate maternal attitudes and feelings when childhood cancer was diagnosed. They described intense feelings of pain, shock, sadness, and despair. They also described feelings of loss and the belief that life had lost meaning. Similar reactions might be expected in mothers of children diagnosed with LQTS.

Parents who care for chronically ill children also face successive hardships and challenges as the child’s illness progresses (Gravelle, 1997), including the need to find reliable information concerning the illness, preparing for the future, and negotiating the amount of time required for care giving. The experience of loss was expressed throughout the changes that occur
during the progress of the child’s illness. Parents who care for children with LQTS may experience similar challenges especially related to finding reliable information concerning the illness and preparing for the future. However, they may not experience losses through the progression of LQTS because the person’s condition does not tend to deteriorate over time.

Overholser and Fritz (1990) examined the relationship between a family’s level of adjustment to childhood cancer and psychosocial adjustment factors following successful treatment. The parents and children were assessed separately, using structured interviews and self-report measures. The 44 children included in the study were assessed two to seven years following successful treatment. All children were in a period of remission. Interviews were rated by two independent interviewers for the following variables: parental perceptions of emotional and instrumental support received from others, tendency to express anger toward the child, critical view of the child, tendency to include or exclude the child from family activities, parental expectations, and parent’s behavioral change toward the other children in the family. The child’s self-esteem was measured by using the Piers-Harris Self-Concept Scale. The Impact-On-Family Scale was used to assess how functioning is affected by chronic disease.

Using correlational and multiple linear regression analyses, Overholser and Fritz (1990) found that the child’s self-esteem was adversely affected by reductions in the quality of family interactions. Additionally, higher emotional distress in a parent was related to higher frequency of angry outbursts toward the child. Most importantly, higher parental mastery scores were related to higher levels of social support. In other words, parents who believed that they were receiving appropriate levels of help and support tended to have the ability to cope with problems in an adaptive fashion. Similarly, families of children with LQTS may experience reduced
quality of family interactions. Parents may tend to treat the child with LQTS differently, especially related to family activities, than other children in the family.

Using qualitative methods, Van Dongen-Melman, Van Zuuren, and Verhulst (1998) examined the experiences of parents of children who had survived cancer. They interviewed the parents of 85 children between the ages of 8 to 13 who had been treated for malignant cancer and were in remission. Parents were interviewed in an open-ended manner over a three year period of time. In most cases (77), both parents participated in the interview. The focus of the interview was on the experiences of the parents after treatment had been concluded. Using variational sampling, the researchers searched for as many differences within the data as possible, and were able to gain a broad picture of the parents’ experiences. Two main, negative themes emerged from their study: losses and perseveration. The experience of loss was expressed in several ways. The first category of losses concerned parents’ perspectives on life: loss of a normal way of life, loss of invulnerability, and loss of a period of their lives. The second category of losses focused on the parents’ relationships to each other. A third specific theme concerned losses specifically related to the child. These losses included both physical and psychological after-effects. The parents were confronted with the loss of the image of a healthy child. Coping strategies of the parents also frequently focused on anticipatory loss. They expressed the dilemma over whether or not to prepare for the death of their child or hope for the child’s survival. Even after successful treatment for cancer, mothers, in particular, tended to worry about a recurrence of the cancer. Parents of children with LQTS might be expected to experience all of these themes related to loss. One obvious difference between this study and the potential experience of LQTS is that there is no end point in the treatment of LQTS.
In a qualitative study of working parents of children with chronic illness, George and Vickers (2006) examined the experiences of 12 parents, using semi-structured interviews and analysis of themes. The parents who were interviewed worked full-time. They had cared for their chronically ill child between 2 to 18 years. The children had a diverse range of conditions including cerebral palsy and spina bifida. The researchers reported that eleven of the parents expressed grief themes related to their child’s illness. Grief-related feelings were most often expressed during the period of the initial diagnosis of the illness. Evidence of chronic grief was uncovered during interviews with ten of the parents. Most expressed feelings of pervasive sadness related to their child’s conditions. Often this sadness was precipitated by thoughtless remarks from family or friends or insensitive questioning from members of the medical community. Some parents relived experiences of loss when the child’s condition began to deteriorate or when encountering unrelated stories concerning death. This study included a broad range of chronic childhood illnesses; this broad range makes comparison with LQTS difficult. As with LQTS, all of the childhood illnesses examined in this study are life-long disorders that can seriously disrupt the lifestyle of the affected person. Most of the themes related to loss uncovered in George and Vickers’ study have the potential to appear in families of children with LQTS. However, unlike LQTS, though, most of these disorders tend to deteriorate gradually over time. Therefore, parents of LQTS may be less likely to relive experiences of loss. The physical manifestations of most of the illnesses included in this study are quite apparent to the observer. LQTS, on the other hand, is virtually invisible to those not privy to the diagnosis.

Vickers (2005) focused another qualitative study on nine working mothers who were caring for a child with a chronic illness. Using in-depth individual interviews and a group experience, she also found themes related to grief. Participants expressed the experience of
having had their normal views of the world significantly altered with the diagnosis. They also expressed the understanding that their lives would never be the same. They expressed the ideas that assumptions and expectations concerning the way the world is supposed to function were lost. Thoughts of vulnerability and helplessness related to the parent’s inability to help their child were noted. Themes related to the ongoing and recurring nature of grief emerged. Various triggers in the environment (i.e., an insensitive remark or a comment about the future) seemed to bring the thoughts and feelings related to grief back to the surface (i.e., feelings of sadness, thoughts related to loss, etc.). The researcher included a diverse collection of childhood illness in her study (i.e., autism, Myotonic dystrophy, autism, Down’s syndrome, etc.), thereby potentially, limiting its relevance to LQTS. On the other hand, many of the themes related to loss and grief related to chronic illness uncovered in this study may be in parents of children with LQTS.

In her research on school age children with sickle cell disease (SCD), Northington (2000) examined the experience of chronic sorrow in the caregivers of these children. She used grounded theory methodology in this study of 12 African-American caregivers. The ages of the children ranged from 6 to 12 years old. The investigator used a demographic questionnaire and two interview forms with which to generate data. The first interview was conducted within an 11 week period; the second interview was conducted approximately one year after the first interview. The data from these two interviews were used to generate a full understanding of the experience of the caregiver’s chronic sorrow.

The investigator identified three distinct but overlapping stages related to chronic sorrow experienced by the caregivers. In the first stage, the caregiver, following diagnosis, began the process of incorporating the reality of the disease into the overall familial situation. Caregivers reflected upon the disruptions and losses that the disease had forced upon their families and also
the ways in which they had adjusted. Later, during the second stage, the caregivers expressed
cognitions and affect related to chronic sorrow in a dynamic and variable manner. Caregivers
expressed the experience of sudden periods of sadness, uncontrollable crying, and difficulty in
concentrating. These expressions of sorrow were related to negative thoughts related to fears
concerning the death of their child. Sorrow was also triggered by external factors (i.e., changing
health of the child, news concerning the death of an unrelated child, etc.). The researcher labeled
the third stage: “doing what you have to do and moving on” (Northington, 2000, p. 152). In this
stage, the caregiver continued to experience sorrow but had found ways of incorporating the new
realities into their lives. Coping strategies and social support played important roles in moving to
this stage. Sickle cell disease is similar to LQTS in several ways. As with LQTS, sickle cell
disease is normally diagnosed in childhood and is potentially life-threatening (Northington,
2000). There is no cure for either disorder. As with LQTS, sickle cell disease is also, largely, an
invisible disorder to the objective observer. In both disorders, caregivers must carefully monitor
their children for unpredictable triggers that can lead to severe complications. This has the
potential of placing excessive stresses and responsibilities on the caregivers over a long period of
time. On the other hand, the triggers for sickle cell disease tend to be less dramatic than for
LQTS. Whereas LQTS does not seem to affect one population more than others, sickle cell
disease predominately affects the African-American population.

Hobdell et al. (2007) examined the presence of symptoms of chronic sorrow in 67 parents
of children with epilepsy, using self-report measures. The children included in the study were
between 2 and 18 years of age. For inclusion into the study, parents had to have known about the
diagnosis for at least three months. The research team used the Adapted Burke Questionnaire
(ABQ) to determine the presence of chronic sorrow in the parents. This self-report questionnaire
uses a Likert scale to determine the presence and intensity of frequently reported mood states related to chronic sorrow (i.e., grief, shock, anger, disbelief, sadness, hopelessness, fear, and guilt). Results indicated that moderate levels of chronic sorrow were reported by parents, as measured by the scores on the ABQ; these included feelings of sadness, grief, helplessness, guilt, fear, and shock.

As with LQTS, childhood epilepsy is a chronic illness that has no cure (Hobdell et al., 2007). As with LQTS, childhood epilepsy is also, largely, an invisible disorder to the objective observer until overt symptoms, such as seizures, occur. The sudden and unexpected nature of the symptoms of both disorders can, potentially, place tremendous stress on caregivers. On the other hand, unlike LQTS, childhood epilepsy is rarely fatal.

Lowes and Lyne (2000) reviewed the research literature to investigate grief reactions of the parents of newly diagnosed children with diabetes (type 1). They conclude that the majority of parents eventually adapted to the management of the child’s illness; however, many continue to experience symptoms of sadness and loss related to chronic sorrow. As with LQTS, childhood diabetes is a chronic, life-long disorder that requires vigilance on the part of caregivers to monitor their child’s condition. Unlike LQTS, symptoms of childhood diabetes do not manifest in a sudden, unpredictable manner.

In a qualitative study of 68 mothers and 64 fathers of children with a neural tube defect (i.e., spina bifida), Hobdell & Deatrick (1996) examined the parental differences with respect to their sorrow response to the diagnosis of the child’s defect. The parents completed the Adapted Burke Questionnaire (ABQ) and three open-ended questions related to chronic sorrow. The investigators utilized content analysis to categorize mood states and any differences that were discovered between parents. Both parents tended to report intense mood responses. As expected,
though, mothers reported more intense sorrow responses, as compared with fathers. This study examined the reactions of parents to the diagnosis of neural tube defect in their child. The sorrow response of parents to a diagnosis of neural tube defect could be similar to the response to the diagnosis of LQTS because in both cases the parents realize that they have lost their ideal child along with their hopes and dreams for the child. On the other hand, the presentation and care of spina bifida is much different from LQTS and therefore limits the relevance of this study.

In a study of the impact of DNA predictive testing for Huntington disease on families, Sobel and Cowan (2003) interviewed 55 individuals from 18 families, using a semi-structured format. Using qualitative methods, a set of themes was produced from analyzing the content of the interview transcripts. A number of themes related to loss arose through the analysis. All of the families regardless of whether or not the individual tested positive, experienced the loss of uncertainty concerning the Huntington disease gene. They also lost the need for vigilance in searching for symptoms of the disease. The families whose member tested positive experienced unique losses: the loss of the future for the individual, the loss of the member’s role in the family, and the loss of meaning. The study also explored the ways in which family members attempted to cope with loss. Behavioral responses included changing the connections between family members, increased use of rituals, and increased pressure on other family members to have the testing. LQTS is a genetic disorder; therefore, when a child is diagnosed with the disorder there is great pressure on the rest of the family to be tested. Similar types of behavioral responses, potentially, could be present in family members of children with LQTS. Unlike LQTS, Huntington disease is always fatal and the progression of the disease is clear. Therefore, the grief and loss response could potentially be much greater in families of persons with Huntington disease.
Siblings’ Psychological Experience of Chronic Illness

Because there has been extensive research examining the reactions of parents of children dealing with chronic illness, there is a small but growing body of research related to the experiences of the siblings of children with chronic illness, using quantitative and qualitative methods (Sharpe & Rossiter, 2002; Woodgate, 2006). Much of this literature has focused on the psychosocial adjustment of siblings. The literature has indicated both positive and negative responses to the stress of dealing with childhood cancer. Some areas of research point to positive experiences: growth in compassion, enhanced maturity, positive self-esteem, growth in social competency (Chesler, Allesewede, & Barbarin, 1991; Haverman & Eiser, 1994; Kramer, 1984; Sargent et al., 1995). On the other hand, other research has indicated that siblings of chronically ill children have higher risks of behavioral problems (Hamama, Ronen, & Feigin, 2000; Sloper & While, 1996). Literature also shows that siblings report experiencing feelings of isolation, anxiety, loneliness, anger, and posttraumatic stress (Alderfer, Labay, & Kazak, 2003; Bendor, 1990; Houtzager, Grootenhuis, & Last, 2001; Koch-Hatten, 1986). Houtzager et al. (2001), focused specifically on the impact of supportive groups on anxiety displayed by sibling of pediatric oncology patients. Obviously the research indicates that the psychological adjustment of siblings in these stressful situations is quite complicated.

Comparatively few studies have examined the experiences of loss and grief in siblings of children with chronic illness. In one notable exception, Walker (1988) examined the coping strategies of siblings of childhood cancer patients, using qualitative methods. Data were gathered from 26 siblings between 7 and 11 years of age from 15 families, using open-ended interviews and a questionnaire. Interviews were individualized according to the developmental level of the
children through the use of puppet play, drawing, and cartoon story telling. The interviews were coded through the use of content analysis to identify themes. The study revealed three distinct themes related to stress: loss, fear of death, and change. Unfortunately, the author does not include detailed results of her analysis. The study is also limited by the demographic uniformity of the families utilized.

Woodgate (2006) utilized qualitative methods to examine siblings’ experiences of childhood cancer. As part of a larger study, she interviewed 30 siblings, individually and in groups, to gather data. The children included in the study spoke English and were 5 years or older. The situation of the child with cancer varied relative to age, diagnosis, and stage of illness in order to capture a broad cross-section of experience. Her analysis supports the previous research in identifying themes related to loss. Specific themes related to loss included loss of a family way of life. This theme included physical and psychological disruption and isolation, feelings that their needs were not being met by the family, and loss of security. A second theme was related to the loss of self in relation to the child’s family. They tended to view the world through the eyes of the ill child rather than through their own. They also expressed feelings of guilt related to their own good health and in denial that the illness had truly impacted their lives.

As mentioned previously, there are potential similarities in parents’ reactions to childhood cancer and LQTS. The reactions of siblings may, likewise, be similar. The changes in the family dynamic and its effect on siblings could potentially be similar in families dealing with LQTS, as the child with LQTS becomes the focus of the family’s care. On the other hand, the loss and grief reactions may not be as strong in siblings of children with LQTS, because the presentation of the disorder is much less visible.
Experience of Loss and Grief in Persons with Chronic Illness

Persons coping with chronic illness are faced with various psychosocial reactions throughout the course of the disease. Several studies have looked at the role that loss and grief play when coping with a chronic illness. Most of these studies have focused on adults with chronic illness which, therefore, limits the relevance to children coping with LQTS.

Ahlstrom (2007) examined the experiences of loss and chronic sorrow in persons with severe chronic illnesses. The study used semi-structured interviews to gather data related to loss and chronic sorrow. The investigator included in the study, 30 Swedish adults between the ages of 18 and 64 years who were coping with severe physical disease or injury. The study utilized both inductive and deductive methods to analyze the data. Content analysis on the narrative text was used to identify themes related to loss. Eight main themes related to loss were uncovered: loss of bodily functions, loss of relationships, loss of autonomous life, loss of the life imagined, loss of roles, loss of activities, loss of identity, and loss of uplifting emotions. The participants were then assessed by the interviewer and by an independent assessor to determine the levels of chronic sorrow they had experienced, based on six criteria. The assessment determined that 53% of the participants had experienced at least four of six criteria of chronic sorrow.

Grief and Loss

Grief is one of the most universal experiences of humankind. Humans inevitably lose an individual or a thing that is personally important to them. It is essential, first of all, to define the terms most commonly associated with loss: bereavement, grief, and mourning. Bereavement is best understood as the objective reality of having lost a close person including parents, partners,
friends, etc. (Stroebe, Hansson, Stroebe, & Schut, 2001). Grief is considered the subjective response to bereavement. The individual reaction may include a vast array of manifestations including emotional, cognitive, behavioral, and physiological reactions. Mourning, though often confused with grief, refers to the social manifestations of grief that are influenced by the specific culture in which the mourner lives.

