Improving Health and Wellness for Persons with Chronic and Disabling Conditions: Evidence for Practice

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Alexa Stuifbergen has no conflicts to report.
Learner Objectives

✓ The learner will be able to:

✓ Discuss philosophical perspectives and the associated data underlying health promotion for persons with chronic & disabling conditions

✓ Describe the evidence supporting health promotion interventions to improve quality of life for persons with chronic & disabling conditions
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Collaborators

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Millions of persons worldwide live with some type of chronic and/or disabling condition.
Trends

✓ Increasing numbers of persons with chronic conditions due to:
  ✓ Aging of population
  ✓ Survival of those with early onset conditions
  ✓ Medical treatment extending lifespan

✓ Direct medical and indirect annual costs associated with disability are increasing rapidly
The traditional focus of many health care systems on cure, longevity and quantity of life is shifting to a focus on increasing the quality and years of life through a healthy lifestyle.
Health Promotion

✓ Process of enabling people to increase control over and to improve their health (WHO, 1986)

✓ Activities directed toward increasing the level of well-being and actualizing the health potential of individuals, families and communities (Pender, 1987)
Health Promotion Activities

✓ Ongoing activities to maximize health
✓ Emphasis on lifestyle
✓ Include
  ✓ Physical activity
  ✓ Healthy eating practices
  ✓ Managing stress
  ✓ Seeking social support
The need for health promotion may be even more critical for persons with chronic disabling conditions whose quality of life and ability to continue living independently are often heavily dependent on maintaining their narrow margin of health.

DeJong & Batavia
Key Question:

✓ Does the practice of health promoting behaviors make a difference in quality of life for persons with chronic disabling conditions?
Program of Research

- Factors related to health promotion in persons with chronic disabling conditions
- Longitudinal study of health promotion behaviors and quality of life
- Development and testing of interventions to enhance healthy lifestyles in persons with chronic & disabling conditions
Focus on the strengths and positive resources that people with chronic conditions use in their everyday lives in the community to maintain and enhance their quality of life.
Findings and “lessons learned” from more than 4,000 research participants over more than 25 years.
Program of Research

✓ 22 related studies
✓ Qualitative and quantitative methods
✓ Some specific to diagnosis or functional limitation (e.g., mobility impairment)
✓ Largest number of studies with persons with multiple sclerosis (MS)
Early Findings

- Interested in health promotion behaviors
- Viewed their health positively
- Need to adapt health behaviors to context of chronic disabling condition
- Need to address barriers and self-efficacy
Interest in Health Promotion

✓ Strong interest by participants “So glad someone is finally studying what works for us”
✓ High response rates (80-90%) despite difficulties in completing studies
Positive Views of Health

✓ In two samples of persons with a variety of chronic and disabling conditions - more than 70% rated their health as good or excellent

✓ Viewed their health in functional terms -- “am I able to do the things I want and need to do?” -- rather than in clinical terms of diagnosis or impairment
Health Behaviors

✓ Must be adapted to their particular context -- “How do I exercise safely and effectively when I use a wheelchair?”

✓ Must recognize the barriers and lack of knowledge of what to do and confidence in how to do it
Self-Efficacy for Health Practices

✓ Developed an instrument specific for persons with chronic and disabling conditions (Self-Rated Abilities for Health Practices; Becker, Stuifbergen, Oh & Hall, 1993)

✓ Consistently the strongest predictor of persons actually engaging in health behaviors and sensitive to change

✓ Across samples -- significantly lower in Self-Efficacy for Exercise/Physical Activity
Early Challenge

✓ Initial focus on predicting and describing health behaviors in persons with chronic and disabling conditions

✓ Little research at the time addressing the key question of how health behaviors were linked to outcomes
Preliminary Study

✓ Frequency of health promoting behaviors and perceived quality of life correlated at $r = .56$

✓ Combination of specific self-efficacy for health practices, financial resources, reciprocity and health promoting behaviors explained 69% of the variance in quality of life

(Stuifbergen, 1995)
✓ Phase I - Qualitative methods used to refine & validate a model of health promotion and quality of life for persons with chronic and disabling conditions (Persons with MS as exemplars)

Phase II

✓ Refined model was tested with a large sample (N=807) of persons with MS

Phase III

✓ Model was cross-validated in test with a sample of persons with a second chronic neurological condition - post-polio (N=1,603)

Phase IV (ongoing)

✓ Longitudinal follow-up of the Phase II MS participants to examine the trajectory of illness-related limitations and quality of life outcomes
✓ Now in its 21st year of follow up
✓ Supported from 1993-2012 by the National Institutes of Health 2R01 NR003195
Phase 1 Qualitative Study

- 20 persons with MS (Mean age= 43 yrs.; 75% were female)
- Interviewed each person twice
- “Tell me what its like for you to live with MS?”
  How does MS affect your life?”
Health Promotion Behaviors

✓ Useful to manage disease-related symptoms
✓ Resulted in ‘feeling better’ and ‘having more energy’
✓ Positive social aspects
✓ Health promoting behaviors essential to maintaining an acceptable quality of life
Phase 1 Outcome

✓ Preliminary model of health promotion and quality of life that could be tested using quantitative methods
1996- Survey Study with Persons with MS (Phase II)

✓ Participant characteristics (N=834)
  ✓ Average age of 48 (range 18-95)
  ✓ 80 % of respondents were female
  ✓ 70 % were married
  ✓ 39 % were employed full or part-time
  ✓ 93 % completed 12 years or more of school
  ✓ Had MS for an average of 11 years (range 6 months to 50 years)
Key Findings

✓ Factors most strongly related to perceived quality of life were:

✓ Social Support (.64)
✓ Barriers (-.63)
✓ Self-efficacy for health behaviors (.54)
✓ Health promoting behaviors (.53)
✓ Severity of MS limitations (-.53)
Model Testing

✓ Antecedent variables (functional limitations, resources, barriers, acceptance, self-efficacy) explained 58% of the variance in health promoting behavior

✓ Antecedent variables and health promoting behaviors explained 66% of the variance in quality of life
Structural Equation Modeling

Overall model fit $x^2 (8, N=786) = 77, P,>05; GFI=0.96, IFl=0.98; CFI=0.98$

Importantly...

