

MANAGING EPILEPSY: PERSPECTIVES OF PROFESSIONALS WITH AND WITHOUT EPILEPSY

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Introduction

Management of epilepsy can be viewed as both the process of managing epilepsy and the steps or behaviors necessary for people to control seizures and manage the effects of having a seizure disorder. Effective management requires partnership between the patient and professionals who support their management efforts. Thus, it is important to understand the current perspectives of both people living with epilepsy and the professionals with whom they interact. This qualitative study sought to describe the perspectives of professionals—health care providers, social service providers, and researchers in epilepsy management—regarding challenges facing patients with the disorder.

During the course of the study, the researchers discovered that nearly a third of the professionals interviewed also had personal experience with epilepsy (either the professional or her/his family member had epilepsy). Differences in perspectives, based on profession type and whether the respondent had personal experience with epilepsy, were examined.

Methods

The study was approved for human subjects research by the University of Michigan's Health Institutional Review Board (HUM00024560).

Development of Survey Instrument

Researchers developed survey questions in collaboration with the project's expert advisory panel, composed of two epileptologists, the President and Education Director of the Epilepsy Foundation of Michigan, a person with epilepsy, a parent of a child with epilepsy, a dissemination expert, and an evaluation expert.

Recruitment

The researchers solicited names of professionals with thorough knowledge of epilepsy self management from clinical, social service, and academic research backgrounds in order to gather diverse perspectives. An initial list of approximately 110 key informants was developed from internet searches of national and international epilepsy organizations, literature searches of epilepsy self management research, and recommendations from members of the expert advisory panel and the Managing Epilepsy Well Research Network.

Names were also solicited using a snowball approach, wherein survey respondents were asked for up to three names of individuals they thought should also be interviewed to better understand what is needed and what would be most effective in the area of epilepsy self-management. A total of 224 potential respondents were contacted throughout the project, and the response rate was 45%.

Data collection

Data were collected from 101 respondents primarily through telephone interview, with each lasting about 40 minutes on average. Four of the 101 interviews were not audio recorded either due to technical problems or at the request of the respondent; one respondent opted to submit written answers. Recorded interviews were transcribed verbatim.

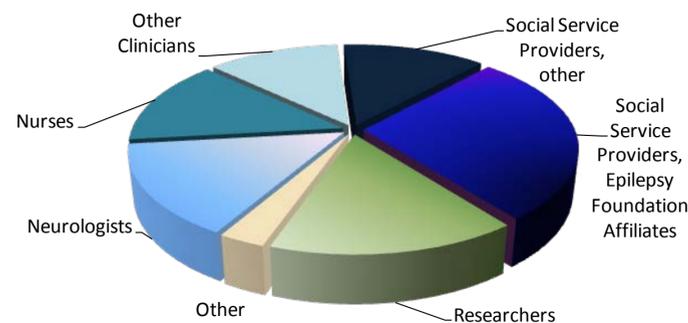
Methods

Analysis

All responses were coded in NVivo 8, a qualitative data coding and analysis software package by QSR, into thematic groups using an iterative process that allowed for multiple codes for a single phrase that represented multiple ideas.

For seven key survey questions, the top five most prevalent responses mentioned were examined to see if the percentage of respondents citing each theme varied considerably among the three major respondent profession types (clinicians, social service providers, and researchers) and by whether or not the respondent had personal experience with epilepsy, defined as a respondent who volunteered that he or she has epilepsy or has a child or other close family member with epilepsy. A chi-square test of homogeneity compared the groups to see if the proportion of respondents who mentioned a particular response differed by profession or by whether or not they had personal experience with epilepsy.

