# Treatment Delay Among Asian-American Patients With Severe Mental Illness

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Length of treatment delay and cultural-familial correlates were studied in a group of 62 Asian-American patients with severe mental illness, and 40 of their relatives. Contrary to prior findings of long treatment delay among Asian Americans, this cohort reported relatively low levels of stigma and shame and relatively short delay between onset of psychiatric symptoms and inception of treatment. Higher levels of shame and stigma felt by the relatives were associated with patients' longer treatment delay.

ast studies have indicated that Asian-American patients in mental health systems tend to underutilize both outpatient (Sue, Fujino, Hu, Takeuchi, & Zane, 1991; Sue & McKinney, 1975) and inpatient (Snowden & Cheung, 1990) mental health services, and that, at the time of admission, Asian Americans are more likely to be diagnosed with a psychotic disorder than are their white counterparts (Akutsu, Snowden, & Organista, 1996; Flaskerud & Hu, 1992). Two smallscale studies have also suggested that Asian-American patients may wait to seek mental health treatment for psychiatric conditions. In a study conducted in Vancouver, Chinese mentally ill patients were kept for more prolonged periods of time at home without formal psychiatric intervention in the beginning stages of the illness, as compared to white patients (T. Lin, Tardiff, Donetz, & Goresky, 1978). In a study in Seattle, comparing help-seeking pathways of three ethnic groups, Asian Americans tended to delay seeking and obtaining treatment much longer (1,553 days) than did African Americans (1,055) and white Americans (607.4 days) (K. Lin, Inui, Kleinman, & Womack, 1982). In support of such research findings, there are clinical accounts of Asian-American pa-

tients and their families' denial of mental illness, resistance to or noncompliance with recommended treatment, and severe stigma associated with mental illness (Tsui & Schultz, 1985), all of which interfere greatly with prompt access to appropriate psychiatric treatment.

Taken together, research evidence and clinical reports to date suggest that moderately disturbed Asian-American patients may not seek mental health services at all, and that even seriously disturbed patients may delay seeking treatment. Treatment delay has been identified as a significant predictor of a more severe course of schizophrenia (Loebel et al., 1992), yet there is a dearth of research regarding the most severely disturbed sector of the psychiatric population in the Asian-American community. For example, in the Seattle study that documented significant treatment delay among Asian-American patients (K. Lin et al., 1982), only three out of the 15 Asian patients in the sample had a psychotic diagnosis. Moreover, the researchers failed to recruit any Asian participants from a mental health clinic and had to rely on a community health care clinic as a source of Asian psychiatric patients.

Since the time of the Seattle study (K. Lin et al.,

Submitted to the Journal in January 1999. Research was supported by a National Alliance for Research in Schizophrenia and Depression Young Investigator Award, while the author was at the University of Wisconsin-Madison, and by National Institute of Mental Health grant K01-MH01506. The author is at the Department of Psychology, University of Illinois, Urbana-Champaign.

1982), many major cities on both the East and West coasts have opened outpatient mental health agencies with bicultural, bilingual Asian-American staff to serve Asian-American clients (Akutsu et al., 1996). Consequently, it is possible that some of the barriers to accessing mental health care may have decreased for Asian Americans, and that the delay in seeking treatment among those with severe mental illness differs from that reported previously. Furthermore, it is unclear to what extent cultural-familial values that were proposed as post-hoc explanations of treatment delay (e.g., stigma and indigenous beliefs about causes of mental illness) may contribute to the help-seeking patterns of severely mentally ill Asian Americans. The present study examined the extent and correlates of treatment delay among Asian-American patients being seen for a psychotic disorder at community outpatient mental health agencies. To assess the potential impact of the family on the help-seeking patterns of the patients, immediate family members were also interviewed.

