



A Consumer Generated Self-Management Intervention Model



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INTRODUCTION

- The 2003 Living Well with Epilepsy II Conference yielded priority recommendations regarding the development and evaluation of self-management programs for people with epilepsy.
- With a paucity of consumer-based needs assessment data in epilepsy self-management programming, we aimed to involve consumers in program development versus rely solely upon professional judgment.

METHODS

- Evidentiary review to determine seizure, health, psychosocial problems, and well-being variables.
- Focus group methodology (2 patient groups) to confirm items from evidentiary review, pilot needs assessment survey.
- Mail survey methodology to collect patient and provider data.

MAIL SURVEY

- Sent to 270 community-dwelling adults with epilepsy ages 18-86.
- \$5 (cash) with physician invitation letter, survey, consent, return SASE; \$5 (cash) sent upon receipt of survey & consent; hand-addressed & stamped.
- Self-report problem domains: work, independent living, socializing, epilepsy management, emotions, cognition, health and well-being, and medical management. Also items related to self-management program design preferences.

RESULTS

1. Response rate: 61% (165 respondents)
2. **Zero-order correlates** of “adjustment” (health, happiness, life satisfaction): *Seizure severity, depression, anxiety, income/poverty line, education, cognitive problems.*
3. **Regression analyses** identified *depression* (PHQ-9) *as best predictor of adjustment.* Cognitive problems also appear to be an issue.
4. **Secondary analyses** identified a more maladjusted subgroup with either *probable Major*

Table 1: Respondent Characteristics

Participants	(n=165)	N (%)	M (SD)
Age			46.05 (14.02)
Gender : Male/Female		71 (43.56)/92 (56.44)	
Ethnicity: Caucasian		148 (91.9)	
Education: AA/Technical degree	23 (13.9)		
Bachelor’s degree		55 (33.3)	
Age at Diagnosis			27.56 (16.04)
Number of Antiepileptic Medications			1.75 (0.86)
Seizure frequency: 1-11 per year		55 (35.3)	
Sz free 2+ years		41 (26.3)	
Employed FT/PT/unemployed		50 (30.7)/25 (15.3)/78 (47.8)	
Lifetime treatment of depression		66 (40.2)	
Lifetime treatment of anxiety		37 (22.6)	

Depressive Disorder or significant cognitive problems. This group rated virtually all life areas as significantly more problematic than the “epilepsy-only” group. However, some problems were also salient for this group.

5. Respondents preferred a self-management program that is individual or group-based; meets for 1 hour on a weeknight; is led by a physician or health professional and a lay person with epilepsy; includes and educational and emotional coping focus, and meets for 8 sessions.

5. Eight-session program content:

- Medical Issues & Epilepsy
- Dealing with Sadness & Stress
- Assertive Communication & My Disability
- Cognition: Memory & Attention
- Cognition: Information Processing
- Increasing Community Participation
- General Health & Well-Being
- Managing My Medical Care

CONCLUSION

- Interventionists need to consider direct input from patients/service recipients for tx design.
- Attention to a more challenged or poorly adjusted subgroup of participants in terms of emotional and cognitive health.
- Self-management programming may need to be more targeted to optimally serve higher-need groups (while still serving mainstream group).
- Address life problem areas within the context of mood management and coping.