Title: SPECIAL SESSION: Improving Health and Wellness for Persons With Chronic and Disabling Conditions: Evidence for Practice

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Type: Oral

Keywords: chronic disabling conditions, health promotion and quality of life

Description/Overview: This presentation will summarize a 25-year program of research describing the impact of health promotion behaviors on quality of life for persons with a range of chronic and disabling conditions. Findings from studies using descriptive and experimental designs and qualitative and quantitative methods will be discussed.

Final Number: K 13
Slot: K 13: Saturday, 29 July 2017: 3:30 PM-4:00 PM

References:


**Learning Activity:**

<table>
<thead>
<tr>
<th>LEARNING OBJECTIVES</th>
<th>EXPANDED CONTENT OUTLINE</th>
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<tbody>
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<td>The learner will be able to discuss philosophical perspectives and the associated data underlying health promotion for persons with chronic and disabling conditions.</td>
<td>The philosophical perspective of health within illness will be illustrated with descriptive data from studies with persons with chronic and disabling conditions.</td>
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<td>The learner will be able to describe the evidence supporting health promotion interventions to improve quality of life for persons with chronic and disabling conditions.</td>
<td>The theoretical and empirical underpinnings of a wellness intervention for persons with chronic disabling conditions will be detailed and findings related to the impact of the intervention with persons with MS, women with fibromyalgia, low income cancer survivors, and women with HIV will be presented.</td>
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**Abstract:**

**Purpose:** One of the most significant and intriguing questions for both researchers and clinicians interested in developing interventions to prevent disability and promote quality of life among persons with chronic conditions is: What factors (other than biological impairment and disease process) influence the development of functional limitations and explain the progression of functional limitations to disability? For more than 25 years we have explored this question with
persons experiencing a variety of chronic disabling conditions through descriptive and intervention research using both qualitative and quantitative methods. The extensive data underlying this program of research comes from persons with a variety of disabilities and diagnoses including those with multiple sclerosis (MS), post-polio syndrome, fibromyalgia, diabetes, mobility impairments, HIV and cancer survivors.

**Methods:** Initially we explored whether persons with chronic and disabling conditions considered the philosophical perspective of health promotion as relevant to their lives. Descriptive and longitudinal data were used to design and test wellness interventions with persons with a variety of chronic disabling conditions.

**Results:** Our early work revealed that these individuals had strong interest in this perspective and that they were challenged by a lack of information about how to practice health promotion within the context of their specific condition. The majority of participants viewed their health as good or excellent despite the fact that they were living with an often serious and limiting chronic condition or disability (Stuifbergen, Becker, Inglasbe & Sands, 1990). Participants had strong interest in improving the skills and knowledge needed to improve health behaviors and address barriers. They identified the positive impact of health behaviors as enhancing their overall well-being, managing difficult symptoms (e.g. fatigue, weakness), and enhancing the social connectedness in their lives (Stuifbergen & Rogers, 1997). A large descriptive study with more than 800 persons with MS as exemplars of those with chronic conditions was used to develop and test a model of health promotion and quality of life for persons with chronic disabling conditions. Findings indicated that health promoting behaviors mediated the impact of functional limitations on quality of life (Stuifbergen, Seraphine & Roberts, 2000). The model was subsequently cross-validated in a sample of 1,600 persons with post-polio syndrome (Stuifbergen, Seraphine, Harrison, & Adachi, 2005).

The initial large descriptive study with persons with MS continued as a longitudinal study, “Health Promotion and Quality of Life in Chronic Illness” and is now in its 21st year of data collection. The data from this study allow detailed exploration of how selected self-directed psychosocial and behavioral factors may influence the trajectory of functional limitations, disability, and quality of life in persons with MS. Most recently we have documented that the practice of health behaviors – specifically exercise – over an eleven-year period improves the trajectory of functional limitations for those with MS (Stuifbergen, Blozis, Becker, Harrison & Kullberg, 2016).

Building on the findings from descriptive and longitudinal research, our team developed a theoretically and empirically-based lifestyle intervention for women with MS (Stuifbergen, Becker, Rogers, Timmerman & Kullberg, 1999). In a randomized-controlled trial, the women in the intervention group had significant improvements in self-efficacy for health behaviors, the frequency of health behaviors and mental health and pain scores compared to those in the control group (Stuifbergen, Becker, Blozis, Timmerman & Kullberg, 2003). Next, the team developed a process for adapting interventions for persons with other chronic conditions (Stuifbergen, Harrison, Becker & Carter, 2004) and the lifestyle based intervention was subsequently adapted and tested for persons with fibromyalgia syndrome, cancer survivors, women with HIV, men
with MS, and cancer survivors with functional limitations (Becker, Henneghan, Volker & Mikan, 2017; Meraviglia, Stuifbergen, Parsons, & Morgan, 2013: Stuifbergen et al, 2010).

**Conclusion:** 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. An emerging body of evidence supports the positive impact of health promotion/wellness interventions on quality of life outcomes for persons with chronic disabling conditions (Stuifbergen, Morris, Jung, Pierini, & Morgan, 2010).