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# The Impact of an Epilepsy Self-Management Program on Healthcare Utilization and Related Costs

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## Research Article

### The Impact of an Epilepsy Self-Management Program on Healthcare Utilization and Related Costs

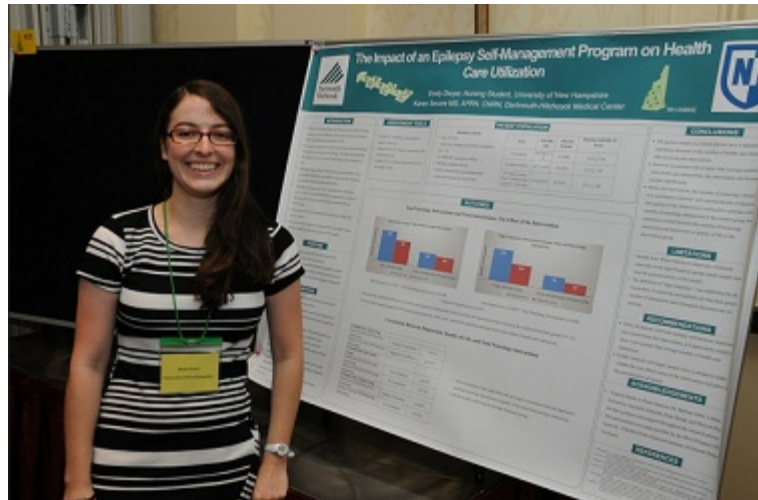
—[Emily Dwyer](#) (Editor: [Rosie Donegan](#), [Jennifer Lee](#))

A chronic medical condition such as epilepsy requires a lifetime of monitoring and management by a medical team and the patient. The treatment is often multidisciplinary and can include medication, surgery, education, and self-management. This last approach focuses on teaching patients to monitor and respond to symptoms on their own while utilizing their healthcare team for guidance and support.

For ten weeks during the summer of 2015, I participated as an intern in evaluating the cost effectiveness of Home Based Self-Management and Cognitive Training Changes Lives (HOBSCOTCH), an epilepsy self-management program developed at the Dartmouth-Hitchcock Epilepsy Center. The center is staffed by nurse practitioners, physicians, and nurses who specialize in epilepsy treatment, and who also conduct research on epilepsy and its management. HOBSCOTCH is an experimental program and is not offered as a part of general epilepsy care at this time.

My internship was part of the IDEa Network for Biomedical Research Excellence (INBRE) Summer Undergraduate Research Fellowship (SURF) in Nursing. This program receives funding from the National Institutes of Health with the aim of increasing undergraduate research opportunities in the state of New Hampshire. As a junior nursing major, I applied for this summer program because research opportunities in nursing are rare for undergraduates. Often nursing is seen as a purely clinical profession, when in reality research is the backbone of all clinical skills.

The HOBSCOTCH program ran from January of 2013 to June of 2014, and the effectiveness of the program was then evaluated. When I began my internship in June of 2015, the research team wanted to assess the cost effectiveness of the program. I helped accomplish this by focusing on how the program impacted participants' utilization of the healthcare system.



The author presented her research at the New Hampshire IDEa Network of Biomedical Research Excellence annual meeting at the Wentworth by the Sea Hotel in New Castle, NH, August 2015 (*Photo by Jon Gilbert Fox*).

## What is Epilepsy?

Before my internship, I did not have an extensive knowledge of epilepsy or its management, but I learned much more by shadowing my mentor in the epilepsy clinic and inpatient unit. Additionally, I was able to observe a surgery on an epilepsy patient. These clinical experiences, in combination with my own research on the subject, helped me to learn a lot about epilepsy and just how great of an impact it can have on someone's life.

More than four million adults in the United States have a diagnosis of epilepsy (4). This is a chronic condition in which an individual experiences recurring seizures (10). Cerebral neurons that ordinarily discharge electrical impulses to complete a specific task, fire suddenly and excessively (10). Epilepsy can be either primary or secondary, and the resulting seizures from both are classified as generalized or focal (partial). Primary epilepsy is idiopathic, meaning it has no known cause, although there may be genetic components. Secondary epilepsy is the result of an underlying condition such as a brain tumor. The resulting seizures present differently in each person and are dependent on the location and type of seizure.

A generalized seizure rapidly engages neurons in both hemispheres and is the type of seizure that most people have heard of. It involves the rhythmic contraction and relaxation of muscles, and the individual often loses consciousness. A focal, or partial, seizure involves only one hemisphere of the brain. The whole body is typically not involved, and there are a number of different presentations, such as the twitching of one limb, behavioral changes, staring, or loss of muscle tone.

