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Rates of treated schizophrenia and its clinical and cultural features in the population isolate of the Iban of Sarawak: a tri-diagnostic approach

ROBERT BARRETT, PETER LOA, EDWARD JERAH, DEREK NANCARROW,
DAVID CHANT AND BRYAN MOWRY*

University of Adelaide, Department of Psychiatry, L4 Eleanor Harrald Building, Royal Adelaide Hospital, Adelaide, SA 5000, Australia; Jalan Sabu, 95000 Sri Aman, Sarawak, Malaysia; Queensland Centre for Mental Health Research, The Park, Centre for Mental Health, Wacol, Q 4076, Australia; Queensland Institute of Medical Research, P.O. Royal Brisbane Hospital, Brisbane, Q 4029, Australia; Department of Psychiatry, University of Queensland, Brisbane, Q 4029, Australia

ABSTRACT

Background. We present results of a study of treated rates of schizophrenia among the Iban of Sarawak, Malaysia. Most Iban live in longhouses, each comprising a kindred group of up to 300 individuals. Cultural practices such as minimal intermarriage with members of adjacent ethnic groups and in-depth genealogical knowledge make them a population suitable for genetic investigation. Iban culture is conducive to a focus on symptoms and illness, and to patterns of treatment-seeking behaviour that are enthusiastic and persistent.

Method. We identified all known cases of psychotic disorder within a defined catchment area based on an exhaustive survey of available medical records. From corresponding Malaysian census data (91056 persons), we report rates of treated schizophrenia in the Iban population, using three diagnostic systems, as well as the demographic and clinical characteristics of these individuals.

Results. The most frequent presenting complaints were insomnia and aggression. We found higher treated rates for narrowly defined schizophrenia among males, but no significant gender difference for age of onset. Estimates of treated rates to age 55 years (per 10 000) for narrow schizophrenia were 41.9 (ICD-10), 56.5 (DSM-IV), and 83 (RDC), while the rates for broad schizophrenia were 105.5, 103.2, and 107.5 respectively.

Conclusions. Treated rates of schizophrenia were higher than the reported prevalence for many populations at risk, including many small-scale societies, although different methodological approaches may partly explain these findings. Given the cultural patterns of Iban treatment-seeking behaviour, treated rates of schizophrenia reported here may closely approximate the population prevalence of this disorder.

INTRODUCTION

In this paper, we present the results of a prevalence study of schizophrenia and other psychotic disorders among the Iban of Sarawak. First we discuss the population history, kinship structure,

genealogical knowledge, and treatment-seeking behaviour of the Iban, before presenting our results, which have provided the epidemiological basis for the molecular genetic phase of our study that is currently being undertaken.

The Iban of Sarawak: population history

The Iban are a people of proto-Malay stock who chiefly live in Sarawak, a Malaysian state

* Address for correspondence: Dr Bryan J. Mowry, Queensland Centre for Mental Health Research, The Park, Centre for Mental Health, Wacol, Queensland 4076 Australia.
(Email: bryan_mowry@qcmhr.uq.edu.au)

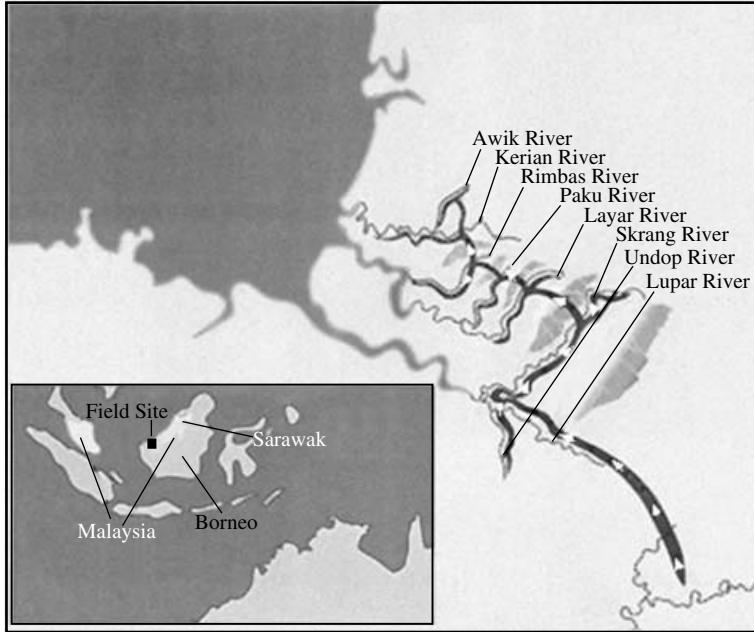


FIG. 1. The Iban of Sarawak: field site and migration routes.

