

**Self-Management Science:  
Past, Present, Future**

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Professor of Pediatrics

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**Objectives**

- ▶ Define self and family management
- ▶ Describe where the science is
- ▶ Illustrate with research on self-management in pediatric diabetes
- ▶ Suggest future directions

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**Self-Management**

- ▶ “cluster of daily behaviors that individuals perform to manage. . .”
- ▶ A dynamic means of maintaining health rather than the submission to prescribed orders implied by the term compliance/adherence

Glasgow, R.E. & Anderson, R.M. (1999). Moving from compliance to adherence is not enough: something entirely different is needed. *Diabetes Care*, 22, 2090-2092.  
Ruggerio, L., et al. (1997). Diabetes self-management: self-reported recommendations and patterns in a large population. *Diabetes Care*, 20, 568-576.

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# Self-management

- A dynamic, interactive, and daily process in which individuals engage to manage a chronic illness<sup>1</sup>
- The ability of the individual, in conjunction with family, community, and health care professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural and spiritual consequences of health conditions<sup>2</sup>

<sup>1</sup>Lorig, K., & Holman, H. (2003). Self-management education: History, definition, outcome, and mechanisms. *Annals of Behavioral Medicine, 26*, 1-7.  
<sup>2</sup>Richard, A. A., & Shea, K. (2014). Self-management: Delineation and associated concepts. *Journal of Nursing Scholarship, 43*, 255-264.

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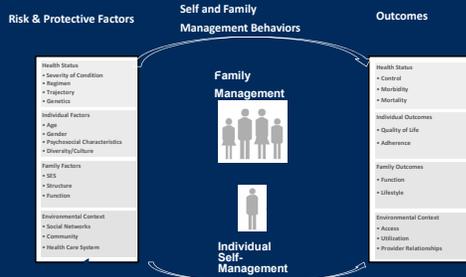
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# Framework



Grey, M., Kraft, K., & McCorkle, R. (2006). A framework for the study of self- and family management of chronic conditions. *Nursing Outlook, 54*, 278-286.

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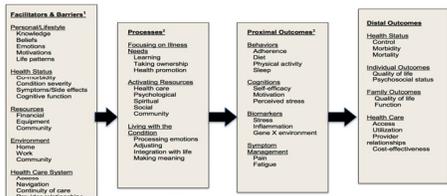
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# Revised Self- & Family Management Framework



\*Schuman-Olsen, et al. (2014). Factors affecting self-management of chronic illness. Unpublished manuscript.  
 \*Schuman-Olsen, et al. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship, 41*, 136-144.  
 \*Ways, Jr. & Sabath, K. (2009). The Individual and Family Self-Management Theory. *Nursing Outlook, 57*, 217-225.

Grey, M., et al. (2015). A revised self- and family management framework. *Nursing Outlook, 63*, 162-170.

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## Facilitators and Barriers

- ▶ **Personal/Lifestyle**
  - Knowledge, beliefs, emotions, motivations, life patterns
- ▶ **Health Status**
  - Comorbidity, severity, symptoms, cognitive function
- ▶ **Resources**
  - Financial, equipment, community
- ▶ **Environment**
  - Home, work, community
- ▶ **Health care system**
  - Access, navigation, continuity of care provider relationships

Schulman-Green, D., et al. (2016). A metasynthesis of factors affecting self-management of chronic illness. *Journal of Advanced Nursing*, 72, 1469-1489.

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## Self-Management Processes

- Focusing on illness needs
- Activating resources
- Living with a chronic illness

Schulman-Green, D., et al. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship*, 44, 136-144.

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## Focusing on Illness Needs

- ▶ **Learning**
  - Acquiring information
  - Learning regimen, skills, strategies
- ▶ **Taking ownership of health needs**
  - Recognizing and managing body responses
  - Completing health tasks
  - Becoming an expert
- ▶ **Performing health promotion activities**
  - Changing behaviors to minimize disease impact
  - Sustaining health promotion activities

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## Activating Resources

- ▶ Health care resources
  - Creating & maintaining relationships with providers
  - Navigating the system
- ▶ Psychological resources
  - Identifying & benefiting
- ▶ Spiritual resources
  - Sustaining spiritual self
- ▶ Social resources
  - Obtaining & managing social support
- ▶ Community resources
  - Addressing social & environmental challenges

