

Engaging Asian Americans for Mental Health Research: Challenges and Solutions

Hongtu Chen,^{1,4} Elizabeth J. Kramer,² Teddy Chen,³ and Henry Chung³

Asian American communities have important and unmet mental health needs, but there is comparatively little research data on process and outcomes that can guide evidence-based approaches to mental health care. This paper describes our experience of building research programs in a community-based health care facility, some of the challenges we faced, and barriers that were overcome. We have learned that a) mental health services research can be carried out in a community health center with minimal intrusion on usual patient flow; b) the effort must be shared between the health center and the community; c) barriers to participation in mental health research programs are multifactorial ranging from conceptual, cultural, and attitudinal biases to practical concerns inherent in the ethnic minority population; and d) resistance can be overcome by working with participants' cultural and social needs and using their explanatory belief models when developing and pursuing studies.

KEY WORDS: research; Asian; barrier; participation.

INTRODUCTION

Asian Americans are the fastest growing racial group in the United States. According to the 2000 census, 10,242,998 individuals (3.7% of the total population) were Asian American, a number that is expected to double by 2025. Asian Americans are distinguished from other racial groups by several characteristics: they include at least 43 ethnic groups who speak more than 100 languages and dialects; approximately 71% are foreign born, with Asian immigrants accounting for 2.6% of the total US population, and limited English speaking proficiency is widespread. The number of effective strategies to overcome the tremendous stigma and suspicion that Asian Americans have toward mental health is limited (1, 2). Established mental health services lack the capacity to meet the mental health needs of many AAPI people (3, 1), and Asian Americans have difficulty seeking, accepting, or remaining in available mental health treatment programs (4–7, 19) and participating in health services research (8–10). In 1997, with grant support from the Robert Wood Johnson Foundation and a number of local foundations, the Primary Care and Mental Health Services Bridge Program was founded at the Charles B. Wang Community Health Center, a neighborhood health center located in the heart of Manhattan's Chinatown, in New York City. The Clinic's bilingual, bicultural staff, many of whom reside or were raised in the neighborhood, serves a patient population consisting primarily of new immigrants and older residents who have been in the United States for a long time but have never learned English or acculturated to life in this country. For the most part their beliefs about health and health care are

fairly traditional, particularly when it comes to mental health. Staff are well attuned to these beliefs and the issues they can encounter. The goals of the Bridge program are 1) to improve access to mental health care by providing mental health services in primary care; 2) to improve community treatment capacity by enhancing the skills of primary care providers to identify and treat mental disorders commonly seen in primary care; and 3) to raise community awareness by providing education on mental health and illness. A mental health research program began in 1998 as an evaluation component of the Bridge Program. Later, a number of research projects were developed, including the Primary Care Research in Substance Abuse and Mental Health for Elders (PRISM-E) Study, a clinical trial testing the efficacy of an antidepressant on neurasthenic Asian American patients, and a survey study assessing emotional distress in the New York Asian American community after the 9/11 terrorist attack. These projects enabled expansion of the research program and allowed the research team to fully experience the challenges and explore the strategies of recruiting Asian American patients and their families into mental health research studies. This paper highlights our experience in engaging the Asian American community for mental health research, and shares some of the solutions we found to be informative for researchers working with similar populations.