located on the north-western coastal region of Borneo (see Fig. 1). They migrated from the headwaters of the Kapuas River in the central highlands of Borneo, over the watershed, and down into the coastal plains of present-day Sarawak (Padoch, 1982). Historical and genealogical evidence indicates that the migration occurred in several distinct waves, the first of which took place 16 generations, or some 400 years ago (Sandin, 1956, 1967). Over the next 10 generations, these pioneers successively invaded and settled the Undop, Lupar, Skrang, Layar, Paku, Rimbas, Kerian and Awik rivers. The last of these invasions occurred approximately six generations ago (*c.* 1800). (Subsequent migrations out to more distant rivers do not concern this project, as case finding is being restricted to those river systems inhabited by the descendants of the original migrating groups.) The migration was spearheaded by expeditionary groups comprising small numbers of closely related male pioneer-warriors, followed by their spouses and children. The Iban almost completely annihilated the small-scale pre-existing hunter-gatherers, the Bukitan and Seru, allowing little intermarriage with these conquered peoples, since among Iban warriors, prestige was measured in terms

of the number of human head 'trophies' accumulated, the heads of men and women being equally valuable. Furthermore, there is no historical record of significant intermarriage with other groups since that first migratory phase. The population has since undergone a rapid increase such that the 1991 census estimated that there are 450 000 Iban in Sarawak (including approximately 100 000 living in the river systems enumerated above), with most living in longhouse communities located along rivers that extend over one third of the state, an estimated 2000 km² (Freeman, 1958).

The longhouse, kinship and marriage

The longhouse, a basic unit of social and physical organization, is a series of up to 50 apartments (*bilik*) joined longitudinally under one roof, and housing up to 300 individuals. *Bilik* are private family spaces that are clearly demarcated from the more public open space (*ruai*) that runs the length of the longhouse. Strict norms regulate the social behaviour appropriate to each of these spaces. Originally, longhouses were founded by a group of male siblings and their spouses, with subsequent generations of longhouse members descending

from this group. In anthropological terms, Iban social structure is an example of a cognatic or ambilineal society, meaning that descent is traced and inheritance flows through both male and female lines (i.e. an absence of matrilineal or patrilineal structures). Kindred groups thus comprise all consanguineous relations traced through male and female links. Interlocking aggregations of kindreds occupy a river system and its tributaries. These aggregations had no formal political structure, but were defined historically as groups 'within which individuals did not take one another's heads' (Graham, 1987).

Traditionally there has been a strong preference for marriage between cousins (either on the mother's or father's side), most commonly second, third, or fourth degree, and while Iban culture allows more distant marriages, in practical terms, spouses have been selected from the same or neighbouring longhouses. They are a monogamous people with a strict taboo on inter-generational unions. Marriage or even sexual congress with a person of one's parents' or one's child's generation (even with a relative at seven or eight degrees of distance) is deemed equivalent to parent-child incest, punishable in former times by severe sanctions that could include the death of both parties. The determination of an accurate, consensually agreed, genealogy is essential, therefore, in the preparation for marriage. As a consequence, genealogical knowledge is central to Iban culture, with individuals able to recount comprehensive family trees stemming back four generations, and from there extending forward to include the individual's generation. This confers a considerable advantage on the researcher when compiling pedigree data.

Iban cultural practices have set them apart from other peoples of Borneo. Inter-marriage with members of adjacent ethnic groups, while permitted by Iban tradition, has been rare. The Islam religion of the Malays prohibits the eating of pork, effectively preventing them from eating in, and therefore marrying into, a longhouse. Where inter-marriage has occurred, it has involved Iban women leaving the longhouse and adopting the Islam faith to marry Malay men. Raised as Muslims, the children do not marry back into the longhouse. In cases of divorce, the woman returns to her parents' longhouse, while the children remain with their father and are integrated into his community. Inter-marriage,

therefore, does not lead to the introduction of new genetic material into the Iban gene pool.

