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Knowledge of and familiarity with epilepsy in U.S. adults: Results from the 2017 ConsumerStyles Online Panel Survey

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Abstract

Examining and improving knowledge and attitudes about epilepsy has been a public health priority because of stigma around the disorder. This study had three goals: (1) to update estimates describing U.S. adults' perceived knowledge about epilepsy, seizure first aid, and confidence in providing seizure first aid; (2) to examine U.S. adults' recognition of common signs and symptoms of generalized and focal seizures to inform public awareness efforts; and (3) to provide baseline estimates of exposure to an Epilepsy Foundation public awareness campaign, #ShareMySeizure, launched in November, 2016. Four sets of epilepsy questions were included on the 2017 Porter Novelli ConsumerStyles survey, an online panel survey of the U.S. adult population. We examined differences in study outcomes by sociodemographic factors and familiarity with someone with epilepsy. Small percentages of U.S. adults felt knowledgeable about epilepsy (16%), knew seizure first aid (25%), or reported having confidence in being able to help someone having a seizure with appropriate seizure first aid (20%). Fewer adults were familiar with signs of focal seizures compared to generalized seizures. About 1% of U.S. adults had heard of the #ShareMySeizure campaign. Television and family and friends emerged as the most common sources of information for those who reported hearing something about epilepsy. About 33% of U.S. adults wanted to learn more about epilepsy. Knowledge about epilepsy among the U.S. public is suboptimal, though generally on par with that of more common conditions such as heart disease, eye conditions, and ovarian cancer. U. S. adults need and want more information about epilepsy, appropriate seizure first aid training, and recognition of seizure symptoms.

Keywords

Epilepsy; Seizures; U.S. public; Survey; Attitudes; Knowledge

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Declaration of interests
Rosemarie Kobau has no conflict of interest to report.
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1. Introduction

About 3.4 million people in the U.S. and 46 million people worldwide have active epilepsy [1,2]. Examining and improving knowledge and attitudes about epilepsy has been a public health priority in the U.S. and internationally because of the longstanding stigma around the disorder [3-7]. Several U.S. studies in the past two decades examined attitudes toward, or perceived knowledge about, epilepsy in nationally representative samples of U.S. adults, or in population subgroups [3,4,8-10]. Despite differences in methodologies, some of these studies have found that negative stereotypes about epilepsy have declined (e.g., people with epilepsy are possessed by spirits; people with epilepsy should not marry), and beliefs about the capacities of people with epilepsy have improved (people with epilepsy can do anything others can do, and can cope with everyday life) substantially in most, but not all, U.S. population subgroups [4,8,9,10]. Yet, continued discomfort with seizures underlies worsening public attitudes associated with the possible avoidance behaviors. For example, more U.S. adults reported in 2013 than in 2005 that they would be nervous around persons with epilepsy (25.4%, 95% CI = 23.4–27.5 vs. 16.8%, 95% CI = 15.4–18.2) and would avoid those with frequent seizures (12.4%, 95% CI = 11.0–13.9 vs. 7.6%, 95% CI = 6.7–8.7) [8]. Almost two decades ago, about one-third of U.S. adults reported knowing someone with epilepsy, but few perceived themselves to be knowledgeable about epilepsy (~25%), familiar with seizure first aid (~23%), or familiar with the U.S. Epilepsy Foundation (~24%) [3]. Epilepsy is a spectrum disorder with varying symptom severity. But in the public mind, epilepsy is typically linked with generalized seizures (commonly referred to with the outdated term “grand mal” seizures) because these symptoms are more easily recognized given their overt physical manifestations, and the historical over-representation of these types of seizures in art, books, television, and other media [11,12]. As recently as 2020, the social media platform TikTok promulgated a “Seizure Challenge” that grossly derided people with epilepsy and perpetuated the focus on generalized seizure symptoms [13]. The perception that epilepsy is characterized primarily by generalized seizure symptoms is especially problematic as focal seizures are more common in the U.S. population [14,15]. Signs and symptoms of focal seizures are more nuanced and therefore may go unrecognized by the person experiencing them as well as by others—who often attribute these symptoms to other causes—resulting in delays in diagnosis, appropriate treatment, and appropriate first aid that could prevent adverse outcomes [11,15]. This study had three goals: (1) to update previous estimates describing U.S. adults’ perceived knowledge about epilepsy and seizure first aid and confidence in providing seizure first aid; (2) to examine, for the first time, U.S. adults’ recognition of common signs and symptoms of both generalized and focal seizures to identify knowledge gaps and inform new public awareness efforts; and (3) to provide baseline reach data coinciding with the November 2016 launch of a U.S. Centers for Disease Control and Prevention (CDC)-supported four-year Epilepsy Foundation public awareness campaign, #ShareMySeizure, conducted in partnership with the CBS Corporation media network’s Community Partnership Division.

