

Philadelphia College of Osteopathic Medicine

Annual Progress Report: 2009 Formula Grant

Reporting Period

July 1, 2010 – June 30, 2011

Formula Grant Overview

The Philadelphia College of Osteopathic Medicine received \$25,305 in formula funds for the grant award period January 1, 2010 through December 31, 2013. Accomplishments for the reporting period are described below.

Research Project 1: Project Title and Purpose

Psychological Functioning, Coping, and Factors Affecting Quality of Life in Persons with Long QT Syndrome - This project is designed to identify and address the psychosocial needs of persons with Long QT Syndrome (LQTS) and distressed subsets of this population. Presently, little is known about the experience of anxiety, depression, quality of life or methods of coping in this population, despite the large numbers of people living with this life-threatening condition, significant lifelong medical treatments and restrictions on activity and diet, and the experience of cardiac arrest and revival in many of these persons. Information gained may inform medical and allied health professionals about the psychosocial aspects of living with LQTS. New knowledge expected will be used to develop clinical resources, interventions, and services for delivery on the internet, and in medical inpatient and outpatient settings.

Anticipated Duration of the Project

1/1/2010 – 12/31/2013

Project Overview

Objective: To examine the psychological morbidity, coping skills, quality of life (QOL) and factors affecting QOL in adults with LQTS.

Specific Aim 1: To describe the psychological morbidity of a sample of adults with LQTS to identify areas of risk or need for intervention for this population. *Specific Aim 2:* To examine if social problem solving skills (SPS) relate to psychological morbidity and health related locus of control (HRLC), as it does in other medical populations, such that social problem solving skills may be a potential route of intervention for coping and adjustment to living with LQTS. *Specific Aim 3:* To determine the QOL maintained by adults with LQTS and the relationship among QOL, HRLC, LQTS history, and compliance with medical recommendations. *Specific Aim 4:* To examine LQTS patients' satisfaction with health care, as frequent users of primary care, cardiology, and emergency room services, and its relationship to LQTS history, SPS, and HRLC.

Specific Aim 5: To examine the relationship of religiosity and spirituality to QOL, psychological morbidity, LQTS history, and HRLC in adults with LQTS. *Specific Aim 6:* To examine if there are differences between LQTS persons with and without automatic internal cardioverter defibrillators (AICDs) in psychological morbidity, QOL, HRLC, and religiosity/spirituality. *Specific Aim 7:* To examine symptoms and expression of post-traumatic stress disorder, generalized anxiety, and panic disorder in persons with LQTS who have experienced an LQTS-related loss, an aborted sudden cardiac arrest (SCA), or a shock from an AICD.

Research Design and Methods: Self-report data will be collected and a cross-sectional observational design will be employed. Recruitment of participants 18 years and older with LQTS via LQTS user group message boards, Facebook LQTS pages, informational websites focused on cardiac arrhythmias and sudden cardiac arrests, and university-based Web pages will direct interested persons to a research phone line or email address (lqtstudies@pcom.edu) to request questionnaire packets via mail. Participants will be given \$15 gift cards for time compensation. Questionnaires will be completed anonymously; completed packets will be mailed separately from an email indicating completion (honor system) and prompt for gift card compensation. All participants will receive a list of mental health websites and referral sources with the questionnaires.

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Expected Research Outcomes and Benefits

The LQTS project will provide new knowledge about psychological morbidity, coping, QOL, and psychosocial needs of persons with LQTS to educate medical and mental health professionals about this population. Emotional upset can be a trigger for SCA in persons with LQTS, and a consequence of having LQTS or an SCA. Thus, health may be directly affected by psychological morbidity and/or improvement of mental health. Empirically-supported treatments for anxiety, depression, and improvement of QOL for many populations are widely available. This project will determine if LQTS persons have need for such interventions, and if so, for what needs specifically. Previous literature on persons with AICDs has suggested depression and anxiety are often present post-implantation, but these studies are typically conducted on persons greater than 60 years old. How younger individuals with LQTS, and persons who are otherwise healthy and asymptomatic cope with and respond to a diagnosis of LQTS or implantation of AICDs, for example, is largely unknown. It is unknown if persons with LQTS who experience shocks from AICDs suffer from post-traumatic stress, panic, or generalized anxiety.

Furthermore, QOL may be greatly affected by medical treatments in persons with LQTS, and compliance with medical treatments is critical for positive health outcomes. As such, identifying LQTS persons' health locus of control, problem-solving skills, and satisfaction with health care are critical variables that could be targeted for intervention to improve medical compliance and proper care. Likewise, increasing medical providers' attention to psychosocial factors may improve patient satisfaction, compliance, and connection with mental health treatment for this population, which could ultimately have positive health implications. Information from this project will direct applications for future funding, development of clinical screening protocols and psychosocial treatment interventions that may address this population's needs. Fact sheets will be developed specific to findings for this population.

Summary of Research Completed

The research project has focused on the enhancement of recruitment efforts during the review period for this report. Details of this development are provided.

Necessary supplies for the study have been obtained to set up a data tracking system and compensation mailing record. Specifically, a laptop computer was purchased to assist with correspondence and monitoring of web-based efforts to recruit participants. The computer programs needed for inquiry and data tracking, and data analysis were loaded, established and prepared for research purposes.

Contacts for recruitment have been maintained with a variety of online Long QT Syndrome sites. These sites are as follows: Cardiac Arrhythmias Research and Education Foundation, Inc. (<http://www.longqt.org>); Sudden Arrhythmia Death Syndrome (SADS) Foundation (www.sads.org); QT Channel (www.qtsyndrome.ch); Yahoo User Group for LQTS. Contact persons at each site have been publicizing the research and will assist in recruitment by doing so. The announcement of the study was posted on the Yahoo User Group and the QTSyndrome Facebook page. However, these methods allow for exposure only on one day for those who choose to view activity on these sites. As such, requests were then made for permanent placement of the call for participants on the webpages of these organizations. Numerous conference calls have been held with SADS, as they underwent staff changes, which affected our recruitment efforts.

SADS now publicizes the study in their newsletter and on their website (<http://www.sads.org/research/Research>) or [http://www.sads.org/research/Research/Evaluating-Women-s-Experiences-With-ICDs-\(1\)](http://www.sads.org/research/Research/Evaluating-Women-s-Experiences-With-ICDs-(1)) . The study is the first one listed on the SADS current research enrolling participants at this time. After revision to the Institutional Review Board proposal, and contractual agreements being signed, we have gained permission for SADS to engage in direct calling and recruitment of persons with LQTS to participate in this study. The protocol for this recruitment process has been established and will begin within the next month. Additional efforts have been initiated to create a call for participants on the Center for Chronic Disorders of Aging website (<http://www.cdda-pcom.org/felgoise.php>) at the Philadelphia College of Osteopathic Medicine (PCOM), and to announce the study at Children's Hospital of Philadelphia by posting flyers that are otherwise online. To direct more people to the websites

and study, GoogleAdWords has been purchased as a recruitment tool to lead persons who are searching the internet for LQTS information through Google to information about the study.

Google AdWords is a paid medium that identifies key words used by individuals searching the web on Google.com to direct them to specific websites. Each click on our actual study site will cost a nominal fee to us. If a person does not click on our site for our study, there is no charge.

Plans are underway for direct marketing and recruitment of the LQTS study by attendance at a family conference hosted by SADS and other LQTS-focused organizations, such as Simon's Fund.

The bulk of participation by recruited individuals is expected to take place during the 2011-2012 reporting cycle.