Professionals in Epilepsy Symposium
New Evidence in Psychosocial Interventions for Managing Epilepsy: Introduction & Overview

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American Epilepsy Society | Annual Meeting
## Disclosure

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Learning Objectives

• Review self-management conceptualization
  • Describe programs under study
• Identify research and practice implications
Introduction & overview

- Self-management conceptualization & outcomes
- Interventions thus far
- Current programs under study
- Research & practice implications
- Conclusion & take home points
Self-management conceptualizations

- Different conceptualizations without consensus in epilepsy

Buelow & Johnson, 2000
Self-management conceptualizations

- Self-management has previously been conceptualized as adherence but literature supports a more complex concept that includes the skills and behaviors needed to manage seizures, life and epilepsy treatments such as medications and is associated with increased quality of life.

Buelow & Johnson, 2000
Self-management conceptualizations

• Self-management has been associated with self-efficacy
• Self-efficacy has been defined by Dilorio and colleagues’ as “the personal conviction of one’s capabilities to initiate and successfully complete tasks associated with the daily management of epilepsy”

*Dilorio et al., 1992*
Self-management definitions

• Bandura and Social Cognitive Theory: self-efficacy and the behaviors a person uses to manage their health
• Bodenheimer; Creer: self-management is a process used by a person to manage their health or chronic illness; an active process

Bandura, 1997; 1998; 1999; Bodenheimer, 2003; Creer, 1997
Self-management definition

- Self-management specific tasks: medical, emotional, & role management
- Skills:
  - problem solving
  - decision making
  - resource utilization
  - the formation of a patient-provider relationship
  - action planning
  - self-tailoring

*Lorig & Holman, 2003*
Self-management definition

- Expansion of self-management to include:
  - Both individuals and families participate in the management of chronic conditions
  - Risk and protective factors influence individuals’ and families’ abilities to manage chronic illness, these factors can be targets for interventions to support self- and family-management

Grey, Knafl & McCorkle, 2006
Self-management definition

• Expansion of self-management to include:
  – Effective self- and family-management of chronic conditions can lead to improved conditions & outcomes

Grey, Knafl & McCorkle, 2006
Self-management definition

• Institute of Medicine (2003) definition:
  – “The systematic provision of education and supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support.”

IOM, 2003
Self-management definition

- *Living Well with Epilepsy* (2003) definition:
  - Self-management is the process of managing epilepsy as well as the behaviors needed to control seizures and manage the effects of having a seizure disorder, and also includes the active partnership between the health care team and the person with epilepsy as critical to improved health outcomes.
Self-management outcomes

- What has been measured overall in chronic illness:
  - Physical factors
  - Psychological factors
  - Health status
  - Knowledge
  - Medication usage
  - Self-efficacy
  - Use of self-management behaviors

Ryan & Sawin, 2009; Robinson et al., 2008
Self-management outcomes

• What has been measured specifically in epilepsy:
  – Medication & prescribed treatment management
  – Seizure and seizure consequence management
  – Information and resources management
  – Safety management
  – Health status
  – Quality of life
  – Social functioning
  – Psychological functioning

* Dilorio et al., 2010
Self-management outcomes: Adults

- In adult epilepsy, Dilorio and colleagues have tested and used the *Epilepsy Self-Management Scale*.

*Dilorio et al., 1992; Dilorio et al., 1994*
Self-management outcomes: Pediatrics

• In pediatrics, this has not occurred but a *Pediatric Epilepsy Self-Management Scale* and *Caregiver Epilepsy Self-Management Scale* have been developed recently by Janelle Wagner, PhD, & colleagues with expert input from Colleen Dilorio, PhD, and Joan Austin, DNSc. The measures are under testing.

• In addition a *Pediatric Epilepsy Medication Self-Management Questionnaire* has been developed and validated by Avani Modi, PhD, & colleagues.

*Modi et al., 2010; Wagner & Smith, 2011*
Types of pediatric interventions

• Overall have referred to self-management but used other outcomes (e.g. anxiety, depression, etc.) not epilepsy specific self-management:
  – Cognitive behavioral therapy (Martinovic, et al., 2006)
  – Education about epilepsy and management (Lewis et al., 1990; 1991; Rau et al., 2006)
  – Psychological counseling (Glueckauf et al., 2002)
  – Relaxation & behavioral therapy (Dahl, et al., 1985)
  – Self-management training about chronic conditions (Tieffenberg, et al., 2000)
Types of pediatric interventions

- One pilot study has used epilepsy specific self-management by measuring self-efficacy

Wagner, et al., 2010; Wagner et al., 2011
Types of adult interventions

• Biofeedback (Lantz, et al., 1998; Nagai, et al., 2004)
• Cognitive behavioral therapy (Davis, et al., 1984; Lundgren, et al., 2006; Tan, 1986)
• Educational interventions (Helgeson, et al., 1990; May, et al., 2002; Olley, et al., 2001)
• Relaxation therapy (Dahl, et al., 1987; Puskarich, et al., 1992; Rousseau, et al., 1985; Snyder, 1983)
Types of adult interventions

• Relaxation & behavioral therapy (Sultana, 1987)

• Self-management programs including interventions provided through web-based computer programs, telephone-based programs (Dilorio et al., 2009a; Dilorio et al., 2009b; Dilorio et al., 2009c; Pramuka et al., 2007; Reisinger & Dilorio, 2009)
To whom interventions are delivered

- **Individuals with epilepsy** (Dahl et al., 1987; Davis et al., 1984; Dilorio et al., 2009; Helgeson et al., 1990; Lantz et al., 1998; Lundgren et al., 2006; Martinovic et al., 2006; May et al., 2002; Nagai et al., 2004; Olley et al., 2001; Pramuka et al., 2007; Puskarich et al., 1992; Rousseau et al., 1985; Snyder et al., 1983; Sultana, 1987; Tan, 1986)

- **Individual with epilepsy and caregivers** (Glueckauf et al., 2002; Lewis et al., 1990; 1991; Rau et al., 2006; Tieffenberg et al., 2000; Wagner et al., 2010; Wagner et al. 2011)
Managing Epilepsy Well Network (MEW)

- Created in 2008 by CDC and Prevention’s Research Centers and Epilepsy Program in response to research and practice priorities identified by Living Well with Epilepsy (LWE) I and LWE II
- Four collaborating centers (Emory University, University of Texas Health Science Center at Houston, University of Michigan, & University of Washington)

*LWE I, 1997; LWE II, 2003*
Managing Epilepsy Well Network (MEW)

• Mission
  – “to advance the science related to epilepsy self-management by facilitating and implementing research, conducting research in collaboration with Network and community stakeholders, and broadly disseminating the findings of research” (Mission statement available at: http://www.sph.emory.edu/ManagingEpilepsyWell/about/mission_stmt.php)
Managing Epilepsy Well Network (MEWN)

• Research agenda
  – Exploratory studies to investigate and understand the self-management needs of people living with epilepsy
  – Intervention studies to test programs aimed at improving self-management skills in a variety of contexts

Dilorio et al., 2010
Current models to be presented:

• **Supporting Treatment Adherence Regimens** – Shanna Guilfoyle, PhD
• **Coping with Epilepsy** – Janelle Wagner, PhD
• **Creating Avenues for Partnership** – Janice Buelow, PhD, RN
• **Management Information & Decision Support Epilepsy Tool** – Ross Shegog, PhD