2. Materials and methods

Four sets of questions designed to assess familiarity with epilepsy symptoms and knowledge about epilepsy causes were developed for inclusion on the 2017 ConsumerStyles survey

(Table 1). ConsumerStyles is one of a series of annual, online panel surveys of the U.S. adult population aged 18 or older conducted by Porter Novelli Public Services using KnowledgePanel [16]. ConsumerStyles is licensed by the CDC for audience analysis in health communication planning. ConsumerStyles collects data on demographics, health conditions, health beliefs, awareness of health risks, and health-related behaviors. Panel members are randomly recruited using probability-based sampling by address to reach respondents regardless of whether they have landline phones or internet access. If needed, households are provided with a laptop computer and internet access to complete one or more of the panel surveys. The Fall ConsumerStyles Survey is the third wave of the online panel surveys. The initial wave (Spring ConsumerStyles) was fielded in the spring of 2017 and sent to 10,916 panelists [16]. Panelists who completed the spring survey received an incentive of cash reward points worth $10.00. Panelists received three different reminders —once each week of the field period. The ConsumerStyles survey (administered from September 21 to October 3, 2017) was sent to a random sample of 4633 panelists 18 years old or older who answered the spring survey. E-mail reminders were sent to non-responders on the 3rd and 7th days of the field period. Respondents who completed the survey received an incentive of cash reward points worth $5.00. The median survey completion time was 29 minutes. Respondents who did not answer at least half of the questions were removed from the final dataset as incomplete cases ($n = 13$). The final sample included 3,547 adults who completed the survey for a response rate of 76.6%. ConsumerStyles data are weighted to match the March 2016 U.S. Current Population Survey proportions on eight factors: gender, age, household income, race/ethnicity, household size, education, Census Region, and metropolitan status. ConsumerStyles survey data have been demonstrated to be valid for reporting health outcomes when compared with the Behavioral Risk Factor Surveillance System [17].

The first set of six epilepsy questions asked respondents about their familiarity with epilepsy —whether they know someone with the disorder, had seen someone have a seizure, or heard anything about epilepsy in the past twelve months (Table 1). Because a new CDC-funded Epilepsy Foundation awareness campaign (#ShareMySeizure) was launched in November 2016, a single question asked respondents if they had seen or heard anything about this campaign. The second set of three epilepsy questions asked respondents about their perceived knowledge about epilepsy and their perceived knowledge of seizure first aid. The third question in the epilepsy set asked respondents in plain language both 11 common symptoms or signs of both generalized and focal seizures (Table 1) and five symptoms or signs known not to be associated with seizures (e.g., blood in the urine; sore throat); such contrasting questions help to distinguish respondents' knowledge versus guessing about epilepsy symptoms and signs. Respondents were instructed to choose all that apply. We identified respondents who selected four or more, eight or more, all, or none of the correct epilepsy symptoms or signs. We developed the following formula to identify respondents who correctly identified all epilepsy symptoms or signs: [(Number correct selected) + (Number incorrect not selected)] = 17 correctly selected items. The final set of epilepsy questions asked respondents about their interest in learning more about epilepsy. In another survey question asking respondents about their familiarity with health-related non-profit organizations (e.g., The American Cancer Society, The American Heart Association, the

Arthritis Foundation, and the Multiple Sclerosis Foundation), the “Epilepsy Foundation” was also included as another response option (not included in Table 1).

Licensed, proprietary aggregated data without individual identifiers were provided to CDC. SAS v 9.4 was used for analysis. We used stratified analysis and descriptive statistics to examine differences in knowledge about epilepsy symptoms and familiarity with epilepsy by age group, sex, race/ethnicity, education, metropolitan status (i.e., urban vs. rural geographic region), and by knowing someone with epilepsy to inform the development of targeted educational interventions. Statistically significant differences (significance level = 0.05) among categorical variables were identified with P-values from chi-square statistics that compare observed values with subgroup expected estimates.

3. Results

Few U.S. adults felt knowledgeable about epilepsy (16%), knew seizure first aid (25%), or had confidence in being able to help someone having a seizure with appropriate seizure first aid (20%) (Table 2). Twenty-three percent of respondents reported they knew someone with epilepsy, and 68% reported that they did not (Table 3). Adults who knew someone with epilepsy were more likely than those who did not to be knowledgeable about epilepsy (29% vs. 11%, $p < 0.001$); to know what to do if someone had a seizure (42% vs. 20%, $p < 0.001$), and to feel more confident about providing appropriate first aid (34% vs. 16%, $p < 0.001$) (Table 2).

