

Epilepsy patients' perceptions about stigma, education, and awareness: Preliminary responses based on a community participatory approach

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Abstract

As individuals directly impacted by their experience of epilepsy and others' responses to it, epilepsy patients' opinions about education and awareness issues are needed. A community-based participatory approach was used to develop a survey of public and patient attitudes and perceptions about epilepsy, which was administered to persons with epilepsy. The majority of the 165 respondents (34% response rate) indicated they perceive misperceptions and stigma related to epilepsy in the general public, which they thought could be ameliorated through educational interventions. Respondents indicated potential avenues of educational intervention for the general public as well as for those with epilepsy, with recommended content and intervention type depending on target audience. The community-based participatory research process and the patients' perceptions gathered through the resulting survey indicate potential activities for overcoming stigma and increasing education and awareness related to epilepsy.

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1. Introduction

Approximately 2.7 million Americans have epilepsy, and about 200,000 new cases are diagnosed each year [1]. An estimated 10% of Americans will experience a seizure at some point, and approximately 3% will be diagnosed with epilepsy by age 80 [1]. The prevalence of active epilepsy is even higher in resource-poor countries with 6 to 10 cases per 1000 being reported [2]. Research indicates that higher rates of epilepsy are experienced by racial and ethnic minorities, people of lower socioeconomic status, people living in rural areas, and males [3].

Although epilepsy is one of the most common disabling neurological conditions, it has not been adequately addressed as a public health concern [4]. Because of social stigma, it is generally poorly recognized and treated by general health services [5]. In addition, studies indicate that neither epilepsy patients [6–11] nor the general public [12–14] are very knowledgeable about epilepsy. Limited public understanding of epilepsy has been found to contribute to stigma by breeding negative attitudes toward epilepsy itself and to people with epilepsy [12]. Misinformation and lack of knowledge among the general community contribute to the social stigma felt by individuals with epilepsy [15]. Stigma has been shown to have a negative effect on seizure control and quality of life in epilepsy patients, with patients often choosing to withdraw socially to cope with discrimination and stigma [16]. Health disparity populations such as racial and ethnic minorities

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may experience still higher levels of stigma [15], which could contribute to more negative health outcomes for these patients.

The present lack of knowledge and understanding demonstrates a need for educational campaigns to improve the public's understanding of epilepsy and to correct misconceptions [13–16]. To date, though, few studies have actually documented the relative success or failure of educational campaigns aimed at ameliorating negative perceptions and attitudes toward epilepsy, especially within the United States. Educational strategies employed in previous studies, although conducted outside the United States, include educational pamphlets directed at college-aged students [17] and small-scale lectures or seminars aimed at the general adult population [14,18]. Methods of measurement included pre- and posteducation questionnaires [14,17,18] and door-to-door interviews [18]. Additional health marketing research has demonstrated the ability of television campaigns to educate the general public as well as a target population [19–22], though to date this has not been tested with epilepsy.

In the formulation of previous educational interventions, the feedback and opinions of epilepsy patients have been overlooked. Information is lacking on patients' perceptions of the most effective education and awareness initiatives, patients' opinions about what information should be featured in such initiatives, how these awareness efforts should be conducted, and at whom to aim them. As individuals directly impacted by their experience of epilepsy and others' perceptions of and responses to it, patients' opinions about these issues are needed. Using a community-based participatory research approach to address social capital and education/awareness needs among epilepsy patients can help address this gap. According to the Institute of Medicine [23], using this approach to assess community capacity may bolster proactive community responses in the face of various social determinants including stigma, discrimination, and psychological distress.

Community-based participatory research involves community members or targeted individuals across the phases of research [24,25]. However, the role of these individuals in the research or project and the extent to which they are involved (ranging from advisory to decision maker) vary from study to study or from program to program [26]. What is critical is that these individuals' input in collaborative research is received [26]. This process ensures that the study or program is relevant and meaningful to the target population [23].

