



# Things my Brilliant Patient Colleagues (and a few Provider Ones) Taught Me about Gastrointestinal Motility Disorders

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# Objectives

- ▶ Overview of my journey in this work
- ▶ General issues regarding health related quality of life and disease burden for persons with GI motility disorders
- ▶ Basic lessons learned during work with persons experiencing GI motility disorders, 1990-2002, with particular learning from our monthly support groups, blending patient and provider reported outcomes
- ▶ Vision for better partnering between providers, patients and families

# My 30 Year Journey in this Work: 1988 Onward



Dr. Thomas L. Abell

# Early Learning

- ▶ Still much to be learned, except that the syndromes are marked by abnormalities that don't "fit into traditional diagnostic boxes." Gastroparesis Clinical Research Consortium (GpCRC) is helping.
- ▶ Abell: "Miserable, Misunderstood, Misdiagnosed, Mismanaged and Mistreated..."
- ▶ Behavioral health providers (if included on the care team) should come into the work at the beginning, not as an afterthought
- ▶ Pain management for visceral pain is very different than for muscular skeletal pain
- ▶ Best to conceptualize these illnesses in a holistic manner, as chronic conditions
- ▶ Self-management
  - ▶ Pacing Activities
  - ▶ Helping explain the illness experience to families, friends, others
  - ▶ Helping patient to deal with unpredictability of illness experience, particularly fear

# Early Learning

- ▶ Psychiatric overlay is still prominent in some clinicians' conceptualization and treatment of these disorders. WHY?
  - ▶ Cyclic and often unpredictable nature of illness
  - ▶ Others often don't "see" symptoms
  - ▶ Our ability to measure root structural causes was limited early on, still lacking; don't fit traditional diagnostic profiles
  - ▶ Trauma (whether emotional or surgical or post viral) can trigger/precede the first presentation of symptoms); Illness experience itself has heavy "disease burden"
  - ▶ Some patients (despite limited ability to eat by mouth) are not underweight
  - ▶ Providers often have limited baseline for understanding GI motility patients' pain and/or diminished quality of life
- ▶ Iatrogenic effects are often real and should be acknowledged WITHOUT creating an adversarial relationship
- ▶ Providers can experience a lack of self-efficacy in terms of impacting pain/discomfort/suffering
- ▶ Partnering between providers and patients and families is key

# Support Group Learning

- ▶ Monthly from April 1990 to 2000; quarterly in 2001-2002; 120 groups conducted; Over 1000 persons attended; scheduled for 90 minutes, rarely ended before 120 minutes; N ranged from 5-45 persons
- ▶ Early comparisons of persons attending groups vs. matched controls showed attendees requiring fewer pain medications, making fewer calls or requests of providers and using fewer outpatient healthcare resources, compared to non-attendees
- ▶ Pre Internet support groups, our monthly meetings were strong venue for sharing information and finding comfort with others with similar lived experience
- ▶ The group was a mandated “safe” space for complaining, but this had to be managed with some. Victimization stories were discouraged.
- ▶ Laughter about nausea, vomiting, bloating, pain, impact on quality of life was “good medicine” for our cohort

# Support Group Learning

- ▶ Unorthodox strategies for relieving pain or pressure were often reported by our patients, as well as dietary strategies that ran counter to traditional medical advice
- ▶ Integrating groups including persons with milder levels of motility disorders with those with more severe cases was sometimes difficult.
- ▶ The group (sadly) after some deaths, became a platform for allowing family and friends to grieve their losses. 25% of our earliest cohort had died over 20 years review; 11.3% gross mortality rate for those treated with Gastric Electrical Stimulation
- ▶ Building trust with a compassionate care team was critical, as was partnering in care plans, etc.

# Patient and Provider Care Team Partnerships

Most critical variable in helping patients achieve their optimal health outcomes and disease management

- ▶ These difficult diseases require all hands on deck, with patient and family input being most critical
- ▶ Institute for Healthcare Improvement's 100M Healthier Lives' mother, Crista Lind, her son, and daughter