Women did not differ from men with respect to being knowledgeable about epilepsy, to know what to do if someone had a seizure, and to feel confident about helping someone with a seizure with appropriate first aid (Table 2). Among all age groups, the youngest (18–24 years) and the oldest (≥65 years) adults were least likely to report knowing what to do if someone had a seizure ($p < 0.01$) and feeling confident that they could help someone having a seizure with appropriate first aid ($p < 0.001$) (Table 2). Compared to adults with at least some college education, adults with a high school degree or less were the least knowledgeable about epilepsy, most unfamiliar with seizure response, and the least confident in their ability to help someone with appropriate seizure first aid (all $p < 0.001$) (Table 2). Perceived knowledge about epilepsy, seizure response, or confidence in providing appropriate first aid for seizure response did not differ among adults by race-ethnicity or by metropolitan region (Table 2).

Thirty-one percent of U.S. adults reported having seen someone have a seizure associated with epilepsy, and 13% were unsure about seeing someone have a seizure (Table 3). Fifty-five percent of U.S. adults reported seeing someone have a seizure on television, and 41% reported witnessing a seizure in a community setting (Table 3). Six percent reported recently reading or hearing about epilepsy in the media. (The question, “If you have heard anything about epilepsy during the past 12 months, where have you heard it?” was asked of all respondents.) Most read or heard about epilepsy by television (10%), family or friends (10%), or the internet (7%) (Table 3). In 2017, over 70% of respondents reported being familiar with organizations such as the American Cancer Society and American

Heart Association. Fewer were familiar with the Multiple Sclerosis Foundation (37%), the Arthritis Foundation (32%), and the Epilepsy Foundation (18%) (Table 3).

More than one-half of adults correctly identified symptoms or signs associated with generalized epilepsy (e.g., eyes fluttering [56%]; rhythmic jerking [67%]; falling to the ground [68%]; uncontrolled shaking [75%]) (Table 3). Fewer identified symptoms or signs associated with focal seizures as symptoms or signs of epilepsy (e.g., walking aimlessly [15%]; hallucinations [10%]; déjàvu [5%]) (Table 3). Between 1% and 3% of adults incorrectly identified as epilepsy symptoms or signs symptoms not associated with epilepsy (e.g., blood in the urine). Of the eleven response items comprising the correct epilepsy symptoms or signs, 60% percent of adults selected a combination of four or more correct symptoms or signs, 9% of adults selected eight or more, but only 1% selected all the correct symptoms or signs (Table 3). Of the **17** response items comprising the total of correct selection of epilepsy symptoms or signs and omission of incorrect epilepsy symptoms or signs, 59% of U.S. adults chose 10 or more symptoms or signs as correctly identifying epilepsy while excluding symptoms or signs not identifying epilepsy; only 8% chose 14 or more symptoms or signs as correctly identifying epilepsy while excluding symptoms or signs not identifying epilepsy (Table 3). Familiarity with seizure signs and symptoms varied by sex, age, race/ethnicity, education, and whether someone knew someone who had epilepsy (data available upon request).

One out of three U.S. adults reported wanting to learn more about epilepsy; 15% reported that they wanted to learn more because they know someone with the disorder; 9% wondered if symptoms in themselves or loved ones were seizures; and among the 32.6% of adults who answered that they wanted to learn more about epilepsy symptoms, 62% of these respondents indicated that they had heard about epilepsy and wanted to learn more about it (Table 3). About 1% of U.S. adults had heard of the Epilepsy Foundation #ShareMySeizure campaign.

4. Discussion

Compared with findings from the 2002 HealthStyles Survey, when respondents were asked similar questions, fewer U.S. adults in 2017 perceived themselves as knowledgeable about epilepsy and about how to help someone having a seizure [3]. Fewer U.S. adults (23%) reported knowing someone with epilepsy in 2017 than in 2002 (30%), but as in 2002, more adults who knew someone with epilepsy perceived themselves to be knowledgeable about it and in seizure first aid [3]. Interestingly, about the same percentages of U.S. adults in 2017 as in 2002 reported seeing someone have a seizure in a community setting (40–50%) and on television (55–57%) [3]. However, differences between 2002 and 2017 must be interpreted with caution because the survey methodology changed over time (e.g., probability sample household mail survey vs. probability sample online panel survey). The U.S. population grew and changed significantly over this time period as well, with a growing older population and increases in racial/ethnic minority subgroups [18,19]. This population shift may underlie worsening trends from 2005 to 2013 for some subgroups regarding personal fear and social avoidance associated with epilepsy previously reported [8].

