



Revising Project UPLIFT from a Treatment Intervention to a Prevention Intervention

Nancy J. Thompson, Ph.D., M.P.H., Ariele Edwards, M.P.H., Amanda Garcia-Williams, M.P.H., Robert T. Fraser, Ph.D.; Charles E. Begley, Ph.D.; & Linda M. Selwa, M.D.; of the Managing Epilepsy Well Network

INTRODUCTION AND BACKGROUND

Depression is a major public health problem, especially among people with chronic diseases such as epilepsy. Compounding this problem are issues like driving restrictions or other mobility limitations that create barriers to accessing depression screening and treatment. Project UPLIFT was designed as a small-group depression intervention for delivery by telephone or Internet to reach people with epilepsy at home.

Home-based group therapy via telephone and Internet is cost effective and allows more individuals to be reached and treated. Another potential benefit of distance delivery is the relative anonymity it allows persons who may feel embarrassed by their physical and/or mental health; distance settings may ease the sharing of this information.

Beck and Colleagues' cognitive therapy of depression (1977) with Segal and colleagues' mindfulness modifications (2002) guided the development of the Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) intervention. The final intervention was comprised of 8 hour-long sessions including discussions, instruction, and skill-building activities.

Many of the skills included in Project UPLIFT, if learned earlier, can be used to prevent depression. As a result, the National Center for Minority Health and Health Disparities recently provided funding through the Challenge Grant Initiative to: (1) revise the Project UPLIFT materials for use in preventing depression; and 2) estimate the effectiveness of these revised materials. This report focuses on the experiences encountered in creating a version of Project UPLIFT for use in prevention.

OBJECTIVE

To describe the experience of revising the Project UPLIFT materials for use in prevention, as well as the formative and process evaluation of the revised materials.

Rates of depressive symptoms and illness are higher in persons with disabilities and chronic conditions than in the general population (Carroll, Cassidy, & Cote, 2003). In particular, the rate of depression in people with epilepsy ranges from 32% to 48% (Jones et al., 2003); one study reported that 14% of deaths in people with epilepsy are suicides (Fukuchi et al., 2002).

Although depression is the most frequent psychiatric disorder among individuals with epilepsy, it is often under-diagnosed or untreated in this population due to concern about medications (people taking epilepsy medications have concerns about adding other medications) and lack of access to services (people with epilepsy may not be granted driver's licenses, or otherwise have limited mobility; American Epilepsy Society & Centers for Disease Control and Prevention, 2003). Limited mobility is common to other groups at high risk of depression including persons with multiple sclerosis (Sadovnick et al., 1996), or persons providing caregiving (White, Townsend, & Stephens, 2000).

Group treatment for depression is important, especially among those with health or care-giving burdens, since group members receive modeling and social support from others with similar circumstances. Unfortunately, the listlessness accompanying depression, especially when combined with illness, makes it difficult to get out and attend a group. This is compounded by limited mobility.

Project UPLIFT was designed to address these concerns through the use of Web and telephone groups. The intervention materials were guided by Beck and colleagues' (1979) cognitive therapy of depression and Segal and colleagues' (2002) mindfulness modifications. The intervention was intended to move participants identifying thoughts, to challenging and changing thoughts, to letting thoughts go. Specific activities were designed to increase knowledge about depression and emotional expression, as well as the skills involved in activities such as imagery, thought stopping, counter conditioning (to encourage pursuit of other activities when depressed mood is likely), reinforcement management (to reward oneself for remaining symptom-free), and mindfulness. Based upon input from experts and focus groups of people with epilepsy, activities were selected and modified to best serve the target population.

The intervention was effective in treating depression. We recognized, however, that many of these skills can also be effective in preventing depression. As a result, we were interested in whether or not Project UPLIFT could be used earlier among people with epilepsy, in hopes of preventing depression from ever starting.

METHODS

The Intervention—Sample Sessions

Session	Activity	Description
One	Check-in	Group members introduce themselves
	Discussion	Moderated group discussion about experiences of negative mood associated with epilepsy
	Teaching	Thoughts and Negative Mood
	Group Exercise	Identifying the Thought
	Skill-building	Introduction of Monitoring Thoughts and Mood
	Homework	Monitoring Thoughts and Mood

Session	Activity	Description
Three	Check-in	Report on homework - "ARMed Against Depression"
	Group Exercise	The What-ifs of Epilepsy--each member provides a what-if, other members participate in modifying it
	Teaching	Coping Thoughts & Relaxation Training
	Skill-building	Body Scan; Progressive Muscle Relaxation
	Homework	Continue Monitoring with Modification & Relaxation

Session	Activity	Description
Six	Check-in	Report on homework - Seeing and Hearing Meditation
	Teaching	Thoughts as changeable, thoughts as impermanent
	Group Exercise	Mindfulness of Sounds and Thoughts
	Discussion	Group discussion of problems and problem-solving—benefits of continued depression?
	Homework	Continue Monitoring with Modification; practice mindfulness 4 times for 20 minutes.

