2024
CHILD NEUROLOGY SOCIETY
53rd ANNUAL MEETING
Nov. 11-14, 2024 • San Diego, CA

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Clinical Methods of Providing Complex Care

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Objectives

1) Recognize benefits/shortcomings of the multidisciplinary clinic
2) Name multiple characteristics of a healthy model of complex care
3) Appreciate the importance of clinical champions



Definition of Medical Complexity? [1]

- Children and youth with special health care needs (CYSHCN)
  - Health care services beyond typically required for healthy child
- Children with medical complexity (CMC)
  - Multiple chronic health problems in multiple organ systems
  - Functional limitations
  - High healthcare need or utilization
  - Often need or utilize medical technology
- CMC ~1% of population, but 1/3 overall health spending



[1] Kuo et al, Recognition and Management of Children with Medical Complexity, AAP Clinical Report-Reaffirmed 2021

Symptom Swatting in Chronic Care

- Healthcare: oriented and organized to respond/react to acute/urgent health problems [1]
- Much we do is in the realm of "symptom swatting" [1]
- "Dual task theory" – when confronted by multiple tasks, priority given to one with >emotional investment (risk of death) [1]
  - Epilepsy: BTC/GTC seizures -> SUDEP
- Leaves little time for other aspects of care
  - e.g. self-management (adherence), education, guideline implementation



[1] Wagner et al. Improving outcomes in chronic illness, *Managed Care Quarterly*, 1996

Causes of Suboptimal Chronic Care[1]

- Inadequate follow-up
- Failure of self-management
  - Epilepsy: ~60% nonadherent with anti-seizure medication [2]
- Poor quality (ineffective interventions)
  - ~10-20 minutes to implement guideline/quality measures
- Inadequate management of psychosocial distress



[1]Wagner et al. Improving outcomes in chronic illness, *Managed Care Quarterly*, 1996
[2]Modi et al. Patterns of nonadherence to antiepileptic drug therapy in children with newly diagnosed epilepsy, *JAMA*, 2011

How to Optimize Chronic Care

- Page from the RCT playbook: "wrapping" [1]
  - Consolidating:
    - Assuring follow-up, compliance, educated patients/families
    - Close monitoring of side effects and outcomes
    - Protocol-driven care
    - Delegation of nonphysician members
- Problems
  - RCT outcomes may not reproduce in real-world practice
  - $$$$

[1] Wagner et al. Improving outcomes in chronic illness, *Managed Care Quarterly*, 1996



Multidisciplinary Clinic

- Initially for rare genetic diseases (CF, hemophilia)
- Widely adopted for other diseases
- Periodic single day visits with multiple specialists
- Intent -> comprehensive, not replace primary care or medical home
- May have access to clinical trials



Grosse, et al. Models of comprehensive multidisciplinary care for individuals in the United States with genetic disorders. *Pediatrics,* 2009
https://www.als.org/navigating-als/resources/benefits-attending-multidisciplinary-clinic

Multidisciplinary Clinic

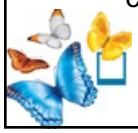
- Determined by: resources available & size (large vs. small)
- With small clinics (e.g., Rett Syndrome Clinic)
  - 35 total
  - 3 children/clinic
  - Registry monitoring, carefully planned visits
  - Preschedule times for each provider with each submitting bills
  - Guidelines followed
  - Outcomes monitored



Multidisciplinary Epilepsy Clinic (Large)

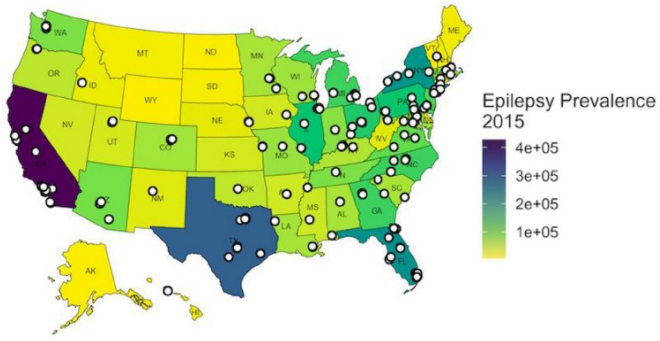
- ~8,000 Children with epilepsy
- Neuropsychology, Social Work, Genetic Counselor, Pharmacist, others
- Dozens of children per clinic
- Best intention access to specialists
- Clinicians may be more efficient, relying on specialists for some aspects of care/counseling
- Most visits not prescheduled, allowing for as need care, entire team collaborating and making music





Multidisciplinary Epilepsy Clinic (Large)

- Long travel times for many
- May not have prescheduled visits, many do not see a specialist other than the epilepsy provider
- Brief specialist visits that may not facilitate billing or be time-effective
- Concern about opportunity cost
- May be too large for registry management/team meetings
- Most outcomes not followed



Louis et al, Disparities in the nationwide distribution of epilepsy centers, *Epilepsy & Behavior*, 2021

Improving the Multidisciplinary Model?

1. Preschedule visits
   - -Provider identify need visit A, plan for visit B
2. Improved collaboration with NP/PA[1]
   - -NP – physician team saw 3 more patients per clinic session
3. Improved utilization of other non-physician team members
4. Identification of subpopulations (Infantile Spasms)
   - -Guideline/Algorithm/Pathway implementation
   - -Manageable registries and outcome monitoring
5. Identification of champions



[1] Hill et al, Improved availability and quality of care with epilepsy nurse practitioners, *Neurology Clinical Practice*, 2017

Clinical Champions

- Yes, a team is required
- What gets done without a Champion?
  - Is there an I in team?
- In business:
  - Workplace champion:
    - A dedicated employee who works to improve a specific area of their company.
- In medicine:
  - Clinical champion:
    - A dedicated person who works to improve a specific health problem.