Grief is considered a normal part of the adjustment to the reality of a significant loss. What does normal grief look like? Stroebe, Hansson, Schut, and Stroebe (2008) define normal grief as “an emotional reaction to bereavement, falling within expected norms, given the circumstances and implications of the death, with respect to time course and/or intensity of symptoms” (p. 25). The difficulty lies in defining those expected norms. Nonetheless, it is understood that extremes in the intensity, circumstances of the loss, and the amount of time devoted to grieving may lead to seriously impaired functioning.

Because there is a range of emotional reaction following a loss, researchers have begun to define levels of normal to extreme grief. This has lead to the development of proposed criteria for a new diagnosis of complicated grief disorder (Horowitz et al., 1997). The criteria would include a period of bereavement of at least 14 months, intrusive symptoms related to the deceased, symptoms of avoidance, and maladaptive behavior.

Many theories of grief have been proposed over the years. Freud (1917/1957) developed the first systematic theory of grief. He stressed the need for grief work on the part of bereaved individuals to cope with the loss. The concept of grief work has been quite influential up to the present. Kubler-Ross (1969) proposed the first stage theory of grief in which an individual progresses through expected and orderly stages: shock; yearning; anger; despair; and acceptance. This theory gained a large popular audience throughout the years and has maintained a strong
influence. Unfortunately, Kubler-Ross’s stage theory has never been studied empirically (Zhang, El-Jawahri, & Prigerson, 2006). Bowlby (1980) asserted a stage theory of grief. As with Kubler-Ross, Bowlby claimed that individuals pass through subsequent stages in the grief process.

Recently, stage theories of grief have come under criticism. Wortman, Silver, and Kessler (1993) stated that stage theories underestimate the range of emotional responses that people experience following loss. They also stress the lack of empirical support for stages in the process of grief.

**Attachment Theory and Grief**

Bowlby’s (1980) attachment theory has been helpful in understanding the evolutionary function of grief and specifically, acute types of grief. He stated that animals form emotional bonds with important others. Although he originally used attachment theory to explain the parental-child bond, Bowlby later extended it to other important relationships as well.

Temporary separations from an attachment figure produce powerful emotional reactions in the individual (Bowlby, 1958). The person will be strongly motivated to reestablish contact with the important figure. Bowlby (1980) claimed separation reactions function well to maintain attachment bonds and are clearly adaptive. Grief reactions are not adaptive and, in fact, are simply the cost of emotional reactions when the bonds of attachment are no longer possible because of death.

Bowlby’s (1969, 1973, 1980) attachment theory also provides insight into what triggers the grief reaction. From the perspective of the theory, grief is a deficit reaction to separation from the attachment figure. The individual’s reaction is to incorporate a picture of the figure along with the goal of attempting to stay close to the figure. The individual will initially protest the
separation from the loved one as a child protests the separation from his or her mother. Anger
and anxiety are commonly expressed during this phase. When protest is unable to restore
proximity because of death, despair will take over with expressions of depressed mood,
decreased appetite, etc.

This period of despair during bereavement has been examined extensively and evidence
has been found to show that it is quite pervasive (for reviews, see Stroebe et al., 2001). Research
has consistently indicated that the death of a significant person in one’s life typically brings out
extreme emotional reactions including distress, guilt, emptiness, sadness, and loneliness.
Research has validated that these expressions of grief are consistent throughout the world
(Stroebe & Stroebe, 1987).

Bowlby (1980) theorized that the bereaved individual needs to proceed through a final
phase of separation distress: reorganization. Within his original theory of child-parent
attachment, Bowlby referred to this phase as detachment (Bowlby, 1958). Adults, according to
Bowlby, do not need to detach totally from the lost loved one (Bowlby, 1980). Instead, they
reorganize their memories and representations of the loved one to serve them as they go on with
life.

Klinger (1975) extended this understanding of the process of grief even more generally.
From a behavioral perspective, Klinger viewed that anytime a reinforcing event fails to occur a
minor grief reaction is initiated. Therefore, grief in Klinger’s theory is a reaction that functions
as a means of accessing an incentive. If one is unable to access the incentive, a negative
emotional reaction occurs. Negative emotional reactions to frustrating events of everyday life
and grief reactions are similar responses.
Cognitive theories of grief tend to work well alongside attachment theory. They tend to focus on the schemas that people use to represent the world around them. Parkes (1971) used the term, assumptive worlds, to explain people’s expectations and assumptions about their world. These assumptive worlds include the person’s important relationships, as well as personal beliefs and assumptions concerning the future and the self. Parkes theorized that a sudden or dramatic change related to the person’s assumptive worlds has the potential to produce a grief-like response. This theory extends the notion of a grief reaction to a broad range of negative events including the loss of a job (Archer & Rhodes, 1993). This theory provides a very important rationale for extending grief research into other areas of important losses in people’s lives including losses associated with chronic illness.

Janoff-Bulman (1989) extended the use of the assumptive worlds theory to traumatic life changes. When internal models are damaged by traumatic events such as an accident or a disaster, the person’s very assumptions about the world as a safe and secure place are at risk. Her theory provides an important understanding of individual variability within a person’s grief response (Archer, 2008). Rather than focusing only on the typical grief response, the context of the person’s loss began to take on great importance.

Bowlby’s (1969, 1980) attachment theory provides not only an understanding of grief reactions in general, but it also provides insight into these individual variations. Based on their studies of parental-child bond, Ainsworth, Blehar, Waters, and Wall (1978) identified three attachment styles: secure, anxious-ambivalent, and anxious-avoidant. Bartholomew and Horowitz (1991) eventually, divided the anxious-avoidant attachment style into two types: fearful-avoidant and dismissing avoidant. Bowlby (1980) linked the anxious-ambivalent attachment style to relatively more intense and prolonged patterns of grief.
Fraley and Bonanno (2004) assessed grief, depression, anxiety, and PTSD at 4 and at 18 months following the death of a loved one, to determine how the change in symptoms differed between and among the four attachment styles. The people with dismissing-avoidant and secure attachment styles tend to display similar levels of resilience when faced with loss. People with a fearful-avoidant style of attachment showed the highest levels of grief symptoms over time. People with a preoccupied style displayed levels of grief lower than the fearful-avoidant style but levels significantly higher than the other two styles.

Disenfranchised Grief and Ambiguous Loss

Recently, several specialized concepts of grief and loss have emerged that have relevance to the discussion. Ambiguous loss and disenfranchised grief have been identified by separate theorists but are very similar in their characteristics. Losses are often not as clearly identifiable as death is. Individuals experience various types of losses that involve people, experiences, relationships, or objects. Many of these losses are not acknowledged by society as legitimate sources of grief (Betz & Thorngren, 2006). Unrecognized losses may include relationships that end, the loss of a job, physical or sexual abuse, physical disability, miscarriage, or chronic illness.

Boss (1999) defines ambiguous loss as “an incomplete or uncertain loss” (p. 5). She went on to identify two types of ambiguous loss. An individual may be perceived as psychologically present when he or she is physically absent. Examples include a divorced mother who does not live with her children or soldiers who are missing in action. The second type of ambiguous loss occurs when an individual is perceived as psychologically absent but they are, in fact, bodily present. Examples include loved ones with alcoholism or chronic mental illness.
Ambiguous loss presents families with a confusing situation (Boss, 1999). Because the loss is incomplete, such as a family member with Huntington disease, there is uncertainty about who is still part of the family and thus the families’ system of belief is threatened (Sobel & Cowan, 2003). Therefore, the family finds it difficult to make sense of the loss in the face of the ambiguity.

Doka (1989) defined disenfranchised grief as “the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported” (p. 12). He went on to identify three broad types of disenfranchised grief: 1) the relationship between the deceased and the griever is not recognized socially, 2) the loss is not recognized and acknowledged as important, and 3) the specific griever is excluded due to some specific characteristic of the individual.

Social support and cultural rituals are acknowledged as important for the successful alleviation of grief symptoms (Doka, 2008). Therefore when social support is not provided, one of the most powerful means of helping the griever is taken away. The griever may become isolated and the grief may become chronic and unresolved.

The concept of loss that is not socially recognized and acknowledged as significant is quite relevant to the present research. Doka (1989) gives a number of examples of losses which can be very profound for individuals but, nonetheless, are often dismissed by the social network of the person as relatively unimportant: perinatal death, abortion, giving up a child for adoption, loss of a pet. All of these losses are actual physical losses. On the other hand, certain types of losses are not socially recognized; they are not even considered real. There are many occasions when individuals experience a significant sense of death and loss even while the person is still alive. Doka & Aber (2002) referred to psychosocial death as “those cases in which the
psychological essence, individual personality, or self is perceived as dead, though the person remains alive” (p. 224). Because of the significant change in the individual, others may perceive the individual as dramatically different from the person they knew prior to the changes in that person. For example, the spouse of an individual affected by Alzheimer’s disease or severe mental illness may grief the loss of the identity and personality of his or her loved one even though the individual is still alive.

The theoretical concepts of disenfranchised grief and ambiguous loss hold great appeal to the present research; however, there has been very little empirical research into the validity of either concept. Families who have had children diagnosed with LQT syndrome have definitely lost something of the child that they knew but, of course, the loss is incomplete. Therefore, ambiguity may be present in the family system. Likewise, the losses the family experiences may not be recognized by their social support system as valid. The family may feel isolated and left to attempt to cope with the loss without their support network. Sobel and Cowan (2003) studied the experiences of disenfranchised grief and ambiguous loss in families who received predictive DNA testing to identify the presence of Huntington disease. This qualitative study used grounded theory methods to identify themes related to disenfranchised grief and ambiguous loss through semi-structured interviews. Through the use of the semi-structured interviews, they found that the families’ responses were consistent with Boss' (1999) definition of ambiguous loss.

The empirical research related specifically to the concept of disenfranchised grief includes Thornton, Robertson, & Mlecko's (1991) study of disenfranchised grievers and the levels of social support they receive from others. In the study, college students read six descriptions of an individual’s experience of grief. The situation was the result either of a
traditional loss or disenfranchised death (miscarriage or abortion). The students reported less sympathy and greater social distance from the disenfranchised griever.

In a qualitative study of a pet-loss support group, Weisman (1991) reported that those whose pet had died were hesitant to discuss the loss with others for fear of criticism, of condescending statements, and of harmful suggestions. An element of disenfranchised grief was indicated by the individual’s fear of reaching out for social support.

**Chronic Sorrow**

Simon Olshansky (1962) first used the term, chronic sorrow, in reference to the persistent psychological responses that he observed in parents of children who have serious mental retardation. He emphasized the fact that the parent’s reaction was an understandable and normal response to an overwhelming and tragic situation. Because the child’s problems are permanent, the experience of loss is ongoing. Therefore, the normal grief reaction related to loss is enduring throughout the lifespan of the child. Olshansky theorized that periodic and ongoing elevations of psychological distress are characteristic of chronic pain. For almost 30 years following this ground-breaking research, virtually no empirical studies attempted to follow-up on Olshansky’s work. In the 1990’s, however, interest began to re-emerge. Dozens of empirical studies have been conducted and published since 1990. The nursing profession, in particular, has been at the forefront of this research, focusing on the experience of chronic sorrow in persons and their families dealing with physical and mental disability and chronic illness (Ahlstrom, 2007; Copley & Bodensteiner, 1987; E.F. Hobdell & Deatrick, 1996; Hobdell et al., 2007; Lowes & Lyne, 2000; Northington, 2000; Wikler, Wasow, & Hatfield, 1979).
Susan Roos (2002), in her book *Chronic Sorrow: A Living Loss*, defines chronic sorrow as: “The essence of chronic sorrow is a painful discrepancy between what is perceived as reality and what continues to be dreamed of. The loss is ongoing since the source of loss continues to be present. The loss is a living loss” (p. 26). Because the loss is a permanent part of the person’s life, chronic sorrow continually requires energy from the person to negotiate the demands of the loss. The person must also deal with the cyclical and ongoing nature of the psychological and emotional reactions. Copley and Bodensteiner (1987), in their study of chronic sorrow in families of disabled children, are in agreement with Roos when they suggest that parents of most disabled children maintain a cyclical pattern through grief and are unable to bring about closure for their loss.

Whereas normal grief is precipitated by the death of a significant other, chronic sorrow is brought on by the permanent loss of a significant relationship (Wikler et al., 1979). The loss of a relationship may relate to the birth of a child with a physical or psychological disability or the diagnosis of a chronic illness. Although it is impossible to define what constitutes a significant loss related to a relationship for everyone, a parent’s experience of the loss of the “perfect” child when confronted with chronic illness of permanent disability presents them at high risk for chronic sorrow (Eakes, Burke, & Hainsworth, 1998). The emotional state of the person affected by chronic sorrow is characterized by significant variability, ranging from periods of happiness with the relationship to pain and sadness following internal or external triggers which remind the person of the losses intrinsic to the relationship (Teel, 1991). These fluctuations of moods help to maintain the cyclical and relentless nature of the problem.

Chronic sorrow usually involves elements of sadness; therefore it is often difficult to distinguish this type of sorrow from depression. Although there are similarities, the construct of
chronic sorrow is quite different from depression. Depression is a disabling and unhealthy
cognitive and affective response to a perceived loss. Chronic sorrow, on the other hand, is a
normal response to a permanent and ongoing loss in a significant relationship or life
circumstance (Freeman & Freeman, 2003). Although depression may be alleviated with
psychotropic medication or psychotherapy, a person suffering with chronic sorrow is rarely
helped by these treatments because the loss remains a significant part of his or her life.

Based on her research, Roos (2002) proposes a theoretical model of chronic sorrow that
is dimensional. First, the specific characteristics of the loss are determined both in objective and
subjective terms. Second, the loss must be perceived as ongoing rather than terminal. Third, the
loss must involve initial, continuing, and recurring grief reactions. The intensity of the grief
reactions is related to the degree of trauma, impairment, and ongoing social support. Fourth, the
level of disparity between the perceived reality of the loss and the ongoing subjective fantasy is
related to the object of the loss. Finally, the object of the loss must be continually present in the
life of the person.

Antecedents to chronic sorrow. As stated previously, the experience of a significant
loss is always the primary event that precedes the onset of chronic sorrow (Eakes et al., 1998).
The most common antecedent that precipitates chronic sorrow involves losses with no
predictable end. The antecedent can take several different forms.

The birth of a child with a mental or physical disability is a common event that brings on
The parents and other caregivers must continually confront the losses associated with fluctuating
or deteriorating health conditions and the ongoing stress and personal sacrifices that are part of
the caregiving process (Eakes et al., 1998; Roos, 2002).
The diagnosis of a chronic illness in a child or adult can also bring on symptoms of chronic sorrow in the caregiver (Ahlstrom, 2007; Lowes & Lyne, 2000). By definition, chronic illness has no predictable end. Actual losses associated with chronic illness include the ongoing deterioration of the person’s health and financial burdens (Eakes et al., 1998). Symbolic losses may include the loss of the hopes and dreams for the person and the loss of the family unit (Roos, 2002).

The loss can also produce unresolved disparity which may lead to chronic sorrow. Eakes et al. (1998) state that unresolved disparity “is created by loss experiences when the individual’s current reality differs markedly from the idealized, when the loss creates a gap between the desired relationship and the actual one” (p. 179). Unresolved disparity has been identified as an important attribute of chronic sorrow in several studies (Eakes, 1993; Hainsworth, 1995; Teel, 1991). Because of its progressive nature, the loss is often experienced in a gradual and inconsistent fashion.