This description of Iban kinship and marriage only holds true up to the current generation. With the rapid modernization that has occurred in the past 15 years, marriage patterns are changing as young Iban attend area schools, gain unskilled, semi-skilled, or professional employment in large towns or in Kuching, the capital city, and often choose spouses from this wider society. These historical and ethnographic data suggest that the Iban constitute a population isolate suitable for genetic investigation. We stress, however, that confirmatory genetic evidence for the 'isolate' status of this population must await the molecular genetic phase of our study.

Previous fieldwork

Trained both as a psychiatrist and a social anthropologist, R.B. previously carried out research into Iban culture that combined ethnographic and clinical research methods. The ethnographic phase comprised a 15-month period of participant-observation carried out in a longhouse community on the upper reaches of the Rimbas River. The research focused on traditional healing (Barrett, 1993), Iban concepts of mental illness (Barrett, 1997), and patterns of treatment seeking. This experience provided R.B. with the necessary fluency in Iban language and familiarity with Iban culture to carry out subsequent clinical research in a setting where cultural belief and psychiatric symptom can easily be mistaken for each other, leading either to underdiagnosis or overdiagnosis; an interesting early study on *latah* drawn from Dr K. E. Schmidt's large-scale community survey of mental morbidity among Malay, Iban and Chinese in Sarawak (Chiu *et al.* 1972) highlights the potential diagnostic complexities. The clinical phase of the research began with the translation into Iban (with appropriate back-translation) of the Present State Examination (PSE; Wing *et al.* 1974). This was done in collaboration with E.J., an experienced psychiatric nurse of Iban background, who was well grounded in psychiatric phenomenology, having himself received early training from Dr Schmidt. Particular attention was given to first-rank symptoms of schizophrenia, where the translation into Iban was problematic (Barrett, 2004). The translated PSE was then used in a comprehensive diagnostic

ascertainment of a sample of 50 Iban individuals with schizophrenia. Assessments were carried out over a 6-month period by travelling to each individual's longhouse and, in remote locations, staying with the family overnight. This carried the advantage of being able to make direct observations of the patient's behaviour and family interactions within the home. Detailed family histories were recorded and pronounced familial clustering [i.e. 12 out of 37 (32%) probands with at least one other relative with schizophrenia within three degrees] was observed within extended pedigrees. On the basis of these ethnographic and clinical data, the current study was planned.

Iban culture and illness behaviour

Several dimensions of Iban culture are relevant to the clinical presentation of, and community response to, psychiatric disorder. Foremost among these are the Iban traditions of heroism, bravery, travel and adventure that derive from their pioneering past and from their gruesome reputation, justly earned, as headhunters of renown. Though a practice long since abandoned, many of the old symbols and sentiments of headhunting are kept alive today, dramatized with vivisectioning enthusiasm during rituals in which the beheading of animals carries associations obvious to any observer. The heroic tradition also remains alive in their collective identity: they see themselves, and are recognized by others, as a vigorous, expansionary, intrepid, people, who engage in a forceful, assertive manner. The reverse side to this culture of bravery is an abiding preoccupation with bodily symptoms and illness, well recognized by doctors and nurses in the medical service, who tend, not without justification, to perceive the Iban as hypochondriacal or somatically focused. Accompanying this preoccupation for the Iban is a fear that such symptoms may represent the malign effects of spirits or souls of the dead. Reflecting these preoccupations and fears is a diverse and active range of healing traditions, from the *manang* (shaman healer) to the *beliau*, the *dukun*, the bone-setter, and the countless hybrid forms that abound in the region.

These concerns directly influence individual and family illness behaviour. Unlike many Malay people and some ethnic Chinese groups in Sarawak, Iban present early and often for

medical attention. In spite of the stigma attached to mental illness once it has been diagnosed, assistance is rapidly sought for earliest symptoms, not the least reason being that many of these symptoms are somatic in expression (restless agitation, a 'spinning' head). Furthermore, patients and their families uniformly seek recourse *both* to traditional healers *and* to the government health service. In 21 months of fieldwork no cases were encountered where medical treatment and traditional help had *not* been sought together. From an Iban perspective, it is illogical *not* to seek help from the medical system to address the bodily manifestations of disease, while at the same time requesting assistance from one or more traditional healers to deal with dead souls or interfering spirits that might be implicated in its cause. While patients are rarely advised by hospital staff to seek a traditional cure, traditional healers do tend to encourage patients to attend for hospital treatment, chiefly because healers are acutely aware of the limited efficacy of their own curing rites in relation to mental illness.

