Six Functions That Impact the Education of Students with Chronic Illness

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PART A: OVERVIEW AND THEORY

- Chronic illness and education
- Importance of accommodating students
- Efficacy theory
- The Fennell Four-Phase model of CI
- Six Functions/Capacities that impact students with CI

Efficacy Theory and Four Phase/CI Theory—WHY?—Mutually Add Value

- Interface/Blend application with CI/disabled
- Blend has universal application

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.

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.
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.)

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

Health, Well-Being & Schooling

SERVING THE “WHOLE CHILD”

Relationships: Health and Learning

• Impact of health status on educational outcomes
  – Definitions of health (mental health, behavioral health, physical health)
  – Definitions of “educational outcomes” (achievement test scores, grades, retention, attendance, graduation rates, employment)

Ready to Learn, Empowered to Teach 2008

• Foundational policy document provides guiding principles for educational policies and practices.

Five Guiding Principles

• Comprehensive curricula matched with individualized instruction.
• Sufficient student support services to address barriers to learning for all students on a continuum of care that engages families and community providers.
• Comprehensive accountability and progress monitoring measures that provide a valid picture of student and school functioning.
Guiding Principles

- Professional development and supports for teachers and other educators necessary for instructional excellence.
- Federal leadership and school-based research to promote effective services that support the whole child in the learning context.

Some Specific Charges

- Education professionals promote development of children’s communication and social skills, problem solving, anger management, self-regulation, self-determination, and optimism.

Perceived Self-Efficacy

- Individual’s beliefs about his/her capabilities to produce designated levels of performance that exercise influence over events that affect their lives.

Self-Efficacy

- A strong sense of efficacy:
  - Enhances human accomplishment and personal well-being.
  - Promotes heightened and sustained efforts in the face of failure. Sense of efficacy after failures or setbacks is recovered quickly.

Relevant Research

- “Research has shown that children’s developmental competence is integral to their academic competence (Masten et al., 2005).
Positive Schools and Sense of Well-Being

- Huebner, Gilman, Reschley & Hall (2009)
  Positive schools = Majority of students experience positive emotions and a strong sense of overall well-being.
- SWB linked to:
  - Positive student engagement
  - Behavior
  - Interpersonal relationships
  - Coping skills
  - Academic achievement

Research

- Antaramian, Huebner, Hills, and Valois (in press):
- Research on Middle School Students
  - "Flourishing" = high SWB & low psychopathology
  - "At Risk" = low SWB & high psychopathology
  - “Vulnerable” youth display significantly lower behavioral, cognitive, and emotional engagement scores and GPA compared to “flourishing” youth.
  - “Vulnerable” = lower levels of perceived academic competence, psychosocial skills, and physical health.

Research

- Interesting outcome of study:
  Vulnerable students would not have been differentiated from flourishing students on traditional mental health screenings (focus on assessing symptoms of disorders).

Research

- Interesting outcome of study:
  Researchers conclude: Vulnerable students are “at risk” despite their apparent lack of symptomatic behavior.

Research

- Research suggests:
  - Need for developing a more comprehensive understanding of students’ functioning in schools when used in a multi-trait, multi-method framework.
  Fennell and Paul-Dona conclude: Far too little attention paid in research and practice to the role of physical health/illness in relation to student learning.
The Fennell Four Phase Treatment (FFPT™) Approach

- Systemic approach
- False dichotomies
- The phenomenon of chronicity
- Traumatization and chronicity
- The integration assumption
- Palliation
- Clinician as active equal participant

Philosophy of the Phase Method

Condition/Syndrome Trauma

- Chronic condition/event 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

Chronic Care in Context and Culture

- Delivery systems
- Levels of discourse
- Socio-cultural factors
- Domain assumptions
- Traumagenic effects

Socio-Cultural Factors

- Cultural intolerance of suffering
- Cultural intolerance of ambiguity
- Cultural intolerance of chronic vs. acute syndromes
- Pre-existing cultural climate toward chronic syndromes
- Media
- Initial syndrome illegitimacy and subsequent enculturation
The Four Phases of Chronic Change:

Nicole’s Story

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
6 Functional Capacities

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

PART B: PRACTICE TOOLS / INSTRUMENTATION

- Six Functions/Capacities that impact students with CI
- Universal screening instrument: Physical Capacity Awareness Tool (PCAT)

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Practice Tools/Instrumentation

- Universal Screening Instrument:
  - Physical Capacity Awareness Tool (PCAT)
- CI Disability Phase of Illness Inventory:
  - Fennell Phase Inventory (FPI)

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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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Duel Purpose of PCAT

Physical awareness for self-management, well-being and optimal learning
Contextualized data together with self report for assistance/support/ intervention
PMCT
Physical Capacity Awareness tool

- 6 Capacities – 10 items
- Daily collection
- Weekly summaries
- Aggregate summaries

Weekly Graphs

**Item #3:**
Do you feel like you want to go to sleep now?
*Week’s responses*

**Response Key**
- 5 = Must sleep NOW
- 4 = Hard to stay awake
- 3 = Hard to pay attention
- 2 = A little bit
- 1 = No

Cumulative Graphs

**Item #3:**
Do you feel like you want to go to sleep now?
*Cumulative responses*

**Response Key**
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PART C: DATA COLLECTION

- The 6 FCs, the Four Phases and the Classroom
- Participate in the Research

Aligning the 6FCs, Phase Theory and the Classroom

How do we do it?
Participate in the Research

• Online participation
• Clinical experts
• [www.AlbanyHealthManagement.com](http://www.AlbanyHealthManagement.com) — click on the special "Conference Attendees" survey link at the top of the home page

References


