

Ethical and Professional Issues for Rehabilitation Counselors Related to Self- Management and Adherence to Treatment

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Purpose

- This presentation explores the ethical and rehabilitation counseling implications of self-management and treatment adherence.
- Rehabilitation counselors are increasingly working with clients with chronic conditions involving complex treatment. These treatments frequently interact with the rehabilitation counseling process.

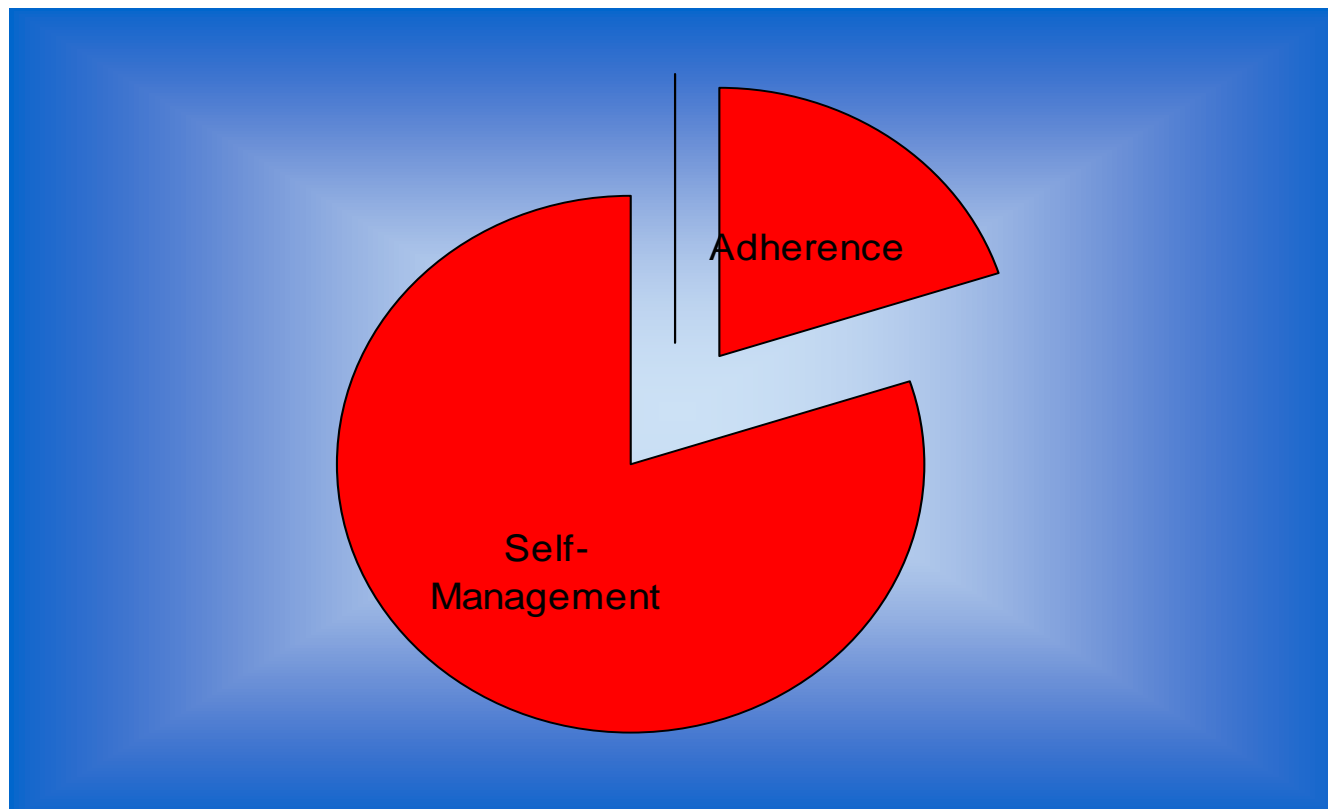
Purpose (cont.)

- Effective rehabilitation counseling incorporates consideration of these elements, which affect every aspect of the individual's life, but which are often neglected in rehabilitation counseling.
- We will define and discuss the ethical and professional considerations in the complex role of the rehabilitation counselor in assisting clients to make informed personal decisions about their illness management and adherence in the context of rehabilitation counseling.