As with many groups indigenous to Borneo (Metcalf, 1991), illness, dying, and the world of the dead loom large for the Iban (Uchibori, 1978). Their animist religion (Jensen, 1974) focuses attention on spirits, both dangerous and helpful, that co-inhabit the world of the living. While conversion to Christianity, the advent of modern education, and internal migration to towns and cities have attenuated these influences, they nevertheless continue to form a substantial substratum of Iban culture. This is especially so for longhouse dwellers who commonly relate experiences of encounters with the dead and with spirits, usually in dreams and to a lesser extent in waking life. The Iban are acutely attuned to sights and sounds of longhouse, field and forest, and they are quick to distinguish between waking experiences, be they auditory, visual, olfactory or tactile, that signify the presence of spirits, and those that signify illness. The former tend to be evanescent, usually occur in the dark, and are experienced in certain auspicious or dangerous places such as the upstairs loft or outside at night; the latter, they say, are more persistent, occurring just as frequently during daylight hours and often in ordinary settings such as the kitchen or living room – all tell-tale signs, to the Iban, that the person's

brain has become sick (*sakit untak*) or broken down (*untak rusak*). Such cases are understood in terms of the indigenous illness concept of *sakit gila* (mad sickness) a broadly encompassing category that approximates the medical category of psychosis.

A striking feature of the presentation of schizophrenia is the almost ubiquitous presence of auditory hallucinations. Of the 50 cases examined in the previous study, 48 reported these symptoms. By contrast only three had experienced subjective (Schneiderian) symptoms of thought disorder such as thought insertion, withdrawal or broadcast. While there are a number of possible explanations for this, including the problems entailed in translating the concept of subjective thought disorder into the Iban language, it has been proposed (Barrett, 2004) that this is most likely a reflection of the emphasis that is placed in this collective culture on spoken interaction as a dominant mode of experience rather than on solipsistic thought.

Mental health services in Sarawak

Mental health services were established following World War II during the British colonial period, and began to develop rapidly alongside general health services after Sarawak entered the Malaysian Federation in 1963. Central to the current study is a mental health unit (a 20-bed in-patient facility and an outpatient service) located in Sri Aman, a divisional administrative centre. The unit is sometimes bypassed, especially in cases of severe psychiatric disorder, where the patient may be admitted directly to the Sarawak Mental Hospital. This is the principal mental health facility for the state and located 180 km away, just outside Kuching, the capital city. Case records maintained by these two in-patient units are written in English and for the most part are of reasonable quality, especially for first admissions, where a history and full symptom checklist is recorded by trained mental health nurses and all cases are reviewed by a psychiatrist. The quantity and quality of admission history and symptom review falls away asymptotically on second and subsequent admissions, although the nursing progress notes continue to provide diagnostically useful observations on patients' behaviour while in the ward, especially in relation to observable thought disorder and disorganized behaviour. When

examining these notes we often found evidence for behavioural disturbance that strongly suggested a diagnosis of schizophrenia but insufficient documentation of patients' subjective experiences to confirm a research diagnosis.

In addition to these two psychiatric facilities, there are three district hospitals to which patients living within the catchment for the current study may also be admitted. Registers of psychiatric cases are maintained at these hospitals, though the quality of records here is diminished. Finally, there is a network of 26 district health clinics extending into the remote areas. It is here that patients may first present for treatment and subsequently receive follow-up, and a simple register is kept for this purpose that details only diagnosis and medication dose.

AIM

The aim of this paper is to provide an epidemiological report on the sociodemographic characteristics and treated rates, of schizophrenia and other psychotic disorders, within the Iban of Sarawak.

METHOD

The highest concentration of Iban is found in two regional divisions of Sarawak, one having its administrative centre in the town of Sri Aman, the other in the town of Betong. The combined census population for the Sri Aman and Betong divisions is 91 056 (males 46 956, females 44 100) (Department of Statistics, Malaysia, 1999). Institutional Review Board approval was obtained from the Department of Health, Kuching, and from the Institute of Medical Research, Kuala Lumpur. All available medical records (1960–2000) for individuals living in the Sri Aman and Betong divisions were screened for the presence of psychosis, covering the two mental health facilities described above, the three district hospitals, and all 26 district health clinics. With this exhaustive coverage, we are confident we have identified all known Iban people with significant psychotic illness within our catchment area who have been treated by the mental health services up to and including the period of data collection.

