Long QT Syndrome: A Pamphlet for Community Awareness in Prevention of Sudden Cardiac Death in the Young

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Abstract
The project was conducted with the purpose of producing a pamphlet, in conjunction with *Sydänlapset ja -aikuiset ry*, for public education in Long QT syndrome (LQTS). This was undertaken in the hope of, as previously mentioned, informing the public of LQTS and thereby decreasing the risk of sudden cardiac death in regards to LQTS. In the thesis information was gathered dealing with LQTS in addition to information on proper pamphlet compilation. Whereby the information was condensed and used to produce the pamphlet. The pamphlet was then given to *Sydänlapset ja -aikuiset ry* in electronic form to be placed on the world wide web for members of the public to print and use as needed.

The theoretical background was based on information gathered from various research papers regarding LQTS and pamphlet production. Information was also gathered from various foundations such as the *Sudden Arrhythmic Death Foundation (SADS*). Upon completion of the theoretical portion, a pamphlet was produced containing basic information regarding LQTS. In order to check the pamphlet for readability, educational contents and overall attractiveness the pamphlet was presented to nursing staff of Jyväskylä Central Hospital whereby feedback was attained in the form of a questionnaire. Additionally the pamphlet was also shown to various members of the public to confirm that the language and terms used in the pamphlet were simple and easy to understand. Thus, the information compiled included a description of LQTS, information regarding the compilation of educational material for public dissemination and lastly feedback received from nursing staff regarding the pamphlet and its educational value.

Overall, the feedback received was positive; fifteen nurses from Jyväskylä Central Hospital paediatric ward participated in the pamphlet's evaluation. Feedback was gathered with the aid of a 13 point questionnaire. Various recommendations were made by the participants and taken into consideration by the authors. Necessary changes were made to the pamphlet whereupon the final electronic version was sent to Sydänlapset ja aikuiset ry. According to the feedback received the pamphlet was universally seen as useful, necessary and practical.

Keywords
Long QT Syndrome, community awareness, prevention of sudden cardiac death, pamphlet

Miscellaneous
The bachelor's thesis is available in the library of JAMK University of Applied Sciences.
Appendix: Pamphlet for Community Awareness of LQTS

CONTENTS

1 LONG QT SYNDROME AND THESIS OBJECTIVES

Long QT Syndrome (LQTS) is an inherited heart arrhythmia that is a cause of syncope and sudden cardiac death in young people. With proper treatment of LQTS, the risks of sudden death may be decreased. Those diagnosed with LQTS are affected physically through limitations caused by treatment and risk factors, and psychologically through uncertainty and anxiety that may be caused by the diagnosis. Consequently, individuals in close contact with persons diagnosed with LQTS have good reason to familiarize themselves with the effects that LQTS has on an individual in order to react appropriately to situations that may arise.

During the Canadian Sudden Arrhythmia Death Syndromes (SADS) Foundation's conference, Preventing Sudden Cardiac Death in the Young, September 20, 2008, the Special Projects Director of the Canadian SADS Foundation, Blake Hurst expressed the importance of community education and awareness towards LQTS in the prevention of sudden cardiac death. It was from there that an idea for a bachelor's thesis was created in the form of a pamphlet to be used as a tool for community awareness in Finland. During the initial planning phase of the thesis *Sydänlapset ja -aikuiset ry* was identified as a possible cooperating association.

After discussing possible project possibilities with the contact person for *Sydänlapset ja -aikuiset ry* and taking her recommendations and concerns heard from parents of children with LQTS, the best course of action appeared to be in the form of a multifaceted information package that would be useful for all target groups.

Improvement of public awareness of LQTS is promoted by providing a tool in the form of a pamphlet for distribution by *Sydänlapset ja -aikuiset ry*, Long QT branch. The target group for the pamphlet includes those in close cooperation with young people possibly suffering from LQTS. This group may include coaches, teachers, family members, and caregivers. Awareness of LQTS and

sudden arrhythmic death will increase among the target group with the assistance of the pamphlet.

The thesis process included gathering information regarding LQTS from various sources such as research papers, various internet sites dedicated to LQTS which are supported by associations such as the SADS Foundation, practice guidelines and other various publications. Whereupon the information was compiled, the most important points regarding LQTS, raising awareness of LQTS and the criteria for an effective information package were filtered to establish a base for the theoretical portion of the thesis. Key words used in the search included: Long QT syndrome, sudden cardiac death, LQTS genes, and patient information pamphlet.

A pamphlet format was chosen as an effective tool for information dissemination using the theoretical information gathered, as a shorter length assures that the reader is able to obtain essential information. In order to effectively evaluate the usefulness and clarity of the pamphlet, it was decided to present the pamphlet and information regarding its use to health professionals in Jyväskylä Central Hospital. Their feedback would be used in the further development of the pamphlet and the information presented, consequently resulting in the final pamphlet produced.

In addition to the previously mentioned aims of the compilation of the thesis, additional goals include the authors' professional development in health promotion, and acquiring knowledge regarding LQTS. Furthermore, the thesis process will facilitate the authors' information gathering skills regarding health issues, which may be constructive in future professional endeavours.

2 LONG QT SYNDROME

2.1. What is Long QT Syndrome?

Long QT syndrome (LQTS) can be defined as a heart rhythm disorder that produces fast chaotic heartbeats which in turn may lead to fainting or in severe cases, sudden death. Long QT may occur as a result of genetic mutation, medical conditions such as congenital heart defects or certain medication. There are various treatments available such as the limitation of physical activity, avoidance of medications that may cause LQTS, prescribing medications that prevent arrhythmias and lastly implantable devices that control heart rhythm. (Mayo Foundation, 2008.)

In further explanation, congenital LQTS is defined by the Levine et al. (2008, 591) as “an inherited disorder of cardiac repolarization that predisposes to syncope and to sudden death from polymorphic ventricular tachycardia.” Thus, in this examination, or rather, attempt to define LQTS whether it be congenital or acquired, it is clear that LQTS is a condition that affects the heart. More precisely, it affects the “electrical system” of the heart and interferes with the heart’s normal rhythm, which may then lead to fainting, seizures or sudden death.

LQTS is a result of various ion channel gene mutations, of which three are most common: KCNQ1 mutation (LQT1), HERG mutation (LQT2), and SCN5A mutation (LQT3). Studies have shown that there are differences in responses and sensitivity to stimulation in the separate genotypes. As a result, triggers of cardiac events vary according to genotype. (Noda et.al. 2002, 975.) Further reference to the triggers is made in conjunction with risk factors. In Finland, approximately one in 3 000 people are carriers of the gene (Toivonen et.al. 2008).

2.2. Symptoms of Long QT Syndrome

Approximately 50% of individuals that suffer from LQTS do not experience symptoms or signs from their condition. Those with LQTS may become aware of their condition from the results of an electrocardiogram (ECG) which is performed for an unrelated reason. One additional form of diagnosis performed due to a family history of LQTS is genetic testing, the results of which identifies gene mutations as a confirmation or indication of LQTS. The most common symptoms and signs for those who suffer from LQTS include: fainting, seizures and sudden death. Although, as previously stated approximately half of the individuals that experience LQTS may not experience any signs or symptoms. (Mayo Foundation, 2008.)

Fainting is the most common sign of LQTS. These fainting spells are also referred to as syncope and are caused by a temporary erratic heart beat. Fainting spells may occur when individuals with LQTS become excited, angry, scared or during exercise; in other words, during times of emotional or physical stress. Warning signs before a fainting spell are unusual for persons with LQTS. However, if signs of fainting are experienced before fainting; such as light-headedness, heart palpitations, weakness and blurred vision, it is recommended that the individual sit or lie down and inform a person near to them. (Mayo Foundation, 2008.)

Seizures occur due to the brain becoming increasingly deprived of oxygen as a result of the heart's continuous erratic beating. According to the authors of mayoclinic.com some individuals with LQTS "have been misdiagnosed as having a seizure disorder and have even been treated with anti-epileptic medications." Furthermore, according to the previously mentioned source most deaths related to LQTS occur in individuals aged between eleven and thirty years; it is also speculated that ten to fifteen percent of sudden infant death syndrome (SIDS) can be attributed to LQTS. Inherited LQTS symptoms may first occur during the first months of life or even as late as middle age. However, those individuals that

experience symptoms of LQTS normally experience their first symptoms before the age of forty. (Mayo Foundation, 2008.)

Due to an increasing understanding of the genetic basis of LQTS it is possible to differentiate between different types of LQTS. For example LQT1 is triggered by exercise, LQT3 with inactivity, in other words, triggered by a low heart rate. LQT2 may be triggered in the affected individual simply by being startled, for example an unexpected loud noise. (Levine et al. 2008, 591.)

