

Lessons Learned: dissertation to retirement

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Chronic Diseases Require Changes in Health Care Practice

- ❖ The goal is function and comfort, not cure
- ❖ The sites of care change from clinic and hospital to community
- ❖ The role of the health care provider changes from principle care giver to teacher and partner
- ❖ The role of the patient changes

How Does the Role of the Patient Change?

- ❖ They must manage the disease(s)
- ❖ They must maintain their life roles
- ❖ They must deal with the emotional consequences of the disease(s)
- ❖ They are sometimes the only carrier of vital information.

Self-Management: What Is It?

Self-management is defined as the tasks that individuals must undertake to live with one or more chronic conditions.

These tasks include having the confidence to deal with the medical management, role management, and emotional management of their conditions.

Institute of Medicine 2004

Stanford Self-Management Programs

- ❖ Built on structured patient and professional needs assessments (usually focus groups)
- ❖ Systematically use strategies to enhance self-efficacy
 - Skills Mastery
 - Modeling
 - Reinterpretation of Symptoms
 - Social Persuasion

Stanford Self-Management Programs

- ❖ Peer led small groups/Internet
- ❖ Standardized training for leaders
- ❖ Highly structured teaching protocol
- ❖ Standardized participant materials
- ❖ Several topics per session
- ❖ Evaluated in randomized trials for long term outcomes

Stanford Self-Management Programs

- ❖ Chronic Disease Self-Management
(14 Languages)
- ❖ Arthritis Self-Management
(5 Languages)
- ❖ Diabetes Self-Management
(2 Languages)
- ❖ Positive Self-Management
(HIV/AIDS) (3 Languages)

Modes of Delivery

- ❖ Six week small Group
(all programs)
- ❖ Six week via the Internet
(chronic disease, arthritis, diabetes)
- ❖ One time mail delivered
(arthritis only)

Chronic Disease Self-Management Program - What Is It?

- ❖ Small groups 10-16 people
- ❖ People with many different diseases and comorbid conditions in same group
- ❖ 2 ½ hours per week for 6 weeks
- ❖ Peer taught
- ❖ Literacy not necessary



What is Taught?

- ❖ Managing pain, fatigue, depression, SOB
- ❖ Exercise
- ❖ Relaxation Techniques
- ❖ Healthy Eating
- ❖ Communication Skills
- ❖ Medication management
- ❖ Advanced directives
- ❖ Problem Solving
- ❖ Action Planning

So Where Is the Evidence?

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Small Group Chronic Disease Self- Management Program - Randomized Trial

Demographic Data

- ❖ Age 62 years
- ❖ Male 27%
- ❖ Education 14 years
- ❖ No. Diseases 2.2



Percent with Common Diseases

❖ Lung disease	21%
❖ Heart disease	24%
❖ Diabetes	26%
❖ Arthritis	42%

Chronic Disease Self-Management

6-Month Improvements in Health Outcomes ($p < .05$)

- ❖ Self-Rated Health
- ❖ Disability
- ❖ Social and Role Activities Limitations
- ❖ Energy/Fatigue
- ❖ Distress with Health State

Chronic Disease Self-Management

Improvements in Utilization and Costs ($p < .05$)

- ❖ Average .8 fewer days in hospital in the past six months ($p = .02$)
- ❖ Trend toward fewer outpatient and ER visits ($p = .14$)
- ❖ Estimated cost of intervention \$200

Diabetes Self-Management Spanish

Small Group



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Diabetes Self-Management What is Taught?

Healthy Eating	6 weeks
Sharing/Problem Solving	6 weeks
Action Planning	5 weeks
Exercise	2 weeks
Preventing Hypoglycemia	1 week
Monitoring glucose	1 week
Stress/Depression	3 weeks
Medications	1 week
Preventing Complications	1 week
Communication skills	2 weeks
Sick Days	1 week

Spanish Diabetes Self-Management small group randomized trial ($n=417$)

Demographic Data

- Age 52.8 years
- ❖ Male 38%
- ❖ Education 7.5 years
- ❖ Born in Mexico 72%
- ❖ All type 2 diabetics



Diabetes Self-Management 6 and 18 month outcome

- ❖ HBA1c(-.36)-----Baseline (7.3)
- ❖ Less Health Distress
- ❖ Fewer Symptoms of Hyperglycemia
- ❖ Fewer Symptoms of Hypoglycemia

- ❖ At 18 months all improvements remained as well as -.5 MD visits and-.2 ED visits in six months

all p<.05

But Something Funny Happened

As reinforcement half the participants received monthly Automated Telephone Calls



Something Funny Happened

At 18 months there were no differences between those receiving and those not receiving reinforcement.

Diabetes Self-Management English

Small Group



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Diabetes Self-Management 6 month outcome *Treatment/Control*

- ❖ HBA1c(0)-----Baseline (6.7)
- ❖ Less Depression *
- ❖ Fewer Symptoms of Hypoglycemia*
- ❖ Increased Aerobic Exercise*
- ❖ Improved Communication with MDs*
- ❖ Improved Self-Efficacy*

❖ p<.05

Diabetes Self-Management 12 month longitudinal outcome

- ❖ HBA1c(-.1)-----Baseline (6.7)
- ❖ Less Depression *
- ❖ Less Weight (-1.1 Kg)*
- ❖ More Frequent Glucose Monitoring*
- ❖ Improved Communication with MDs*
- ❖ Improved Patient Activation*
- ❖ Improved Self-Efficacy*

❖ p<.05

What Really Happen to HbA1c

- ❖ 88% of those with baseline HbA1c less than 7 continued to have a 12 month HbA1c less than 7 (change .2)
- ❖ 45% of those with baseline HbA1c greater than 7 had a had a 12 month HbA1c 7 less than 7 (change -1.1)

Internet Chronic Disease Self Management

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Intervention Characteristics

- Six-week workshop (entirely on-line anywhere there is Internet access)
- 20-25 people with different types of chronic disease participate together
- New workshop session starts each week
- No "real time" commitment
- Peer led by two moderators
- Highly interactive (discussion boards)
- Participants asked to log on 2-3 times a week for a total of 1-2 hours.