Relevant medical record information on all cases with evidence of psychosis was collected

from the above sources and assigned to 25 demographic variables and 90 clinical variables. A narrative history for each case was also recorded. Data were entered on to a spreadsheet developed by R.B. and P.L. specifically for use in this study; containing diagnostic algorithms for DSM-IV (APA, 1994), ICD-10 (WHO, 1993), and RDC (Spitzer *et al.* 1978) diagnostic systems. We determined that a tri-diagnostic approach might best capture a genetically relevant subgroup or symptom dimension. Each case was then diagnosed by two experienced research psychiatrists (R.B., B.M.), using a consensus best-estimate diagnostic procedure, based on medical record information. We rated each case separately and then reviewed the same material independently; while detailed data were not recorded, an initial consensus was achieved in over 70% of cases; in all remaining cases a consensus diagnosis was arrived at by discussion. During the course of R.B.'s previous fieldwork among the Iban, 50 individuals were diagnosed with schizophrenia using the translated PSE. These individuals were again identified, independently of previous diagnosis, in our current survey.

The rate of treated schizophrenia was calculated (i) as a crude rate with the number of cases as the numerator and population size, using census data, as the denominator; and (ii) as an age-adjusted rate according to the complete life-table approach (Chiang, 1968; Gottesman & Shields, 1982) and based on the 5-year age groupings given in the most recent Sarawak census document (Department of Statistics, Malaysia, 1999). We consider (ii) to be a valid method in the circumstances as the data in the census document provides a close to contemporary census of the population from which our cases are obtained. (Had we been fortunate enough to have individual-level data on the entire population, rather than for cases only, then we could have applied more powerful methods, for example the product-moment approach, to the estimation of age-adjusted prevalence; see e.g. Kessler *et al.* 2003.) We give the age-adjusted rate for persons of at most 55 years of age in order to cover the period of risk for disease onset and avoid the statistically distorting effects of the small number of late-onset cases among a small number of surviving individuals.

Narrow schizophrenia was defined according to ICD, DSM and RDC schizophrenia diagnostic criteria; RDC 'probable' schizophrenia was grouped with 'broad' schizophrenia. We defined 'broad' schizophrenia to include those disorders known to segregate in families of individuals with schizophrenia, namely schizophrenia, schizoaffective disorder, other non-affective psychoses, schizophreniform disorder, delusional disorder, and schizotypal and paranoid personality disorders (Levinson & Mowry, 2000). We excluded affective psychoses (e.g. DSM bipolar disorder with psychotic features) from this definition.

Areas that are notoriously ambiguous were given special attention when assigning diagnoses. For example, in cases where there was a significant affective component, care was taken to ensure that diagnostic criteria for schizoaffective disorder were clearly met. Of 27 cases in this group, a diagnosis of schizoaffective disorder could be established in 25. Two cases did not meet the criteria (one bipolar disorder with psychotic features, one major depressive disorder with psychotic features). Ambiguity also characterizes the differentiation of schizotypal personality disorder from both schizophrenia and paranoid personality disorder, but there were no cases in this series that raised these particular diagnostic problems. We were less confident, however, in our ability to accurately judge length of illness from the case record material available, leading to potential errors, therefore, in the distinction between schizophrenia (or schizoaffective disorder) and brief psychotic disorder.

RESULTS

A total of 500 potential psychotic cases were diagnostically evaluated. Ninety-five were excluded for the following reasons: depression without psychosis ($n=18$), lack of evidence for psychosis ($n=17$), epilepsy ($n=14$), mental retardation ($n=10$), dementia ($n=6$), other organic disease ($n=4$), alcohol-related disorders ($n=10$), too old (>65 years) or too young (<15 years) ($n=7$), and living out of the target districts ($n=9$). The remaining 405 psychotic cases formed the basis for age-specific prevalence of psychotic disorders among the Iban.

