THE ROLE OF THE GENETICIST IN THE PATIENT-CENTERED MEDICAL HOME

CHRISTINE M. BRUHA, B.S.
PURPOSE & AIMS

To identify:

- the role of the medical geneticist within the PCMH;
- which PCMH specialist roles medical geneticists assume;
- the roles geneticists, patients’ parents, and PCPs see medical geneticists filling in the PCMH; and
- the ideal role geneticists, patients’ parents and PCPs would like to see medical geneticists assuming in the PCMH
STUDY DESIGN

- Three population groups
  - Medical geneticists
  - PCPs
  - Parents of pediatric genetics patients
- Surveys
- Interviews
- Analysis
- Identifying influencing factors
RESULTS
DEMOGRAPHICS

Geneticists
- Majority Caucasian
- 88% worked in an academic medical center
- Most had 20+ years experience

PCPs
- Majority Caucasian & female
- Variable levels of experience
- Most worked in a practice with 10+ PCPs

Parents
- 100% Caucasian
- 57% college graduates → 36% with post-graduate degrees
<table>
<thead>
<tr>
<th>Current Role of the Geneticist</th>
<th>Geneticists (%)</th>
<th>PCPs (%)</th>
<th>Parents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No role or interface in the PCMH</td>
<td>37.5</td>
<td>8.3</td>
<td>30.8</td>
</tr>
<tr>
<td>PCMH-N</td>
<td>87.5</td>
<td>62.5</td>
<td>7.7</td>
</tr>
<tr>
<td>Medical home subspecialist</td>
<td>12.5</td>
<td>8.3</td>
<td>7.7</td>
</tr>
<tr>
<td>PCP educator</td>
<td>87.5</td>
<td>58.3</td>
<td>7.7</td>
</tr>
<tr>
<td>Consultant/quaternary care provider</td>
<td>25.0</td>
<td>58.3</td>
<td>38.5</td>
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<tr>
<td>Medical home co-manager</td>
<td>63.5</td>
<td>25.0</td>
<td>7.7</td>
</tr>
<tr>
<td>Family-directed PCMH supporter</td>
<td>50.0</td>
<td>0</td>
<td>0</td>
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WHAT FACTORS INFLUENCE THE ROLE OF THE GENETICIST?

“I can’t do follow-up from 1,000 miles away.”

- Location of the geneticist
- Availability and access of genetic services
- Type of condition and complexity of patient

“It was a lot easier for me to travel than for families to travel...the easiest is in the spring and summer and fall, but that’s when they’re busiest at the farms.”
“If [it’s] a metabolic disorder, I expect more direct geneticist involvement.”
<table>
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<tr>
<th>Roles</th>
<th>Geneticists</th>
<th>PCPs</th>
<th>Parents</th>
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<tr>
<td>PCMH-N</td>
<td>PCP Educator</td>
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<td>PCP Educator</td>
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<td>Consultant/quaternary care provider</td>
<td>No role</td>
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| Satisfaction | 63% | 92% | 53% |

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<tr>
<th>Challenges</th>
<th>Communication</th>
<th>Insurance coverage</th>
<th>Referral process</th>
<th>Communication</th>
<th>Insurance coverage</th>
<th>Access &amp; availability</th>
<th>Communication</th>
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</table>
“At this point I just wish I felt like it was more of a team effort and not just the patient in the middle trying to go between several doctors relaying information hoping it is right...”

“good for...getting tests ordered that the insurance company will not pay for...”
DISCUSSION
CHARACTERIZING THE GENETICIST’S ROLE IN THE PCMH

PCMH-N

• Flexibility to adapt to situation

“type of interaction is a function of the clinical situation being addressed, the professional judgment of the physicians involved, and the expressed needs and preferences of the patient (ACP, 2010).”
FACTORS INFLUENCING THE GENETICIST’S ROLE

Geneticist role in PCMH

Location

Access & Availability

Type & complexity of disease
OTHER FINDINGS

- Communication
- Insurance difficulties
  - Difficulties reported by all groups
  - Barrier to provision of services by PCP
  - Poor communication impacts care

- Part of a larger issue
  - Evident issue in medical care

- Communication skills training
- Communication standardization
LIMITATIONS & FUTURE RESEARCH

- Differences in geographic location
  - Small sample size

- Telemedicine/teleconsultation
  - Parent participants

- Disease specific
  - Survey design

- Differences in satisfaction
  - Format consistency

- PCP satisfaction in various locations
CONCLUSIONS

PCMH-N

Factors influencing geneticist’s role

Preliminary research
ACKNOWLEDGEMENTS

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QUESTIONS?


REFERENCES (CONTINUED)


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