# Patient and Provider Care Team Partnerships

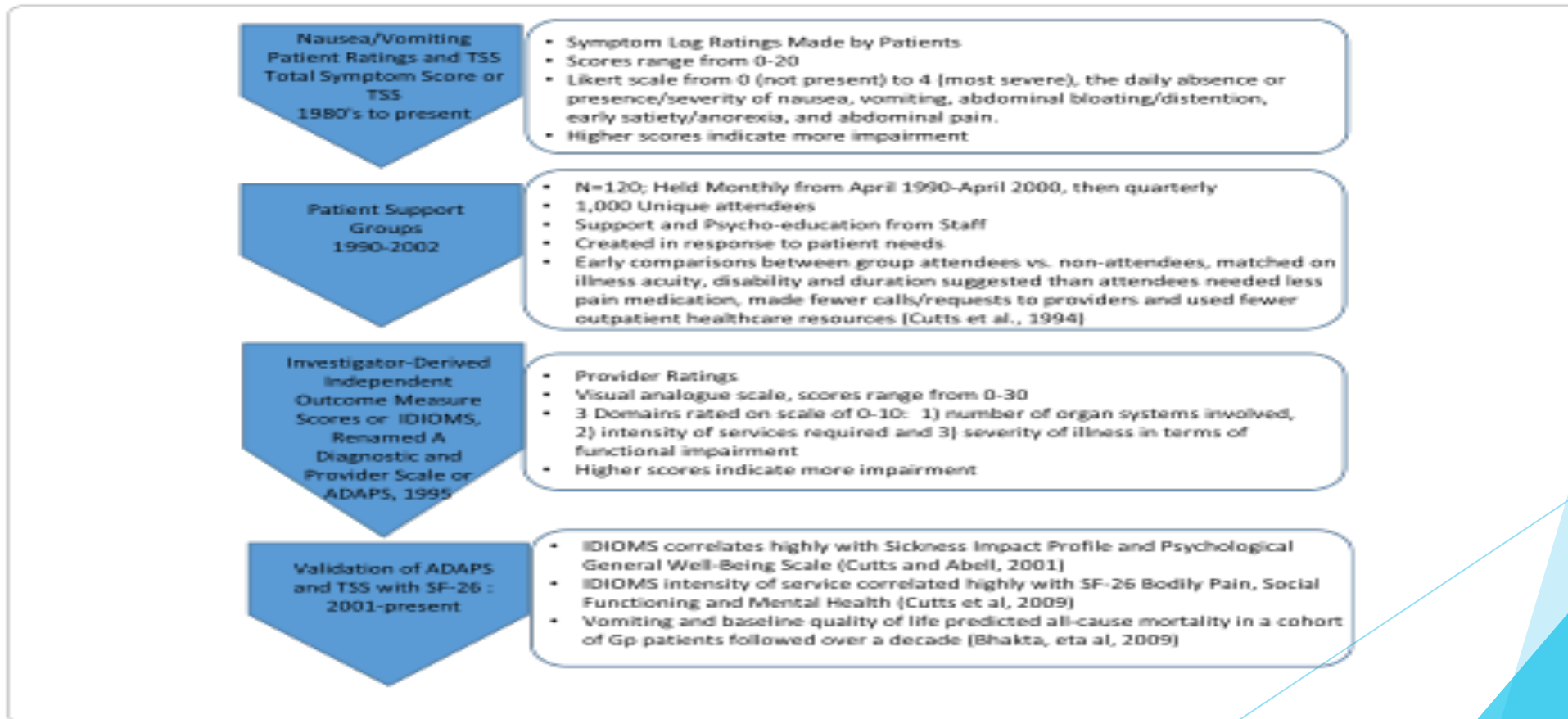
- ▶ Providers' listening to and incorporating patient and family input into treatment plans is vital
- ▶ Cross sharing, learning and teaching among patients, families and providers can move the field in terms of healthy advocacy, care delivery, treatment and more...
- ▶ Open communication and transparent sharing also instills hope for patients, offers comfort and expedites the process of trying new disease management or treatment modalities
- ▶ Robust partnerships can also alleviate provider burn out and/or compassion fatigue

# Pre Patient Reported Outcomes Work

- ▶ Working to incorporate patient reporting and data, symptom reporting and provider ratings into care plans for over 25 years
- ▶ Health Related Quality of Life (HRQL) refer to either disease specific or global measures of subjective well-being
- ▶ Patient Reported Outcomes: (PROs): “Any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.” Many now evaluated and catalogued in NIH’s Patient Reported Outcomes Measure Information System (PROMIS).
  - ▶ Not in widespread use in clinical practice
  - ▶ Lack data about how aggregating patient-level outcomes for measure the performance of the healthcare entity or provider delivering care

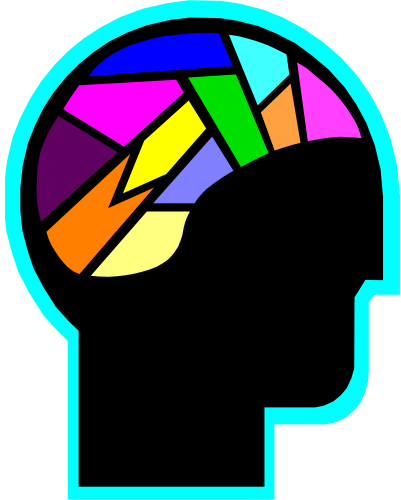
# Pre Patient Reported Outcomes Work

Used Patient Ratings and Support Group data to create our early version of the provider rated A Diagnostic And Prognostic Screening or ADAPS/Investigator Derived Independent Outcome Measures or IDIOMS (measuring other organ system involvement, healthcare utilization, intensity of symptoms), coupled with the patient-rated Total Symptom Score (TSS), to help drive care plan development and delivery.



# Pre Patient Reported Outcomes Work

- ▶ Convergent Validity between the IDIOMS and the Sickness Impact Profile, Psychological General Well-Being Scale and Short Form or SF-36.
- ▶ Higher anxiety and depression scores correlate highly with disease severity and longer symptom duration, not gastric retention (Hasler, et al., 2010)
- ▶ Study of 441 Gp patients indicated that the baseline IDIOMS score, as well as high vomiting scores on the TSS, were highly significant indicators of mortality; other indicators, such as inflammation
- ▶ Ultimate aim is to dispel the notion that psychiatric symptoms or emotional trauma cause gastroparesis



# Questions and Answers? Words of Wisdom?

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