Table 1 lists the distributions of clinical and demographic variables by DSM-IV diagnosis (schizophrenia, and all other psychotic disorders). There was a wide age range (15–94 years), and associated high mean age (47.5 years) for all disorders. The preponderance of farming as an occupation reflects the agricultural economy of the Iban. Approximately 90% live in longhouses, the remainder living in Sri Aman or Kuching. Among those with a diagnosis of schizophrenia, there were more males than females, compared with the gender ratio among other psychotic disorders (not significant, $\chi^2=1.32$, $df=1$, $p=0.25$). There was a wide range of age at onset (defined as age at initial mental health assessment according to medical records, as information about age at symptom onset is not available, see discussion below), with a mean of 31.7 years. Just 3.2% of males and 3.8% of females with schizophrenia had an early age of onset (≤ 18 years), while 7.7% of males and 5.5% of females had an onset at age ≥ 55 years. Patients with schizophrenia, particularly males, were significantly more likely than those with other psychotic disorders to present with aggression of all forms (females, $\chi^2=10.9$, $df=1$, $p=0.001$; males, $\chi^2=28.9$, $df=1$, $p<0.001$). The most frequent presenting complaints for these disorders were insomnia, any form of aggression (termed global aggression), talking to oneself, aimless wandering, and restlessness. As expected, the mean number of hospital admissions and length of illness for schizophrenia was greater than for other psychotic disorders.

Table 2 lists the frequencies of responses to DSM-IV symptoms. It is noticeable that bizarre delusions, a category that includes Schneiderian delusions of thought insertion and withdrawal have a relatively low frequency of presentation ($n=22$ or 5.4%) when compared to Schneiderian auditory hallucinations ($n=48$) and hallucinations in the broader sense ($n=347$). This is consistent with the earlier study of 50 cases discussed in the Introduction. Like that study, these results indicate a high frequency of auditory hallucinations as presenting symptoms, compared to Schneiderian symptoms of subjective thought disorder, which are quite rare.

Table 3 shows the rates of treated schizophrenia, per 10000 among the Iban. Life-table estimates of these rates to age 55 years for

strictly defined (narrow) schizophrenia were 41.9 (ICD-10), 56.5 (DSM-IV), and 83.0 (RDC), while the rates for broadly defined schizophrenia were 105.5, 103.2, and 107.5 respectively. For all diagnostic systems, the rates were higher for males than for females; for example, DSM narrow schizophrenia has higher lifetime rates for males than for females (Wilcoxon log-rank test, $\chi^2=8.53$, $df=1$, $p=0.004$). For comparison, crude (i.e. number of treated cases divided by the total population, not corrected for age) for narrow schizophrenia were lower: 17.7 (ICD), 23.5 (DSM), and 34.5 (RDC).

DISCUSSION

Comparisons

Based on exhaustive medical record and census data for our project's catchment area, we found age-adjusted rates of treated schizophrenia that were relatively high compared to prevalence figures reported in a number of studies of small-scale societies, but lower, or in keeping with, those reported in more recent studies of isolated populations. Strictly defined schizophrenia rates were in the 40–80 range (per 10000) (females 36–75, males 48–91), while broadly defined schizophrenia fell within the 105–107 range (females 93–95, males 119–121). These figures reflect the different approaches (e.g. duration of illness, overlap of schizophrenia and affective syndromes) adopted by the three classification systems. The ICD was the most restrictive due to hallucinations and delusions together accounting for only one criterion, and the requirement for the schizophrenia syndrome to occur before the affective syndrome. DSM criteria are easier to satisfy, with hallucinations and delusions accorded two separate criteria; moreover, mood exclusion is based on relative duration of affective and schizophrenia syndromes without the temporal requirement of ICD. RDC is cross-sectionally similar to the others but has only a 2-week requirement for the presence of psychotic symptoms, explaining the larger number of cases fulfilling diagnostic criteria. On the other hand a small number of patients having a brief affective syndrome overlapping with a longer schizophrenia syndrome were diagnosed as RDC schizoaffective disorder, while DSM classified this illness as schizophrenia.