2.3. Causes of Long QT Syndrome

LQTS occurs due to an electrical disturbance in the heart. The heart's pumping actions are controlled by electrical impulses created in the sinus node. The sinus node is a group of cells contained in the upper right chamber of the heart. The impulses created in the sinus node cause the heart's chambers to contract and relax; in other words, to beat. After every heart beat the sinus node in effect needs to "recharge" itself in preparation for the next heart beat; this process is referred to as repolarization. Thus, in LQTS the act of repolarization takes an extended amount of time. It is possible to monitor the heart's electrical impulses with the aid of an electrocardiogram (ECG). The electrical impulses are displayed as waves of electrical activity and five distinct waves are identified in an ECG which are labeled P, Q, R, S and T. (See Figure 1.) When examining an ECG printout display waves labelled Q, R, S, T depict electrical activity in the lower chambers of the heart. The QT interval indicates the time the cells in the lower chambers of the heart require to discharge and recharge, thus, indicating the time at the heart's disposal to contract and refill with blood prior to the next contraction. Therefore, it is possible to measure the QT interval and determine whether it is normal or not. (Mayo Foundation, 2008.)

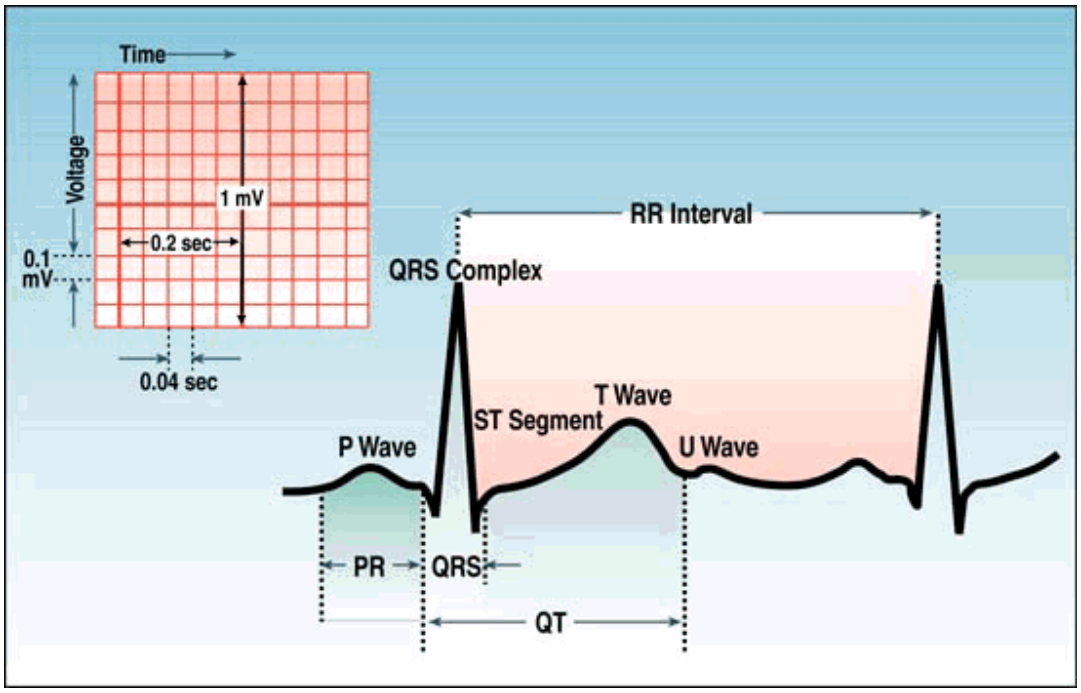

Figure 1. ECG intervals and waves (Yanowitz, 1997)

As has been mentioned previously, “LQTS may occur as a result of genetic mutation, medical conditions such as congenital heart defects or certain medication.” According to Goldenberg et al. (2008, 2192) “The congenital LQTS is caused by mutations that encode cardiac ion channel proteins which regulate the flux of sodium, potassium, and calcium ions across myocellular membranes, resulting in prolonged ventricular repolarization and an increased risk for sustained ventricular tachyarrhythmias.” Therefore, congenital LQTS is a condition that exists before or at birth and is hereditary, in other words, occurring or tending to occur among family members. Goldenberg et al. further state that “These genetic disorders are associated with sudden cardiac death in young individuals without structural heart disease.”

2.4. When To Seek Medical Advice

Those at risk of LQTS include children, teenagers and young adults, including these persons’ family members who have experienced unexplained fainting

episodes, seizure episodes, near drowning or have a history of cardiac arrest. Furthermore, individuals related to persons known to have LQTS and individuals taking medication that is proved to be a cause of prolonged QT intervals are also at risk of LQTS. Lastly, individuals that suffer from eating disorders such as anorexia nervosa may also be at risk of LQTS due to low potassium, magnesium or calcium blood levels which are essential minerals for the functioning of the heart's electrical system. (Mayo Foundation, 2008.)

To reiterate the previously mentioned points, Levine et al. (2008, 599) state that "Congenital long QT syndrome should be suspected when the electrocardiogram shows the characteristic QT abnormalities when there is a history of syncope or ill-defined "seizures" in the patient or in the patient's family." Thus, by examining this information it is possible to deduce that individuals that experience any of the previously mentioned symptoms or meet any of the previously mentioned criteria should seek medical advice in order for the appropriate steps to be taken.

2.5. Diagnosis and Treatment of Long QT Syndrome

It is generally recommended that individuals see a medical professional if sudden fainting occurs during physical exertion, emotional stress or after the use of a new medication. Furthermore, since LQTS is a genetic disorder it is also recommended that individuals with close relatives whom have been diagnosed with LQTS also be tested. (Mayo Foundation, 2008.)

Several test are available for confirming LQTS; these include an electrocardiogram (ECG), ambulatory ECG monitoring, event ECG monitoring, nonexercise stress test, electroencephalogram (EEG) and genetic testing. An EEG is performed to rule out any neurological causes of fainting such as a seizure disorder. (Mayo Foundation, 2008.)

Treatment of LQTS may involve surgery, the use of medical devices, medications or lifestyle changes. Treatment is undertaken with the goal of preventing arrhythmic heartbeat and sudden death. In the case of drug-induced LQTS treatment may simply involve the elimination of the drug in question; however additional treatment may be required. (Mayo Foundation, 2008.)

Clinical management of Long QT Syndrome varies according to the response to treatment and risk stratification. Procedures that have been proven effective and have been generally accepted as beneficial for those diagnosed with LQTS include lifestyle modification, beta blocker treatment for those with a prolonged QT interval, and implantation of an implantable cardioverter-defibrillator (ICD) along with the use of beta blockers for patients with previous cardiac arrest who have reasonable expectation of survival with good functional status for more than one year. Treatment recommendations are explored in following discussion as according to the ACC/AHA/ESC Practice Guidelines-Executive Summary. (Zipes, Camm 2006, 1088.)

Recommendations for treatment based on evidence or opinion that supports it's usefulness include beta blocker treatment for those with a molecular LQTS analysis but a normal QT interval to prevent sudden cardiac death, and the implantation of an ICD combined with beta blocker treatment to reduce sudden cardiac death in LQTS patients experiencing syncope and/or VT despite beta blocker treatment. (Op. cit. p.1089.)

Treatment that is less established by evidence or opinion as being effective includes left cardiac sympathetic neural denervation for LQTS patients with syncope, torsades de pointes, or cardiac arrest while receiving beta blockers, and implantation of an ICD with the use of beta blockers for prophylaxis of sudden cardiac death for patients in categories possibly associated with higher risk of cardiac arrest such as LQT2 and LQT3. (Op. cit. p. 1089.)

Patients diagnosed with Long QT syndrome are recommended to make lifestyle changes to prevent cardiac events and avoid factors that may contribute to symptoms of LQTS. These factors vary according to the type of LQTS with which

the patient is diagnosed. Recommendations include avoidance of competitive sports activity for all types of LQTS. For LQT1, swimming should be limited or performed under supervision. LQT2 patients should avoid auditory stimuli especially during sleep which may include telephones and alarm clocks. All patients with LQTS should avoid drugs known to prolong the QT interval and those that deplete potassium/magnesium. (Op. cit. p. 1089.)

Lifestyle changes may also include restrictions for sports and leisure activities. These restrictions should be discussed with a cardiologist to define the risks involved with LQTS, and the care being provided. It may be recommended to patients of LQTS to avoid forms of physical exercise in which a sudden loss of attention and functional ability may lead to accident or trauma. Sudden strenuous physical activity is prohibited for those with LQTS; however, endurance training and muscle strengthening improve the performance of the circulatory system and improve quality of life. (Käypä hoito, 2008.)