The present study, which enlisted the input of patients with epilepsy in the design of a survey for patients with epilepsy, is an example of community-based participatory research. The survey addressed potential health disparity demographics, treatment, psychological factors, and educational needs and methods. Responses were examined for trends in patients' perceptions regarding (1) whether epilepsy education would be useful in addressing stigma; (2) the degree to which the general public and other

patients with epilepsy are educated about epilepsy; (3) the most common misunderstandings about epilepsy in the general public; (4) the most effective ways to educate the general public and other patients with epilepsy; and (5) what information should be included in an epilepsy education and awareness campaign. This community-based participatory process and the patient perceptions gathered thereby provide an important beginning in determining means for overcoming stigma related to epilepsy.

2. Method

2.1. Participants

Participants in this study consisted of 165 adult (≥ 18 years) patients treated for epilepsy at the Via Christi Comprehensive Epilepsy Center in Wichita, KS, USA, who responded to the study survey. A nonresidential tertiary treatment facility, the Center serves more than 1000 patients annually. All adult patients treated at the Via Christi Comprehensive Epilepsy Center ($N = 484$), with the exception of patients residing in group homes or developmental centers, were sent a survey. The 165 participants represent a response rate of 34%.

2.2. Survey instrument

Because a literature review did not identify similar instruments for assessing patients' perspectives about addressing awareness needs, existing validated items or instruments were not used in the development of the current survey instrument. Survey categories and items were selected based on relevancy to the study's research questions, feedback and input provided by patients with epilepsy, and suggestions made by epilepsy experts.

The researchers in this study worked with three patients with epilepsy to develop and test the survey instrument through a community-based participatory research process. The resulting survey consisted of 48 items in five sections: patient demographics (8 items); patient epilepsy characteristics (12 items); patient perceptions of stigma, epilepsy awareness (their own and in the general public), and educational needs (15 items); patients' perceptions of treatment satisfaction and barriers (4 items); and patients' perceptions of available social support (9 items). The current study analyzed items in the first three sections.

Space was provided for write-in answers for many of these questions. Some questions consisted of "yes" or "no" responses and other forced choices, and in several instances space was provided for further elaboration on these as well. On several survey questions, respondents were asked to rank the multiple answers provided by order of importance (on a scale of 1–5, with 1 being the patient's judgment of the best provided answer). Respondents ranked their choices using inconsistent methods: some ranked multiple options as a top choice, some ranked only their top three or five choices, and some ranked all answers provided. When the results were tabulated for this summary, *only* rankings of "1" were recorded and counted toward totals to create a consistent picture of respondents' perceptions. See Fig. 1 for a selection of the survey questions.

2.3. Procedure

Approval for the study was obtained from the institutional review boards of Via Christi Regional Medical Center and the University of Kansas School of Medicine—Wichita. The community-based participatory research approach used in this study involved input from the target community. General interest for the study was ascertained from brief informal conversations conducted with four patients with epilepsy from a previous, unrelated study. These four female patients indicated that researchers should assess patients' perspectives about what should be done to increase awareness about their condition and to address associated stigma. Consid-

1. Do you feel you are well informed about your epilepsy?	
_____ No	_____ Yes
2. Do you feel the general public is well informed about epilepsy?	
_____ No	_____ Yes
3. In your opinion, what are the most common misunderstandings among the public regarding epilepsy? (Please rank the top 5, 1–5: 1 = most common, 5 = least common)	
_____ Epilepsy is a mental illness	_____ Epilepsy is passed from parent to child
_____ Epilepsy is contagious	_____ Persons with epilepsy should be socially avoided
_____ Epilepsy is an “excuse” for poor behavior (e.g. drug abuse, disruptiveness)	_____ All epilepsy patients experience severe seizures (e.g., severe shaking, thrashing about)
_____ Epilepsy is a “punishment” for immoral/sinful behavior	_____ People do not know how to react to seizures (e.g., grab tongue, restrain patient during seizure)
_____ Other _____	
OR check: _____ There are no misunderstandings.	
4. What, in your opinion, would be the best way to educate the general public about epilepsy? (Please rank the top 5, 1–5: 1 = most effective, 5 = least effective)	
_____ Educational pamphlets	_____ Information in doctors’ offices
_____ Television advertisements	_____ Workplace programs
_____ Extension services/agents	_____ Radio announcements
_____ Billboards	_____ Other _____
5. What kind of information would you like to see promoted in an epilepsy awareness campaign targeted at the general public? (Please rank the top 5, 1–5: 1 = most important, 5 = least important)	
_____ Information about reactions to epilepsy	_____ Information about reactions to seizures
_____ General information about epilepsy	_____ Information about supporting epilepsy patients
_____ Information about origins of epilepsy	_____ Other _____
6. Does a lack of public knowledge about epilepsy discourage you from seeking medical treatment for your epilepsy? _____ No _____ Yes	
7. Would educating the public about epilepsy decrease stress or problems you may experience because of epilepsy? _____ No _____ Yes	

