

Knowledge, Attitudes, and Practice towards Epilepsy (KAPE) Survey of Chinese and Vietnamese College Students in the U.S.

Kenny Chung,^{1*} Susan L. Ivey,² Wenting Guo,³ Kevin Chung,⁴ Catherine Nguyen,⁵ Corina Chung,⁶ Christine Nguyen,⁷ and Winston Tseng⁸

¹Public Health and Molecular and Cell Biology, 5th Year, School of Public Health, UC Berkeley

²MD, MHS-A, School of Public Health, UC Berkeley

³Public Health, 4th Year, School of Public Health, UC Berkeley

⁴Chinese and Molecular and Cell Biology, 4th Year, School of Public Health, UC Berkeley

⁵BA Integrative Biology 2009, School of Public Health, UC Berkeley

⁶Public Health, 3rd Year, School of Public Health, UC Berkeley

⁷Integrative Biology, 3rd Year, School of Public Health, UC Berkeley

⁸PhD, School of Public Health, UC Berkeley

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ABSTRACT

We conducted the first national cross-sectional survey of Chinese and Vietnamese American adults about their knowledge, attitudes, and practice towards epilepsy. We used a convenience sampling method to recruit 2,831 adults in 37 cities from 7 states. In this article, we present our results from the analysis of a subset of the college student population. A 34-item survey instrument available in English, Chinese (Mandarin and Cantonese), and Vietnamese was administered by trained surveyors to 371 college students in 4 states. Chinese and Vietnamese college students generally held the same attitudes towards and had similar misunderstandings about epilepsy. One notable disparity in attitudes is that 15% of Chinese, as compared to 40% of Vietnamese, felt that PWE have below-average intelligence. We found that misunderstandings about and discrimination towards epilepsy among college students generally did not differ between different genders or ethnicities.

strong surge of electrical activity in the brain, which can either be generalized or partial in nature. One of the most common and widely recognized forms is the tonic clonic (formerly grand mal) seizure, accompanied by muscle contractions. However, seizures may also be much more subtle as in the case of absence or petit mal seizures, where the person briefly loses awareness and seems to be daydreaming or staring blankly for a few seconds. In contrast to certain other neurological disorders that generally only affect specific groups of people, epilepsy does not discriminate and has the potential of affecting people of both genders, all age groups, and all ethnicities (1). Estimates of direct and indirect costs linked to epilepsy in the U.S. run upwards of \$15.5 billion annually (1-5). According to the Epilepsy Foundation, over 3 million Americans currently live with epilepsy and 200,000 more are diagnosed each year. Unfortunately, the cause for 70% of epilepsy cases in the U.S. remains unknown and about one-third of people with epilepsy (PWE) or one million Americans do not have medication capable of controlling their seizures. These figures are much more dire in developing or resource-poor countries where the majority of the world's epilepsy cases occur and the cost of anti-epileptic drugs

INTRODUCTION

Epilepsy is a neurological condition in which a person experiences recurring seizures, a temporary

**Corresponding author: Health Research for Action, 2140 Shattuck Avenue, 10th Floor, School of Public Health, Berkeley, CA 94704-7388
Cell: 626-512-3939. E-mail: kchungvietnam@gmail.com*

(AEDs) is often prohibitively expensive. Worldwide, there are an estimated 50 million people living with epilepsy and the cost of AEDs can be greater than half their annual income (1, 6). Furthermore, the World Health Organization contends that the social consequences of epilepsy are a main obstacle in the path of obtaining health parity and better care for those living with epilepsy (1). Consequently, people living with epilepsy worldwide suffer misunderstandings and social stigma regarding their condition in addition to the constant sense of uncertainty and fear generated by their condition. Moreover, these misconceptions lead to discriminatory practices that may detrimentally affect people with epilepsy socially, financially, and sometimes even legally. For example, the United Kingdom did not repeal a law that forbade PWE from marrying until 1970 (7, 8). 18 states in the U.S. had statutes that allowed for the “eugenic sterilization” of PWE until nearly the 1960s (7). Most states in the U.S. allowed the barring of PWE from public places such as restaurants, theaters, and other public areas until the 1970s (7). Marriage was not legally permitted for PWE in all U.S. states until 1980 (7).