Recruitment Methods

- ❖ Web Site Links
- ❖ Search Engines
- ❖ Press Releases
- ❖ Media Interviews
- ❖ E-newsletters
- ❖ Referral from friends

Log-In Page for Workshop

SELF-MANAGEMENT @ STANFORD
Healthier Living with Diabetes • diabetest.med.stanford.edu

New to this site?
Stanford School of Medicine is sponsoring a workshop and study to help people with type 2 diabetes manage the problems caused by diabetes.

Benefits of joining

- Learn to manage your symptoms better
- Learn to manage your blood glucose (sugar) better
- Learn ways to balance food, exercise, medication and stress
- Learn tips to manage your day-to-day activities
- Get support from others with diabetes
- Share your experiences and help others

[Click here to learn more](#)

[Learn More Now](#)

If You Are Native American, Click Here

Already a member?

Member Sign In

Your username:

Your password:

[Forgot your user name or password?](#)

Home Page

Home | Learning Center | Discussion Center | My Tools | Post Office | Class Profile | Help

Healthier Living with Ongoing Health Problems / Learning Center / Welcome to Session 1 of 6

Welcome to Session 1 of 6

Learning Center

This week's session:

- [Introduction to Healthier Living On-Line](#)
- [Workshop Responsibilities](#)
- [Acute Versus Chronic Conditions](#)
- [Mind and Body Connection](#)
- [Self-Management Tasks?](#)
- [Problem Solving](#)
- [Choices of Pain](#)
- [The Power of Our Minds](#)
- [Short-Term Distraction](#)
- [Goal Setting](#)

Discussion Center

- [Action Planning How?](#)
- [Celebrations How?](#)
- [Relaxing Exercises](#)
- [Problem Solving How?](#)

My Tools

- [Action Plans](#)
- [Fitness Logs](#)
- [Goals](#)
- [Journal](#)
- [Health Profile](#)
- [Distraction Zone](#)

Things To Do in This Session

Complete Session 1 in the Learning Center.

Discussion Center

This week's hot topics	Total Messages	New Messages
Action Planning	26	topics: 5 replies: 13
Celebrations	12	topics: 6 replies: 8
Difficult Emotions	13	topics: 6 replies: 3
Problem Solving	43	topics: 19 replies: 24

Discussion Center Reply

Original Message - Having to change my career

Grace [View Profile](#) **07/19/2007 12:34 PM**
 I am starting to think that my health problems and job demands are just too much. I run my own business out of my home, and more and more I feel too tired to keep up with it all. I love what I do, and the thought of not having that in my life makes me very sad.

[Go to Next Unread Message](#) [Reply](#)

Replies

SuzieQ [View Profile](#) **07/19/2007 12:50 PM**
 It is great that you have gotten student involved to help you out. Can you bring them in more often to take some of the stress off? Think about what you really do like about your work. Is it running a business, being with the kids, making plans.... Focus on what you really like from the experience to help you with your future plans. The future plan does not have to happen right now, but make it something you will still be excited about.

emp123 [View Profile](#) **01/28/2008 02:21 PM**
 I agree with SuzieQ. Think about what really matters to you and how other people can help you out from time to time.

Who Participated?

- ❖ Randomized: 958 participants with heart disease, lung disease, and type 2 diabetes
- ❖ Age: 57 years (22-89)
- ❖ Education: 15 years (8-23)
- ❖ Female: 71%
- ❖ Married: 68%
- ❖ Caucasian: 87%
- ❖ Access: 97% logged on either at home or at work
- ❖ Average number of visits to health related web site in 6 month period: 10

* No significant difference between treatment and controls at baseline.

1 year Improvements

Treatment (n= 354) vs. Controls (N=426)

- ❖ Health distress
- ❖ Fatigue
- ❖ Shortness of breath
- ❖ Pain
- ❖ Exercise
- ❖ Practice Stress Management
- ❖ Self-efficacy

*all p<.05

These results are not significantly different than those seen in community based small group studies.

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England Expert Patient On-Line Demographics (N=594)

- ❖ Average Age 44 YEARS
- ❖ Male 22 %
- ❖ Employed 33%
- ❖ Professionals 50%
- ❖ Chronic Conditions 1.6
- ❖ Caucasian 94%

Expert Patient Program On-Line One Year Longitudinal Improvements

- ❖ Fatigue
- ❖ Health Distress
- ❖ Shortness of Breath
- ❖ Pain
- ❖ Communications with Physicians
- ❖ Exercise
- ❖ Self-Efficacy

p<.05
74% return rate

Expert Patient Program On-Line One Year Longitudinal Outcomes

- ❖ Reduction in Visits to Physicians
- ❖ Reduction in visits to emergency departments

P<.05

Translation

- ❖ Program being used by 700+ organizations in 20 countries and 14 languages.
- ❖ 1000 to 15,000 trainers world wide.

Characteristics of Successful Programs

- ❖ Based on patient needs assessment
- ❖ Emphasis on:
 - Problem-solving
 - Goal-setting/action planning
 - Improving self-efficacy
 - Patients helping patients
 - Self-tailoring
 - Modeling
 - Presentation in broadcast language
 - Developed for translation

What Next

- ❖ Cancer Survivors small group
- ❖ Cancer Survivors on-line
- ❖ Caregivers on-line
- ❖ Whatever looks interesting and fun



Questions and Discussion

Please!!

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