Six Functions That Impact the Education of Students with Chronic Illness
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OVERVIEW AND THEORY

Overview
Chronic illness, Education and The Importance of Accommodation

Theory
Efficacy theory/Positivity/Mindfulness
Cultural Health Attitude/Physical Functioning Literacy
FFPM=6 Functions/Capacities that impact students with CI

Response to Intervention Model
Assessment: PCAT Interview/ PCAT/ CHAI/FPI
Intervention: FFPT/PCAT Effects

Acute Illness Vs. Chronic Illness

Acute Illness Model
• Well-------------Acute------------------Well

Chronic Illness Model
• Well---------------Chronic----Ph1----Ph2----Ph3----Ph4 (integration)
Current Research Needs Part 1

- Increased understanding of how specific socio-cultural influences shape attitudes toward illness/disability
- Practical flexible interview schedules to capture culture/nation specific beliefs, attitudes and concerns

Research Needs Part 1
Chronic Care in Context and Culture

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

Research Needs Part 1-Socio-Cultural Factors
National/Political/Legal/Religious/Ethnic Influences

- 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
Cultural Health Tolerance (CHT)/Physical Functioning Literacy (PFL)

- Health tolerance continuum
- Cultural barriers to health tolerance
- National/Legal
- Religiosity and ethnicity
- Language
- 6 Functional Capacities – Cross Cultural/Universal Experiences

Current Research Needs Part 2

- 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, optimism (positivity), and mindfulness.

Chronic Illness and Education

The Importance of Accommodating Students

- 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 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

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
Questions?

- On a scale of 1-5... How prevalent is CI in your school district?
- Elementary?
- Middle School?
- Secondary?
- How well does your school district address the needs of CI children?

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.

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.

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
  – Academic achievement
Research Suggests

Need for developing a more comprehensive understanding of students’ functioning in schools when used in a multi-trait, multi-method framework.

Fennell, Paul-Dona, and Fantauzzi conclude: Far too little attention paid in research and practice to the role of physical health/illness in relation to student learning.

Response to Intervention Model
Instrumentation/Assessment

PCAT Interview
PCAT
CHAI
FPI

6 Functional Capacities

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

ASSESSMENT/ INSTRUMENTATION
UNIVERSAL SCREENING INSTRUMENTS

- PCAT - Physical Capacity Awareness Tool Interview
- PCAT - Physical Capacity Awareness Tool
- CHAI - Cultural Health Attitude Interview
- FPI - Fennell Phase Inventory™
Physical Capacity Awareness Tool Interview
What does it do?
• Builds data base of culture/ nation specific attitudes, beliefs and norms regarding health/disability
• Reveals language/grammar usage as pertains to attitudes, beliefs and norms
• Acts as a awareness building tool
• Direct data source for CHAI and PCAT development

PCAT Capacity Awareness Tool Interview
• Teacher Interview-Script- 7 Items
• Guardian/Parent Interview-Script- 10 Items
• Interviewer Observation Notes-Additional Comments- 4 Items
• Collection/Administration prior to PCAT Administration

Sample PCAT Interview Items
T1. Do you notice this child has/is:
   ___ pain that is mentioned or demonstrated?
   ___ fatique that indicates tired, but awake?
   ___ sleepy?
   ___ mood presentation?
   ___ mental focus or cognition issues?
   ___ movement or ambulation issues?

T3. How is this child's school attendance?
   excellent ___ seldom absent ___ absent half the time___ seldom there ___

Dual Purpose of PCAT Interview
• Enhances understanding of the language and concepts contained within the PCAT.
• Adds supplemental information regarding the student's daily performance in and out of school as seen through the eyes of a teacher or parent/guardian
• Direct data source for Chai and PCAT development
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 → Mindfulness → Self Efficacious/Self Management → Positivity → Well Being → Learning

PCAT
Physical Capacity Awareness Tool
• 6 Capacities – 10 items
• Daily collection
• Weekly summaries
• Aggregate summaries

Sample PCAT Items
• Q.2 - Are you feeling pain right now? If so, how much? *
  None
  A little bit
  Uncomfortable
  Can’t concentrate
  Very high
• Q.3 - Do you feel tiredness, weakness (fatigue, tired but awake) right now? *
  No
  A little bit
  Hard to pay attention
  Hard to pay attention / want to sit
  Spaced out / want to lie down

Dual Purpose of PCAT
Physical awareness for self-management, well-being and optimal learning
Contextualized data together with self report for assistance/support/intervention
Weekly Graphs

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

Cumulative Graphs

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

Weekly Feedback Report

Cultural Health Attitude Interview
What does it do?

• Identifies cultural barriers/promoters to health tolerance including:
  - National/Legal concerns
  - Religiosity and ethnicity
• Develops understanding of regional health nomenclature/language
• Inform the 6 Functional Capacities – Cross Cultural/Universal Experiences
• Health Tolerance Continuum – National/Cultural placement
Cultural Health Attitude Interview

- Self Assessment instrument
- 22 Items
- Additional Comments
- Collection/Administration prior to PCAT Administration

Sample CHAI Interview Items

- A2. Do you talk about your own or other people’s health conditions in daily conversations? What types of conditions, and how often?
- A5. Are there certain stories, phrases, or words used to talk about illness, or sickness, or death? What are some of these terms?
- A21. How might you prepare for, and deal productively with, questions that make you feel uncomfortable?

Dual Purpose of CHAI Interview

- Develops insight into the cultural perspectives of others
- Enhances understanding of cultural orientation regarding cultural background influences on perspectives and feelings about topics dealing with life events, health, illness and disability.

Fennell Phase Inventory: What does it do?

- Measures CI/Disability within Phase of Illness
- Phase Placement
FPI

• Four Phases - 20 items
• Empirical/Clinical
• Phase Placement
• Longitudinal application

Dual Purpose of FPI

• Clinical Phase Placement
• Empirical Application
• Contextualized data together with self report for assistance/support/intervention

Response to Intervention Model Intervention

FFPT/PCAT Effects

Dual Purpose of Instruments
The Fennell Four Phase Treatment (FFPT™) Approach

Philosophy of the Phase Method

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

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
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

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Questions? Comments?

www.AlbanyHealthManagement.com
References