Through genetic analysis, it is possible to identify all carriers of the gene mutation with a LQTS family. Identification of carriers allows treatment with a beta blocker prophylaxis against life-threatening arrhythmias for those identified as silent carriers. Additionally, genetic counseling may be provided to gene carriers to learn about the risk of transmitting the gene to offspring. (Zipes, Camm 2006, 1089.)

Recommendations for treatment of pediatric patients that have a high risk of sudden cardiac death and a genetic basis who have survived a cardiac arrest due to Long QT syndrome include ICD implantation when the patients are receiving optimal medical therapy. The benefit of the implantation must be considered, taking into account the risk of device malfunction, infection or lead failure. The role and benefit of ICD implantation for prevention of sudden cardiac death in young children has not been defined. However, in older children and adolescents, prophylactic ICD implantation may be considered based on data derived from clinical trials from adult patients suffering from Long QT syndrome. (Op. cit. p. 1093.)

Patients with an ICD device should receive regular follow-up and analysis of the status of the device. The ICD is programmed to achieve optimal sensitivity and specifity according to the nature of the underlying arrhythmia. Measures are taken to minimize the risk of inappropriate ICD treatment. The ICD in itself does not decrease the incidence of arrhythmias. However, it protects the patient from the consequences of the life-threatening arrhythmias characteristic of Long QT syndrome. (Op. cit. p. 1093-1094.)

Treatment of Drug-Induced Long QT Syndrome includes the removal of the offending agent, management with intravenous magnesium sulfate, or potassium ion repletion for patients taking QT-prolonging drugs presenting few episodes of torsades de pointes and prolonged QT time. Atrial or ventricular pacing or isoproterenol is reasonable for patients taking QT-prolonging drugs who present with recurrent torsades de pointes. (Op. cit. p. 1094.)

Patients diagnosed with Long QT syndrome have reason to avoid QT-prolonging drugs. (appendix 1.) These include some bronchodilators, anti-viral drugs, anti-arrhythmic drugs, antidepressants, antihistamines and antibiotics, as well as others. (Toivonen et al. 2008.)

3 LONG QT SYNDROME AND THE YOUNG

3.1. Psychological Effects

With the diagnosis of Long-QT syndrome comes the acknowledgement that the diagnosis includes a chance of sudden death in affected families. Advice may be given about the avoidance of strenuous exercise, mental stress, and loud noise to avoid trigger situations. According to studies of families going through screening for inherited cardiac arrhythmias, high levels of anxiety have been reported in parents of children at risk. (van Langen, Hofman, Tan, Wilde, 2004,116.) According to a recent study regarding fears and anxiety with Long-QT

syndrome, conducted by Guiffre et al. (2008, 423), it is possible that children with Long-QT are not able to discuss feelings of anxiety and find difficulties in coping with anxiety. This, in some cases may result in behavioural symptoms.

Results of a study regarding parental perceptions about congenital long QT syndrome revealed that parents did not report fear about their own death, but rather fear of their children dying. Parents alleviate their fear by making lifestyle changes, educating the community, and teaching children about their own health to enable them to make educated decisions. The study also revealed that parents experience frustration about the lack of knowledge regarding LQTS among health care professionals. (Farnsworth et al. 2006, 284.)

Quality of life is affected with a diagnosis of Long QT. Families must make decisions to avoid situations that may trigger an event and are forced to make lifestyle decisions to avoid putting their children at risk. The family is forced to evaluate their attitudes toward life and make decisions about treatment options, possible maintenance issues and potential complications or side effects. In most cases, the decisions are made to protect the children, but not limit lifestyle. The timing of the diagnosis may also have a more significant impact on the life of an adolescent than a young child. Adolescents are at a vulnerable stage in life, and the diagnosis may mean that career or other life goals may need to be re-evaluated. These patients are at a risk for depression, and close observation and follow-up is crucial. (Op.cit. p. 288-289.)

Parents are given the responsibility for deciding treatment and therapy options for children. These decisions may have a great impact on the life of the child. The study suggests that the uncertainty regarding treatment options and life with a potentially fatal disease does not seem to be an ongoing emotion. Parents adjust once they become more knowledgeable and a treatment plan is decided. (Op. cit. p.289.)

Parents of carrier children remain vulnerable to high levels of distress. Distress levels were high among parents who were highly distressed at previous assessments, were familiar with the disease for a longer time, had experienced a sudden death in the family, were lesser educated, and who were unsatisfied with the given information. Results of this study suggest that “most parents who have carrier children seem to experience difficulties adjusting to the new status of their children.” (Hendriks et al. 2005, 107,110.)

If the diagnosis has been made after the death of a family member, the patients especially may feel guilt for the death of their loved one, and transmitting the gene mutation to one’s child may have an emotional impact on the parent. Patients and family members are encouraged to find information and support from various foundations aiming to provide support for those diagnosed with a genetic cardiac arrhythmia. (Levine et al. 2008, 598-599.)

3.2. Effects of Treatment

Long QT Syndrome, as mentioned earlier, is usually treated pharmacologically with beta-blockers, with the implantation of an internal cardioverter-defibrillator or pacemaker, or through surgical left cardiac sympathetic neural denervation. Treatment may have side-effects with which patients must learn to cope.

Side effects of beta-blockers may include dyssomnia or sleep disturbances, nightmares, bradychardia, weakening of peripheral circulation, shortness of breath, muscle weakness and fatigue. During the beginning of treatment, the patient may experience dizziness when rising from a sitting or laying position. Beta-blockers may also disguise the symptoms of hypoglycaemia and strengthen symptoms of anaphylactic shock. Continual treatment of Long-QT with beta-blockers is recommended throughout pregnancy and breastfeeding. Although beta-blockers are excreted in the breast-milk, the probability of adverse side

effects is low. Medication must be taken regularly, and must not be stopped suddenly. (Pharmaca Fennica, 2009)

The implantation of an ICD does not usually put dramatic limits on the life of the patient. Light exercise, a normal sexual life and travelling are not limited. However, swimming alone, combat sports and diving should be avoided. (Raatikainen, 2007.) Although limitations are not drastic upon the implantation of an ICD, some consequences on the everyday life of the patient are observable. Patients may experience anxiety and depression, may feel a loss of control over life, and as a result may in some cases experience a lowered quality of life. Patients strive to gain control in their lives to reduce feelings of anxiety, depression and uncertainty. It is suggested that education and psychosocial support would be provided for patients following ICD implantation. (Flemme 2009, 49.)

4 RAISING AWARENESS OF LONG QT SYNDROME

4.1. Risk Factors of Long QT Syndrome

Data on specific risk factors for sudden cardiac death in children with LQTS is limited. Based on a study that utilized the International LQTS Registry to follow up on LQTS children to evaluate risk factors contributing to sudden cardiac death in children, male gender, QTc duration, and a history of prior syncope were identified as risk factors. The risks vary among patients, and are influenced by age, gender, genotype, environmental factors, therapy and possibly other modifier genes. The study concluded that careful follow-up is necessary for children with LQTS, as risk factors are time dependant and age specific. (Goldenberg et.al. 2008, 2185, 2190)

Arrhythmogenic syncope is often provoked by physical, emotional or auditory stimulation. According to a prospective longitudinal study of 328 families with Long QT Syndrome, 47% of probands (the first member of a family to be diagnosed with LQTS) had syncopal episodes in association with intense emotions, 41% with vigorous physical activity, 19% on awakening, 15% while swimming and 8% on arousal by auditory stimuli such as an alarm clock. (Moss et al. 1991,1139). However, triggers of events vary according to the type of LQTS. Those with LQT1 are more likely to experience events triggered by exercise, while events are more likely to be triggered by emotion in those with LQT2. (Schwartz et al. 2001,91) The variance in triggers for events may be seen in Figure 2.