CHALLENGES AND SOLUTIONS

Collaborating With Clinical Staff

Studies that must be done in clinical settings inevitably cause a certain degree of intrusion or interruption to the normal clinical flow. Given the productivity requirements and incentives to keep patients moving through the system, it is important to gain cooperation and support from the providers who will be impacted by the study, as well as their support personnel. The relative dearth of evidence concerning both the delivery of mental health care and the types of treatments available for Asian Americans, particularly in health centers where providers may experience some of the same stigma as patients (11), behooves research staff to stress the uniquely potential impact of certain elements of the study on both the medical staff and the patients. It is particularly important to stress: 1) how the study might benefit patient care in the future, and the compelling clinical need for such research; 2) any known or suspected risks, especially those that are unique to the population; 3) whether the existing clinical flow may be altered; 4) the clinical staff's respective roles in the study; and 5) how the study can best be communicated to patients. It is extremely important to emphasize the cultural competence elements of the study and how findings are expected to improve patient care. A pamphlet that reinforces the verbal presentation can be very helpful, both as a reference and as a tool that can help to gain cooperation from less enthusiastic members of the medical staff. Having physicians and nurses participate in the design and planning of the study and review protocols as they are developed can be extremely helpful in devising ways to minimize the impact of the study on patient flow and clinic operations. Staff also can help to identify the best times and ways to recruit study participants. Simple protocols and study descriptions also should be provided to the clinical staff, with an emphasis on the types of participants being recruited for each specific study. This will better enable physicians and

nurses to identify possible candidates and expedite referrals to the research team. It is important to be aware of the existing workload of clinical staff and the extra burden that the research procedure will add. Especially in situations where the physicians do not obviously benefit from the research project, a conscientious discussion with them about the best strategies to reduce their burden is a win-win solution for all parties involved. The physicians' direct support of the study is often the most influential factor to prospective study participants. Physicians, particularly primary care providers, are considered important authority figures to Asian patients, and a physician's recommendation or encouragement usually has an important influence on changing the patient's attitude toward participating in a research program. If a physician expresses his understanding of the patient's stigma and his view that mental illness is the same as physical illness that needs to be treated and is treatable, a patient usually will agree to give it a try. Therefore, the physicians must be convinced that the study will potentially or eventually benefit participating patients. Most primary care providers who work with Asian American populations are aware of the stigma associated with mental disorders. In order to reduce stigma, we trained the primary care providers to emphasize the linkage between stress and general health, state that this topic was important to the patient and community, and then bring in the more diagnostically defined issues of mental health after buy-in is achieved. This supports the mind-body dualism model of health with which many Asians are familiar and then allows fuller discussion of risks and benefits of participation.

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A physician who comments that the patient seems to be under some "pressure" and that the research project is a good opportunity for further examination, is much more persuasive than a research staff member who says the exact same words to the patient. Finally, enthusiastic endorsement of the program and individual studies by the clinic's executive staff, especially the Medical Director, can go a long way toward obtaining support and cooperation from the medical staff. Although, some of these experiences may not be unique for Asian Americans, issues such as staff participation, physician authority figure, and stigma toward mental health seem to be particularly pronounced in Asian American communities, given their limited exposure to research and their immigrant and cultural background.

Using Culturally Appropriate Instruments

Most of the psychometric scales and instruments used in mental health research are developed and available only in English. Fortunately many of the scales have been translated and validated in some Asian languages, while others may only be translated into Asian languages but have not been validated. The instruments we have used include: The General Health Questionnaire (GHQ-12) (12, 13); the Mini-Mental Status Examination (MMSE) (14); MINI International Neuropsychiatric Interview (MINI) (15); the Center for Epidemiological Study-Depression (CES-D) (16); and the Geriatric Depression Scale (GDS) (17). A thorough literature search of instruments that have already been developed and obtained linguistic and cultural validity is the

first step one should take before exerting any elaborate effort. Even if some of the instruments have already been validated in an Asian population, it is a good idea to pretest all instruments on the study population to determine the need for adaptations due to differences in dialect or literacy level. Sometimes, a wrong choice of words can cause serious underreporting or over reporting by the patient. For instance, we were using the Blessed Orientation-Memory- Concentration Test (18). One item asked the respondent to learn the name and address of a person, and recall the information a few minutes later. The version we received was a word-for-word translation of English names of person, street, and city (John Brown, 42 Market Street, Chicago) into Chinese. When we used it to screen elderly patients for potential cognitive disorders, many monolingual Chinese speaking patients screened positive for a disorder because these names were all strange to them. After we modified the translation by using familiar Chinese names to replace the English ones, the test became more appropriate to match the respondent's linguistic background and therefore valid for screening for cognitive disorders, rather than mere learning ability. When no appropriate and or even imperfectly adapted instrument can be found, one may have to translate an existing instrument originally developed from other linguistic contexts, if one does not plan to carry on another study validating the desired instrument. In translating a survey instrument, not only should the items and questions be accurately translated, the response choices of each question also must be culturally appropriate. In one screening question we asked patients to report their drinking behavior to determine whether they have more than two drinks per day. Several weeks into the study, we realized that some Chinese people made their own rice wine which contains much less alcohol than regular commercial wine. To avoid overreporting we had to add a new item to the list of alcoholic beverages to cover this situation and to adjust the criterion for a "drink" of such wine.

