

Genetic Counseling: Specialist Perspective

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Task Force on a Perinatal System of Care

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No conflicts of interest.

Current:

- Assistant Program Director at UNC Greensboro MS Genetic Counseling Program
- Pediatric Genetic Counselor (GC) at Cone Health System

Past employment:

- Past Prenatal GC at Duke University Medical Center
- Past Multispecialty GC in Fullerton Genetics Center

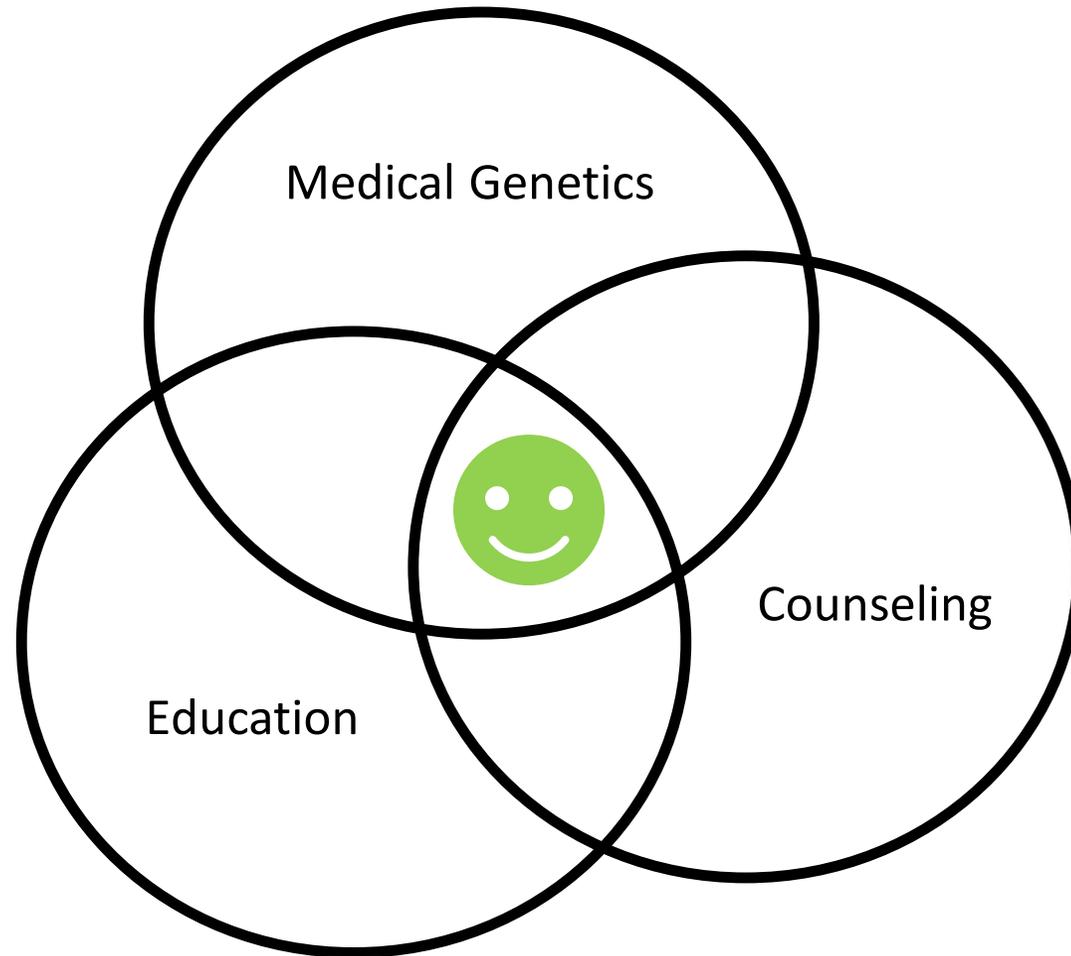
Learning objectives

- Prenatal and postnatal genetics services
- Referral patterns and access to care
- Billing
- Barriers to access
- Service delivery models & telehealth