Despite the relatively small percentages of U.S. adults who perceived themselves to be knowledgeable about epilepsy, more than one-half of U.S. adults are familiar with a range of seizure symptoms. In a methodologically comparable 2017 panel survey of U.S. adults that examined perceptions, feelings, and knowledge related to heart health, 59% of U.S. adults know very little about heart health; although most recognized some typical heart attack symptoms (e.g., pressure/squeezing/fullness or pain in the center of one's chest, pain in one or both arms), significantly fewer recognized more nuanced symptoms (e.g., pain in the back or jaw and nausea/vomiting) [20]. Another methodologically comparable 2016 panel survey examining the U.S. public's attitudes and awareness of eye health found that knowledge about specific eye disorders and risk factors was suboptimal and varied significantly by population subgroups [21]. Purvis-Cooper et al. (2016) used 2012 ConsumerStyles data to show that more than 70% of U.S. women without a history of gynecologic cancer did not know about common symptoms associated with ovarian cancer [22]. Our study findings suggest that knowledge about epilepsy among the U.S. public is suboptimal, though generally on par with that of more common conditions such as heart disease, eye conditions, and ovarian cancer.

Although more than one-half of U.S. adults reported in 2017 not hearing anything about epilepsy in the previous year, television and family and friends emerged as the most common sources of information about epilepsy for those who reported hearing something about the disorder. This suggests that more recent public awareness strategies such as those launched by the Epilepsy Foundation in partnership with the CBS Community Partnership Division, in 2017 (#ShareMySeizure) and in 2019 (#StaySafeSide) in multiple television markets, may be an effective way to reach substantial proportions of the U.S. adult population. Although only 1% of the population in 2017 indicated exposure to the #ShareMySeizure campaign of the Epilepsy Foundation and CDC, this campaign was only formally launched in November 2016 on the CBS station in Chicago, with several nationwide digital/social media placements. Because ConsumerStyles was fielded in the summer of 2017, only a few respondents outside of the Chicago region or who did not access CBS media would have been exposed to the campaign. Because the #ShareMySeizure campaign was expanded in 2017 and later in 2019 to include more television markets (Philadelphia and Atlanta) and social media markets (Los Angeles and Tampa), our study findings can serve as baseline estimates for future evaluation studies to assess whether exposure to the campaign and any corresponding campaign web traffic increased with increasing reach into additional major U.S. metropolitan markets, resulting in increased knowledge about epilepsy and seizure first aid. Although this type of campaign evaluation requires substantial planning, it has been successfully used to assess reach and impact in mental illness [23].

This study's large sample size enabled us to identify priority subgroups for intervention regarding epilepsy knowledge, symptom awareness, and first aid education and training —adults 18–24 and ≥65 years of age, and adults with a high-school degree or less. Moreover, testing of educational messages should be done to assess whether different content (e.g., medical information vs. personal testimonies) is more salient and motivational for these subgroups based on whether they strongly disagree with or are unsure of being knowledgeable about epilepsy or seizure first aid. The unsure group may have had some limited exposure to first aid training, may (incorrectly) believe calling for emergency assistance is sufficient first aid, and may require different educational content than those who strongly disagree (e.g., "remedial" vs. "introductory" messages). This requires additional study.

Although reassuring that U.S. adults who knew someone with epilepsy were more likely to express being knowledgeable about the disorder and believed themselves capable of providing seizure first aid, the relatively low percentages even here indicate a need for improvement. Whether respondents had close or distant relationships with the person with epilepsy they know could affect individual motivation to become more knowledgeable about epilepsy or seizure first aid. Noteworthy is the finding that one out three U.S. adults wanted to learn more about epilepsy, most of whom indicated general curiosity about the disorder, with fewer indicating they wanted to learn more because they knew someone with epilepsy or were concerned about symptoms in themselves or others. These findings underscore the importance of applying a theoretical approach to design and evaluate communication strategies so that targeted messages are framed appropriately and applied to mobilize different actions (e.g., acquiring information; talking to a doctor about symptoms) depending on an individual or group's "stage" of readiness or motivation to acquire epilepsy information [24].

This study has several limitations. First, all findings are based on unvalidated self-reports of perceived knowledge about epilepsy, appropriate seizure first aid, and confidence in providing first aid. Perceived knowledge may overestimate direct knowledge of these outcomes or seizure first aid behaviors. Second, although seizure symptoms range widely at an individual level, we were limited to describing the more commonly occurring seizure symptoms. Because some respondents could have been familiar with other symptoms not captured by our survey, we may have underestimated how familiar respondents were with different seizure symptoms. Third, the online panel's experience with epilepsy may have been skewed because of sampling bias, but the survey weights should account for this limitation. The finding that 1.6% of respondents indicated that they wanted to know more about epilepsy because they had epilepsy themselves indirectly validates the survey methodology because this estimate is consistent with other U.S. population-based estimates of self-reported epilepsy prevalence based on differing survey methodologies [25,26]. Fourth, response bias related to question responses or format could have occurred, but this is unlikely because the survey randomizes responses for multiple response option questions, thereby minimizing this bias. Fifth, because the ConsumerStyles survey requires English fluency, it omits non-English speakers who may differ in their knowledge and experience with epilepsy. Finally, statistically significant differences among groups might be overestimated because of multiple comparisons.

