TELEGENETICS AT UNIVERSITY OF FLORIDA: A HISTORICAL VIEW

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WHO WE ARE:

- Division of Genetics and Metabolism at University of Florida is one of three Centers receiving state grant funding to providing genetic services to State funded patients in Florida (along with University of South Florida and University of Miami).

[Map of Florida showing catchment areas and sites.]
WHAT WE DO:

- **Diagnosis** of patients with birth defects, intellectual disabilities, possible inborn errors of metabolism - clinical exam (dysmorphology) labs - cytogenetic, metabolic, molecular,

- **Treatment** of metabolic disorders many identified through the Newborn screening program

- **Genetic counseling** for future pregnancies, risks for other family members, support and anticipatory guidance
CURRENT TELE-GENETIC PROGRAMS:

Primary Care:

- Clinical:
  - Initial and follow up evaluations, nutritional counseling and treatment of metabolic conditions and genetic counseling - primary care office/CMS office or home – direct to patient (? Method of reimbursement)

- Newborn screening:
  - Initial contact with families identified through the metabolic newborn screening program to discuss the diagnostic workup and potential treatments - CMS clinic
CURRENT TELE-GENETIC PROGRAMS:

Research:

- **Cystic Fibrosis Foundation:**
  - 2 year funded research project from the CFF QI committee:
  - Providing genetic counseling to the Cystic Fibrosis Newborn screening programs in Florida, Connecticut, West Virginia & Utah
  - Current IRB protocol to evaluate learning and comfort with genetic counseling provided in this manner
CURRENT TELE-GENETIC PROGRAMS:

Secondary care:

- Specialty Clinics:
  - monthly neurogenetic clinics in Pensacola with Neurologist at the patient site. Allows for multidisciplinary assessment of complex patients with neurologic problems of a potential genetic causation.
  - consultation at the Florida School for the Deaf and Blind, Autism clinics, Craniofacial clinics, Retinal clinics, etc
CURRENT TELE-GENETIC PROGRAMS:

Tertiary care:

- Inpatient consultations in NICU & PICU sacred heart pensacola:
  - Diagnosis
  - Utilization of testing – cytogenetic metabolic molecular testing
  - Treatment for metabolic patients
  - Genetic counseling and family support

- Transfer of critically ill patients decreased
- Decreased expensive testing

- Fee for service payment
WHY WE BECAME INTERESTED:

Access – Patient CARE:
- Catchment area is large & underserved (only access to genetics services is in Tallahassee, Orlando & Jacksonville)
- More referrals than we can accommodate, especially in the Panhandle
- Need for more frequent monitoring of fragile patients
- Lack of Genetic subspecialty in some medical centers (Sacred Heart)

Patient Economics cost:
- Patients are low income and have difficult time traveling up to 6 hour ride (80% Medicaid)
- Cost of— transport - overnight stay-childcare- loss of work
- Decreased Compliance

Division Economics cost:
- Travel costs to outreach clinics – travel time (MD, counselor, nutritionist) car, hotel,
- Others-fatigue, several days away from home and office. – divisional business, family, risk – 5 hour drive after 4 days away in clinic
HISTORY IN TELEMEDICINE:

2003 - CMS (Childrens Medical service) office in Pensacola, FL

• 1) grant funding for Polycomm system & for local physician (pediatrician) time
• train MD on evaluation methods
• 2) perform clinical evaluations via telemedicine with local MD
• 3) perform follow up in person with specialist
• 4) results published – no change in diagnosis or plan after in person evaluation
  – telemedicine well received by pts.

Conclusions from experience:

  Good
  Able to perform dysmorphology exam successfully
  Pts happy

  BAD
  Frequent technical difficulties, lots of IT involvement
  Funding only through grant
HISTORY IN TELEMEDICINE:


- Evaluated patients via telemedicine then re-evaluated in person.
- No new diagnoses on re-evaluation
- No incorrect diagnoses
- High degree of patient satisfaction
- High degree of provider satisfaction
- Would refer family & friends
- Prefer telemedicine to travel or waiting longer
HISTORY IN TELEMEDICINE:

2004 – Sacred Heart Hospital in Pensacola, FL

• Evaluations of patients in NICU
• Presentations by neonatologists/pediatric residents
• Immediate evaluation of children, multidisciplinary discussion, education of residents/medical students

• Each patient seen this way saves transportation to UF Health, unnecessary invasive diagnostic evaluations, directs use of expensive genetic tests, counseling done in patients environment with their support nearby
• Fee for service contract negotiated

• Initially many IT issues – firewall connection problems

• Evaluated over 200 children to date
HISTORY IN TELEMEDICINE:

2008 – Transition to other CMS offices – can it be done with a nurse instead of MD?

