Riding the Chronic Illness Rollercoaster

What Does it Mean in Your Life???

“Amid War on a Mystery Disease, Patients Clash With Scientists”

Wall Street Journal--March 12th 2011

AGENDA

- The Twin Rollercoasters
- Quality Of Life Factors
- CI and the Medical Paradigm Shift
- CI and the Four Phase Treatment Approach
- Nicole’s Story: The Phases from All Perspectives
- Research, CI and Q of L Factors Research
- Understanding the Twin Rollercoasters

QUALITY OF LIFE FACTORS

1. Cultural intolerance of suffering
2. Cultural intolerance of ambiguity
3. Cultural intolerance of chronic vs. acute syndromes
4. Pre-existing cultural climate toward chronic syndromes
5. Media
6. Initial syndrome illegitimacy and subsequent enculturation
Increased Prevalence of Chronic Illness Worldwide

- Advances in public health
- Advances in medical care
- Aging population

Paradigm Shift in Medicine

- 20th century: focus on acute illness;
- 21st century: focus on chronic illness
- Chronic vs. acute care
- Necessity of chronic care models
- Chronic comprehensive case management vs. clinical treatment

Chronic vs. Acute Illness

- Chronic illness can be difficult to define, measure and treat
- Medicine has not adapted to a CI model of care- Pts. often fare poorly in acute care
- Patient needs vary over the duration and phase of the illness
- Patients suffer from social stigma, economic losses, and lack of knowledge and understanding about their conditions
- Everyone becomes frustrated with the unpredictability and chronicity of symptoms

4 Groups of Chronically Ill

- Traditional chronic (CFS, FM, MS, asthma, lupus)
- Acute illness survivors with lingering symptoms (cancer, cardiovascular disease)
- “Persistent acute” (HIV/AIDS, stroke)
- Natural consequences of aging in an aging population

Chronic Illness and The Fennell Four Phase Treatment (FFPT™) Approach
Philosophy of the Phase Method
• A Systemic Approach
• False Dichotomies
• The Phenomenon of Chronicity
• Traumatization and Chronicity
• The Integration Assumption
• Palliation
• Clinician as Active Equal Participant

Trauma Types
• Disease/Syndrome Trauma
• Iatrogenic Trauma
• Cultural Trauma
• Vicarious Trauma
• Pre-Morbid / Co-Morbid Trauma

Traditional Disability vs. Chronic Conditions
• Chronic conditions on a continuum
• Static vs. dynamic disability/illness
  – Fixed disability
  – Relapse and remission
  – Waxing and waning
• Legal definitions of disability/chronic illness
• Social or colloquial definitions
  – Disability
  – Illness
  – Disease/condition/syndrome

The Four Phases of Chronic Change
Nicole’s Story: A Survivor of CFS/ME and Disability

“Everyone’s Story” The Phases From All Perspectives
• Nicole
• Family
• Friends
• Treatment/Management professionals
• Workplace, School, Community
• Pharma, The Academy, Government Org

“Everyone’s Story” (Part II)
• Gender
• Race/Ethnicity
• Family
  – Traditional/non-traditional
  – Partner/spouse
  – Parent/child
• Religion
• Community
  – Workplace
  – School
  – Neighborhood
  – BUSINESS
Phase I – Trauma / Crisis
• Physical/Behavioral
  – Coping Stage
  – Onset Stage
  – Acute / Emergency Stage
• Psychological
  – Loss of Psychological Control/ Ego Loss
  – Intrusive Shame, Self Hatred, Despair
  – Shock, Disorientation, Dissociation
  – Fear of Others, Isolation, Mood Swings
• Social/Interactive
  – Others Experience Shock, Disbelief, Revulsion
  – Vicarious Traumatization
  – Family/Organizational Maturation
  – Suspicion/Support Continuum

Phase II – Stabilization / Normalization Failure
• Physical / Behavioral
  • Plateau
  • Stabilization
• Psychological
  • Increased Caution / Secondary Wounding
  • Social Withdrawals, Social Searching
  • Service Confusion/Searching
  • Boundary Confusion
• Social/Interactive
  • Interactive Conflict/Cooperation
  • Vicarious Secondary Wounding
  • Vicarious Traumatic Manifestation
  • Normalization Failure

Phase III – Resolution
• Physical/Behavioral
  – Emergency Stage/Diminishment/Improvement
  – Continued Plateau/Stabilization
  – Relapse
• Psychological
  – Grief Reaction/Compassion Response
  – Identification of Pre-crisis – “Self”
  – Role/Identity Experimentation
  – Returning Locus of Control
  – Awareness of Societal Effects
  – Spiritual Development
• Social/Interactive
  – Breaking Silence/Engulfment in Stigma
  – Confrontation
  – Role Experimentation – Social, Vocational
  – Integration / Separation / Loss of Supporters

Phase IV – Integration
• Physical/Behavioral
  – Recovery Stage
  – Continued Plateau/Improvement/Relapse
• Psychological
  – Role/Identity Integration
  – New Personal Best
  – Continued Spiritual/Emotional Development
• Social/Interactive
  – New/Reintegrated Supporters
  – Alternative Vocation/Activities

Quality of Life Factors and CI
1. Cultural intolerance of suffering
2. Cultural intolerance of ambiguity
3. Cultural intolerance of chronic vs. acute syndromes
4. Pre-existing cultural climate toward chronic syndromes
5. Media
6. Initial syndrome illegitimacy and subsequent enculturation
“Amid War on a Mystery Disease, Patients Clash With Scientists”

Wall Street Journal--March 12th 2011

Impact of Research on Quality of Life Factors and CI

1. Cultural intolerance of suffering
2. Cultural intolerance of ambiguity
3. Cultural intolerance of chronic vs. acute syndromes
4. Pre-existing cultural climate toward chronic syndromes
5. Media
6. Initial syndrome illegitimacy and subsequent enculturation

Understanding the TWIN Rollercoasters

The Chronic Illness Rollercoaster
- Moving through the Phases
- Developmental changes (sex, kids, age)
- Media
- It Takes a Village...

The Research & Media Rollercoaster
- Conflicting research findings
- Dueling experts
- Media, press releases
- Your doctor

Participate in the Research

- Online participation
- Clinical experts
- Patients

Go to: www.AlbanyHealthManagement.com
Click on the “Conference Attendee” link at the top of the home page

The Chronic Illness Workbook

Using her extensive experience with chronic illness patients, Patricia Fennell has created an original, comprehensive, research-validated approach that brings clarity and order to what feels like an unmanageable and isolating experience.

For More Information:

For further information on the following please contact AHMA at——
communications@albanyhealthmanagement.com
www.albanyhealthmanagement.com

- certification in the FFPT™ approach
- the Fennell Phase Inventory™
- research projects
- books and related articles
- clinical services
- consulting
- education and training