ALBANY HEALTH MANAGEMENT ASSOCIATES, INC.
582 New Loudon Road, Latham, NY 12110
Patricia A. Fennell, MSW, LCSW - R, President
(518) 782-0551 Fax (518) 783-4793
E-Mail: uhmn2@worldnet.att.net
website: www.albanyhealthmanagement.com

Quality of Life Considerations and Behavioral Health in CFS:

Delivering Care in the New Chronic Illness Era

Paradigm Shift in Medicine

- 20th century: focus on acute illness
- Expectation was that treatment resolved illness OR patient died
- 21st century: increasing focus on chronic illness

Paradigm Shift in Medicine

- Increased prevalence of chronic illnesses
- Chronic vs. acute care
- Necessity of chronic care models
- Chronic comprehensive case management
- Comprehensive case management vs. clinical treatment

Chronic vs. Acute Illness

- Traditional chronic illness manifests differently than acute illness
- Chronic illness can be difficult to measure and treat
- Chronic illnesses tend to affect several different body systems at the same time
- Impact of chronic illness on the physical, emotional and social domains persists and affects reporting, compliance and coping

Chronic vs. Acute Illness

- Medicine has not adapted to the chronic model of care
- Patients with chronic conditions often fare poorly in the acute, episodic care-delivery environment
- Necessary interventions require multiple disciplines and tight coordination of care

Chronic vs. Acute Illness

- 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
- Health care providers, patients, family members and friends can become frustrated with the unpredictable symptoms and chronicity
- These factors may exacerbate the patient's condition

Why the Shift to Chronic Illness?

- Increased prevalence of chronic illnesses
- Advances in public health
- Advances in medical care
- Aging population

Chronic Illness is the Leading Cause of Death and Disability

- One third of U.S. doctor visits are for chronic conditions
- Two-thirds of all U.S. deaths are caused by a chronic condition
- 78% of total U.S. medical care expenditures are related to chronic conditions – over a trillion dollars a year
- 2005: 129 million people with chronic conditions
  2030: 171 million predicted (32% increase)

4 Groups of Chronically Ill

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

Sociological Factors in Chronic Illness

- Chronic illness and the global community
- Chronic illness differentiated by:
  - gender, ethnicity, religious/philosophical belief, SES, etc.
  - geographic region
  - political environment
  - economic environment

Chronic Illness Management and Managed Care

- Historically there has been little coordination across multiple settings, providers and treatments
- Managed care has not achieved initial promise of truly coordinated care
- Managed care doesn't address the complexity of chronic conditions, so it may result in more, rather than fewer, encounters with the health care system
- Management strategy influences behavioral health

Chronic Illness and The Fennell Four Phase Treatment (FFPT™) Approach

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

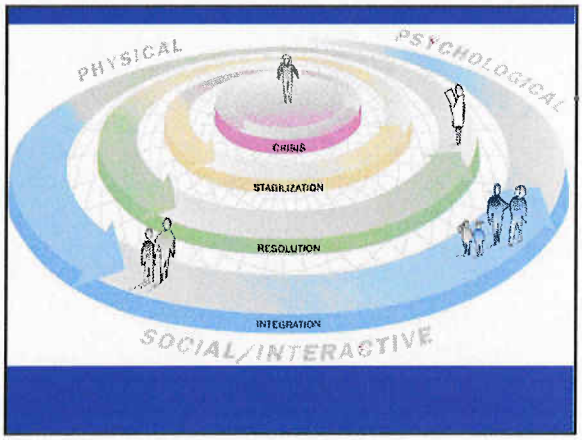
- The Health Care System
- Levels of Discourse
- Socio-Cultural Factors
- Domain Assumptions
- Traumagenic Effects

Quality of Life 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

Betty's Story: A Survivor of Chronic Illness and Disability



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

Quality of Life Factors: Chronic Syndromes and Traumagenic Effects

Quality of Life 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

Factor: Intolerance of Suffering

DYNAMICS	EFFECTS
• Social/Clinical Controversy	• Avoidance of Intimacy
• Pressure for Non- disclosure	• "Passing"
• Negative Reinforcement for "Genuine Reporting"	• Addiction
• Attitude Conveyed of Characterlogical Inferiority	• Social Abandonment/Rejection
• Iatrogenic Health Care Experiences	• Social Contract Violation

Factor: Intolerance of Ambiguity

DYNAMICS	EFFECTS
• Contagion/Contamination Powerlessness/Fear Transferred	• Generalized Guilt
• Unknown Etiology/Prognosis	• Grief
• "Just" World or Deserved Punishment Notion	• Depression
• Survivor as Burden	