The primary purpose of the KAPE (Knowledge, Attitudes, and Practice towards Epilepsy) project was to conduct a survey to assess knowledge of and attitudes and practices towards epilepsy in a multi-site study of Chinese and Vietnamese persons living in the United States, including a sample of college students (9). While numerous similar studies among other populations have been conducted in the United States and other countries since 1979, including one done relatively recently for Spanish-speaking adults in the US, there is no literature specific to the Asian and Asian-American populations in the United States (9-16). This study sought to fill this void by conducting a survey tailored to two Asian-American populations (Chinese and Vietnamese) in hopes of gaining a more in-depth and comprehensive understanding of attitudes, beliefs, fears, and understanding regarding seizures, epilepsy, and persons with epilepsy. In addition to canvassing the chosen Asian American populations about their KAPE, we also included an advocacy arm in our research project. At the end of each survey we provided brochures containing general and first aid information about epilepsy in hopes of providing basic education about epilepsy to the general public and helping in the fight against social stigma against

PWE (12).

A secondary objective was to establish a best-practice model for a low-budget public health research project that is initiated, led, and run by college undergraduates. There is evidence that students can serve as effective public health advocates (17-19). Our experiences are very relevant to the times as a record number of undergraduate students become more interested in public health and university budgets tighten due to the recent economic downturn. Furthermore, the successful execution of this project has positive implications for the mobilization and empowerment of more undergraduate students to take charge of their own research project.

The study population for the data described in this paper was Asian-American college student populations in the United States, more specifically Chinese and Vietnamese populations over the age of 18. These two specific populations were chosen for specific reasons. The Chinese were chosen because they comprise the largest grouping within the Asian Pacific Islander population in the U.S. (20). The Vietnamese were chosen because a recent study showed that elderly Vietnamese may be at a higher risk for suffering from mental illnesses and consequently social stigma (21).

MATERIALS AND METHODS

DESIGN OF SURVEY INSTRUMENT

A forward and backward translation process was used to translate consent forms and survey instruments to ensure accuracy and ease of comprehension. Multiple meetings were held with the translators to ensure that all the documents across all the languages conveyed the same content. We used qualified student translators instead of professional translators because of greater time flexibility and lower fees/rates. We used a signed consent form process in the requested language prior to enrolling each subject. The study then employed a 34-item survey instrument, available in English, Chinese (both simplified and traditional), and Vietnamese. Participants were completed the survey on their own and surveyors were available for clarifications and to answer any other questions participants may have had. Upon completion of the survey, we also offered brochures containing general and first aid information about epilepsy in English,

	Count	Percentage (%)
Total	371	100
Sex		
Male	176	47
Female	198	52
Ethnicity		
Chinese	213	56
Vietnamese	159	42

Table 1: Demographics of Chinese and Vietnamese College Students in the U.S. (N=371): Knowledge, Attitudes, and Practice towards Epilepsy (KAPE) Survey, 2008-2009. Note: Categories may not sum to 100% because small number of individuals gave responses that were not easily categorized or may have abstained from answering.

Chinese (both simplified and traditional), and Vietnamese to our participants. The Office for Protection of Human Subjects at UCB reviewed and approved all instruments and protocols.

STUDY POPULATION

Overall, trained student surveyors (fluent in languages of the interviews) administered the survey to 371 college student participants in 4 states. In California and Washington, we sampled students from the following colleges: East Los Angeles College (in Monterey Park, CA), Pasadena City College (in Pasadena, CA), UC Berkeley, UC Irvine, UCLA, UC Riverside, UC San Diego, and the University of Washington. For Nevada and Oregon, we surveyed in areas containing college students but not on specific college campuses. Aside from surveying in colleges, we also went to areas that are known to have a high density of Chinese and Vietnamese inhabitants, e.g., San Francisco (CA), San Jose (CA), Fremont (CA), Irvine (CA), Las Vegas (NV), Los Angeles (CA), Portland (OR), San Diego (CA), and Seattle (WA). To be included in this study, participants must be adults (over the age of 18) of Chinese or Vietnamese descent living in the US and able to either read in or comprehend verbal questions in English, Cantonese, Mandarin, or Vietnamese. This study population is a subset of a larger study that included participants of all occupations and educational levels.

STATISTICAL ANALYSIS

Data entry was completed using Excel 2003. Subsequent frequencies and chi-square analyses were also done with Excel 2003.

RESULTS AND DISCUSSION

STUDY POPULATION

We were able to obtain a diverse sample of college students by surveying not only in large universities but also in smaller community colleges and other areas where non-traditional college students may be found, such as in supermarkets and cafes. In our sample of 371 college student participants, 47% were male and 52% female, 56% were Chinese and 42% Vietnamese. While the large majority of our participants were within the 18-24 age category, we had participants in every category from 25-34 to 65-74.

