

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

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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

CURRENT ROLE OF THE GENETICIST

Current Role of the Geneticist	Geneticists (%)	PCPs (%)	Parents (%)
No role or interface in the PCMH	37.5	8.3	30.8
PCMH-N	87.5	62.5	7.7
Medical home subspecialist	12.5	8.3	7.7
PCP educator	87.5	58.3	7.7
Consultant/quaternary care provider	25.0	58.3	38.5
Medical home co-manager	63.5	25.0	7.7
Family-directed PCMH supporter	50.0	0	0

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.”

SUMMARY

	Geneticists	PCPs	Parents
Roles	<ul style="list-style-type: none">• PCMH-N• PCP Educator• Medical home co-manager	<ul style="list-style-type: none">• PCMH-N• PCP Educator• Consultant/quadernary care provider	<ul style="list-style-type: none">• No role• Consultant/quadernary care provider
Satisfaction	63%	92%	53%
Challenges	<ul style="list-style-type: none">• Communication• Insurance coverage• Referral process	<ul style="list-style-type: none">• Communication• Insurance coverage• Access & availability	<ul style="list-style-type: none">• Communication

“good for...getting tests ordered
that the insurance company will
not pay for...”

“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...”

DISCUSSION

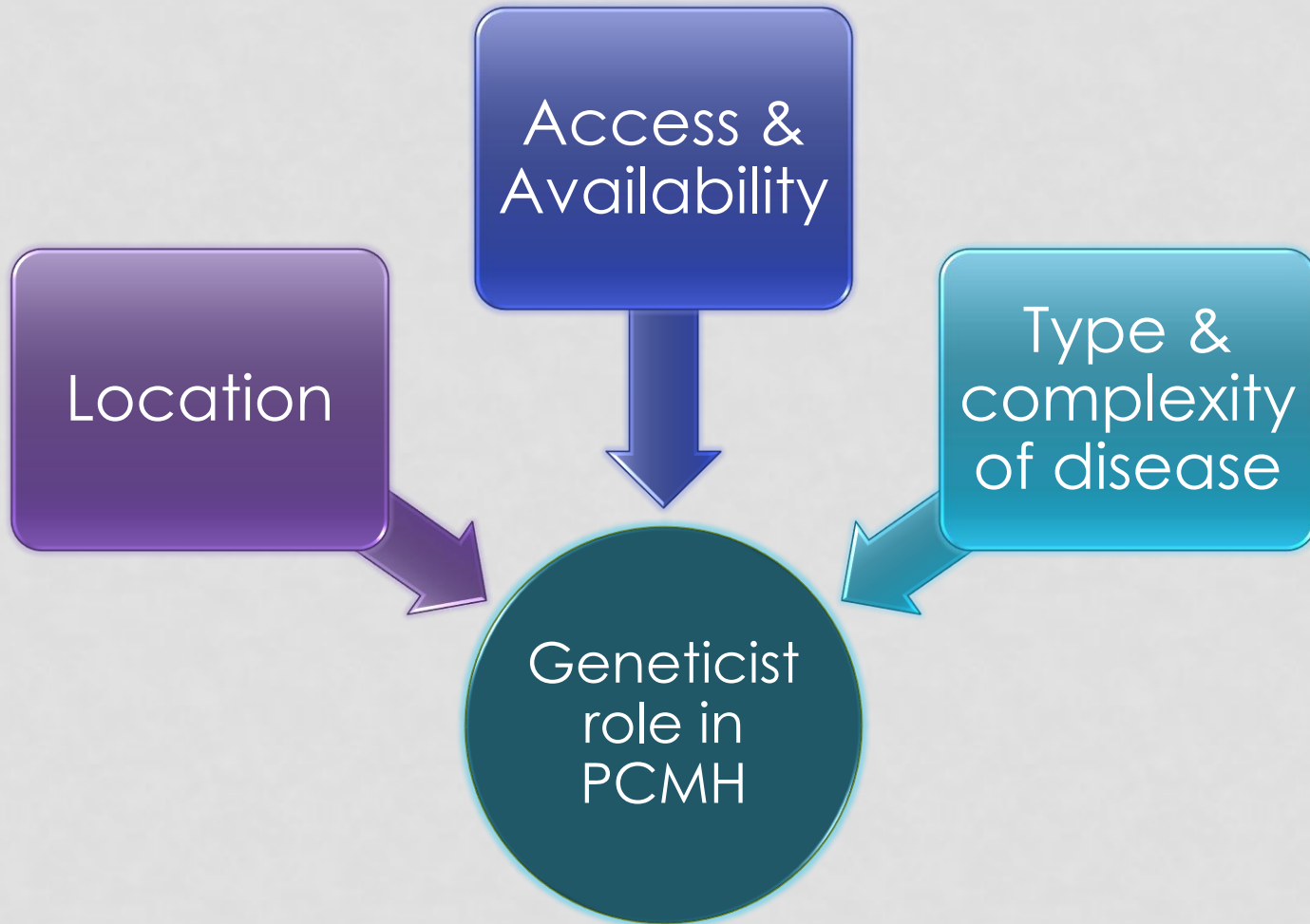
CHARACTERIZING THE GENETICIST'S ROLE IN THE PCMH

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



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

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QUESTIONS?

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