Working With the Community

The concepts of both "research" and "mental health" are still new especially to immigrants of South-Eastern Asian origins. Overemphasizing the academic needs of research could be interpreted as a sign of self-serving intent that is irrelevant to a community's need. Service-based community agencies are very sensitive to whether a project can bring any benefit to the community in general and patients in particular. The Supplement to the Surgeon General's Report, Mental Health: Race, Culture and Ethnicity, cited stigma as the major barrier for Asians to accessing mental health care. In Asian communities there are different degrees of stigma associated with different types of mental disorders. For example, depression is generally less stigmatizing than psychosis. The less stigma that is linked to a project, the more support a community is likely to give. Without detailed knowledge, people tend to overgeneralize and oversimplify, possibly misrepresenting reality in the process (e.g., regarding everyone with mental health problems as "crazy"). We found that most Asian community leaders appeared to be understanding and sympathetic regarding the mental health aspects of research projects. They all agreed with the need for services but also believed that the stigma would potentially obstruct the project. Explaining study procedures also was difficult. For example, it was very hard for us

to frame randomization in a manner that was both understandable and acceptable to potential study participants. Our consumer advisory group suggested we tell people exactly what would happen to a patient, rather than dwelling on the name of the procedure. This resulted in our simply saying, “. . . afterwards, the patient will have an equal chance of going to either of the following two treatment models” This proved to be less of a problem for all parties than we originally had anticipated. In a dual effort to recruit study participants and to educate the community about mental illness, we employed intensive community outreach.

Activities included lectures on depression and anxiety at several local senior centers, home care agencies, and social service centers, public education articles on mental illness in the local newspapers, and distributing brochures on the prevention, diagnosis, and treatment of depression, anxiety, and alcohol disorders. We also used radio programs, which have the advantage of wide and regular access. The radio often is played all day in many places of employment. We found that the anonymity of a radio dialogue between a patient and a clinician, or an engaging conversation between a clinician and an audience, is a very effective way to introduce a new topic. A series of programs is an excellent way to raise awareness of certain health issues and increase the normalcy of a stigmatized topic. The factors that usually make radio programs successful are an interesting topic, an experienced speaker (or clinician), and presentation with interesting and representative symptoms or case discussion. An interactive radio program may generate phone calls from an audience who are eager to ask questions about themselves. Based on the number of phone calls it generated, we found that a good newspaper article that is based on a case study written in the patient’s voice is the most effective method for reaching elderly Asian Americans with mental health needs. Articles that focus solely on institution-based announcements of new programs attract the least attention. Printed material other than newspaper articles may not be helpful because many Asian American immigrants, especially elders, have relatively lower literacy levels. Although we have developed a number of pamphlets and flyers, they seldom generate phone calls to inquire about or request mental health services. In sharp contrast, the printed materials developed for infant care and pregnant women are often read and used by their target audience. A consumer advisory group that meets regularly can be a good source of opinion, as well as a forum for hypothesis testing, and brain-storming for strategizing and planning for the community educational campaign. For one of the research projects, a consumer advisory council was established whose membership was comprised of mental health consumers, pastors of Chinese churches, caregivers of mental health patients, and home attendants. The major functions of the consumer advisory council were to: 1) ensure that community interests were represented in the design and implementation of the study; 2) provide consultation and support in the development of materials needed for community education and outreach; 3) advise on how to effectively recruit and retain elderly Chinese patients’ participation in the study and 4) assist in disseminating the lessons and knowledge gained from the study. The research team and the consumer advisory council had a number of meetings to capture consumers’ and advocates’ thoughts about the current mental health status of the community; the major barriers to seeking mental health services among elders and the solutions to improve the