Learning Objectives

- Understand the concept of adherence to therapy; the benefits of adherence, and the significant and complex barriers to adherence faced by people with disabilities/chronic illnesses.
- Understand the concept of self-management as a multidimensional framework for maintaining optimal personal health.
- Explore the complex ethical and professional role of the rehabilitation counselor in assisting clients to make informed personal decisions about self-management and adherence.
- Learn an assessment and counseling approach for counseling clients about self-management and adherence.

Self-Management & Adherence



Beginning with a Question

- Do Rehabilitation Counselors have a role in promoting self-management and adherence?
- (And if so, Why? and How?)
 - We can approach this question by considering the definitions and meanings of these concepts

Defining Self-Management

- Coined by Thomas Creer in the 1960's in work on rehabilitation with children with chronic illnesses, indicating that the patient was an active participant in treatment
- We are all individually responsible for our own health, and if living with a chronic illness, for the management of that illness.
- **“One cannot not manage”**- the question is how one manages (Lorig & Holman, 2003).

Defining Self-Management

Self-management has been broadly defined as learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition (Lorig, 1993).

Self-Management

- Self-care, management of one's condition, including medication and treatment management, communicating with physicians, and caring for oneself through exercise and diet;
- Maintaining, changing, and creating new meaningful behaviors and roles, engaging in life activities, including work and leisure activities, and maintaining social relationships; and
- Coping emotionally with the feelings associated with living with illness, and realizing and developing a new sense of future (Corbin and Strauss, 1988)

Self-Management

- “Chronic illness does not present a uniform set of problems inviting a uniform response.” (Newbold, Taylor, & Bury, 2006)
- Although many concerns are common across conditions, there are always individually unique concerns and differences between groups
- Self-Management is uniquely and specifically applied and person-focused
- Different from Patient Education (imparting illness-specific information and technical skills),
- Self-management is a comprehensive, multidimensional framework of self-care and skill building, incorporating elements of illness treatment management, relationships with health care and providers, and coping or QOL.

Adherence Defined

- Adherence to treatment is has typically been defined in terms of the degree to which patients or health care recipients follow, or adhere to, treatment recommendations.
- “The extent to which patients follow the instructions they are given for prescribed treatment” (Haynes, 2002)
- “The degree to which patient behavior coincides with the clinical recommendations of health care providers” (Otsuki et al., 2009)

Adherence

“The extent to which a person's behavior - taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (World Health Organization's working group on adherence to long-term therapies, 2003).

Adherence

- Adherence implies a collaborative decision between the patient and the healthcare provider;
- a relationship where the patient and healthcare provide come to a consensus on the most appropriate treatment options for the patient.

Adherence

- “Compliance” suggests a passive approach where the patient follows the advice and directions of the healthcare provider. Compliance implies a paternalistic viewpoint where the patient unquestionably follows the advice of the physician or other healthcare provider.
- The Royal Pharmaceutical Society has now changed its terminology from compliance to *concordance*, which means agreement and harmony. The essence of the concordance model is the patient as a decision maker.

Adherence

A preferable adherence definition may be:

“Informed participation in a recommended health-related behavior at a level that is sufficient to produce the mutually established and understood intended or optimal benefit.”

Additional Definitional Points

- Although frequently conceived as a dichotomous variable, adherence is not generally, or inherently dichotomous.
- “There is no gold standard for what defines ‘satisfactory’ [or effective] or ‘poor’ [or ineffective] adherence across all health behaviors.” (Otsuki et al., 2009).

Adherence

May be considered in terms of

- Rejection or discontinuation of therapy or treatment or recommended behavior
- Adjusting dosage or degree of therapy or treatment or recommended behavior
- Variability in management (missed or extra doses, on and off participation)

The Scope of Non-adherence

- In a meta-analysis of 569 studies of adherence to medical treatment recommendations between 1948 and 1998, DiMatteo (2004) found 24.8% average non-adherence across treatments, with a range of 4.6–100% non-adherence.
- Non-adherence rates differ among conditions, types of intervention/treatment, and methods of defining and measuring adherence.

