

A Feasibility Study of a Problem-Solving Workshop for Children Diagnosed with LQTS and their Parents: A Pilot Study of Two Dyads

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INTRODUCTION

- Long-QT Syndrome (LQTS) is an inherited cardiac condition that predisposes individuals to cardiac arrhythmias.
- Commonly diagnosed in childhood.
- Affects approximately 1:2000 persons.
- The clinical manifestation of LQTS is syncope, ventricular tachycardia, or a fast heart rhythm, and sudden death often triggered by: Physical exertion, emotional stress/anger, 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.
- Living with chronic medical conditions in adolescence comes with many critical lifestyle changes and restrictions.
- These lifestyle changes and restrictions may compromise psychosocial development.
- Social problem-solving skills have been shown to enhance one's ability to cope with both minor and major daily stressors and minimize psychological problems associated with physical health problems.
- The present pilot study was developed to identify the feasibility and efficacy of a problem-solving workshop to increase problem solving, self-efficacy, coping, and locus of control in children with LQTS and problem solving, worry, hope, and coping in parents of children diagnosed with LQTS.

METHOD

Participants	Children	Parents
Total	2	2
% Male	50	50
Age	9;13	40;42
LQTS Diagnosis (%)	100	0
LQTS Related Event(%)	50	N/A
Food Restrictions (%)	100	N/A
Implanted Devices (%)	50	N/A
School Accommodations	Y	N/A

Procedure

- IRB approved Study
- Participants recruited through online methods (e.g. Facebook, Craigslist, SADS) & local hospitals.
- Families arrived at PCOM at 9:00am and completed baselines questionnaires.
- The workshop ran for approximately 4 hours.
- Workshop conducted jointly by two advanced clinical psychology doctoral candidates
- Children and their parents were introduced to and taught the steps of the Social Problem-Solving Model, which included Problem Orientation, Problem Definition and Formulation, Generation of Alternatives, Decision Making, Solution Implementation, and Solution Verification.
- Vignettes of common LQTS-related problems were presented to the group for practice and implementation of the Social Problem-Solving Model.
- Participants completed follow-up questionnaires at 1- and 3-months post workshop.
- Compensated with \$20 in gift cards for follow-up questionnaire completion via SurveyMonkey.
- Integrity checks conducted by 3 independent raters to verify integrity of the workshop to the prescribed protocol.

Questionnaires

- Social Problem-Solving Inventory-Revised, Short-Form (SPSIR-S)
- Personal Information Questionnaire (PIQ)
- Adult State Hope Scale
- PedsQL Family Impact Module
- Coping Health Inventory for Parents (CHIP)
- Social Problem-Solving Inventory-Adolescent, Short Form (SPSI:A)
- General Self-Efficacy Scale
- Children's Coping Strategies Checklist
- Children's Health Locus of Control Scale
- Satisfaction Questionnaire

RESULTS & DISCUSSION

The baseline assessments and workshop follow-up (1- and 3-month) assessments were analyzed to evaluate change:

- Child participants in problem-solving abilities, coping, self-efficacy, and locus of control.
- Parental participants in problem-solving abilities, coping strategies, worry, and hope.

Child Participants

Figure 1. Change in Total Score on SPSI: A.

