

# Information Shared on YouTube by Individuals Affected by Long QT Syndrome: A Qualitative Study

Stephanie Felgoise, Ph.D., Maggie Monk, M.S., M.S., &  
Karen Gentis, MFT, M.S.  
Philadelphia College of Osteopathic Medicine

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OSTEOPATHIC  
MEDICINE



## Background

- Long QT Syndrome (LQTS) is an inherited cardiac condition which predisposes individuals to life threatening arrhythmias and is often diagnosed in childhood<sup>1</sup>.
- 1 in 2,000 individuals are diagnosed with LQTS<sup>2</sup>.
- Few studies address the psychosocial impact of LQTS<sup>3</sup>, though dietary, physical, and social restrictions are required<sup>4</sup> and lifelong medication and implantable devices may be needed.
- Research has demonstrated an increase in Internet utilization for social support for health and wellness related topics.<sup>5</sup>
- Online support groups have been found to improve the overall well-being of individuals who share their needs, expectations and habits with others.<sup>6</sup>
- Social media websites like YouTube, Facebook, and Twitter, chat rooms and message boards provide opportunities to connect or share stories with others.
- A qualitative study evaluated how individuals with LQTS utilized an Internet user group. Results suggested participants obtained information, normalization, and validation from other members who were impacted by the syndrome. Parents often asked other users to provide advice on coping with daily stressors associated with LQTS<sup>7</sup>.
- YouTube appears to be a popular resource for medical support and/or to gain medical information, because of its ease of access<sup>8</sup>. Individuals who are coping with chronic illnesses often use internet resources to increase their perceived support<sup>9</sup>.

## Objectives

- This study investigated what individuals and their families shared about LQTS via YouTube.
- Information from this study could be used to inform practitioners of shared information among patients regarding concerns and experiences, important resources for patients, areas for future research, and areas of intervention.

## Methods

### Research Design

- Qualitative analysis was used to describe and interpret concepts and themes that emerged from the information shared by the participants on their YouTube video posts.
- Grounded theory method was used to systematically generate theory and understanding of the patterns that emerge from the data<sup>10</sup>. This type of qualitative procedure has been shown to yield valid, reliable, and standardized information that can be used to guide future research<sup>11</sup>.
- Internet-based qualitative research allows investigators to observe participants in an anonymous and comfortable environment that is not influenced by experimenter effects<sup>7,12</sup>.

### Inclusion Criteria

- Participants were English-speaking individuals, families with LQTS, and friends of individuals with the condition who had posted videos on YouTube.
- Videos were posted between the dates of January 2008 to October 2013.
- Videos were retrieved by searching “LQTS” and “Long-QT Syndrome”.

### Exclusion Criteria

- Videos posted or sponsored by medical professionals that did not contain narratives.
- Videos posted by individuals who did not have LQTS or did not have a relationship with someone who has LQTS.
- Videos that did not contain a narrative.
- Videos longer than 4 minutes.

## Results

- Findings revealed individuals’ thoughts, feelings, behaviors, and experiences about biopsychosocial aspects of living with LQTS.
- Themes included experiences with initial diagnosis, survival stories, treatment, misdiagnoses, and mistreatment.
- Participants shared medical and psychological aspects of their experiences with symptoms, diagnosis, and treatment.
- Themes of “worry” and “fear” of the unknown emerged. Participants frequently used terms to describe the sudden onset of the symptoms and frustration surrounding misdiagnoses.
- Videos also provided information regarding quality of life and coping of the individuals and families with LQTS.
- While some videos highlighted resilience, optimism, and gratefulness for positive outcomes and care, others highlighted life losses, perceived malpractice, and intimations of lawsuits.
- Not all information communicated about symptoms in the videos seemed accurate, but the messages emphasized personal experiences and highlighted the need to advocate for oneself.
- Reasons for posting videos to YouTube included increasing advocacy and awareness of LQTS, feeling connected and supported by others, and as a coping strategy.

## Future Plans

- Future research should investigate if individuals diagnosed with LQTS who utilize online methods of support (by creating or accessing YouTube videos) report lower levels of distress relating to LQTS as compared to individuals who do not use online methods of support.
- Future research could also investigate if one forum of online support yields better results when compared to other forums.

## Conclusion

- YouTube offers cost-effective means to learn about medical populations’ psychological needs, experiences, and useful sources of information.
- Specific to LQTS, YouTube may provide an understanding of information communicated among patients and families that may impact questions asked of their physicians and psychosocial aspects of the condition.
- The information gathered from this study can be used to inform physicians of individuals’ experiences (positive/negative) in order to be able to communicate more effectively with patients and reduce psychosocial impact.

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