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## Living with the illness

- ▶ Processing & sharing emotions
- ▶ Adjusting
  - To illness
  - To 'new' self
- ▶ Integrating illness into daily life
  - Modifying lifestyle to adapt to disease
  - Seeking normalcy in life
- ▶ Meaning making
  - Reevaluating life
  - Personal growth
  - Striving for personal satisfaction

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## Proximal Outcomes

- ▶ Behaviors
  - Adherence, diet, physical activity, sleep
- ▶ Activating resources
  - Health care, psychological, spiritual, social community
- ▶ Cognitions
  - Self-efficacy, motivation, perceived stress
- ▶ Biomarkers
  - Stress, inflammation, gene x environment
- ▶ Symptom management
  - Pain, fatigue

Ryan, P., & Sawin, K. (2009). The individual and family self-management theory. *Nursing Outlook*, 57, 217-225.

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## Distal Outcomes

- ▶ **Health status**
  - Control, morbidity, mortality
- ▶ **Individual outcomes**
  - Quality of life, adherence
- ▶ **Family outcomes**
  - Function, lifestyle behaviors
- ▶ **Health care outcomes**
  - Provider relationships, utilization of care

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## Diabetes Self-Management

- ▶ **Initial concept**
  - Adherence behaviors
- ▶ **Later**
  - Activities
  - Processes
  - Goal setting



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## Diabetes Self-management Education (DSME)

- ▶ **Knowledge or Information**
- ▶ **Lifestyle behaviors, inc. diet & physical activity**
- ▶ **Skill development**
- ▶ **Psychosocial interventions**
  - Coping skills training
  - Motivational interviewing
  - Self-management education
- ▶ **Systems approaches**

Hass, et al. (2012). National standards for diabetes self-management education and support. *Diabetes Care*, 35, 2393-2401.

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## Improving self-management in teens with type 1 diabetes



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## The Problem

- ▶ Diabetes management in teens compromised by adolescent development
- ▶ Excellent diabetes control associated with reduced risk for long-term complications
- ▶ Primary & secondary control coping associated with better outcomes
- ▶ >70% of youth fail to achieve target HbA1c levels
- ▶ Behavioral approaches assist teens to make better health decisions & have better outcomes

Grey, M., Cameron, M. E., Lipman, T. H., & Thurber, F. W. (1995). Psychosocial status of children with diabetes in the first two years after diagnosis. *Diabetes Care*, 18, 1330-1336.

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## Early descriptive work

- Girls had worse metabolic control than boys
- DSME improved knowledge but not associated with better metabolic control
- Coping behaviors & psychosocial status stable over 1<sup>st</sup> year after diagnosis, but worsen in 2<sup>nd</sup> year
- Avoidance coping associated with poorer metabolic control & quality of life
- Could we target coping skills?

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## Coping Skills Training

- ▶ Increase sense of mastery & competence by retraining non-constructive coping styles & forming more positive patterns of social behavior.
- ▶ Behavioral & cognitive behavioral approaches, usually in small groups, to teach a variety of coping skills

Davidson, M., Boland, E. A., & Grey, M. (1997). Teaching teens to cope: Coping skills training for adolescents with insulin dependent diabetes mellitus. *Journal of the Society of Pediatric Nurses*, 2, 65-72.

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## Coping Skills

- ▶ Problem solving
- ▶ Social skills
  - Assertiveness
  - Negotiation
- ▶ Stress reduction
- ▶ Cognitive behavior modification
- ▶ Conflict resolution

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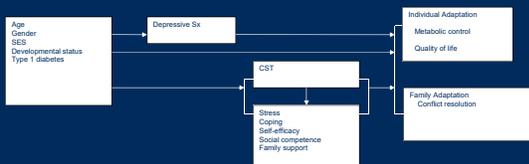
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## Conceptual Framework



Whittemore, R., Jaser, S., Guo, J., & Grey, M. (2010). The Childhood Adaptation to Chronic Illness Model: An update. *Nursing Outlook*, 58, 242-251.

