Agenda

- Chronic Illness Overview
- Improvisation Capacities and Application
- Fennell Four Phase Model of Chronic illness
- Phase III: Creating Meaning from Suffering
Patricia Fennell

Patricia is a researcher and clinician specializing in chronic illness, trauma, forensics and hospice care. Her organization, Albany Health Management Associates, treats and examines global health care concerns through clinical care, consulting, and professional education utilizing the Fennell Four Phase Treatment (FFPT™) approach.

She is frequently invited to lecture and consult with government, academic, business and patient organizations in areas including chronic illness, innovation and trauma. Her publications include Managing Chronic Illness: The Four Phase Treatment Approach and The Chronic Illness Workbook.

Paradigm Shift in Medicine

• 20th century: focus on acute illness; 21st century: focus on chronic illness
• Chronic vs. acute care
• Necessity of chronic care models
• Chronic comprehensive case management vs. clinical treatment

Increased Prevalence of Chronic Illness Worldwide

• Advances in public health
• Advances in medical care
• Aging population

Chronic vs. Acute Illness

• Chronic illness can be difficult to define, measure and treat
• Medicine has not adapted to a CI model of care -- patients often fare poorly in acute care
• Patient needs vary over the duration and phase of the illness
• Patients suffer from social stigma, economic losses, and lack of knowledge and understanding about their conditions
• Everyone becomes frustrated with the unpredictability and chronicity of symptoms
Living with Chronic Illness

- Intermittent, waxing and waning symptoms
- “Invisible” illness – people 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.)

Chronic Illness is Increasing

- Childhood rates of chronic health problems more than doubled in the U.S. in 12 years, from 12.8% in 1994 to 26.6% in 2006.
- Older children are more likely than younger children to have a chronic health conditions.
- Poverty and hunger are major risk factors for chronic illness in children and adolescents worldwide. Obesity, tobacco, and alcohol are other important risk factors.

Chronic Illness In Developing Countries

A UNICEF study in 1999 found:
- “The proportion of disabled children in developing countries is generally higher than in developed countries.”
- “With half the world's population under 15 years old, the number of adolescents and youth with disabilities can be expected to rise markedly over the next decade.”

4 Groups of Chronically Ill

- Acute illness survivors with managed symptoms (cancer, cardiovascular disease)
- Traditional chronic (MS, FM, CFS, asthma, lupus)
- “Persistent acute” (HIV/AIDS, stroke)
- Natural consequences of aging in an aging population
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

Trauma Types

• Disease/Syndrome Trauma
• Iatrogenic Trauma
• Cultural Trauma
• Vicarious Trauma

• Pre-Morbid / Co-Morbid Trauma

Chronic Illness is Increasing Among Students

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

Culturally Competent Teachers

Core Values:

• Difference
  -- gender, ethnicity, culture, race, HEALTH
• Care
• Leadership
• Service
• Competence
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

Accommodating Students With Chronic Illness

• 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

Improvisation Capacities and Application

Module
Innovation & Creation

- Improvisation $\rightarrow$ Creation $\rightarrow$ Innovation
- Change is:
  - Inevitable
  - Good
  - Bad
- Improvisation, creation & innovation help us respond to change.

Creation

- A powerful stance against helplessness.
- Requires active reflection and creative action.
- Must be authentic.

Authenticity

- In the process of creation, it's absolutely necessary to maintain insight about your limitations and your abilities.
- This is often painful.
- It's necessary to consistently strive for authenticity, and thus freedom, in the creative process.
- “The price of freedom is eternal vigilance.” — Thomas Jefferson

The 5 Capacities

- Allow people with acute and chronic illnesses to establish acceptance and meaning in their changed circumstances.
- Your discipline, personality or circumstances may mean other capacities are required.
- Discover and define them.
1. Tolerate Ambiguity

- Ambiguity is unavoidable.
- Learn how to survive the “not knowing.”
- Take the time to be uncomfortable to get to where you need to be.
- Learn how to do the “emotional heavy lifting.” This leads to wisdom.
- Wisdom: Appreciating the value of the unknown. The realization that something good can come of this.

2. Become Curious

- Change is an opportunity.
- Curiosity leads to innovation and change.
- Our culture squelches children’s curiosity, wonder and risk-taking.
- Culture’s toleration of curiosity is influenced by gender, race and social class.
- It has positive (childlike wonder), negative (nosy, “killed the cat”) and ambiguous (questioning authority) connotations.

3. Take Risks

- Take the risk of getting started (every day).
- Conscious v. unconscious (impulsive) risk taking.
- Calculated risk taking:
  – Informed by knowledge of limits and abilities.
  – Isn’t impulsive.
  – Minimizes shame, embarrassment, fear of failure.
  – Has an “exit strategy” if things don’t go as planned.

4. Take Action

- Improvisation requires that you make a choice.
  – Statement/choice → action → reaction → react to the reaction
- Choosing in the moment: do you pick up the paintbrush? What color will you use?
- Did you get the light bulb? Do you need to?
5. Innovate

• You've been curious, taken risks, made choices, taken action, innovated.
• The result – an idea, a paragraph, a picture, a tune – whether small or large, is a victory.
• Ask for outside help. Get training, instruction or assistance.
• Accommodate your limits and abilities.

Application

Using the 5 Capacities to Respond to Change

“You never want a serious crisis to go to waste. And what I mean by that is an opportunity to do things you think you could not do before.”