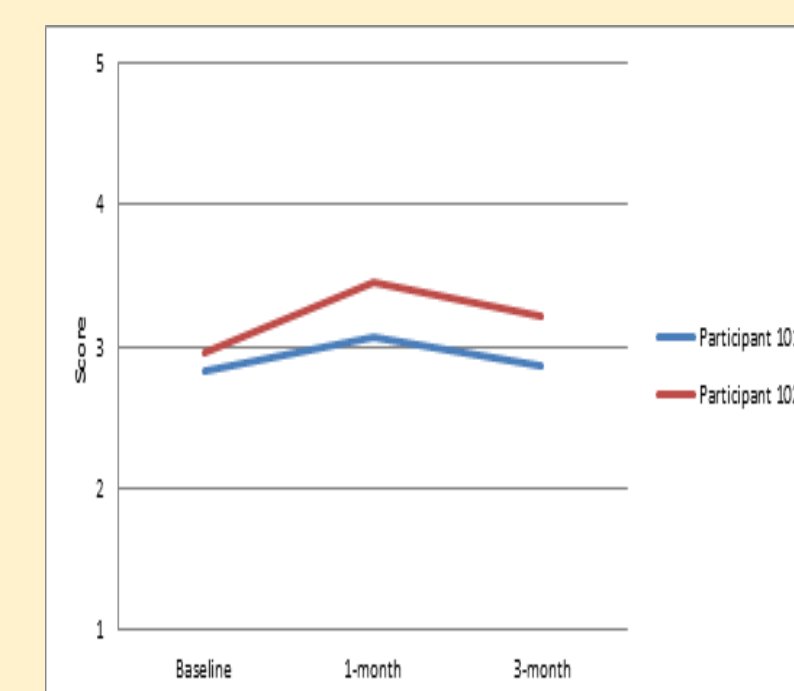


Figure 2. Change in POS Score on SPSI-A.

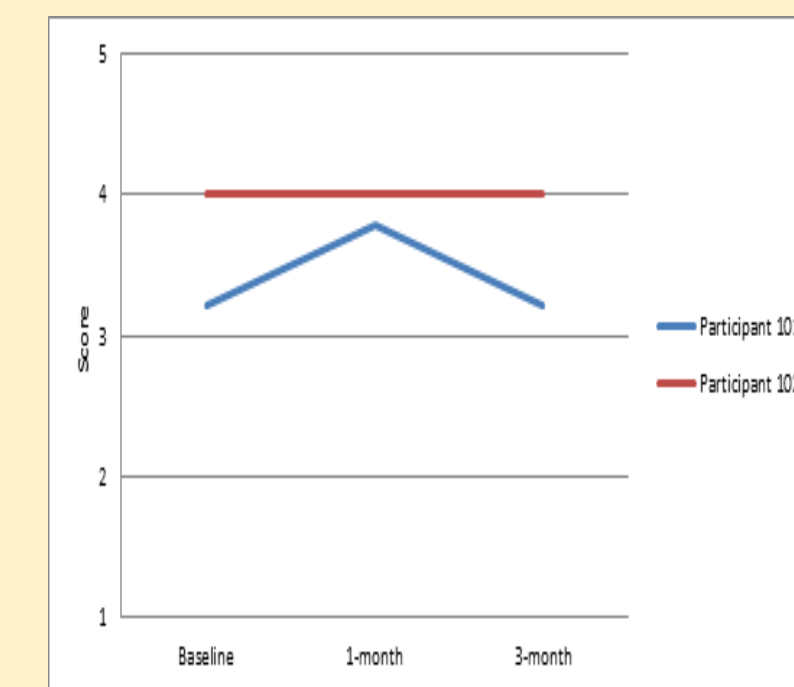


Figure 3. Change in Active Coping Factor Score.

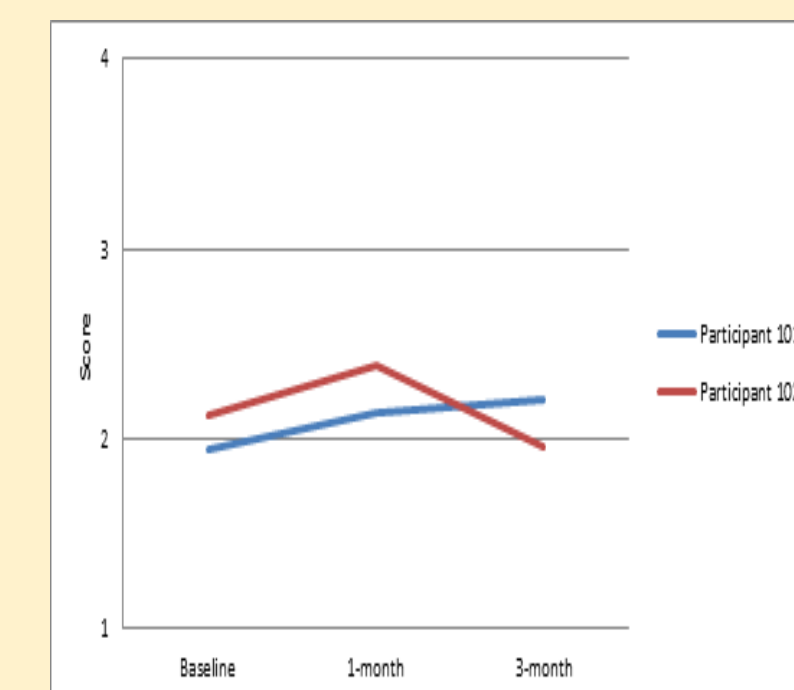


Figure 4. Change in Support Seeking Strategies Factor Score.

