

Development and Formative Evaluation of a Mindfulness-Based Cognitive Therapy Program for People with Epilepsy



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Abstract

Depression is a major public health problem (1), especially among people with chronic diseases such as epilepsy (2-4). Treatments, such as Cognitive Behavioral Therapy (CBT), have been shown to be effective in reducing depressive symptoms (5). Recently, mindfulness techniques have been integrated into depression treatment. Mindfulness is rooted in Buddhist practices and is defined as "...paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally" (6, 1994, p. 4). Mindfulness can aid in treating depression because it teaches people to develop a different relationship with their thoughts, one that is more 'detached' and less reactive (7). Therefore, mindfulness can be important in preventing relapse (8, 9).

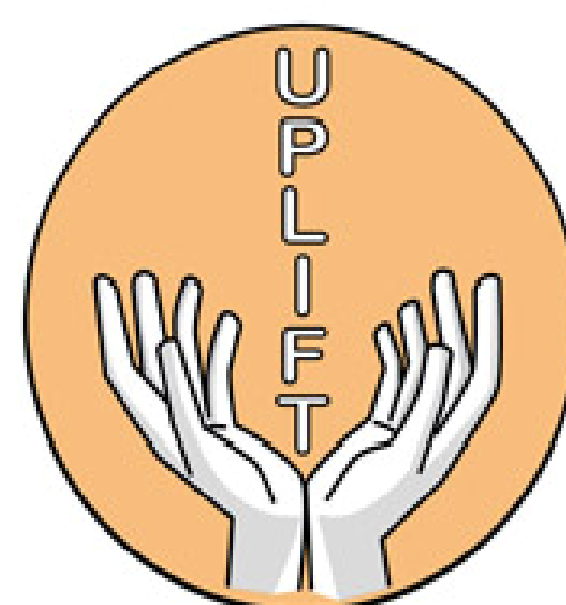
In response to the high rates of depression among people with epilepsy, the Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) intervention was developed based on CBT (10) with mindfulness modifications (7). Three focus groups of people with epilepsy assessed the appropriateness of the information, activities, and measures proposed for inclusion in the intervention. The participants valued the group delivery, responded favorably to the cognitive and mindfulness activities, and provided suggestions for improvement. Based upon input from experts and the focus groups, activities were selected and modified to best serve the target population. Implementation of the program is currently underway, with preliminary results suggesting that participants responded favorably to the intervention.

Phase I: Development

The intervention materials were guided by Beck and colleagues' cognitive therapy of depression (10) and Segal and colleagues' mindfulness modifications (7).

Cognitive Behavioral Therapy (CBT)

- Recognize, monitor, and record negative thoughts
- Modify negative thoughts
- Use coping thoughts
- Examine logic, validity, and role in maintaining depression
- Use skills learned to prevent relapse



Mindfulness - Meditations, relaxation exercises, and discussions to:

- Become aware of the body and pay attention to experiences
- Become aware of the present moment
- View thoughts as passing events that do not necessarily represent a state of reality
- Appreciate oneself and others

Project UPLIFT Format:

- 8 sessions – 1 hour long, 1 session per week
- 6-7 participants per group, facilitated by a person with epilepsy and research assistant
- Designed for phone and internet
 - Phone sessions: conference calls
 - Internet sessions: website with discussion boards
- Sample structure of weekly meeting:

| Activity | Description |
|-------------------------|------------------------------------------------------------|
| Check-In | Greet group members; discuss experiences with the homework |
| Teaching | Learn new information and skills |
| Skill Building Exercise | Practice skills presented in the teaching |
| Group Discussion | Discuss experience with the new skills |
| Homework | Practice skills throughout the week |

Phase II: Formative Evaluation

Purpose: Improve the effectiveness of the intervention and maximize its chance of being adopted within the target population. People with epilepsy and depressive symptoms participated in 3 focus groups, where they gave feedback on the proposed intervention materials, activities, and measures.

Participants: Adults with epilepsy and depressive symptoms.

