



An Examination of Physician Decision Making with Children and Adolescents Diagnosed with Long QT Syndrome: A Qualitative Study

Julie Radico M.S., M.S. , Stephanie H. Felgoise, Ph.D., ABPP, Allison Burns-Pentecost, M.A.,M.S. , Karen Gentis , MFT

Philadelphia College of Osteopathic Medicine

Introduction

LQTS...

- Is a life threatening, hereditary cardiac arrhythmia disorder.
- Affects 1 in 2,000 people in the United States¹
- may be the cause of SIDS and unexplained death in children.²
- Is unpredictable.

Physicians...

- Are faced with ongoing challenges in diagnosis and treatment due to unpredictability and individual patient characteristics.

Research Question

What impacts physician's decision making with regard to the treatment of children and adolescents with LQTS when medical information is uncertain?

Method

Recruitment

- Flyers, letters, and website posting to 120 pediatric cardiologists of Heart Rhythm Society and Pediatric & Congenital Electrophysiology Society (PACES).

Participants

- 10 pediatric cardiologists
 - ages 34 - 60

Method

- Informed consent
- Semi-structured interview via phone
- 30-65 minute interviews audio recorded and transcribed
- Transcripts coded by 3 doctoral level students
- Themes identified using strategies guided by Corbin & Strauss (2008)
- Conceptualization developed by principal investigator

Results

THEMES IN PHYSICIAN DECISION MAKING:

1. Constant Reevaluation of Decisions

Dr. Jake stated, "People with long QT never really feel sick. They feel fine or they feel dead. It's a frustrating diagnosis to deal with."

a. Changing guidelines

Physicians (6 of 10) constantly reevaluated their treatment decisions due to the evolving nature of LQTS literature and guidelines.

Dr. Mark stated, "...a lot of times guidelines do change. New evidence comes out and physicians know that. They certainly put value in them and they think about risk benefit ratio. But they also know that in a year the guidelines could be completely different."

b. Individualized Treatment Approach

The individual symptoms presented by each patient were used as the basis of the physicians' (10 of 10) decision making process.

Dr. Jake stated, "symptoms are the data."

2. Years of Experience/Amount of LQTS Patients Treated

a. Anecdotes

Physicians with greater years of experience (4 of 7) incorporated more of their personal experiences.

Younger counterparts (2 of 3) relied primarily on the treatment guidelines.

Results

3. Differentiating Versus Joining with Other Physicians

a. Comparing and contrasting

Physicians (6 of 10) often joined with colleagues by using collective language or differentiated their decision making by highlighting the positive aspects of their treatment compared to others.

4. Patient Sports Involvement and Activity Level

a. Age

8 of 10 physicians said age of patient affected their decision making.

Dr. Mark stated, "Having the conversation when they're older is life altering. You have to be sensitive that restricting them from sports can be a more devastating blow than the diagnosis itself."

b. Suspected adherence level and health

Physicians (9 of 10) indicated that they occasionally doubted their patient's adherence to prescribed restrictions. Non-adherence affected decision making about ICD implantation.

Dr. Roger stated, "there was one patient who clearly was not being compliant with medications...that we did implant a pacemaker, an ICD in them... so that was obviously a change in, you know, in treatment."