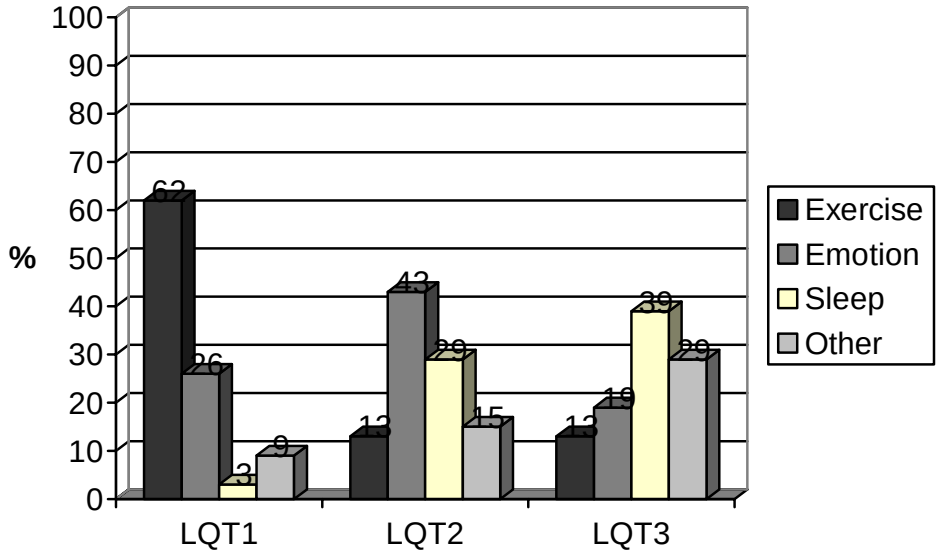

Figure 2. Triggers for Cardiac Events in Long QT Syndrome (Schwartz et al. 2001.)

Patients with a longer QTc and faster heart rates are at a greater risk of experiencing events compared to those with shorter QTc and slower heart rates. However, it is not determined how heart rate affects the risk of an event.

It has been observed that there is an increased probability of cardiac events in women compared to men. However, although the inheritance of LQTS is autosomal dominant, it has been observed through a study conducted by

Imboden et al. (2006, 2744) that LQTS is more often transmitted to females. It has also been stated that women typically have longer QT intervals than men, and this difference increases at slower heart rates. The incidence of prolonged QT intervals and torsade de pointes is higher in women than men. (Zipes, Camm. 2006, 1092)

The influence of pregnancy on the risk for cardiac events in patients with hereditary Long QT syndrome has been investigated by Rashba et al. (1998,455), and it was determined that the postpartum period is associated with an increased risk for events for probands. First degree relatives may also be at risk, but not to the extent of probands. Rashba states that this increased risk may be related to cardiovascular changes that occur during pregnancy. Especially during the third trimester, heart rate increases. In Long QT patients, slower heart rates exaggerate the prolongation of the QT interval. After delivery, heart rate slows, and the QT interval increases. The psychological stress of caring for a newborn may also be related to the increase in cardiac events in the postpartum interval.

It has been determined that age is a possible risk factor for sudden cardiac death, or life-threatening cardiac events among patients with Long QT syndrome. It has been suggested that patients with LQTS over the age of 40 have a lower risk of cardiac events than their younger counterparts. However, in a study conducted to investigate LQTS after the age of 40, Goldenberg et al. (2008, 2200) states that the risk remained for life-threatening cardiac events after the age of 40.

Age has been proven to be a factor in risk stratification for cardiac events in patients with LQTS. Hobbs et al. (2006, 1249) concluded in a study conducted regarding LQTS and adolescence that males aged 10 to 12 years had four times a greater risk for cardiac events compared to females of the same age. However, there was no significant difference between the risks of females and males aged 13-20 years.

The screening of athletes for cardiovascular diseases such as cardiomyopathies and ion channel abnormalities has been argued to prevent sudden cardiac death, and awareness campaigns have attempted to proclaim the importance of awareness of treatable genetic arrhythmias. Recommendations have been made by Zipes, Camm (2006, 1092) in the ACC/AHA/ESC Practice Guidelines for the gathering of preparticipation history and physical examination which includes a family history of premature or sudden cardiac death and evidence of cardiovascular diseases. As of yet, there is no protocol for athlete pre-participation screening, however, it is recommended that all athletes that have experienced syncope should be evaluated to uncover cardiovascular disease or rhythm disorder, and cessation of competition is necessary for those suffering from serious symptoms. The possibility and effectiveness of ECG-screening and echocardiography as preparticipation screening for heart disorders in athletes has been considered and researched.

4.2. Strategies for Prevention of Sudden Cardiac Death

Sudden cardiac death is defined by Viitasalo (2009) as a natural unexpected death that is a result of cardiac malfunction, in which the patient suddenly loses consciousness because of impaired circulation and dies within one hour after the beginning of symptoms. Sudden cardiac death is a result of a fatal arrhythmia or a structural defect of the heart caused by cardiac disease.

The prognosis of survival of cardiac arrest drops dramatically if primary blood circulation is not restored within eight minutes. Viitasalo suggests that sudden cardiac death may be prevented by arranging that cardiopulmonary resuscitation would be accessible in all areas. The readiness of citizens to begin CPR must be developed. Family members of cardiac patients should especially master the skills of CPR. Automated external defibrillators for public use are widely available, and should be made available at public events and places. (Viitasalo, 2009)

Education on CPR is provided in Finland by the Finnish Red Cross. They maintain clear instructions for resuscitation. See appendix 2 and appendix 3 for flow charts of resuscitation for adults and children as recommended by the Finnish Red Cross (2009).

4.3. Community Education of Long QT Syndrome

Long QT Syndrome affects the lives of many young people. If it is detected and treated early, sudden cardiac death may be prevented. Community education is important to increase awareness about cardiac arrhythmias and the warning signs involved with them. Warning signs should be monitored and those exhibiting signs should be referred to a cardiologist for assessment. Promotion of CPR training and the installation of Automated External Defibrillators in schools and sports facilities are effective at reducing the risk of cardiac death in all people experiencing cardiac arrest. (The Canadian SADS Foundation)

Steps to educate the community about the recognition of warning signs of Long-QT and the significance of Automated External Defibrillators in public buildings have been taken by Long QT or Sudden Arrhythmic Death foundations. Warning signs commonly include syncope during physical activity, syncope resulting from emotional distress or startle, and a family history of unexpected death of an otherwise healthy young person. (The Canadian SADS Foundation)

Promotion of cardiopulmonary resuscitation training and promotion of Automated External Defibrillators would be beneficial especially for those in close cooperation with those diagnosed with Long QT Syndrome. Local CPR courses are available for education in these areas. The guidelines according to the Red Cross of Finland for cardiopulmonary resuscitation may be found in the appendix.

5 LONG QT SYNDROME PAMPHLET DEVELOPMENT

5.1 Pamphlet Development for Community Education of Long QT Syndrome

Using the theoretical information gathered, a pamphlet format was chosen as an effective tool for information dissemination. Shorter length assures that the reader is able to obtain essential information in a condensed form. According to Coulter et al (1998,16), during the making of a pamphlet matters that should be taken into account should include making the information accessible, acceptable, readable and comprehensible. In other words, the pamphlet should be made available to all those who may need the information and should contain reliable, accurate information in a simple, structured format. Coulter continues that the pamphlet should be attractive to the reader, and sufficiently cover the relevant topic with current information using understandable terminology. Also, the authors of the pamphlet should arrange for editorial review, make referral to evidence-based knowledge and sources, and include information on where to find further information about the subject. The credibility of the authors, publishers and sponsors also determine the reliability of the pamphlet. (Coulter et. al 1998,16.)

Aldridge suggests (2004, 375) that to assure the readability of leaflet material, font size should be at least 12-point using bold or italics to emphasize key points. Text should be justified to the left margin and text should be divided using headings and subheadings. The use of bullets assists the reader in following the information and the overall appearance of the leaflet should be uncluttered.

The guidelines for pamphlet development were adhered to as best as possible. As previously mentioned, the pamphlet should be attractive to the reader. Thus, a simple and structured layout was chosen. The colours were chosen to attract the eye of the reader without interfering with the information presented and three pictures were added to make the pamphlet aesthetically pleasing. Of these, one

picture depicting a grandmother with a grandchild was selected to represent the continuation of life and the genetic nature of LQTS.

In order to effectively evaluate the usefulness and clarity of the pamphlet, it was decided to present the pamphlet and information regarding its use to health professionals in Jyväskylä Central Hospital. Their feedback would be used in the further development of the pamphlet and the information presented consequently, resulting in the final pamphlet produced.

5.2. Presentation of the Pamphlet

In order to effectively evaluate the pamphlet on LQTS for public education it was presented to nursing staff working in Jyväskylä Central Hospital: ward one (pediatric ward), and the pediatric cardiac outpatient clinic in which young patients with LQTS are provided care. The wards in question were chosen on the assumption that the staff in these wards would benefit from the information presented and evaluate the content of the pamphlet.

The presentation was designed to provide the participants with general information concerning LQTS, and an overall view of the aim of the thesis and pamphlet. In an attempt to evaluate the usefulness and information contained in the pamphlet, a questionnaire (see Appendix 4, 5) was formulated for distribution amongst the nursing staff of the previously mentioned wards immediately after the presentation. According to Bork and Francis (1985, 907) “properly designed questionnaires can collect valid and reliable data for analyzing a research problem.”