- 32 screened: 16 ineligible, 6 unable to attend, 1 unable to contact
- 9 participants: mild to moderate depressive symptoms; variety of seizure types
- 3 focus groups:
 - 9 participated in 2 focus groups to evaluate the intervention materials
 - 5 returned for the 3rd focus group to assess the instruments and website

Formative Evaluation Results

Acceptability

- Favorable response overall, felt the exercises were "Functional" and "Practical"
- Felt the exercises could be helpful and understood their purpose
 - "...I get stressed out at school...and it's nice to, like, feel relaxed or just to, you know, take a few minutes or even take a little...cat nap."
- Expressed how they could try the exercises
 - "You know, this is, it's rather relaxing and, and I can find time to do that."

Complexity

- Time constraints, physical limitations, feeling guilty
 - "...I feel guilty when I do stuff like this...because it's like there's not enough time in the day to be resting."

CBT and Mindfulness Exercises

- Beneficial to look at thinking, helpful for reducing worry
 - "Yeah, if I ... could get rid of some of the what ifs, especially worrying about...disease, and epilepsy, and stuff like that, I think...that would help me."
- Aids in relaxing and relieving stress
 - "Well I'm the queen of extra thoughts...it would be great to force myself to be quiet."
- Meditations could possibly help with seizures
 - "And sometimes, you know, when I'm doing laundry I do this...I guess I didn't realize I was mindfully meditating."

"...I know that there would be times I would get extremely excited or overexerted that I would have seizures...So, for these, [meditations] could be, it could be a tool that could be used...to help with prevention, other than just the medication."

Responses to website

- Easy to use
- Liked the use of technology
- Brings people together
 - "Because in a way that...helps alleviate some of the depression... Because it widens your world."

Additional Findings

- Group setting valuable: "...groups...such as this help you better understand what other people are going through..."
- Desire to share experiences of living with epilepsy with each other
 - Major themes related to isolation, relationships, and stigma

Recommendations

- Provide multiple media - website plus written materials
- Suggested additional materials like CD and wallet cards
- Provide links to resources

"I like it because this is the most people I've ever met with epilepsy."

Phase III: Preliminary Evaluation from Pilot Study

Purpose: Assess pilot study participants' satisfaction and experiences with the Project UPLIFT Program. After completing the program, participants were asked to provide feedback about the program.

Participants: Adults with epilepsy and depressive symptoms.

- 98 screened: 53 enrolled in study, 34 ineligible
- Preliminary analysis of comments from 28 people

"All they do is want to live and I think about how I used to want to die – puts your life in perspective."

Process Evaluation Results

Acceptability

- In general, the participants felt they benefited and learned skills from the program
- Two participants expressed interest in participating in future programs

Complexity

- Scheduling, initial feelings of nervousness or embarrassment, not feeling engaged in the material, and wishing people would participate more

Delivery

- Phone group expressed more overall satisfaction than web group
 - Phone group felt more connected
 - Web group felt it was difficult to "read the tone," did not want to "put myself out there"
- Opportunity to share with others and see other perspectives
- "We were able to share our communication and give each other suggestions – I enjoyed that, learning from one another"
- Some experienced difficulties navigating the website or discussion board

"The program was very helpful and that surprised me. I printed everything out and recorded the meditations on my MP3 player."

CBT and Mindfulness Exercises

- Overall, felt that exercises were beneficial and valuable
- Liked sharing with the group about experiences
- Mostly referred to benefits of meditations, though a couple had difficulties
 - "I liked the meditations and enjoyed telling about my experiences."

Conclusions

Project UPLIFT

- CBT and mindfulness techniques can be adapted for distance delivery to groups
- Small-group, CBT and mindfulness-based program delivered over phone or internet may be acceptable and relevant to people with epilepsy
 - Supports purpose, format, and content of Project UPLIFT
- Group setting and opportunities to share stories and information are of particular importance
- Provides a view of people with epilepsy who experience depressive symptoms

Public Health Implications - Distance and Group Delivery of Therapy

- Potential to reach people who may not otherwise have sought treatment or had access to it – especially for populations with limited mobility
- More cost effective than individual therapy
- Can promote development of social support networks
- Addresses mental health needs of people living with chronic disease