A number of treatment options exist for individuals with epilepsy, but these do not guarantee freedom from all symptoms. Patients and providers struggle to maintain the balance between a safe, effective medication dose and the numerous possible side effects. Examples of side effects are dizziness, sedation, weight gain, and cognitive slowing, among many others. Surgery is another treatment option if medication options are not successful. When an individual's epilepsy stems from a singular, well-defined area of the brain, this section may be removed to help control the individual's epilepsy. Depending on the location, there can be a number of physical and cognitive effects. Another option is the surgical placement of a vagus nerve stimulator (VNS). Similar to a cardiac pacemaker, it is placed in the chest and sends electrical impulses to the brain via the vagus nerve. Individuals can induce additional electrical impulses during the onset of a seizure. These impulses help to reduce seizure severity and frequency.

## HOBSCOTCH and Memory Impairment

Many individuals with epilepsy report cognitive impairments, particularly regarding memory (5). As a result, HOBSCOTCH was designed to specifically address memory impairment in those with epilepsy. Multiple factors contribute to memory impairment, including both the seizures themselves and the form of treatment. Regardless of cause, the treatment of cognitive changes due to epilepsy is multidisciplinary and involves general medication management, behavior management, support, and memory and cognitive training (7). HOBSCOTCH specifically aims to help patients by providing this training and support.

The program structure includes an initial group visit; six individual, weekly telephone sessions; and a final visit. Each of these takes place with a memory coach, a nurse practitioner or nurse who specializes in epilepsy and has received training in problem solving therapy. In this therapy, the coach teaches the patient how to assess external factors, such as the environment, and internal factors,

such as feelings, that contribute to memory impairment. The memory coach can then use different strategies to help the patient work with these contributing factors (3).

During the initial group visit at the medical center, patients are educated on epilepsy and how it affects cognitive function, with an emphasis on memory. The patients are then introduced to the program, given a workbook and a day planner. In the planner, patients record seizure activity and write down events they need to remember. Pages in the workbook are dedicated to each week of the program. Here they record any memory problems they are experiencing and brainstorm ways to work with them. Patients are prompted to evaluate the pros and cons of each potential solution and pick the most appropriate one. They then put the chosen plan into action and evaluate it at the next weekly telephone session. During these sessions the coach teaches them new strategies to work with memory impairment and offers support. The program concludes with the final, in-person visit.

Between January 2013 and June 2014, a total of fifty-seven patients participated in the HOBSCOTCH program. These patients all had subjective, or self-reported, memory complaints; were between eighteen and sixty-five years of age; had an IQ above 70; no difficulty reading or writing; reliable telephone access; and were on a stable medication regime (antiepileptics and antidepressants) for at least one month. The fifty-seven patients were randomized into one of three groups: those who participated in the program (the intervention group), the intervention plus computerized cognitive training group, and the control group. Those in the computerized cognitive training group participated in HOBSCOTCH and additionally used a Nintendo DS for cognitive training. Those in the control group did not participate in HOBSCOTCH and received care as usual.

In the follow-up evaluative study in 2014, the primary outcome, or variable of interest, was quality of life. The Quality of Life in Epilepsy (QOLIE-31) questionnaire was used to measure this variable. One secondary outcome was objective memory, or memory that can be measured through cognitive testing such as the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS). Another secondary outcome was mood, measured by depression scores calculated from the Patient Health Questionnaire (PHQ-9). All participants filled out these questionnaires at the beginning and end of the program.

The study found that HOBSCOTCH was effective in improving objective memory, particularly with regard to attention (3). This was demonstrated by a statistically significant increase in scores on the RBANS for those in the two intervention groups as compared to those in the control group. While there was an increase in quality of life for those in the intervention groups, it was not found to be statistically significant. Depression scores, as measured by the Patient Health Questionnaire (PHQ-9), did not change significantly for those in the intervention or control groups. No statistically significant difference was observed between the two intervention groups.

### Measuring Cost Effectiveness of HOBSCOTCH

My research over the summer of 2015 involved evaluating the results of the 2013-2014 HOBSCOTCH program in terms of its cost effectiveness. Karen Secore, APRN, was one of the clinicians researching HOBSCOTCH and became my mentor. Given the short, ten-week timeline and our resources, Karen and I chose to evaluate cost effectiveness by measuring healthcare utilization before and after HOBSCOTCH was implemented. Our goal was to determine if a self-management program like HOBSCOTCH could be effective in decreasing healthcare costs in addition to helping patients meet specific health goals.

