Accommodating Students With Chronic Illness, Life Changing or Life Threatening Illness

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Agenda

- Chronic illness and education
- Importance of accommodating students
- The Fennell Four-Phase Model of chronic illness
- Aligning FFPM and classroom practice

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Culturally Competent Teachers

Core Values:

- Competence
- Care
- Leadership
- Difference
  - gender, ethnicity, culture, race, **health**
- Service

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Chronic Illness is Increasing

- Childhood rates of chronic health problems doubled in just 12 years, to 1 in 4 children in 2006, up from 1 in 8 in 1994.
- Rates of chronic illness are higher among boys and Hispanic and black children.
- Older children are more likely than younger children to have a chronic health conditions.

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Chronic Illness is Increasing

Chronic illness is rising among the student population due to factors such as:

- Better medical care
- Infant mortality declines
- Increased prevalence of conditions like diabetes, asthma, autoimmune diseases, depression, autism, obesity

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Chronic Illness & Education

- Students with chronic conditions (or who are caring for family members with chronic conditions) are at higher risk for school absenteeism and drop-out.
- Dropouts are more likely to suffer from illness or disability.
- Education is one of the strongest predictors of health: the more schooling people have the better their health is likely to be

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Chronic Illness

- Intermittent, waxing and waning symptoms
- “Invisible” illness – students don’t look sick
- Sudden emergencies
- Bed or housebound; general frailty
- Less time available due to illness symptoms and management of illness (doctor’s appointments, social service management, medications, etc.)

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Accommodating Students With Chronic Illness

- Legal mandates (IDEA, Section 504, ADA)
- Maintain student’s participation in learning
- Avoid disparities among the traditionally disabled, chronically disabled, and non-disabled - equal access
- Reduce dropping out and poverty
- Prepare students for workforce

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The Fennell Four Phase Treatment (FFPT™) Approach

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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

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Condition/Syndrome Trauma

- Chronic Condition/Event Trauma
- Iatrogenic Trauma
- Cultural Trauma
- Vicarious Trauma

- Pre-Morbid / Co-Morbid Trauma

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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

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Chronic Care in Context and Culture

- Delivery Systems
- Levels of Discourse
- Socio-Cultural Factors
- Domain Assumptions
- Traumagenic Effects

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Socio-Cultural 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

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The Four Phases of Chronic Change:

The Smith Family's Story

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The Four Phases

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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

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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

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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

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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

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Socio-Cultural Factors Chronic Syndromes and Traumagenic Effects

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Factor: Intolerance of Suffering

DYNAMICS

- Social/Clinical Controversy
- Pressure for Non- disclosure
- Negative Reinforcement for "Genuine Reporting"
- Attitude Conveyed of Characterlogical Inferiority
- Iatrogenic Health Care Experiences

EFFECTS

- Avoidance of Intimacy
- "Passing"
- Addiction
- Social Abandonment/Rejection
- Social Contract Violation

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Factor: Intolerance of Ambiguity

DYNAMICS

- Contagion/ Contamination Powerless Fear Transferred
- Unknown Etiology/Prognosis
- "Just" World or Deserved Punishment Notion
- Survivor as Burden

EFFECTS

- Generalized Guilt
- Grief
- Depression

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Factor: Intolerance of Chronic vs. Acute Syndromes

DYNAMICS

- Pressure for "Cure"/ Normalization
- Inadequate Treatment Models
- Competence Frustration Conveyed
- Punishment of Healthy Self Care
- Reward of Unhealthy Self Care

EFFECTS

- Normalization Failure
- Identify Confusion
- Increased Salience of Abuse Issues
- Avoidance of Intimacy
- "Passing"
- Social Withdrawal / Suicide

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Factor: Cultural Climate

DYNAMICS	EFFECTS
• Pre-sentiment of Suspicion Conveyed	• Social Shame
• Negative Personality Characteristics Assigned	• Diminished Self-worth
• Survivor perceived as Damaged/Social Example	• Cultural "Pariah"

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Factor: Media

DYNAMICS	EFFECTS
• Scapegoating	• Loss of Privacy
• Public Ridicule/Support	• Increased Fear/Anxiety
• Public Judgment	• Increased Isolation
• Public Assignment of Role and Worth	• Increased Grief
	• Decreased Sense of Worth

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Factor: Syndrome Enculturation

DYNAMICS	EFFECTS
• Inadequate Language/ Models/ Metaphors	• Increased/Decreased Powerlessness
• Impact of Discourse	• Increased/Decreased Sense of Efficacy
• Disease Maturity - Societal Acceptance	• Increased/Decreased Sense of General Safety, Trust and Stigmatization

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Aligning FFPT and Classroom Instruction

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Alignment of Practice with FFPT Through Differentiation/Accommodation

- By using FFPM to take into consideration the medical, social, familial and psychological situation the student is facing, educators can use differentiated instruction and accommodations to develop curriculum and assignments that are relevant to the student's life, interests and abilities.

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Alignment of Practice with FFPT Through Differentiation/Accommodation

- Combining these approaches offers students a greater opportunity to continue their education while coping with the relapsing/remitting nature of chronic illness.

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Classroom Practices Aligned to Phase 1

Classroom Strategies
- Provide assignment sheets
- Provide weekly overviews
- Allow for connections between concepts, identify similarities/differences

Phase 1:
- Contain the crisis; manage urgency
- Assessment – psych/med evaluation
- Analyze ADLs and restructure
- Relationship building
- Personal narratives

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Classroom Practices Aligned to Phase 2

Classroom Strategies
- Use a modified group memory strategy (S)
- Monitor study time (S)
- Offer steps in process (T)
- Provide color coded handouts (T)
- Vary use of color (T)
- Provide thinking maps (T)

S=Student; T=Teacher

Phase 2
- Stabilize symptoms – med/psych
- Review/modify all activity groups–value clarification
- Counseling – grief, coping
- Illness etiquette – family/ case management
- Use logs for symptoms and activities
- Classroom modification

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Classroom Practices Aligned to Phase 3

Classroom Strategies
- Generate/test own hypotheses (S)
- Review /monitor for consistency (T)
- Use time for written reflection & learning (S)
- Write study/test questions (S)
- Provide thinking maps (S)
- Use modified group memory (S)

Phase 3
- Personalize/find meaning
- Establish self-regulation and priorities

S=Student; T=Teacher

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Current Research Needs

- Increased understanding of how physical capacities interact with learning outcomes
- Valid, practical measurement system to capture capacities based on “state” not “trait” models
- Progress-monitoring paradigm for designing effective interventions
- Intervention design that adheres to current research regarding self-efficacy, self-determination, self-regulation, coping, and optimism (positivity)

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6 Functional Capacities

- Pain
- Fatigue—”tired but wired” “tired but awake”
- Sleep quality
- Mood / presentation
- Mental focus / cognition
- Movement / ambulation

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Physical Capacity Awareness Tool What Does it Do?

- Need for tool that teaches “Physical Awareness” *AND* collects data
- A progress monitoring assessment tool—**Daily and Dynamic**
- **Teaches Self Management → Creates Insight**
- Physical Awareness → Self Efficacious/Self Management → Well Being → Learning

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Participate in the Research

- Online participation
- Clinical experts
- Patients

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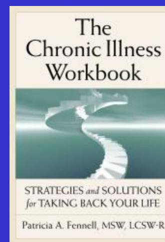

The Chronic Illness Workbook

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.

Available for $20.00 from Albany Health Management Publishing © 2007

For more information or to order, visit:
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For More Information:

For further information on the following please contact AHMA at---

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- certification in the FFPT™ approach
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