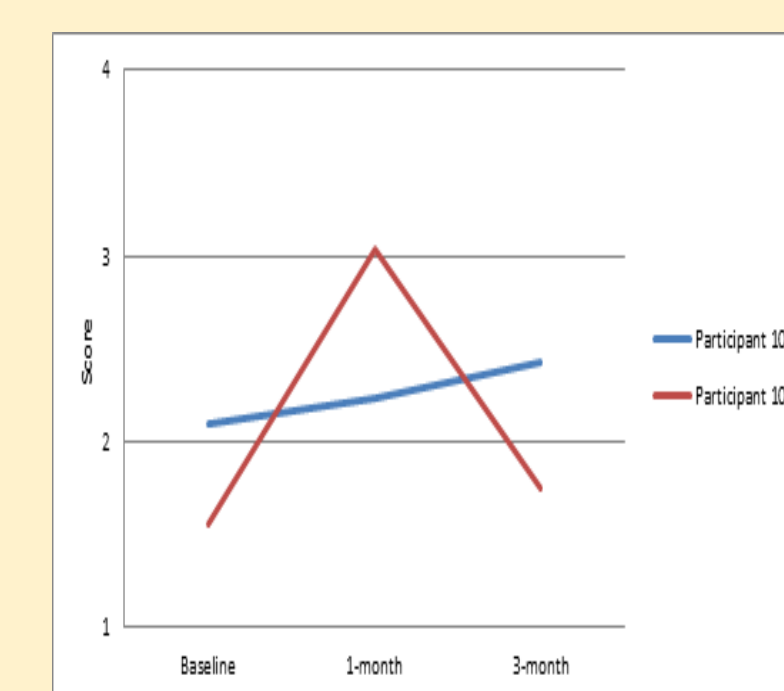


Figure 5. Change in CHLOC score.

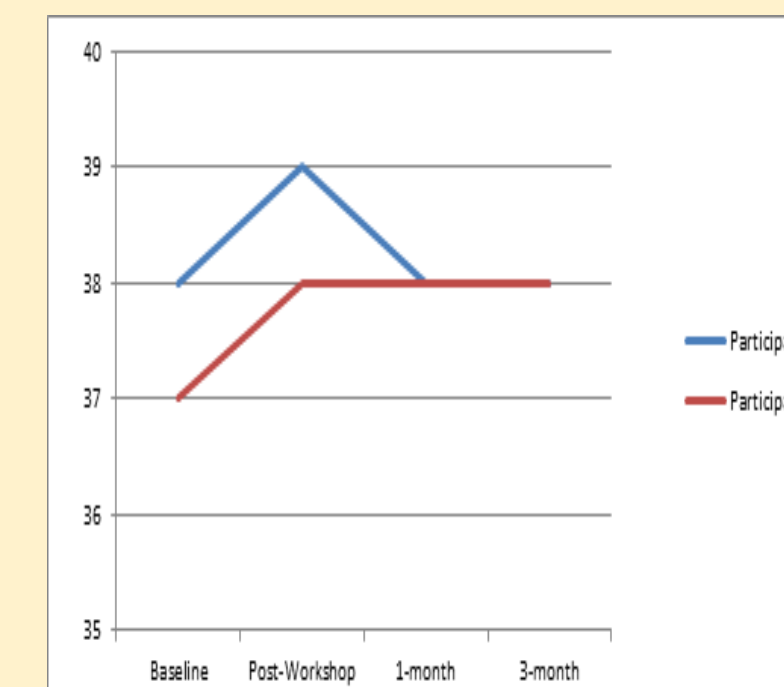
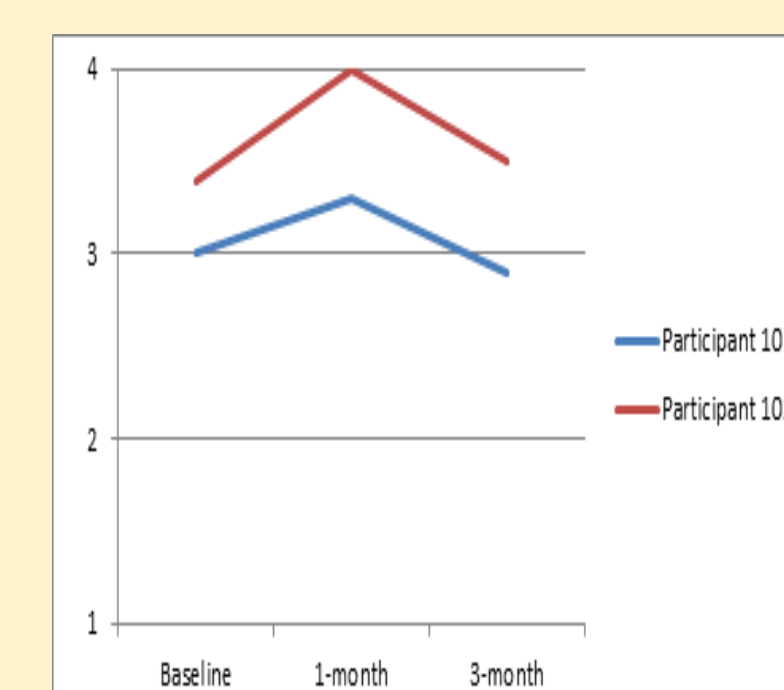


