Definition of Self-Management

Dr. Dilorio defined epilepsy self-management in the following way: “Broadly speaking, epilepsy self-management is the sum total of steps taken and processes used by a person to control seizures and manage the effects of a seizure disorder.”

Naturalistic Inquiry

- Interviewed 25 people with chronic (bad) epilepsy.
- Management philosophy – proactive or reactive.

Management strategies

- Prescriptions
  - Planned compliance
  - Planned non compliance
- Seizure Event
  - Lifestyle change
  - Abort
  - No plan
- Social situations/Employment Education
  - Planned disclosure
  - Planned non disclosure
  - Control interactions

The Self-Management Continuum

Proactive behaviors were associated with positive QOL scores.

- Behaviors to manage seizures
- Behaviors to manage life
- Behaviors to manage physician orders (meds)

Reactive behaviors were associated with negative QOL scores.

Quality of life

Until Now

- We have assumed that if we improve things like
  - self-confidence,
  - problem-solving skills,
  - knowledge and understanding,
  ...patients will change and assume the appropriate behaviors.

Complexity of Self-Management

- Previously we looked to single ideas to explain self-management such as:
  - Self-confidence
  - Self-determinism
  - Self-control versus controlled by others
- But personal systems are created by a number of diverse and independent agents that are constantly changing and interacting.
- Studying just one of those parts leads to an incomplete understanding (Plexus Institute).
Patients (like all of us) Live in Complex Worlds

Management of Disease (Sleep, diet, exercise)

Management of Meds (Rx)

Management of life as it is affected by disease condition

Family

Education

Self confidence, Knowledge, Understanding

Social Environment

Physical Environment

Health and illness

Work and Leisure

Health Care Providers

Religion and Worship

Finances

Managing Epilepsy Well Network

Mr. Farmer has just been diagnosed with epilepsy.

• Mr. Farmer is 66 years old.
• His children all work full time.
• He is a farmer and is the primary caregiver for his wife, who had just had a stroke.
• His wife is recovering nicely from her stroke but has cognitive deficits.

• He has been placed on a medication that produces serious side-effects.
• He lost his driver’s license because of his seizures.
• He can no longer operate heavy farm machinery.
• He has Medicare but not all of his medication costs are covered.

Managing Epilepsy Well Network

Looking for patterns

• Complexity science looks for patterns to emerge from these relationships.
• How do we help patients like Mr. Farmer address these issues and manage?

Managing Epilepsy Well Network

Responsibilities

• Self-management is an ongoing process.
• Patterns from each person’s complex systems will emerge over time that explain self-management behaviors.
• To help patients become better self-managers we have to help them address the many parts of their systems and also help them begin to identify emerging patterns.

Managing Epilepsy Well Network

In Summary

• People with epilepsy are complex as is the management of their disorder.
• We cannot expect them to change their behavior just based on what they know.
• Bandura states, “Knowledge is necessary but not sufficient for behavior change.”
• We need to help them develop a plan that is sustainable and that works for them.
Introduction to Behavior Change Theories

Nancy J. Thompson, Ph.D., M.P.H.
Associate Professor
Behavioral Sciences and Health Education
Rollins School of Public Health
Emory University

Common Building Blocks

- The Environment where the behavior occurs
- Steps through which behavior change takes place
- Awareness of the behavior and its effects
- Weighing of beliefs about the behavior
- Confidence in performing the behavior
- Skills to perform the behavior
- Sustained motivation to continue the new behavior

Steps to Change

Environment

Confidence
Weighing
Awareness

Knowledge, Cues to Action

Skills

Self-efficacy, self-liberation

Maintenance

Sustained Motivation

Strategies

Steps

Social

Physical

Medication Adherence
Sleep Management
Self-Management

Father models with BP meds
Community passes a noise ordinance
F.O.C.U.S. ON EPILEPSY

Pharmacy is on bus line
Bedroom is free of distractions
PEARLS

Environment Applied

Table:

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Social</th>
<th>Physical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication Adherence</td>
<td>Father models with BP meds</td>
<td>Pharmacy is on bus line</td>
</tr>
<tr>
<td>Sleep Management</td>
<td>Community passes a noise ordinance</td>
<td>Bedroom is free of distractions</td>
</tr>
<tr>
<td>Self-Management</td>
<td>F.O.C.U.S. ON EPILEPSY</td>
<td>PEARLS</td>
</tr>
</tbody>
</table>

A Little Background

- A Theory requires
  - The building blocks (constructs)
  - Relationships among the blocks

- Rather than talk about particular theories and their names
  - Common building blocks
  - How they might vary among theories
Steps Applied

- Computer program determines where a person with epilepsy is on the steps
- Sends the person to materials designed to help move to the next step

Example
- Two sleepiness scales determine whether a person has current sleep problems
- Additional questions determine if they are trying to change but not succeeding
- If both of these are true, they are sent to materials that help
  - Identify where their sleep confidence is low
  - Learn to increase it by removing barriers and seeking help

Awareness

Information
Must be made accessible

Attention
Without attention to it, information is useless. Make it relevant!

Awareness Applied

- **F.O.C.U.S. ON EPILEPSY**
  - Skill building for people with epilepsy and training for their support persons
  - Starts with a 1-day workshop

Example
- Topics for people with epilepsy include common concerns like information about cognitive/memory issues
- Topics for support persons include ways to enhance the support provided
- Through this raised awareness, one couple chose to make their communication a focus of their participation
- The husband learned to give his wife choices in how to receive information (e.g., oral, written)

Weighing

Weighing is part of making a decision

If the reasons for outweigh the reasons against, we decide to change

This gives us the motivation to take action

Weighing Applied

- Computer program
  - Helps patients and their HC providers communicate about epilepsy self-management

Example of Weighing
- Scales identify problematic behaviors
- MINDSET provides options and choices among possible self-management goals
- Advice box presents evidence on benefits and harms to patient and lets patient decide on behaviors to discuss with physician

Confidence

Action requires confidence

Practice helps build confidence

As we build confidence we become ready to change

MOOD STIGMA
Confidence Applied

Sample Epilepsy Scale Items
RESPONSES: 0 (cannot do at all) to 10 (sure can do)
• I can always plan ahead so that I do not run out of seizure medication
• I can always call my doctor when I need to ask a question or report a seizure
• I can always get between 7 and 9 hours of sleep every night
• I can always try to stop a seizure in my own way

Self-Management Skills

• Manage Medications
• Manage Sleep
• Manage Mood
• Manage Stress
• Gain Seizure Control
• Advocate for Self
• Communicate with HC Provider
• Seek Support from Others and more...

Skills Applied

• PEARLS
  – Stepped approach to problem solving for mood management
  – Example: Barbara
    – clarify and define a problem: not taking her medicine on time
    – set realistic goals: take medicine on time this week
    – generate and evaluate potential solutions, then select and implement a feasible solution: developed a schedule that she would follow from the moment she got up
    – evaluate the outcome: if she doesn't follow the schedule and remember her medicine, the quality of her life declines

Sustained Motivation

• Change can become tiring
• People need sustained motivation to keep it up
• Motivation must be internal—commitment is required
• People weigh what they actually experienced from the change against what they expected

Don’t oversell the benefits of changing

Sustained Motivation Applied

• and Sustained Motivation Applied
  – Intervention = mindfulness of thoughts and mood
  – Last Session = Action Plan and Commitment
• Example
  – Plan includes:
    • Reasons to keep practicing mindfulness
    • Listing what to do when tempted to slip into depression
      – for pleasure (call a friend, have a warm drink)
      – for accomplishment (e.g., exercise, clean out a drawer)
  – Commitment: “I am committing to you that I will turn to the 3-minute breathing space whenever I need it”