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## CST for Youth with Diabetes: Group Model

- ▶ Randomized controlled trial of youth with type 1 diabetes
- ▶ CST compared to advanced diabetes education
- ▶ Age 12.5-20 years at entry
- ▶ No other chronic illness
- ▶ Appropriate grade for age

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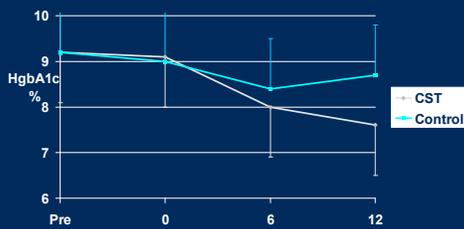
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## Metabolic Control after 1 Year (N=77)



Gray, et al. (2000). Coping skills training for youth on intensive therapy has long-lasting effects on metabolic control and quality of life. *Journal of Pediatrics*, 137, 107-103

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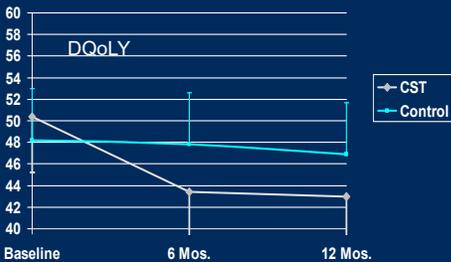
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## Quality of Life



Gray, et al. (2000). Coping skills training for youth on intensive therapy has long-lasting effects on metabolic control and quality of life. *Journal of Pediatrics*, 137, 107-103

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## Moving to implementation

- ▶ Reach more teens
  - 50% of eligible teens too busy
  - 93% of youth access internet regularly
- ▶ On their own time and schedule
- ▶ Characters teens can relate to
- ▶ Less didactic, more interactive

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## TeenCope Development

- ▶ Multi-phase mixed methods approach
  - Focus groups
  - Prototype development
  - Think-aloud interviews
  - Pilot study

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## TeenCope

- ▶ Internet-based coping skills training program
  - Graphic novel format
  - Includes asynchronous discussion board
- ▶ RCT comparing to *Managing Diabetes* – web-based diabetes education & problem solving
- ▶ Teens 11-14 years

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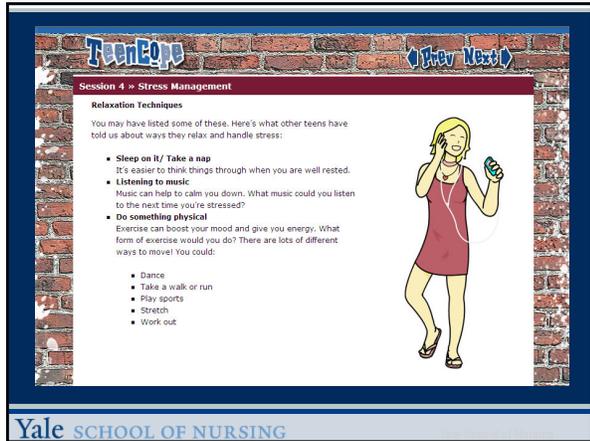
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## Acceptability

- ▶ **Session Participation**
  - Completed 4/5 = 78%
  - TeenCope – 77%
  - Managing Diabetes – 52%
  - Completed at least 1-90%
- ▶ **Discussion Board – 52%**
- ▶ **Retention rate – 12 months – 78%**

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## Hypotheses

- ▶ Youth who participated in **TEENCOPE** will have better quality of life and HbA1c than those in **Managing Diabetes** after 12 months
- ▶ Participating in both programs rather than only one leads to better outcomes

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## HbA1c, controlling for covariates (n=320)