Table 1. *Clinical and demographic variables by DSM-IV diagnosis*

Variable	Attribute ^{a,b}	Any psychotic disorder			Schizophrenia			Other psychotic disorder		
		Persons	Females	Males	Persons	Females	Males	Persons	Females	Males
Iban	<i>n</i>	405	184	221	214	93	121	191	91	100
Current age (years) ^c		397	180	217	207	89	118	190	91	99
Range		15–94	15–84	16–94	23–87	26–84	23–87	15–94	15–82	16–94
Median		45	47	45	46	51	43.5	44.5	44	45
Mean		47.4	48	47	48.1	49.9	46.7	46.8	46.1	47.4
s.d.		14.8	15	14.6	14	14.3	13.6	15.6	15.6	15.7
Occupation										
Farmer	<i>n</i>	128	46	82	73	30	43	55	16	39
Housewife	<i>n</i>	34	33	1	13	13	0	21	20	1
Unemployed	<i>n</i>	39	18	21	24	10	14	15	8	7
Other occupations	<i>n</i>	64	18	46	32	9	23	32	9	23
Residence										
Longhouse	<i>n</i>	335	148	187	176	73	103	159	75	84
House	<i>n</i>	31	17	14	11	6	5	20	11	9
Other residence	<i>n</i>	7	3	4	2	2	0	5	1	4
Marital status										
Single	<i>n</i>	166	59	107	97	28	69	69	31	38
Married	<i>n</i>	156	83	73	70	39	31	86	44	42
Divorced	<i>n</i>	40	24	16	19	13	6	21	11	10
Widowed	<i>n</i>	11	9	2	8	7	1	3	2	1
Age at onset (years) ^d	<i>n</i>	400	181	219	209	90	119	191	91	100
Range		11–87	11–75	12–87	12–77	14–67	12–77	11–87	11–75	12–87
Median		28.5	28	29	28	28	28	30	28	32.5
Mean		31.7	31.1	32.1	30.8	31.2	30.6	32.6	31	34
s.d.		13.3	12.8	13.7	12.4	11.5	13	14.2	13.9	14.3
≤18	<i>n</i>	54	26	28	21	8	13	33	18	15
Presenting symptoms										
Aggressive verbally	<i>n</i>	100	35	65	73	24	49	27	11	16
Aggressive carries weapons	<i>n</i>	80	32	48	60	23	37	20	9	11
Aggression toward objects	<i>n</i>	101	31	70	79	22	57	22	9	13
Aggression toward people	<i>n</i>	95	32	63	67	20	47	28	12	16
Global aggression	<i>n</i>	219	90	129	142	55	87	77	35	42
Inappropriate laughter	<i>n</i>	59	33	26	42	22	20	17	11	6
Talking to self	<i>n</i>	193	95	98	118	57	61	75	38	37
Unintelligible	<i>n</i>	111	50	61	79	34	45	32	16	16
Withdrawal	<i>n</i>	109	45	64	72	27	45	37	18	19
Restlessness	<i>n</i>	158	71	87	95	34	61	63	37	26
Wandering aimlessly	<i>n</i>	145	55	90	104	36	68	41	19	22
Running away	<i>n</i>	64	27	37	41	14	27	23	13	10
Insomnia	<i>n</i>	250	108	142	147	60	87	103	48	55

Hypersomnia	<i>n</i>	8	3	5	6	2	4	2	1	1
Decreased appetite	<i>n</i>	80	40	40	48	24	24	24	16	16
Increased appetite	<i>n</i>	1	0	1	0	0	0	0	1	1
Weight loss	<i>n</i>	14	9	5	7	4	3	7	5	2
Weight gain	<i>n</i>	1	1	0	0	0	0	0	1	0
Number of admissions ^e	<i>n</i>	339	155	184	183	80	103	156	75	81
Range		1-75	1-75	1-39	1-43	1-43	1-31	1-75	1-75	1-39
Median		2	2	2-5	3	3	4	1	1	1
Mean		4-4	3-9	4-9	5-6	4-5	6-4	3-1	3-2	3
S.D.		7-2	7-8	6-7	6-6	6-5	6-5	7-7	8-9	6-4
Length of illness (years) ^f	<i>n</i>	349	156	193	190	83	107	159	74	86
Range		0-01-38-2	0-01-22-9	0-02-38-2	0-01-22-8	0-01-22-1	0-02-22-1	0-02-38-2	0-02-22-9	0-02-38-2
Median		0-9	0-6	1-4	4-7	3-1	5-3	0-1	0-1	0-1
Mean		4-7	4-2	5-1	6-3	5-5	7-0	2-8	2-7	2-8
S.D.		6-5	5-9	6-8	6-3	6-2	6-4	5-9	5-1	6-5

^a Where *n* is the only attribute of a variable, it denotes the number of patients with that attribute.

^b When the range, median, mean, and standard deviation (s.d.) of a variable are reported, *n* denotes the corresponding sample size.

