The Economic Value of Post-Mortem Genetic Testing

15.777 Healthcare Lab 2020
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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

Probability-adjusted model to evaluate the financial impact of post-mortem genetic testing on long-term testing/monitoring costs. Example of Probability-adjusted Decision Tree: Normal Autopsy

FINANCIAL ANALYSIS & OUTCOMES OF POST-MORTEM GENETIC TESTING

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

COST IMPACT: After Normal Autopsy

Cost Savings (vs. private insurance)

- Medicare: $597
- Private Insurance: $2,708

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

COST IMPACT: After Positive Autopsy

Cost Savings (vs. private insurance)

- Medicare: $1,071
- Private Insurance: $4,424

INTEGRITY 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.