Respond To Your Crisis

• Define your crisis.
• How can the 5 capacities of improvisation be applied to the crisis/trauma of illness?
• Which of the capacities are your strengths?
• Which are your weaknesses?
Apply The 5 Capacities

• What is your creative medium?
  – Music
  – Visual art
  – Writing
  – Drama
  – Etc.
• What kind of help do you need?

Persistence & Fortitude

• Willingness to fail, developing self-reliance.
• Importance of community:
  – When you don’t feel you can persevere, you can
    borrow from strength of others.
  – Faith
• Allow yourself extra time or help to do the
  more difficult things.
• “Fall down 7 times, get up 8.”

Fennell Four-Phase Model of Chronic Illness

Module
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

Trauma Types

- Disease/Syndrome Trauma
- Iatrogenic Trauma
- Cultural Trauma
- Vicarious Trauma
- Pre-Morbid / Co-Morbid Trauma

Chronic Care in Context and Culture

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

Socio-Cultural/Quality of Life 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
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-Phase Model

- Phase 1 (Crisis)  Traumatic effects of a new illness
- Phase 2 (Stabilization)  Order from chaos, eventual stabilization of some symptoms
- Phase 3 (Resolution)  Patient works toward developing meaning and accepting the ambiguity and chronicity of chronic illness
- Phase 4 (Integration)  Patient integrates pre- and post-illness "self" concepts

The Four Phases of Chronic Change

A Family’s Story of Chronic Illness
Phase 1 – Trauma / Crisis

- Physical/Behavioral Domain
  - Coping stage
  - Onset stage
  - Acute / emergency stage

- Psychological Domain
  - Loss of psychological control / ego loss
  - Intrusive shame, self-hatred, despair
  - Shock, disorientation, dissociation
  - Fear of others, isolation, mood swings

- Social/Interactive Domain
  - Others experience shock, disbelief, revulsion
  - Vicarious traumatization
  - Family / organizational maturation
  - Suspicion / support continuum

Phase 2 – Stabilization / Normalization Failure

- Physical/Behavioral Domain
  - Plateau
  - Stabilization

- Psychological Domain
  - Increased caution/secondary wounding
  - Social withdrawals, social searching
  - Service confusion / searching
  - Boundary confusion

- Social/Interactive Domain
  - Interactive conflict / cooperation
  - Vicarious secondary wounding
  - Vicarious traumatic manifestation
  - Normalization failure

Phase 3 – Resolution

- Physical/Behavioral Domain
  - Emergency stage diminishment / improvement
  - Continued plateau / stabilization
  - Relapse

- Psychological Domain
  - Grief reaction / compassion response
  - Identification of pre-crisis – “self”
  - Role/identity experimentation
  - Returning locus of control
  - Awareness of societal effects
  - Spiritual development

- Social/Interactive Domain
  - Breaking silence / engulfment in stigma
  - Confrontation
  - Role experimentation – social, vocational
  - Integration / separation / loss of supporters

Phase 4 – Integration

- Physical/Behavioral Domain
  - Recovery stage
  - Continued plateau / improvement / relapse

- Psychological Domain
  - Role / identity integration
  - New personal best
  - Continued spiritual / emotional development

- Social/Interactive Domain
  - New / reintegrated supporters
  - Alternative vocation / activities
Creating Meaning from Suffering

Module

Creating Meaning from Suffering:
Working the Third Phase
The Four-Phase Model

Phase 1 (Crisis)  Traumatic effects of a new illness
Phase 2 (Stabilization)  Order from chaos, eventual stabilization of some symptoms
Phase 3 (Resolution)  Patient works toward developing meaning and accepting the ambiguity and chronicity of chronic illness
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Phase 3: Resolution Goal

• Goal: to develop meaning about suffering.
• Recognize deeply that your old life will not return.
• Begin to find meaning in your experience, establish an authentic new self and develop a supportive, meaningful philosophy.
• Artistic expression and community offer pathways toward establishing meaning in the chronic illness experience.

Transformation Steps

• By coming to terms with your own feelings, you can develop meaningful responses to your illness experience.
  – Allowance of suffering
  – Meet suffering with compassion
  – Meet suffering with respect
  – Integrate suffering

Phase 3 Transformation Step: Meeting The Suffering With Respect

• Regarded with appreciation
• Heroic captivity
• Antithetical interpretation
• Engaging the creative process
• Standing with self
Working the Third Phase Tasks: Time In The Tunnel

- Maintain insight and reframe issue
- Deep grief for lost self
- Existential dilemma
- Dark night of the soul
- Defining the pre-crisis self
- Analysis of actual losses - external
- Internal changes
- Faith
- Committing to time in the tunnel

Working the Third Phase Tasks: Phoenix From The Ashes

- Importance of countertransference
- Baseline authenticity
- Antithetical experimentation
- Creative process
- Supportive materials
- Clinician as storyteller
- The noble-disabled danger

Working the Third Phase Tasks: Meaning Development

- New vision of societal attitudes
- Exploring different traditions
- Meaning development
- Faith and humor

Persistence & Fortitude

- Willingness to fail, developing self-reliance.
- Importance of community:
  - When you don't feel you can persevere, you can borrow from strength of others.
  - Faith
- Allow yourself extra time or help to do the more difficult things.
- “Fall down 7 times, get up 8.”
Participate in the Research

- Online participation
- Clinical experts
- Patients

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- certification in the FFPT™ approach
- the Fennell Phase Inventory™
- research projects
- books and related articles
- clinical services
- consulting
- education and training

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.

New Edition Coming Soon!
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