Adherence Barriers

Most rehabilitation counseling clients will be using at least one medication. Many people who use medications are not fully informed about:

- The reasons that they are taking the medication (diagnosis, positive effects);
- The side effects of the medication;
- Potential interaction effects of medications and medications with other foods/drink;
- The importance of dosing and schedule
- This may be particularly true for Minors, Persons with learning disabilities, cognitive disabilities, Elderly

Adherence Barriers

- Economic Factors (Financial, transportation, child care, time off work)
- Cultural Factors (Language, communication, culture and health care)
- Somatic Factors (presence of symptoms)
- Regimen Factors (complexity, frequency, duration)

Adherence & Self-Management

The Questions of Paternalism and Ethical Practice

The goal of Adherence counseling...

- Informed Decision Making

The Role of the Rehabilitation Counselor:

- Promote informed decision making
- Promote personal health through promoting access, effective communication, skill building
- Promote successful rehabilitation outcomes

Applying the Ethical Principles in the Self-Management/Adherence Context

Beneficence

- A moral obligation to promote good and prevent or remove harm and to promote the welfare, health, and safety of society and individuals in accordance with their values, preferences, life goals, and beliefs (Falvo, 2004)
- When is promoting adherence unethical?

Applying the Ethical Principles in the Self-Management/Adherence Context

- Nonmaleficence
 - First, do no harm
- Involves weighing the probability of harm to the consumer
- What is the relationship between nonmaleficence and informed consent?

Applying the Ethical Principles in the Self-Management/Adherence Context

Justice

Justice refers to fairness, equal access, and equal treatment. Professionals do not discriminate on the basis of disability, ethnic or minority status, or gender of the consumer

Applying the Ethical Principles in the Self-Management/Adherence Context

Fidelity

The principle of fidelity refers to being honest, loyal, and keeping promises (including confidentiality and informed consent)

Applying the Ethical Principles in the Self-Management/Adherence Context

Autonomy

Autonomy refers to the idea and belief that individuals have the right to make their own decisions about their own course of action, or, in other words, the right to self-determination

Veracity

- Truth, Honesty, Respect

Applying the Ethical Principles in the Self-Management/Adherence Context

Informed Consent

- Competence
- Comprehension
- Deliberation
 - (Dreeben, 2010)

Providing the client sufficient information to make an informed and considered choice

Applying the Ethical Principles in the Self-Management/Adherence Context

The rationale: “Individuals have the right to know what they are getting into when they come for counseling”
(Blackwell & Patterson, 2003)

1. Informed consent supports client Freedom, Choice, and Autonomy
2. Informed Consent establishes clear Guidelines/Expectations
3. Informed Consent is a method of Preventing and Preparing for future problems

Are Self-Management and Adherence RC Issues?

(How/When/Why) are self-management and adherence rehabilitation counseling issues?

- Should self-management have a role in our increasingly crowded curriculum, increasingly complex professional practice?
- Does it relate to our mission?
- Our training?
- Our Counseling and Professional Goals?

Scope of Practice Perspective

- Rehabilitation counseling is a systematic process which assists persons with physical, mental, developmental, cognitive, and emotional disabilities to achieve their personal, career, and independent living goals in the most integrated setting possible through the application of the *counseling process*.
- The counseling process involves communication, goal setting, and beneficial growth or change through self-advocacy, psychological, vocational, social, and behavioral interventions.

An Advocacy Perspective: Chronic Illness in America

- In 2005, 133 million Americans (almost 1 in 2) had one or more chronic conditions (defined as health conditions that last a year or more and require ongoing medical attention *and/or* limit activities of daily living).
- This number is projected to increase by more than 1% each year through 2030.
- Between 2000 and 2030, the number of Americans with chronic conditions will increase by 37%, an increase of 46 million people.
 - Source: Wu, S, & Green, A. *Projection of Chronic Illness Prevalence and Cost Inflation*. RAND Corporation, October 2000

Chronic Illness and Age

- The prevalence of multiple chronic conditions increases with age.
- Among people age 80 and older 92% have at least one chronic condition and 73% have two or more.
- By 2030, 20% of the population will be people age 65 and older with chronic conditions.
 - Source: U.S. Bureau of the Census. *Projections of the Total Resident Population by 5-Year Age Groups and Sex with Special Age*

Chronic Illness and Age

Leading chronic conditions vary among age groups.