Healthcare utilization data provides information on how often and which healthcare services patients utilize. I conducted a literature review on how healthcare utilization data has been used to measure cost effectiveness. The simplest method is to compare the number of encounters with the healthcare system the patient has before and after an intervention (1). This data can be further related to actual healthcare costs (6, 10, 11), and it can be combined with secondary measures, such as quality of life data, to further examine the effectiveness as well as cost of an intervention (12). I found that studies similar to ours had been usually conducted in the primary care setting (2). Some studies have additionally focused on patients with a higher than average number of encounters (8). This review validated the process we had chosen to use.

I analyzed the medical records of the fifty-seven participants to determine healthcare utilization six months before and six months after participating in the program by counting the number of encounters during those periods. These encounters included outpatient visits, telephone calls, emergency department visits, admissions, surgeries, and diagnostic tests. Outpatient visits and phone calls were divided into those specific to the neurology department and those with other departments to determine if the program affected neurology encounters more than others.

For this study both intervention groups were combined as there was no significant difference in outcomes for these groups. In addition, eighteen patients who had five or more encounters in the six months prior to the program were categorized as high frequency patients. We wanted to look at this group separately to determine if HOBSCOTCH was more effective for these individuals than for others.

I analyzed the data using SPSS statistics software version twenty-one. When looking at the combined intervention group, I found a decrease post-program in both total and neurology encounters, but the decrease was not statistically significant ( $p > 0.05$ ). However, there was a statistically significant decrease in the total number of encounters for those in the high frequency group ( $p = 0.001$ ). (See Figures 1 and 2)

I then took the depression and quality of life data from the first study and compared it to the data on neurology encounters. Before the program, high depression scores (meaning a deeper depression)

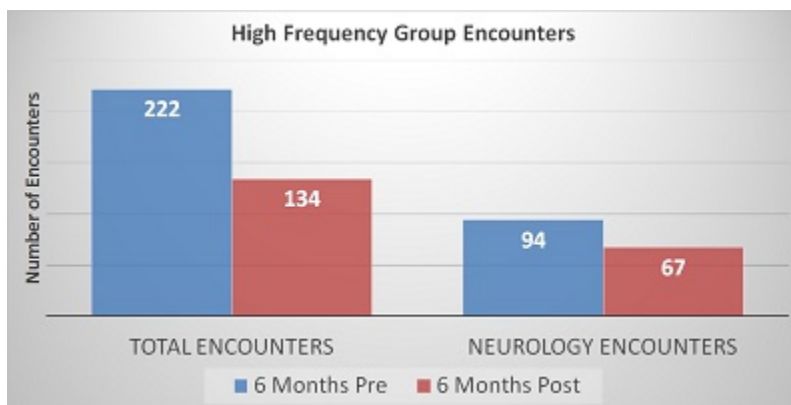


Fig. 1: Comparing total encounters and neurology encounters for the high frequency group before and after HOBSCOTCH. Total Encounters:  $p=0.001^*$  Neurology Encounters:  $p=0.886$ . \*Statistical Significance,  $p < 0.05$

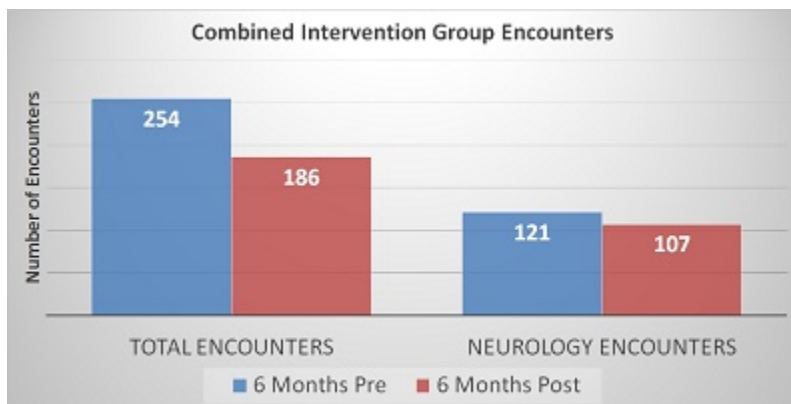


Fig. 2: Comparing total encounters and neurology encounters before and after the HOBSCOTCH program. Total Encounters:  $p=0.246$  Neurology Encounters:  $p=0.548$

were associated with a high number of neurology encounters. Low quality of life scores were also associated with a high number of encounters. This means that patients with depression and/or a decreased quality of life had more neurology encounters.

After the patients completed HOBSCOTCH, high depression scores and low quality of life scores were not always associated with a high number of neurology encounters. In the control group high depression scores continued to be associated with a high number of neurology encounters although low quality of life scores were not.