## METHOD Participants

Asian-American patients receiving psychiatric treatment from one of five participating outpatient mental health clinics in the greater Los Angeles area were recruited for the study. All five referring clinics were receiving partial or total funding from the Los Angeles County Department of Mental Health, and four of the clinics were ethnic-specific or "parallel" services staffed by bilingual, bicultural Asian clinicians and serving primarily Asian-American patients. Clinic staff was asked to approach all patients who met the following eligibility criteria: a) of Asian or Asian-American descent; b) over age 18; c) diagnosed (by psychiatric staff of the referring clinic) with DSM-III-R or DSM-IV schizophrenic disorder, schizoaffective disorder, mood disorder, or other psychotic disorder involving at least one past psychotic episode; d) in regular contact with at least one family member; e) psychosis not due to organic factors or substance abuse; and f) not currently diagnosed with an active case of post-traumatic stress disorder. Eligible patients were contacted by a bilingual interviewer (matched on language capability) and were recruited into the study. Some study participants who did not meet all the above criteria (e.g., not Asian American, no history of psychosis) were excluded from the present analyses.

Of 71 patients meeting the eligibility criteria who had initially agreed to participate, five changed their minds, one was deemed too psychotic for an interview study, two were not reached after multiple attempts, and one spoke a language (Burmese) for which there was no interviewer available. Thus, 62 (33 male, 29 female) Asian-American patients and 40 (15 male, 25 female) relatives were included in the present study. Although efforts were made to recruit a relative for each participating patient, 22 (36%) had no relative involved in the study (four patients requested that relatives not be contacted, seven relatives were unreachable or unavailable, and 11 relatives declined to participate; of those who declined, many were suspicious about research or preferred not to discuss the patient's condition).

The demographic characteristics of patients and relatives are presented in TABLE 1. Average age of the patients was 34.0 years (SD=7.3) and that of the relatives was 57.7 years (SD=12.3). As shown in the table, the present sample contained a fairly diverse representation of major Asian ethnic groups, with Chinese Americans constituting the largest group. Less than 20% of the patients were U.S.-born; of the others, average age at immigration was 21.6 years (SD=9.6). Similarly, only 10% of the relatives were U.S.-born; average age at immigration was 38.8 years (SD=16.6). Also indicative of the acculturation status of the sample, nearly two-thirds (64%) of the interviews with the 62 patients and 40 relatives were conducted in Asian languages (35 Cantonese, 19 Vietnamese, 1 Mandarin, 4 Japanese, 6 Korean). Thus, the Asian-American patients and relatives in this study represent a largely foreign-born group who immigrated to the U.S. as adults and who have yet not acquired English fluency.

One-third (N=13) of the relatives reported a household income of less than \$10,000; 25% (N=10) reported income of \$10,000-\$19,999; 12.5% (N=5) \$20,000-\$29,999; and 7.5% (N=3) \$30,000-\$39,999. Only 22.5% of the relatives reported household income above \$50,000. These figures indicate that the sample is largely of lower socioeconomic status. With respect to current living arrangement, a majority (58.1%; N=36) of the patients were living with one or two parents, while an additional 29.0% (N=18) lived with other relatives or a spouse. Only four patients (6.5%) were living alone, two (3.2%) were living with nonrelatives, and two (3.2%) were in sheltered group

Table 1
PATIENT AND RELATIVE CHARACTERISTICS

CHARACTERISTIC	PATIENTS (N=62)		RELATIVES (N=40)						
	N	%			CILLA DA CITTO	PATIENTS (N=62)		RELATIVES (N=40)	
Sex Male Female Ethnicity Chinese Chinese-Vietnamese Filipino/a Japanese Korean Vietnamese Other Place of Birth U.S. China Hong Kong Taiwan Vietnam Cambodia Japan		% 53.0 47.0 40.3 9.7 8.1 14.5 9.7 17.7 0.0 17.7 11.3 4.8 8.1 37.1 1.6 1.6	N 15 25 19 0 3 7 3 7 1 4 8 0 3 13 0 3	%  37.5 62.5  47.5 0.0 7.5 17.5 7.5 17.5 2.5  10.0 20.0 0.0 7.5 32.5 0.0 7.5	CHARACTERISTIC Marital Status Married Widowed Separated Divorced Never married Current Employment Status Not working Full-time paid Other Religion Protestant Catholic Buddhist No religion Diagnosis Schizophrenic disorder	N 5 0 0 4 52 48 1 10 3 10 15 4 39	NTS (N=62)  8.1 0.0 0.0 6.5 85.5  77.4 1.6 16.1 4.8 37.1 16.1 24.2 22.6 62.9	RELATI N 32 1 2 2 3 24 14 2 0 10 8 14 8	80.0 2.5 5.0 5.0 7.5 60.0 35.0 5.0 0.0 25.0 20.0 35.0
Korea Phillippines Other	5 5 1	8.1 8.1 1.6	3 5	7.5 7.5 12.5 2.5	Schizoaffective disorder Bipolar disorder Major depressive disorder Other	11 3 2	17.7 4.8 3.2		