SOME RESOURCES
Summary of Theories

<table>
<thead>
<tr>
<th>Building Block</th>
<th>Theories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environment</td>
<td>Social Cognitive Theory, Social-Ecological Theory</td>
</tr>
<tr>
<td>Steps</td>
<td>Transtheoretical Model, Diffusion of Innovations, Self-Regulation Theory</td>
</tr>
<tr>
<td>Awareness</td>
<td>Diffusion of Innovations, Transtheoretical Model, Health Belief Model</td>
</tr>
<tr>
<td>Weighing</td>
<td>Health Belief Model, Self-regulation Theory, Social Cognitive Theory, Theory of Reasoned Action, Transtheoretical Model, Motivational Interviewing</td>
</tr>
<tr>
<td>Confidence</td>
<td>Social Cognitive Theory, Theory of Planned Behavior, Transtheoretical Model</td>
</tr>
<tr>
<td>Skills</td>
<td>Transtheoretical Model, Self-regulation Theory, Social Cognitive Theory</td>
</tr>
<tr>
<td>Sustained Motivation</td>
<td>Self-regulation Theory, Transtheoretical Model, Diffusion of Innovations</td>
</tr>
</tbody>
</table>

Applied to MEW Products

<table>
<thead>
<tr>
<th>Product</th>
<th>Theories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on Epilepsy</td>
<td>Self-regulation Theory, Social Support</td>
</tr>
<tr>
<td>MINDSET</td>
<td>Social Cognitive Theory, Transtheoretical Model, Motivational Enhancement Therapy</td>
</tr>
<tr>
<td>PEARLS</td>
<td>Chronic Care Model; Collaborative Care; Problem-solving Therapy</td>
</tr>
<tr>
<td>UPLIFT</td>
<td>Transtheoretical Model; Social Cognitive Theory; Mindfulness-based Cognitive Therapy</td>
</tr>
<tr>
<td>WebEase</td>
<td>Social Cognitive Theory; Transtheoretical Model; Motivational Interviewing</td>
</tr>
</tbody>
</table>

Questions

Improving Mental Health Outcomes in People with Epilepsy: The PEARLS Program

Naomi Chaytor, PhD, ABPP
Director of Neuropsychology
University of Washington Regional Epilepsy Center
Seattle, WA
Intervention Summary

- Home based treatment for depression
- Collaborative care model
  - Master’s level practitioners
  - Psychiatric supervision (adjust/add medication if needed)
  - Communication with neurologist
- Intervention:
  - Problem Solving Treatment
  - Behavioral Activation
  - Pleasant Activities Scheduling
- Eight 50 minute in-home sessions over 19 weeks, then monthly 5-10 minute phone calls
Cognitive-Behavioral Therapy (CBT)

• Noting Thought Patterns

<table>
<thead>
<tr>
<th>Feelings</th>
<th>Situation</th>
<th>Automatic Thoughts</th>
<th>Assumptions</th>
<th>Thinking Pattern</th>
</tr>
</thead>
<tbody>
<tr>
<td>sad</td>
<td>turned down for date tonight</td>
<td>I disgust her</td>
<td>I disgust her because I have seizures</td>
<td>Magnifying — no one will ever date me</td>
</tr>
</tbody>
</table>

Changing the Pattern thru CBT

<table>
<thead>
<tr>
<th>Notice</th>
<th>Question</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joe is upset with me</td>
<td>All I really know is that Joe is frowning</td>
<td>I can ask Joe why he is frowning. I might be able to help.</td>
</tr>
<tr>
<td>I am an idiot</td>
<td>I am over-generalizing and calling myself names</td>
<td>One small mistake does not make me an idiot.</td>
</tr>
</tbody>
</table>

A Recent Addition to CBT—Mindfulness

- defined as, “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally.”
- CBT focuses on changing thought content while mindfulness changes relationship to the thoughts—see them as passing events that do not necessarily represent a state of reality.