Our study indicates that U.S. adults need more information about epilepsy, appropriate seizure first aid training, recognition of seizure symptoms, and familiarity with the Epilepsy Foundation as a resource for epilepsy information.

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Disclaimer

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Data availability statement

The Porter Novelli ConsumerStyles dataset is a proprietary dataset. Permission for use can be addressed to Dr. Deanne Weber, Porter Novelli. Supplementary tables for outcomes by select subgroups are available from CDC upon request.

References

[1]. Zack MM, Kobau R. National and state estimates of the numbers of adults and children with active epilepsy — United States, 2015. MMWR Morb Mortal Wkly Rep2017;66:821–5. 10.15585/mmwr.mm6631a1. [PubMed: 28796763]

[2]. Global Burden of Disease Epilepsy Collaborators. Global, regional, and national burden of epilepsy, 1990–2016: A systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol2019;18:357–75. 10.1016/S1474-4422(18)30454-X. [PubMed: 30773428]

[3]. Kobau R, Price P. Knowledge of epilepsy and familiarity with this disorder in the U.S. population: Results from the 2002 HealthStyles survey. Epilepsia2003;44:1449–54. 10.1046/j.1528-1157.2003.17603.x. [PubMed: 14636355]

[4]. Dilorio CA, Kobau R, Holden EW, Berkowitz JM, Kamin SL, Antonak RF, et al.Developing a measure to assess attitudes toward epilepsy in the US population. Epilepsy Behav2004;5:965–75. 10.1016/j.yebeh.2004.08.020. [PubMed: 15582846]

[5]. Price P, Kobau R, Buelow J, Austin J, Lowenberg K. Improving understanding, promoting social inclusion, and fostering empowerment related to epilepsy: Epilepsy Foundation public awareness campaigns — 2001 through 2013. Epilepsy Behav2015;44:239–44. 10.1016/j.yebeh.2014.12.044. [PubMed: 25726152]

[6]. Fernandes PT, Snape DA, Beran RG, Jacoby A. Epilepsy stigma: What do we know and where next?Epilepsy Behav2011;22:55–62. 10.1016/j.yebeh.2011.02.014. [PubMed: 21458385]

[7]. Herrmann LK, Welter E, Berg AT, Perzynski AT, Van Doren JR, Sajatovic M. Epilepsy misconceptions and stigma reduction: Current status in Western countries. Epilepsy Behav2016;60:165–73. 10.1016/j.yebeh.2016.04.003. [PubMed: 27208826]

[8]. Cui W, Kobau R, Zack MM, Buelow JM, Austin JK. Recent changes in attitudes of U.S. adults toward people with epilepsy — results from the 2005 SummerStyles and 2013 FallStyles surveys. Epilepsy Behav2015;52(PTA):108–18. 10.1016/j.yebeh.2015.08.040. [PubMed: 26409138]

[9]. Sirven JI, Lopez RA, Vazquez B, Van Haverbeke P. Que es la epilepsia? Attitudes and knowledge of epilepsy by Spanish-speaking adults in the United States. Epilepsy Behav2005;7(2):259–65. 10.1016/j.yebeh.2005.04.015. [PubMed: 16054871]

[10]. Austin JK, Shafer PO, Deering JB. Epilepsy familiarity, knowledge, and perceptions of stigma: report from a survey of adolescents in the general population. Epilepsy Behav2002;3(4):368–75. 10.1016/S1525-5050(02)00042-2. [PubMed: 12609335]

[11]. Fisher RS, Cross JH, French JA, Higurashi N, Hirsch E, Jansen FE, et al.Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the

ILAE Commission for Classification and Terminology. Epilepsia2017;58(4):522–30. 10.1111/epi.13670. [PubMed: 28276060]

[12]. Trimble M, Hesdorffer DC. Representations of epilepsy on the stage: From the Greeks to the 20th century. Epilepsy Behav2016;57(PtB):238–48. 10.1016/j.yebeh.2016.01.008. [PubMed: 26857183]

[13]. Epilepsy Foundation. Epilepsy Foundation responds to videos posted by TikTok users mocking seizures Retrieved from https://www.epilepsy.com/release/2020/5/epilepsy-foundation-responds-videos-posted-tiktok-users-mocking-seizures, ; 2020.

[14]. Hauser WA, Annegers JF, Kurland LT. Prevalence of epilepsy in Rochester, Minnesota: 1940–1980. Epilepsia1991;32(4):429–45. 10.1111/j.1528-1157.1991.tb04675.x. [PubMed: 1868801]

[15]. Sapkota S, Kobau R, Pastula DM, Zack MM. People with epilepsy are diagnosed most often with unspecified epilepsy, followed by focal epilepsy, generalized convulsive epilepsy, and generalized nonconvulsive epilepsy—US MarketScan data, 2010–2015. Epilepsy Behav >;79:244–6. 10.1016/j.yebeh.2017.11.004.