homes. The average age of onset of the disorder for the patients was 21.8 years (SD=5.9), which is consistent with the late adolescence to early adulthood onset of schizophrenia and bipolar disorders.

### Procedure and Instruments

A semistructured interview was conducted with each participant, face-to-face, for a period of about one hour (for patients) to one hour, 30 minutes (for relatives) by a trained bilingual interviewer. Each participant was paid \$25, and the interviews were conducted in the language preferred by the interviewee. All written materials for the study, as well as the interview protocol, were translated from English to appropriate Asian languages by experienced translators, and each Asian-language version was checked for accuracy of translation by a second translator with a background in psychology or psychiatry. The Asian-language responses to interview questions were also translated by experienced translators. The interviews were audiotaped with the respondents' permission.

Acculturation. In addition to standard demographic questions such as age, ethnicity, education, income, occupation, place of birth, and immigration history, respondents were asked to complete the Suinn-Lew Asian Self-Identity and Acculturation scale (Suinn, Rickard-Figueroa, Lew, & Virgil, 1987), a 21-item questionnaire from which a single unidimensional index of acculturation (1=traditional Asian to 5=very Americanized) is derived. The internal reliability of this measure

in the present sample, as indicated by Cronbach's alpha, was .93.

Stigma. Perceived level of stigma associated with the patient's psychiatric condition was assessed using the Stigma Module of the Family Experiences Interview Schedule (Tessler & Gamache, 1994). The items include worries about people finding out about the illness, neighbors treating them differently, friends and neighbors avoiding them, and being treated differently by even their best friends. Other items ask about the need to hide the illness or keep it a secret, avoidance of social events, not seeing friends, and feelings of shame and embarrassment. Tessler and Gamache reported that the Cronbach's alpha for this nine-item scale was .85. In the present study, responses were on a four-point scale (0=not at all, 1=a little, 2=some, 3=a lot), with a theoretical range of 0-27. Internal reliability figures for the present sample, as indicated by Cronbach's alpha, were .88 for both the patients and the relatives.

Treatment delay. Treatment delay is defined as the lag in time between onset of the disorder and appropriate treatment involving psychiatric medication (K. Lin et al., 1982). The delay (in months) was estimated for each patient based on the interviews with the patient and relative and on the medical records kept by the clinician. With patients and relatives, the interview protocol first ascertained the date of the onset of symptoms. For this purpose, a semistructured interview was devised based on the Interview for the Retrospective As-

sessment of the Onset of Schizophrenia (IRAOS) (Hafner et al., 1992). The IRAOS assesses timing of the appearance of 66 signs and symptoms of mental disturbance based on the items from the Present State Examination (Wing, Nixon, Mann, & Leff, 1977) and the Disability Assessment Schedule (World Health Organization, 1988), in addition to collecting information on all episodes with psychiatric symptoms from age 12 onward. Thus, it is a lengthy interview in and of itself.