### What can this Mean?

This study found that HOBSCOTCH lowers the number of healthcare encounters in those who utilize the healthcare system more than others, that is, the high frequency group. While these are positive results, they also highlight a bigger picture. The program aims to help patients manage a particular healthcare problem: memory impairment related to epilepsy. Improving a patient's memory improves his/her quality of life and can also help decrease healthcare encounters. For example, memory impairment can contribute to not consistently taking medications. This can lead to an increased occurrence of seizures and poor control of other health conditions, which in turn lead to more healthcare encounters. After participating in HOBSCOTCH, the total number of encounters decreased in patients in the high frequency group. It is hypothesized that this decrease is the result of improved memory.

As a part of the program, patients learn to recognize and manage memory impairment, which contributes to a decrease in the number of total healthcare encounters. This decrease results in a lowering of healthcare costs to both the patient and the healthcare system.

The effect HOBSCOTCH has on healthcare utilization can also be seen in its effect on the association between depression, quality of life, and the number of neurology encounters. After participating in the program, low quality of life and/or high depression scores did not always result in a high number of neurology encounters. This suggests that the program empowers patients by giving them the tools to self-manage and cope with the cognitive changes associated with epilepsy.

The small sample size is a limitation of this study. Fifty-seven and eighteen patients are relatively small sample sizes. A larger sample size would be needed to further generalize results. In addition, the increased number of encounters experienced by those in the high frequency group and the subsequent decrease could be random.

Overall, these results make the case that self-management programs, both in epilepsy and in other chronic health conditions, can have a multitude of effects. This is particularly true for patients who utilize the healthcare system more than others. Rather than continuing to treat a problem solely with medication, providers can offer education and support, which can empower patients to better manage their conditions and decrease their number of healthcare encounters.

Conducting this research helped me to grow as a nurse. It opened my eyes to the role nurses play in research, and to the extensive amount of work conducted behind the scenes of research studies. As I move forward in my nursing career, I plan to attend graduate school, which will involve conducting research. Before completing this internship, my skill set was primarily clinical. At this point, I know that my knowledge can be applied in a research setting, and that conducting research is very rewarding. I have gained a new sense of confidence in myself and an appreciation for research in

nursing. In addition, I learned about what it takes to conduct research, and how you can learn a lot from negative results.

*There are many people whom I would like to thank for making this research experience possible. First, the INBRE ISURF program gave me the opportunity to conduct research as an undergraduate nursing student. Staff from both Dartmouth College and Dartmouth-Hitchcock Medical Center worked together to make this program possible. Second, I would like to thank Karen Secore, Dr. Barbara Jobst, and the rest of the HOBSCOTCH team for allowing me to spend the summer with them. It was an honor to work with them on a program that they created for their patients. Finally, I would like to thank Dr. Susan Fetzer for bringing this opportunity to my attention, and helping me use the research as a part of my honors thesis. It has been an invaluable experience.*

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## Author and Mentor Bios

**Emily Dwyer**, a senior from Canaan, New Hampshire will graduate in May with her bachelor of science degree in nursing. A member of the University Honors Program, Emily experienced her first foray into research during the summer of 2015 by interning at Dartmouth-Hitchcock Medical Center. Her article is based on one of two projects she was involved with during her internship, and it is also the subject of her honors thesis. Emily gained great insight during her experience, not only about what it means to live with a chronic condition like epilepsy, but that research can be a highly rewarding experience, noting that “I never knew how many people it takes to create a program, implement it, and simultaneously conduct research on it” and “you can learn something even from the negative results.” Emily hopes to work as a nurse in an inpatient critical care setting after graduation before going on to graduate school to become a Nurse Practitioner and to continue developing her research skills in the process.

Dr. **Susan Fetzer** RN CNL is a professor in the Department of Nursing at the University of New Hampshire, where she has been for 26 years. Her areas of specialization are medical-surgical and adult health nursing. She became Emily’s honors thesis mentor because Emily’s project related to her specializations. Professor Fetzer feels it is useful for students in her discipline to learn to write for *Inquiry*’s broad audience “especially if they plan, like Emily, to continue onto graduate and doctoral education.”

During her summer’s internship, Emily worked closely with two members of the Dartmouth-Hitchcock Medical Center. **Karen Secore**, MS APRN CNRN is a nurse practitioner and coordinator of the Dartmouth-Hitchcock Epilepsy Center. Dr. **Barbara C. Jobst**, M.D., is a professor and section chief of the Department of Neurology, Geisel School of Medicine, Dartmouth College, and director of the epilepsy center.

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