

Building Capacity for Youth Self Care Management

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Presentation Summary

- Need for self care skills management
- Programs enhancing SCSM
 - Self care skills management intervention (SMI)
 - Train the trainer
- Summary of evaluation results

Why Are Self-Care Skills Management Programs Needed?

- Increase in:
 - Perinatally infected youth aging into adolescence and young adulthood
 - Behavioral infection in teens & young adults
- HIV change from acute to chronic illness
- Differences between pediatric, adolescent & adult care venues

Why Are Self-Care Skills Management Programs Needed (cont.)?

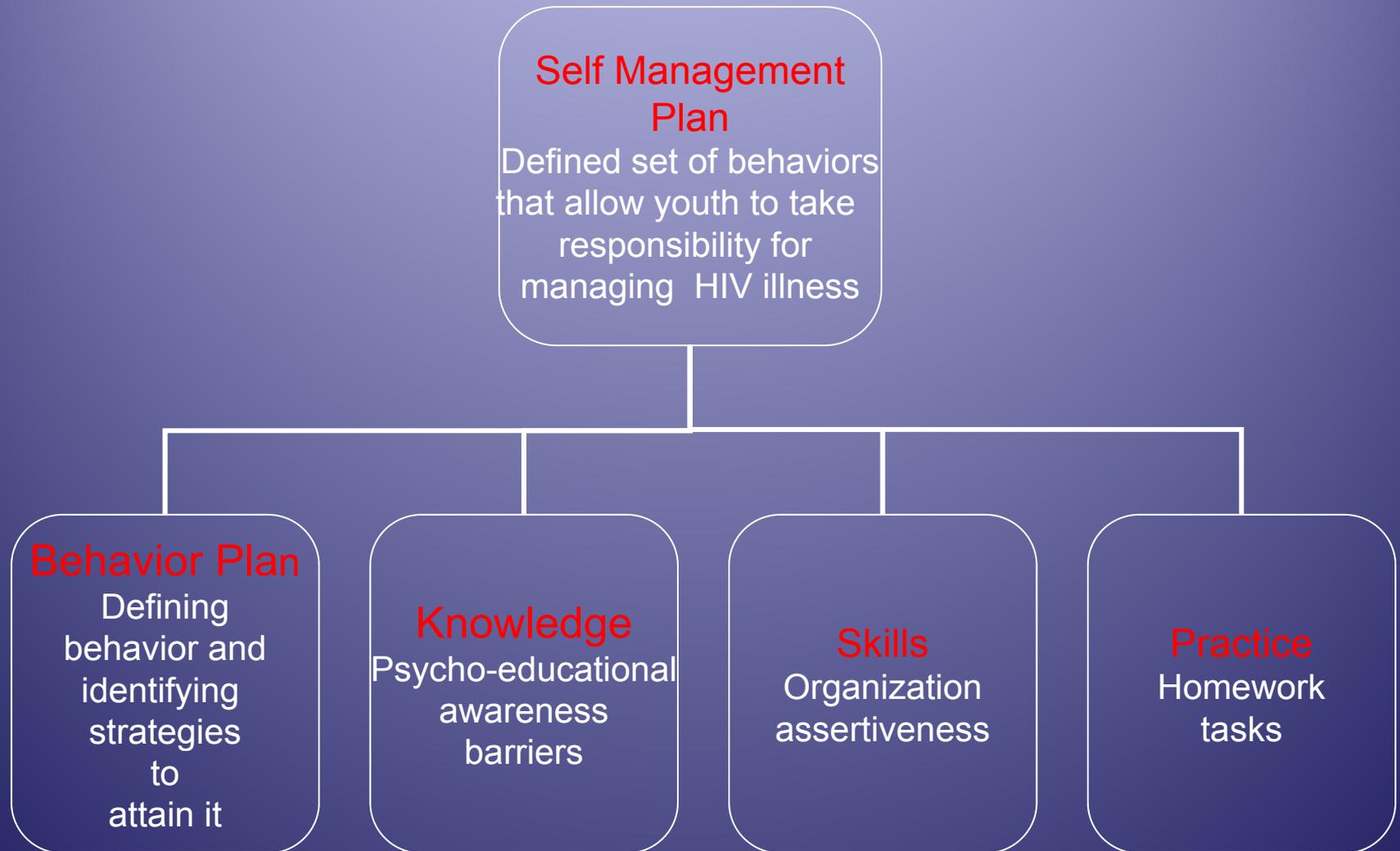
- Poor levels of adherence among youth (Martinez, 2000)
- Lack basic information to help them manage their health (Barnes, 2007)
- Lack peer support available to others with chronic illness (Abramowitz, 2009)