Results

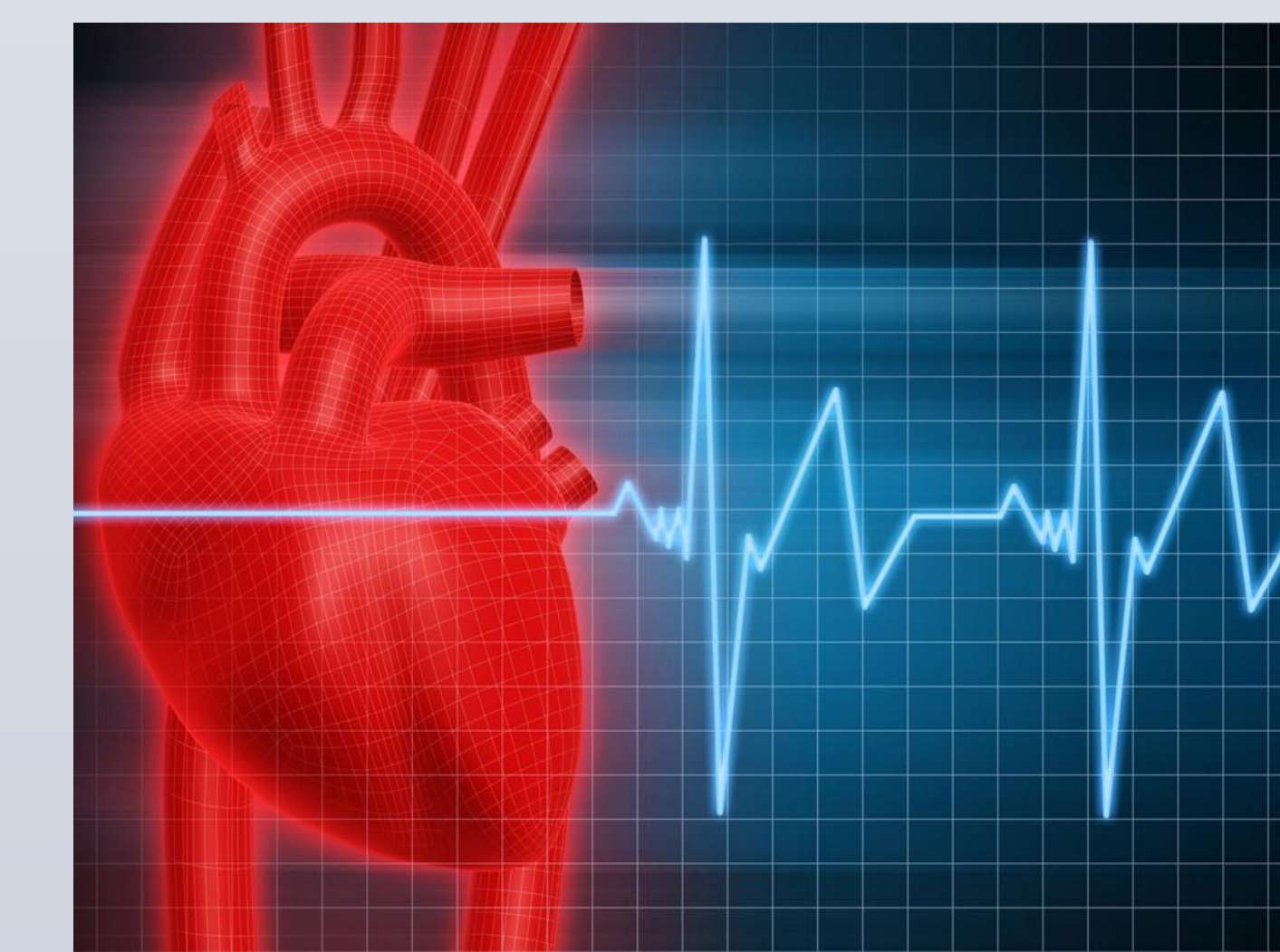
5. Physicians as Recommenders Versus Decision Makers

a. Joint decisions versus parent/patient decision.

10 of 10 physicians recommended treatment options, but felt the decision was to be made by parents and patients.

Dr. Mark stated, "We are leaning on the parents and the family for the decision... for the most part I would heed their decision."

Dr. Jake stated, "As a doctor I make recommendations and it's up to the family to follow them."



Conclusions

Physicians need to...

- Consider the biopsychosocial implications of their decisions.
- Create open lines of communication and transparency regarding the roles of patients and parents in the decision making process.
- Encourage children and adolescents to express their treatment goals.
- Involve parents and children in a shared decision making process.
- Be aware of effective decision making strategies (e.g. problem solving) and collegial support, to reduce stress related to the uncertainty they may feel when making decisions.

References

1. Schwartz, P.J., Stramba-Badiale, M., Crotti, L., Pedrazzini, M., Besana, A., Bosi, G.,... Spazzolini, C. (2009). Prevalence of the congenital long-qt syndrome. *Circulation*, 120, 1761-1767. doi:10.1161/CIRCULATIONAHA.109.863209
2. Tester, D.J., & Ackerman, M.J. (2007). Postmortem long QT syndrome genetic testing for sudden unexplained death in the young. *Journal of the American College of Cardiology*, 49(2), 240-246. doi:10.1016/j.jacc.2006.10.010
3. Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Los Angeles, CA: Sage.