Telegeneic: A Case Study in Effectiveness
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The Mountain States Collaborative

- One of seven regional collaboratives
- Federally funded by the US. Department of Health and Human Services, Health Resources and Services Administration, Genetic Services Branch
- Administered by Texas Health Institute
- MSGRC Mission: to ensure access to exemplary genetic services in the eight states in the region
The Mountain States

- Arizona
- Colorado
- Montana
- New Mexico
- Nevada
- Texas
- Utah
- Wyoming
A Look at the Mountain States

• 1,081,813 sq miles (almost 1/3 of U.S.)
• Population over 47M (15% of U.S. population, 20% by 2025)
• Annual births more than 718,000 (15% of U.S. births, projected to increase to 20% by 2025)
• Large proportion of rural and frontier counties (40% of all counties are rural or frontier)
Frontier Counties

Frontier Counties of the United States, 2010

Source: U.S. Census Bureau, 2010 Redistricting Data (Public Law 94-171) Summary File.
Note: Alaska and Hawaii not shown to scale.
Access in Rural Communities

Source: Dokpesi, et al
Telegenetics

• Telemedicine: “delivery of health care services via electronic means from a health care provider in one location to a patient in another” (Source: American Medical Association)

• Recognized as a tool for service delivery in underserved communities

• Geneticists work in urban areas, primarily, through large health systems and academic health science centers

• Access to genetic services limited in rural communities
Case Study Objectives

1. Describe the evolution of a telegenetics program

2. Describe progress and outcomes over time

3. Identify key elements of an effective telegenetics program
Case Study Methods

• Single site case study
• Key informant interview with physician leader (Dr. Mary Kukolich)
• Data elements identified
  – Total genetics visits by year and outreach location
    • Stratified by clinic visits in Ft. Worth, in person outreach visits, and telemedicine visits
  – Telemedicine visits/volume by year, specialty, and outreach location
  – Physician and patient satisfaction
  – Estimated cost savings (physician and patient travel)
• Data collection conducted by Administrative Director at Cook Children’s (Kim Epperson, MBA)
Cook Children’s Hospital in Fort Worth, TX

- Private, non-profit hospital
- >500 physicians on staff representing over 30 specialties
  - 8 MD geneticists (3 with biochemical training) + 1 genetic counselor + 1 metabolic nutritionist + several case managers
- No academic requirements for physicians
- No residency program
- Primarily a service mission
- Implemented a successful telegenetics program in 2004
Telegentic Implementation

- Start-up grant of $500,000 (2004, OAT)
- Additional funding in 2011 for equipment update
- 1st telemedicine clinic: 2005 in Abilene, Texas
  - Genetics was first specialty to provide telemedicine services
  - Hematology/oncology, endocrinology, and nephrology followed
- Encountered early technical challenges, resolved quickly and with equipment upgrades
Telegenetics Implementation

• Expansions into other communities where Cook already had outreach clinics
• Building on outreach program helped minimize costs (rent, staff)
• Currently using telemedicine:
  all geneticists, the genetic counselor, and the metabolic nutritionist
Patient Characteristics

- 90% are pediatrics patients
- 50% have Medicaid coverage
  - Remainder private or self pay
- Most visits are follow-up visits
- Patients seen in person at least once every 2-3 years
- Patients tend to see the same physician at each visit
Key Findings
• Telemedicine volume increasing since 2012
Key Findings

- Outreach visits as a percent of total visits are increasing
- Telemedicine visits as a percent of total outreach visits are increasing
Key Findings

• Families express satisfaction (data from 2004-2006)
Key Findings

- Families express satisfaction (data from 2004-2006)

Parent: If telemedicine were not available, what would the patient have done?

- Travel to FW 48%
- Waited in Abilene 49%
- Other 3%

Physician response: 100% - Patient would have waited until I held clinic in Abilene.
Key Findings

- Cost savings in travel and time
Key Findings

• ~$146,458 saved in patient travel and lost income costs (2012-2016)

• Average of $568 per family in cost savings for each telegenetics visit
  – Travel savings estimated using mileage and GSA mileage rate
  – Lost income estimated using travel time and median household incomes

• ~$58,483 in costs savings related to reduction in physician travel time and potential gained income (2012-2016)
  – Travel savings estimated using mileage and GSA mileage rate
  – Physician time saved estimated using travel time avoided
  – Potential gained income estimated using the number of patients that could have been seen during that time (for which reimbursement was available)
  – Note: no change in clinical workload for providers
Elements of Success

- Institutional support at the CEO and Board level
- The primary clinical and outreach mission of the institution
- Use of telemedicine institution wide, grafted onto an existing outreach program within a single state and facilitated by institutional credentialing
- Availability of good equipment and easy scheduling
- Trained nurse and receptionist in each local site
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