Mindfulness is especially important in preventing relapse into depression.
Using Practice and Learning to Increase Favorable Thoughts

Project UPLIFT
- Funded by the CDC
- Delivery of Mindfulness-based CBT
- To People with Epilepsy
- Via Web and telephone
- In Groups of 6-7 people
  - for support surrounding Epilepsy
- By mental health trainees and peer facilitators with epilepsy
  - supervised by a licensed psychologist

<table>
<thead>
<tr>
<th>Session #</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Monitoring Thoughts</td>
</tr>
<tr>
<td>2</td>
<td>Challenging and Changing Thoughts</td>
</tr>
<tr>
<td>3</td>
<td>Coping and Relaxing</td>
</tr>
<tr>
<td>4</td>
<td>Attention and Mindfulness</td>
</tr>
<tr>
<td>5</td>
<td>The Present as a Calm Place</td>
</tr>
<tr>
<td>6</td>
<td>Thoughts as Changeable and Impermanent</td>
</tr>
<tr>
<td>7</td>
<td>Pleasure and Reinforcement</td>
</tr>
<tr>
<td>8</td>
<td>Relapse Action Plans</td>
</tr>
</tbody>
</table>

Depression Scores By Intervention Type
- Phone vs. Web vs. Waitlist
  - $F_{\text{overall}} = 41.65, p = .0001$
  - $F_{\text{interaction}} = 5.93, p = .006^*$

Yvan Bamps, PhD
Managing Epilepsy Well
Rollins School of Public Health
Emory University

Unsolicited Findings
- “I've been really struggling with my son over his homework. Now, I go into the hall and take a 3-minute breathing space so we don’t argue.”
- “My husband noticed a difference in me. He said I seem like I'm more in control of my life.”
- “I told my therapist I think I like this way a lot better...I've always went and talked to somebody versus learning to work through things just using my own mindset.”
- “This is how I expected to feel when I started [drug] therapy.”
- “I have trouble with short term memory and I think working through these lessons can help me with that.”
Coming to a screen near you

- Theory-based, web-based program to promote self-management in people with epilepsy
- Epilepsy Awareness Support and Education
- Goal: direct people toward taking responsibility for self-management
- Stage-tailored information
- Three self-management behaviors
  - Medication management
  - Stress management
  - Sleep management

WebEase Components

**Primary**
- Modules
  - Medication, stress, sleep
  - By working through, participants learn about, think about, and plan next steps for behavioral change
  - MyLog
  - Tracking medications, seizures, triggers, side effects, stress, and sleep

**Secondary**
- Fact Sheets
- Resources
- Video and audio testimonials

Randomized Controlled Study

<table>
<thead>
<tr>
<th>Baseline</th>
<th>Interim</th>
<th>Posttest</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.6</td>
<td>5.8</td>
<td>6.0</td>
</tr>
<tr>
<td>6.2</td>
<td>6.4</td>
<td>6.6</td>
</tr>
<tr>
<td>6.8</td>
<td>7.0</td>
<td>7.2</td>
</tr>
<tr>
<td>7.4</td>
<td>7.6</td>
<td></td>
</tr>
</tbody>
</table>

Treatment Waitlist

\[ P = 0.049 \]
Randomized Controlled Study

Pre-intervention Post-intervention

Self-Efficacy Score

Completer Non-completer

P = 0.013

Next steps

• There is an app for that! (iOS and Android)
• WebEase site usage monitoring
• Upgrades: interface with healthcare providers

FOCUS on Epilepsy:
- engages adults with epilepsy and a significant family member or friend
- centers on developing self regulation skills
- combines group discussion and one-on-one interaction with a coach
- provides education on topics that influence quality of life
- is based outside the clinical setting

Self regulation steps in the program

Figure out the problem or issue
Observe your routine
Choose a change goal
Undertake a specific change strategy
Study the results and select a reward

Shelley Stoll, MPH
Center for Managing Chronic Disease
University of Michigan
Emphasis
Individuals with Epilepsy  Family Members or Friends
A management problem or issue affecting quality of life
Providing effective support in general

