Engagement and Communication in the ClinSeq® Genomic Sequencing Study: How much do they care and how do we know if they do?

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I was trying to figure out which is worse, ignorance or apathy...

Then I realized I don’t know and I don’t care.
A Stressful Decision Aid?

CD-rom based decision aid to help BRCA carriers make management decisions

- Prev. shown to be effective
  - ↑ likelihood of reaching a decision
  - ↓ decisional conflict
  - ↑ decisional satisfaction

- Different longitudinal patterns of distress

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Med Dec Making. 31(3) 412 - 421.
Engagement

- Cognitive engagement

- How much you think and care about a particular thing

- Assumes a set amount of “thought space”

- Distinct from
  - Knowledge
  - Arousal
  - Activities stemming from engagement (e.g. “engagement with a website”)

The Precaution Adoption Process Model

- A “stage” model

Unaware → Unengaged → Deciding → Decided to Act → Acting

Decided Against

**Genomics**

Weinstein, Sandman and Blalock in Health Behavior and Health Education 2008
ClinSeq® - Overview

- A pilot study of large scale medical sequencing, started in 2007
- Participants brought to clinical center for consent, physical and evaluation for a common set of cardiovascular features
- Participants recruited in “bins” based on risk of cardiovascular event
- Broad consent for possible return of results, with patients given the option to learn (or not) most results
ClinSeq® BL Survey

- Contents
  - 36 Scales
  - >400 Questions
  - 45 minutes to complete

- Eligibility
  - No results yet (N=962)
  - >1 month since enrollment

- Administration
  - Online and paper
  - 3 recruitment attempts
Engagement Study Aims

- Describe engagement

Knowledge of Genomics → Engagement with Research → Decision Making/Appraisals → Decision To Communicate → Communication

Decision not to Communicate

- Test relationships predicted by PAPM, anchoring on the decision to communicate about ClinSeq participation

- Provide additional evidence for validity of engagement as a construct
Response to ClinSeq® BL Survey

- 594 responses received (61%)
- 551 survey responses used for analysis

Respondent characteristics
  - White & Not Hispanic or Latino (91%)*
  - Bin 1-3 (80%)
  - College Educated or Higher (87%)*
  - Income > $100,000 (74%)
  - Married (73%)
  - At least 1 biological child (74%)

*Respondents were significantly (p<0.05) more likely than the overall eligible population to have had these characteristics.
How often do you think about your participation in ClinSeq®?

- Never (1)
- Yearly (2)
- Monthly (3)
- Weekly (4)
- Daily (5)
Engagement, Knowledge and Communication

Knowledge of Genome Sequencing \( r = 0.11 \) \( P = 0.02 \) → Engagement

Frequency of Communication With Family \( r = 0.38 \) \( P < 0.001 \)

Frequency of Communication With Friends \( r = 0.35 \) \( P < 0.001 \)

Frequency of Communication With Doctors \( r = 0.28 \) \( P < 0.001 \)
## Who do they tell?

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Percent Having at Least 1 Living Relation</th>
<th>Percent of Relatives Communicated to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>87%</td>
<td>97%</td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological Son(s)</td>
<td>59%</td>
<td>77%</td>
</tr>
<tr>
<td>Biological Daughter(s)</td>
<td>61%</td>
<td>77%</td>
</tr>
<tr>
<td>Parents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>41%</td>
<td>63%</td>
</tr>
<tr>
<td>Father</td>
<td>25%</td>
<td>58%</td>
</tr>
<tr>
<td>Siblings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological Sister(s)</td>
<td>68%</td>
<td>68%*</td>
</tr>
<tr>
<td>Biological Brother(s)</td>
<td>73%</td>
<td>56%</td>
</tr>
<tr>
<td>Physicians</td>
<td>N/A</td>
<td>77%</td>
</tr>
</tbody>
</table>
## Other Correlates of Engagement

<table>
<thead>
<tr>
<th></th>
<th>$r$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better Overall Health</td>
<td>0.13</td>
<td>0.02</td>
</tr>
<tr>
<td>More Frequent Doctor’s Visits</td>
<td>-0.11</td>
<td>0.01</td>
</tr>
<tr>
<td>More Frequent Health Information Seeking</td>
<td>0.17</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Have Had Genetic Testing</td>
<td>0.10</td>
<td>0.03</td>
</tr>
<tr>
<td>Hold Graduate Degree</td>
<td>0.09</td>
<td>0.03</td>
</tr>
<tr>
<td>Time Since Enrollment</td>
<td>-0.19</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
Summary

- Most ClinSeq® participants think about their participation on a yearly basis.

- As predicted by the PAPM, Engagement is related to knowledge and communication.

- Healthier, information seekers with a history of graduate school and genetic testing are more likely to be engaged.

Limitations

- Response bias
- Single item measure
- Cross sectional data
### Future Directions

- **Refining measurement**

### Engagement with ClinSeq®

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often does ClinSeq® come up in conversations with others?</td>
<td>Daily, Weekly, Monthly, Yearly, Never</td>
</tr>
<tr>
<td>How often do you look up information about the ClinSeq® study on the internet or in your own records?</td>
<td>Daily, Weekly, Monthly, Yearly, Never</td>
</tr>
<tr>
<td>How often do you wonder about results you might learn from ClinSeq®?</td>
<td>Daily, Weekly, Monthly, Yearly, Never</td>
</tr>
<tr>
<td><strong>In general, how often do you think about your participation in the ClinSeq® Study?</strong></td>
<td>Daily, Weekly, Monthly, Yearly, Never</td>
</tr>
<tr>
<td>If I had a question or concern about ClinSeq®, it would be easy for me to contact the study team.</td>
<td>Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree</td>
</tr>
<tr>
<td>I feel like I understand the goals of the ClinSeq® study.</td>
<td>Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree</td>
</tr>
<tr>
<td>I enjoy receiving mailed updates about the ClinSeq® study.</td>
<td>Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree</td>
</tr>
<tr>
<td>I feel motivated to continue participating in the ClinSeq® study.</td>
<td>Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree</td>
</tr>
</tbody>
</table>
Future Directions

- Testable Hypotheses

- Short-term engagement (1-month post-disclosure) with carrier results will predict cumulative communication with family members in the long term (*pending*).

- Short-term engagement with actionable, risk-associated variants will predict uptake of risk management behaviors (visiting specialists, screening, prevention).

*Long-term (wildly speculative) hypothesis*

- Genetic counseling interventions aimed at promoting engagement among the disengaged will lead to positive health outcomes.
Tangential Plugs

- Practice Guidelines Committee
  - Move towards systematic evidence reviews as a prerequisite for genetic counseling guidelines
  - In GREAT need of genetic counselors with research training
  - Watch for applications in the next month or so (around the AEC)

- Research SIG
  - Aiming to increase SIG activity and visibility (engagement?)
  - Move towards work groups (Research in Industry, Using Patient Portals, Qualitative Research in GC, other?)