Self-management for people with epilepsy: The SMART program

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Managing Epilepsy Well Network

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Introduction

Epilepsy is a chronic neurological condition often associated with social exclusion. People living with epilepsy (PLWE) in semi-rural and rural communities may be particularly burdened because of suboptimal access to support services. This research poster describes: 1.) A qualitative process (Phase 1) to adapt a standardized, virtually-delivered (internet or phone) epilepsy self-management intervention (SMART) for PLWE who live in semi-rural and rural setting and 2.) Preliminary experience with a randomized controlled trial (RCT, Phase 2) of SMART implementation in 2 mid-western U.S. states (Ohio and Iowa).

Methods

Phase 1: Researchers adapted the SMART program conducting focus groups of rural stakeholders (PLWE, family members, care providers, N=34) to:

1) gather information on barriers and facilitators to participate in SMART
2) elicit overall perceptions of the program as well as suggestions for modifications.

Phase 2: 6-month prospective randomized controlled trial (RCT) of SMART vs. wait-list (WL)

- Primary outcome: changes in negative health events (NHEs) defined as seizure, self-harm attempt, emergency department visit, or hospitalization.
- Additional outcomes: quality of life, health functioning and process measures of program adoption.
- Residence status assessed using the 2013 Rural and Urban Continuum Codes (RUCC) based on county where 1 = the most urban and 9 = the most rural setting.

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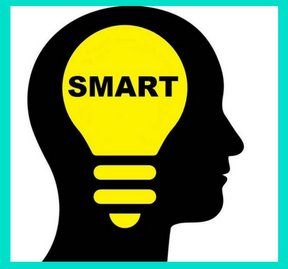


Self-MAnagement foR people wiTh epilepsy and a history of negative health events (SMART)

Fig. 1 : SMART Curriculum:

SMART Curriculum	
Session 1	Orientation and introductions; Emphasize ground rules; Establishment of a therapeutic relationship; Facts and myths about epilepsy and general epilepsy management principles
Session 2	Relationship of epilepsy and stress; Stigma and "double stigma"; Strategies to cope with stigma; Introduction to personal goal-setting
Session 3	Treatments for epilepsy; Complications of epilepsy; Minimizing epilepsy complications; The importance of daily routine and good sleep habits
Session 4	Problem-solving skills and the IDEA approach (Identify the problem, Define possible solutions, Evaluate the solutions, Act on the best solution); Talking with your health care providers; Role play of communication with care providers
Session 5	Nutrition for best physical and emotional health; Substance abuse and its effects on epilepsy; Specific stress-management approaches
Session 6	Effects of exercise and being outdoors on physical and emotional health; Medication routines; Prioritizing medication side effects and discussing it with your clinician
Session 7	Social supports and using your available supports; Advocacy groups for epilepsy; A personal care plan to take care of the mind and the body
Session 8	Normalizing your life in spite of having a chronic but unpredictable condition; Self-management as a life-style; Acknowledgement of group progress; Setting the stage for Ongoing Illness Management and Recovery (Step 2)

Results

Phase 1:

- PLWEs (n=13) were white, mostly married, college educated, with a mean age of 48.5 (SD=11.5).
- Age of epilepsy diagnosis ranged from 1-47 years (M=15.9; SD=14.7).
- Barriers with particular relevance for rural PLWE: Geographic and social isolation, limited access to epilepsy care
- Supplemental "toolkit" was developed

Fig. 2: Perceived strengths and challenges of SMART

THEMES	CATEGORIES
Strengths of the Program	▪ Fills a gap in epilepsy care ▪ Comprehensive curriculum ▪ Use of peer educators ▪ Zoom format decreases isolation ▪ Group format provides interaction with others
Challenges to Implementation	▪ Access to internet ▪ Access to cell phones
Suggestions for Improvement	▪ Provide support to help access zoom meetings ▪ Curriculum issues ▪ Involve caregivers in meetings
Suggestion to Facilitate Patient Participation	▪ Enhance recruitment strategies ▪ Enhance engagement and retention strategies

Current Phase 2 RCT Enrollment

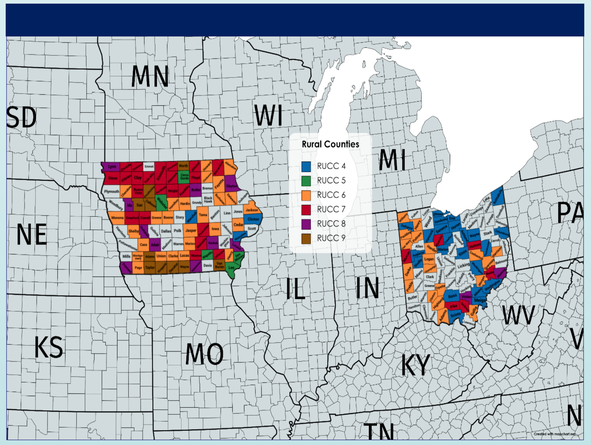
- 44 PLWEs, mean age 38.5 years, male (16, 37.2%) female, (27, 62.8%) Black/African-American (1, 2.3%), White (38, 88.4%), Unknown (4, 9.3%)
- RUCC categories: RUCC 1-3, n=17 (39.5%), RUCC 4-6, n=20 (46.6%) and RUCC 7-9, n=6 (14%).
- Mean number NHEs = 26.4 (SD 42.9)
- Retention thus far is excellent with zero attrition.

Program Synopsis

Step 1: 8 online group sessions held over a 12 week time period, co-led by a nurse educator and a trained peer educator. The peer educator is someone with epilepsy and a history of NHEs. Educators use a written curriculum. Interactive sessions last 60-90 minutes. Groups are limited to about 6 -12 adults.

Step 2: Individuals have telephone maintenance sessions with the nurse educator and/or the peer educator.

Fig. 3 : Targeted Ohio and Iowa Counties with RUCC of ≥ 4.



Conclusions

PLWE from diverse communities can help to refine a web-based epilepsy self-management program, but recruitment of individuals from the most rural settings remains a challenge.