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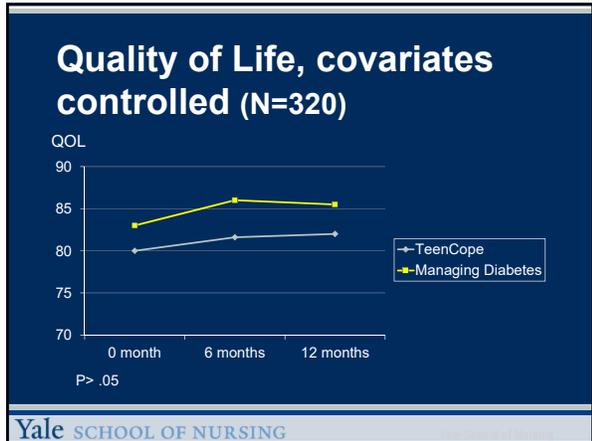
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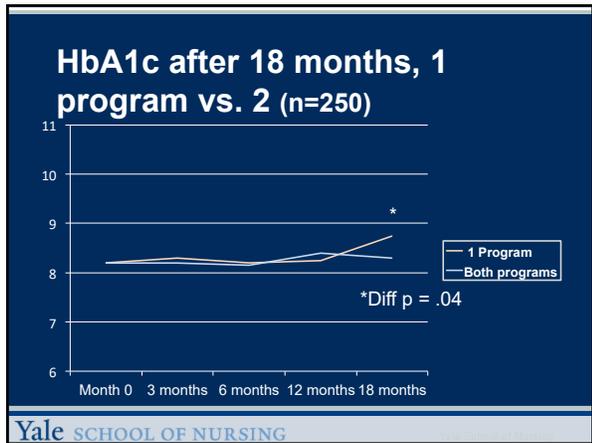
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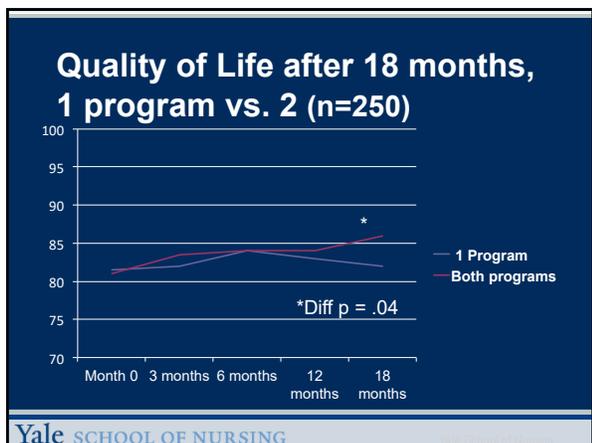
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## Potential Cost-benefit

- ▶ Cost to develop ~ \$325K
- ▶ Maintenance ~ \$43K, \$137/youth
- ▶ Reduction in long-term complications by 10%
- ▶ Potential for savings of >\$1 Million over long-term

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## Dissemination

- ▶ Purpose
  - To evaluate the efficacy and cost-effectiveness of provider-prescribed Teens-Connect in pediatric diabetes practice compared to prescription to Planet-D™

Funded by the American Diabetes Association, 1-12-SAN-10

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Home Lessons Teams Game FAQs

WELCOME! LOGOUT

**Teens.Somerset**  
to manage diabetes

What's on your mind?  
Post

The next trivia question is...can you name 1 Olympic athlete that has type 1 diabetes? (I can be someone who is competing in this year's Olympics or who competed in the past?)  
-12/10/12 7:48:35 AM  
Post your Comment here  
Post

What is everyone's favorite sport in the Olympics? I know mine is Basketball. Guess!  
-12/10/12 7:42:24 PM  
Post your Comment here  
Post

HELLO! So our area got 22 inches of snow today and it's still raining. We are going to get 3.5" of a delayed opening today and they cancelled school tomorrow. Only our town and one other area got 15 inches!  
-12/10/12 9:15:33 PM  
Post your Comment here

**Teens.Manage**  
A program for teens with type 1 diabetes about staying healthy.

**Teens.Cope**  
A program for teens with type 1 diabetes about dealing with friends, stress, conflict, and other challenging situations.

Badges

Leaderboard

Team	Female	Male
CHOP	[Bar]	[Bar]
Yale	[Bar]	[Bar]

Sponsored by:  
National Institutes of Health, U.S. Award for Health Services Research and YSN President's Fund for Research

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## Methods

- ▶ Randomized controlled trial
  - Teens.Connect vs. “Planet D”
- ▶ Mixed methods
  - Outcomes
  - RE-AIM components
  - Cost-effectiveness
- ▶ N=123, age 11-14 years
  - Age, 11-14 years (>50% < 13 years)
  - Gender, 61% female
  - Race/Ethnicity, 79% White
  - HbA1c, 8.2 ± 1.4%

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## RE-AIM Framework

- ▶ **Reach** – Participation rate among those approached, representativeness
- ▶ **Efficacy** – Does it work?
- ▶ **Adoption** – Percentage & representativeness of settings adopting intervention
- ▶ **Implementation** – Intervention fidelity
- ▶ **Maintenance** – Extent to which intervention institutionalized

Dzewaltowski, D. A., Glasgow, R. E., et al. (2004). RE-AIM: Evidence-based Standards and a web resource to improve translation of research into practice. *Annals of Behavioral Medicine*, 28, 75-80.