Figure 6. Change in Total GSE Score.



Parental Participants

Figure 7. Change in Total Score of SPSI-RS.

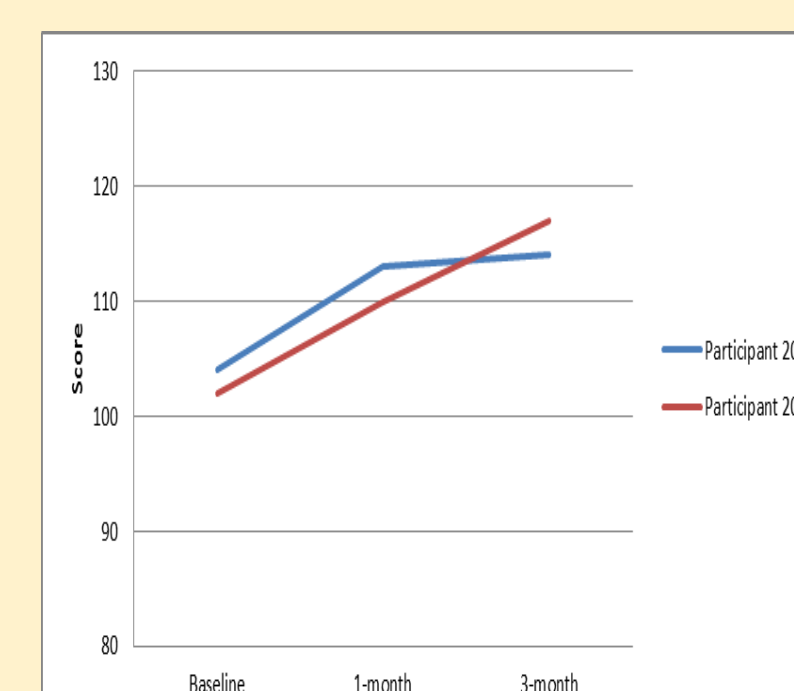


Figure 8. Change in PPO Scores on SPSI-RS.

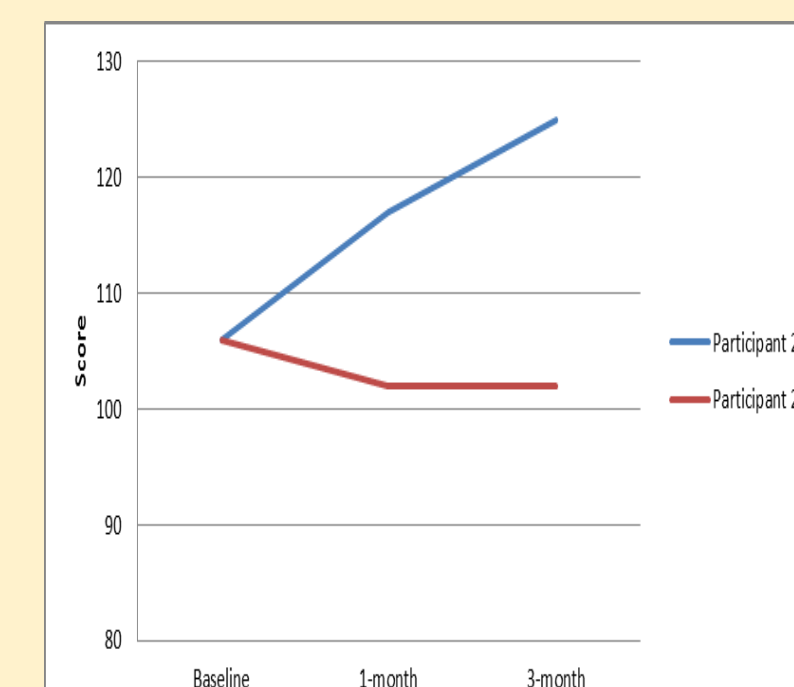


Figure 9. Change in NPO Scores on SPSI-R.

