The Economic Value of Post-Mortem Genetic Testing

15.777 Healthcare Lab 2020
Grissel Cervantes, Valerie Huang, Sara Gabriel

MIT MANAGEMENT SLOAN SCHOOL · H-Lab · Boston Children's Hospital Heart Center

PROJECT CHALLENGE & BACKGROUND

PROJECT CHALLENGE: Determine the cost-effectiveness of post-mortem genetic testing for sudden cardiac death (SCD) victims <40 years old

What is SCD?

- Abrupt, unexpected death due to a cardiovascular cause, generally happening within 1 hour from onset of cardiovascular symptoms
- Claims 300,000 - 400,000 lives annually in the US with about 20% of cases occurring in victims under 40 years old

What happens after SCD?

- A detailed autopsy is performed, where the victim is diagnosed with a positive (cardiomyopathies) or a normal autopsy (arrhythmogenic syndromes)
- All first-degree family members are screened for genetic cardiac diseases, through clinical testing and investigation

How can genetic testing help?

- Genetic testing can help identify or exclude family members with a genetic cardiovascular disorder, resulting in peace of mind and potentially lowering future screening and monitoring costs of family members; post-mortem genetic testing after SCD is currently not covered under insurance

PROJECT METHODOLOGY

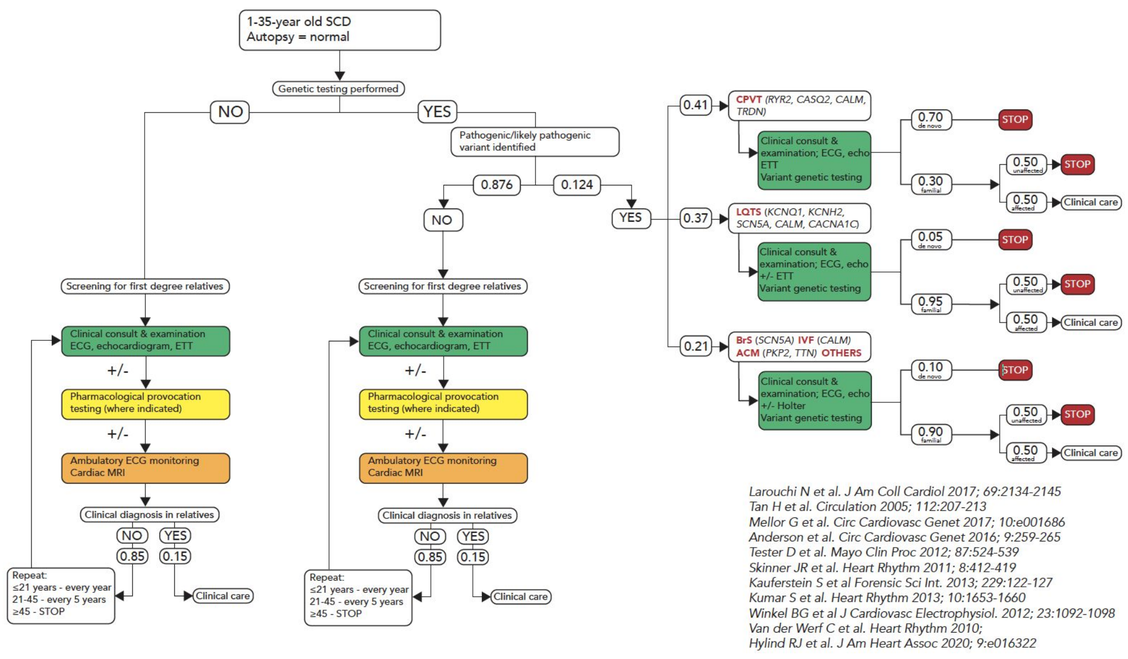
METHODS:

- Probability-adjusted model to evaluate the financial impact of post-mortem genetic testing on long-term testing/monitoring costs
- Comparison of cost impact for various family scenarios with vs. without post-mortem genetic testing

ASSUMPTIONS:

- **Epidemiology:** literature review of epidemiological studies on SCD
- **Testing and monitoring requirements**: APHRS/HRS guidelines
- **Family composition**: U.S. census and CDC data to create representative family structures based on decedents age
- **Financial assumptions**:
  - Medicare costs: 2019 CMS Physician Fee schedule
  - Private insurer costs: multipliers applied to Medicare rates
  - Genetic testing: Blueprint Medicines
  - 3% discount rate

Example of Probability-adjusted Decision Tree: Normal Autopsy



Larouchi N et al. J Am Coll Cardiol 2017; 69:2134-2145
Tan H et al. Circulation 2005; 112:207-213
Mellor G et al. Circ Cardiovasc Genet 2017; 10:e001686
Anderson et al. Circ Cardiovasc Genet 2016; 9:259-265
Tester D et al. Mayo Clin Proc 2012; 87:524-539
Skinner JR et al. Heart Rhythm 2011; 8:412-419
Kauferstein S et al Forensic Sci Int. 2013; 229:122-127
Kumar S et al. Heart Rhythm 2013; 10:1653-1660
Winkel BG et al J Cardiovasc Electrophysiol. 2012; 23:1092-1098
Van der Werf C et al. Heart Rhythm 2010;
Hylind RJ et al. J Am Heart Assoc 2020; 9:e016322