Study Design

- **Materials Revision:**
 - Reviewed language for references to "treatment," or to "being depressed".
 - Reviewed follow-up interviews with prior Project UPLIFT participants with epilepsy for comments about difficulty or recommendations regarding changes
 - Revised the intervention modules accordingly.
- **Formative Evaluation:** 2 focus groups reviewed the revised intervention modules
- **Process Evaluation:** Assessed ability to recruit persons with epilepsy for participation in the prevention intervention.

Participants

The Project UPLIFT Preventive Intervention is intended for English-speaking people with depressive symptoms, but who do not meet criteria for depression.

Focus Group Inclusion Criteria:

- Diagnosed with epilepsy for at least one year.
- Recruited from the Emory Epilepsy Center of Emory HealthCare
- Age 21 or over
- Participated in Project UPLIFT for Treatment

Intervention Inclusion Criteria:

- Diagnosed with epilepsy for at least three months.
- Recruited through a member university of the Managing Epilepsy Well Network
- Age 21 or over
- Score of 9-21 on the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977).

METHODS (continued)

Procedure

- **Materials Revision:** 2 independent reviewers read through the materials from each module to identify needed wording changes. Two independent reviewers also reviewed transcripts from the Project UPLIFT for Treatment's exit interviews to identify problem areas or recommended changes.
- **Formative Evaluation:** Revised materials were mailed to focus group participants. Two focus groups were then convened by telephone to obtain feedback about the revised intervention modules.
- **Process Evaluation:** At Emory University, counts were obtained for the number of people approached, and the number willing to be screened. From all sites, counts of those screened were obtained for those who were eligible and ineligible.

RESULTS

Materials Revision:

- Changed wording to include terms like "feeling blue," "feeling down," and "low mood," rather than depressed.
- Talked about coping with precursors to depression, like stress
- Skills were framed as useful to "keep from getting depressed"
- Preventing relapse into depression was framed as preventing falling back into old patterns (e.g., negative thinking)

Formative Evaluation:

8 prior Project UPLIFT participants participated in two telephone focus groups

Suggested Improvements:

- Ensure the materials recognize that epilepsy was only one of their life circumstances that can lead to depression
- Limit the number of objectives per session
- Reduce the check-in period during the first session
- Increase participants' discussion with one another
 - *I thought that was really, very interesting is a good way to describe it, about other people's experiences and thoughts. Because it really made me feel very fortunate because I don't have reoccurring seizures on a regular basis, so I appreciate the opportunity to see what other people are going through.*
 - *It really made me feel very grateful in listening to other people. I just think that some other people's occurrences with epilepsy...they just seem to be a lot worse than mine, so I felt really grateful about that.*
- Simplify the Body Scan and Progressive Muscle Relaxation exercises
 - Participant Quote:...it does seem like this is almost an advanced routine and it's coming so early.
 - Participant Quote: It wasn't really relaxing to me...It was like an exercise...
- Establish real-time contact in the Web group
- Have at least one meditation per session

RESULTS (continued)

Formative Evaluation (continued): 8 prior Project UPLIFT participants participated in two telephone focus groups

What Was Helpful: Participants noted that some exercises were especially helpful.

- Pebble Exercise –using a pebble as an object of mindfulness
 - *I found the pebble exercise to be extremely relaxing. And it brought to the forefront many of my senses that I don't use for fear of sparking a seizure.*
 - *I think [the Pebble Exercise] helped me with my attention span. This particular session, it had a significant impact on learning coping skills for me.*
- Walking Meditation—practicing mindfulness of walking
 - *That's a pretty good exercise for someone who's hyper. So it was actually easier for me to meditate when I moved than it was when I tried to do the body scan.*
 - *...it puts it into perspective. It's that first fresh breath of air in the morning going out for my walk that sort of reminds me that...just because I have a seizure disorder doesn't mean that life has come to an end.*
 - *... even just doing my walk and the walking meditation, I feel like, again, I've accomplished something in the day because I've been out and about.*
- 3-minute Breathing Space—a brief focus on the breath
 - *I've done [the exercises] since [participating in UPLIFT], of course I've done the 3-minute breathing exercise. I think they are absolutely wonderful. They help you just to be able to stop and have time for yourself and put everything else aside, and it helps you just to focus on yourself. And it... I don't know, whenever you have time just to focus on yourself, it just does something to the body, and the seizures just go away. I think it's wonderful.*

Process Evaluation – Recruitment

- At Emory, 158 people were approached with 70 (44%) not interested in participating in the PREVENTION study
- At all sites, of those interested in the study, 41% were already too depressed for the PREVENTION study.

CONCLUSIONS

- Depression continues to be a serious problem for people with epilepsy
- Project UPLIFT is a helpful intervention, and can be modified for use in prevention.
- We need to intervene earlier for people with epilepsy if we hope to prevent depression

For additional information please contact:
Nancy J. Thompson, Ph.D., M.P.H.
Behavioral Sciences and Health Education
Rollins School of Public Health, Emory University
nthomps@sph.emory.edu