Addressing Parental Responsibilities, Concerns, and Coping Strategies Using the Four Phase Model
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Agenda
• Philosophy of the Phase Method
• Chronic Care in Context and Culture
• The Four Phases of Traumatic and Imposed Change
• Socio-Cultural Influences and Traumagenic Dynamics
• Fennell Four-Phase Treatment™ Within Four-Phase Case Management

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

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

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

The Four Phases of Chronic Change:

The Smith Family’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

Socio-Cultural Factors
Chronic Syndromes
and Traumagenic Effects

Factor: Intolerance of Suffering
DYNAMICS
• Social/Clinical Controversy
• Pressure for Non-disclosure
• Negative Reinforcement for “Genuine Reporting”
• Attitude Conveyed of Characterological Inferiority
• Iatrogenic Health Care Experiences

EFFECTS
• Avoidance of Intimacy
• “Passing”
• Addiction
• Social Abandonment/Rejection
• Social Contract Violation

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
Helping Families of Children with ASDs Using FFPT™ Within Four Phase Case Management (FPCM)

Matching Intervention to Phase

Unique Characteristics of FFPT™

• Integrates the physical/medical, psychological, sociological, legal and financial aspects of chronic conditions
• Helps clinicians to develop better, targeted management strategies that move patients toward healing.
• Pursues this integration through the chronic phased experience.
The Four Phases: Treatment Goals

- Treatment Phase I: Reduction of Trauma Symptomatology
- Treatment Phase II: Stabilization and Restructuring
- Treatment Phase III: Meaning Development
- Treatment Phase IV: Integration

Treatment Summary

I  II  III  IV

Bond  Collect Data  Give Ingrate
Alim  Differentiate  Maintain
Tech  Inspect  Revise
Given  Nourish
Sight

Unique Characteristics of Four Phase Case Management

- Utilizes a focused priority approach
- Facilitates treatment/management within a chronic framework
- Incorporates all stakeholders/participants

FPCM Focus/Priority Criteria

- Disability
- Treatment/triage support (self-management)
- Psychological support/intervention
- Matching medical intervention to Phase

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 Information:

For further information on the following, please contact AHMA 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

Available for $20.00 from
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For more information or to order, visit:
www.albanyhealthmanagement.com or contact: communications@albanyhealthmanagement.com
Integrating the Fennell Four-Phase Framework to Improve Quality of Life

A Group for Parents

Sue Ann Hochberg, BSN, JD

Parent Research Project

- Pilot project proposed with group of parents of children with ASDs
- Goals:
  - teaching parents the FFPM
  - collecting data on efficacy
- Utilizes The Chronic Illness Workbook by P. Fennell

Module 1: Crisis Phase

- Goal: Contain the crisis; getting to a manageable, secure place where you'll be safe while you figure out what to do next
- Strategy: 3 components:
  - Physical you who is feeling pain or exhaustion and debilitation
  - "Inside" you who can be feeling fear, confusion, grief, anger, and frustration
  - Helping you relate more successfully to the people around you in your family, your community, and your workplace

Module 1: Exercise Examples

- Categories of activities
- New activity boundaries
- Trading off activities
- Revising your expectations
- Small steps for a bit of control
- Trying to "pass"
- Learning from the experience of collapse
- Making a new daily schedule
- Including all activity categories
- Getting an activity keeper
- Hanging on psychologically
- Changes in time: Your public self and your private self
- Emotional "passing"
- Illness involves others
- Family and friends suffer too
- Couples issues
- Friendships

Parent Research Project

- Pretest
- Module 1, Crisis Phase: 13 exercises
- Module 2, Stabilization Phase: 8 exercises
- Module 3, Resolution Phase: 7 exercises
- Module 4, Integration Phase
- Module 5, Q & A, Discussion Wrap-up
- Post-test
- 6 month/12 month follow-up
- Evaluation

Module 2: The Stabilization Phase

- **Goal:** to stabilize and begin restructuring your life

- **Strategy:** lead a very conscious, structured life
  - Learning your new physical boundaries
  - Regrouping Psychologically
  - Working with the reaction of others

Module 2: Exercise Examples

- Readjusting your physical activities
- Personal Energy Process (PEP)
- Impaired PEP cycle
- Basic constitution
- Four categories of activity: ADLs, personal-enrichment activities, socially interactive activities, and work activities
- Using your PEP cycle to determine how much you can do
- Differing capabilities
- Overcoming psychological defenses
- Assessing your hurts or traumas
- Maintaining insight
- Values clarification and norm development
- Failure to return to the original you
- Changed reactions
- Roles and responsibilities
- Vicarious trauma
- "Reducing keystrokes"

