

# Lifestyle Counts

Quantifying the Effects of  
Interventions to Promote  
Health & Quality of Life

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# Background

- Clinical Background
- Focus not on disease or disability but the person's response to living with disease or disability
- Sharing "lessons learned" from almost 4,000 research participants over an 18 year period

# Key Questions

- What makes a difference in how persons experience their quality of life?
- What can we do to help individuals promote their health and quality of life?

# Series of Related Studies

- What health promotion practices do persons with chronic disabling conditions engage in?
- Are there differences in health promotion behaviors related to age, gender, medical condition, or environmental context (rural/urban)?

- What factors are associated with the frequency of health promoting behaviors?
- How are health promotion behaviors associated with quality of life outcomes?

- How can we enhance health promotion practices in persons with chronic disabling conditions?
- What are the outcomes of improving health promoting behaviors?

# Variety of Study Populations

- Clients of Independent Living Centers
- Persons with Multiple Sclerosis (MS)
- Persons with post-polio syndrome
- Women with mobility impairments
- Women with fibromyalgia



# Key Sources of Support

- National Institutes of Health
  - National Institute of Nursing Research
  - Office of Research on Women's Health
  - National Institute of Child Health & Human Development - National Center for Medical Rehabilitation Research
- National MS Society
- Rehabilitation Nursing Foundation
- The University of Texas at Austin
- National Institute of Disability & Rehab Res.

# Key Questions

- What is the ultimate goal of your program of research?
- What will it take to get you to that point?

- Descriptive Pilot Work - document there is a problem or need
- Instrumentation - are existing measures valid for your population
- Develop intervention
- Pilot Intervention
- Trial of Intervention

## For each proposal articulate

- What you have done
- What you need to do and why this is the right next step
- How this study will help move you to the “ultimate” goal

# Health Promotion in Persons with Chronic & Disabling Conditions

- Pilot Study - 1988
  - Do health promotion & wellness concepts apply to persons with disabilities
  - Interviews with students with disabilities
  - Major findings
  - Beginning documentation of need and interest

# Descriptive Correlational Studies

- Examining predictors of health promoting behaviors in larger samples
- Testing instruments - reliability and validity
- Issues related to administration of instruments
- Qualitative component to study

# Key Findings of Early Studies

- Strong interest in health promotion & wellness
- Excellent participation rates and retention
- Consistent finding that most rated their health as good or excellent
- Health described in non-clinical terms

I can get the disease message  
and I can get the general health  
promotion message, but how do I  
promote my health in the context  
of my disability?



What is the “so what” of  
health promotion  
behaviors?

- Initiated studies to examine the empirical relationship between health promotion and quality of life outcomes
- Qualitative study to verify inclusion of key factors and validate measurement

# Findings

## – Antecedents

- Attitudinal factors predict health behaviors more strongly than illness or demographic factors

## – Outcomes

- Frequency of health behaviors positively related to quality of life, depression, perceived health

## – Measurement

- Adaptation and extension to current measures

# Longitudinal Studies

- Verify that cross-sectional findings hold over time
- Now in 7th year of study with over 600 persons with MS
- Persons with MS who are “high health promoters” accumulate significantly less impairment over time than those who are “low health promoters”

# Intervention Studies

- Use findings from earlier studies to build an intervention that would increase health behaviors and impact quality of life outcomes
- Intervention targets modifiable factors most closely linked to health behaviors - self-efficacy, barriers and social support

## Findings - Women with MS

- Randomized clinical trial of efficacy based intervention resulted in significant improvements over 8 months in
  - Self-efficacy
  - Health Behaviors
  - Health Outcomes

# Competing Continuation - “Lifestyle Counts”

- Funded July 2003 to June 2007
- Adaptation and testing of intervention with women with fibromyalgia syndrome
- Address concerns from earlier intervention

# Issues of Concern

- How do you conduct a study that will yield practical information applicable in the current health care context?
- What are the implications for study sample, design and measurement?



# Sample Recruitment/Retention

- Traditionally - study select populations with strict inclusion/exclusion criteria
- Expanding representation with fewer exclusions increases generalizability
- Allow for broad-based community recruitment rather than specific select settings
- Increasing heterogeneity of sample can make it more difficult to find group differences

- Difficulties advertising a randomized clinical trial
- Recruitment and retention of minority participants
- Maintaining connection to study over eight-month period - logos, incentives

# Design of Intervention

- Is a randomized design feasible?
- Issues related to standardization of intervention vs individualization
- Assessing the impact of different components of the intervention & different sites
- Tracking impact of intervention over a meaningful time period

# Measurement Issues

Valid change measures demonstrate observable differences when the underlying characteristics being measured changes sufficiently to be meaningful in applications such as clinical setting (Lipsey, 1990)

- Potential for ceiling effects in standard measures
  - Who volunteers to be in health promotion studies?
- Goal Attainment Scaling as an additional measure of study outcomes

Becker et al,(2000). Goal attainment scaling to measure individual change in intervention studies. *Nursing Research* 49(3), 176-180.

# How do you know if your intervention is responsible for the change?

- Other factors to consider
  - Time/Maturation
  - History (changes in medical treatment, new research findings - e.g. HRT study)
  - Attention effects
  - Cohort Effects
- Measure change in multiple outcomes that are meaningful

# Concluding thoughts

- Building a program of research - may not always be linear but relationships among studies should be evident
- Persevere
- The best known instruments may not work well with your population and may not be sensitive enough to measure change in your intervention

- Learn from your successes and challenges
- Listen to your participants and your critics
- Design your intervention to reflect what you have learned in your earlier studies
- The easiest and most direct path may not be the right path