

# **An Online Epilepsy Self-Management Program (WebEASE): Development and Process Evaluation**

Cam Escoffery, PhD, MPH, CHES, Katherine Yeager, MS,  
RN, Frances McCarty, PhD, Elizabeth Reisinger, BA,  
MPH, Elise Robinson, MPH, Bethany Wexler, MPH

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# Acknowledgements

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## Research Collaborators:

- Rollins School of Public Health
  - Colleen Dilorio, PhD, RN, FAAN,
  - Katherine Yeager, MS, RN,
  - Frances McCarty, PhD,
  - Elizabeth Reisinger, BA, MPH
  - Elise Robinson, MPH
  - Bethany Wexler, MPH
  
- Department of Neurology, School of Medicine
  - Thomas Henry, MD (now at University of Minnesota)
  - Archana Koganti, MD
  
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# Background of WebEASE (Epilepsy Awareness Support and Education)

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- The aims of the WebEase project were to:
  - Create a web-based, theory driven epilepsy self-management program for older adolescents and adults with epilepsy
  - Test the feasibility, acceptability, and usability of the program among people with epilepsy
- The behavioral objectives were to determine if participants show improvement in:
  - Epilepsy-related knowledge
  - Medication adherence
  - Stress management
  - Sleep time and quality
  - Sense of support

# Background on Epilepsy

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- Epilepsy: a *seizure disorder that affects the nervous system*; it is usually diagnosed after a person has had at least 2 seizures that were not caused by some known medical condition
- Epilepsy self management encompasses 5 domains: medication, seizure, safety, information, and lifestyle management
- People with epilepsy must take antiepileptic drugs (AED) to control seizures
- Stress and sleep deprivation have been identified as the two most common precipitants for seizures

# Theoretical Framework for WebEASE

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- Transtheoretical Model of Behavior Change
  - Module tailored to participants' stages of readiness to change behavior (Prochaska & DiClemente, Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research and Practice*. 1982;20:161-73)
  
- Social Cognitive Theory
  - Behavioral capability: knowledge and skills on how to adhere to medicines and to manage sleep quality and stress
  - Role modeling through epilepsy testimonies (Bandura, *Social foundations of thought and action: A Social Cognitive Theory*. Englewood Cliffs, NJ: Prentice-Hall 1986)
  
- Motivational Interviewing
  - Reflective listening on participant's statements
  - Handling barriers and discrepancies in thoughts (Miller & Rollnick, *Motivational Interviewing*. 2nd ed. New York: Guilford Press 2002)

# Theoretical Constructs in the Modules

Intervention Component	Social Cognitive Theory (SCT), Transtheoretical Model (TTM), and Motivational Interviewing (MI) Constructs
<b>Modules</b> Self-Assessment and Stage-Tailored Feedback	<b>SCT:</b> Behavioral capability Outcome expectations Self-efficacy Goal setting
	<b>TTM:</b> Stage of behavior change Consciousness raising Decisional balance Self-reevaluation
	<b>MI:</b> Dealing with barriers Discrepancy Eliciting commitment Readiness Reflective listening Summaries
<b>My Log</b>	Consciousness raising Feedback Self-monitoring
<b>My Voice</b> Discussion Boards	Helping relationships Reinforcement Social Support
<b>Quizzes</b> <b>Daily Poll Questions</b>	Behavioral capability
<b>Fact Sheets and</b> <b>Epilepsy Web Resources</b>	Behavioral capability

# WebEASE Modules

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- The Modules for medication, stress, and sleep management are core of the WebEase
- By working through the modules, participants\*:
  - Assess their current status in each of three self-management areas
  - Reflect on their behavior
  - Create a plan for change or to maintain their behavior if no change is required
- Each module has five sub-modules based on the stages of change
- Collaborative development process with input from patients with epilepsy (focus groups and individual interviews), content expert panel, and research team

\*Dilorio et al., WebEase: Using theory to develop a web-based epilepsy self-management intervention, *Preventing Chronic Disease*, submitted



Welcome, Elizabeth; Monday, May 19, 2008

Epilepsy Awareness, Support, and Education

[Logout](#)[Home](#)[My Log](#)[Modules](#)[Fact Sheets](#)[My Voice](#)[Quizzes](#)[Daily Polls](#)[Resources](#)[Help](#)

## Welcome to WebEase.com!

WebEase is an online program developed by a team of researchers and physicians who treat patients with epilepsy. The team is based at the Rollins School of Public Health of Emory University and works with the Centers for Disease Control and Prevention.

This interactive program is designed to help you better manage your epilepsy. The program encourages you to think about things that are important to you in taking medications, managing stress and getting a good night's sleep. You will probably find this website different than others you have visited because it does not tell you what you should do. Instead it guides you to think about what is important to you and to make decisions that are consistent with your goals.