Fig. 1. Selected questions from the survey.

ering time and resource limitations, the patients were amenable to the idea of mail surveys, which would also reach larger numbers of participants compared with focus groups or individual interviews.

Following the development of a survey draft based on the recommendations of the previous study’s participants, the community-based participatory research process continued with the enlistment of two female patients and one male patient from the Via Christi Comprehensive Epilepsy Center to evaluate the survey draft. These patients, who were not included in the final survey sample, evaluated the survey for readability, comprehension, appropriateness and completeness of issues covered, as well as general feasibility. In a group setting, consensus was reached among the patients and researcher in determining how the proposed survey draft should be modified. As a result, some terminology was changed or simplified, questions perceived to be irrelevant were omitted, and the manner in which some questions were presented was revised for clarity.

The draft survey was subsequently presented for medical expert attention, being reviewed by an epileptologist and a physician assistant who specialized in the care of patients with epilepsy. A few minor revisions were made. The survey was then again reviewed individually by the three patients and finalized by the researcher. The Flesch–Kincaid readability levels ranged from 5.6 to 7.8 for various sections of the survey.

The three patients recommended the epileptologist’s letterhead and envelope be used to distribute the survey, as they believed patients were more likely to be responsive to their physician as opposed to the university’s request to complete the survey. The final survey was mailed to all adult patients treated at the Via Christi Comprehensive Epilepsy Center, except for those patients who resided in group homes or developmental centers. Names and addresses of the patients were not requested on the survey, and the cover letter from the director of the Via Christi Comprehensive Epilepsy Center indicated that participation was strictly voluntary and anonymous. A stamped, self-addressed envelope was included in the mailing for the respondents’ convenience and for improved response rate.

Incentives were not offered for completing the survey. The survey was mailed to 484 patients, and a total of 165 surveys were returned, yielding a 34% response rate. Descriptive statistics were calculated for participant demographics and responses using SPSS 14.0 for Windows.

3. Results

3.1. Demographics and epilepsy characteristics

Of the 165 respondents, 62% were women and 38% were men. The survey respondents consisted of 81% white, 4% African American, 4% Native American, 3% Hispanic, and 8% other race or ethnicity. There were no Asian-American patients represented in this sample. All patients were 18 years of age and older, with 25–34 (29%) and 18–24 (23%) being the two highest modal categories. Approximately 46% were married, 40% were single, and 14% were divorced or widowed. Approximately 86% had some type of health insurance.

Forty-two percent (42%) of respondents were employed, 15% were unemployed but seeking employment at the time of data collection, 30% reported being disabled, 7% were students, and 6% were retired. Approximately 54% had household incomes of \$20,000 or less, 21% had household incomes between \$21,000 and \$40,000, 15% had household incomes between \$41,000 and \$60,000, and 10% had house-

hold incomes of \$61,000 or more. See Table 1 for respondent demographics.

Varying types of seizures, including complex partial (23%), tonic-clonic (13%), simple partial (10%), multiple/combination seizures (8%), and unknown (40%), characterized the respondents' epilepsy condition and were self-reported by the participants. The majority of the respondents (65%) reported having been diagnosed with epilepsy for 10 years or longer, 12% for 5–10 years, 19% for 1–5 years, and 4% for less than 1 year. Forty-nine percent of respondents reported not being legally able to drive, whereas 51% were legally able to drive.