Clinical Champions

- Required: Passionate, motivated
- Effective: Leader, team builder





Infantile Spasms ~~Clinic~~ ➡ Program

- 2012: Within the large multi-D epilepsy clinic
- Providers often unavailable
- For children with IESS, fixed weekday incompatible with needs
  - Not family-centered, did not address social determinants
  - Did not address urgency of care



Infantile Spasms Program

1. Determined needs (urgent nimble care)
2. Determined the resources available
   -Could not do LTM after each treatment, but could do 1 hr EEG w/ sleep
3. Secured leadership support
   -Same workload, modified clinic schedule for champion
4. Evaluated the evidence, develop an algorithm or pathway
   -Patient/family centered!
5. Built the team to implement
   -Large team, most important members: residents, nonclinical
6. Baseline data, monitored outcomes

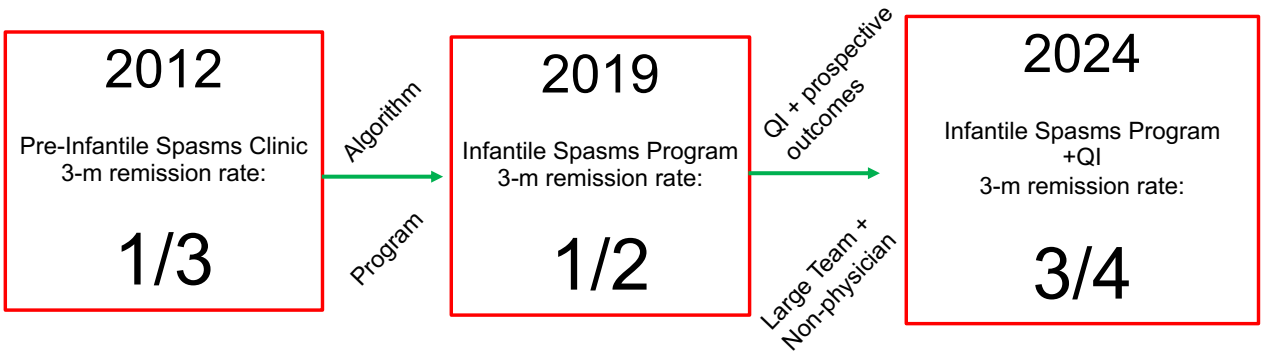
Infantile Spasms Program

- Residents
  - Front-line algorithm implementation, notification of larger team
- Non-physician personal
  - Documentation management and scheduling
  - Proactive prior authorization of specialty medication
  - Critical role in triage:

a. Do the events occur on awakening? Yes/No
b. Do the events cluster (repeating events)? Yes/No
c. Has your child lost developmental skills? Yes/No
d. Do you have a video? Yes/No



Infantile Spasms Program + QI



Fedak, et al. Optimizing care with a standardized management protocol for patient with infantile spasms. *J Child Neurology,* 2015

Mytinger, et al. Compliance with standard therapies and remission rates after implementation of infantile spasms management guideline, *Pediatric Neurology,* 2015

Mytinger, et al. Prioritizing hormone therapy over vigabatrin as the first treatment for infantile spasms – A quality improvement initiative, *Neurology,* 2022

Drivers of Poor Outcome

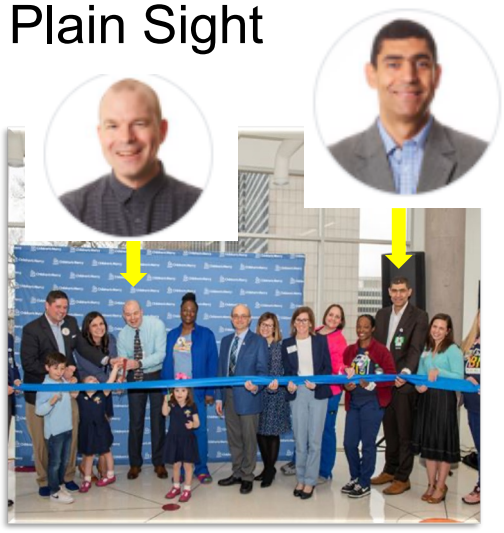
- Inadequate management psychosocial distress
- Failure of self-management
- Inadequate follow-up
- Poor quality/ineffective

Champion – Team Model Interventions

- Time/flexibility to see families
- Leadership support
- Registry
- Algorithm/pathway family-center, resource feasible
- Monitor outcomes

Champions are Hiding in Plain Sight

- Dr. Le Pichon created an innovative AS Clinic based on the Medical Home model
  - Accessible
  - Family-centered
  - Continuous
  - Comprehensive
  - Coordinated
  - Compassionate
  - Culturally effective



https://www.aap.org/en/practice-management/medical-home/medical-home-overview/what-is-medical-home/

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Conclusions

- Let's go beyond symptom swatting
- Don't settle for the system you have
- Improve what you can!
  - Do you have an algorithm/pathway for best practice?
  - "We have great outcomes" – what does the data show?
- Hey leaders: find the champions



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