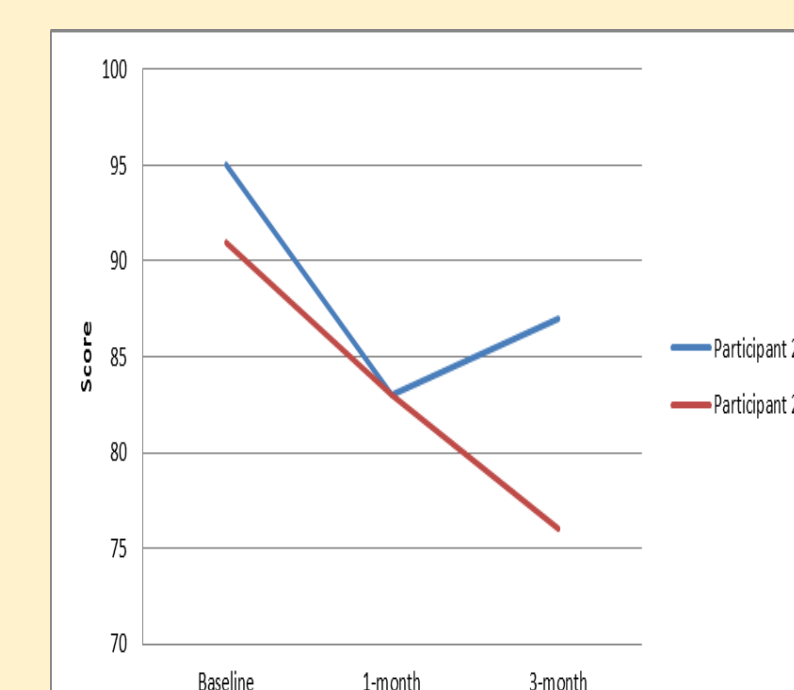


Figure 10. Change in Worry Score on PedsQL.

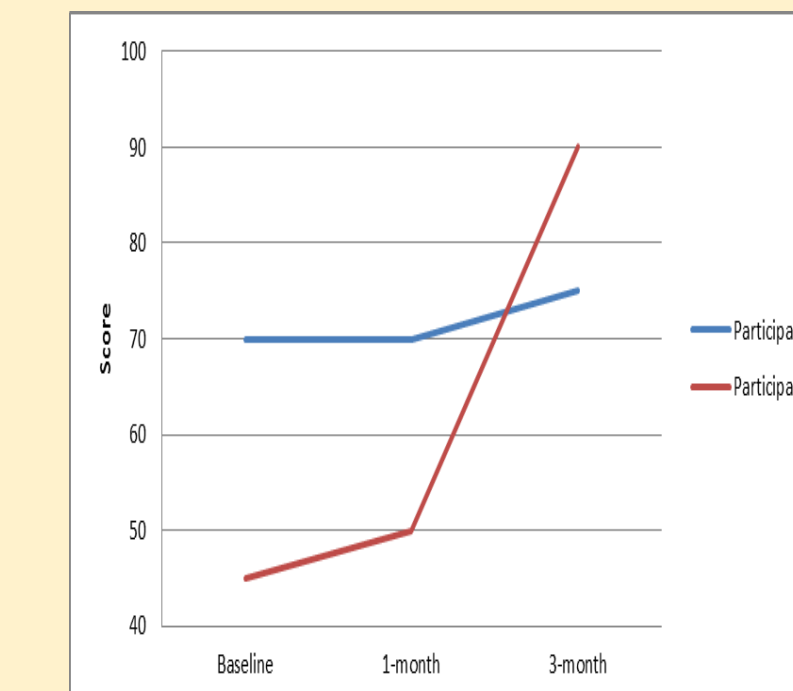


Figure 11. Change in Total Score on Adult State Hope Scale.