[16]. Porter Novelli. ConsumerStyles & YouthStyles. Retrieved from: http://styles.porternovelli.com/consumer-youthstyles/.

[17]. Kobau R, Sniezek J, Zack MM, Lucas RE, Burns AWell-being assessment: an evaluation of well-being scales for public health and population estimates of well-being among US adults. Health Well-Being2010;2(3):272–97. 10.1111/j.1758-0854.2010.01035.x.

[18]. United States Census Bureau. Population distribution and change: 2000 to 2010 Retrieved from: https://www.census.gov/prod/cen2010/briefs/c2010br-01.pdf, ; 2011.

[19]. United States Census Bureau (2015). Population division. U.S. Population Trends: 2000 to 2060. Retrieved from https://www.ncsl.org/Portals/1/Documents/nalfo/USDemographics.pdf.

[20]. Cleveland Clinic. Cleveland clinic heart health survey Retrieved from https://newsroom.clevelandclinic.org/wp-content/uploads/sites/4/2018/01/2017-ClevelandClinic-Heart-Health-Survery.pdf, ; 2017.

[21]. Scott AW, Bressler NM, Ffolkes S, Wittenborn JS, Jorkasky J. Public attitudes about eye and vision health. J Am Med Assoc Opthalmol2016;134 (10):1111–8. 10.1001/jamaophthalmol.2016.2627.

[22]. Cooper CP, Gelb CA, Trivers KF, Stewart SL. Intended care seeking for ovarian cancer symptoms among U.S. women. Prev Med Rep2016;3:234–7. 10.1016/j.pmedr.2016.01.011. [PubMed: 27419020]

[23]. Centers for Disease Control and Prevention, Substance Abuse and Mental Health Services AdministrationNational Association of County Behavioral Health & Developmental Disability DirectorsNational Institute of Mental HealthThe Carter Center Mental Health Program. Attitudes toward mental illness: results from the behavioral risk factor surveillance system. Atlanta (GA): Centers for Disease Control and Prevention; 2012. Retrieved from https://www.cdc.gov/hrqol/Mental_Health_Reports/pdf/BRFSS_Full%20Report.pdf.

[24]. Centers for Disease Control and Prevention. (2020). Building Our Understanding: Key Concepts of Evaluation Applying Theory in the Evaluation of Communication Campaigns. Retrieved from https://www.cdc.gov/nccdphp/dch/programs/healthycommunitiesprogram/tools/pdf/apply_theory.pdf.

[25]. Kobau R, Zahran H, Thurman DJ, et al.Epilepsy surveillance among adults—19 states, Behavioral Risk Factor Surveillance System, 2005. MMWR Morbid Mortal Week Rep2008;57(No.SS-6):1–20. Retrieved from https://www.cdc.gov/mmwr/preview/mmwrhtml/ss5706a1.htm.

[26]. Kobau R, Gilliam F, Thurman DJ. Prevalence of self-reported epilepsy or seizure disorder, and its associations with depression and anxiety—results from the 2004 HealthStyles Survey. Epilepsia2006;47(11):1915–21. 10.1111/j.1528-1167.2006.00612.x. [PubMed: 17116032]

Table 1

Epilepsy questions on the 2017 Porter Novelli ConsumerStyles Survey.

Survey Questions	Response format/options
I. Familiarity with Epilepsy (all respondents)	
Preface: Epilepsy or seizure disorder is a medical condition in which there are periods of abnormal electrical activity in the brain that causes seizures. Seizures can cause a temporary change in a person's physical behavior or awareness. Please answer the following questions about your experience with epilepsy or seizure disorder.	
1. Do you currently know anyone with epilepsy?	Yes; No; Not sure
2. Have you ever seen someone have a seizure associated with epilepsy?	Yes; No; Not sure
3. Have you ever seen someone have a seizure on TV?	Yes; No; Not sure
4. Have you ever seen someone have a seizure in a real life setting such as at school or work, or in a grocery store?	Yes; No; Not sure
5. Have you read or heard anything about epilepsy in the media recently?	Yes; No; Not sure
6. If you have heard anything about epilepsy during the past 12 months, where have you heard it? ***(responses randomized; select all that apply)***	• Television • Radio • Internet • Family or friends • Brochures, flyers or pamphlets • Doctor, hospital, clinic, or other health provider • Not sure • I have not heard anything
7. Have you seen or heard of a campaign called #ShareMySeizure?	Yes; No; Don't know
II. Perceived knowledge about epilepsy and confidence with first aid (all respondents)	
Preface: For each statement, please indicate whether you personally agree or disagree with it.	
1. I am knowledgeable about epilepsy.	1–5 Likert scale:1 = strongly disagree5 = strongly agree
2. I would know what to do if someone around me had a seizure.	1–5 Likert scale1 = strongly disagree5 = strongly agree
3. I am confident that I can help someone having a seizure with appropriate first aid.	1–5 Likert scale1 = strongly disagree5 = strongly agree
III. Symptoms or signs of epilepsy (all respondents; responses randomized; *select all that apply*)	
1. To the best of your knowledge, which of the following may be symptoms or signs of epilepsy?	• Staring into space[*] • Uncontrolled shaking[*] • Ear ache

