Epilepsy Care: A Provider Perspective

Quality and Access to Care in Urban Settings and Minority Populations

Christi Heck, M.D., M.M.M.

University of Southern California
A Provider Perspective

Academic Medical Center
USC Keck School of Medicine
Private

Los Angeles County + USC Medical Center
Public
Los Angeles County + USC Medical Center Demographics

Community
• Hispanic – 56.4%
• Black – 11.9%
• Asian and Pacific Island – 14.3%
• White - 16.3%
• Other - 2.1%

Hospital
• Hispanic – 67%
• Black – 14%
• Asian and Pacific Island – 7%
• White - 12%
THE PROBLEM:

• The prevalence of epilepsy is rising California
  – Lifetime prevalence of 1.3% in 2003 (Ca Health Interview Survey)
  – Lifetime prevalence of 1.5% in 2005 (Ca Health Interview Survey)
  – This represents a 15% increase over 2 years.

• For LA County alone, this represents 150,000 patients
  – 50% are unemployed and have not reached retirement
  – 20% (30,000) are uninsured (by self-assessment)
THE BIGGER PROBLEM

• ~ 2/3 are controlled by anti-convulsant medications
• ~ 1/3 have medically intractable/refractory epilepsy:
  • 10,000 uninsured patients live with refractory epilepsy in LA County alone
• Many not fully documented
LAC+USC Medical Center

• ER Visits 2009-2010 153,162
  – Diagnoses: 780,345 2,018 (1.3%)

• New Monthly Referrals Epilepsy Clinic 200

• Intractable Epilepsy Monthly Clinic Visits 140-200

• Adult epilepsy clinic at LAC+USC (Kalayjian, 2005)
  • Average 6.7 seizures per month
  • Average Number of AED’s: 2-3
  • Duration of epilepsy: 20.5 years
LOS ANGELES COUNTY + USC
EPILEPSY CASES
Sept ’07 – Jan ‘09

Number monitored | Neuropsych Assessments | WADA’s | Total Surgeries | VNS implants | Total Monthly Adult Epilepsy Clinic visits | Total Monthly Peds Epilepsy Clinic visits

(~1500 annually) | (~900 annually)
Burden of Intractable Epilepsy

• Physical/Medical
  – Injuries (fractures, burns, head trauma)
  – Higher mortality (SMR 4.69)\(^1\): SUDEP (1/500pts/yr)
  – Cognitive decline
  – Medication side effects

• Psychosocial
  – Depression, anxiety
  – Driving restrictions
  – Loss of employment

• Monetary – takes up disproportionate amount of cost
  – 42% of the $1.7 billion annual direct costs of epilepsy in U.S.
  – 86% of the $10.8 billion indirect costs in U.S.\(^2\)

When free of disabling seizures...

- **Physical/Medical**
  - Mortality rates equal that of general population\(^6\)
  - Medication regimens reduced\(^1\)

- **Psychosocial**
  - QOLIE-89 scores improve\(^2,3\)
  - Employment status improves\(^1\) : 100% vs 61% \(^4\)
  - Depression and anxiety scores improve\(^1\)

- **Monetary**
  - **Costs decrease:** $582 vs $2094\(^5\) (6 mo period, 18 mo after surgery)

---

Barriers to Care in All Patients

• **Education**
  - Patients and families (EF, Other members of 20/20)
  - Primary care medical providers
  - General neurologists- Must be well-trained prior to leaving residency

• **Insurance companies**
  - More resistance given for authorizations for meds or surgical work-up
    - Need to demonstrate cost-effectiveness of interventions
    - Need evidence based medicine to demonstrate AED differentials
Barriers to Care in Minority Populations

• Cultural and religious barriers
  – Perceptions of Epilepsy
  – Fear of being “found out”
  – Perceptions of Medications
  – Perceptions regarding surgery, anesthesia

• Costs or perceived costs to patients and families

• Inadequately reimbursed Psychosocial support systems
Statement of Task

1) Public Health Surveillance, Collection, and Data Integration:
   - Just how many people suffer from epilepsy in this country? Must have accurate assessments of the health burden across all populations. Can Meaningful Use and EMR help in this regard?
   - How/Are the minority populations accessing care? (Clinica de Familia/Herbalists)

2) Population and Public Health Research:
   - What are the perceptions of minority patients regarding
     • Epilepsy
     • Western medical interventions for epilepsy
     • Surgery/Anesthesia

3) Health Policy, Healthcare and Human Services
   - changes in public health and health services policies and practices
     • Provision of cognitive services
     • Provision of psychiatric services
     • Availability of AED’s as ordered or changes in FDA guidelines for bioequivalence of generics in epilepsy
Statement of Task

4) Patient, Provider, and Public Education:
   • What prevents acceptance of quality care?
   • How do we deliver education in culturally sensitive manner? Who does so? How do we support the psychosocial aspects of epilepsy care?
     – Cognitive assessments and therapy need adequate reimbursements
     – Social work support needs adequate reimbursements
     – Caregiving networks need to include primary care teams
   • How do we affect the primary care referral stream without bankrupting the primary care/general neurologist?