**Triggers of chronic sorrow.** Throughout the experience of chronic sorrow, specific triggers have been identified; they sharpen the disparity that results from the loss (Eakes et al., 1998; Teel, 1991). These triggers may be the result of specific situations and conditions that make it more likely that chronic sorrow is expressed.

Individuals who are affected with chronic illnesses may experience disparity with social or developmental norms (Eakes et al., 1998). They may come to the recognition that they are isolated and stigmatized by society or that their ability to participate in society is limited. The person may also be unable to meet the predictable milestones of development. For example, an adolescent may be unable to participate in high school sporting activities because of limits imposed by his or her chronic illness.
These triggers are not limited to affected individuals. Members of the family are often confronted with disparities between the child that they had dreamed of and the actual child (Olshansky, 1962). For example, a father of a child with a physical disability may experience disparity when he sees another child playing baseball with his father and realizes that he will never have that experience with his own child.

Chronic sorrow has characteristics similar to disenfranchised grief. As with disenfranchised grief, the person enduring chronic sorrow has very few of the normal social supports and rituals associated with traditional loss (Roos, 2002). The source of the loss tends to be unrecognized by society. If the loss is unrecognized by those around those who are suffering, then grief remains unrecognized and unanswered.

**Anticipatory Grief**

Anticipatory grief has been described as an individual’s experience of the affective, physical, and cognitive responses associated with the anticipation of the death of a significant person (Corr & Corr, 2000; Rando, 1986). The concept of anticipatory grief was introduced by Erich Lindemann (1944) in a study of persons’ reactions to normal death. Lindemann focused on the process of grief work that an individual engages in when anticipating a significant loss. Since the introduction of the concept, research on anticipatory grief has centered, to a large extent, on the experience of women dealing with the death of their husbands (Parkes, 1970; Parkes & Weiss, 1983) and parents dealing with children who are terminally ill (Bozeman, Orbach, & Sutherland, 1955; Richmond & Waisman, 1955).

Research has provided inconsistent results concerning whether anticipatory grief is an adaptive or a maladaptive response (Rando, 1986). Lindemann (1944) suggested that negative
reactions to anticipatory grief may lead to early affective estrangement from the person who is
dying. Fulton and Fulton (1971) found that the experience of anticipatory grief has the potential
to minimize the normal grief response when the person actually dies. This may lead to social
disapproval or ostracism by those who might provide support. On the other hand, other studies
have indicated that there are significant positive effects of anticipatory grief. Having the ability
to anticipate the death of a significant individual may allow families the opportunities to “say
goodbye” to the dying individual and allow for completion of relational tasks (Byock, 1997;
Corr, 1992). Therefore anticipatory grief has the potential to result in a healthier process of grief
for the family following the person’s death.

Therese Rando (1986) provided a thorough analysis of anticipatory grief in her book, Loss and
Anticipatory Grief. In defining anticipatory grief, Rando emphasized the
multidimensional nature of the concept. Since the significant loss has yet to occur, the grief is
normally experienced from two different perspectives: the dying individual and those who hold a
significant relationship with that person. The term “anticipatory grief” implies that a future loss
is being grieved; in fact, grief is experienced by losses that have happened in the past, those that
are presently occurring, and those that have yet to happen. Finally, the experience of anticipatory
grief is influenced by psychological, social, and physiological factors in complicated ways.

Rando (1986) defines anticipatory grief as “the phenomenon encompassing the processes
of mourning, coping, interacting, planning, and psychosocial reorganization that are stimulated
and begun in part in response to the awareness of the impending loss of a loved one” (p. 8). The
process of anticipatory grief entails balancing the difficult needs of remaining attached and
letting go of the dying person.
Cultural and developmental issues can affect the ability of individuals and families to process the news concerning the future loss and thus shape the overall trajectory of grief (Die-Trill & Holland, 1993; Rando, 1986). The ages and developmental levels of the persons affected by the impending loss can interact with the specific types of illness in determining the experiences of those involved (Rolland, 1994). For example, the experience of grief in a family of a young adult who is dying is likely to be very different from the experience for families of a young child. The level of communication and active involvement is likely to be higher for the family of the young adult because of the overall perceived level of maturity.

Futterman, Hoffman, and Sabshin (1972) found that, for parents of a terminally ill child, the process of anticipatory grief has the potential to lead to moderate amounts of detachment from the child. On the other hand, parents were able to maintain the overall care and nurture of their child.

**Summary of the Literature**

A substantial amount of the research literature related to chronic illnesses in children focuses on the psychological distress that parents experience relative to the child’s diagnosis and long-term prognosis. Caregivers of children with chronic illness tend to experience acute anxiety related to their child’s initial diagnosis and treatment outcome. Caregivers of children with chronic illness express themes related to the experience of loss and grief. These themes relate to the loss of a normal life, the loss of the caregiver’s hopes and dreams for the child, loss of activities, loss of relationship, etc. Caregivers’ experiences of loss and grief have been identified in the stages of initial diagnoses and treatment as well as in later stages of managing and coping.
with the illness. Although there are differences in the presentation of most of the chronic illnesses in childhood, compared with that of LQTS, there are significant similarities including the initial reaction to diagnosis and long-term caregiving needs.

Psychological theories related to grief and loss have evolved since Freud’s initial efforts to understand grief and the need for grief work. Theorists understand that individuals not only experience loss and grief in relation to the death of significant persons but also when they experience dramatic and chronic changes in significant persons. Grief reactions do not necessarily progress in predictable stages. Loss associated with chronic illness may be experienced not only in the initial stage of adjustment of the illness but may also recur throughout the progression of the illness. Periods of relative happiness may alternate with periods of sadness as internal and external triggers remind the caregiver of the losses that they continue to experience.

A review of the literature has indicated that the psychosocial experiences of individuals affected, directly or indirectly, by Long QT Syndrome are an area of research that remains largely uninvestigated. Specifically, the constructs of loss and grief in those affected by LQTS have received no attention. Specific features of the syndrome have been identified; these encourage further research into various psychosocial factors potentially related to LQTS. LQTS is a chronic illness that represents major lifestyle changes not only for the one diagnosed with the syndrome, but also for the caregivers. Likewise, the potential for traumatic physical events associated with LQTS may produce significant psychological distress in those affected by the disorder. This study represents an initial effort to identify and understand the experience of grief and loss in individuals affected by LQTS.
Chapter 3

RESEARCH QUESTION

The focus of this study is on one question. What are the experiences of grief and loss for individuals affected by LQT Syndrome as communicated via internet message boards? The goal of this study is to describe the grief and loss reactions of user group participants.
Chapter 4

METHODOLOGY

Overview

Two major research paradigms have been used extensively within the field of psychology: quantitative and qualitative (Kazdin, 2003). Scientists, though, have tended to view the quantitative research paradigm as the only legitimate approach to research. Quantitative research rests in the positivistic tradition and uses, among other things, careful control of the subject being investigated, quantification of constructs, and methods of statistical analysis. Qualitative research, on the other hand, rests on the notion that the world is complex and, therefore, straightforward and simple explanations of phenomena are rare (Corbin & Strauss, 2008). Qualitative methodology attempts to work with the complexity of phenomena rather than attempt to simplify and sanitize it. The qualitative researcher must be willing to enter into the world of the phenomena under investigation and use all of his or her senses to gain a complete picture of the subject.

The value of qualitative research has come under scrutiny in many scholarly circles as not being a legitimate research methodology. Because of the underlying criticism, the qualitative researcher must bear the burden of articulating the value and logic of the research design. The quality of the research must be explained in a manner that will be judged sound by those who might benefit from the research (Marshall & Rossman, 2006). The present study is part of a
larger study designed to gain understanding of quality of life and related issues in the LQTS population. This specific study seeks greater understanding of the grief and loss experiences of individuals who have been affected, directly or indirectly, by Long QT Syndrome as expressed via internet message boards.

The process of understanding the experience of grief and loss in LQTS family members via an internet user group is best accomplished by analyzing and interpreting archival data obtained from the message board. The vast amount of data available through the message board provides a tremendous resource for understanding the phenomena under consideration. The writings and interactions of the message board users may reveal potential patterns of themes related to grief and loss.

Qualitative methods will be used to explore the themes related to experiences of loss and grief of the user group participants. Exploratory methods will be used because there is minimal research into the psychosocial factors of families affected by LQTS. Because LQTS is a relatively uncommon medical disorder and because there are very few physical support groups for families, the utilization of an online message board will provide a unique opportunity to explore the experiences of a broad cross-section of the LQTS population.

Design and Design Justification

The design of this dissertation is focused in qualitative research methodology. As defined by Corbin and Strauss (2008), qualitative analysis is “a process of examining and interpreting data in order to elicit meaning, gain understanding, and develop empirical knowledge” (pg. 1).
Although there are a wide variety of differences within the practice of this methodology, Denzin and Lincoln (2005) characterize qualitative research as:

a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researches study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meaning people bring to them (p. 3).

The goal is, through analysis and interpretation procedures, to make the world that is being investigated clearer and more understandable to the outside observer. In this specific study, the goal is to understand the patterns of grief and loss of family members affected by LQTS.

The study will use archival data. Qualitative research of archival data downloaded from this specialized message board will provide a unique opportunity to gain a deep understanding about the interactions of the message board users in their natural setting. The large number of participants on this message board allows for a broad exploration of the experience of grief from various cultural settings around the world.

The design of this study will allow for the possibility of addressing the key characteristics of qualitative research. All research must ensure that the findings of the study, whether qualitative or quantitative, are trustworthy or, as Marshall and Rossman (2006) say, the research must reach the “criteria of soundness” (pg. 200). They outline four characteristics of quality qualitative research: credibility, transferability, dependability, and confirmability. Each of these constructs will be an integral part of the design of this study and will inform the research throughout various stages in order to avoid poor analysis, bias, and data mismanagement.

Internet based research methodologies have been separated into three distinct types: passive analysis, active analysis, and interview and surveys (Eysenbach & Till, 2001). The
current study will be using passive analysis. Passive analysis studies data obtained on web sites or discourses in user groups and chat rooms without the active participation of the researcher in the site (Eysenbach & Wyatt, 2002). Examples of this type of study include the work done on support mechanisms and online support groups for breast cancer (Sharf, 1997) and Alzheimer’s disease (White & Dorman, 2000).

Grounded theory will be used to generate a theory from the data (Corbin & Strauss, 2008). After the data have been collected, the researcher analyzes the data and identifies themes that arise. From these themes, categories are developed, which form the basis for developing a theory. The theory is, therefore, grounded in the data.

**Participants**

The research participants for this study were drawn from an online message board for individuals who have been affected directly or indirectly by Long QT Syndrome. The persons have self-selected to be involved in the internet-based message board formed to support individuals affected directly or indirectly by LQTS.

An internet-based message board was chosen for this research project because LQTS is a relatively uncommon disorder and face-to-face support groups for families affected by this disorder are rare. Approximately 780 individuals from around the world participated in this message board at the time of the study. Therefore, the site provided a very large cross-section of the LQTS population. All individuals who have decided to be involved in the user group by posting messages on the site were included in the study. No user group participants or entries were excluded from this study, unless they do not contain information about grief or loss.
The internet-based message board is composed of messages written by individuals affected by LQTS or interested in LQTS. The term “message” refers to individual posts that are contained in a thread. The message contains the information written by the user and the user’s identifying information, as well as the date and time it was submitted. The term “thread” refers to a collection of messages, normally displayed from oldest to newest. A thread is defined by a title and an opening message.

The data to be used in the research are archival and are available to the public through the internet. This user group has been in existence for nearly a decade and the moderators of the group have given permission to analyze the data. The data utilized in this study included all messages posted on the user group during the months of February and September 2008. The decision was made to limit the data to two months of messages because of the high volume of messages posted monthly. The month of February was selected, based on proximity to the December holiday season, and because it is nationally known as “Heart Month.” The month of September was selected, based on potential concerns related to summer vacation and the beginning of the school year.

The moderators of the message board have been contacted and permission was requested and granted to download messages from the board for analysis. Very little demographic information is volunteered on the message board. Therefore demographic information of individuals included in this study, for the most part, remained unknown to the researcher, although geographical information that is available was reported as a whole. This specific study was approved by the Institutional Review Board as part of the larger study of LQTS.

The study will focus on persons who have been diagnosed with LQTS and on their family members. The participants, identified by pseudonyms, will be selected, based on identified
language related to loss and grief expressed on the message board. The participants’ discussions of loss and their cognitive, affective, and behavior responses with other message board users will be a focus of exploration.

**Measures**

Although quantitative research attempts to use objective instruments to measure the constructs in question, qualitative research relies on the researcher as the sole instrument to measure the phenomena in question (Corbin & Strauss, 2008). Therefore, it is essential to understand the method of gathering data by the researcher.

The vast amount of data entails eight years of messages that were posted by approximately 780 message board users. Decisions have been made throughout the process of analysis to limit the amount of data, based on the number of messages identified that fit the constructs to be examined and also when the themes have reached a saturation point.

**Data-analysis Procedures**

The data to be analyzed were downloaded from the archives of the user group. One month of entries was downloaded at a time and copied onto a Word document. A copy of the entries was given to two teams of four coders who then proceeded with data analysis. Coders were advanced doctoral candidates and two psychologists. Each individual coder analyzed the entries separately. Individual coders identified general themes related to grief and loss, as expressed through the entries. The coders then met as a team and analyzed the data a second
time. They discussed the themes that were uncovered and worked toward a consensus, based on their individual work. The researcher then analyzed the results of the coding and generated specific categories and themes related to grief and loss that emerged. Throughout the process of analysis, the researcher developed integrative interpretations of the themes that emerged. Through the process of interpretation, the researcher started to bring meaning to the themes and eventually developed an orderly and coherent story line (Marshall & Rossman, 2006). The results of the interpretation were brought together into a manuscript. The manuscript will be submitted to the moderators of the user group for comments, criticism, and feedback before potential publication of the manuscript.

As themes related to grief and loss began to emerge, the researcher kept a record of the frequency with which specific themes occur. The researcher counted the number of occurrences of each theme and reported the results in the manuscript. This process added a quantitative dimension to the research.

Qualitative archival research deals with large amounts of data. The data, therefore, must be maintained in an organized manner (Marshall & Rossman, 2006). When analyzing specific data, a log was kept which recorded the date, time, place, and activity in which the researcher was engaged. Careful notes were taken during each period of analysis and recorded in a specific notebook. Data were organized and themed using a coding procedure that uses different colors to identify specific themes (Corbin & Strauss, 2008). A journal was maintained throughout data analysis in order to self-reflect, continually on personal biases that may be informing the analysis.
Informed Consent Procedures

The message board that is being studied is a public message board. The data that is being examined are archived by the message board. All identifying information such as email address, full names of the user, and names of medical doctors will be blacked out at the initial stage of research. There are no evident hazards to the participants in the user group because no personal information will be described. The researchers approached the moderators of the board to ask their permission to analyze the messages. The moderators, after having been assured that the information examined would be held in strict confidence and that moderators would have the opportunity to examine any final document prior to its being made public, gave their permission on behalf of the message board group. A decision was made with the permission of the moderators not to approach message board users individually to obtain their informed consent because of ethical considerations and because of the risk of threatening a safe environment for the participants (Eysenbach & Till, 2001). As stated previously, the moderators will have the opportunity to examine any document produced from studying this data prior to its being made public in order assure that the best interests of members of the user group are maintained.

Trustworthiness

In a quantitative research study, the truth of the study is related closely with internal validity. For the qualitative researcher, the corresponding construct to internal validity is the credibility of the research. The goal of credibility is to determine that the study has been
“conducted in a manner as to ensure that the subject was appropriately identified and described” (Marshall & Rossman, 2006, pg. 201).

In order to safeguard the credibility of the research, the researcher will continue to analyze data until the point of saturation is reached. The researcher will attempt to minimize distortions in data analysis through the use of a peer coding team. The coding team of three peers will analyze data sets separately and, then, as a group, compare analysis to determine consistency on the coding. A self-reflection journal will be used throughout the study. The journal will include thoughts, decisions, and questions related to the ongoing process of the research.