mental health status and health seeking habits of elders in the community. The discussions generated many valuable ideas regarding ways of presenting the study to elderly Chinese and the community served by the clinic as well as ways of recruiting study participants. Although we were successful in initiating and maintaining the consumer-researcher collaboration throughout the project, we did encounter some challenges over the years. For example, while the consumer-researcher collaboration was a success, we were unsuccessful in our efforts to find a consumer leader to help us mobilize the community and play the role of advocate to promote mental health. With one exception, we also found it difficult to find people who could help us improve the community's awareness of mental health and reduce stigma toward mental health services.

Another challenge is to sustain the consumer advisory council activities after grant support ends. Despite willingness and enthusiasm, extra resources are needed to organize consumer-based activities.

Working Through Enrollment Problems

Low-income immigrants may be hesitant to incur any additional expense that results from participation in a treatment study, and undocumented immigrants may fear they will be deported if they choose to participate. Others, particularly elders, may be responsible for rearing children or grandchildren thus precluding their ability to commit the time required for the study. Offering patients reimbursement for their inconvenience such as babysitting service and transportation can be helpful. We paid nominal transportation costs and reimbursements for their completion of various phases of a longitudinal observation.

Because the traditional Asian view of health does not separate body and mind, Asian Americans may seek alternative explanations for their symptoms rather than accept psychiatric diagnoses and treatment. When we tried to recruit Asian patients for a study of depression, denial was a typical response—some patients simply do not consider depressed moods a medical condition that requires treatment. Many also doubt the treatability of mental problems. For instance, a patient attributes her depressive symptoms to her relationship with a bad tempered daughter-in-law, and she believes that there is no way that this can be changed as long as they live together. Another patient may attribute his anxiety to a housing problem, and believe that only giving him a decent place to live, rather than participating in a treatment study program, can solve his problem. Many Asian Americans simply do not believe that talk therapy can help or that taking medicine can solve emotional problems that are deeply rooted in a social context.

A key strategy in explaining the essentially Western concepts of mental disorders and psychiatric treatment to a patient is to employ a culturally competent person who will be viewed by the patient as an “insider” or “the same people.” That person can be a nurse, a clinician, a research assistant, or a community volunteer who can think and behave on the patient's behalf, thus building the fundamental trust between a skeptical patient and a health service program, between a cautious and distrustful immigrant and a culturally and conceptually challenging experience.

Our Research Assistants, who were recruited from the community, played this important role for us. Several strategies were employed to reduce the refusal rate. The most useful one was research team meetings. Discussing issues and sharing experiences with experienced mental health clinicians was the most helpful way to improve research assistants' skills of engagement. Community education, especially Chinese radio programs, newspaper articles, and presentations at the senior centers also probably were helpful. To improve the retention rate, we also employed a number of strategies: a) we made it very clear to patients that they would be compensated for time spent on assessments; b) we sent a greeting/reminder letter after the baseline assessment, in order to both consolidate the established rapport and prepare the patient for the upcoming follow-up assessments; c) the research assistants emphasized that the follow-up assessment would not be contingent on participating in the recommended clinical treatment; d) at the initial assessment, the research assistants would request alternative contact information in case the patient moved away or could not be reached; e) we managed to catch the patients in the clinic at the time of their next appointment with their primary care provider if the appointment was within the window of the follow-up assessment; f) we carefully monitored the follow-up assessment "windows" for each study participant and tried to schedule them into the early part of the window; g) we flexibly arranged interview time and used evenings or weekends when subjects could not be reached during the week; and h) we made sure that timely compensation was sent to the patients interviewed on the phone.