Module 3: Resolution Phase

- **Goal:** to develop meaning and to construct a new self

- **Strategy:** "finding meaning in the tunnel"
  - Assuming management of your physical care
  - Acting creatively to develop meaning
  - Taking control in your wider world

Module 3: Exercise Examples

- Static vs. dynamic disability
- Committing to time in the tunnel
- Maintaining insight and issue reframing
- Defining your pre-crisis self
- What is lost? Being a burden
- Your situation arouses fear and depression in others
- Others experience a dark night of the soul
- Working together with your social network
- Change of supporters
- You and political action
- Reintegration and old supporters
- Work issues
Module 4: Integration Phase

• **Goal:** integrate your suffering into a meaningful, sustaining, and rewarding life

• **Strategy**
  – Living wisely in the now
  – Growing creatively and spiritually
  – Expanding your social horizons

Module 4: Exercise Examples

• Maintaining medical reviews
• Maintaining activity reviews
• Maintaining your personal narrative
• Maintaining your new self and your new "personal best"
• Exercising free will

• Continuing creativity
• Continuing meaning development
• Evaluating and revising your family/partner/friend maintenance reviews
• Continuing social action
• Recruiting and maintaining "integrated" supporters
• Workplace or vocational changes

Parent Research Project

• Pretest
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• Post-test
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For Further Information

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Adolescence to Adulthood: Making the Transition
Fred Coulter, PhD

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Transition to Adulthood

- I’m working with families who have adolescents and young adults with ASD though the Hench Autism Studies Program at Defiance College.
- Adolescents with ASD are high functioning.
- Families have done a remarkable job at using Four Phase Case Management and reaching Phase 2 or 3

HOWEVER:

Obstacles to Transition

- Families are not being encouraged to fully implement transition to adulthood skills.
- Two reasons:
  - School districts are concerned with academics, especially with high functioning and higher intelligence adolescents with ASD.
  - Families have reached homeostasis in Phase 2 or Phase 3. They do not want to reinitiate Phase 1 – Crisis.

Developmental Transitions in ASD

- Developmental stage theory
- Developmental stages/transitions – legal, cultural
- ASD transitions and the Four Phases

Specific Developmental Transitions in ASD

<table>
<thead>
<tr>
<th>ASD transition 1: Behavioral/symptom presentation – diagnosis</th>
<th>Phase 1: Crisis Phase with symptom/behavior initiation and subsequent diagnosis</th>
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<tbody>
<tr>
<td>ASD transition 2: School/home/community adaption and accommodation</td>
<td>Phase 2: Stabilization with accommodation and adaption and/or Phase 3: Development of meaning</td>
</tr>
<tr>
<td>ASD transition 3: Adolescence/young adulthood</td>
<td>Phase 1: Crisis Phase reactivation</td>
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Legal Transitions

- Age 14 – required by Ohio Special Education law to make plans for transition in the IEP
- Age 16 – required by IDEA to implement transition plans
- Age 18 – student becomes an adult
- Age 22 – student ages out of special education services. At this time resources may be limited.
Parent Partnership Program

- The parent partnership program hosts speakers to assist parents with the transition to young adulthood. Topics include:
  - Medicare waivers
  - Social Security and SSI
  - Legal guardianship
  - Risk management
  - Social graduation

Resources

- Hench Autism Studies Program at Defiance College supports these families with an autism resource center at the college library.
- The room is filled with books, magazines, videos, and other resources to help parents understand more about autism and what they can do.
- At the Open House on June 18, parents and community members checked out over 30 books and other materials related to autism.

Parent Partnership Coordinator and FFPT™

- I am available as the Parent Partnership Coordinator to help with their questions.
- I utilize Family-Centered Practices to empower them to self-advocate. (Coulter, 2006)
- I utilize the FFPT™ model as a framework when working with families.
  - Families stabilized in Phases 2 and 3
  - Revisiting the Phase 1 Crisis Phase voluntarily or involuntarily

Community Collaborations

- Defiance College has collaborated with the Defiance City School District to administer an education unit on campus for up to 12 adolescents with ASD.
- The goal is to use the entire Defiance College campus as the classroom to help adolescents with ASD to transition to adulthood alongside typically developing college students.
- College students enroll in course to learn to be peer mentors to students with ASD

Defiance College and the Hench Autism Studies Program

Defiance College seeks to be an educational/social community wherein all students/adolescents, including those with ASD and those who are neurotypical, can successfully make the transition to adulthood.

Engaging the College Campus and Wider Defiance Community

- The author is coming to speak to the student body about his life with ASD on September 16.
- He is scheduled to speak to community members, as well.
For Further Information

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