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## RE-AIM Findings

- ▶ **Reach**
  - 78% of those approached randomized
  - 100% of providers participating
- ▶ **Efficacy**
  - No difference in outcomes between Teens.Connect and Planet D
- ▶ **Adoption**
  - All sites approached agreed to participate
- ▶ **Implementation**
  - Process of 'provider prescription' implemented well at all sites
  - Intervention fidelity
    - Consistent with Internet delivery
    - Planet D undergoing revisions at present
- ▶ **Maintenance**
  - Unable to determine from this study

Whittemore, R. et al. (2016). Efficacy and implementation of an internet psychoeducational program for teens with type 1 diabetes. *Pediatric Diabetes*, 17, 567-575.

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## Self-Management Research

- ▶ **Important processes**
  - Engagement of youth & parents in development
  - Focusing on illness needs AND living with chronic illness important
- ▶ **May change over time**

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## Next steps in self-management science

- ▶ **Clarify bio-behavioral mediators and moderators**
- ▶ **Design & evaluate sustainable interventions for primary and secondary care**
- ▶ **Translational research**
  - Pragmatic, longitudinal trials
  - Comparative effectiveness
  - Cost-effectiveness

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## Self-management of sleep in diabetes

- ▶ **Fewer than 30% of youth with T1D achieve goals for metabolic control (HbA1c)**
- ▶ **70% of youth – short sleep duration, variability**
- ▶ **Poor sleep associated with poorer executive function, necessary for diabetes self-management**
- ▶ **Glucose fluctuations may impact sleep**

Grey, M. & Reichenberg, K. (2018). Sleep and glycemia in adolescents with type 1 diabetes. *Diabetes*, 67, A212.

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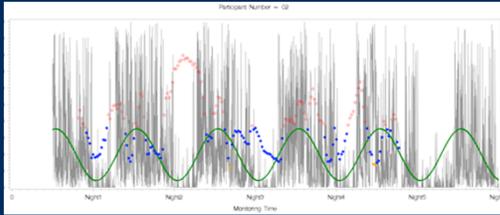
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## Sleep & Glucose Levels



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## Biobehavioral Mediators

- ▶ Link markers with mechanisms
  - Genetics
  - Gene-Environment interactions
  - Neuro-processing
  - Psychological factors
- ▶ Perhaps lead to new approaches to tailoring interventions

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## Sustainable Interventions

- ▶ Can be adopted in clinical settings
- ▶ Cost-efficient
- ▶ Use of monitoring devices
- ▶ Point of care devices
- ▶ Patient and clinician engagement

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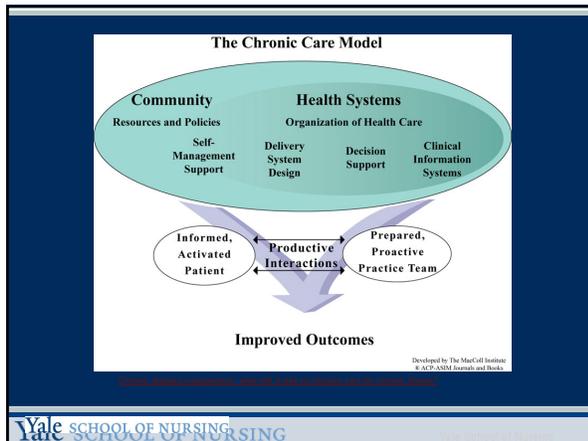
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## New Methods/Approaches

- ▶ Comparative effectiveness
- ▶ Cost-benefit
- ▶ Pragmatic designs
- ▶ Longitudinal follow-up

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## Conclusions

- ▶ Self-management has many components
- ▶ Address individual & caregiver factors to influence behavior change
- ▶ Science evolving
- ▶ Focus on sustainability
- ▶ Potential to transform population health

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