- Leading chronic conditions: 65 and older:
 - Hypertension (51%)
 - Arthritis (37%)
 - Heart disease (29%)
 - Eye disorders (25%).
- Leading chronic conditions: 18 to 64:
 - Hypertension (23%)
 - Respiratory diseases (20%)
 - Arthritis (18%)
 - Chronic mental conditions (16%)
 - Johns Hopkins University, Partnership for Solutions

Is Self-Management a RC Issue?

If you are a person with a disability in America, you are at risk:

- Source: Steimetz, 2006; NOD/Harris Poll 2004; ACS 2007

At Risk

1. You are at risk for lower levels of employment

- Less than half as likely to be employed-
- Unemployment rate 18% and
- Only 37 percent of people with disabilities reported being employed full or part time, compared to 78 percent of those who do not have disabilities.

At Risk

2. You are at risk for living in poverty

- Three times more likely to live in poverty (with annual household incomes below \$15,000) 3/10 vs 1/10

3. You are at risk for further chronic illness and disability

- You are less likely to have health insurance
- Less health insurance coverage and use of the health-care system for preventative and diagnostic care
- Lower rates of recommended health behaviors, e.g. smoking cessation, cardiovascular, strengthening, and flexibility activities

Prevalence of Secondary Conditions

Condition	PWD	No Dis
• Chronic pain	55%	14%
• Periods of depression	33%	12%
• Weight or eating problems	39%	13%
• Respiratory condition	20%	8%
• Falls/other injuries	21%	7%
• Asthma	12%	3%
• Significant Anxiety	20%	6%

Kinne, Patrick, & Doyle, (2004) Prevalence of secondary conditions among people with disabilities. *AJPH*, 94(3), 443-446

Disability & Health

Disability ≠ poor health

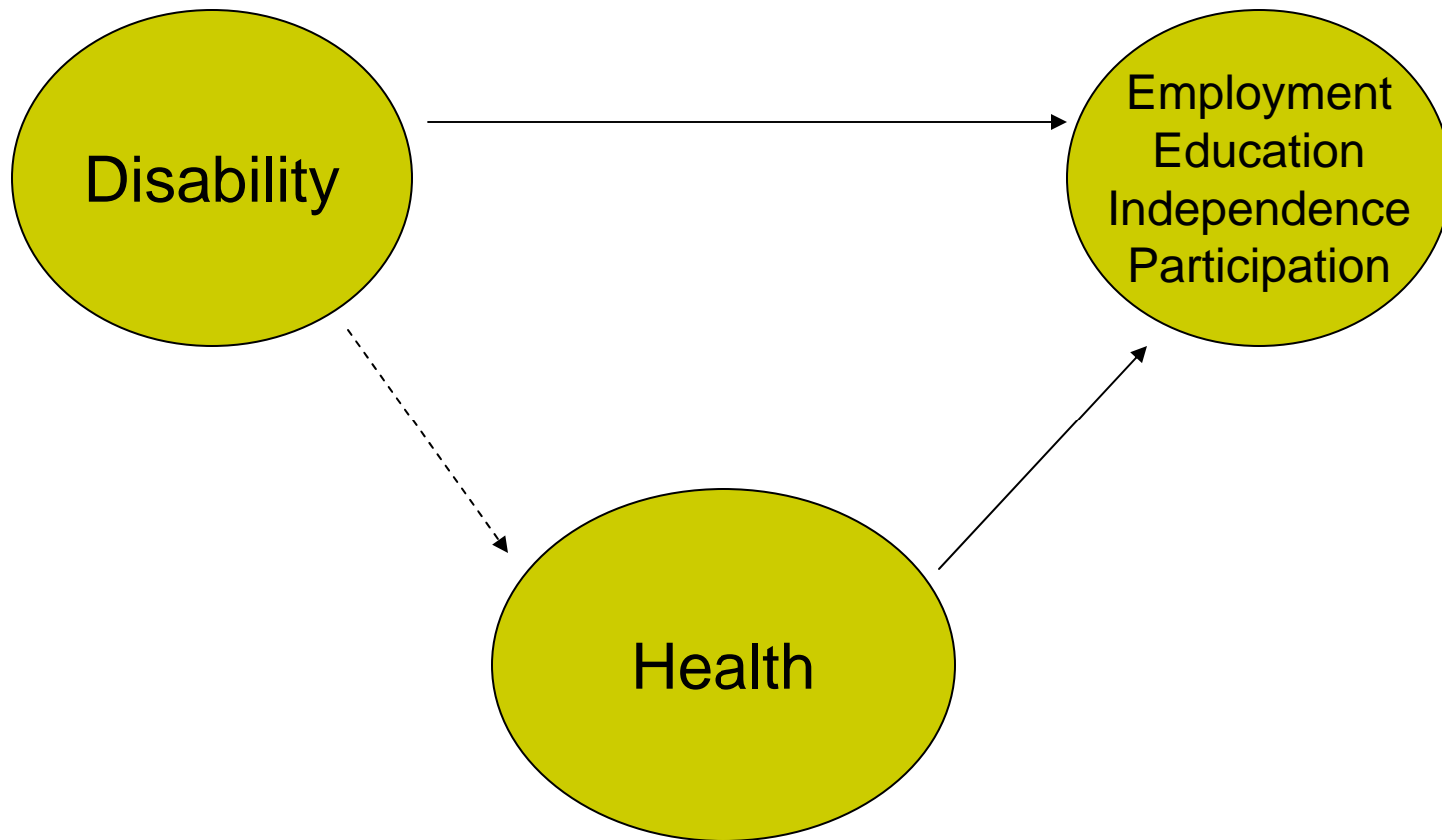
But having a disability puts you at increased risk for poor health and secondary health conditions.