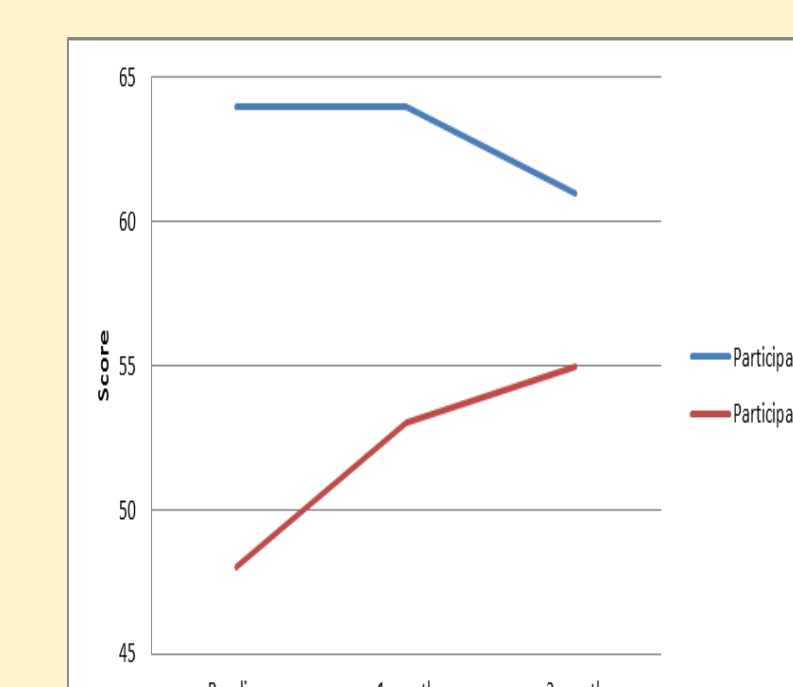


Figure 12. Change in Coping on CHIP.

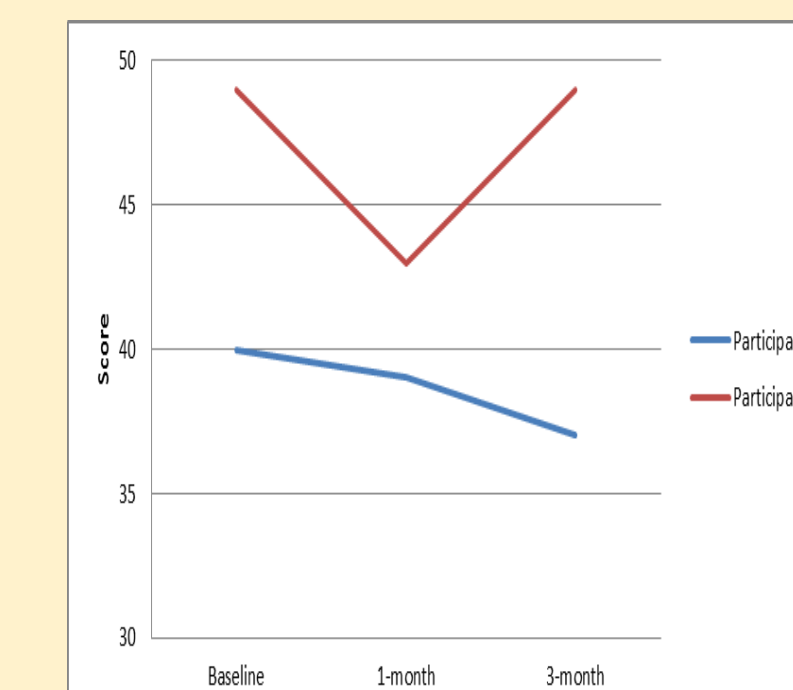


Table 1. Feasibility of Workshop as Measured by Satisfaction Questionnaire.

	Children	Parents
Overall Satisfaction	96%	93.67%
Workshop Information	95%	95%
Workshop Materials	93%	100%
Presenter Qualities	97%	98.8%
Topics Covered	95%	91.9%
Length/Location	100%	85%
Parents Only	N/A	91.3%

- Interrater reliability ratings $\kappa = 0.986$ indicated very good agreement between the raters of the extent to which the protocol was implemented as intended.
- All of the raters identified that each of the particular steps of the Social Problem-Solving model was explained in detail, and that utilization of the worksheets and handouts for the participants further facilitated the participants' learning of the model.
- The workshop was implemented with satisfaction as rated by the leaders, $\kappa = 0.969$.
- Specifically, the leaders had mutual agreement that the topics covered during the workshop were useful and informative to the participants; the workshop was well planned and executed; incorporated participants' LQTS specific problems in the workshop materials; and that participants were actively engaged in the workshop.