Background

- Genetic counseling - the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease (www.nsgc.org)
 - How inherited diseases and conditions might affect them or their families
 - How family & medical histories may impact the chance of disease occurrence or recurrence
 - Which genetic tests may or may not be right for them, and what those tests may or may not tell
 - How to make the most informed choices about healthcare conditions
- Specialties:
 - Prenatal/Preconception, Pediatrics, Cancer, Adult, Cardiology, Neurology, Laboratory, Industry, Research, Education, Metabolism, Personalized Medicine, Infertility

Genetic Counseling



Prenatal Genetics Services

- Common indications:
 - AMA (>35y at delivery), fetal ultrasound findings, family history concerns, prenatal exposures, some maternal conditions, abnormal prenatal test result (screen or diagnostic test), carrier screening, preconception
 - Referred for what service?
- Referral base:
 - Ob/Gyn providers & care team (NP, midwife, etc.)*
 - Maternal Fetal Medicine (MFM) physician*
 - Infertility, Endocrinology, Hematology, Family Practice, Pediatrics, Oncology
 - Patient self-referral?
- Genetics care team:
 - MFM, Genetic Counselor, Ultrasound technologist/Sonographer
 - Other – Nurse, Medical Interpreter, Financial Aid Counselor, Social Work, Other

Postnatal Genetics Services

- Common indications:
 - Developmental delays, autism, LD/ID, suggestive physical or facial features, birth defect, mental health condition, behavioral problems,
 - Diagnosis of or “rule out” for chromosome condition (ex. Down syndrome), single gene disorder (ex. Marfan syndrome, Achondroplasia), deletion/duplication syndrome, etc.
- Referral base:
 - PCP: pediatrician or family practice*
 - Developmental pediatrics, neurology, Behavioral health / psych, Cardiology
 - Patient self-referral?
- Genetics care team:
 - Medical geneticist, Genetic Counselor
 - Possibly others – Medical Interpreter, Cardiology, Endocrinology, etc.
 - Bio or adoptive parents, foster care, CPS worker, Social work, extended family, etc.

Postnatal Genetics Services



- Mechanism for communication of prenatal & postnatal genetics teams?
- If baby born with genetic diagnosis, suggestive features or high risk
- Newborn metabolic screen performed
 - If screen positive, repeat sample and/or present to care
 - Early Check – Opt-in research study in NC to test for Fragile X syndrome and Spinal Muscular Atrophy (SMA)
- Hospital consult after birth by genetics team
- Scheduled in outpatient genetics clinic
- Follow up plan determined case by case



Value of Genetics Services

- Assess genetic risks
- Educate patient about options, risks, diagnosis, management, follow up
- Facilitate (complicated, expensive, specialized!) genetic testing
 - Nondirective, autonomous patient decision-making
- Pre-test & post-test counseling
- Ensure right genetic test is ordered for the right patient
- Provide support & short-term psychological counseling
- Help with care for complex medical cases (mom and baby)
- Participate in Prenatal-Postnatal Case Conferences
- Educate health care providers and medical learners
- Focus on individual patient & family
- Cost savings for genetic testing ordered
- Downstream revenue

Who shows up for genetic counseling?

- Typically have insurance
- Willing and able to come to appointment
 - Have transportation
 - Can get off of work during clinic hours
- Informed of referral
- Often unaware of reason for referral or purpose of appointment
- Misconceptions about genetics or utility of genetic testing
- Unclear expectations
- Stressed or anxious because of concerns
- No one can “figure out what is wrong with their child”
- Either learned to be a super advocate already or does not know how/understand need for advocacy