- exams performed by nurse under direction of direction at distant site, Grant funding for Polycomm system & for nurse
- evaluation and counseling for newborn screen patients by nutritionist and geneticist
- dietary/treatment counseling by metabolic nutritionist for patients with inborn errors of metabolism

- Anectodally
  - Good –pts happy, Good system for inborn errors of metabolism
  - Negatives –exam more limited so not appropriate for detailed on site exam “hands on”

- Why not do at home?? direct
HISTORY IN TELEMEDICINE:

Expand to Multidiscipline Clinic 2015-2016:
- Piloted a multidisciplinary tele-specialty cms clinics throughout the State in conjunction with CMS
- Funding from CMS with services provided by UF Gainesville and Jacksonville, Nemours Jacksonville, UM Miami dermatology and private specialty practitioners
- Funding through CMS 2014 funded coordinator
- provide services NOT currently available to patients in some of the CMS sites
- Enhance present services
- On site guided physical exams by coordinator directed by specialists at the specialty site
- Allows multidisciplinary conferencing on medically complex patients
- Cost effective sharing of service

Patient Survey Post-Encounters
Overall Satisfaction Rating (1-5):

“Excellent” (1)

VERSUS

Physicians’ Survey After Same Encounter
Average Overall Satisfaction Rating (1-5):

“Slightly Below Average” (3.25)
CONCLUSIONS:

• Patients generally enthusiastic – clinics and care coordinators content
• Challenge remains convincing physicians.
• Primary predictor of participation is attitude towards telemedicine
• Disconnect between patient satisfaction and physician satisfaction
• Coordination of care difficult identifying appropriate patients- MDs had variable demands - availability
“I didn’t know what I didn’t know until after the session”

“Addition of genetic counseling to our newborn screening program has been transformational”

“Thanks for all you do for us”

“Telemedicine is much more convenient than having an additional appointment in another location”

“Thanks for your time and expertise”

“Face to face meetings are more personal and informative”
Collaborations on connection modalities: long journey

- Florida Department of Health - polycom initially isdn phone lines now internet - CMS clinics, sacred heart hospital, newborn screening meetings – statewide
- Southeast Regional Genetics Group – own private development LSU -dead
- Sprint - portable cell based technology – dead
- Skype – HIPPA compliance ?dead

Other modalities in use:

- Cisco Jabber/MOVI- neurogenetics, Pensacola
- Vidyo- newborn screening CF nationwide, home based.
CURRENT TELEMEDICINE METHODS:

At CMS offices and Hospital level:
Polycomm system with hand-held examination camera at the patient end to either a Polycomm unit or Polycomm real presence at the Physician end.

Bluetooth devices:
- stethoscopes
- Ultrasounds
- Ophthalmoscopes
CURRENT TELEMEDICINE METHODS:

At Specialists office: Cisco Telepresence connection Jabber/MOVI at both ends

Newborn screen or Home:
Vidyo *desktop* connection to an *iPad* at patient end

iPad at the distant site allows the least expensive, most flexible connection for intermittent/unplanned evaluations or for ultimately providing in-home follow up services
Doxy.me

Created by Brandon Welch, MS, PhD, Assistant Professor at Medical University of South Carolina
SERGG telemedicine collaboration

Simple, free & secure telemedicine solution
Initially developed for a prenatal care clinical trial
Now available for all clinical services to all providers.
Establishes encrypted peer to peer conduit for PHI transmission between patients and providers
POSSIBLE FUTURE TELEMEDICINE METHODS:

Using MOVI through EPIC with storage of encounter in medical records
<table>
<thead>
<tr>
<th>Question</th>
<th># Responses</th>
<th>Score</th>
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<tbody>
<tr>
<td>1. Satisfaction with performance of Genetic Counselor</td>
<td>22</td>
<td>4.95</td>
</tr>
<tr>
<td>2. Concern and caring attitude</td>
<td>22</td>
<td>5.00</td>
</tr>
<tr>
<td>3. Able to answer questions clearly</td>
<td>22</td>
<td>4.95</td>
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<tr>
<td>4. Enough time provided</td>
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<tr>
<td>5. All questions answered</td>
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<td>4.95</td>
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<td>6. Found GC session useful</td>
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<td>4.82</td>
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<td>7. Sufficient information to make informed decisions</td>
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<td>4.86</td>
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<td>8. Comfort with telemedicine format</td>
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<td>4.73</td>
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<tr>
<td>9. Likely to recommend GC to a friend/relative</td>
<td>20</td>
<td>4.73</td>
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<tr>
<td>10. Likely to recommend telegenetics to friend/relative</td>
<td>20</td>
<td>4.63</td>
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5 point Likert scale: Strongly disagree to Strongly agree/Very unlikely to Very likely
TELEMEDICINE RESOURCES IN FLORIDA:

Florida Telehealth Network:
- Network of all stakeholders in Telemedicine in Florida
- Part of a national federal program
- Advocate for State and Federal legislation

SERGG Telegenetics Workgroup:
- Providing a workshop on telegenetics at annual SERGG
- Working on presentation for ACMG meetings in Tampa, 2016.
CURRENT TELEMEDICINE BILLING:

Via Contract:
- Contracting for services directly with the hospital/provider/patient
- Ideal since it doesn’t rely on reimbursement

Insurance Billing:
- Medicaid/CMS accept billing on par with direct patient evaluation for rural use
- Some insurance companies also accept billing, but others do not - evolving
- Billing uses a telemedicine “prefix” on standard genetic evaluation codes

Experience with billing:
- Payments have been received for some direct insurance and Medicaid billing, but not for all.

Successful legislation for telemedicine billing in Florida would be helpful
TELEMEDICINE LEGISLATION – NATIONAL VIEW

• 23 states have legislation in place that require insurance reimbursement for telemedicine services at the same rate as in person visits.
CONCLUSIONS:

Good

- Tele-genetics works for genetics and has a niche
- It is well accepted by families and most providers who are motivated
- Provides opportunity for specialist to specialist collaboration-teaching

Not so good

- Motivation of providers is still a problem and will require routine use - the most challenging part of process

Promising

- Technology is much improved both in quality and ease of use
- Billing is becoming more feasible over time
- Interest is growing