On the 27th of October 2009 the pamphlet was presented to nursing staff in Jyväskylä Central Hospital paediatric ward and the paediatric cardiac outpatient clinic. The ward was selected on the principle that the pamphlet is especially

aimed at reducing the risk of sudden cardiac death in the young. The presentation consisted of a 14 slide Microsoft PowerPoint presentation lasting approximately 30 minutes, a 13 point questionnaire and a printed colour copy of the pamphlet. Six copies of the pamphlets were made available and distributed before the presentation in order for the nursing staff to have adequate time to examine the pamphlet. Fifteen nurses attended the presentation and all of those that attended answered the questionnaire (See appendices 4, 5).

The presentation contained a brief explanation of LQTS, warning signs and symptoms of LQTS, diagnoses and treatment of LQTS, triggering factors of LQTS, possible psychological effects related to LQTS and its treatment, side effects of treatment, prevention of sudden cardiac death, pamphlet development and lastly the content of the pamphlet.

5.3 Discussion and Evaluation of the Pamphlet

Evaluation of the pamphlet was conducted with the assistance of a questionnaire containing questions to assist in the development and evaluation of the effectiveness and reliability of the pamphlet. It contained questions regarding work experience, the nurse's previous knowledge regarding LQTS, the need of the pamphlet produced, and the overall contents of the pamphlet concerning reliability, comprehensibility and format.

Overall the feedback received was positive. Of the 15 participants two were students, one nurse had nil to three years work experience, six of the participants had four to nine years work experience and lastly, six of the participants had ten or more years work experience. Twelve of the thirteen points on the questionnaire were multiple choice questions with the last point available for the participants own comments and suggestions.

The feedback concerning the presentation made concerning LQTS and prevention of sudden cardiac death was overall unanimously positive. The majority of participants indicated that they were somewhat familiar with LQTS (ten participants) with a broad majority being aware of the risks associated with LQTS and agreeing that the information presented was beneficial. Three participants indicated that they had a basic knowledge level regarding LQTS, of which two participants were aware of the risks associated, and one participant somewhat aware of the risks. Lastly, two participants indicated that they had no knowledge at all regarding LQTS or the associated risks of sudden cardiac death.

Feedback received concerning the pamphlet on LQTS revealed that the nurses deemed the topic of the pamphlet to be current, with over half of the nurses agreeing that the pamphlet responds to practical needs. However, seven of the participants felt that there should be more information regarding resuscitation; one of these participants commented especially that information should have been added regarding resuscitation in the case of no signs of life with another remarking that the resuscitation directions given in the pamphlet were too complicated. One of the participants also indicated that the language used in the pamphlet could have been simpler. 100 percent of participants found the information presented in the pamphlet to be reliable. All the suggestions were taken into consideration with the necessary changes made to the pamphlet.

5.4 Conclusion

Upon evaluation according to the criteria for a pamphlet of good quality, as discussed in chapter 5.1, the pamphlet met the majority of requirements concerning the layout and information content. The pamphlet is widely accessible on the world-wide web, was deemed acceptable under review by partaking evaluators, and was written in a format to ensure the comprehensibility and fluency of the content. The pamphlet contained current information from reliable sources and was supported by a foundation specializing in the subject.

To improve the reliability of the pamphlet, the contents were shown and evaluated by the paediatric cardiac outpatient clinic in the Jyväskylä Central Hospital, the contact person for *Sydänlapset ja –aikuiset ry*, and arrangements were made for doctoral approval of the contents. As a result of insufficient time it was not possible to evaluate the effectiveness of the pamphlet upon publication and distribution among the target group.

In conclusion, it is possible to evaluate the reliability of the pamphlet, but due to previously mentioned reasons, the effectiveness regarding the initial aims are not able to be assessed. However, taking into consideration the lack of availability of similar material, one may assume that the pamphlet will be useful in raising awareness concerning Long QT Syndrome and sudden cardiac death.

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APPENDICES

Appendix 1. Drugs to be avoided by Congenital Long QT Syndrome patients

(http://www.qtdrugs.org)

	Generic Name	Brand Name	Class/Clinical Use
	Albuterol	Ventolin®	Bronchodilator / Asthma
	Albuterol	Proventil®	Bronchodilator / Asthma
	Alfuzosin	Uroxatral®	Alpha1-blocker / Benign prostatic hyperplasia
	Amantadine	Symmetrel®	Dopaminergic/Anti-viral / Anti-infective/ Parkinson's Disease
	Amiodarone	Pacerone®	Anti-arrhythmic / abnormal heart rhythm
	Amiodarone	Cordarone®	Anti-arrhythmic / abnormal heart rhythm
	Amitriptyline	Elavil®	Tricyclic Antidepressant / depression
	Amphetamine	Dexedrine®	CNS stimulant / ADHD
	Amphetamine	Adderall®	CNS stimulant / ADHD
	Arsenic trioxide	Trisenox®	Anti-cancer / Leukemia
	Astemizole	Hismanal®	Antihistamine / Allergic rhinitis
	Atazanavir	Reyataz®	Protease inhibitor / HIV
	Atomoxetine	Strattera®	norepinephrine reuptake inhibitor / ADHD
	Azithromycin	Zithromax®	Antibiotic / bacterial infection
	Bepridil	Vascor®	Anti-anginal / heart pain
	Chloral hydrate	Noctec®	Sedative / sedation/ insomnia
	Chloroquine	Aralen®	Anti-malarial / malaria infection
	Chlorpromazine	Thorazine®	Anti-psychotic/ Anti-emetic / schizophrenia/ nausea
	Ciprofloxacin	Cipro®	Antibiotic / bacterial infection
	Cisapride	Propulsid®	GI stimulant / heartburn
	Citalopram	Celexa®	Anti-depressant / depression
	Clarithromycin	Biaxin®	Antibiotic / bacterial infection
	Clomipramine	Anafranil®	Tricyclic Antidepressant / depression
	Clozapine	Clozaril®	Anti-psychotic / schizophrenia
	Cocaine	Cocaine	Local anesthetic /
	Desipramine	Pertofrane®	Tricyclic Antidepressant / depression
	Dexmethylphenidate	Focalin®	CNS stimulant / ADHD
	Diphenhydramine	Benadryl®	Antihistamine / Allergic rhinitis, insomnia
	Diphenhydramine	Nytol®	Antihistamine / Allergic rhinitis, insomnia