Because the data are archival, potential problems in gathering the data should be minimal. A tremendous amount of archival data is available for this research. Therefore, decisions need to be made about those data to be included and those to be excluded. A careful record will be kept of this decision-making process throughout the study.

The current study intends to produce information that will be transferable to similar settings with similar questions (Marshall & Rossman, 2006). Generalizability has been viewed as a weakness of qualitative research. To counter this problem, the research intends to refer, continually, to the theoretical framework upon which the research has been built.

Qualitative research should always attempt to account for changes in the phenomenon that is being examined (Marshall & Rossman, 2006). The data to be analyzed in this study are archival; therefore, there is minimal potential for changes in the phenomenon.
GRIEF AND LOSS

Personal Biography

In quantitative research, the researcher is expected to maintain an objective distance from the study participants. In qualitative research, on the other hand, “the researcher is the instrument” (Marshall & Rossman, 2006, pg. 63) of the research and, therefore, intimately involved in the lives of the participants. The researcher’s presence is not unwelcome; instead, it is viewed as a fundamental element in the methodology. Therefore the researcher must constantly evaluate ethical issues and personal biases that may impact upon the participants and the study. Although the researcher in this study will not be interacting directly with participants, nonetheless he will be immersed in their personal stories.

The primary researcher comes to this study as a middle-aged Caucasian male. He is married with two grown children. He has worked as a Christian clergyperson for the past 20 years and is studying for his doctoral degree in clinical psychology. He lives in the United States and has traveled overseas on several occasions. The individuals who use this message board are able to access it from all over the world. Therefore, a vast array of worldviews and cultural perspectives are, undoubtedly, expressed via the message board. The researcher must keep in mind his cultural perspective and worldview that have the potential to bias his work with individuals from other religious and cultural perspectives.

This researcher, as a child, experienced the death of a significant family member. The cognitions, affect, and behavioral responses that surrounded this experience played an important role in defining the direction of the researcher’s life. As a teenager the researcher began the pursuit of a career as a professional, ordained clergyperson. Throughout the subsequent training and career, the importance of responding effectively and compassionately to individuals’
experiences of grief and loss was paramount. He witnessed and walked with many individuals 
and families dealing with death in a broad variety of circumstances. The subsequent grief 
experiences and attempts to cope with the loss have always held both personal and professional 
interest.

The researcher has witnessed the traumatic nature of families grieving the sudden loss of 
a child or adolescent whether through accident, illness or suicide. He has observed a few parents 
successfully achieve some sense of normalcy following the death. On the other hand, he has 
observed many other parents struggle to cope with the reality of their loss individually and 
relationally. Parents have divorced in large part, based on the stress of their loss. Individuals 
have become preoccupied with the memories of their child and have lost the ability to function in 
adaptive ways in their everyday life. It has been challenging to care for these families in the 
midst of their grief.

The researcher has counseled parents of children who have been diagnosed with cancer 
and with other chronic illnesses. The parents’ experiences of the loss of their hopes and dreams 
for their child have been quite apparent as they struggle to cope with this new reality. Although 
the researcher has no personal experience of childhood chronic illness, his professional 
experience has been an important factor in his interest in this topic.

The researcher is a male and a father, and therefore, approaches the topic from that 
perspective. Many of those who utilize the message board will be mothers. Their experiences of 
attachment and loss may be more profound, in some ways, than fathers who have lost children or 
who have dealt with the losses associated with childhood chronic illness. As is the case with 
most parents, the researcher has endured traumatic situations with his children and has an
understanding of the feelings of panic and helplessness that parents inevitably experience in similar situations.

**Procedures for Maintaining Confidentiality**

Confidentiality and privacy are essential for any research study. Therefore, individuals using the internet for the basis of their research need to be aware of the dangers of unintentionally violating the privacy of participants (Eysenbach & Till, 2001).

The issue of whether or not user groups are considered public or private is an important consideration for the internet researcher. The level of privacy of a particular user group is determined by the number of participants in the user group (Eysenbach & Wyatt, 2002). For example, a large community (i.e., 800 participants) is considered to be a relatively public community, whereas a group with only 25 participants is considered a private community (Mann & Stewart, 2000).

Because this particular study uses archival data, informed consent was not required (Eysenbach & Till, 2001). Nonetheless, the three moderators of the user group were approached and asked for their consent to proceed with the analysis as part of the larger study. The moderators agreed to allow the data to be used for the purpose of this study.

The individuals whose messages will be included in this study have not given their consent for inclusion within this study. They are participating in a user group with the probable assumption that their personal information will be held in confidence. Therefore, strict confidentiality procedures are essential.
Although very little identifying information is expressed on this message board by the users, information quoted in the dissertation and then subsequently published has the potential for providing enough information to uncover the identity of the user. Therefore, when handling the data, any identifying information such as full names, email addresses, etc. was blacked out prior to reading messages. When discussing a participant, a pseudonym was used rather than their identifying user name. Careful attention was given to the use of actual quotes from participants. In many instances, actual quotes were not used in order to reduce the potential for identification of the participant. When quotes were used, any unique or identifying words were altered.
Chapter 5

RESULTS

Living with the Loss

In this section, themes related to perceived losses encountered by individuals living with or caring for children affected by LQTS will be reported. The two major themes expressed on the message board relate to the loss of a “normal” life and the loss of physical activity. These individuals were faced with the reality of dramatic changes in their families’ lives due to the initial diagnosis or to ongoing adjustments in their lifestyles precipitated by the disorder. Although most of the individuals had adjusted to their own personal lifestyle changes, several individuals expressed the desire that their child would be able to live a normal life again. One parent placed limitations on her child’s activities for the child’s safety and she struggled with the implications of this limitation and what these might mean for her child’s ability to live a normal life in the future. Other individuals grappled with the imposed limitations on their physical activity as a result of LQTS.

Loss of a Normal Life

**Jennie’s story.** Jennie’s school-aged son, Paul, was diagnosed with LQTS and the family was starting to adjust the diagnosis.\(^1\) The decision was made to allow Paul to continue in all of

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\(^1\) Please note that certain characteristics of the user group participants and their family members were changed to mask their identities. For example, all participants were de-identified at the outset of the study. All name of individuals identified in the body of the messages were given pseudonyms. Some descriptions of geographical locations were altered to protect identities. Finally, the gender of some children was changed.
the activities that he had been involved in prior to the diagnosis. Jennie indicated that the family was “living life pretty normally.” The only significant change following the diagnosis was that Paul’s parents monitored him very carefully during physical activities.

Jennie indicated that life was getting back to normal, then “Wham!” One day at school, Paul was at his desk in the classroom when he suddenly fell out of his desk and hit his head. Reports from two of Paul’s classmates indicated that he just slumped over. Paul’s teacher quickly attempted to assist him, but Paul was already recovering and attempting to get back up. According to Jennie, Paul could not remember hitting his head when he slumped over but he had a bruise on the side of his face. Paul indicated that he “felt funny” prior to hitting the floor. When the school contacted Jennie, they assured her that Paul was doing okay and that he was on the way to the hospital. At the hospital, it was discovered that his blood sugar was low and his QT wave was longer than normal. Jennie wrote, “They monitored him at the hospital for a couple of days and things started to normalize (as normal as it gets).” Paul was fitted with a holter monitor for home use and was required to return to the hospital daily for a new monitor.

Following the episode, Paul’s original EP no longer felt comfortable treating him because he specializes in adults and, therefore referred him to a new EP. Jennie stated, “I’m scared that things will change drastically. You know we have tried to be extra careful every time he does something physical and then he just passes out sitting at his desk.” She is now required to check Paul’s glucose monitor every morning because fluctuations in glucose levels is sometimes a side effect of beta blockers. She stated, “He stated that he just wants to be like everyone else. I might be jumping the gun a bit and maybe things will go back to normal after we change a few things with his betas but it is hard to be optimistic.”
Ann’s story. Ann’s daughter, Kate, suffered a sudden cardiac arrest when she was two years old during a bout of stomach flu. The cardiac arrest was the first symptom of LQTS that she experienced. She was life-flighted to the local trauma hospital. Even at the hospital, a crash cart was constantly next to Kate’s crib for several days in the ICU because they had difficulty stabilizing her heart. Kate, who survived the arrest is now five years old, and is the only one of Ann’s five children who has been diagnosed with LQTS. She was diagnosed with LQT type 3. Kate’s EP advised her parents to wait until she is older to get an ICD implanted. Therefore her LQTS is managed by medication. She is unable to take her medication when she is sick or dehydrated. She also has an automatic external defibrillator.

Kate’s symptoms have tended to occur when she is resting or sleeping. Therefore, she always sleeps in the same bed with her parents. The change in Kate’s parents sleeping arrangement was initially difficult for them, “but not having her next to us makes us so nervous we can’t sleep anyway.” Ann acknowledges that this change has also been difficult for the rest of their children. Ann stated that, “The younger ones (now ages 2 and 6) didn’t understand why she gets to sleep with us.” As a result, their six-year-old also sleeps in the parent’s room. Ann wrote, “It was never the way we raised our children before, but we have learned to make adjustments.” Once Kate is old enough to have an ICD implanted, they intend to allow her to sleep on her own, “before she is at an age where having her sleep with us becomes awkward.”

Kate’s EP clearly expressed the implicit problems with implanting ICDs in children as young as she. So they have decided to wait until she is older to get an ICD implanted. In the meantime, Kate is dependent upon the automatic external defibrillator in the event of a cardiac arrest. This reality has forced Kate’s parents to be very vigilant with her. Ann stated that, “We are okay with an AED for now since we never let Kate out of our sight.” Ann, in fact, is a stay-
at-home mother, and as stated previously, Kate sleeps with her parents at night. When Ann needs to use the restroom or take a shower, she has one of the older children look after Kate. Kate’s EP acknowledged that depending upon an AED demands a high level of responsibility on the caregivers and may lead to difficulties with stress on the part of these caregivers.

Because Kate’s parents are always vigilant for future cardiac events, they prefer to stay close to their hospital. They, therefore, never travel far from their home. They take the family only to the nearest city, one hour from their home, to the zoo and museums. Ann indicated that her family used to travel frequently to various destinations including Europe and many locations in the United States. Ann stated, “All of that has stopped.” They even decided to sell their property because it was located too far from the hospital. Instead, they built a guest house on their property so that friends can visit them because they cannot travel to visit their friends anymore. They worry about taking Kate to public places such as Chuck E. Cheese because they fear she will come down with the stomach flu again. So they use the guest house for children’s parties. Ann and her husband never go out on dates anymore. She stated, “Life has definitely changed.”

Ann described the new reality of their home life. She acknowledged that Kate has become the focus of the family life, and will remain so until she is old enough to have the ICD implanted. Until then, she wrote, “We have committed as a family to doing everything we can to keep her safe until that time.” She realizes that her family life is far from normal. In fact, she feels that some people believe they are “crazy”. In reality, Ann stated, “If you had asked me what our lives would have been like (two years ago), I could never have imagined this.”

Lisa’s story. Lisa’s daughter, Amy, received an invitation to a birthday party where there would be swimming. Neither Amy’s age nor type of LQTS is disclosed in the message thread.
Lisa does indicate that Amy is young. Because cardiac events are often precipitated by swimming, Lisa is concerned that Amy will not be monitored closely enough at the party and requested that she could come to the party as a “lifeguard”. Lisa was notified that adults were not invited because there would not be enough food.

Lisa was concerned that the adults present at the party would not understand how serious the health concerns were related to LQTS and would allow Amy to swim. Therefore, Lisa felt that she could not allow Amy to go to the party. Lisa asked, “Do I ruin Amy’s social life so early by banning her from swimming parties? Do I tell the mom, it’s OK, I won’t even ask for a glass of water? P.S. Why is it so bloody hard to have a child with LQTS?”

**John’s story.** John posted a thread on the message board inquiring about various food and drink issues related to LQTS. Janet posted a response that warned John about any kind of drinks with caffeine, including energy drinks because caffeine tends to increase the heart rate which can be dangerous for individuals with LQTS. She also warned him to avoid grapefruit because it can interfere with the effectiveness of beta blockers. In response John indicated that “Cheese kick’s my heart off, not all the time just now and again.” He also indicated that he is intolerant of beta blockers, so he is unable to take them. He stated, “I don’t have anything to help me!”

**Linda’s story.** Linda was told only a few days prior to leaving for a six month stay in British Columbia that she probably has LQT4. She will be having further tests after she returns to her home in France. She is quite physically active and became very dizzy one time while playing soccer in British Columbia. She emailed her cardiologist about the event and he required her to start taking beta blockers. She expressed concern about taking the beta blockers. She stated, “I really like sports and with the beta blockers I find it hard to do that because my heart
rate won’t go up, so my legs tire a lot quicker.” She questioned the other message board users if anyone else felt really dizzy when they startle. She reported feeling dizzy while swimming underwater. She took Ciloxan following laser surgery on her eyes and reported almost fainting every time she used it. She wrote, “I’m just wondering what life will bring if I really have LQTS; do I need to change a lot of things?”

Other individuals responded to Linda’s inquiries on the thread. One person wrote, “Hi. The bad news is that you may have some changes in your life. The good news is that you will have a life. It is a difficult trade off for some.” Linda responded by writing, “Thanks for those wise words, it is hard for me, not knowing.” She indicated that her father died in a car accident under strange circumstances. He had been in an accident prior to the fatal accident. She wonders if he had LQTS. She also indicated that both her mother and sister fainted frequently. She still is holding out hope that further tests will indicate that she does not have LQTS.

In response to further advice on the thread of messages that she should take her beta blockers, Linda indicated that she realized that it is important to take them, “but I hope it is not the definitive solution.” She went on to write, “I hope that the tests in December say I don’t have LQT but the longer I think about it the more I’m convinced that I have it; there were too many symptoms the last few years that point in that direction without even knowing it.”

Karen’s story. Karen shared her ongoing problems with her ICD. She had her first ICD implanted at the age of 14. The ICD was placed in her abdomen because she was a very thin child and the device was too large to be placed in her chest. At the age of 16, the lead of her ICD fractured. Therefore she had another ICD implanted along with a new lead. The second ICD lasted five years and was replaced. The third ICD was replaced, she said, “A year or so later fluid leaked into the device because the docs tried a new hook up system.” Several years later the
second lead fractured and they replaced the fourth ICD and the lead. Her fifth ICD was recalled and replaced with her sixth and present ICD.

Over the span of 15 years, Karen has had six different surgeries related to her LQTS. Although she recognizes that her ICDs have undoubtedly saved her life, the ongoing complications and surgeries interfered with her ability to lead a normal life as an adolescent and young adult.

**Loss of Physical Activity**

**Catherine’s story.** Catherine introduced herself on the user group as a person just recently diagnosed with LQTS. She is a 41 year old woman from Alabama. As with many others who join the user group, Catherine proceeds to write in detail about her personal story. She related that at the age of 13 she was diagnosed with a heart murmur and sinus tachycardia. Since these early diagnoses, she has had multiple episodes of syncope which, in most instances, were treated by a physician. The cause of these episodes of syncope was assigned to several different medical issues including hypoglycemia, seizures, and rheumatic fever. Three years ago she was diagnosed with fibromyalgia, neuropathy, and Epstein-Barr syndrome. She has ongoing difficulty with serious episodes of fatigue, “that keep me in bed for days at a time.”

Catherine recently experienced another episode of syncope and was taken to the local emergency room by ambulance. She wrote that her heart was “tachy” and she was experiencing severe nausea and mild chest pain. She was given an EKG which revealed a long qt interval. Subsequently she was admitted to the hospital for observation. She was on multiple prescription medication including Prozac, Methadone, and Levaquin to help her recovery from pneumonia.
She was released from the hospital the following day but returned to the emergency room two more times over a two week period.