3.2. Perceptions of stigma and epilepsy awareness

Approximately 42% of the respondents indicated they had the belief that the general public had negative feelings and reactions toward individuals with epilepsy, and about 41% of those patients stated that this belief negatively affected how they viewed themselves. Twenty percent of respondents reported that they had denied having epilepsy

Table 1
Respondent demographics ($N = 165$)

Demographic	Percentage of respondents (%)
<i>Gender</i>	
Female	62
Male	38
<i>Race/ethnicity</i>	
White	81
African American	4
Native American	4
Hispanic	3
Other	8
<i>Age</i>	
18–24	23
25–34	29
35–44	14
45–54	19
55 years or older	15
<i>Marital Status</i>	
Married	46
Single	40
Divorced/widowed	14
<i>Income</i>	
0–\$20,000	54
\$21,000–\$40,000	21
\$41,000–\$60,000	15
\$61,000 or more	10
<i>Employment</i>	
Employed	42
Disabled	30
Unemployed (seeking work)	15
Student	7
Retired	6
<i>Insurance Status</i>	
Insured	86
Uninsured	14

at some point, and 39% reported that they did not know anyone else with epilepsy. Eighty-nine percent of the respondents did not believe that the general public was well-informed about epilepsy, and almost two-thirds of the sample (65%) believed that stress and problems in their own lives would be decreased if the public was better educated about epilepsy and seizures.

When asked to rank their perceptions of the most common misunderstandings in the general public regarding epilepsy, 63% of respondents ranked “People do not know how to react to seizures” as their perception of the most common misunderstanding held by the general public. Fifty-one percent (51%) of respondents ranked “All epilepsy patients experience severe seizures,” 37% ranked “Epilepsy is a mental illness” as their perception of the most common misunderstanding, 22% ranked “Epilepsy is passed from parent to child,” 20% ranked “Epilepsy is contagious,” and 19% ranked “Persons with epilepsy should be socially avoided” as their perception of the most common misunderstanding held by the general public (as some respondents chose more than one top-ranked option, these and other totals exceed 100%) (Fig. 2).

3.3. Awareness and education for the general public

Eighty-eight percent (88%) of the respondents indicated that they believed an awareness program would be helpful in educating the general community. When asked to indicate their perceptions of the best ways to educate the general public about epilepsy, 52% of respondents ranked television advertisements as their perception of the best way to educate the general public. Forty-seven percent (47%) ranked information in doctors' offices, 42% ranked workplace programs, 38% ranked educational pamphlets, 24% ranked radio announcements, 23% ranked billboards, and 18% ranked extension services or agents as the best method of educating the general public about epilepsy (Fig. 3).

When asked to indicate the types of information they would like to see promoted in an epilepsy awareness campaign for the general public, “information about reactions to seizures” was top-ranked by 59% of respondents. Fifty-eight percent (58%) top-ranked “general information about epilepsy”, and 43% indicated the same for “information about reactions to epilepsy.” Forty-two percent (42%) of respondents ranked “information about supporting epilepsy patients” as the most important type of information, and 32% indicated that “information about origins of epilepsy” was the most important type of information to promote in an epilepsy awareness campaign for the general public (Fig. 4).

3.4. Awareness and education among patients with epilepsy

A large majority of respondents (85%) indicated they were well-informed about their own epilepsy. However,

