Future Trends and Challenges in Chronic Illness Management: Coping with SLE

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Paradigm Change in Chronic Illness Management: Why?

- Increased longevity of population
- Effective biomedical treatment adds to prevalence of chronic disease
- More patients living longer with chronic health problems
- Increased concern about quality of life issues

Emergence of Interdisciplinary Inquiry

- **Behavioral Medicine:** *Multidisciplinary* field concerned with the *interplay* of biological, psychological, social, and cultural factors in the (1) prevention of disease, (2) enhancement of health, (3) treatment of disease, and (4) analysis of health care system and service delivery

- **Behavioral Medicine Specialists:** Professionals who intervene to help patients maximize their health, prevent disability, and cope with chronic disease. Most typically, they are clinical psychologists who are also skilled in research.

Changing Model of Care

- **Biomedical model**: Symptoms and functional problems are the product of underlying disease.

Assumptions:

Manage disease to control symptoms
Reliance on biomedical interventions alone
Health care team in charge of patient
Neglect of psychosocial factors

Biopsychosocial Model: Psychological, Social, and Cultural Factors, in Addition to Disease, Affect Symptoms and Health Functioning

Assumptions:

Manage psychosocial dimensions of illness
Consider adjunctive/complementary treatments
Patient as self-manager
Emphasis on education and management skills
Mind-body integration

Relationship Between Chronic Disease and Psychological Dysfunction (Depression, Poor Quality of Life)

- **Scenario: Chronic disease leads to psychological dysfunction.**

CD → *PD*

Goal: Lessen the psychosocial impact of disease

- **Scenario 2: Psychological dysfunction leads to chronic disease.**

PD → *CD*

Goal: Alter psychosocial functioning to affect disease

- **Scenario 3: Reciprocal relationship between CD and PD**

CD → *PD* → *CD*

Goal: Lessen impact of disease and psychological dysfunction

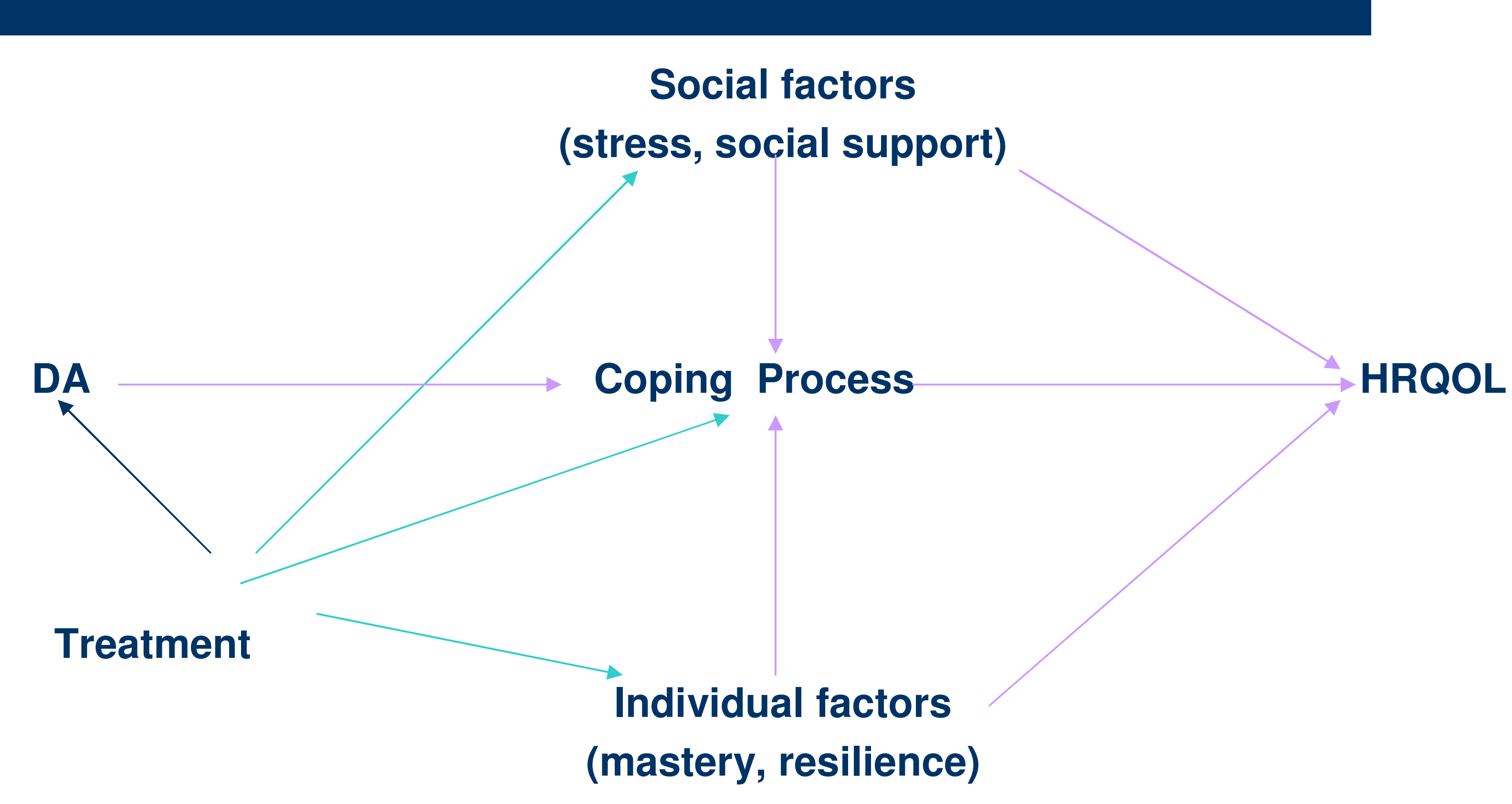
Changing Objectives of Treatment: Control disease *and* Enhance Health-Related Quality of Life (HRQOL)