Catherine wrote that the physician “in charge of my care felt the long qt was brought on by the methadone and weaned me off of it over a 10 day time frame.” She was finally referred to a cardiologist who set up a battery of tests. One of the first things that her cardiologist did was to show her an ICD and explain its function to Catherine and her husband and indicated that she might need to have one implanted. She wrote, “I have to say that I was floored by what he said.” Because the physician at the hospital had given her the impression that her long qt interval was due to the methadone, she assumed that her qt interval would return to normal after she went off the methadone. Her cardiologist, though, explained that once she was diagnosed with LQTS she would always have it.

**Susan’s story.** Susan’s 15-year-old daughter was diagnosed with LQT5 at the age of 13. Susan has been frustrated in her attempts to gather information on LQT5. Her daughter had a syncope episode while swimming competitively. Susan had her daughter tested following this episode. Following her diagnosis, she was placed on beta blockers and has not had another syncope episode.

Susan responded on the message board to another thread because she has been unsuccessful in finding any reliable information on LQT5. She is most concerned about identifying possible triggers for LQT5. She questioned whether or not her daughter’s blackout was actually related to LQT or may have been the result of overtraining and dehydration. Susan’s younger daughter’s QT interval has been tested every six months and, until recently, has been normal. The younger daughter’s most recent ECG, though, looked suspicious.
Susan’s older daughter was a competitive swimmer at her school. Susan wrote, “She hasn’t swum competitively again and she’s very moody, but I reckon that’s more hormonal and the swimming restrictions than the side effects of the betas.”

**Tina’s story.** Tina has LQTS and has an ICD implanted. She is concerned about the potential harm that her ICD might do to her cat if it fires while the cat is on her lap. Although other message board users are able to reassure her about this concern, one individual mentions that if Tina lives a “simple lifestyle” then she will be fine. Tina responded by writing, “I don’t plan on living a “simple” lifestyle. I bike or jog everyday (I did intervals the past two days) and love basketball. I also just signed up for flag football (I’m thinking about wearing some under armor chest protection for the ICD). I think I’ve said this about a million times on this site to the chagrin of some of the others, but I agreed to the betas and the ICD as a safeguard with the intention of continuing my active lifestyle.”

Tina claims that her EP told her that she could still engage in physical activity but warned her against certain types of weight training. She struggled with this limitation because she likes to engage in weight training. She has followed her doctor’s orders and uses only light weights or does pushups. She continues to be resistant to restricting her physical activity any further. She wrote, “Now maybe I will stop in my tracks and completely change may attitude when Kevin (the name of my ICD) decides to sock (sic) me, but until then I’m going hardcore. I just figure I’d better be prepared for the big one.”

In response to another poster’s frustrations with the physical activity restrictions placed on him, Tina expressed her own frustrations. She stated, “Yeah, it’s frustrating as the recommendation to keep heart, bones, muscles strong and healthy is to weight train and do
cardio, but then we’re “limited” with this stupid condition. I figure I’ll take my chances with the condition since I have the ICD and betas and work on the other.”

Allison’s story. Allison’s six-month-old son, Andrew was diagnosed with LQTS during the first few hours following his birth. He did not test positive for any of the known genetic mutations for LQTS. She claimed that no one in her family or her husband’s family have displayed symptoms related to LQTS. She is struggling with accepting that her son, in fact, has LQTS because the genetic tests were negative for any of the mutations. She stated, “Telling me that he has LQT because he has SOME points on the clinical test leads me to be very resistant to accepting the diagnosis.”

Allison and her husband are lifelong competitive athletes. They lead very active lifestyles. She struggles with the notion that if her son does have LQTS, then he would not be able to participate in the same level of physical activity that they enjoy. She wrote, “You might think that maybe our son wouldn’t have wanted to join in the activities that every single, dingle member of his immediate and extended family participate in on a daily basis. But, for him to not even have that choice is heartbreaking. I can’t imagine that he won’t feel odd or different, knowing that everyone he is related to plays competitive sports but he can’t.”

Allison struggles with the decision about whether or not to have another child. She indicated that she and her husband have not made a decision at this point. If they did decide to have another child and he or she turned out not to have LQTS, then she worries that, “his or her health would magnify all the things that Andrew can’t do.” She indicated that although she rarely worries that Andrew might die anymore, she still struggles with what his quality of life will look like as he grows up. She wrote, “The precautions we will take will keep Andrew alive (we hope), but, at what cost? Do I want to have another child with the same limitations?”
Allison reflects some concerns related to loss of normal life. In particular, she struggles with the adjustments that she has had to make in caring for her son. She is required to wake him twice every night to give him his beta blockers. She wrote, “It isn’t as if we thought we would get a lot of sleep with a newborn, but, it is hell to wake up a sleeping baby to give him his meds – we both usually end up crying. And, there is no end in sight to the nightly lack of sleep even if he COULD sleep through the night.”

Sarah’s story. Sarah’s ten-year-old son has been diagnosed with borderline LQTS. He is athletic and, “is allowed to run because his condition improves with exercise (very unusual!).” He is required to follow a strict regimen of supplements, diet and hydration. They also have a portable defibrillator in case of a cardiac episode. At this point he enjoys running and is successful at it. She wrote, “His EP has told us as he gets older he will probably not be able to run anymore.”

Although Sarah’s son has been diagnosed with LQTS, he has been allowed to continue his involvement with vigorous physical activity. Sarah anticipates that this is only a temporary situation and eventually he will be required to give up running, which has been a very important aspect of his life.

Emotional Reactions: Grieving the Loss

Denial

Andy’s story. Andy had been searching for support and advice on Long QT Syndrome for a long time. He expressed gratitude to the other message board users for finally giving him the advice and support he had been searching to find. Andy’s son, Jimmy, was diagnosed with
LQTS two years ago. Jimmy is taking beta blockers and his parents are considering having an ICD implanted. Andy admits that they are “still having problems accepting it.” Jimmy is also deaf. Andy, himself, and his daughter also have been diagnosed with LQTS but neither of them displays symptoms of LQTS. Both Andy and his daughter have normal ECG. Andy states that he “feels punished” with all of these LQTS-related problems in his family.

Andy admits to being confused by the various types of LQTS and has had a difficult time getting advice or support. He claimed that following Jimmy’s diagnosis the hospital did not offer any support, counseling, or advice. He said that we were “just left to find out ourselves.” He indicated that they inquired into other heart organizations but they “do not really know enough to give advice about long qt so I am hoping people out on this site can give me some idea of situations/experiences that you have.” Although he claims to have an understanding of the dangers associated with LQTS and what to do for his son, he is attempting to understand whether or not individuals have cardiac events while on beta blockers and also about the reliability of ICDs.

Although Andy has followed through with all of the medical advice concerning Jimmy’s treatment and is considering having an ICD implanted, he admitted that even two years following the diagnosis, he continues having difficulty accepting what the diagnosis means for his son, his daughter and himself. In some ways, emotionally, Andy may be hanging on to the image of his son prior to the diagnosis and denying the losses associated with LQTS. There are even possible feelings of anger and frustration indicated by his admission that he “feels punished.” He seems to understand that the lack of support during the initial diagnosis has not allowed him to fully accept this new reality. He seems to be seeking the support and the stories
of others who have gone through the diagnosis and adjustment as a means of accepting what this means for his children and himself.

In another thread, Andy talks about the realization that Jimmy will need to have an ICD implant. Andy and his wife have been struggling with the decision to have the ICD surgery even though Jimmy “has been fine.” Andy is concerned about the emotional impact that the surgery will have on his son. In fact he indicated that he talked with Jimmy about the ICD and Jimmy “says no way he wants it…and you know the funny thing in Scotland, the child has a right to refuse this!!!” Andy feels than when the final decision is made that Jimmy will not refuse. But Andy admits that “It’s like we wait for something to happen next before we move to the next stage…that’s what feels like we are waiting for something to happen?!”

Andy and his wife have attempted to be as open and honest as possible about LQTS with Jimmy because “he has a right to know.” He indicated, though, that Jimmy “thinks this will go away next month etc. he doesn’t talk to anyone about it not even his pals (u know what us guys are like) and we don’t want to force him to speak to anyone.”

It seems likely that Jimmy is also in denial about his health situation. He seems to believe that LQTS is a temporary condition that “will go away next month.” If he agrees to have the ICD implant, he would be acknowledging the finality of his condition. At this point he seems to prefer to avoid any discussion of LQTS.

**Tammy’s story.** One user group message thread focused on the frustration that parents of children with LQTS faced when attempting to get their insurance companies to pay for genetic testing. This is an ongoing source of frustration expressed on the message board. Tammy’s young daughter, Lisa, has LQTS. Tammy stated that she “tried to get life insurance on Lisa and has been denied time and time again.” The insurance company indicated that Lisa probably
GRIEF AND LOSS

would not be covered until she reached the age of 18. A local funeral home contacted her about a form of life insurance available through the funeral home. Tammy stated, “I’ve thought about it but haven’t done it yet.”

Tammy may be hesitant to sign up for a life insurance policy through a funeral home. There seems to be some element of denial in her hesitation. She may not be willing to face the possibility of the loss of her child.

**Connie’s story.** Connie began a thread on the message board. She indicated that she was new to the group and proceeded to tell her family’s story. In 2001, her six-year-old son, Billy, was swimming with her in her mother-in-law’s swimming pool. After Connie got out of the pool and was drying off, she turned to tell Billy to get out of the pool and “he was bobbing in the water.” Initially she believed that he was “playing around” with her but then she realized that he was in distress. Connie stated, “I pulled him out of the water and he was blue, not breathing and no pulse. At that point I had forgotten CPR and my husband attempted CPR (he was never taught). I just prayed that GOD would breathe the breath of life back into him. He came to.” They took Billy to the hospital where the doctor indicated that he must have had a concussion that they did not notice.

A similar event occurred two months later at a pool party. Two nurses were at the party and they believed that he was having a seizure. The physicians in the emergency room concurred that he had had a seizure. Another event occurred four months following the previous incident. Billy was next to the pool when it occurred. At that point he was referred to a neurologist who, though Billy’s EEG was normal, prescribed anti-seizure medication. Connie wrote, “God impressed on me that I wasn’t supposed to give it to him. I didn’t.”
Jimmy was finally sent to a cardiologist who immediately realized that he had a QT interval of 670. The cardiologist took EKGs of Connie and her three other children and discovered that all of them had LQTS. They had genetic testing later and at that time found that her husband also has LQTS. Connie said that her husband “denies it.”

Connie indicated that Jimmy has LQT 1 and 5. Her oldest daughter has LQT 5 and 6. Her middle daughter has LQT 6. Her youngest daughter was diagnosed with LQT 1 and 5. Connie has LQT 1 and 5 and her husband has LQT 6. In retrospect, Connie recalls that she had a cardiac arrest when she was 17 which, at the time, was blamed on her use of diet pills. She also fainted after coming home from the hospital following the birth of one of her children. Given her history, their EP decided that Connie, as well as Jimmy, needed to have ICDs implanted. Later Connie’s oldest daughter had an ICD implanted.

Every member of this family was diagnosed with LQTS. She indicated that various types of interventions have been indicated. LQTS is a dominant presence for this family. But Connie indicated that her husband denies that he has LQTS. She does not go into further detail about her husband but he may be displaying strong grief reactions and is, at present, unwilling or unable to acknowledge the loss that he personally is experiencing.

Cathy’s story. Cathy reported that, even though she had tested positive for LQTS, her brother and his wife had been resistant to get their family tested. She indicated that “it’s been such a source of sadness for me that my brother had refused to get tested or take his kids for testing.” She was relieved that her sister-in-law was finally pursuing genetic testing for their children even though her brother still refused testing for himself. She stated that the EP whom they were seeing insisted that her brother get the genetic testing first, but “my sister-in-law explained that was just not going to happen.” After reviewing the family’s medical records, the
EP decided to go ahead with the testing for the rest of the family. Cathy indicated that their EP is working to get the genetic testing preapproved by their health insurance for the children. He has also scheduled the children for stress tests and holter monitors. Cathy stated, “My sister-in-law is on board with this, even if my brother isn’t.”

Cathy expressed frustration at her brother’s unwillingness to get tested. She insists that “major denial is exactly what I’d call it.” She is clearly worried about her brother and has learned some concerning details about his health. She stated that “I found out that he gets palpitations sometimes and has been brushing it off. I suppose it’s possible it’s stress or an SVT (supraventricular tachycardia) (like me) or something, but still… Talk about stubborn!” Cathy believes that her sister-in-law is beginning to become more concerned about the potentially serious nature of LQTS. She indicated that her sister-in-law realizes, “that my brother is the one who’s wrong about this – that I’m not exaggerating and he’s in denial.” She claims that “in my family, some people (mostly the men) believe that LQT really only affects women (since it’s been the women in our family who have displayed the symptoms…including sudden death). The men seem to think they’re immune to the effects!”

As opposed to the previous situation, Cathy’s brother has not been diagnosed with LQTS. In fact none of his children has been diagnosed. Cathy implies that not only she, but other biological family members have also been diagnosed with LQTS. She has been urging her brother to get himself and his children tested. She implies that he does not think that LQTS could affect him and has been unwilling to get tested. Cathy’s brother seems to be expressing a form of denial that men often employ when confronted with potential health issues. He may be anticipating the negative effects of LQTS on his life and is choosing to minimize the risk.
Sadness or Depression

**Deborah’s daughter.** Many individuals with LQTS are faced with the prospect of surgery in order to implant an ICD. The ICD may represent the final reality that LQTS is a permanent and irreversible part of their lives. Deborah’s daughter, Mary, was scheduled for ICD placement surgery. Her mother indicated that Mary had prepared herself for this significant event and was ready. Unfortunately, the day prior to the surgery, the family’s insurance company refused to preauthorize this procedure. According to Deborah, they had determined that it was not a medically necessary surgical procedure. The surgery was canceled and tentatively rescheduled. Deborah indicated that “Mary was extremely disappointed with this as she was completely ready for it.”

Deborah intends to fight the insurance company’s decision. Deborah expressed her anger and frustration at the insurance company. She is also concerned that this decision will negatively impact her daughter’s health and functioning. She stated that, “It’s simply sick; they initially are refusing to pay for something that will keep my daughter living and able to live a semi-normal life.”

Deborah reported that the insurance company’s decision has negatively affected Mary’s emotional well-being. She stated that Mary “secluded herself in my bedroom yesterday after finding out because she could identify the she was completely angry and refused to put herself in a position to take it out on any other member of our family.” Although Mary, in fact, may be very angry, she may be expressing sadness or depression at the loss she is experiencing and may be isolating herself from others.

**Susan’s daughter.** Susan’s 15-year-old daughter, Marsha, was discussed in the previous section. She had been a competitive swimmer and had an episode of syncope while swimming.
She was tested for LQTS following the episode and placed on beta blockers. Although Marsha has had no further symptoms, she has not swum competitively since the episode. Her mother stated that, “She’s very moody…but I reckon that’s more hormonal and the swimming restriction than side effects of the beta.”

Marsha was diagnosed with LQTS at the age of 13. Although Susan does not indicate how long her daughter had been swimming competitively, it seems likely that swimming was a very important part of her life both athletically and socially. In order to swim competitively, she would have had spent many hours practicing each week. By the age of 13, she had most likely also built a strong network of friends on the swim team. Suddenly and finally, a major aspect of her life was taken away. Potentially, she may no longer have felt accepted by the other swimmers and therefore had become isolated from much of her social network. The loss of the physical activity and, potentially, the social support seems to have been a major factor, not only in Marsha’s being “very moody” but also in being possibly depressed. Both moodiness and even depression are common grief reactions.