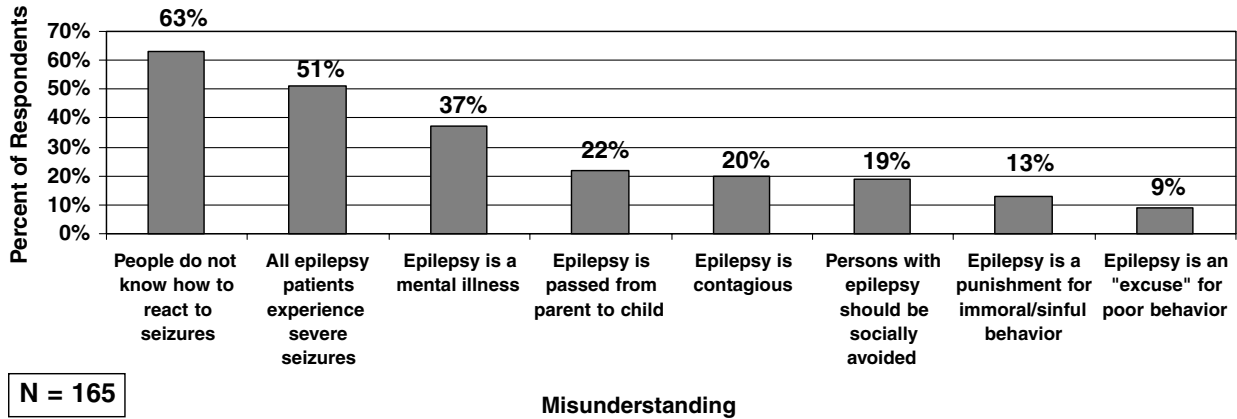


Fig. 2. Top-ranked most common misunderstandings of the general public regarding epilepsy.

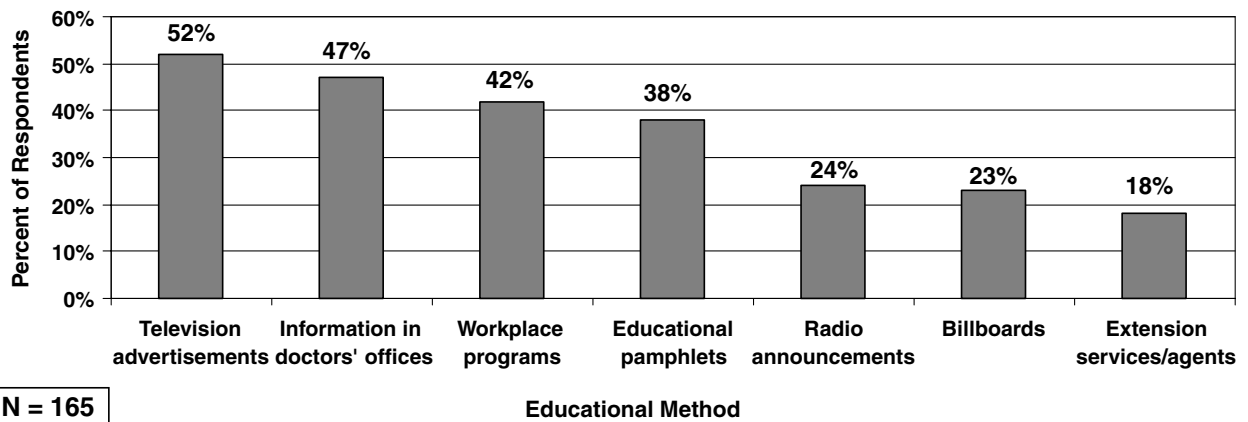


Fig. 3. Top-ranked most effective ways to educate the general public about epilepsy.

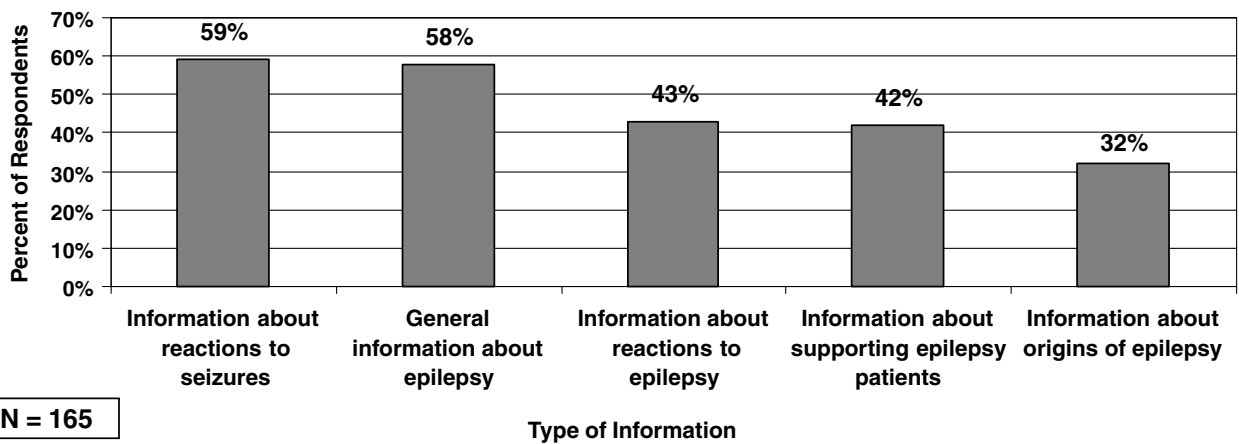


Fig. 4. Top-ranked most important information to be promoted in an awareness campaign for the general public.