Survey Questions	Response format/options
	• Funny feeling in stomach[*] • Eyes fluttering[*] • Back pain • Hallucinations[*] • Not being able to respond to questions[*] • Falling to the ground[*] • Sore throat • Rhythmic jerking[*] • Déjà vu (a situation feeling familiar)[*] • Walking aimlessly[*] • Repeating the same words[*] • Blood in the urine • Chest pain • None of these
IV. Interest in learning more about epilepsy (all respondents; responses randomized)	
1. Would you like to learn more about epilepsy symptoms?	Yes, I would like to learn more about epilepsy symptomsNo, I would not like to learn more about epilepsy symptoms
2. Why would you like to learn more about epilepsy symptoms? (Respondents universe = those who said yes to wanting to know more.)	• I myself have epilepsy • I care for someone with epilepsy • I know someone with epilepsy • I have heard about epilepsy and would just like to know more • I wonder if my symptoms or those of a loved one are associated with some type of seizure • Some other reason

Notes.

[*] A correct sign or symptom of epilepsy or seizure disorder.

Table 2

Percent agreement with perceived knowledge about epilepsy and seizure first aid response—U.S. adults, 2017 ConsumerStyles Survey.

	Number	I am knowledgeable about epilepsy				I would know what to do if someone had a seizure				I am confident I can help someone having a seizure with appropriate first aid			
		Disagree %	Neither %	Agree %	*P*-value	Disagree %	Neither %	Agree %	*P*-value	Disagree %	Neither %	Agree %	*P*-value
Overall	**3530**	**60**	**24**	**16**		**51**	**24**	**25**		**54**	**26**	**20**	
Know someone with epilepsy					<0.001				<0.001				<0.001
Yes	832	43	28	29		34	24	42		38	29	34	
No	2460	67	22	11		57	23	20		61	23	16	
Sex					0.266				0.096				0.338
Men	1770	61	25	14		51	26	24		54	27	19	
Women	17631	60	24	17		51	23	27		54	25	21	
Age group (years)					0.111				0.008				<0.001
18–24	211	67	20	13		56	22	22		63	23	14	
25–34	486	56	26	18		44	24	32		45	30	24	
35–44	513	61	24	15		49	26	25		55	23	23	
45–54	642	57	26	17		48	25	27		49	27	24	
55–64	816	58	25	17		51	24	25		54	26	20	
65 or older	865	63	24	13		56	23	21		60	25	16	
Educational level					<0.001				<0.001				<0.001
≤High school	1210	67	21	12		58	24	18		60	25	15	
Some college	1127	56	27	17		44	26	30		50	26	24	
≥Bachelor’s degree	1196	55	26	19		47	23	30		49	27	24	
Race-ethnicity					0.601				0.098				0.083
White, Non-Hispanic	2681	60	24	16		48	25	27		52	26	22	
Black, Non-Hispanic	275	60	26	14		55	24	21		57	24	19	
Other, Non-Hispanic	119	66	21	14		60	19	21		66	18	16	
Hispanic	404	60	24	16		55	23	23		55	26	19	
2 + Races, Non-Hispanic	54	45	26	29		46	23	31		42	35	23	
Metropolitan Area					0.420				0.303				0.394
Non-Metro	509	57	26	17		48	23	28		51	26	23	

	Number	**I am knowledgeable about epilepsy**				**I would know what to do if someone had a seizure**				**I am confident I can help someone having a seizure with appropriate first aid**			
		Disagree %	**Neither %**	**Agree %**	***P*-value**	**Disagree %**	**Neither %**	**Agree %**	***P*-value**	**Disagree %**	**Neither %**	**Agree %**	***P*-value**
Metro	3024	61	24	15		51	24	25		54	26	20	

Notes. Disagree = Moderately or Strongly disagree; Agree = Moderately or Strongly agree. Unweighted sample size; percentages represent weighted estimates.

Table 3

Familiarity with epilepsy, seizure symptoms, and information sources about epilepsy —U.S. adults, 2017 ConsumerStyles Survey.