Factor: Intolerance of Chronic vs. Acute Syndromes

DYNAMICS	EFFECTS
• Pressure for "Cure"/ Normalization	• Normalization Failure
• Inadequate Treatment Models	• Identify Confusion
• Competence Frustration Conveyed	• Increased Salience of Abuse Issues
• Punishment of Healthy Self Care	• Avoidance of Intimacy
• Reward of Unhealthy Self Care	• "Passing"
	• Social Withdrawal / Suicide

Factor: Cultural Climate

DYNAMICS	EFFECTS
• Pre-sentiment of Suspicion Conveyed	• Social Shame
• Negative Personality Characteristics Assigned	• Diminished Self-worth
• Survivor perceived as Damaged/Social Example	• Cultural "Pariah"

Factor: Media

DYNAMICS	EFFECTS
• Scapegoating	• Loss of Privacy
• Public Ridicule/Support	• Increased Fear/Anxiety
• Public Judgment	• Increased Isolation
• Public Assignment of Role and Worth	• Increased Grief
	• Decreased Sense of Worth

Factor: Syndrome Enculturation

DYNAMICS	EFFECTS
• Inadequate Language/ Models/ Metaphors	• Increased/Decreased Powerlessness
• Impact of Discourse	• Increased/Decreased Sense of Efficacy
• Disease Maturity - Societal Acceptance	• Increased/Decreased Sense of General Safety, Trust and Stigmatization

Treating Patients 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 illness
- 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	Grieve	Integrate
Affirm	Differentiate	Maintain	
Teach	Insight Dev.	Reframe	
Observe	Norms/Goals		
Safety 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

FPCM Focus: Disability

- Disability assessment
- Disability prep
- Record review
- Referral
  - Legal
  - Medical
  - Auxiliary/Social Services

FPCM Focus: Treatment/Triage Support

- Enhancing capacity to network
- Enhancing capacity to negotiate medical systems
- Facilitating family/community/workplace participation
- Facilitating patient/family self-management

FPCM Focus: Psychological Support/Intervention

- Chronic illness orientation/education
- Capacity for self-management
- Locus of control
- Societal awareness
- Health system sophistication

Four Phase Case Management and Phase 1 Treatment

- Clinical goal: Trauma and crisis management
- FPCM goal: Establish case management focus

FPCM and Phase 1

- Clinical goal: Trauma and crisis management -- BATOS
  - Bond
  - Affirm
  - Teach-Grief Response, Trauma Reaction, Phases
  - Observe
  - Safety Plan
- FPCM goal: Establish case management focus

FPCM and Phase 1

- Clinical goal: Trauma and crisis management
- FPCM goal: Establish case management focus
  - Restructuring Activities of Daily Living
  - Family Case Management
  - Health Care System Management
  - Workplace/Employer Intervention
  - Clinician Advocacy

Four Phase Case Management and Phase 2 Treatment

- Clinical Goal: Stabilization
- FPCM Goal: Data collection/activity restructuring

FPCM and Phase 2

- Clinical Goal: Stabilization--CDIN
  - Collect Data
  - Differentiate
  - Insight Development
  - Norms/Goals
- FPCM Goal: Data collection/activity restructuring

FPCM and Phase 2

- Clinical Goal: Stabilization
- FPCM Goal: Data collection/activity restructuring
  - Assess and Restructure Activity Levels
  - New Parameter and Norm Development
  - Family Case Management
  - Health Care System Management
  - Workplace/Employer Intervention
  - Clinician Advocacy

Four Phase Case Management and Phase 3 Treatment

- Clinical goals: Development of meaning and Construction of new self
- FPCM goal: Self-management skill development

FPCM and Phase 3

- Clinical goals: Development of meaning and Construction of new self—GMR
  - Grieve
  - Maintain
  - Reframe
- FPCM goal: Self-management skill development

FPCM and Phase 3

- Clinical goals: Development of meaning and Construction of new self
- FPCM goal: Self-management skill development:
  - Activity Monitoring
  - Medical Coordination
  - Health Care Advocacy
  - Self Advocacy

Four Phase Case Management and Phase 4 Treatment

- Clinical goal: Integration
- FPCM goal: Ongoing self-management

For More Information:

For further information on the following please contact AHMA at---

ahma2@worldnet.att.net

www.albanyhealthmanagement.com

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