Theoretical Frameworks for 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

Cognitive Behavioral Treatment Framework



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

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: 17787

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
- Incorporated SM content within a healthy lifestyles framework

Healthy Living Framework

Part of growing up is learning how to take care of yourself and that means learning to live a healthy life. People are often happier when they are in good health. Everyone can benefit from good health, but health isn't a noun; it's a verb! It's a way of life. We call it Healthy Living. People with HIV can live a healthy life and be happier people if they take care of themselves. Healthy Living means making good health care choices.

Healthy Living Program

- Week 1 – Introduction to Healthy Living
- Week 2 – Healthy Living Maps and Health Plans
- Week 3 – Rough Waters: Barriers & Strategies
- Week 4 – Emotional Health
- Week 5 – Healthy Treatment
- Week 6 – Sex, My Friends, and Me
- Week 7 – Planning for a Healthy Future
- Week 8 – Quality Health Care: Becoming an Informed Consumer
- Week 9 – Closure

Additional Summer Activities

- Team Building Exercise
- Scavenger Hunt in the Hospital
- Eroticizing Safe Sex & HIV Testing Day
- Booster Sessions on Substance Use, Managed Care, etc.
- Trip to Splish Splash

Healthy Living Framework (cont.)

- Assessment of who does what for whom
- Healthy living map & destinations
- Behavior plan development
 - Health goals
 - Emotional triggers
 - Future Planning

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				

Health Plan

1. What would I like to change/improve? Or things I would do differently

2. What gets in the way of making these changes?

3. What steps will I need to take to accomplish this?

4. How will I know that something has changed or

5. Who can help me accomplish this?

Healthy Living Map #1



Measuring Impact of SMI

- Self care skills
 - Skills check list
 - HIV management self-efficacy
 - Taking care of yourself
- HIV knowledge
 - Know CD4 and viral load
 - Understand CD4 and viral load
- Physical and mental health function
- Social support

Pre/Post Test Program Evaluation

- 44 youth from three different sites
- 60% Male
- Mean age 20
 - 15 – 18 (27%)
 - 19 – 24 (64%)
 - 25+ (9%)

Pre-Post Test Results

Measure	Time 1	Time 2	T score
HIV Knowledge	87.0	92.7	4.73
Know VL	0.48	1.00	6.716
Know CD4	0.43	1.00	7.394
Physical Function	0.51	0.27	-3.736
Depressed	1.03	0.51	-4.434
Feel Good	2.5	3.4	5.321
Social Wellbeing	2.8	3.3	3.839
MOS	3.1	3.6	4.756
HIV Self Efficacy	3.9	4.4	5.172

Behavioral Observations

- See youth come out of their shells
- Glad for the opportunity to meet others
- Learn how to talk about issues and themselves
- Better able to advocate for themselves -
Prepared 50 questions they wanted the physician to answer
- More willing to explore mental health issues -
25/29 youth scheduled or completed a bio-
psychosocial assessment
- Glad to receive a stipend

Train the Trainer Curriculum

- Introduction to Healthy Living Program
- HIV/AIDS Review
- Appreciating Differences
- Facilitation Skills
- Healthy Living Facilitation Practice
- Closing

Training Results from Feedback Questionnaire

	T1	T2	p
Allow others to make own choices	1.64	1.27	0.04
Confident in Peer Leader skills	1.45	1.00	0.05
Confident in Peer Leader knowledge	1.64	1.09	0.05
Confident as facilitator	1.64	1.09	0.05
Help others take care	1.91	1.09	0.00

Next Steps

- Small wait-list control study of efficacy
- Growing interest in another Train the Trainer group
- Expand capacity for holding groups at other sites
- Testing of companion caregiver curriculum

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.

Ann Landers



Image courtesy www.troubledteentransports.com

Acknowledgments

The Lower New York Consortium is funded by Ryan White Care Act:

- Part C grant no. 2H7600043-13-01
- PART C Capacity Building Grant
- Part D grant, no. 5H12HA0019-12-00
- Part D Youth grant no.H12HA03805-01-00

And

- NY State AIDS Institute Youth Specialized Center for Care and Youth Access Program grant no. C019100