Billing for genetic counseling

- CPT 96040 (created in 2007)
 - Replaced physician billed E&M time based code for genetic counseling
 - For “trained genetic counselors”
 - Time-based, stackable 30min code
 - Some but not all genetics clinics bill for GC services
 - Might still be billed as incident to physician
 - Some hospital barriers to using 96040
- Payers
 - Medicaid and other third party payers allow direct billing for GC
 - Medicare does not allow direct billing for GC (allow E&M code)
- Reimbursement
 - Billable services ≠ Reimbursement
 - Some health plans only reimburse for services when provided by a HCP credentialed within their plan
 - Some payer policies restrict payment of services to only “licensed” HCPs

Billing for genetic counseling & testing

- Institutional considerations
 - Is institutional billing an option?
 - Institutional mark-ups for special sendout (genetic testing)?
- Insurance companies have different policies, and may cover some genetic tests, but not others.
- Some companies cover counseling and testing under specific circumstances, or insist that certain requirements are met before they agree to cover genetic testing.
- Patients should check on insurance coverage before proceeding with genetics evaluation/testing

Barriers to access

- Workforce challenges
 - Genetic counselors
 - Medical geneticists (pediatric/adult settings)
 - Increased wait time for pediatric genetics services
- Genetic counselors are not licensed in NC
 - Downstream impacts
 - Cannot order genetic testing, bill for services, limits practice options,
- Cost for services
 - Genetic counseling
 - Ultrasound
 - Procedures
 - Genetic testing
- Genetic testing laboratories do not accept out-of-state Medicaid
 - Financial aid options?

Barriers to Access

- Distance/travel
- Educate referral base
 - Are they fully aware of services offered, patient benefits, opportunity for collaboration?
 - How is option of genetics referral presented to patient and by whom?
 - Timing of referral (time-sensitive nature of pregnancy)
- Front end model vs. back end model?
 - Pros and cons of both
 - Importance of pre-test and post-test counseling!
 - Nongenetics providers ordering genetic testing
- Clinical rotation placements directly limits training opportunities

GC Licensure Status

- States issuing licenses
 - CA, CT, DE, ID, IL, IN, KY, MA, MN, NE, NH, NJ, NM, ND, OH, OK, PA, SD, TN, UT, VA, WA,
- Passed bills/in rulemaking
 - HI, IA, LA, MI
- Bill introduced or preparing to introduce bills:
 - CO, DC, FL, GA, KS, ME, MD, MN, MS, MO, NY, **NC**, NV, OR, RI, TX, WI

Licensure update

- Pursuit of licensure is gaining momentum in NC
- Current focus of North Carolina Medical Genetics Association (NCMGA)
- Loose plan for licensure:
 - Seek and obtain the support of the State Medical Board, who we will be asking to provide the licenses before moving forward with any bill-specific language
 - Work with NSGC attorney to define the minimum criteria for licensing (which is typically ABGC Certification) that will be entered into the bill
 - Work with our local legislators to draft it, introduce it, and then we rally the community to support it

Access to Genetic Counselor Services Act of 2019

- Was supposed to be introduced in early April to recognize certified GCs as providers of Medicare. (do not have status update)
- The Act provides coverage of services furnished by GCs under part B of the Medicare program.
- GCs are those licensed by states as such, or for those in states without licensure, the Secretary of HHS will set criteria through regulation (likely ABGC certification).
- Other practitioners that currently provide the service will not be affected.
- GCs would be paid at 85 percent of the physician fee schedule.
- If E/M codes are used for billing the service, a CPT code modifier would be used to note the service was done by a genetic counselor.
- GCs would be able to assign reimbursement to their employer.