Why?

By affecting access to positive health behaviors (nutrition, exercise, health information and education, preventative health care, mental health care, etc.) and ability to adhere to health treatment and behavior regimens.

Therefore, self-management and adherence are advocacy issues

A Rehabilitation Outcome Perspective



A Rehabilitation Outcome Perspective: Evidence

- Across numerous studies, self-management program participants have been found to experience:
- Decreased
 - pain, disability, anxiety, health care utilization
- Increased
 - Psychological functioning, role functioning, adherence, use of cognitive coping techniques

In Rehabilitation Counseling:

- From an ethical perspective,
- From a professional scope perspective,
- From an RC outcome perspective,
- From an advocacy perspective,

Self-management and adherence should be elements of our professional identity, education, and professional practice

Barriers to implementing self-management and adherence

- Perception (reality) that this is not our focus, not what our consumers are seeking
- Not a focus of practice or educational preparation
- Rehabilitation Counseling Systems are not set up for self-management counseling
- Paternalism, ethical concerns

Approaches to addressing Self-Management and Adherence

- Comprehensive assessment
 - Asking the questions
- Being/Becoming informed about self-management process and core elements

Core Self-Management Tasks

Lorig, K.R., & Holman, H.R. (2003), Sabaté (2003).

1. Problem Solving

- Teaching problem-solving skills
 - Defining the problem
 - Generating alternatives
 - Gathering information
 - Implementation
 - Evaluation

Core Tasks

2. Decision Making & Becoming informed/Aware

- When is a symptom medically serious?
- When do I need to see a doctor about changes in my condition?
- When should I disclose and how?
- When should I discontinue medication?
- Is this a normal response to this medication

Core Tasks

3. How to find and use resources

- Where are the resources?
- How do I find them?
- Casting a wide net and exploring resources, rather than a linear try-fail-try approach

Core Tasks

4. Helping people form effective relationships with health care providers
 - Changed focus of health care from acute care (diagnose and treat) to chronic illness model (educate and inform, treat)
 - Effective management requires skill of all patients to effectively report changes, questions, and to seek information
 - SM training to take on these tasks

Core Tasks

5. (Developing skills in) Taking Action

- Making a plan (short-term, goal oriented, accomplishable)
- Assessing confidence, capacity
- Taking action

Self-Management

Effective self-management involves a multidimensional approach. Each dimension may present specific challenges to the individual.

Self-Management

- Examples of the elements of self-management include
- (a) understanding and staying up-to-date on information about this complex condition and emerging treatment options;
 - (b) adhering to treatments that may be expensive, may require self-injection, and often have significant side effects;
 - (c) participating in treatment decisions and communicating effectively with physicians; and
 - (d) engaging in behaviors to maintain physical and emotional health.

