Professionals in Epilepsy Symposium
New Evidence in Psychosocial Interventions for Managing Epilepsy: Conclusion

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Learning Objectives

• Review self-management conceptualization
  • Describe programs under study
• Identify research and practice implications
Conclusion

• Today we reviewed self-management:
  – Conceptualizations and definitions
  – Outcomes
  – Literature & studies
  – Current self-management interventions

• Now we will review:
  • Current theoretical implications from research
  • Implications for practice and research
MEW Research Findings
C. Dilorio, personal communication, September 11, 2011
Theoretical Basis

• Social cognitive theory
• Transtheoretical model (stages of change)
• Motivational interviewing

C. Dilorio, personal communication, September 11, 2011
Theoretical basis

• The MEW model was developed from adult epilepsy research (MEWN, 2011)
• Pediatric self-management and family-management models have been proposed and are under study

Grey et al., 2006; Modi et al., in press; Ryan & Sawin, 2009
Implications for practice

• Moving from medical model & emphasizing home over hospital management
• Effective outcomes, sustainability, & costs
• Promoting self- and family-management in epilepsy

Grey et al., 2006; Lorig & Holman, 2003
Implications for practice

• Recent survey of 101 epilepsy professionals identified
  – Need to increase professionals’ ability to view epilepsy comprehensively in terms of how persons with epilepsy and families are affected

Clark et al., 2010
Implications for practice

• Global variations must be considered:
  – Access to specialist care and family centered culturally competent care
  – Availability of medications and treatments
  – Existence of epilepsy specific lay resources
  – Stigma of epilepsy
  – Community resources and capacity

Johnson et al., 2008; World Health Organization, 2005
Implications for research methods

• Define conceptualization and measurement of self-management to better integrate findings from future epilepsy self-management studies

Grey et al., 2006; Lorig & Holman, 2003; Robinson et al., 2008; Ryan & Sawin, 2009
Implications for research methods

• Support the use:
  • of common terms, definitions, and measurements
  • measuring self-management specifically
  • of the same instruments to measure outcomes
  • Instruments that include + and - aspects

Grey et al., 2006; Lorig & Holman, 2003; Robinson et al., 2008; Ryan & Sawin, 2009
Implications for research methods

- Include caregivers and other family members
- Measure cost-effectiveness and sustainability of interventions

Grey et al., 2006; Lorig & Holman, 2003; Robinson et al., 2008; Ryan & Sawin, 2009
Implications for research study design

- Multi-site and randomized control trials to maximize generalizability
- Sample description, randomization, allocation, power calculations
- Recruitment, drop-outs & retention
- Blinding of clinicians, researchers

*Lindsay & Bradley, 2010; Ramaratnam et al., 2011*
Implications for research study design

- Descriptions of who provides the intervention, the intervention, and evaluation process for replication.
- Describe contextual factors (condition specific, physical & environmental, individual & family – Ryan & Sawin, 2009).
- Account for pre-existing comorbidities, baseline functioning, and treatment changes during the intervention to understand possible effects on intervention outcomes.

*Lindsay & Bradley, 2010; Ramaratnam et al., 2011*
Implications for research study design

• Individual vs. family interventions
• Children & adults, transition to adulthood
• Processes individuals and families use for self-management need to be studied
• What are the similarities & differences regarding:
  – Younger to older ages, developmental stages
  – Other family members (parents, siblings)

Ryan & Sawin, 2009
Implications for research measurement

• Instruments: measurement error
  – Consider respondent factors (over- or underreporting in any of the participants)
  – All negative vs. positive vs. mix
  – Validity of instruments for persons with epilepsy, e.g. depression presents differently in persons with epilepsy

*Dilorio, 2005; Redding et al., 2006*
Model of the Individual and Family Self-management Theory

© Ryan & Sawin, 2008 Self-management Science Center (1P20NR0010674-01)

Context
Risk & Protective Factors
Condition Specific
Complexity of condition
Complexity of treatment trajectory
Physical & Social Environment
Access to care, setting
and provider transitions,
Transportation
Culture, Social Capital
Individual & Family
Developmental stages
Perspectives, Literacy,
Information processing,
Capabilities

Process of Self-management
Knowledge & Beliefs
Self-efficacy
Outcome expectancy
Goal congruence
Self-Regulation
Skills & Abilities
Goal setting, Self-monitoring
and reflective thinking, Decision
making, Planning and action,
Self-evaluation, Emotional Control
Social Facilitation:
Influence
Support
Collaboration

Outcomes
Proximal
Self-management Behaviors:
Condition Specific
Cost of Health Care Services

Outcomes
Distal
Health Status
Quality of Life or Well Being
Cost of Health

Self-management Science Framework

Self-management is a process by which individuals, dyads, and families use knowledge and beliefs, self-regulation skills and abilities, and social facilitation to achieve health-related outcomes. Self-management takes place in the context of risk and protective factors specific to the condition, physical and social environment, and individual and family. Self-management leads to proximal and distal health-related outcomes. Proximal outcomes are self-management behaviors and cost of health care services; distal outcomes are health status, quality of life and cost of health. Self-management is applicable to chronic conditions as well as health promotion. [1-3]

Take home points

- Exciting time in epilepsy research and practice regarding comprehensive care for the person with epilepsy and their family
- Progress is being made and there is a lot more to do
Take home points

• Epilepsy is more than just seizures and affects more than the person with epilepsy
• Self-management is multidimensional and complex
• Comorbidities and quality of life can be improved with self-management but more research is needed
Take home points

- Definitions, measurements and methodology must be agreed upon
- Studies must include other family members
- Costs and sustainability must be evaluated
- Managing Epilepsy Well Network
Thank you for your time!

Questions?
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