LQTS Patients' Satisfaction with Emergency Department Care

(Work-in-Progress)

Stephanie H. Felgoise, Ph.D., ABPP[1], Katherine Lawrence, Ed.S.[1], and Victoria L. Vetter, M.D., MPH[2]

[1]Philadelphia College of Osteopathic Medicine & [2]The Children's Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania

INTRODUCTION

Long QT Syndrome (LQTS) is a

- Life threatening, unpredictable, genetically-inherited, cardiac arrhythmia disorder affecting approximately 1:2500 persons[1, 6] .
- It is commonly diagnosed in childhood.

Persons with LQTS may be asymptomatic, or may have symptoms triggered by

- Physical exertion, emotional stress/anger, during sleep, medications that affect the QTc interval , electrolyte imbalance , often associated with dehydration.

Treatment includes medication, implantable cardiac devices or personal AEDs, or other lifestyle modifications including exercise restrictions.

Previous Research

- Recent research suggests that LQTS experience in the ED has been negative and ED treatment is a concern among this population[2].
- Patient satisfaction in the ED is a measure of quality of care. Perceived quality of communication between physician and patient, information and understanding of care, wait times, and acuity are related to satisfaction[3].
- Positive perceptions of physician performance by parents were related to physicians' careful listening, interactive conversation, and inquiry about home management, individualized short term goals, and long term treatment plans[4].
- Cardiac training in ECG interpretation in emergency medicine residents is limited [5].
- Patient satisfaction may be tied to physicians' ability to care for LQTS appropriately.
- Problem-solving skills training have been effective for helping other medical patients navigate the healthcare system[7], and may be appropriate for LQTS patients.

Hypothesis: Social problem-solving skills and perceived therapeutic alliance with physicians will predict satisfaction with emergency room care.

METHOD

Participants

- 21 diverse adults (ages 19-63, x =49.15, SD=15.07) completed the survey at time of analysis
- **Positive genetic tests were present in** 6 with LQTS1, 2 with LQTS2, 1 with LQTS3
- **Others reported** 1 with borderline LQTS, and the rest replied, "Other"
- **Implantable cardioverter defibrillators were reported in 4**
- Anxiety, Depression, Psychosis, and other Mental Health Disorders were reported in 5
- Mental health support was sought by 5 of 12 respondents

Questionnaires

- Working Alliance Inventory-Client Short Form (WAI-S)[8]
- Pediatric and Adult Patient Satisfaction Questionnaires[9, 10]
- Social Problem-Solving Inventory-Revised, Short-Form for Research (SPSIR-S)[11]
- Personal Information Questionnaire

Procedure

- IRB approval obtained; participants recruited via websites; measures completed online anonymously via Survey Monkey; $10 gift cards given when notification of completion was received via email.

RESULTS & DISCUSSION

- The sample was characterized by people who report poor working alliance and maladaptive problem-solving skills. See Table 1.
- While overall care was perceived as poor, interactions with physicians were rated as neutral
- Respondents reported 50% of ED physicians knew of LQTS, 2/3 consulted cardiologists.

Table 1. Descriptive Statistics of SPSIR-S and WAI Measures

	N	Minimum	Maximum	Mean	Std. Deviation
NPO Standard Score	15	93	146	117.13	16.92
RPS Standard Score	10	101	136	117.3	10.11
ICS Standard Score	10	109	157	130.2	16.55
AS Standard Score	10	105	153	127.4	15.34
PPO Standard Score	12	100	131	120	9.52
WAI Total	14	12	64	49.54	12.86

NPO= Negative Problem Orientation, RPS= Rational Problem Solving, ICS= Impulsivity/Carelessness Style, AS= Avoidance Style, PPO= Positive Problem Orientation

Table 2. Adult Patient Satisfaction with Emergency Department, NRC Adult Satisfaction Survey

Dimensions	Positive	N
Access to Care	22%	13
Continuity and Transition	15%	13
Coordination of Care	15%	13
Emotional Support	21%	13
Information and Education	27%	12
Involvement of Family and Friends	20%	10
Patient Safety	0%	4
Physical Comfort	0%	7
Respect for Patient Preferences	22%	10

- At this point in data collection, patient experiences in the Emergency Department are predominantly negative, according to NRC and PIQ measures. See Tables 2, 3.
- The expectation is that a larger sample will allow for analysis of how Working Alliance and Social Problem Solving Skills contribute to satisfaction with Emergency Department experiences.
- It is possible that our data represent a self-selection bias of persons who volunteered because they had a negative experience in the ED. Also, respondents' LQTS diagnosis was not verified by the researchers.

Table 3. Questions from the PIQ about Emergency Room Experiences.

Question	Scale				
Was the Emergency Department physician…	**(1) Not at all**	**2**	**(3) Neutral**	**4**	**(5) Very Much So**
friendly?	0.00%	0.0%	26.7%	13.3%	3.30%
generally knowledgeable?	0.00%	3.30%	23.30%	13.30%	3.30%
knowledgeable about LQTS?	6.70%	20.00%	6.70%	6.70%	3.30%
helpful in treating LQTS?	13.30%	13.30%	6.70%	6.70%	3.30%

Table 4. Personal Information Questionnaire Results

Question	Scale				
Did your Emergency Department physician…	**(1) Not at all**	**2**	**(3) Neutral**	**4**	**(5) Very Much So**
respond to your presenting symptoms?	3.30%	16.70%	13.30%	6.70%	3.30%
clearly explain what you should do at home?	3.30%	20%	10%	6.70%	3.30%
answer all of your questions	3.30%	16.70%	13.30%	6.70%	3.30%
answer all of your questions about LQTS?	13.30%	6.70%	13.30%	10.00%	0.00%
encourage you to talk about your worries?	13.30%	3.30%	23.30%	3.30%	0.00%
ask for your opinion about treatment?	20.00%	3.30%	16.70%	3.30%	0.00%
spend enough time talking to you?	0.00%	16.70%	16.70%	3.30%	6.70%
treat you with respect?	0.00%	0.00%	26.70%	10.00%	6.70%
listen to you?	0.00%	6.70%	20.00%	10.00%	6.70%
explain your condition?	6.70%	10.00%	20.00%	3.30%	3.30%
involve you in the decision-making process?	10.00%	3.30%	13.30%	10.00%	3.30%
give you a sense of control over your medical care?	13.30%	3.30%	16.70%	10.00%	0.00%
address your tests properly?	6.70%	6.70%	16.70%	6.70%	3.30%

CONCLUSION

- Cardiac training in ECG interpretation in emergency medicine residents is limited.
- Individuals with LQTS are encouraged to be empowered consumers about their condition.
- Recommendations include having LQTS patients be prepared by cardiologists in advance for how to handle possible ED services; carry information related to LQTS and medications with them; wear medical ID bracelets; and inquire about local ED staff and LQTS knowledge in their local area, before needed.

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