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 chronic condition. Effecive 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.

Methods

The study was approved for human subjects research by the University of Michigan’s Health Institutional Review Board (HUM0002490).

Development of Survey Instrument

Researchers developed survey questions in collaboration with the project’s expert advisory panel, composed of two epidemiologists, 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, 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 management research, and recommendations from members of the expert panel and the Managing Epilepsy Well 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 98 (43.8%) agreed to participate. A total of 89 (89.8%) respondents were included in the analysis after excluding two respondents whose completed surveys were unanswerable due to technical problems or at the request of the respondent; one respondent opted to submit written answers. Recorded interviews were transcribed verbatim.

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 carried out due to technical problems or at the request of the respondent; one respondent opted to submit written answers. Recorded interviews were transcribed verbatim.

Analysis

All responses were coded in NVivo 8, a qualitative data coding and analysis software. Categorization was performed 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 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.

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<0.046). Twenty percent of clinicians mentioned lack of supportive services, whereas 5% of social service providers and no researchers mentioned it. Among respondents, keeping up-to-date medically and providing self-management education were in the top five, and among social service providers, social barriers replaced lack of supportive services as one of the five most frequently cited responses.

What is the most important thing a person with epilepsy can do to help him or her control his or her condition?

Of the top five response themes to this greatest challenge question, two varied significantly by respondent type: lack of supportive services (p<0.031) and finding best treatment (p<0.0057). Among clinicians, 27% cited lack of supportive services, whereas 9% of social service providers and researchers mentioned this. Among researchers, 43% of those with no personal experience cited stigma and lack of public understanding as the greatest challenge; in contrast, cognitive difficulties was among the top five themes cited among the top five responses among those with no personal experience.

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

Among researchers, gaining seizure control replaced affording medications 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 experiences. 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.