

HIV/AIDS Self-Care Skills Management Program

S. Abramowitz, PhD; M. Dasari, PhD; J. Lewis, PsyD;
D. Moschel; N. Obten, LCSW; K. Krasinski, MD

Lower New York Consortium



Why Are Self-Care Skills Management Programs Needed?

Increase of Perinatally infected Youth Aging into Adulthood

- 76% Decline in Mortality in Youth 13 - 24 Because of HAART (Nostlinger, 2004)
- Increasing Percent of Children Diagnosed at 13 Years Still Alive (NYCDOH, 2007)
- HIV Change from Acute to Chronic Illness

Characteristics of Clinical Programs

Pediatric	Adult
Family Centered	Client of One
Developmentally Oriented	Disease Focused
Long-standing Relationships	Easy for Youth to Fall thru Cracks
Involve Parental Direction & Consent	Assumes Patient Autonomy
Nurturing, High Level of Support	Assumes Functional Independence

Self-Management: The Key

- “Ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition.”
- “Ability to monitor one’s condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life.”

Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self management approaches for people with chronic conditions: a review. Patient Educ Couns 2002; 48: 177-87

Theoretical Frameworks of Self Management Interventions (SMIs)

- Social Cognitive Theory - Promote self efficacy with problem solving & goal setting
- Transtheoretical Model - Promote development through role modeling and group discussion
- Cognitive Behavioral Theory – Change how people think about their illness and themselves using emotional management and problem solving skills

Neman S, Steed L, and Mulligan K. Self Management interventions for chronic illness. www.lancet.com 2004; 364: 1523-37

Self Management Tasks

- Medical Management
- Developing New Roles
- Coping with Emotions

Corbin J, Straus A. Unending Work and Care: Managing Chronic Illness at Home. San Francisco, CA: Jossey-Bass Publishers, 1998

Skills Development

- Problem Solving
- Decision Making
- Resource Utilization
- Forming Patient-Provider Partnerships
- Self-tailoring

Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms *Ann Behav Med* 2003 Aug;26(1):1-7.

Action Plan Preparation

Work with Client to Identify:

- Client Goals
- Barriers to Accomplishing Them
- Strategies to Address Them Using SMI Skills

SMI Experience To-date

Adults

- Contributes to improved adherence in the chronically ill (Bodenheimer, 2002)
- Improved outcomes compared to standard of care (Newman, 2004)

Youth

- Focus predominately on education
- Need for multi-modal, manualized SMI

Skills Needed to Manage HIV

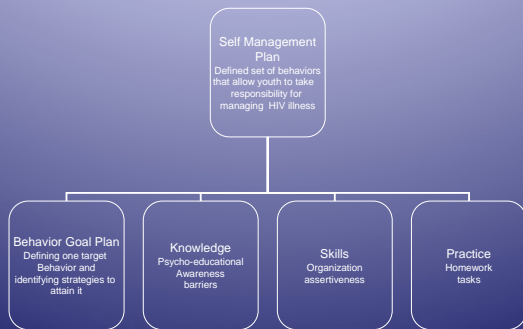
- Knowledge & Understanding of HIV
- Knowledge & Engagement in Wellness Behaviors
- Communication & Self-Advocacy with Providers
- Ability to Manage Health Care Independently
- Knowledge & Demonstration of Responsible Sexual Activity
- Knowledge of Health Insurance Process
- Ability to Plan for the Future
- Availability of Adequate Social Support to Accomplish Goals

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Developing Self-care Skills Management Curriculum

- Conceived as follow-up to CDC-funded Adolescent Impact
- Identified SM topics & processes from the literature
- SM topics cross-walked with AETC Assessment Instrument
- Conducted focus groups with 4 – 5 youth/session and incorporated their feedback

CBT Framework for Self-Management Manual



Self-Care Skills Management Curriculum

- Week 1 – Introduction to Self-care Skills Management & Behavior Change Plan Development
- Week 2 – Barriers to Self-care Skills Management & Strategies to Address Them
- Week 3 – Managing Feelings
- Week 4 – Applying Understanding of HIV & Medications to Managing One's Health
- Week 5 – Planning for the Future
- Week 6 – Consumer Involvement in Care
- Week 7 – Review & Closure

Managing Emotions

Goals

- To introduce the variety of ways youth react to different situations
- To explore how feelings influence and/or get in the way of accomplishing goals.
- To review alternative ways to address ones feelings

Objectives Participants will identify:

- 1 – 2 triggers in their life and the feelings that come from them
- reactions to feelings that help a situation and reactions that do not
- 1 – 2 reactions to feelings they would like adopt

Overview This session introduces the concept of emotion management by illustrating that situational triggers generate feelings that cause reactions. The goal is to help participants understand that they can learn to evaluate alternative reactions to feelings giving themselves an opportunity to let go of feelings that will not get them what they want and adopt feelings that will accomplish their objectives.

Activities and Timetable

Dinner	30 minutes
Welcome & Review of Past Week's Homework	10 minutes
Emotion Reaction Video Clip & Discussion	30 minutes
Introduction to the Emotion Management Model	40 minutes
Review of Knowledge and Skills Gained	10 minutes

Total Time

2 Hours

Measuring Impact of SMI

- Self Care Skills
 - Skills Check List
 - HIV Management Self-Efficacy
 - Adherence
 - Understanding CD4 and Viral Load
- Physical and Mental Health
 - CD4 & Viral Load
 - SF 36

Skills Check List

Check the column to the right to indicate who is MOST responsible for each activity below	Not Done	My Provider	My Caregiver	Me
Makes appointments with the doctor				
Makes your annual dental appointments				
Calls the doctor with questions				
Gives a medical history to a new provider				
Orders medication refills				
Discusses problems about taking medications with the doctor				
Knows when caregiver's insurance ends				
Arranges transportation				
Has plans to graduate from high school				

HIV/AIDS Self-Efficacy: How sure are you that you can do each of the following, almost all of the time? Circle the number that best reflects how sure you are that you can do the task ALL THE TIME from "1", meaning not at all sure to "5" meaning you are completely sure.

1. Identify your highest priorities for your health?
2. Identify things that could get in the way of managing your HIV?
3. Manage your HIV even when you feel overwhelmed?
4. Manage your HIV the way your health care team wants you to?
5. Talk to your doctor or nurse about any problems you're having taking care of HIV?
6. Get to your doctor's appointment even if you are really busy?
7. Manage your own health care needs?
8. Identify goals for the future?
9. Identify someone who can help you accomplish your goals?
10. Work with the health care team to accomplish your goals?

HIV/AIDS Literacy

- Have you ever heard of the term Viral Load?
 - What does viral load mean?
 - What is your viral load?
- Have you ever heard of the term CD4?
 - What does CD4 mean?
 - What is your CD4?

Integration of SM Training into Program of Care

- ❖ Begin process in pre-adolescence
- ❖ Annual Social Work assessment of youth skills
- ❖ Promote participation in TOPS+ Impact followed by Skills Management Training
- ❖ Send providers letter of completed sessions
- ❖ Incorporation of Skills Management goals in interdisciplinary treatment plan and development of milestones by providers, caregivers, and clients

Challenges

- Organizing Groups
- Studying Effectiveness
 - Costs & Length of Multi-center Studies
- Need for New Methodologies

In the final analysis

..It is not what you do for your children, but what you have taught them to do for themselves that will make them successful human beings.



Image courtesy www.troubledteentherapy.com

Ann Landers

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