**Megan’s story.** Megan is a 17-year-old girl who reported that she was born with LQTS. She indicated that LQTS was passed down from her mother’s side although none of them knew that they had LQTS until her diagnosis. Megan was diagnosed at the age of six. She received a pacemaker/defibrillator when she was 13. She takes beta blockers and does not engage in competitive sports. “When I was younger” she stated, “it used to bum me out because I loved sports.” She described how she adjusted to the reality that she would not be able to participate in competitive sports. Even though she loved playing sports, she stated that, “I focused on what I could do such as academics and I recently received an application from Harvard.”
Megan stated that the imposed limitation on her physical activity, “used to bum me out”. Clearly, when Megan was younger, she felt sad because she was unable to participate in the sports that she enjoyed. She connects this negative reaction to the loss of a significant aspect of her life. Although she does not describe this period of her life in detail, she would have had to work through this grief reaction over a period of time. She made a decision at one point not to focus on her limitations but upon the activities in which she could still involved.

The Unpredictable Loss

Although many of the individuals using the message board are living with LQTS themselves or have a family member living with LQTS, others have experienced the death of a significant other because of LQTS. Several people have been diagnosed with LQTS and reflect upon past deaths in their families that were likely the result of LQTS. Others are coping with recent deaths of family members while they care for children with LQTS. Some individuals expressed the stories of resuscitation from sudden death. Finally, certain parents recognized the unpredictable nature of LQTS and anticipate the loss of their living child. Although the circumstances vary, loss from LQTS invariably is unpredictable and traumatic for those affected.

Experiencing Sudden Death

Ann is a nurse who, at the age of 40, experienced cardiac arrest while in her bed. She was resuscitated by her husband and expressed her sense of luck when referring to her resuscitation. She also believes that her symptoms leading up to the arrest were not taken seriously by the medical community. She states, “I was told my symptoms were stress related cause (sic) I am a
nurse and have some knowledge, then 6 days later cardiac arrested in my bed.” As mentioned in a previous section, Connie’s six-year-old son experienced a cardiac arrest while swimming at his grandmother’s house.

Both Connie and Ann had very little or no warning prior to the cardiac episodes. As a nurse, Ann was concerned about symptoms that she had been experiencing prior to the episode, but she felt that her medical providers did not take the symptoms seriously. Connie did not mention any symptoms prior to her son’s episodes. The cardiac episode just seemed to occur without warning. As mentioned previously, she believed that her health care providers struggled to identify and diagnosis her son’s LQTS. The stories of these two persons are examples of the sudden and traumatic nature of the initial symptoms of LQTS. There are rarely strong warning signs prior to a traumatic cardiac event. Even though these individuals were successfully resuscitated, they did experience sudden death. Both Ann and Connie’s son experienced sudden and traumatic loss and Ann and Connie will always be on guard for future losses no matter what medical treatments are in place.

**Anticipating the Loss**

Beth has been diagnosed with LQTS and she had her ICD implanted three months prior to posting her message. She claimed that she is doing well and “not a bit nervous anymore.” She is worried about her 9-month-old daughter who also has LQTS. Beth stated that her daughter “is doing well” and “hasn’t had any episodes.” But Beth is “constantly watching her when she’s asleep and awake and if she even takes a deep breath I go weak in the knees… I’m just so scared that her first episode will be her last.”
Beth struggles to understand what to expect with her infant daughter. She stated that of the six members of her family with LQTS only she (Beth) and her mother have displayed symptoms. She wonders if it common that only some people with LQTS display symptoms.

Clearly, Beth is very much worried that her infant daughter will die suddenly. She is trying many things to safeguard the life of her daughter. Along with medical interventions, she stated, “I have taken my baby to a faith healer and as we haven’t been back to the hospital yet I don’t know if it was a success but I suppose that’s wishful thinking and I pray every night that she will be ok.”

With all of the uncertainty and unpredictably surrounding a diagnosis of LQTS, Beth seems to be anticipating the possibility that she will lose her child. She is expressing grief symptoms in her writing, stating that “I also feel so guilty for giving her this condition.” She was uncertain about whether or not she would have children because of the risk of inheriting LQTS. She indicated, however, that her daughter’s birth was not planned. She expressed her inability to bond fully with her daughter. She stated that, “As much as I love my baby part of me is reluctant to get close to her in case I lose her which makes me a bad mother.” Not only is Beth feeling guilty about giving her child the LQTS gene mutation, she also feels guilty about her inability to bond with her daughter. She is anticipating the possibility that suddenly her daughter will die and therefore she is guarding herself against the loss by avoiding full emotional attachment.

As mentioned in a previous section, Cathy’s brother and sister-in-law had been unwilling to get their children tested for LQTS even though multiple members of Cathy’s family have LQTS. Finally, Cathy’s sister-in-law decided to get her children tested but her brother is still unwilling to be tested. Cathy expressed relief that the children will be tested but indicated that
the ongoing resistance to testing had been a source of sadness for her. Implicit in her sadness may be the anticipation that her brother or one of the children will die before they are tested.

**Remembering the Loss**

Throughout the message board, users frequently remember family members who have died from LQTS. Some seem to have a very clear sense that the family member died from LQTS. Others look back on the suspicious circumstances of the family deaths and draw the conclusion that the death was the result of LQTS.

One message thread discussed the frustration that Randy experienced when his insurance company was resisting payment for genetic tests for his three children. He had experienced a cardiac arrest himself and then went to a pediatric EP for advice concerning his children. His 12-year-old child had two episodes of syncope by the age of nine. Although the EP recommended full workups, he put the workups on hold until he received the results of his Familon genetic test. Randy claimed that the EP said that “There was no urgency here with the kids – if mine didn’t show itself until I was almost 40, the odds that something would happen with them were very small.” He started the process to receive preapproval from his insurance company for his genetic test. The insurance company denied his request because they considered it experimental and, therefore, would not pay for the test. So Randy is uncertain how to proceed. Should he pay for the test out of pocket or just take the children for regular workups?

In response to Randy’s concerns, individuals attempted to help him by giving him practical information. On the other hand, one woman challenged the reassurance of the pediatric EP who insisted that there were minimal health concerns for Randy’s children at their ages. With an air of frustration, she claimed that the EP may not have “kept up on long qt research.” In fact,
she wrote about losing family members at various ages and she wishes she “would have known years ago and treated them.” Another woman claims that most teenagers with untreated symptoms of LQTS do not survive and that Randy should tell this to his insurance company. “Some of us were lucky” she wrote, “but my cousins were not, and one did wait till he was 40 to have his first symptom.” They both have lost family members to LQTS.

In response to the concerns of a person who had been diagnosed with borderline LQTS, a woman stressed the importance of having everyone in the family tested for LQTS. “This condition” she wrote, “is genetic and may also be affecting your family and they don’t know it!” She stressed the unpredictability of LQTS within families. “I’m the oldest of three children” she wrote, “and I’m the only one to have QT. My dad has it and we believe his dad suddenly died of it 17 years ago.”

In the same thread, a woman claimed that some cardiologists are not aware of how serious LQTS can be for those afflicted. She stated, “My mom went to a cardiologist who informed her that she has ‘lived a long life’ and probably has nothing to worry about if she made it this far.” Another woman responded to this comment with frustration saying, “It always bothers me when I hear the ‘you’ve lived this long with it…’ line.” She wrote that her mother had many episodes of syncope during her life. Her mother was never diagnosed with LQTS nor treated for it. She wrote, “She died from it at age 57.” Although her mother was never diagnosed, her retrieved EKG from earlier in her life indicated a prolonged QT interval.

**Uncertainty Surrounding the Loss**

Some individuals come to the user group having lost loved ones but are unclear about whether or not LQTS played a part in the death. They struggle with the uncertainty of not
knowing. Because of the lack of knowledge about LQTS in the general medical community, emergency room physicians often do not consider LQTS as a possible factor in, for example, car accidents.

Judy started a thread to ask several questions about LQTS. Her brother died in the aftermath of a car accident five years prior to posting the message. At the time there was a great deal of uncertainty surrounding his condition. Following the accident, he was in the intensive care unit. After eight days, she wrote, “His potassium started to rise suddenly and it basically ‘killed’ his heart.” The medical staff was unable to resuscitate him.

Judy reviewed some symptoms that her brother had displayed prior to his death. He would get dizzy or shaky when physically active and would need sugar but he was never diagnosed with diabetes. She also mentioned that a few months prior to his death he had chest pains. He was taken to the hospital. As Judy recalled it, the physician said that her brother had a “cramp” in his heart muscle.

Judy stated that she used to experience that same type of symptoms, i.e. dizziness and shakiness following physical activity. She also had blackouts. She described the blackouts as “Everything around me went still and I could not hear for a few seconds like a pause button went on.” She denied any episodes of fainting. She is contemplating getting her brother’s ECG rechecked from his medical records. She wrote that she does not, “have the energy to reopen it all now though.”

Judy does not know whether or not her brother had LQTS. But she is still searching for answers five years after her loss. Definitive answers may help bring some closure to her brother’s death; however, she seems to be hesitant to revisit the circumstances surrounding his death.
Judy also indicated that her father died in a car accident and “Nobody knows what happened, it was a really strange accident.” Although he was never tested for LQTS, she draws the conclusion that because she has LQTS then her father’s accident and resulting death must have been the result of LQTS, too. Beside the fact that she has LQTS, Judy indicated that her paternal grandmother had multiple fainting events and her father’s sister continues to have fainting episodes. The uncertainty surrounding the cause of her father’s death continues to preoccupy Judy. She stated that “It is hard for me, not knowing.”

In response to Judy’s post, one woman indicated that her sister had died in her sleep following the birth of a baby. Another woman who clearly had a long history of posting on the message board indicated that other members of the user group had shared stories that were similar to Judy’s story. She claimed that “Unexplained car accidents and drowning/near drowning are often found in LQT families before they know about LQT.” She implied that there is a great deal of uncertainty and mystery surrounding the deaths that occur within families affected by LQTS.

Because of the different types of LQTS, there tends to be a great deal of variability in symptoms and triggers of cardiac events. In the midst of a long message thread discussing various triggers of cardiac episodes, one woman indicated that her “ICD is set to shock at 200 bm. I had atrial tachycardia while in the hospital recovering from surgery. My understanding was this placed me at risk but did not set off the ICD. The atrium was working hard. It was mainly all due to the hemodynamic changes from surgery.” She explained that her sister died in her sleep three months following the birth of her child. Her uncle had a cardiac arrest in the midst of his normal ten mile run. She stated, “A passing motorist happened to be a doctor and revived him.” Finally, her brother had a cardiac arrest upon waking from sleep. She does not state if her brother
died from the cardiac episode. But this woman’s list of losses just within her family is extensive and gives a dramatic example of the various types of losses from LQTS that one family can experience.

There is also variability in the LQTS genetic mutations. Although researchers have identified several of the most common types of genetic mutations that indicate LQTS, there are still many individuals whose genetic mutations have yet to be identified. In the same message thread on the various triggers of cardiac episodes, Hazel explained that physicians have suspected for a long time that many members of her family have had LQTS. She listed the members of her family who died early in their lives. She stated that “I lost my mother when she was 32, my sister when she was 16 and my brother just passed away last month at the age of 29.” She indicated that both her mother and brother died in their sleep. Her sister died after running after a ball in the driveway.

Unfortunately, Hazel indicated that no one in her family “has had any symptoms and when test were performed such as the EP study, stress test and 24 hour monitor nothing showed up.” She, therefore, decided to pay for a genetic test on her brother following his death, to determine if he had LQTS, but the test came back negative. She stated, “They say we are in the 25% of families that the gene has not been identified.”

Hazel is preparing to receive an ICD implant. She also has appointments scheduled for both her children. She did not indicate whether or not her children’s appointments are for testing or for ICD implantation. She said, “They are 15 and 11 and I am terrified.” She is also anxious because she believes that other members of her family have LQTS and they do not realized that they have it. Not only do family members have LQTS but the medical community has not been able to identify the gene mutation in order to determine specific triggers and treatment. She
indicated that, “I was praying that we would be able to identify the gene so we could protect the ones that need it.”
Theoretical Analysis of Descriptive Findings

In this study, the loss experiences and grief reactions of persons affected, directly or indirectly, by Long QT Syndrome were examined. Because the data utilized for the study were archival user group messages, the responses were limited to those specific topics that were discussed online during the two months of collected data. In spite of this limitation, numerous references to various types of loss and grief reactions were expressed by participants in the user group during this period of time.

In the messages, the persons who wrote about losses indicated that they experienced perceived losses related to a normal life and physical activity. These two categories of loss were by far the ones most frequently expressed by participants. Although there were other expressions of perceived loss, they were not included because they did not meet the criteria for inclusion of three or more expressions. Others expressed their experiences of the actual loss of significant individuals due to LQTS. Various grief reactions were expressed by individuals including denial and sadness.

The persons writing to the user group clearly had experienced significant changes as a result of their experience of LQTS. In many cases, it is difficult to determine how long persons have been affected by LQTS because archival data do not permit direct communication with user group participants. Several individuals had just recently learned that they or their child had been
diagnosed. Others seem to have been dealing with the implications of the diagnosis for longer periods of time.

The choice of the individual to post messages on the board at a specific time may imply that they may have been more cognizant of the loss associated with the disorder. The act of posting may serve as a coping technique when dealing with the negative cognitions related to the loss.

Although not all of the expressions of loss identified in this study fit into the concept of chronic sorrow, i.e. actual deaths of significant individuals, many of the persons’ experiences of loss do support this concept. As explained previously, the chronic sorrow model of grief involves responses that are “pervasive, profound, continuing, and recurring” (Roos, 2002). The unique nature and pattern of the grief responses results from “a significant loss or absence of crucial aspects of oneself (self-loss) or another living person (other-loss) to whom there is a deep attachment” (pg. 26).

Although she did not originate the concept of chronic sorrow, Susan Roos (2002) expanded and clarified the definition of the concept. She also proposed a model of chronic sorrow which is dimensional. This key characteristic of Roos’ model allows elements of chronic sorrow to be presented on a continuum, depending upon factors present in the specific loss. As demonstrated in the discussion of findings, each individual’s emotional response to the loss and perceived reality of the loss is dependent upon various factors specific to the situation.

The findings of a significant portion of this study can be addressed by the five dimensions of Roos’ model of chronic sorrow. Dimension 1 is the specific characteristics of the perceived loss related to LQTS. This dimension includes the specific loss, the individual’s subjective perception of the loss, and the objective reality of the loss as it relates to LQTS.
Dimension 2 involves the continuity of the loss related to LQTS. This dimension includes the perception that the loss will continue for an ongoing and unknown time period, rather than a specific termination point. Dimension 3 includes initial grief responses related to the diagnosis of LQTS and the ongoing and recurring grief responses as individuals live and cope with the syndrome. Dimension 4 examines the discrepancy between the perceived reality of the losses related to LQTS and the present nature of the dream. Finally, dimension 5 involves the continued presence of source or object of the loss whether or not it involves an individual directly or indirectly affected by LQTS. As mentioned previously this model is dimensional rather than linear. These dimensions of grief and loss are present on a continuum. Each individual examined in the study has his or her own specific background and circumstances that impact the way in which he or she experiences the loss. From one day to the next, an individual may experience significant fluctuations of emotions such as sadness or denial related to their perception of LQTS. External circumstances that impact the individual’s life may, on the other hand, bring on feelings of hopefulness with their circumstance. The messages that are utilized in this study represent specific snapshots in the lives of these individuals as they deal with the ongoing reality and perception of losses related to LQTS. Because of the nature of chronic sorrow, another snapshot is likely to look very different as the grief responses ebb and flow. Certain stories used in this study will reflect multiple dimensions of chronic sorrow and some aspects of those stories will be repeated to illustrate these different dimensions.