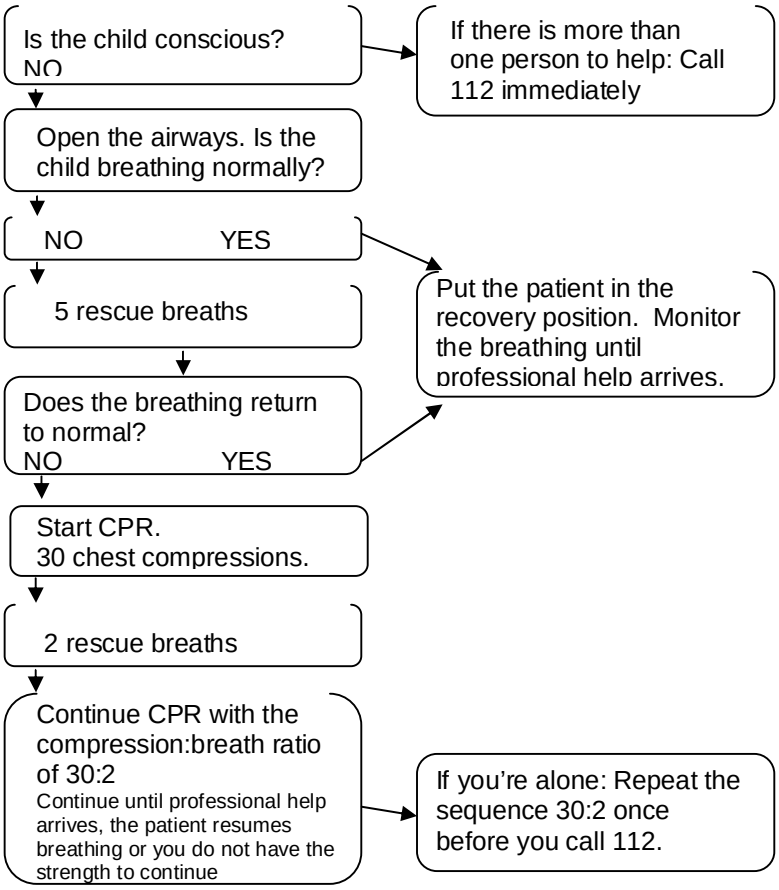
	Disopyramide	Norpace®	Anti-arrhythmic / abnormal heart rhythm
	Dobutamine	Dobutrex®	Catecholamine / heart failure and shock
	Dofetilide	Tikosyn®	Anti-arrhythmic / abnormal heart rhythm
	Dolasetron	Anzemet®	Anti-nausea / nausea, vomiting
	Domperidone	Motilium®	Anti-nausea / nausea
	Dopamine	Intropine®	Inotropic agent / heart failure; hypotension; shock
	Doxepin	Sinequan®	Tricyclic Antidepressant / depression
	Droperidol	Inapsine®	Sedative;Anti-nausea / anesthesia adjunct, nausea
	Ephedrine	Broncholate®	Bronchodilator, decongestant / Allergies, sinusitis, asthma
	Ephedrine	Rynatuss®	Bronchodilator, decongestant / Allergies, sinusitis, asthma
	Epinephrine	Bronkaid®	catecholamine, vasoconstrictor / anaphylaxis, allergic reactions
	Epinephrine	Primatene®	catecholamine, vasoconstrictor / anaphylaxis, allergic reactions
	Erythromycin	Erythrocin®	Antibiotic;GI stimulant / bacterial infection; increase GI motility
	Erythromycin	E.E.S.®	Antibiotic;GI stimulant / bacterial infection; increase GI motility
	Felbamate	Felbatrol®	Anti-convulsant / seizure
	Fenfluramine	Pondimin®	Appetite suppressant / dieting, weight loss
	Flecainide	Tambocor®	Anti-arrhythmic / abnormal heart rhythm
	Fluconazole	Diflucan®	Anti-fungal / fungal infection
	Fluoxetine	Prozac®	Anti-depressant / depression
	Fluoxetine	Sarafem®	Anti-depressant / depression
	Foscarnet	Foscavir®	Anti-viral / HIV infection
	Fosphenytoin	Cerebyx®	Anti-convulsant / seizure
	Galantamine	Reminyl®	Cholinesterase inhibitor / Dementia, Alzheimer's
	Gatifloxacin	Tequin®	Antibiotic / bacterial infection
	Gemifloxacin	Factive®	Antibiotic / bacterial infection
	Granisetron	Kytril®	Anti-nausea / nausea and vomiting
	Halofantrine	Halfan®	Anti-malarial / malaria infection
	Haloperidol	Haldol®	Anti-psychotic / schizophrenia, agitation
	Ibutilide	Corvert®	Anti-arrhythmic / abnormal heart rhythm
	Imipramine	Norfranil®	Tricyclic Antidepressant / depression
	Indapamide	Lozol®	Diuretic / stimulate urine & salt loss
	Isoproterenol	Medihaler-Iso®	Catecholamine / allergic reaction

	Isoproterenol	Isupres®	Catecholamine / allergic reaction
	Isradipine	Dynacirc®	Anti-hypertensive / high blood pressure
	Itraconazole	Sporanox®	Anti-fungal / fungal infection
	Ketoconazole	Nizoral®	Anti-fungal / fungal infection
	Lapatinib	Tykerb®	Anti-cancer / breast cancer, metastatic
	Lapatinib	Tyverb®	Anti-cancer / breast cancer, metastatic
	Levalbuterol	Xopenex®	Bronchodilator / asthma
	Levofloxacin	Levaquin®	Antibiotic / bacterial infection
	Levomethadyl	Orlaam®	Opiate agonist / pain control, narcotic dependence
	Lisdexamfetamine	Vyvanse®	CNS stimulant / ADHD
	Lithium	Lithobid®	Anti-mania / bipolar disorder
	Lithium	Eskalith®	Anti-mania / bipolar disorder
	Mesoridazine	Serentil®	Anti-psychotic / schizophrenia
	Metaproterenol	Metaprel®	Bronchodilator / asthma
	Metaproterenol	Alupent®	Bronchodilator / asthma
	Methadone	Methadose®	Opiate agonist / pain control, narcotic dependence
	Methadone	Dolophine®	Opiate agonist / pain control, narcotic dependence
	Methylphenidate	Ritalin®	CNS stimulant / ADHD
	Methylphenidate	Concerta®	CNS stimulant / ADHD
	Mexiletine	Mexitil®	Anti-arrhythmic / Abnormal heart rhythm
	Midodrine	ProAmatine®	Vasoconstrictor / low blood pressure, fainting
	Moexipril/HCTZ	Uniretic®	Anti-hypertensive / high blood pressure
	Moxifloxacin	Avelox®	Antibiotic / bacterial infection
	Nicardipine	Cardene®	Anti-hypertensive / high blood pressure
	Nilotinib	Tasigna®	Anti-cancer / Leukemia
	Norepinephrine	Levophed®	Vasconstrictor, Inotrope / shock, low blood pressure
	Nortriptyline	Pamelor®	Tricyclic Antidepressant / depression
	Octreotide	Sandostatin®	Endocrine / acromegaly, carcinoid diarrhea
	Ofloxacin	Floxin®	Antibiotic / bacterial infection
	Ondansetron	Zofran®	Anti-emetic / nausea and vomiting
	Oxytocin	Pitocin®	Oxytocic / Labor stimulation
	Paliperidone	Invega®	Antipsychotic, atypical / Schizophrenia
	Paroxetine	Paxil®	Anti-depressant / depression
	Pentamidine	NebuPent®	Anti-infective / pneumocystis pneumonia

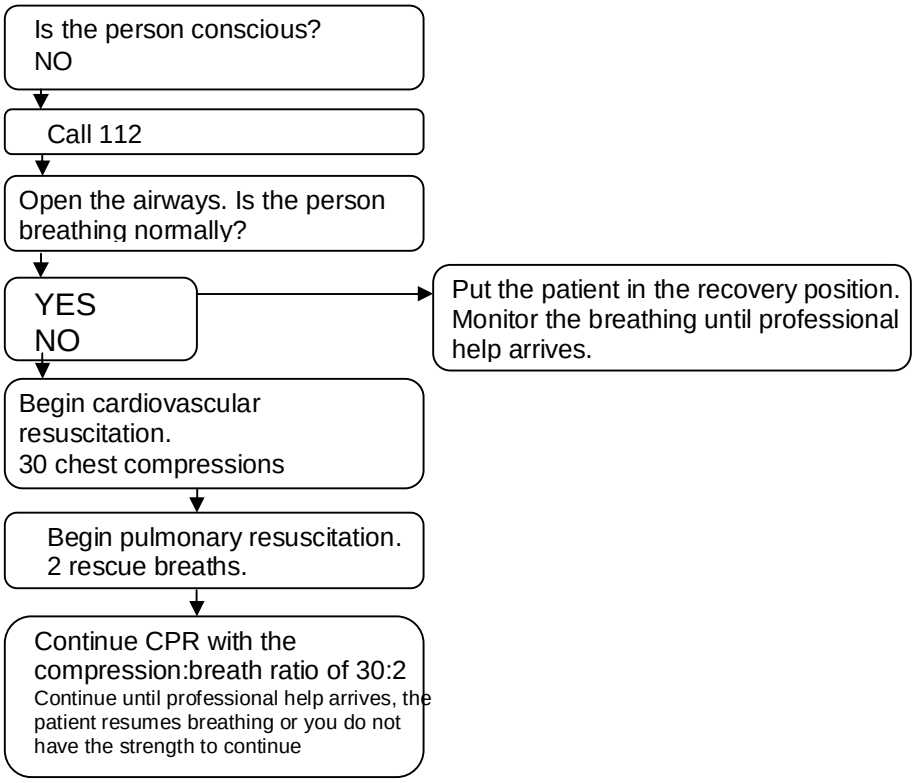
	Pentamidine	Pentam®	Anti-infective / pneumocystis pneumonia
	Perflutren lipid microspheres	Definity®	Imaging contrast agent / Echocardiography
	Phentermine	Fastin®	Appetite suppressant / dieting, weight loss
	Phentermine	Adipex®	Appetite suppressant / dieting, weight loss
	Phenylephrine	Neosynephrine®	Vasoconstrictor, decongestant / low blood pressure, allergies, sinusitis, asthma
	Phenylpropanolamine	Dexatrim®	Decongestant / allergies, sinusitis, asthma
	Phenylpropanolamine	Acutrim®	Decongestant / allergies, sinusitis, asthma
	Pimozide	Orap®	Anti-psychotic / Tourette's tics
	Probucol	Lorelco®	Antilipemic / Hypercholesterolemia
	Procainamide	Pronestyl®	Anti-arrhythmic / abnormal heart rhythm
	Procainamide	Procan®	Anti-arrhythmic / abnormal heart rhythm
	Protriptyline	Vivactil®	Tricyclic Antidepressant / depression
	Pseudoephedrine	PediaCare®	Decongestant / allergies, sinusitis, asthma
	Pseudoephedrine	Sudafed®	Decongestant / allergies, sinusitis, asthma
	Quetiapine	Seroquel®	Anti-psychotic / schizophrenia
	Quinidine	Quinaglute®	Anti-arrhythmic / abnormal heart rhythm
	Quinidine	Cardioquin®	Anti-arrhythmic / abnormal heart rhythm
	Ranolazine	Ranexa®	Anti-anginal / chronic angina
	Risperidone	Risperdal®	Anti-psychotic / schizophrenia
	Ritodrine	Yutopar®	Uterine relaxant / prevent premature labor
	Roxithromycin*	Rulide®	Antibiotic / bacterial infection
	Salmeterol	Serevent®	Sympathomimetic / asthma, COPD
	Sertindole	Serdolect®	Antipsychotic, atypical / Anxiety, Schizophrenia
	Sertindole	Serlect®	Antipsychotic, atypical / Anxiety, Schizophrenia
	Sertraline	Zoloft®	Anti-depressant / depression
	Sibutramine	Meridia®	Appetitie suppressant / dieting, weight loss
	Solifenacin	VESIcare®	muscarinic receptor anatagonist / treatment of overactive bladder
	Sotalol	Betapace®	Anti-arrhythmic / abnormal heart rhythm
	Sparfloxacin	Zagam®	Antibiotic / bacterial infection