CONCLUSION

- The findings of this study suggest that a one-time problem-solving workshop may be feasible and effective for parents of children diagnosed with LQTS.
- The inclusion of parents in the workshop is believed to have helped facilitate children's short-term gains on outcome measures.
- Although the outcomes are preliminary, they suggest that there may be important benefits to teaching children problem-solving skills and helping parents to coach their children in learning skills to deal with LQTS-related problems.
- The preliminary results also offer some indication about the potential effectiveness of the intervention.
- Results demonstrate that continual support and review of problem-solving skills is likely necessary to facilitate long-term gains of problem-solving, coping, and adaptive skills.
- It is suggested that future workshops provide parents with guidelines on how to reinforce the use of problem-solving skills, which may include telephonic coaching of problem-solving skills at 1- and 3-months post-workshop.
- Results of this study can assist physicians and medical professionals to refer social problem-solving skills to children diagnosed with LQTS.
- This study demonstrates that continual support and review of problem-solving skills may be necessary to facilitate long-term gains of problem-solving, coping, and adaptive skills in children.
- Further investigation of utilization of this workshop as a tool to help children and their parents better cope with the daily LQTS-related events is needed.

REFERENCES

- Ellis, I., Mannion, G. G., Ladusans, E. E., Connelly, D. D., Syrris, P. P., & Jeffrey, S. S. (2003). Predictive Testing for the Long QT Syndrome in Children and Teenagers- Whose Best Interests are Served?. *Journal Of Medical Genetics*, 40, pS23-S23.
- Giuffre, R., Gupta, S., Crawford, S., & Leung, A. (2008). Fears and anxiety in children with long-QT syndrome compared to children with asthma. *Journal Of The National Medical Association*, 100(4), 420-424.
- Goldenberg, I. & Moss, A. J. (2008). Long qt syndrome. *Journal of the American College of Cardiology*, 51,2291-2300. doi:10.1016/j.jacc.2008.02.068
- Liu, J. F., Jones, C., Moss, A. J., McNitt, S., Peterson, D. R., Qi, M., & Zareba, W. (2011). Risk factors for recurrent syncope and subsequent fatal or near-fatal events in children and adolescents with Long QT Syndrome. *Journal of the American College Of Cardiology*, 57, 941-950.
- Meijer, S. A., Sinnema, G., Bijst, J. O., Mellenbergh, G. J., & Wolters, W. H. (2002). Coping styles and locus of control as predictors for psychological adjustment of adolescents with a chronic illness. *Social Science & Medicine*, 54, 1453-1461.
- Murray, A., Potet, F., Bellocq, C., Baró, I., Reardon, W., Hughes, H., & Jeffery, S. (2002). Mutation in KCNQ1 that has both recessive and dominant characteristics. *Journal of Medical Genetics*, 39(9), 681-685.
- Nezu, A. M., Nezu, C. M., (2012). *Problem-Solving Treatment: A Treatment Manual*. New York, New York: Springer Publishing Company.
- Schwartz, P., Stramba-Badiale, M., Crotti, L., Pedrazzini, M., Besana, A., Bosi, G., ... & Spazzolini, C. (2009). Prevalence of the congenital long QT syndrome. *Journal of the American Heart Association*, 120, 1761-1769.
- Wedekind, H., Burde, D., Zumhagen, S., Debus, V., Burkhardtmaier, G., Mönning, G., & ... Schulze-Bahr, E. (2009). QT interval prolongation and risk for cardiac events in genotyped LQTS-index children. *European Journal Of Pediatrics*, 168, 1107-1115.

ACKNOWLEDGEMENTS

Dr. Victoria Vetter, M.D., MPH, Director, Youth Heart Watch, Professor of Pediatrics, Children's Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania
Dr. Susan Panichelli-Mindel, Ph.D., Philadelphia College of Osteopathic Medicine
Sarah Hittinger, Jacqueline Blessinger, & Danyelle Salpietro, Philadelphia College of Osteopathic Medicine