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Knowledge, attitudes, and practice toward epilepsy (KAPE): A survey of Chinese and Vietnamese adults in the United States

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ABSTRACT

We conducted, in four languages, the first national cross-sectional survey of the knowledge, attitudes, and practice with respect to epilepsy of Chinese- and Vietnamese-American adults. We used a convenience sampling method to recruit 2831 adults in seven states. Eighty-four percent had heard or read of epilepsy and 58% had seen a seizure, whereas only 34% knew someone with epilepsy. Forty-two percent would object to their children marrying a person with epilepsy, and 43% would not knowingly hire someone with epilepsy. We examined bivariate associations for questions of knowledge, attitudes, and practice with age, gender, ethnicity, nativity, language, and education. χ^2 analyses showed differences in knowledge of and attitudes toward epilepsy by age group, gender, ethnicity, and education. Although misconceptions and negative views about epilepsy are held by Chinese and Vietnamese populations living in the United States, our results show noteworthy differences in attitudes and practice in relation to previous studies in Asian countries.

1. Introduction

According to the Epilepsy Foundation [1], approximately 3 million Americans are currently living with epilepsy, and 200,000 new cases are diagnosed each year. Although epilepsy may affect people of either gender and persons of all ages and ethnicities, prevalence tends to be higher in males [1,2], children under 2 years of age [1,2], adults older than 65 [1,2], and minority groups including Asian-Americans [1]. Worldwide, epilepsy remains one of the most common neurological conditions, with an estimated 50 million people currently living with epilepsy [1–4]. Estimates of direct and indirect costs linked to epilepsy in the United States run upward of $15.5 billion annually [1,5–8].

People with epilepsy (PWE) in the United States and around the world continue to suffer from discrimination and social stigma, along with the constant sense of uncertainty and fear, all generated by their condition [4,9–17]. The World Health Organization contends that the social consequences of epilepsy pose a major obstacle to health parity and improved care for PWE, claiming that "the discrimination and social stigma that surround epilepsy worldwide are often more difficult to overcome than the seizures themselves" [3]. Moreover, these misconceptions about epilepsy and PWE lead to discriminatory practices that may detrimentally affect PWE socially [4,13,14,18–32], financially [6,33–35], and sometimes even legally [36–41]. For example, the United Kingdom did not repeal a law that forbade PWE from marrying until 1970 [40,41]. Eighteen states in the United States had statutes that allowed for the "eugenic sterilization" of PWE until nearly the 1960s [40]. Most states in the United States allowed the barring of PWE from restaurants, theaters, and other public places until the 1970s [40]. Marriage was not legally permitted for PWE in all U.S. states until 1980 [40].

The purpose of the Knowledge, Attitudes, and Practice toward Epilepsy (KAPE) Project was to conduct a national cross-sectional survey to assess knowledge of and attitudes and practice toward epilepsy in a multistate study of Chinese and Vietnamese adults living in the United States. Although numerous similar studies among other populations have been conducted in the United States and other countries since 1949 [42–50], including a recent study among Hispanic Americans [51], our study is the first to focus specifically on Asian-American populations in the United States. Results from this study will help form a foundation for further research into this understudied topic and also for interventions to help reduce the stigmatization of and discrimination toward PWE in Asian-American communities.

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2. Methods

2.1. Overview

We conducted surveys in multiple sites: 37 cities in seven states (California, Illinois, Nevada, New York, Oregon, Texas, and Washington). Major metropolitan areas in the sample included Chicago, Houston, Los Angeles, New York, Portland, San Diego, San Francisco, San Jose, and Seattle. A total of 2831 surveys were completed between November 2008 and April 2009. Our fieldwork team consisted of a core team of 6 University of California, Berkeley (UCB), undergraduate students and an auxiliary team of 30 university students and community members/professionals in different cities, all of whom completed human subject research training.