The interview protocol used in the present study adopted the IRAOS approach of gathering retrospective information about symptom onset but focused on 18 symptoms from the Brief Psychiatric Rating Scale (BPRS) (Overall & Gorham, 1962) for the sake of brevity and applicability to psychotic mood disorders as well as schizophrenia. Both the IRAOS and the present interview make use of personal or external events (e.g., death of a family member) to anchor the time-line of the onset of symptoms. In the present study, respondents were first prompted to give an overview of the illness with respect to the time at which there was a perception, by the patient or others, that something was the matter, so as to establish other external (personal or public) events surrounding that time period as well as the time of first hospitalization. Next, respondents were asked about the presence or absence of each of the 18 signs of mental disturbance from the BPRS. Finally, they were asked about the approximate order and timing of the appearance of various symptoms in relation to the first help-seeking episode. The dates obtained from patient and relative interviews were compared (when both were available) against the medical records to arrive at the best convergent estimate of the date of onset of disorder and treatment; length of delay between onset and treatment for each case was estimated based on these sources. This method for making the "best estimate" of illness duration has been used by other researchers studying the initial onset of schizophrenia (Mintz, Nuechterlein, Goldstein, Mintz, & Snyder, 1989). Treatment delay could not be estimated in six cases due to insufficient information (e.g., patient was a poor historian and a relative or medical records were not available).

#### **RESULTS**

First, those patients who had a family member participate (N=40) and those who did not (N=22) were compared post-hoc on the main variables of

interest. Two-sample comparisons (t-test) of the two groups of patients revealed no statistically significant differences in the mean delay of treatment, global functioning (as indicated by current and past GAS scores [Endicott, Spitzer, Fleiss, & Cohen, 1976]), patients' reported level of stigmatization, or patients' acculturation level.\* Subsequently, all analyses involving patients' responses used the entire sample of patients in the study.

Acculturation. The mean acculturation scores for patients and relatives were 2.27 (SD=.79) and 2.00 (SD=.85), respectively. Paired sample t-test showed that acculturation levels of patients and relatives did not differ significantly; mean scores for both indicate that this sample is relatively unacculturated to the American mainstream.

Stigma. The mean stigma scale scores were 11.7 (SD=8.09) for patients and 6.68 (SD=5.97) for relatives. In the cases for which both patients' and relatives' scores were available, paired sample t-test revealed that patients' reported levels of stigma were significantly higher than those of relatives, t(38)=3.79, p<.001. While patients reported higher level of worries about the stigmatizing effects of the illness and feelings of shame and embarrassment, Asian-American relatives in the present study reported a surprisingly low level of shame and stigma regarding their ill family member's condition. Neither patients' nor relatives' stigma scores were significantly associated with their acculturation levels.

Treatment delay. The mean treatment delay derived from the "best estimate" method (Mintz et al., 1989) among the 56 cases for which enough information was available was 17.34 months (SD=30.60). Because the standard deviation for treatment delay was not reported by K. Lin and colleagues (1982), the two psychiatric samples' treatment delays could not be compared statistically. However, the treatment delay estimate for the present Asian-American patient sample appears to be notably shorter than the 1,553 days (nearly 52 months) reported by K. Lin et al. in a sample of Asian-American patients with less severe psychiatric problems.

In further examining treatment delay in the present sample, it must be noted that the distribution had a strong positive skew (skewness=3.23) such that many patients and families reported relatively

<sup>\*</sup>Alpha was adjusted to a lower level to correct for simultaneous test of statistical significance (p=.05 divided by 7).

short delay while a smaller number reported moderate to long delay. In fact, although the range of treatment delay was from less than one month to 168 months, over half (55.4%) of the patients had obtained psychiatric treatment involving neuroleptic medications within six months of the onset of the symptoms and only 10.9% had delayed treatment beyond 36 months. Thus, before proceeding with correlational analyses, the treatment delay variable was logarithmically transformed to normalize it (Tabachnick & Fidell, 1996).

Pearson's zero-order correlation coefficients were computed between treatment delay and acculturation and stigma scores to examine which patient and family variables were associated with treatment delay. Patients' levels of acculturation (r=.05) and stigma (r=.07) were not significantly correlated with treatment delay, nor was relatives' level of acculturation (r=.04). However, relatives' reported level of stigma concerning the patient's condition was significantly and positively related to treatment delay (r=.40, p<.01). The more stigma the relatives reported, the longer the treatment delay among their ill family members.