In addition, most Asian American immigrant patients, especially elders, have a wide range of needs for help, the most prevalent of which are interpreting medical test results, assistance with applying for health or housing benefits, or just reading a few complicated English sentences. The most successful mental health clinicians are those who are willing either to provide some of these concrete services or to help find the right person to do them for the patient. Because the need for better moods is as important as the need for lessening the burdens of living a normal life, the best mental health service for this population seems to be truly integrated services, broadly defined. By using these strategies, we have greatly improved our chance for involving Asian American people in mental health research.

In the PRISM-E study, for example, a total of 1500 primary care patients aged 65 and older were screened for psychological distress, suicidal ideation, and alcohol misuse. Based on our review of the literature, we calculated that about 6.4% of primary care patients would qualify and agree to participate in the study. Of those 1500, 109 participants were enrolled in the study, a figure slightly higher than we expected. We expected our attrition rate to be around 30%. During the first 3 months of longitudinal follow-up it was 19.3%, and between 3 and 6 months it was very minimal. Overall, the Asian American participants in this study had a relatively low drop-out rate throughout the longitudinal follow-up observations.

Handling Polite Refusals

A patient is unlikely to tell the researcher that he does not want to participate in a mental health research program because it is embarrassing and shameful to see a mental health clinician, especially if his relatives and friends find out. Rarely would an Asian patient tell a researcher that he strongly doubts the effectiveness of psychotherapy, although he might comfortably share this opinion with a nurse who he knows. A more likely response is, "Let me think about it," "Let's discuss it later.," or, "I'll try my best (to make the appointment), but I cannot guarantee." Another common answer is, "I will discuss it with my children, and let you know later." Refusal or no show is often implied in most of these responses. We found that the best strategy is to accept them at face value, and ask the patient if he or she would schedule another appointment with the researcher to discuss the possibility of participation again. It is common for a patient to feel hesitant or cautious about participating in a new activity. However, as long as the researcher believes that the project is valuable or that participation is a worthwhile experience for the patient, his or her persistence will often be rewarded by the patient's gratitude later.

Obtaining Informed Consent

Obtaining informed consent from an Asian American immigrant patient can be a challenging task for two major reasons. Asians are not accustomed to the process of giving written informed consent for treatment, and they are relatively inexperienced in participating in research trials, which they may view with suspicion. Study protocols approved by Institutional Review Boards typically require translation of consent forms into languages other than English, and the wording must be as close to that in the original document as possible. However, the relatively formal language and tone can seem quite intimidating. After reading the translated consent form, many immigrant adults refused to participate in a study because of their suspicion of a possible scam behind any legal documents. In our experience the best way to handle this is to go over the informed consent document with patients, summarizing and explaining every paragraph at a pace slow enough for them to process the information.

We also sought to obtain consent immediately after the physician indicated the patient's willingness to take part in the study and approved for participation. For those patients who verbally agreed but could not stay any longer that day, the research assistant scheduled another appointment with the patient within 1 week to explain the study, obtain the consent, and conduct the eligibility interview. Even when patients verbally agree to participate after going through the consent document, some may still refuse when they get to the signature page. A common concern among immigrants is that any signature may have legal consequences that might potentially affect their immigration process. The researcher who is soliciting the signature needs to reiterate the confidentiality of the study. The signature form should be presented to the patient in a professional and confident manner. We have found this an effective way to improve their willingness to participate. Sometimes, even after patients have signed the consent, they later realize that participation in the study involves more than they originally expected because of

transportation, the time required, or financial costs associated with participation. These factors can easily cause them to change their minds. Some patients will call back after they discuss the project with their family members and decide to withdraw. Withdrawal can be reduced by clarifying the procedures with key family members and reinforcing the modest reimbursement for patient inconvenience. It is often helpful to have a family member present at the time consent is obtained.