The Key Informants



Examples of Interviewee Professions
psychologist • epileptologist • health educator • nurse practitioner • executive director • program coordinator • professor of behavior sciences • social worker • physician assistant • counselor • neuropsychiatrist • program director • clinical nurse specialist • professor of nursing

Respondent Characteristics

- 16: average years working in epilepsy
- 14% in mental health
- 71% female
- 95% Caucasian
- 5% live outside the US

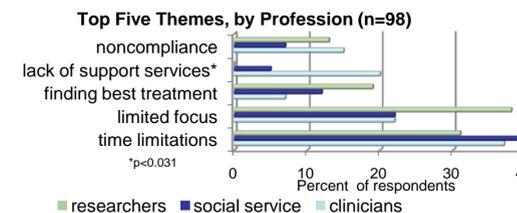
Personal experience with epilepsy:
 ■ 18% have epilepsy
 ■ 16% have family member with epilepsy

personal experience no personal experience with epilepsy

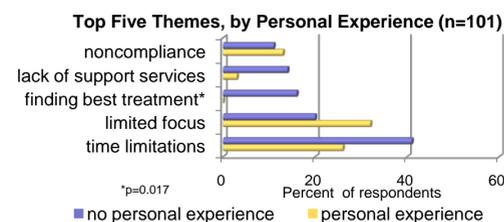
Results

What do you think is the greatest difficulty facing clinicians in helping their patients with epilepsy better manage their condition?

Of the top five response themes to this question, only one varied significantly by respondent profession type: **lack of supportive services** ($p < 0.031$). Twenty percent of clinicians mentioned lack of supportive services, whereas 5% of social service providers and no researchers mentioned the same. Among researchers, **keeping up-to-date medically** and **providing self management education** were in the top five, and among social service providers, **financial barriers** replaced lack of supportive services as one of the five most frequently cited responses.

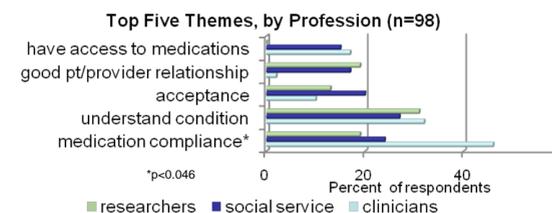


Of the top five response themes to this question only one varied significantly by whether the respondent had personal experience with epilepsy: **finding the best course of treatment** ($p = 0.017$). Sixteen percent of respondents with no reported personal experience with epilepsy mentioned finding the best course of treatment, whereas none of the respondents with personal experience did.



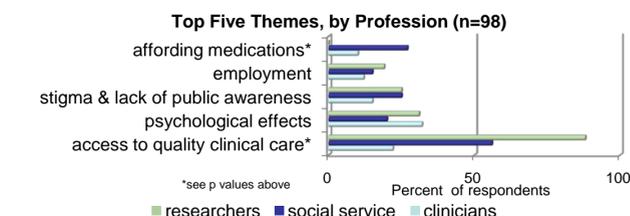
What is the most important thing a person with epilepsy needs to be able to do to manage his or her condition?

Of the top five response themes to this question, only one varied significantly by respondent profession type: **medication compliance** ($p < 0.046$). Medication compliance was the most frequently mentioned response from clinicians, but it was mentioned by smaller proportions of social service providers and researchers. More researchers and social service providers mentioned the need to **"understand their own condition."** None of the top five response themes to this question varied significantly by whether the respondent had personal experience with epilepsy.



What would you say is the most significant challenge people with epilepsy face in managing their condition?

Of the top five response themes to this greatest challenge question, two varied significantly by respondent profession type. A higher percentage of researchers cited **access to quality clinical care** compared with other profession types ($p < 0.001$). Clinicians cited **compliance** and **cognitive problems** as greatest challenges. **Affording medications** was cited by 27% of social service providers but no researchers ($p < 0.018$). Among researchers, **gaining seizure control** replaced affording medications in the top five.



Of the top five response themes, two varied significantly by whether the respondent had personal experience with epilepsy: **stigma and lack of public understanding** ($p < 0.0057$) and **affording medications** ($p < 0.0625$). Only 3% of those with personal experience cited stigma and lack of public understanding as a greatest challenge; instead, **cognitive difficulties** was among the top five they cited. Affording medications was cited by more people with personal experience; **compliance** replaced affording medication as one of the top five responses among those with no personal experience.



Conclusions

Professionals need to recognize that their perspectives may be influenced by their disciplinary orientation and personal experience. Services and programs that accommodate different perspectives and are based on a broader picture of epilepsy control may provide more assistance for people trying to manage the condition.