approximately 88% indicated there was a need for epilepsy awareness among patients with epilepsy. When asked to indicate the importance of certain types of information for an awareness program for patients, 55% indicated that “information about self-management of epilepsy” would be most important to include. Additional percentages and responses indicated as most important by respondents were

“treatment information” (indicated as most important by 54% of respondents), “general information about epilepsy” (45%), “information relating to resources or available help” (38%), “information about support groups” (28%), and “information for counseling services” (25%) (Fig. 5).

When asked to indicate the best way to increase awareness of these “most important” topics among epilepsy

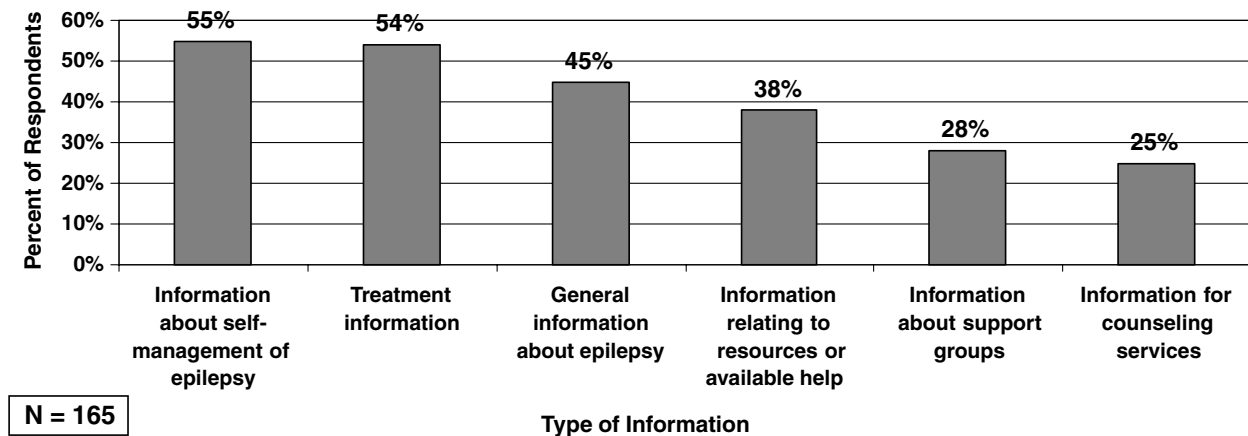


Fig. 5. Top-ranked most important types of information to include in an awareness campaign for persons with epilepsy.