Question	N	%, (95% CI)
Do you currently know anyone with epilepsy or seizure disorder?		
Yes	833	23.4 (21.8–25.1)
No	2466	68.4 (66.5–70.2)
Not sure	242	8.2 (7.0–9.4)
Have you ever seen someone have a seizure associated with epilepsy?		
Yes	1215	31.2 (29.5–33.0)
No	1930	56.1 (54.2–58.0)
Not sure	393	12.6 (11.3–14.1)
Have you ever seen someone have a seizure on TV?		
Yes	1984	55.2 (53.3–57.2)
No	1162	33.0 (31.2–34.9)
Not sure	391	11.7 (10.4–13.1)
Have you ever seen someone have a seizure in a real life setting such as at school or work, or in a grocery store?		
Yes	1529	40.5 (38.6–42.4)
No	1839	53.2 (51.3–55.1)
Not sure	173	6.3 (5.2–7.5)
Have you read or heard anything about epilepsy in the media recently?		
Yes	202	5.9 (5.0–7.0)
No	3112	87.3 (85.9–88.7)
Not sure	229	6.7 (5.7–7.8)
If you have heard anything about epilepsy during the past 12 months, where have you heard it?$^{\pm}$		
TV	366	10.2 (9.0–11.4)
Radio	46	1.4 (0.9–2.0)
Internet	224	6.8 (5.8–7.9)
Family or Friends	315	9.8 (8.6–11.1)
Brochures, flyer	74	2.0 (1.5–2.6)
Doctor, hospital, clinic, or other health provider	164	5.2 (4.4–6.2)
Not sure	431	11.8 (10.6–13.1)

Question	N	%, (95% CI)
I have not heard anything	2297	64.3 (62.4–66.2)
Which of the following organizations are you familiar with?		
American Cancer Society	2879	77.4 (75.5–79.1)
American Heart Association	2861	77.5 (75.7–79.2)
Epilepsy Foundation	719	18.0 (16.6–19.4)
Arthritis Foundation	1300	31.8 (30.1–33.6)
Multiple Sclerosis Foundation	1474	37.2 (35.4–39.0)
None of these	488	16.9 (15.4–18.5)
Symptoms or signs of epilepsy		
Uncontrolled shaking	2640	74.6 (72.8–76.4)
Falling to the ground	2457	68.2 (66.2–70.1)
Rhythmic jerking	2418	67.2 (65.2–69.2)
Eyes fluttering	2033	56.3 (54.3–58.4)
Not being able to respond	1949	53.5 (51.5–55.6)
Staring into space	1550	42.6 (40.6–44.6)
Repeating the same words	666	19.4 (17.8–21.0)
Walking aimlessly	512	14.6 (13.2–16.1)
Hallucinations	312	9.5 (8.3–10.7)
Déjà vu: situation feels familiar	181	5.4 (4.5–6.4)
Funny feeling in stomach	156	4.5 (3.7–5.5)
Incorrect epilepsy symptoms or signs		
Chest pain	94	3.4 (2.6–4.4)
Ear ache	61	2.1 (1.4–2.8)
Back pain	52	1.8 (1.3–2.5)
Sore throat	29	1.0 (0.6–1.6)
Blood in the urine	26	1.0 (0.6–1.7)
Correct epilepsy symptoms or signs		
Selected 4 or more	2210	59.7 (57.7–61.7)
Selected 8 or more	326	9.1 (8.0–10.3)
Selected all	24	0.7 (0.4–1.2)
Selected none	353	11.3 (9.9–12.7)

Question	N	%, (95% CI)
Total correct symptoms or signs [*]		
10 or more	2195	59.0 (57.1–61.1)
14 or more	281	7.8 (6.8–9.0)
Would you like to learn more about epilepsy symptoms?		
Yes, I would like to learn more about epilepsy	1073	32.6 (30.7–34.5)
No, I would not like to learn more about epilepsy	2445	67.4 (65.5–69.3)
Why would you like to learn more about epilepsy symptoms? [¥]		
I myself have epilepsy	12	1.6 (0.7–3.0)
I care for someone with epilepsy	37	3.8 (2.5–5.5)
I know someone with epilepsy	162	14.8 (12.5–17.4)
I have heard about epilepsy and would like to learn more	685	61.9 (58.3–65.4)
I wonder if my symptoms or those of a loved one are associated with some type of seizure	80	8.5 (6.7–10.8)
Some other reason	269	27.6 (24.3–31.0)
Have you heard of a campaign called #ShareMySeizure? [**]		
Yes	19	0.8 (0.4–1.4)
No	3415	99.2 (98.6–99.6)

[*] [(Number correct selected) + (Number incorrect not selected)].

[**] #ShareMySeizure launched in November 2016 for National Epilepsy Awareness Month airing on the CBS station in Chicago. In November 2017, the PSAs expanded to include the Philadelphia CBS station (source: https://www.epilepsy.com/make-difference/public-awareness/sharemyseizure).

[±] Question asked of all respondents, not just those who said “yes” to the question “Have you read or heard anything about epilepsy in the media recently?”

[¥] Question asked only of respondents who said yes to, “Would you like to learn more about epilepsy symptoms?” Total exceeds 100% because respondents could select more than one response.