Workshop Topics

All
• Introduction to FOCUS Steps
• Focus Areas to Consider
• Healthy Behaviors
• Cognitive effects
• Social and emotional health

People with Epilepsy (PWE)
• Criteria for issue selection
• Identify focus area
• Develop observation plan

Support People (SP)
• Sharing of challenges and positive aspects of supporting PWE
• Develop observation plan

Coaching Calls

<table>
<thead>
<tr>
<th>Call</th>
<th>Content</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>• Select focus area&lt;br&gt;• Develop observation plan</td>
<td>Within week following workshop</td>
</tr>
<tr>
<td>II</td>
<td>• Debrief observation period; make connections&lt;br&gt;• Set goal&lt;br&gt;• Develop strategy; address barriers</td>
<td>1-2 weeks after Call I</td>
</tr>
<tr>
<td>III</td>
<td>• Debrief strategy implementation&lt;br&gt;• Adjust goal or strategy if needed&lt;br&gt;• Celebrate successes</td>
<td>1-2 weeks after Call II</td>
</tr>
<tr>
<td>IV</td>
<td>• Content depends on progress of participant&lt;br&gt;• May continue with same goal or select new</td>
<td>1-2 weeks after Call III</td>
</tr>
</tbody>
</table>

Pilot Participants

Eligibility requirements:
• At least 21 years of age
• Diagnosed with epilepsy for at least one year
• Have at least one seizure in the last year
• Mentally able to participate
• Can recruit a close friend or family member willing to participate in the program

Promising pilot results (significant and/or in right direction)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Baseline score (SD)</th>
<th>4 month f/u score (SD)</th>
<th>Sig (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive affect and well-being</td>
<td>31.12 (5.7)</td>
<td>34.06 (5.3)</td>
<td>p=0.008</td>
</tr>
<tr>
<td>Quality of life (QOLIE-10-P)*</td>
<td>3.47 (0.7)</td>
<td>2.90 (0.8)</td>
<td>p=0.001</td>
</tr>
<tr>
<td>Depression (PHQ-9)*</td>
<td>9.29 (6.1)</td>
<td>7.94 (5.4)</td>
<td>p=0.121</td>
</tr>
<tr>
<td>Healthy days (of past 30) BRFSS</td>
<td>15.65 (2.7)</td>
<td>18.24 (2.5)</td>
<td>p=0.302</td>
</tr>
<tr>
<td>Self management behaviors</td>
<td>44.82 (7.6)</td>
<td>45.53 (7.6)</td>
<td>p=0.671</td>
</tr>
</tbody>
</table>

*increase in score is desired
From pilot participants with epilepsy

“I plan to keep moving forward to empowering and taking my life into my hands regardless to how epilepsy has tried to conquer me. I am mine and this program just reassured me of that.”

“The group support was the most important part. I am not the only one out there. I have felt so alone for so long. I don’t anymore.”

“Once I started taking care of myself more, I reduced the seizures, was able to do more things that I hadn’t been able to. I took a trip by myself to visit some friends and worked this summer.”

From friends or family members in pilot

“Having gone through the FOCUS workshop allowed me to better appreciate what the individual with epilepsy is trying to contend with. It allows the support people to position themselves to be more supportive.”

“. . . the fact that my mother asked me to come (was most rewarding). We made the connection that she wants some support in this. The program helped equip me to support her.”

Key process findings from pilot

Participants most valued:

• One-on-one coaching
• Interacting with others
• Meeting in-person at the workshop
• Information presented at the workshop
  • Social and emotional impacts
• Using the FOCUS approach as a tool
• Workbook

Next Steps for FOCUS on Epilepsy

Questions

Special thanks to:
CDC Epilepsy Program
Epilepsy Foundation

To receive news from the MEW Network contact or provide feedback: Yvan Bamps at ybamps@emory.edu

MEW Network Website
http://www.sph.emory.edu/ManagingEpilepsyWell/
PEARLS
http://www.pearlsprogram.org/