Self-Management

Rehabilitation counselors can promote self-management and assist clients to overcome challenges by understanding these elements and gaining an understanding of their clients' personal experience with, and **barriers** to, self-management.

Assessment as Entré

MS Self-Management Scale (Bishop & Frain, 2007)

1. Treatment Adherence:
2. Care Provider–Patient Relationship
3. Emotional health and social support/resources
4. Health and Symptom Awareness
5. MS Knowledge and Information
6. Health Maintenance Behavior
7. Communication about Symptoms/Changes

Scale for Assessing MS Self-Management

7 factors (subscales)

- “Treatment Adherence” includes several items addressing the respondent’s attitude toward adherence, barriers to treatment maintenance, and understanding of the purpose of treatments.
- “Care Provider-Patient Relationship” addresses elements of communication with health care providers and degree of participation in treatment decision making.
- “Emotional Health and Social Support/Resources” including feelings about self, adherence self-efficacy, and support from family members and others.

MS Self-Management Scale

- “Health and Symptom Awareness” addresses knowledge of and participation in symptom management behaviors
- “MS Knowledge and Information” addresses the individual’s understanding of MS and active information seeking behavior.
- “Health Maintenance Behavior” assesses awareness of and participation in positive health behaviors.
- “Communication about Symptoms/Changes” explores the respondent’s willingness and comfort to discuss problems and changes with health care providers.

MS Self-Management Scale

- I take my medication exactly the way my doctor prescribes.
- Taking my medication is a routine part of my daily activities (like brushing my teeth)
- I have a good understanding of why I take my medications and what they are supposed to do
- I am able to plan things so I am always able to take my medication when I should
- I am confident I need to take my medication to be healthy
- It may be dangerous to stop taking my medications without asking my doctor
- I have insurance that pays for my medication

Improving Adherence

1. Examine professional assumptions
2. Understand motivations and adherence predictors

Adherence Predictors

- Researchers have applied, with some success, health decision-making models (e.g., trans-theoretical model of behavior change) to explain the decision to initiate DMT
- The premise that a successfully initiated behavior will be maintained, however, is at odds with growing evidence that these models do *not* predict behavior maintenance-only initiation
- The determinants of behavior change over time, and those responsible for behavior initiation (e.g., favorable expectations) differ from those involved in behavior maintenance (e.g., satisfaction with experiences).

Variables directly or indirectly influencing adherence:

- Primary: Availability of economic and social resources- the most frequently studied and perhaps the least manipulable
- Understanding and expectations
 - if expectations are accurate and informed, adherence is higher.
- Social acceptability- Familial, cultural, societal acceptance of the treatment behavior.

Variables directly or indirectly influencing adherence:

- Socioeconomic status, cognitive functioning, motivation, and expectations
- Whether the consumer recognizes the condition as a situation that they are motivated to change, or not
- Duration from diagnosis/onset of treatment

Improving Adherence

3. Counselor-Consumer Communication

Improving Adherence

Ensuring informed decision making

- Input on feasibility, acceptability
- Clarity of instruction and permission to ask questions

Shared understanding of:

- What is the goal
- What is the schedule, procedure
- What is an effective level of adherence
- What are potential barriers?

Improving Adherence

- What is the cost, what is covered?
- What adverse effects may be expected?
- What if I have questions?
 - When is a symptom medically serious?
 - When do I need to see a doctor about changes in my condition?
 - When should I disclose and how?
 - When should I discontinue medication?
 - Is this a normal response to this medication

Improving Adherence

How to find and use resources

- Where are the resources and how do I find them?

Adherence

- The greatest decline in adherence with most medications occurs early (i.e., first days to weeks) in the course of therapy. This may result from a number of factors including medication side effects or delayed onset of effect of the medications.
- Early and frequent follow-up has been found to be an important factor in adherence to therapy.

Implications for Rehabilitation Counseling

- Empowering clients
- Understand motivations for and barriers to adherence at a personal level, and realize these change over time
- Based on individual's barriers, explore resources for knowledge, financial assistance, effective communication with care providers

Questions?

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