KNOWLEDGE, ATTITUDES, AND PRACTICE TOWARDS EPILEPSY

39% of those surveyed know a person with epilepsy, 55% of the survey sample have seen an episode of epilepsy either in real-life or on television, 35% of the sample believe that epilepsy is a mental illness, 71% of the sample believe that people with epilepsy should be able to marry, 55% of the sample believe that people with epilepsy should be able to have their own children, 39% of the sample would object to their

	Count	Percentage (%)
Total	371	100
Do you know a person with epilepsy?		
Yes	148	39
No	223	59
Have you ever witnessed a seizure?		
Yes	208	55
No	164	43
Is epilepsy a mental illness?		
Yes	131	35
No	239	63
Are people with epilepsy dangerous?		
Yes	68	18
No	303	80
Do people with epilepsy have a lower IQ than other people who do not?		
Yes	96	25
No	277	73
Should people with epilepsy get married?		
Yes	270	71
No	94	25
Would you object to your child marrying someone with epilepsy?		
Yes	149	40
No	215	56
If you were an employer, would you hire someone with epilepsy?		
Yes	214	57
No	145	38
Should people with epilepsy have children?		
Yes	207	55
No	157	41
Would you allow your child to play or interact with someone who has epilepsy?		
Yes	63	17
No	307	81

Table 2: Results from Chinese and Vietnamese College Students in the U.S. (N=371): Knowledge, Attitudes, and Practice towards Epilepsy (KAPE) Survey, 2008-2009. Note: Categories may not sum to 100% because small number of individuals gave responses that were not easily categorized or may have abstained from answering.

*The complete survey used in this study is available by contacting the corresponding author.

child marrying a person with epilepsy, and 57% of those surveyed would knowingly hire a person with epilepsy.

DISCUSSION

The primary objective of this cross-sectional study was to assess the current knowledge, attitudes, and practices towards epilepsy among a sample of college students (contained in a larger multi-site survey). We found that Chinese and Vietnamese college students generally held the same attitudes towards epilepsy. About 1/5 of both ethnic groups felt that people with epilepsy (PWE) pose a danger to other people. A little less than half of each group thought that children with epilepsy should be enrolled in special education and would object to their children marrying a person with epilepsy. More than half of both Chinese and Vietnamese would hire someone with epilepsy. However, one notable difference in attitudes between the two ethnicities is that 15% of Chinese college students, as compared to 40% of Vietnamese, considered PWE to have below-average intelligence ($p \leq 0.0001$), which is generally not true although it is possible that frequent episodes of seizures during class may be disruptive to learning.

While in the field, we approached many participants who have heard of epilepsy but had very limited knowledge of the disorder and its symptoms. On several occasions, participants equated taking the survey to taking an exam for which they had almost no time to study. Further, it was heartening to see that many students were especially interested in learning more about epilepsy through the brochures because the survey had raised many questions about their understanding of epilepsy.

Many respondents wrote comments next to their answers to qualify and explain their responses. We also heard anecdotes of epilepsy experiences from many participants who openly and enthusiastically shared their thoughts and stories. These experiences support other studies concluding that additional in-depth research should be conducted (22-23). Furthermore, many participants expressed their appreciation for our efforts to study the Asian-American population and for making their opinions matter and voices heard. In fact, at the end of their survey, hundreds of our participants either returned their monetary incen-

tives in hopes of allowing us to survey more people or chose to donate their incentive to one of our sponsoring organizations.

CHALLENGES OVERCOME

We are very proud to have been able to complete our project on a national level in spite of the challenges we faced. The largest obstacle we had to overcome was financial, as we received very limited funding for our project. We eventually secured nearly two dozen separate grants and awards by submitting applications to funds specifically intended for undergraduate research. As students, we were also limited to when and how much time we could spend in the field. Moreover, funding for travel was limited. In order to complete our national survey in a timely fashion and within the limited budget, we completed the majority of our fieldwork during winter and spring breaks, and we trained and led auxiliary teams of surveyors around the country, using the same survey protocol and language options so that the team of UCB student researchers did not have to travel to every field site. Partnering with community-based organizations, religious establishments, and student associations proved to be very valuable as an effective way to quickly learn about the local community and greatly increase our efficiency. Finally, analyses were limited to those methods that could be taught to novice statistics students in a two-semester research apprenticeship.

CONCLUSION

College students tend to be better educated than other cross sections of Asian Americans because they receive higher education. We found that misunderstandings about and discrimination towards epilepsy among college students generally did not differ between different genders or ethnicities. Since misunderstandings do exist and these misunderstandings can lead to stigmatization, it is imperative that greater action be taken to educate API college student populations about epilepsy. We hope that future education programs and interventions may help bring the Asian-American community towards a greater understanding and acceptance of epilepsy.

Our research project is unique in that it is initiated, led, and run by undergraduate students with faculty guidance. We hope that our successful completion of

a research project on a national level in face of numerous obstacles will encourage other undergraduate students to actively seek out faculty for guidance and to initiate and take charge of their own research projects.

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