Self-Management Science: Past, Present, Future

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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

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

Self-management

- A dynamic, interactive, and daily process in which individuals engage to manage a chronic illness
- 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


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Framework

<table>
<thead>
<tr>
<th>Risk &amp; Protective Factors</th>
<th>Self and Family Management Behavior</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td></td>
<td>Individual Management</td>
<td>Family Management</td>
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Revised Self- & Family Management Framework

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


Self-Management Processes

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


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
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

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

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

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

Diabetes Self-Management

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

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

Improving self-management in teens with type 1 diabetes

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


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 1st year after diagnosis, but worsen in 2nd year
- Avoidance coping associated with poorer metabolic control & quality of life
- Could we target coping skills?
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


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Coping Skills

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

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Conceptual Framework


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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

Metabolic Control after 1 Year (N=77)

Quality of Life

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

TeenCope Development

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

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
Multi-site trial

- 4 sites: Yale, Children’s Philadelpia, Univ. of Miami, Univ. of Arizona
- N=320
  - 11-14 years; Mean=12.3, 45% male
  - 10.5% Black; 19% Hispanic
  - SES=21.4% <$40,000
  - Duration, mean=4.6 years
  - A1c, mean=8.3%
  - Parent education, mean = 14.6 years
  - 53% pump users
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%

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

HbA1c, controlling for covariates (n=320)

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<table>
<thead>
<tr>
<th>Time</th>
<th>TeenCope</th>
<th>Managing Diabetes</th>
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<tbody>
<tr>
<td>0 month</td>
<td>7.5</td>
<td>7.5</td>
</tr>
<tr>
<td>6 months</td>
<td>8.0</td>
<td>8.0</td>
</tr>
<tr>
<td>12 months</td>
<td>8.5</td>
<td>8.5</td>
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P > .05
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

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
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%

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


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

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

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

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

Sleep & Glucose Levels

Biobehavioral Mediators

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

Sustainable Interventions

- Can be adopted in clinical settings
- Cost-efficient
- Use of monitoring devices
- Point of care devices
- Patient and clinician engagement
New Methods/Approaches

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

Conclusions

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