Dimension 1: Characteristics of the Loss

Loss of normal lifestyle. Ahlstrom (2007) found in his study of individuals with severe chronic illness that individuals frequently experienced the loss of autonomous life and the life
imagined. Six of the individuals in this study expressed either their experiences or their children’s experiences of the loss of a normal life. For Linda and Ann, the experience of the loss of a normal life came at the outset of the diagnosis of LQTS. As an adult, Linda was physically active prior to the onset of LQTS symptoms. Following the recognition of initial symptoms, her physician placed her on beta blockers. At the time of her message board post, she had not had a confirmed diagnosis of LQTS. Linda expressed serious concerns about the limitations that beta blockers were already having on her normal levels of physical activity. For example, she tired more easily during physical activity because beta blockers limit her heart rate. Her activity level has been an important part in her life and she is concerned about how many other things will have to change in her life if she is firmly diagnosed with LQTS. Ann’s daughter, Kate, was diagnosed with LQTS following a sudden cardiac arrest. Her daughter has LQT3 and her symptoms normally occur while resting or sleeping. She, therefore, sleeps in her parents’ bed. Ann admits that this change has been difficult for her and her husband as well as for the other children. Their six-year-old child struggled so much with the change that they also allow that child to sleep with them too. Ann never leaves Kate unattended and if she is unable to watch Kate, even briefly, she has one of the other children watch her. Prior to Kate’s diagnosis, the family traveled frequently to Europe and many parts of the United States. They have greatly restricted their travel in order to be close to their hospital. They have made significant changes in the way that they have raised their children and in their lives as a couple in response to Kate’s diagnosis.

Jennie, Lisa, John, and Karen have experienced loss at various stages following the diagnosis. Karen has struggled over many years with complications and surgeries because of problems with her ICDs, which have limited her ability to live a normal life. Individuals with
LQTS may be required to exclude certain foods that they had previously enjoyed from their diets. John explained that certain foods including cheese have caused problems with his heart.² Other posters stressed the need for monitoring the use of and even avoiding certain types of food which can be dangerous for those with LQTS.

Following her son’s diagnosis with LQTS, Jennie indicated that her family’s life continued “pretty normally”. They did monitor his physical activity carefully but she did not perceive this as significant change in the family’s lifestyle. Only after an episode in which Paul suddenly passed out at his desk in school did they perceive changes to their normal lifestyle. They are required to monitor his glucose levels carefully since the episode. Paul now has begun to view himself as different from other children and unable to have a normal life. Jennie herself struggles with the loss of the normal lifestyle too. Lisa struggles with the limitations that must be imposed on her daughter, Amy. Her perception of the loss for Amy includes the ability to have a full social life because of the risks of swimming at pool parties. She worries that she is ruining Amy’s social life by limiting her ability to go to swim parties.

**Loss of physical activity.** Catherine, Susan, Tina, Allison, and Sarah experienced the loss of physical activity. Catherine indicated that she had just recently been diagnosed with LQTS. She has struggled with periods of fatigue that have limited her activity levels for years. Because she has been diagnosed with comorbid disorders, it is unclear from the post whether or not the fatigue is primarily the result of LQTS. She continues, though, to deal with the reality that her activity level is limited. Tina is clearly struggling with the limitations placed on her as a result of her diagnosis. She reported being very physically active including biking, basketball, and jogging. She intends to continue her active lifestyle and indicated that her physician

² Although foods containing caffeine can have negative effects on individuals with LQTS, there is no documented evidence that cheese can have any negative effects directly related to LQTS.
approved most of her activities. Clearly, though, she is struggling with the loss of full physical activities including weight training.

Susan, Allison and Sarah have children with LQTS. Susan’s daughter was a competitive swimmer at the time of her diagnosis. Although she continues to swim, she has been unable to swim competitively since the diagnosis. Susan recognized that her daughter has been very moody as a result of the loss of this important part of her life. Although she continues to be physically active, both Susan and her daughter recognize the significant loss of competitive swimming. Allison has been very resistant to accept her son’s diagnosis of LQTS. Allison and her husband have lived very physically active lifestyles throughout their lives. She recognizes that a diagnosis of LQTS will seriously limit her son’s physical activity and this potential loss for her son is extremely difficult for her to bear. Because sports have been such a major part of her family’s life, she worries that he will not fit fully into the family and feel different. Sarah’s son has been allowed by his physician to continue physical activity presently. She recognizes, though, that, as he gets older, he will be required to give up running.

Both Catherine and Tina have been diagnosed with LQTS. Catherine has struggled with multiple health problems throughout her life including multiple episodes of syncope. She has ongoing episodes of fatigue that often keep her bedridden for days. Although it is unclear if the fatigue is primarily due to her LQTS, she continues to experience serious and ongoing limitations of her physical activity. Tina struggles with accepting any limitations placed on her physical activity as a result of LQTS. She continues to engage in vigorous activities on a daily basis. Although she does admit that her EP has limited her involvement in weight training, she struggles with even these moderate limits and resists any further limitations. She recognizes that
she has lost her full ability to engage in physical activities but clearly remains determined to limit the loss as much as possible.

**Dimension 2: Continuity of the Loss**

**Perception of ongoing loss.** One of the unique characteristics of chronic sorrow is the perception that the significant loss that is being experienced is ongoing rather than having a foreseeable endpoint (Roos, 2002). Ahlstrom (2007) found that individuals coping with chronic illness experienced losses repeatedly and not just during the period of initial diagnosis. Although the stories of individuals examined in this study are simply snapshots of their experiences of LQTS, many individuals perceive and express the fact that the losses that they experience will be ongoing in their lives.

Since her son, Paul’s, fainting episode, Jennie is finding it difficult to be optimistic that his life will ever be normal again. She is implying that there will be ongoing events that will limit his ability to live a “normal” life. Kate’s parents express their perceptions of ongoing loss by remaining vigilant for future cardiac events. They recognize that cardiac events are unpredictable and may occur even with safety precautions in place. They, therefore, are prepared to alter their normal lifestyle including limiting travel. As stated above, Karen has had ongoing complications with her multiple ICDs over a span of 15 years. Although there have undoubtedly been periods of time when her ICD’s have been functioning properly, multiple issues have left her with the perception that her life will continue to punctuated by complications.

Allison continues to struggle with the reality of the limitations of physical activities upon her son. In reflecting upon her son’s future and the decision to have another child, she recognizes that these limitations will be an ongoing part of his life. She wrote, “The precautions we will take
will keep Andrew alive (we hope), but, at what cost?” From Allison’s perspective, the ongoing loss of physical activity may be too steep a cost. Although Andrew may or may not experience the same level of continuing sorrow of the loss of physical activity, clearly Allison is deeply troubled by this ongoing loss.

Sarah writes about the strict regimen that her son with borderline LQTS must follow in order to continue exercising. She recognizes that there have been mild limitation and changes imposed upon her son at the present. On the other hand, her EP has warned her that as her son gets older he will probably no longer be allowed to run. Sarah’s story is an instance of perceived ongoing losses that potentially may increase as her son grows older.

One of the user group participants, Megan, has lived with LQTS since her diagnosis at the age of six. Now 17 years old, Megan has never been allowed to participate in competitive sports because of LQTS. She acknowledged that she struggled with this loss when she was younger. The loss of physical activity will continue throughout her life. Although she recognizes that this loss will be an ongoing reality for her, she has learned to cope with this loss by focusing on other areas of her life including academics.

**Dimension 3: Initial, Continuing, and Recurring Grief Responses**

**Initial grief responses.** Following her initial diagnosis with LQTS, Megan (referenced above) wrote that “It used to bum me out” because she was restricted from participating in competitive sports. Megan experienced initial periods of sadness over the loss of an important aspect of her life.

According to her mother, Marsha, a 15-year-old girl, has become very moody following her diagnosis with LQTS. Competitive swimming was an important part of her life, and
following the diagnosis she has been restricted from this activity. Although it is impossible to define exactly what her mother means by “very moody”, she likely is experiencing periods of sadness or irritability. These emotions are common grief responses to loss.

These two situations are examples of grief responses in reaction to initially learning of the loss. These responses are typical of any type of sorrow, normal or chronic. On the other hand, continuing and recurrent grief responses may be more common when individuals experience living and ongoing losses.

**Continuing grief responses.** Andy’s son, Jimmy, was diagnosed with LQTS two years prior to his participation on the user group. Although Andy has been compliant with all the advice from Jimmy’s doctors, he admitted that, even two years after the diagnosis, he continues to struggle with fully accepting the implication of his son’s illness for Jimmy and for the family, including the loss of the child that he knew prior to the diagnosis. Connie indicated that her six-year-old son was diagnosed with LQTS in 2001 following several cardiac events. Not long after her son’s diagnosis, the rest of the family was genetically tested for LQTS. Connie, her husband, and the three remaining children were found to have LQTS. She indicated that her husband denied that he, in fact, had LQTS. Even though the rest of the family is being treated for LQTS, even years later her husband continues to deny that he has the syndrome. Denial is a common grief reaction in response to all forms of loss. The continuous nature of Andy’s denial may be a unique response to the ongoing nature of losses related to chronic illness.

The ongoing grief response of denial related to LQTS may not be limited to immediate family members. Cathy wrote about her brother’s continuous unwillingness to get him or his family tested for LQTS for an extended period following Cathy’s diagnosis. Cathy stated that her sister-in-law has become more concerned about having her family tested for LQTS. Her brother,
though, has remained opposed to getting tested even though their children are scheduled for stress tests and holter monitors. Cathy indicated that only women in her family have displayed LQTS symptoms. Therefore, men in her family have tended to assume that they do not have the disorder and do not get tested. Ongoing denial may be more likely with chronic illnesses like LQTS because the family member with the disorder is still alive and, for the most part, displaying few outward symptoms.

Andy’s son, Jimmy, was diagnosed with LQTS two years prior to posting his message. Following Jimmy’s diagnosis, Andy and his daughter were also diagnosed with LQTS. Andy admitted that he continues to have problems accepting the reality and the meaning of the disorder in their lives. Andy indicated that the hospital did not offer any support, counseling, or advice to his family following Jimmy’s diagnosis. He seems to make a connection between the perceived lack of support and his inability to accept, fully, the implications of the disorder.

Although Andy indicated that he continues to struggles with the implications of LQTS for his family, his son, Jimmy, seems to believe that the disorder is temporary and is unwilling to talk with anyone about the situation. Faced with the decision to have an ICD implanted, Jimmy has reacted very negatively. He does not want the procedure. If he does agree to the implantation, Jimmy would have to accept the reality of his health situation, which he is clearly unable or unwilling to do at this time. It seems that Jimmy has been struggling to accept the reality of LQTS since his diagnosis; however, the imminent decision to have an ICD implanted may be triggering stronger grief responses. External and internal triggers that arise at various times have the potential to produce recurring and strong grief responses in individuals with LQTS.
Recurring grief responses. It should be noted that the messages posted on the user group are, for the most part, snapshots of these individuals’ lives. Therefore, it is very difficult to recognize recurring grief responses. Nonetheless, Deborah’s daughter, Mary, experienced anger and, possibly, sadness when the family’s insurance company refused to preauthorize her ICD surgery. As stated previously, individuals with chronic sorrow may seem to have adjusted to the loss, but specific triggers, i.e. the refusal of the insurance company, may trigger recurrence grief responses, i.e. anger or sadness, connected to the initial experience of loss.

Dimension 4: Discrepancy between Perceived Reality and Continuing Dream

When faced with a chronic illness such as LQTS, the individual may struggle with the discrepancy between the perceived reality related to the illness and the ongoing fantasy dream of how the life of the individual affected should be at the present and in the future. Roos (2002) theorized that, “in chronic sorrow one is forced into an almost untenable position: letting go of unrealistic dreams and images of how things should be now and should be in the future is experienced as disowning a part of a cherished identity” (pg. 64). Roos recognizes that this position is especially difficulty when the chronic illness affects children who often serve as “the repositories of our idealization, our hopes for completeness, and our dreams and aspirations for the future” (pg. 65). Therefore, this ongoing discrepancy may be especially painful for parents or guardians of children affected by LQTS.

The degree of discrepancy between reality and fantasy theoretically depends upon the current degree of impairment and by the current nature of the fantasy (Roos, 2002). The degree of impairment depends upon the characteristics of the loss and the effects on daily living. The nature of the fantasy depends upon the positive and negative functions and how realistic or
unrealistic the expectations are. Several examples of this discrepancy were observed in the user group messages.

Following Paul’s original diagnosis period, Jennie indicated that the family was “living life pretty normally.” Then Paul suddenly passed out at his school desk. He was hospitalized for several days and was subjected to ongoing monitoring at home. Although Jennie expresses a realization that significant changes will be required, Paul is clearly holding onto a fantasy about his life. According to Jennie, Paul stated that “He just wants to be like everyone else.” This statement implies the desire to live the normal life of a child without restrictions, ongoing tests, and physical symptoms that will disrupt his school and social life. Paul is obviously distressed by the discrepancy between the current realities of ongoing monitoring, hospitalizations, and sudden disruptions and the desire to go back to his normal life.

Lisa monitors her daughter, Amy, very closely when she is at social events. Because cardiac events are often precipitated by swimming, she recognizes that Amy must be monitored at a birthday swim party. Because of the restrictions placed on Amy, Lisa realizes that her social life has been affected. Lisa is distressed by the discrepancy between the restrictions that affect Amy’s social life and the fantasy of allowing her daughter to live the normal life of a child with no restrictions on her social life.

Although the message leaves some uncertainty over her diagnosis, Linda has been placed on beta blockers following a cardiac event. Currently, she reports difficulty getting the full physical impact from her physical activities because the beta blockers restrict her heart rate and she tires more quickly. In the initial message posted by Linda, she holds out hope that she will be cleared of LQTS. In latter post, she is beginning to accept the reality of LQTS but is holding onto
the hope that she will not have to remain on beta blockers. This fantasy would allow her to imagine herself with no physical restrictions.

Since her diagnosis, Susan’s daughter has not been allowed to resume competitive swimming at her school. Susan reported that her daughter has been very moody since these restrictions were imposed. Although there were no direct reports from Susan’s daughter, she may be struggling with perceived reality of never being able to swim competitively and the fantasy of swimming in competitions once again.

Tina has a history of rigorous physical activity. Since her diagnosis, she continues to engage in most of the previous activities. She indicated that her doctor has restricted her involvement only in certain types of weight training. Although the limitations seem minor compared with other people’s limitations in the user group, Tina struggles with even these restrictions and is resistant to any further imposed limitations. Her fantasy related to her illness is the continued belief that until her ICD shocks her, she will continue to engage in a “hardcore” lifestyle of strenuous physical activity. In fact, she continues to perceive herself as invulnerable to the effects of LQTS. The effects of this fantasy on Tina’s life help her to remain active but, on the other hand, it may put her at risk for cardiac episodes.

Allison indicated that she and her husband are both competitive athletes who continue to lead very active lifestyles following the birth of their son. Not only is physical activity very important to them as individuals but they also view it as an essential component of their family life. Therefore when their son was diagnosed with LQTS, they were informed that he will not be able to participate in the full range of physical activities they enjoy. Clearly, they perceive the reality of their son’s impairment as very severe. In fact, Allison seems to believe that he will be unable to participate fully in their family life. The fantasy that Allison holds onto involves a
family life in which all members of their family, including their son, will engage in competitive sports. She is resisting the full acceptance that her son does have LQTS in the hope that he will be able to participate in sports as do Allison and her husband. This fantasy seems to have a high level of importance to Allison. She implied that even though the precautions they are taking will keep their son alive, the loss of physical activity may be too high.

**Dimension 5: Continuing Presence of the Object of the Loss**

The object of the loss related to the effects of LQTS may no longer be present in the life of the individual affected by grief and loss. Of the 67 messages that expressed elements of grief or loss, 12 individuals wrote about loved ones who had died from complications of LQTS or about the possibility that the disorder was suspected in their deaths. One of these individuals wrote about the loss of her daughter and expressed cognitions anticipating the death of her younger daughter who also has LQTS. She stated, “I am constantly watching her when she’s asleep and awake and if she even takes a deep breath I go weak in the knees… I’m just so scared that her first episode will be her last.”