Same analysis is repeated for positive autopsy cases, adjusted for epidemiology, monitoring requirements & cadence, and baseline testing

FINANCIAL ANALYSIS & OUTCOMES OF POST-MORTEM GENETIC TESTING

Financial Impact: After Normal Autopsy

Model Assumptions					Cost Difference (with vs. without Genetic Testing)			
					Medicare	Private Insurance		
Proportion of SCD Cases	Decedent Age	Parent Ages	Children Age(s)	Sibling Age(s)	*0x Multiplier*	10th Percentile *2.11x Multiplier*	50th Percentile *3.95x Multiplier*	90th Percentile *6.19x Multiplier*
19%	1 - 5	30	-	1	-$581	$769	$2,991	$5,701
1%	6 - 10	35	-	6	-$804	$297	$2,110	$4,320
4%	11 - 15	40	-	11	-$1,060	-$245	$1,098	$2,736
23%	16 - 20	45	-	16	-$1,354	-$866	-$62	$918
13%	21 - 25	50	-	21	-$1,579	-$1,343	-$952	-$477
20%	26 - 30	55	1, 3	26	$153	$2,390	$6,072	$10,563
21%	31 - 35	65	6, 8	31	-$180	$1,686	$4,757	$8,503
				Weighted Cost Difference:	**-$685**	**$597**	**$2,708**	**$5,283**

Genetic testing leads to cost savings, weighted by decedent age and demographic data, when using private insurance rates

Financial Impact: After Positive Autopsy

Model Assumptions					Cost Difference (with vs. without Genetic Testing)			
					Medicare	Private Insurance		
Proportion of SCD Cases	Decedent Age	Parent Ages	Children Age(s)	Sibling Age(s)	*0x Multiplier*	10th Percentile *2.11x Multiplier*	50th Percentile *3.95x Multiplier*	90th Percentile *6.19x Multiplier*
19%	1 - 5	30	-	1	$765	$6,027	$13,142	$21,818
1%	6 - 10	35	-	6	$793	$5,440	$12,064	$20,141
4%	11 - 15	40	-	11	$676	$4,164	$9,696	$16,443
23%	16 - 20	45	-	16	$471	$3,081	$7,672	$13,272
13%	21 - 25	50	-	21	$230	$2,165	$5,963	$10,594
20%	26 - 30	55	1, 3	26	$1,973	$11,096	$22,876	$37,244
21%	31 - 35	65	6, 8	31	$1,705	$8,805	$18,636	$30,624
				Weighted Cost Difference:	**$1,071**	**$6,424**	**$14,034**	**$23,314**

Genetic testing after positive autopsy (diagnosed cardiomyopathy) leads to cost savings in all family and insurer scenarios

- Sensitivity analyses showed that number of young children and use of advanced testing/monitoring were key factors in determining cost impact
- Results were less sensitive to age of family members and genetic prevalence rate

INTANGIBLE IMPACT OF GENETIC TESTING

- Post-mortem genetic testing can provide key intangible benefits to family, including closure on their child's death and greater certainty about risk of remaining family members
- ~57% of first-degree relatives seek professional help from a grief counselor or psychologist, particularly relating to the cause of death (Yeates 2013)
- Among parents of SCD victims, ~72% desired to know the genetic cause of death, with ~67% reporting that need as unmet (McDonald 2020)

CONCLUSIONS AND NEXT STEPS

- Post-mortem genetic testing after SCD leads to significant reductions in testing and monitoring costs in most family and insurer scenarios
- Key factors influencing financial impact of post-mortem genetic testing:
  - Costs and reimbursement rates for clinical testing
  - Number of young family members (children or siblings)
  - Increased frequency of additional monitoring procedures
  - Our analysis shows strong support for covering cost of post-mortem genetic testing after SCD
- BCH plans to continue this work, extending the analysis with global colleagues and assessing payer willingness to pay

PROJECT SUMMARY

We developed a financial model to evaluate the cost impact of post-mortem genetic testing after sudden cardiac death (SCD). We created a probability-adjusted decision tree model, using key assumptions on epidemiology, costs, and family demographics from literature and other secondary sources.

We find that post-mortem genetic testing leads to cost reductions in most family scenarios and across a wide range of insurer reimbursement rates. Furthermore, sensitivity analyses on family composition and monitoring interventions support the robustness of our conclusions. Future research on the validity of these results in ex-U.S. geographies and evaluation of payer willingness to pay is needed.

ACKNOWLEDGEMENTS: *We would like to thank our hosts, Dominic Abrams, Robyn Hylind, Thomas Roston, Molly Regan, Kathleen Jay, our mentor, Don Triner, and the 15.777 course staff for their help and support with our project.*