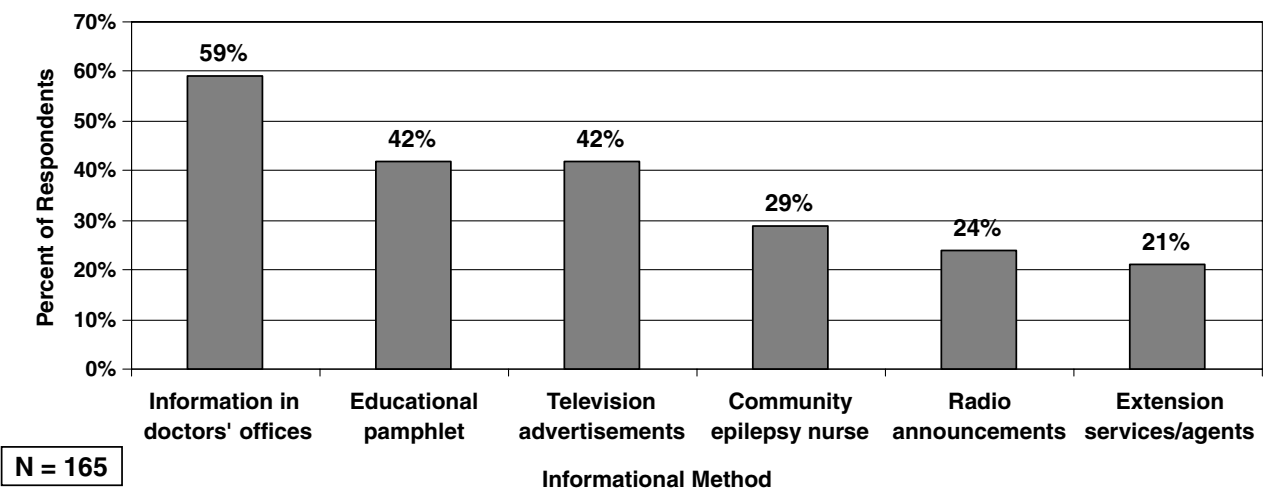


Fig. 6. Top-ranked most important ways to increase awareness about epilepsy.

patients, 59% indicated that information in doctor's offices would be the best method. Forty-two percent (42%) each indicated educational pamphlets and television advertisements, 29% indicated a community epilepsy nurse, 24% indicated radio announcements, and 21% indicated extension services or agents as the best way to increase awareness among epilepsy patients (Fig. 6).

3.5. Completeness of data and use of written responses

The degree of quantitative responses was strong. With the exception of survey questions that required participants to rank their answers (e.g., information they would like to see promoted in an epilepsy awareness campaign), responses were fairly complete. "Missing" responses accounted for 0–6% of each survey item.

Write-in responses were common, ranging from as few as 3% of participants responding to a particular survey item to as many as 30%. On average, the responses reiterated or elaborated on items previously selected on the survey by the respondent. For example, in addition to selecting "television" as the best way to educate the general

public about epilepsy, some participants explained whether these television efforts should include documentaries or commercials or be incorporated into the plot of a movie. In some cases, respondents included brief editorials about the importance of addressing a particular issue. For instance, in response to the item asking whether respondents thought educating the public about epilepsy would decrease stress or problems they experienced because of epilepsy, many participants submitted responses about why it was necessary to educate the public. However, in cases where write-in responses did not reiterate a previously selected answer or did not provide additional information about the importance of a particular issue, they were grouped by theme. Yet, resulting percentages were so low for written responses of this type that they were not included in the final analysis.

4. Discussion

The present study used community-based participatory research methods to develop and pilot a survey of patients' perceptions about knowledge and stigma related to their

condition, as well as effective methods for educating patients and the general public about the disorder. The results collected offer insight into the potential development of educational interventions, as well as implications for the continued development of the community-based participatory research process.

Respondents held different perceptions about the educational content and format that would be effective for the general public as opposed to patients with epilepsy. Although television campaigns and information in doctor's offices were highly ranked for both groups, respondents ranked television ads as the best way to educate the general public, and information in doctors' offices was the second most commonly indicated choice. For educating patients, the reverse was true: information in doctors' offices was most commonly indicated as the best educational method, and television campaigns were the second most commonly indicated choice along with educational pamphlets (the fourth most commonly chosen method for educating the general public). In general, patients indicated a perception that patients would be more receptive to being educated through printed materials, particularly those associated with a physician, than would the general public. This could simply reflect the greater familiarity that patients with a long-term medical condition would have with receiving information through doctors' offices and medical pamphlets.

Survey responses also indicated knowledge gaps—not only those perceived in the general public, but those possessed by patients themselves. Although the majority of the respondents (85%) indicated their own knowledge about epilepsy was sufficient, about 88% believed that education and awareness for other patients like themselves would be beneficial. Therefore, the respondents tended to believe that they were better-informed than other patients. This is not supported by other survey results, which revealed that 40% of patients did not know what type of epilepsy they had, and 39% did not know anyone else with epilepsy. Overestimation of one's own knowledge is not an uncommon phenomenon; previous research has found that people consistently overestimate (inaccurately) their own knowledge and abilities compared with others [27]. Patient self-reported knowledge of epilepsy is an important piece of information, but because of the gaps between perception and reality, this should not replace empirical assessment of knowledge needs.