For the majority of the message board users who expressed loss and grief, the object of the loss continued to be present in the life of the individual. Of the individuals examined in this study who continue to live with the loss, the loss of a normal life and the loss of physical activity stood out as the two crucial aspects of the losses that they were experiencing. The diagnosis of LQTS, in most cases, necessitates significant changes in the lifestyle both of the individual directly affected and of the caregivers of the individual, including altered family patterns and significant limitation on physical activities. LQTS is a chronic illness and as long as the individual remains adherent to physician’s recommendations, he or she should live a normal
lifespan. Because the ongoing losses tend to result from the directives put in place to keep the individual healthy, there is normally no foreseeable end to the losses during the life of the patient.

**Clinical Impressions**

Although some individuals may never experience significant or recurring grief responses in relation to the diagnosis of LQTS, the findings of this study indicate that some individuals do experience significant and ongoing symptoms of chronic sorrow. Specific external and internal triggers related to the perceived loss that recur, may heighten the disparity that results from this loss. Negative cognitions may then arise in response to these triggers which, in turn, lead to negative affect and, potentially, specific behavior. This cycle has the potential to develop into dysfunctional patterns for the person (Needleman, 1999).

**External and Internal Triggers**

As mentioned previously, specific triggers recur at various times; these serve to sharpen the disparity between the perceived reality and the continuing fantasy related to the object of the loss. Although many triggers are easily identified because they are external, other triggers may be internal in origin. These triggers may produce intense effects upon the individual affected by LQTS. The individual may have been coping well for long periods of time when a trigger suddenly sharpens and intensifies the disparity that results from the loss.
Cognition

Following the occurrence of external or internal triggers, there is evidence that vulnerable individuals tend to react with negative cognitions related to the perceived loss. It could be argued that these negative cognitions related to loss or the potential death of the individual may develop into cognitive distortions. Cognitive distortions have the potential to develop into significant dysfunction (Nezu, Nezu, & Lombardo, 2004).

Most individuals affected by LQTS experience triggers related to the losses they have experienced as a result of the disease. Some individuals may react more intensely than others to these triggers. Potentially, a person’s tendency toward negative cognitions and cognitive distortions may predispose him or her to intense and recurring reactions. However, this does not dismiss the reality of the loss that person experiences. But there is a level of subjectivity in the way individuals experience their losses. When experiencing a trigger, the intensity of the individual’s sorrow response is a function of how the individual interprets the loss (Roos, 2002). Many factors may influence a person’s interpretation of a trigger including: (a) history of significant losses, (b) nature of the person’s support network, (c) overall mental health, and (d) acute and long term stressors. Therefore, the person’s interpretation of triggers can significantly affect his or her overall chronic sorrow response.

Emotional Response

In this study, the individual’s explicit emotional responses to specific triggers were very difficult to determine because the individuals were not interviewed. Nonetheless, there are some indications that individuals reacted with negative affect when confronted by triggers related to their loss.
The emotional response of individuals dealing with depression or anxiety tends to maintain a relatively high level of intensity. On the other hand, there are indications that the emotional response of individuals coping with chronic sorrow may not maintain the same levels of intensity for extended periods of time. Roos (2002) indicates that individual’s “emotional arousal and expression are blunted in any direction” (pg. 87). Theoretically, individuals may not experience intense positive or negative affect for extended periods. Given the long term nature of the losses experienced by those coping with LQTS, the muted emotional aspect of chronic sorrow may actually serve a functionally adaptive purpose. Although the individuals studied clearly experience a broad range of emotional responses, blunted emotional response may serve as a strong defense mechanism against further trauma related to loss. Triggers inevitably intrude into the life of the individual affected by LQTS and have the capacity to produce cognitions and emotions related to the perceived loss.

Implications

Long QT Syndrome (LQTS) is a life-threatening chronic disorder that affects a significant percentage of the general population. Children and adolescents are particularly susceptible to the effects of the disorder. Because initial symptoms of LQTS may manifest as a sudden and fatal cardiac event, LQTS has the potential to result in traumatic losses for LQTS families. As reflected in the user group messages, individual may lose multiple family members to the disorder. Even when they are successfully treated for the disorder, these individuals and their families may experience significant ongoing losses related to physical activity and lifestyle.
Medical specialists in the electrical heart disorders, including electrophysiologists, understand the signs, symptoms and treatment of LQTS and provide expert care for those diagnosed with the disorder. On the other hand, other health care professionals may not be as familiar with the disorder. Continued education of health care professionals regarding the signs and symptoms of LQTS is essential as a means of preventing sudden death in this population.

Because there has been very little research into the psychological effects of LQTS on those directly affected and on their families, few health care providers are equipped to provide information and guidance into the potential psychosocial effects that the diagnosis and long term treatment of LQTS may have upon these individuals. Families and individuals may be relatively ill equipped to deal with the potential psychosocial effects that the initial diagnosis and the ongoing reality of life with LQTS could potentially have on them. Therefore, individuals affected directly or indirectly by this disorder would profit from detailed information about the illness and potential psychological issues which may develop as a result.

The individuals studied in this project expressed various types of psychological responses to the illness, including anxiety. The purpose of this specific study was to observe and describe any grief or loss experiences expressed by the message board users. The majority of the messages studied did not express loss or grief responses; however, a significant portion of the population did. On the other hand, certain individuals studied in this user group expressed negative emotions and cognitions related to the perceived losses as a result of the diagnosis and/or the treatment implications.

The grief and loss responses experienced by individuals and parents of children who have LQTS can be complicated and chronic. Multiple factors including external stressors and coping skills can affect the individual’s ability deal effectively with the reality of this chronic illness.
Many individuals may experience minimal grief and loss responses, yet others may experience ongoing and severe reactions. It is essential for mental health professionals who may have direct contact with families affected by LQTS to have information regarding the potential grief responses that certain individuals may experience. Behavioral health psychologists, social workers, and even clergy may be able to assist families and individuals dealing with LQTS in understanding and recognizing signs and symptoms of grief and sorrow, help to normalize these responses, and provide education in adaptive coping skills during the initial diagnosis phase as well as in the long term.

Recognizing that the grief and sorrow responses associated with LQTS may recur and change throughout the lifespan of the individual with LQTS, it is critical that families be provided with information concerning these potential ongoing grief responses and access to support services. Because the initial diagnosis of LQTS normally occurs in childhood or adolescence, the child and family must also deal with developmental and social issues as the child grows and matures. As the child or adolescent develops his or her interests and needs naturally evolve as well. Therefore the perceived losses that the child and family grieve when he or she is 10 may be dramatically different when he or she reaches the age of 13.

Although medical experts continue to provide ongoing testing and recommendations as the child grows, mental health professionals should be available to assist families in dealing with developmental changes in their child’s life.

LQTS is a disorder that, for the most part, is largely invisible to those outside the immediate family. Therefore, the child and family may have little social support from the extended community who are unlikely to acknowledge or even recognize the losses experienced by the family. The family may then be left to deal with the losses without the social support that
is extended when faced with more conventional and visible losses. The lack of social support is likely to become even more pronounced following the initial diagnosis because the losses become a permanent part of the individual’s life. The potential for families to become isolated from their typical social supports such as religious institutions or friends is significant. Specific social support networks for individuals affected by LQTS are needed to help them cope with the ongoing losses as well as with other important issues resulting from life with this disorder.

Support groups both live and online can be critical for families dealing the perceived losses associated with LQTS. Medical and mental health professionals can help to develop these programs and provide guidance for families seeking these services.

Therefore, the perceived loss that the individual and family experiences following the initial diagnosis is only the beginning. As the individual affected by LQTS develops and his or her needs change, the perceived losses, likewise, may change or intensify. Whereas the caregivers may initially experience strong social support from extended family and friends following the diagnosis, they may quickly find themselves isolated in their ongoing experiences of sorrow and loss. Access to information regarding potential grief reactions following initial diagnosis and also in the long term is critical for families coping with LQTS. Likewise, social support resources are needed for individuals who find themselves isolated in chronic sorrow. Psychologists, other mental health professionals, and clergy who have been educated in long term grief reactions are needed to assist families cope with their evolving sorrow.

Electrophysiologists are normally charged with the task of breaking the news of a positive diagnosis of LQTS to patients and their families. EPs can provide patient-centered care by listening and communicating an understanding so that the family’s grief can be expressed. Along with essential information related to the course of the syndrome, EPs can provide relevant
information concerning possible grief and loss reactions. They can also promote a sense of hope, control, and balance related to the diagnosis and the losses experienced. With knowledge of potential chronic sorrow reactions, EPs can provide guidance for possible sources of support including support groups and therapeutic interventions.

When treating individuals dealing with the implications of a diagnosis of LQTS, psychologists can, first of all, educate patients on potential grief reactions related to the initial diagnosis. Initially, they can focus on normalizing and legitimizing grief reactions and experiences of loss. There are no tools available to formally assess for chronic sorrow; however, psychologists who are trained in cognitive-behavioral therapy should assess for maladaptive cognitions and their resulting emotional, physiological, and behavioral responses related to the perceived losses (Malkinson, 2007). They can then help the patients modify these maladaptive thoughts. They can assist patients in developing adaptive grief responses and coping behaviors. Psychologists can train patients in emotional regulation including mindfulness meditation. Eventually, patients can be assisted in the task of retelling the stories of their loss in light of the new realities. They can also be educated in the recurring nature of chronic sorrow throughout the lifespan of the object of loss.

**Limitations and Future Directions**

The sample for this study used archival data. The archival data were drawn from an online message board for individuals who have been affected directly or indirectly by Long QT Syndrome. Individuals self-selected to be involved in the internet-based message board. Because the sample was drawn from archival data, demographics of the individuals including age, gender,
race, ethnicity, nationality, and religious background were limited to the information volunteered by the individuals on the message board. Therefore, although the sample utilized is large, it is impossible to ascertain whether or not the sample represents a cross-section of the population.

Because of the archival nature of the data, the researcher was unable to interview the individuals. Therefore, specific questions related to their experiences of loss and grief could not be addressed to the participants. Because there was no direct contact with the participants, the researcher was unable to clarify or question statements made in the data.

The data utilized for this study were collected from two months of messages during 2008. The data, therefore, represents a brief window into lives of these individuals during these two months. In theory, chronic sorrow tends to recur and fluctuate as the individual develops and internal and external stressors arise at various moments. This study was unable to observe any longitudinal changes in grief and loss.

The results of this qualitative study suggest several directions for future research. First, although the data examined in this study allowed for insight into the lives of a large cross-section of the population affected by LQTS, future research should focus on detailed interviews of individuals affected by the syndrome with specific emphasis on grief issues. Focused interviews would allow an opportunity to gain a richer understand of the experiences of loss and the emotional reactions of individuals.

By definition, chronic sorrow is ongoing and recurring throughout the lifespan of the individual. Future research should focus on a longitudinal exploration of individuals affected by LQTS. Such a study would allow a more complete picture to develop of the potential, recurring grief reactions related to the syndrome.
There was very little social and cultural information volunteered in the messages. Future research should attempt to identify and explore cultural factors of those affected by LQTS. Future studies could examine the possible differences in experiences of loss and grief reactions as they relate to the cultural and ethnic backgrounds of those affected.

Conclusion

In respect to grief and loss issues related to LQTS, individuals expressed themselves in a variety of ways. In the sample studied, many individuals expressed no obvious grief or loss reactions. Numerous individuals expressed their experiences of loss through written cognitions including a loss of normal life and physical activity. Others expressed grief reactions through emotions such as sadness and denial. Some individuals expressed significant grief responses immediately following the initial diagnoses of LQTS. On the other hand, there were indications that these grief responses continued long after the initial diagnosis. Likewise certain individuals expressed long term grief reactions that seemed to recur and evolve as the object of grief developed or specific stressors triggered reactions.

Those who have been affected by the diagnosis of LQTS and experience loss, clearly deal with the new reality on a significant and ongoing basis. They must cope with the reality that the person’s life has been unalterably changed. Although most of the individuals with LQTS described on the message board are being treated medically, there remains the small but significant chance that a cardiac event may be triggered by an environmental factor. Therefore, those affected by LQTS must daily cope with the possibility that they or their loved one could die unexpectedly. Beyond this very significant concern, the medical treatment and lifestyle
changes required to reduce the risk of a cardiac incident often require the individual and family members to sacrifice significant aspects of their lives. Further, caregivers perceived and expressed the loss of certain expectations for the lives of their children. In this study the two main themes related to perceived loss centered on the loss of a “normal” life and the loss of physical activity.

Individuals in this study expressed dimensions of chronic sorrow as they described the losses associated with LQTS. They expressed specific characteristics of the perceived loss. The loss was recognized by the individual as ongoing with no recognizable endpoint due to the chronic nature of LQTS. Depending upon how long the individual had been coping with the disease, there were indications that the grief response occurred during the initial phase of diagnosis, as well as, throughout the course of the disease in a recurrent fashion. There were indications that individuals in this study also recognized the discrepancy between perceived reality of life with LQTS and their continuing dream for themselves or their child. Finally, the object of the loss continued to be present in the life of the individual.

Individuals in this study affected directly or indirectly by LQTS were confronted by the losses associated with the initial diagnosis of the syndrome. Many factors may influence how intensely individuals experienced these initial losses or even if they experienced them as losses at all, including history of losses, stressors and social support. As the reality of the diagnosis set in, they experienced recurring cognitions and emotions when exposed to specific triggers related to the perceived losses. The developmental changes in the lives of the individuals seem to affect their perceptions of the loss as well. Given the chronic nature of the losses and grief associated with LQTS, a central task of those affected by LQTS is to develop methods of coping with the losses and deal with the reality of life with LQTS.
Table 1

*Frequency Counts of Data in the Overall Study*

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Number of Threads</td>
<td>80</td>
</tr>
<tr>
<td>Total Number of Messages</td>
<td>771</td>
</tr>
<tr>
<td>Number of People with LQT1</td>
<td>11</td>
</tr>
<tr>
<td>Number of People with LQT2</td>
<td>1</td>
</tr>
<tr>
<td>Number of People with LQT3</td>
<td>2</td>
</tr>
<tr>
<td>Number of People with LQT5</td>
<td>7</td>
</tr>
<tr>
<td>Number of People with LQT6</td>
<td>3</td>
</tr>
<tr>
<td>Number of People with Borderline</td>
<td>5</td>
</tr>
<tr>
<td>Number of People with JLN</td>
<td>1</td>
</tr>
<tr>
<td>LQTS in Self</td>
<td>40</td>
</tr>
<tr>
<td>LQTS in Child</td>
<td>41</td>
</tr>
<tr>
<td>LQTS in Spouse</td>
<td>4</td>
</tr>
<tr>
<td>LQTS in Sibling</td>
<td>10</td>
</tr>
<tr>
<td>LQTS in Parent</td>
<td>4</td>
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</tbody>
</table>
Table 2

*Frequency of Messages Related to Loss and Grief*

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Number of Participants</td>
<td>89</td>
</tr>
<tr>
<td>Total Number of Messages</td>
<td>711</td>
</tr>
<tr>
<td>Total Number of Messages Related to Loss and Grief</td>
<td>67</td>
</tr>
<tr>
<td>Messages Related to the Loss of Normal Life</td>
<td>18</td>
</tr>
<tr>
<td>Messages Related to the Loss of Physical Activity</td>
<td>10</td>
</tr>
<tr>
<td>Messages Related to Death or Near Death of Loved One</td>
<td>21</td>
</tr>
<tr>
<td>Messages Expressing Emotional Reactions</td>
<td>16</td>
</tr>
<tr>
<td>Messages Expressing Denial</td>
<td>4</td>
</tr>
<tr>
<td>Messages Expressing Sadness or Depression</td>
<td>6</td>
</tr>
</tbody>
</table>
References


children with the congenital long-QT syndrome. *Circulation, 117*(17), 2184-2191.