	Sunitinib	Sutent®	Anti-cancer / RCC, GIST
	Tacrolimus	Prograf®	Immunosuppressant / Immune suppression
	Tamoxifen	Nolvadex®	Anti-cancer / breast cancer
	Telithromycin	Ketek®	Antibiotic / bacterial infection
	Terbutaline	Brethine®	Bronchodilator / asthma
	Terfenadine	Seldane®	Antihistamine / Allergic rhinitis
	Thioridazine	Mellaril®	Anti-psychotic / schizophrenia
	Tizanidine	Zanaflex®	Muscle relaxant /
	Tolterodine	Detrol®	Bladder Antispasmodic /
	Tolterodine	Detrol LA®	Bladder Antispasmodic /
	Trimethoprim-Sulfa	Bactrim®	Antibiotic / bacterial infection
	Trimethoprim-Sulfa	Sulfa®	Antibiotic / bacterial infection
	Trimipramine	Surmontil®	Tricyclic Antidepressant / depression
	Vardenafil	Levitra®	phosphodiesterase inhibitor / vasodilator
	Venlafaxine	Effexor®	Anti-depressant / depression
	Voriconazole	VFend®	Anti-fungal / anti-fungal
	Ziprasidone	Geodon®	Anti-psychotic / schizophrenia

Appendix 2: Cardiopulmonary resuscitation for children under 8 years (Finnish Red Cross, 2009)



Appendix 3. Cardiopulmonary resuscitation for adults (Finnish Red Cross, 2009)



Appendix 4. Questionnaire for Pamphlet Development

Long QT Syndrome: A Pamphlet for Community Awareness in Prevention of Sudden Cardiac Death in the Young, Bachelor's Thesis
Pierre Lettenga, Helena Lustig

Please help us to further develop our bachelor's thesis and pamphlet by answering the following questions.

Personal Information

1. What ward do you work in? _____

2. How many years of nursing experience do you have?

   a.) 0-3 years
   b.) 4-9 years
   c.) 10 or more years

Feedback on Presentation in the Ward on Long QT Syndrome

3. Was Long QT Syndrome familiar to you before the presentation?

   a.) not familiar at all
   b.) somewhat familiar
   c.) I have had the basic information concerning Long QT Syndrome
   d.) I have considered myself an expert on Long QT Syndrome

4. Have you been aware of the risks (namely sudden cardiac death in young) connected to Long QT Syndrome and the value of community awareness regarding it?

   a.) this information was new to me
   b.) I have been somewhat aware of these issues
   c.) I have been aware of these issues
   d.) I have been aware of these issues and have worked in their development

5. Was the information presented useful?

   a.) I did not find the information at all useful
   b.) somewhat useful
   c.) yes
   d.) I find it difficult to determine the usefulness

Feedback on Pamphlet for Long QT Syndrome

6. How would you evaluate the need for the pamphlet presented?

   a.) there is enough information on the topic available to all sectors
   b.) information is still needed and the topic is timely and useful
   c.) information is still needed and the pamphlet responds to practical needs

d.) I am unable to evaluate the need of the pamphlet

7. In your opinion, is the length of the pamphlet suitable?

   a.) the pamphlet contains the right amount of information in the right amount of space
   b.) the pamphlet should include more information
   c.) information in the pamphlet should be more concise.

8. Evaluation of the contents of the pamphlet:

   a.) the pamphlet contains all the essential information
   b.) the pamphlet should contain information on: _____
   _____

9. Is the route of distribution planned for the pamphlet effective in your opinion, in that those who may benefit from it will be able to access it?

   a.) yes
   b.) no
   why not?_____
   _____

10. Is the information provided in the pamphlet, in your opinion, reliable?

    a.) yes
    b.) no
    why not? _____
    _____

11. Is there any way that the information could be made more reliable?

    a.) yes
    how? _____
    _____
    b.) no

12. Is the information provided in the pamphlet written in a way that is understandable for the target group (members of the community)?

    a.) The information is readable and understandable
    b.) Some improvements may be made to make the information easier to read and understandable for the target group, namely:
    _____
    _____
    _____

13. Please give suggestions for improvements for the pamphlet or other comments/suggestions:

_____
_____
_____

Appendix 5. Questionnaire for Pamphlet Development (Finnish)

Pitkä QT -oireyhtymä –esite: Yleisen tietoisuuden lisääminen nuorten sydänperäisten äkkikuolemien ehkäisemiseksi
opinnäytetyö
Pierre Lettenga, Helena Lustig

Pyydämme ystävällisesti sinua auttamaan meitä opinnäytetyömme ja esitteen kehittämisessä vastaamalla seuraaviin kysymyksiin.

Esitiedot

14. Millä osastolla työskentelet? _____

15. Kuinka monta vuotta olet työskennellyt hoitotyössä?

    d.) 0-3 vuotta
    e.) 4-9 vuotta
    f.) 10 tai enemmän

Palaute Pitkä QT -oireyhtymä –esityksestä

16. Oliko Pitkä QT -oireyhtymä sinulle tuttu ennen esitystä?

    e.) ei lainkaan tuttu
    f.) tiesin joitakin yksittäisiä asioita sairaudesta
    g.) halitsin perustiedot
    h.) olin perehtynyt tarkasti sairauteen

17. Oletko ollut tietoinen Pitkä QT -oireyhtymän riskeistä (erityisesti sydänperäiset äkkikuolemat nuorilla) ja riskeihin liittyvän yleisen tietoisuuden merkityksestä?

    e.) tämä tieto oli uutta minulle
    f.) olen ollut osittain tietoinen asiasta
    g.) olen ollut tietoinen asiasta
    h.) olen ollut tietoinen asiasta ja työskennellyt tietoisuuden lisäämisen kehittämiseksi

18. Oliko esitetty tieto hyödyllistä?

    e.) ei lainkaan
    f.) osittain hyödyllistä
    g.) kyllä
    h.) en osaa sanoa

Palaute Pitkä QT -oireyhtymä –esitteestä

19. Kuinka arvioisit esitteen tarpeellisuutta?

    e.) tietoa on ollut aikaisemmin riittävästi saatavilla kaikille sitä tarvitseville

f.) tietoa tarvitaan edelleen ja aihe on ajankohtainen
g.) tietoa tarvitaan edelleen ja esite vastaa käytännön tarpeita
h.) en osaa sanoa

20. Onko tiedon määrä sopiva suhteessa esitteen pituuteen?

a.) tietoa on riittävästi ja pituus on sopiva
b.) esite kaipaa lisää tietoa
c.) esitettä tulisi tiivistää

21. Esitteen sisällön arviointi

a.) esitteessä on kaikki oleelliset asiat
b.) esitteestä puuttuu oleellista tietoa, mitä _____
_____

22. Onko esitteen jakelu suunniteltu mielestäsi siten, että kaikki tietoa tarvitsevat saavat sen helposti?

c.) kyllä
d.) ei, miksi?
_____
_____

23. Onko tieto esitteessä mielestäsi luotettavaa?

c.) kyllä
d.) ei, miksi?
_____
_____

24. Voisiko esitteen luotettavuutta jollakin keinolla lisätä?

c.) kyllä, miten?
_____
_____
d.) ei

25. Onko esite kirjoitettu ymmärrettävästi kohderyhmä huomioiden?

c.) Sisältö on luettavaa ja ymmärrettävää
d.) Osan tekstistä voisi muokata siten, että kohderyhmän olisi sitä helpompi lukea ja ymmärtää. Kerro tarkemmin:
_____
_____
_____

