

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*

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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

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

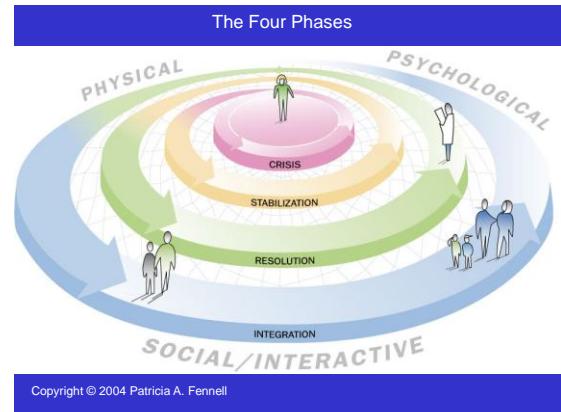
- Delivery Systems
- Levels of Discourse
- Socio-Cultural Factors
- Domain Assumptions
- Traumagenic Effects

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

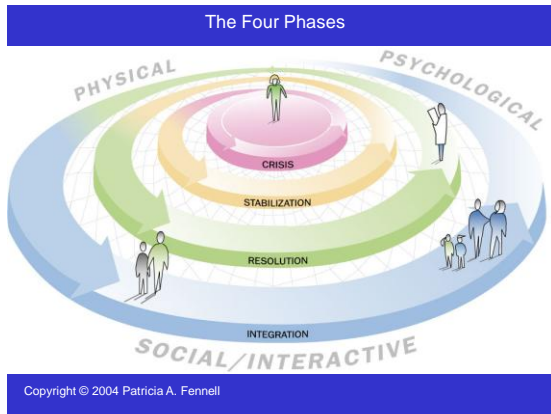
- **Physical / Behavioral**
 - Plateau
 - Stabilization
- **Psychological**
 - Increased Caution / Secondary Wounding
 - Social Withdrawals, Social Searching
 - Service Confusion/Searching
 - Boundary Confusion
- **Social/Interactive**
 - Interactive Conflict/Cooperation
 - Vicarious Secondary Wounding
 - 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

EFFECTS

- | | |
|---|--|
| <ul style="list-style-type: none"> • Social/Clinical Controversy • Pressure for Non- disclosure • Negative Reinforcement for “Genuine Reporting” • Attitude Conveyed of Characterological Inferiority • Iatrogenic Health Care Experiences | <ul style="list-style-type: none"> • Avoidance of Intimacy • “Passing” • Addiction • Social Abandonment/Rejection • Social Contract Violation |
|---|--|

Factor: Intolerance of Ambiguity

DYNAMICS

EFFECTS

- | | |
|---|--|
| <ul style="list-style-type: none"> • Contagion/ Contamination
Powerless Fear Transferred • Unknown Etiology/Prognosis • “Just” World or Deserved Punishment Notion • Survivor as Burden | <ul style="list-style-type: none"> • Generalized Guilt • Grief • Depression |
|---|--|

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

Factor: Cultural Climate

DYNAMICS

- Pre-sentiment of Suspicion Conveyed
- Negative Personality Characteristics Assigned
- Survivor perceived as Damaged/Social Example

EFFECTS

- Social Shame
- Diminished Self-worth
- Cultural “Pariah”

Factor: Media

DYNAMICS

- Scapegoating
- Public Ridicule/Support
- Public Judgment
- Public Assignment of Role and Worth

EFFECTS

- Loss of Privacy
- Increased Fear/Anxiety
- Increased Isolation
- Increased Grief
- Decreased Sense of Worth

Factor: Syndrome Enculturation

DYNAMICS

- Inadequate Language/ Models/ Metaphors
- Impact of Discourse
- Disease Maturity - Societal Acceptance

EFFECTS

- Increased/Decreased Powerlessness
- Increased/Decreased Sense of Efficacy
- Increased/Decreased Sense of General Safety, Trust and Stigmatization

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
Build	Collect Data	Grieve	Integrate
Assess	Differentiate	Maintain	
Teach	Insight Dev.	Refine	
Oversee	Nursing Goals		
Support	Plan		

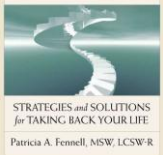
Unique Characteristics of Four Phase Case Management

- 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



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
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For more information or to order, visit:
www.albanyhealthmanagement.com
or contact:
communications@albanyhealthmanagement.com

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

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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 do
- Differing capabilities
- Overcoming psychological defenses
- Assessing your hurts or traumas
- Maintaining insight
- Values clarification and norm development
- Failure to return to the old you
- Changed reactions
- Roles and responsibilities
- Vicarious trauma
- "Reducing keystrokes"

From *The Chronic Illness Workbook: Strategies and Solutions for Taking Back Your Life*, Second Edition. Albany Health Management Publishing, Albany, NY: © 2006. No reprinting without express permission of the author.

Exercise 14
Your Activities by Activity Group

Activities of Daily Living (ADLs)	Personal Enrichment Activities	Social Activities	Work Activities

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Exercise 17 **My Personality Characteristics**

Describe what you were like before your illness.

Describe what you are like now.

What were your strengths in the past?

What are your strengths now?

What were your weaknesses in the past?

What are your weaknesses now?

What about your personality now most interferes with your changing your behavior?

What about your personality now most assists with your changing your behavior?

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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

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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 through 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 reinstate 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

ASD transition 1:
Behavioral/symptom presentation – diagnosis

Phase 1: Crisis Phase with symptom/behavior initiation and subsequent diagnosis

ASD transition 2:
School/home/community adaption and accommodation

Phase 2: Stabilization with accommodation and adaption and/or Phase 3: Development of meaning

ASD transition 3:
Adolescence/young adulthood

Phase 1: Crisis Phase reactivation

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 entire entering class is reading John Elder Robison's book, *Look Me in the Eye*, during Fall semester 2009.
- 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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