# WebEase MEDICATION MODULE

Welcome, Elizabeth; Monday, May 19, 2008

Epilepsy Awareness, Support, and Education

[Medication](#) | [Stress](#) | [Sleep](#)

**Choose the statement that best describes you:**

- I do not take my medications the way my doctor told me to and I do not plan to in the future.
- I do not take my medications the way my doctor told me to but I am thinking about changing.
- I do not take my medications the way my doctor told me to but I am taking steps to start soon.
- I usually take my medications the way the doctor told me to take them and I am much better at taking my medications now than 6 months ago.
- I always take my medications the way the doctor told me to take them and have been doing so for more than 6 months.

Staging  
Questions

PREVIOUS

NEXT

# WebEase MEDICATION MODULE

Welcome, Elizabeth; Monday, May 19, 2008

Epilepsy Awareness, Support, and Education

Medication | Stress | Sleep

What would it take to raise your confidence level higher, say to an 8 or a 9?  
(Or in other words, what barriers would you need to overcome to increase your confidence to take your medications?)

Type here:

Sometimes I fall asleep before I take my night time dose, so setting an alarm might help

Click [here](#) to hear about barriers that others had to deal with.

PREVIOUS

NEXT



# WebEase MEDICATION MODULE

Welcome, Elizabeth; Monday, May 19, 2008

Epilepsy Awareness, Support, and Education

[Medication](#) | [Stress](#) | [Sleep](#)

Elizabeth, let's look at how you can continue to take your medications every day at the correct time. To increase your confidence, you mentioned:

- ◆ **Sometimes I fall asleep before I take my night time dose, so setting an alarm might help**

What might be some ways to make this happen?

PREVIOUS

NEXT





## Discussion Board Home

This is a forum for online discussion groups, where you can exchange open messages about epilepsy. There is a general discussion board about Epilepsy and Me, medications, stress, and sleep.

Choose a forum topic from the list below to view and contribute to important discussions about epilepsy.

To return to all of Main forums, click on Discussion Board Home link in the blue row. The name of the Topic that you are in will appear in the Orange row.

For help using the Discussion Board, click [here](#).

Forum	Last Post	Posts
<a href="#">Epilepsy and Me</a> (Share your experience with epilepsy)	Wednesday, April 18, 2007 9:48 AM	37
<a href="#">Medications and Me</a> (Share your challenges and successes in taking medications to control seizures)	No Posts	0
<a href="#">The Anti-Stress Zone</a> (Share strategies on handling stress in your life and the resulting effects on your seizures)	No Posts	0
<a href="#">The Search for Sound Sleep and Sweet Dreams</a> (Share strategies for getting a good night sleep and the resulting effects on your seizures)	No Posts	0

# Methods

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- Design: Pre-test, post-test intervention design
- Sample: participants recruited from two hospital-based clinics serving individuals with epilepsy
- Intervention:
  - 6 weeks (each module of medication, sleep and stress) lasted 2 weeks
  - Users logged on using a log in and password to program

# Methods

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- Data Collection Instruments
  - Webtrends report (track usage and most visited pages)
  - Process evaluation questions in post-test
  - Focus group with participants
  
- Data Analysis
  - Process evaluation questions:
    - SPSS Version 14 was used for descriptive statistics and bivariate analyses
  - Focus group
    - discussions were transcribed verbatim by the research assistants.
    - Major themes from participants' thoughts and reactions were compiled
    - Summary narrative were written of the qualitative comments supplemented with representative quotes

# Instrument: Process Evaluation

## Question

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- Questions asked about value of program components, satisfaction and usability of the program, and beliefs about effects of the program on their epilepsy self-management
- Usability items measured ease of navigation, organization of the site, and whether images were appealing
- Open-ended questions about each program components, utility of the program (liked most, like least), and recommended changes to the program

# Instrument: Focus Group

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- Purpose was to elicit participants' opinions about the program and mode of delivery and thoughts about the impact of the program
- Questions asked:
  - how the program helped the participant overall
  - how it assisted them in coming up with strategies to manage their medication taking, stress or sleep
  - what activities that they did and liked
  - what they liked most and least
  - recommended changes, and
  - what other information should be included in an epilepsy self-management program.
- Lead by an experienced nurse and two trained research assistant attended
- The session lasted approximately an hour and a half in duration



# Demographics of Participants (n=35)

Age (years)	20-63
Mean (SD)	37.5 (12.6)
Gender, n (%)	
Female	21 (60.0)
Race, n (%)	
White	23 (65.7)
Black	11 (31.4)
Hispanic	1 (2.9)
Education level, n (%)	
Less than grade 12	1 (2.9)
Grade 12 or GED	8 (22.9)
Non-academic certificate, trade school program	2 (5.7)
College 1-3 years	8 (22.9)
College 4+ years	12 (34.3)
Other	3 (8.6)
Seizures in the past year, n (%)	28 (80.0)
Yes	
Type of seizure usually experienced, n (%)	
Tonic-clonic (grand mal)	2 (5.7)
Complex partial	9 (25.7)
Other primary generalized type (myoclonic, clonic, tonic)	1 (2.9)
Simple partial	10 (28.6)
Absence (petit mal)	6 (17.1)
Don't know	7 (20.0)