26. Muita kommentteja ja ehdotuksia:

_____
_____
_____
_____

My child's treatment includes:

- ☐ medication _____, ___times per day
- ☐ cardioverter-defibrillator/pacemaker
- ☐ other information concerning my child´s care:

_____

_____

My child's symptoms have included:

- ☐ fainting
- ☐ dizziness
- ☐ has not experienced symptoms
- ☐ other: _____

_____

Triggers of events have included:

- ☐ physical activity
- ☐ sleep
- ☐ startle/loud noises
- ☐ emotional stress
- ☐ other: _____

_____

_____

Other information: _____

_____

_____

_____

_____

_____

In case of symptoms or in an emergency please contact: _____

_____

_____

_____

_____

_____

_____

More information may be found:

Sydänlapset ja -aikuiset ry:
www.sydanlapsetja-aikuiset.fi

Suomen Punainen Risti
www.redcross.fi

Suomen Sydänliitto ry
www.sydanliitto.fi

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In cooperation with:
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Jyväskylän Ammattikorkeakoulu

Long QT Syndrome

What is Long QT Syndrome (LQTS)?

- LQTS is an inherited heart rhythm disorder in which the ion channels in the heart muscle cells do not function properly.
- The heart muscles take longer than normal to recharge between beats; this may cause heart arrhythmias in which the heartrate increases to a point where the heart is not able to pump blood to the brain.
  → This causes syncope and in severe cases ventricular fibrillation that causes cardiac arrest and sudden death.
- First symptoms usually occur during childhood or young adulthood.
- Syncope may resemble fainting or epileptic seizure.

Warning signs

- Dizziness, weakness, paleness, clammy skin, nausea, or lack of consciousness
  - → during physical exertion
  - → during emotional stress
  - → while nervous or when startled
- Family history of sudden deaths or syncope.
- Family history of unexplained accidents/deaths especially while swimming.

Treatment

- Avoidance of risk factors, for example physical overexertion, swimming, crapulence, fasting, fluid and salt unbalance, startles, certain medications.
- Betablocker medication.
- Implantable cardioverter-defibrillator.

Good to know

- Symptoms (and syncope) usually occur with little or no warning.
- Diagnosis and treatment may be followed by anxiety, depression and may cause behavioural symptoms.
- Medication may cause: fatigue, lowered blood pressure, blood sugar fluctuation.

Preventive Action:

- Sudden cardiac death may be prevented through CPR (cardiopulmonary resuscitation). Contact the local Red Cross for First-Aid course information.
- Automated external defibrillators should be made available at public events and places.

First aid

1. Clarify whether the person is conscious.

2. Clear and secure the airways: Lift the chin upwards with two fingers of one hand and bend the head back with the other hand by pressing on the forehead. Check to see if the chest is moving, whether you can hear normal breathing sounds or whether you can feel the person breathing on your cheek.

3. If the person does not awaken or react to stimulation, get help and call the emergency number 112. Follow the directions given.

4. If the person has a definite diagnosis of Long QT Syndrome, strike the person in the sternum with your fist. This may cause the heart rhythm to return to normal.

5. If breathing is normal, turn the person into recovery position on their side to secure their breathing. Observe the condition of the person carefully until professional help arrives.

6. Make sure the head is in a position in which the airways are open. Monitor breathing and consciousness level until professional help arrives.

Lapseni hoitoon kuuluu:

- ☐ lääkitys _____, ___kertaa päivässä
- ☐ tahdistin
- ☐ muuta hoitoon liittyvää tietoa: _____
  _____

Lapsellani on esiintynyt seuraavia oireita:

- ☐ huimaus
- ☐ tajunnan menetys
- ☐ ei ole esiintynyt oireita
- ☐ muuta: _____
  _____

Oireet ovat esiintyneet seuraavissa tilanteissa:

- ☐ fyysinen rasitus
- ☐ nukkuminen
- ☐ jännittäminen, pelästyminen, kovat äänet
- ☐ henkinen rasitus
- ☐ muuta: _____
  _____

Lisätietoa: _____
_____
_____
_____
_____
_____

Oireiden ilmaantuessa ja hätätilanteissa ota yhteyttä: _____
_____
_____
_____
_____
_____

Lisää tietoa saat:

Sydänlapset ja -aikuiset ry:
www.sydanlapsetja-aikuiset.fi

Suomen Punainen Risti
www.redcross.fi

Suomen Sydänliitto ry
www.sydanliitto.fi

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Helena Lustig

Yhteistyössä:
Sydänlapset ja -aikuiset ry, Pitkä QT-jaosto
Jyväskylän Ammattikorkeakoulu

Pitkä QT-oireyhtymä

Mikä pitkä QT-oireyhtymä on?

- Sydämen rytmihäiriösairaus, jossa sydänlihassolujen ionikanavat eivät toimi normaalisti.
  → Sydämen palautumisaika lyönnin jälkeen pitenee.
- Yleensä perinnöllinen.
- Saattaa aiheuttaa rytmihäiriökohtauksia, jossa syke muuttuu niin nopeaksi, että sydän ei pysty pumppaamaan verta aivoihin riittävästi.
  → Tämä aiheuttaa tajunnan menetyksen, joka voi muistuttaa ohimenevää pyörtymistä tai epileptistä kohtausta.
  → Pahimmillaan rytmihäiriö voi aiheuttaa kammiovärinän ja johtaa sydämen pysähtymiseen.
- Ensimmäiset oireet esiintyvät yleensä lapsilla tai nuorilla aikuisilla.

Varoittavat oireet ja merkit

- Huimaus, heikkouden tunne, kalpeus, kylmä hiki, pahoinvointi tai tajunnan menetys
  - → fyysisen rasituksen aikana
  - → henkisen rasituksen aikana
  - → jännittäessä tai pelästymisen seurauksena
- Suvussa esiintynyt äkkikuolemia tai tajunnan menetystä.
- Suvussa esiintynyt selittämättömiä onnettomuuksia erityisesti uimatilanteissa.

Hoitokeinot

- Riskitilanteiden välttäminen, esim. liian voimakas fyysinen rasitus, uinti, krapula, paasto tai neste-ja suolatasapainon järkkyminen, pelästyminen, tietyt lääkkeet.
- Beetasalpaajalääkitys.
- Rytmihäiriötahdistin.

Hyvä tietää

- Tajunnan menetykset ilmenevät yleensä äkillisesti ilman ennakkovaroituksia.
- Oireyhtymän toteamisen seurauksena voi esiintyä ahdistusta, masennusta ja käyttäytymisvaikeuksia.
- Lääkitys voi aiheuttaa väsymystä, alhaisen verenpaineen tai verensokerin vaihteluja.

Ennakoivat toimenpiteet:

- Sydänperäisiä äkkikuolemia voi ehkäistä paineluelvytyksellä. Ota yhteyttä Suomen Punaiseen Ristiin saadaksesi tietoa ensiapukursseista.
- Sähköisiä defibrillaattoreita (sydämen rytminsiirtolaitteita) tulisi olla saatavilla julkisissa tapahtumissa ja paikoissa.

Tajunnan menettäneen ensiapu

1. Selvitä, onko hän herätettävissä puhuttelemalla ja ravistelemalla.
2. Avaa hengitystiet ja tarkista hengitys: kohota toisen käden kahdella sormella leuan kärkeä ylöspäin ja taivuta päätä taaksepäin toisella kädellä otsaa painaen. Katso, liikkuuko rintakehä, kuuluuko normaali hengityksen ääni tai tuntuuko poskellasi ilman virtaus.
3. Jos henkilö ei hengitä, eikä reagoi käsittelyyn, hae apua, ja soita hätäkeskukseen 112. Noudata hätäkeskuksen ohjeita.
4. Jos henkilö sairastaa epäilyksettä pitkä QT-oireyhtymää, lyö henkilöä nyrkillä rintalastaan. Nyrkiniskulla sydän saatetaan saada tahdistettua normaaliin rytmiin. Aloita tarvittaessa painelu-puhalluselvytys.
5. Jos hengitys on normaalia, käännä henkilö kylkiasentoon hengityksen turvaamiseksi. Seuraa hänen tilaansa kunnes ammattihenkilö ottaa vastuun.
6. Varmista pään asento niin, että hengitystiet pysyvät auki. Tarkkaile hengitystä ja mahdollista heräämistä muun avun saapumiseen asti.