- Disease Activity: (immune system dysregulation, inflammation, organ involvement, physical symptoms—pain, fatigue, etc.)
- HRQOL: How SLE affects your daily functioning
- Important to distinguish between the two clinically
- Patient reported outcomes (PRO's): Examine effects of treatment on aspects of functioning most important to the patient and that may be independent of the physician

What are the Elements of HRQOL?

- Physical activity, activities of daily living, mobility
- Social, occupational, emotional functioning (depression, anxiety, positive states of well being)
- Body Image disturbances: Thinking you are unattractive, worrying about physical appearance
- Marital functioning/intimacy
- Life satisfaction: Is your life meaningful to you?

Model Linking Lupus Disease Activity and HRQOL



Theory of Mind

Illness Representation: Your perspective on the significance, disease course, severity, and controllability of your disease, symptoms, and health concerns

Objective and Subjective Dimensions of the Illness Experience

Objective	Subjective
Diagnosis	Ebb and Flow of Symptoms
Underlying DA	Illness Beliefs
Objective Prognosis	Functional Impairments
Medical Treatments	Emotional Responses

Importance of Illness Cognition: Helplessness and Catastrophizing

- **Helplessness ("My condition is controlling my life") directly related to depression, pain, disability, passive coping in RA, SLE, FM (Nicassio et al., 1985; Nicassio et al., 1999; Tayer et al., 2001).**

- **Helplessness *mediates* the effects of health status on mood.**

  Pain → Helplessness → Depression

- **Catastrophizing ("My pain is killing me") leads to anxiety and worry (Keefe & Rosenstiel, 1983) and greater pain and disability in arthritis patients.**

Coping and Chronic Disease

- **Definition of coping**: Daily cognitive and behavioral efforts to manage the disease course, deal with difficult symptoms, prevent disability, and enhance HRQOL in SLE

- **Examples of Coping:** Passive (avoidance, denial), active (problem solving, seeking support), meaning-based (acceptance, finding benefits, spiritual mechanisms)

Coping Makes a Difference in SLE

- Positive reinterpretation and growth related to better HRQOL and avoidant coping related to poor functioning in Italian SLE patients (Rinaldi et al., 2006)
- Benefit finding related to less pain and psychological distress (Katz et al., 2001)
- Self-efficacy (“I am able to manage my illness”) correlated with less disease activity and disability (Karlson et al., 1997)
- Passive coping related to more mood disturbance and disability over time, while problem solving related to better adjustment (McCracken et al., 1995)

Changing Needs for SLE Management

In addition to effective biomedical management and efficient access to care and service delivery, SLE patients need skills to:

- Develop support
- Regulate pain, mood, and fatigue
- Manage stress
- Prevent disability
- Develop a resilient focus to their lives

Importance of Resilience: Dealing with Adversity and Moving Forward with Your Agenda

- ***Recovery*** **and** ***sustainability*** **are central components of resilience. Focus is on enhancing the self and personal growth as ways to maximize HRQOL and manage disease.**

Treatment Objectives

Recovery → Sustainability

Recovery	Sustainability
Increased awareness	Behavioral activation
Acceptance	Mood regulation
Challenge Beliefs	Finding meaning
Coping with loss	Social engagement
Prevention of disability	Values-based action

Resilience: Acceptance and Values-Based Action

- Acceptance: The willingness to experience difficult symptoms without judging them or the need to control them
- Values-Based Action: The aligning of actions with personally meaningful purposes rather than with the elimination of unwanted experiences
- Can be integrated into psychosocial treatment programs

Important Components for Skill Development and Resilience

- **Patient education:** Absolutely critical for long-term management. Broad overview of illness, treatments, and general management issues (doctor-patient relationship, health care system)
- **Cognitive behavior therapy (CBT):** Has established empirical efficacy for chronic illness. Development of self-efficacy, pain management, stress management, mood regulation, problem-solving, personal growth (Greco et al., 2004; Karlson et al., 2004)
- **Exercise:** Physical endurance, cardiovascular health, mood regulation
- **Development and maintenance of effective social support network and mechanisms:** Important for self-esteem, stress resistance, enhancement of coping

Formula for Effective Self-Management in SLE

Education

+

Resilience

+

Skills of Management

+

Effective Medical Care and Support

Importance of Interdisciplinary Collaboration in Health Care for SLE Patients: Present and Future Paradigm

- No discipline has all the answers for chronic illness management
- Synergy from diverse experts creates synthesis of scientific knowledge and optimal treatment alternatives based on patient needs

Behavioral Research in SLE: Cedars Sinai and UCLA

- Develop and evaluate intervention program for SLE patients
- Measurement of HRQOL
- Factors affecting HRQOL

Participants will be needed soon.