Using Incentives

Many Asian American patients have little experience participating in research and show clear surprise at what they receive. They typically will comment that they always pay in clinical settings and have never received any money or souvenirs from medical staff. In one of our studies of mental health service experiences, the hour-long interview was often perceived as a rare and valuable service concerning the patients' emotional situations. They believe that they are the ones who should pay for our service, not the other way around. In addition, patients and their families may feel puzzled and raise suspicion about the intent of the project. Some patients, especially elderly ones, may not fully understand the meaning of the incentive they have received. When they bring it back to their families, family members may call back to request a further explanation, or ask us to allow them to return the money but still agree to participate in the program. They do not want to be pressured by the extra obligation caused by money.

Some older Asian patients may feel uncomfortable accepting money, because it reminds them that part of them (e.g., the information) has been sold as part of a cheap material exchange. They will only express this discomfort by saying ritualistically, "No. It's too embarrassing." To ease the awkwardness, and create the perception of a decent gift or token of gratitude, rather than a wage for the information, we were advised to put the money into a red envelope that is customarily used as a gift-wrap among Chinese. Clinical and moral incentives also have been found to be moderately effective in engaging some patients in the research process. The clinical incentive emphasizes a potential benefit of the treatment to the patient's condition. Its goal is to raise the patient's awareness of his need for treatment and convince the patient of the possible effects of the treatment. The moral incentive, or the altruistic approach, emphasizes how participation in the study may eventually help other people who have similar conditions or the community in general. This approach can effectively persuade many Asian people to participate and it is sometimes necessary in order to convince some patients who have a general distrust of anyone who asks them to join a program. In either approach, it is important that the interviewer truly believe that the research program will be beneficial.

Making the First Visit

The no-show rate for the first visit to a mental health clinician is high among Asian American patients. A telephone reminder prior to the appointment is necessary to ensure that the patient will show up at the scheduled appointment. Such a reminder call often will become a mini

counseling session to persuade and encourage the hesitant patient. Therefore, mental health clinicians should make such phone calls themselves, rather than asking a support person to handle this important engagement step. Alternatively, the individual making the calls must be well trained and prepared to deal with contingencies that may arise in the course of the conversation. What happens at the first visit will weigh heavily in determining whether an Asian patient will continue the recommended treatment. With the stigma of mental health services and doubt about the effectiveness of therapy, an Asian patient may come into the mental health clinician's office only to confirm his or her preexisting disbelief that "this won't help." What would give those patients a sense that "this might help"? Clinical social workers who have worked with Asian American patients for many years believe that the most effective strategy is to present the clinician's view of the patient's problems to the patient and to make it clear that it is only the clinician's point of view. The clinician can then summarize the patient's view of his or her problems, and discuss the difference between the two viewpoints. It is also important to point out the potential negative consequences if these problems are not dealt with. Although there is no guarantee that such a cognitive set-up with sensible communication will ensure the patient's continuation of the visit, it seems to be an effective way to engage a highly stigmatized and skeptical Asian patient.

CONCLUSION

Despite the success in improving general health status of Asian Americans over the last decade, community participation in mental health services and research remains low due to stigma and variations in knowledge, attitudes, and beliefs about mental health care. One effective way to overcome such limitations is to accumulate more knowledge through the development of colocated research and service programs. Through our experience of building a research program in a community-based health facility, we have learned that: a) Establishing a successful research program in an Asian American community relies on both clinical and community-based support from various groups both within and outside the health care system. b) The barriers to participation in mental health research programs span knowledge, attitudes, beliefs, and health care seeking behaviors, as well as practical concerns inherent to ethnic minority populations such as fears of deportation. c) Overcoming resistance requires research organizers to employ culturally and socially sensitive strategies at every step of the research process, from planning through evaluation. We have learned that the many challenges of doing in vivo research in a clinical setting are more than offset by the knowledge gained about the community. Further, the issues relating to design and implementation, especially those relating to impact on the clinical staff, are generalizable to all settings whose primary mission is to provide clinical service. We believe that well-planned clinical research programs in ethnic minority communities can provide a firm foundation for health care practitioners, participating consumers, and policy makers, to advance the state of knowledge and to provide high quality, culturally competent care.

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