Health Promoting behaviors mediated the impact of MS-related functional limitations on quality of life.
Model Development & Testing

✓ The model, developed initially with data from persons with MS, generalized to persons with post-polio syndrome

✓ Explanatory model has subsequently been used to guide intervention work with women with MS, FMS, HIV, persons with heart failure and low income cancer survivors
The Long-Term Impact of Health Promoting Behaviors on Functional Limitations and Quality of Life for Persons with Multiple Sclerosis
Ongoing Longitudinal Study

✓ Longitudinal descriptive design to assess patterns of change
✓ Sample for the longitudinal study recruited from the participants in the cross-sectional study (Phase II, 1996-97)
Participants

- Study information & questionnaires mailed to 749 persons from cross-sectional study who had agreed to subsequent contacts.
- Once enrolled in 1999, they have received questionnaires annually unless they requested to be dropped from the study.
- 621 chose to continue in longitudinal study.
Response Rates Over Time

- Each year 83-90% of eligible participants have responded
- Currently more than 300 remain actively enrolled in Year 20 of the longitudinal data collection
Findings regarding progression of functional limitations - longitudinal study with persons with multiple sclerosis.
Study Purpose

✓ Explore the trajectories of functional limitations, health behaviors (physical activity) and perceived quality of life over time in a sample of persons with MS
Data Analysis

✓ Multivariate latent curve modeling
✓ Change in an outcome is estimated at the population level as well as the individual level
✓ Allows for individual differences in rates of change over time - very important in MS research
✓ Also consideration of multiple outcome variables simultaneously to study correlations between characteristics of change
Findings
Correlations Among Rates of Change

- Rates of change in functional limitations were negatively correlated with rates of exercise behaviors and quality of life ratings.
- Changes in functional limitations and level of exercise behaviors at Time 1 were negatively related - suggesting that higher exercise levels at Time 1 were related to decreasing functional limitations over time.

Stuifbergen, Blozis, Harrison & Becker, 2006
More recently…

✓ Longitudinal studies using analyses that allow examination of both individual and group level of change are particularly appropriate when examining trajectories of change in persons with MS and other chronic conditions that have variable or individualized progression and presentation of the disease (e.g., lupus, arthritis)
Using Descriptive and Longitudinal Data to Build Interventions
Intervention Development

✓ Originally - theoretically and data-based intervention to promote health and well-being of women with MS
✓ Subsequently adapted for men with MS
✓ Adapted and tested with women with fibromyalgia, women with HIV, cancer survivors and others
Theoretical Basis

✓ Self-Efficacy Theory (Bandura)
✓ Health Promotion Theory (Pender)
✓ Health Within Illness (Moch)
Model Guiding the Intervention

Context of Living with Fibromyalgia

- Barriers
- Resources
- Self-Efficacy

Health Promoting Behaviors

Perceived Health and Well-Being
Wellness Intervention Goals

✓ Engage participants in assessing their present health behaviors
✓ Assist in setting meaningful goals for change
✓ Address barriers, resources and skills necessary to change
Intervention Processes

- Providing accurate information specific to health promotion within the context of their chronic condition or disability
- Enhancing self-efficacy for health behaviors
  - Verbal Persuasion
  - Modeling
  - Performance accomplishment
- Individualized goal setting and monitoring
Intervention Structure

✓ Randomized clinical trial
✓ Phase I - educational and skill building lifestyle change program
  ✓ 8 sessions over an 8 week period
  ✓ Sessions co-led by nurse and person with the condition
✓ Phase II - supportive phone follow-up
  ✓ Bi-monthly phone calls from intervention facilitator
  ✓ Goal setting and monitoring
Intervention Sessions

✓ Maximizing health while living with a chronic disabling condition
✓ Lifestyle adjustment
✓ Physical Activity (2 sessions)
✓ Healthy eating
✓ Stress management
✓ Relationships, intimacy & sexuality
✓ Women’s health issues
Changes in Health Behaviors

Cont

RX

T1 T2 T3 T4

Control

RX
Overall findings - MS Sample

- Significant improvements in self-efficacy scores, health behaviors and selected dimensions of quality of life (pain and mental health scores, employment status)

✓ Adaptation of intervention and successful outcomes in
✓ Women with fibromyalgia
✓ Men with MS
✓ Women with HIV
✓ Low-Income Cancer Survivors
✓ Cancer Survivors with pre-existing disability
Implications for Practice

Based on Evidence from Longitudinal and Intervention Studies
Low cost health promotion interventions may hold substantial promise as a complementary strategy for decreasing the burden of functional limitations among persons with chronic disabling conditions.
✓ Persons with chronic conditions generally have positive perceptions of their health and a strong interest in health promotion activities
✓ Participation in health behaviors is related to positive changes in health and well being
✓ Persons with chronic disabling conditions need the knowledge and skills to exercise safely
  ✓ Adaptive fitness
  ✓ Access to facilities
  ✓ Cultural issues
✓ Most important predictors of participation in health behaviors are attitudes, not demographic or illness-related variables
✓ Attitudes can be changed
✓ Importance of messages from media and health care professionals
Encourage collaboration between providers, community and researchers for

- Appropriate, culturally sensitive interventions
- Systematic evaluation of innovative programs
- Dissemination of findings to community of persons with chronic and disabling conditions