#### DISCUSSION

While earlier research may have painted a pessimistic picture of Asian-American psychiatric patients and their families as tending to delay treatment for serious psychiatric disturbances (K. Lin et al., 1982; T. Lin et al, 1978), the present study provides evidence that a substantial number of Asian-American patients with severe psychiatric illnesses obtain appropriate treatment relatively soon after the onset of symptoms of schizophrenia or other psychotic disorders. In contrast to the multiple years of treatment delay among Asian-American outpatients reported close to two decades ago (K. Lin et al., 1982), a majority of the patients and families interviewed in the current study had sought psychiatric treatment within six months of the onset of the symptoms.

There are several possible explanations for the differences between the previously documented long delay and the current finding. First, the 15 Asian-American psychiatric (but predominantly nonpsychotic) patients in the Seattle study (K. Lin et al., 1982) were recruited from a community health clinic, whereas the whites and African Americans in the same study were drawn from outpatient mental health clinics. The failure to recruit Asian Americans from a mental health clinic

was partly attributed to Asians' cultural tendencies to somatize psychological problems and to seek help from health care facilities. Indeed, the somatic symptoms that accompany mood or anxiety disorders may be consistent with the Asian cultural conceptualization of the distress as a manifestation of underlying medical problems that are amenable to indigenous, alternative, or home remedies—and may thereby contribute to treatment delay. By contrast, the present study's cohort of Asian-American patients had exhibited severe psychotic symptoms (e.g., auditory hallucination, delusions) or consequent behavior (e.g., suicidal, violent, or bizarre) that are less likely to be amenable to indigenous or alternative remedies. Thus, the differences in severity and acuteness of symptoms between the patients in this and the earlier study may have contributed to the differences in treatment delay.

Second, an increase in general societal knowledge and an accompanying decrease in stigmatization of psychiatric conditions or psychiatric treatment over the last two decades may have played a role in the present group of Asian Americans' relatively prompt help-seeking behavior. Indeed, evidence of a trend toward decreased treatment delay over the past several decades was also present in the study by K. Lin et al. (1982), which contrasted its findings with respect to treatment delay among African Americans (1,055 days, or 2.9 years) to those reported in an earlier study of help-seeking among young, inner-city African-American males in Baltimore (Brody, Derbyshire, & Schleifer, 1967, cited in K. Lin et al., 1982), where the average treatment delay was 16.1 years. While these comparisons are indirect, they are suggestive of a possible societal trend over time that may have affected the help-seeking behavior of psychiatric patients and their relatives.

Third, most of the Asian-American patients and families in this study were recruited from ethnic-specific community mental health agencies in the metropolitan Los Angeles area that are staffed by bilingual, bicultural Asian-American clinical staff. Such services have been demonstrated to provide effective care for Asian-American clients (Zane, Hatanaka, Park, & Akutsu, 1994). The fact that these psychiatric patients were currently engaged in treatment by these ethnic-specific agencies may attest to the success of the agencies in reaching out to the previously difficult-to-reach communities and assisting in the early detection of symptoms of severe mental illness.

In the present study, relatives of Asian-American patients tended to report lower levels of stigma and shame than did the mentally ill patients themselves. That the relatives' average stigma score was in the lower quartile of the scale suggests that, overall, they did not worry excessively about other people knowing of their family member's mental illness, nor did they express inordinate shame or embarrassment about the illness. This finding with regard to the relatives contrasts sharply with earlier characterizations of the Asian-American family as viewing mental illness as a shameful family secret (Lee, 1986). In past studies, cultural-familial stigmatization of mental illness has often been cited as a post-hoc explanation for treatment delay (K. Lin et al., 1982; T. Lin et al., 1978) or underutilization of mental health services (Tracey, Leong, & Glidden, 1986). Here, the level of stigma concerning mental illness of family members was directly assessed, and the present finding of a relatively low level of stigma among Asian-American relatives strikes a promising note.

However, these findings must be interpreted with caution given the selective nature of the sample studied. This research sampled only those who were currently in treatment at public-sector outpatient mental health clinics. Because those Asian-American patients who have had successful early help-seeking experiences may have been more likely to have stayed in the community mental health system, they may have been more likely to be included in the present study than those who had delayed treatment or had gotten "lost" in the system. The sampling scheme also precluded patients in treatment with private doctors or alternative sources. Thus, the present findings may not apply to Asian-American patients and families who are not engaged in treatment in a community mental health facility.