# General Results

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- Of the 35 individuals who participated (use):
  - 27 completed both weeks of the Medication Module (77.1%)
  - 18 completed both weeks of the Stress Module (51.4%), and
  - 21 completed the Sleep Module (60%)
  
- Usage:
  - 1<sup>st</sup> 3 weeks of the study period, participants were most likely to visit the site on Mondays, with the majority of participants visiting the site from late afternoon (3-4 pm) to early evening (6-7 pm)
  - Last 3 weeks, participants were most likely to visit on Fridays and Saturdays, with participants logging on between noon and 2 pm
  - 6.9% reported using the WebEase program daily, whereas 41.4% stated they used the program between two and six times a week
  - 9 participants (25.7%) posted messages to My Voice
  
- 83% reported that the program was easy to navigate, and information was well organized
  
- 62% reported that the material was easy or very easy to understand
  
- 65.5% responded that the information was informative or very informative

# Distribution of Value Ratings for WebEase Components (n=29)

	Not at all/Not very	Somewhat	Valuable/ Very valuable
Modules	2 (6.9%)	5 (17.2%)	22 (75.9%)
Fact Sheets	4 (17.4%)	2 (8.7%)	17 (73.9%)
Resources	5 (23.8%)	2 (9.5%)	14 (66.7%)
My Log/Graphs	4 (13.8%)	7 (24.1%)	18 (62.1%)
Daily Poll	5 (19.2%)	5 (19.2%)	16 (61.5%)
Quizzes	7 (26.9%)	6 (23.1%)	13 (50.0%)
Discussion Board/ My Voice	7 (31.8%)	6 (27.3%)	9 (40.9%)
Entire WebEase Program	2 (7.7%)	4 (15.4%)	20 (76.9%)

# Distribution of Participants' Desire to Share Program (n=29)

Statement	n (%)
Recommend program to a friend	28 (96.6%)
Increased desire to seek info on the web	22 (75.9%)
Show info to friends and family members	19 (65.5%)
Show info to your doctor	1 (3.4%)

# Distribution of Satisfaction with WebEASE (n=29)

<b>Statement</b>	<b>Strongly agree/Agree</b>	<b>Neither agree/ disagree</b>	<b>Disagree/Strongly Disagree</b>
<b>My privacy was respected</b>	<b>29 (100%)</b>	<b>0 (0%)</b>	<b>0 (0%)</b>
<b>I felt comfortable using the computer for the WebEase program</b>	<b>27 (93.1%)</b>	<b>2 (6.9%)</b>	<b>0 (0%)</b>
<b>I felt comfortable using the computer for the assessments</b>	<b>27 (93.1%)</b>	<b>2 (6.9%)</b>	<b>0 (0%)</b>
<b>I felt comfortable answering questions on the WebEase program.</b>	<b>20 (69.0%)</b>	<b>5 (17.2%)</b>	<b>4 (13.8%)</b>
<b>The WebEase overall program was about the right length.</b>	<b>19 (65.5%)</b>	<b>8 (27.6%)</b>	<b>2 (6.9%)</b>
<b>Each weekly session was about the right length.</b>	<b>13 (46.4%)</b>	<b>10 (35.7%)</b>	<b>5 (17.9%)</b>
<b>The audio stories were helpful.</b>	<b>8 (28.6%)</b>	<b>19 (67.9%)</b>	<b>1 (3.6%)</b>
<b>The WebEase program was difficult for me to use</b>	<b>1 (3.4%)</b>	<b>3 (10.3%)</b>	<b>25 (86.2%)</b>

# Participant's Quotes

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## Modules:

*“The modules were very interesting and helped me to make plans and schedules to help me manage my medication, stress and sleep. It helped me to see how each one of them played a part in my treatment to manage my seizures.”*

*The modules “gave me a model for working out improvements to the way in which I handle problems.”*

# Participant's Quotes

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## My Voice:

*“As a person with epilepsy who basically has had **no known contact with others who have epilepsy**, it was a new experience to communicate with others having different or similar types of epilepsy...I learned how others ‘coped’ and/or their experiences living with epilepsy... [and that] we could help each other through this [the discussion board] resource...we are not alone.”*

# Discussion

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- Over 75% of participants thought the program was valuable; therefore, people with epilepsy are receptive to an online self-management intervention
- Modules, fact sheets and resources were considered most valuable
- They are satisfied with many program components that apply theoretical constructs of behavior change
- Process evaluation data was helpful in tracking participation, use of intervention components, satisfaction, and dosage



# Discussion

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- Outcome Evaluation
  - Participants improve on overall self-management
  - There was a trend in a positive direction for many outcome variables such as medication adherence and epilepsy self-efficacy
  - Sample size is a limitation for data analysis

Dilorio et al., Evaluation of WebEase: An Epilepsy Self-Management Website, *Health Education Research*, in press