John Richardson
Director, NSGC Policy and Government Relations
March 22, 2019

Future of genetics services

- Demand for genetics services continues to increase
- General shortage of genetics providers
- Growing niches for GCs
- Limitations from lack of licensure
- Billing and reimbursement challenges
- How can we keep up?
 - Front end vs. back end service
 - Explore all options for clinical training of GCs
 - Explore service delivery models
 - Multi-faceted approach

Service delivery models (SDMs)

- In-person / face-to-face
- Telephone
- Telemedicine (phone + audio)
- Group counseling
- Automation
- Motivating factors to pursue alternative SDMs
 - Distance, wait time, convenience

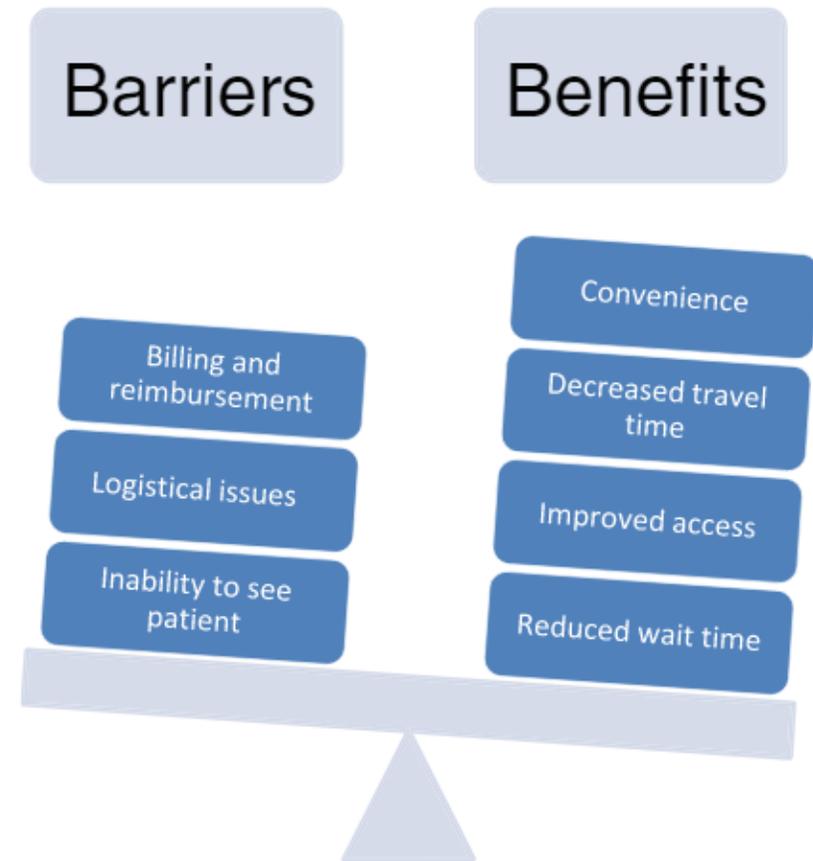


Fig. 1 Weighing the barriers to implementation and benefits of alternative genetic counseling SDMs

Telehealth in NC

- Currently being investigated by North Carolina Medical Genetics Association (NCMGA)
 - To be reported at upcoming SERGG (7/2019) and NCMGA meetings (11/2019)
- Several medical centers appear to be offering telehealth in some specialties
- Some genetic testing laboratories
 - Free telecounseling?
 - Might limit where samples are sent
- Private companies – contract basis
- In person counseling ideal if/when possible

Telehealth options



<https://www.gene-matters.com/>



<https://www.genescreen.com/>



<https://www.pwnhealth.com/>



<https://www.invitae.com/en/>



<http://www.metisgenetics.com/>



<https://www.labcorp.com/resource/genetic-counseling-services#>



<https://informeddna.com/>



<https://www.color.com>

...and many more!

References

- National Society of Genetic Counselors (NSGC): www.nsgc.org
- North Carolina Department of Health and Human Services /
NC Newborn Metabolic Screening Program:
<https://slph.ncpublichealth.com/Newborn/default.asp>
- Early Check: <https://earlycheck.org/>
- Genetic Counselor Professional Issues. Presentation by John Richardson on March 22, 2019. North Carolina Medical Genetics Association.
- Cohen et al. Analysis of Advantages, Limitations, and Barriers of Genetic Counseling Service Delivery Models. *J Genet Couns* (2016) 25:1010-1018.

Thank you!