When the preliminary findings of this study were discussed with clinicians who had referred patients, a number of them gave anecdotal accounts of a sense of shame and stigma on the part of their Asian-American patients and families, so strong that it may have deterred some eligible patients and families from participating in the study.

For example, a Korean-American clinician told of his Korean-American patients and their families being sufficiently concerned about hiding the patient's illness that they would become agitated when the clinician was even slightly late for an appointment, lest they be seen in the waiting room of a mental health clinic by others in the Korean-American community. Thus, the cohort of relatives who participated in the present study may represent the least stigmatized sector of the Asian-American families of the mentally ill.\*

Alternatively, it is possible that while some Asian-American families express low levels of stigma and shame, and thus appear to be accepting of the patient's illness, such seeming acceptance may have a negative impact on the patient. A Chinese-American clinician who works with patient participants in the present study observed that some of the families that become knowledgeable about the chronicity of the psychiatric condition tend to label the patient as not only ill but dysfunctional and incapable of leading a normal life. These families then limit the patient's activities and responsibilities, which in turn tends to exacerbate feelings of apathy and low self-esteem in the patient. Past research has shown that family emotional environment, or the quality of social interaction between patient and caregiver, influences the course of schizophrenia and other mental illness (Bebbington & Kuipers, 1994). Clinicians working with families of severely mentally ill immigrant Chinese patients have noted a strong sense of shame and guilt, as well as apparent enmeshment and overprotectiveness, in these families (Lam, Chan, & Leff, 1995). Given that Asian-American families tend to be highly involved in the care of severely mentally ill patients, future research must clarify the cultural meanings attached to the family's acceptance, as well as feelings of shame and stigma regarding the family member's severe mental illness.

Finally, it is worth noting that neither patients' nor relatives' levels of acculturation to the American society were associated with their reports of stigma or the estimate of treatment delay. On the one hand, this lack of associations may be due to

<sup>\*</sup>Also worth noting is the differential effect of economics on the participation rate of the various Asian ethnic groups in the study, particularly the relatively low number of Korean Americans. Since Korean Americans in the greater Los Angeles area generally are of higher socioeconomic status than other Asian-American groups, the nominal payment for participating was unlikely to be a great incentive, especially in light of the high degree of stigma in the Korean-American community. In contrast, the Vietnamese-American patients tended to come from poorer families. One bilingual interviewer reported that an elderly Vietnamese-American mother of a schizophrenic patient, upon receiving \$25 for completing the interview, started crying with joy. As a refugee dependent on public assistance, it was apparently the first time she had done something to "earn" money in the United States.

the limited range of acculturation in the overall sample of Asian-American patients and their relatives, as the majority of patients and relatives were foreign-born non-English speakers. However, there appeared to be an adequate distribution of scores for both patients (1.00-3.90) and relatives (1.00-4.30) on the acculturation scale (theoretical range: 1-5). Low acculturation may generally disadvantage Asian Americans or other immigrant groups with respect to their knowledge of and access to appropriate mental health care in the community (Loo, Tong, & True, 1989). In this case, because of their access to culturally responsive, languagematched treatment from ethnic-specific mental health agencies, the individual differences in the acculturation level among patients and their relatives in this study may not have played a significant role in their stigmatization or their helpseeking behavior.

The present findings suggest that this relatively unacculturated group of Asian Americans with severe mental illness and their families are fairly sophisticated consumers of mental health services. However, given the limitations of the present sample, further studies of stigma and shame among Asian American individuals with mental illness who are not in treatment are needed. Consistent with previous research (K. Lin et al., 1982; K. Lin, Miller, Poland, Nuccio, & Yamaguchi, 1991; T. Lin et al., 1978), the present study points to the key role that relatives play in obtaining psychiatric care for Asian Americans who are mentally ill. It is imperative that mental health professionals continue to work toward improving the acceptance of psychiatric treatment for the severely mentally ill in the Asian-American community.

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