2.2. Measures

The 34-question survey instrument had domains specific to demographics, knowledge of epilepsy, attitudes and practice toward people with epilepsy, and understanding of where to get help or information about epilepsy. The instrument contained items based on previous surveys conducted in the United States and other countries [42,44,46–48,52,53], combined with new items of interest. All instruments were created in English and then underwent a rigorous translation process, with both forward and backward translation stages, including oversight not only by a senior researcher with Chinese-language and multilingual translation capacities, but also by UCB language professors. Our written instruments were available in English, simplified and traditional Chinese text, and Vietnamese. Interviewers spoke English, Cantonese, Mandarin, and/or Vietnamese. The Office for Protection of Human Subjects at UCB reviewed and approved all instruments and protocols.

2.3. Sampling

As part of the preparations for field surveys, we examined U.S. census data to determine states and cities with large numbers of Chinese and Vietnamese Americans [54]. Next, we contacted community-based organizations (CBOs) to enlist their help in identifying areas or establishments that would be most fitting for our surveying and to inquire about their availability as survey sites, because CBOs have been identified as good liaisons to the local Chinese and Vietnamese communities [55,56]. We also worked with nonprofit organizations and college student associations in close proximity to these local Chinese and Vietnamese communities to build mutually beneficial partnerships in which the surveying event served as a fundraiser by creating a venue for donations to their organizations. In return, organizations assisted in subject recruitment. Finally, we conducted surveys at strategic locations and also filled gaps in the day by surveying in public areas and small businesses in or near the local Chinese and Vietnamese communities. In sum, the survey is a cross-sectional study using convenience sampling in locations with high concentrations of Chinese and Vietnamese populations.

In particular, specific examples of survey sites in the respective cities where the surveys were conducted included universities and city colleges with sizable Asian-American student populations, weekend Chinese or Vietnamese language schools, the streets of Chinatowns and Little Saigons in many large cities, Catholic churches, Buddhist temples, supermarkets, large shopping plazas, restaurants, nail/beauty salons, coffee shops, parks/playgrounds, and cultural centers in predominantly Asian communities.

We faced challenges when conducting surveys that were not prearranged with local organizations. It was necessary to improvise our work sites: we set up tables or stood in public areas offering the surveys as people passed by. We used clipboards and often borrowed tables and chairs from the various organizations with which we partnered. In one instance, we used linked shopping carts to form survey stations in front of a supermarket. Also, we used collapsible cardboard boxes along downtown sidewalks that had high pedestrian traffic (such as in Chinatowns). The interviewers greeted potential subjects, and depending on the location of our work site certain investigators would take the lead in recruitment, based on their own language ability and that of the respective community. We also offered an incentive to encourage participation: after being screened for eligibility, participants received a $5 cash incentive in a red envelope, a cultural practice prevalent in Asian societies in which monetary gifts are presented. To pass, screening participants had to be at least 18 years old, of Chinese and/or Vietnamese descent, a U.S. resident, and able to read or comprehend verbal questions in English, Cantonese, Mandarin, or Vietnamese; furthermore, participants could not have epilepsy. Participants were also required to read and sign a consent form prior to beginning the survey. The demographics of the sample are outlined in Table 1.

Table 1
Demographic characteristics of Chinese and Vietnamese adults in the United States (N = 2831): Knowledge, Attitudes, and Practice toward Epilepsy (KAPE) Survey, 2008–2009.

	Number	%
Total	2831	100
Age		
18–24	704	25.0
25–34	379	13.4
35–44	495	17.5
45–54	522	18.5
55–64	413	14.6
65+	308	10.9
Sex		
Male	1298	46.6
Female	1488	53.4
Ethnicity[a]		
Chinese	1615	57.6
Vietnamese	1126	40.2
Country of origin		
Not born in United States	2409	85.1
Born in United States	422	14.9
Language spoken at home[a]		
English	142	5.1
Mandarin	662	23.7
Cantonese	363	13.0
Vietnamese	825	29.5
English and another language	650	23.3
Marital status		
Single	1091	39.4
Married/living together	1498	54.0
Widowed/divorced	183	6.6
Education		
Up to primary/elementary school	159	5.7
Some secondary/high school	460	16.6
Completed high school	631	22.7
Some college/associate's degree	750	27.0
Bachelor's degree	496	17.9
Graduate degree	279	10.1
Occupation[a]		
Student	755	27.0
Employed	1346	48.1
Homemaker	319	11.4
Retired/unemployed	376	13.4

[a] Some categories may not total to 100% because a small number of individuals gave responses that were not easily categorized.