In terms of stigma, 42% of the respondents indicated they believed the general public perceived individuals with epilepsy negatively. A full 65% of the respondent sample also indicated the belief that they would experience reduced epilepsy-related stress and problems if the public was better educated about the condition. In the field of mental health, stigma has been found to affect negatively the degree to which patients take advantage of available services and supports [28,29], and similar factors may affect patients with epilepsy as well. Indeed, a European survey of International League Against Epilepsy staff found that respon-

dents perceived that stigma against epilepsy was universally prevalent in both underserved and adequately served areas [30].

In summary, respondents communicated that specific types of epilepsy education and awareness efforts are needed, which should be tailored to help decrease stigma in the general public and help patients learn more about available treatment and coping mechanisms (e.g., support groups or self-management activities). As Young et al. found, even a small educational effort (such as a brochure in a classroom setting) can significantly improve knowledge, though not necessarily attitude [17]. Researchers on stigma as it relates to other conditions, such as HIV/AIDS, have found that both individual education and change in the social environment are needed to create a significant difference [31]. One social mechanism for reducing stigma is to encourage those living with a stigmatized condition to speak publicly about their condition and, in doing so, demystify it and provide a human face for a misunderstood issue [32].

The present study did contain some limitations. Although the respondents' demographics closely represent those of the Kansas state population, the overall minority sample was small. Previous studies have indicated that cultural factors can influence minority experiences of epilepsy, and it would be important to develop this study further to address potential issues of cultural competency [15]. In addition, the survey response rate was somewhat low at 35%. However, this was an exploratory study conducted on a convenience sample, and other information about education and awareness needs from the patient's perspective is limited. The present sample of 165 patients provides a strong basis for further research, though larger sample sizes will be needed in future studies for better analyses.

Another limitation of the study is the possible desire of participants to provide socially acceptable responses. Because the survey was mailed from the medical facility in which the respondents received treatment, some patients might have been reluctant to express inadequate knowledge about their conditions or needs. Finally, generalizability might be an issue as respondents were patients of a tertiary epilepsy treatment facility; their experiences and views may differ from those of other patients with epilepsy. However, the respondent sample was very diverse in terms of household income, employment status, age, and type of epilepsy. The high proportion of young respondents (52% were ≥ 34 years of age), which includes a student population, may account for the large number of respondents who reported being single and having low income.

Because the literature lacks patients' perspectives on epilepsy education needs, the current study of patients' views about epilepsy education and awareness needs provides a necessary perspective for the development of interventions. As this study demonstrates, individuals affected by epilepsy are not only aware of the stigma their condition has in the broader community, but also believe that educational campaigns can help ameliorate stigma, negative self-image, and

the stress they feel in their own lives. They have concrete ideas about what these education efforts should consist of and how they should be implemented, not only for the general public but also in efforts to help other individuals with epilepsy.

The community-based participatory research process and the patient perceptions gathered through it provide an important beginning in determining means for overcoming stigma and increasing education and awareness. As a pilot study, the current findings should serve as the first phase of a community-based participatory research project. Further research could include patients with epilepsy and the agencies that serve them in developing studies or interventions aimed at increasing awareness and reducing stigma. Specific activities might include conducting focus groups and/or convening an advisory committee consisting of the target group and related agencies and organizations to inform the study's process, guide development of materials, help interpret findings, and assist in disseminating results. At each phase of the community-based participatory research process, involvement and input from the target group should be included.

In addition to including individuals affected by epilepsy and organizations or agencies that serve them, multiple community partners and resources should be considered. On the basis of the venues patients indicated should be used for education and awareness (e.g., television, physician/medical offices), the media, health care providers, human service agencies, and schools would be accepted as community partners by patients with epilepsy. Multiple change agents should be considered in the process of developing research and promoting education and awareness. Various partners are needed to help develop community, state, and federal plans for improving the condition of patients with epilepsy [33]. Only with the continued development of such efforts can meaningful steps be taken to eliminate stigma and educate patients and the public about epilepsy.

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