^c Age in 2001.

^d Defined as age at initial mental health assessment, according to medical records.

^e Defined by the number of distinct admissions, according to medical records. The maxima (75, 43, 39) are outliers, as reflected by the median numbers of admissions in the range 2-4.

^f Defined as the time, in decimal years, from admission for the initial mental health assessment, to the most recent discharge.

Table 2. Frequencies of DSM-IV symptoms (*n* = 405)^a

Symptom	No	Yes
At least one of		
Bizarre delusions	382	22
Auditory hallucinations: running commentary, or 2+ voices conversing	357	48
Or at least two of		
Delusions	168	237
Hallucinations	58	347
Thought disorder	243	162
Grossly disorganized/catatonic behaviour	253	151
Negative symptoms	330	75
Social/occupational dysfunction	6	396
Overall duration: at least 6 months	106	296
Active symptoms duration: at least 1 month	61	341
Schizoaffective and mood disorder exclusion: either no concurrent episodes, or relatively brief in duration	48	354
Organic exclusion	4	398
DSM Schizophrenia	191	214

^a Row totals are occasionally less than 405 due to missing values.

Table 3. Rates of treated schizophrenia (per 10 000) by gender and diagnosis

Diagnosis	Variable	Persons	Female	Male
ICD: Sz Narrow	<i>n</i>	161	72	89
	Population size	91 056	46 956	44 100
	Crude rate ^a	17-68	15-33	20-18
	Rate to 55 ^b	41-95	35-98	48-82
ICD: Sz Broad	<i>n</i>	393	180	213
	Crude rate	43-16	38-33	48-3
	Rate to 55	105-52	93-47	119-34
DSM: Sz Narrow	<i>n</i>	214	93	121
	Crude rate	23-5	19-81	27-44
	Rate to 55	56-51	48-96	65-28
DSM: Sz Broad	<i>n</i>	385	176	209
	Crude rate	42-28	37-48	47-39
	Rate to 55	103-22	92-06	116-07
RDC: Sz Narrow	<i>n</i>	314	146	168
	Crude rate	34-48	31-09	38-1
	Rate to 55	83	75-57	91-61
RDC: Sz Broad	<i>n</i>	395	179	216
	Crude rate	43-38	38-12	48-98
	Rate to 55	107-56	95-12	121-87

^a Crude rate, calculated as number of cases divided by population size.

^b Rate to 55 years – age-adjusted rate up to 55 years, calculated by the life-table method.

Advantages of tri-diagnostic system

We recognize that methodological (e.g. case finding, ascertainment) and population (e.g. prevalence, treatment, migration) differences may confound comparisons across studies. With these caveats in mind, the polydiagnostic feature of our study facilitates comparisons between the

rates of treated schizophrenia in the Iban, and the prevalence of schizophrenia in other small-scale studies. In a sample of 160 RDC schizophrenia cases in Palau, lifetime prevalence was 199 per 10 000 overall (277 males, 124 females) (Myles-Worsley *et al.* 1999); this result is substantially higher than our corresponding RDC age-adjusted rate of 83. Kosrae, a Micronesian island with 5500 inhabitants has a reported (DSM-IV) prevalence of 68 (Waldo, 1999), similar to rates reported here. Iban rates are higher than the 14–46 range reported for most populations at risk (Jablensky, 2000). It must be noted, however, that these other studies are mostly point prevalences compared to our age-adjusted estimates. Given this caveat, our rates are higher than reported prevalences in other small-scale societies such as the indigenes of Taiwan with a prevalence decrease from 22 to 14 over a generation (Rin & Lin, 1962; Lin *et al.* 1989), rural Sri Lanka (Jayasundera, 1969), Tonga (Murphy & Taumoepeau, 1980), and Papua New Guinea (Torrey *et al.* 1974). However, when compared with the point prevalences from the WHO 10-country study (Jablensky *et al.* 1992), our rates of broadly defined schizophrenia (approximately 100) fall within the reported WHO range of 50 (Honolulu) to 172 (Chandigarh), while our narrow ICD prevalences (42) also fall within the WHO study range of 26 (Honolulu) to 54 (Nottingham), with our DSM and RDC rates being higher.

Do treated rates approximate prevalence in this community?

The principal question arising in relation to the data presented here is the extent to which our rates, calculated solely on the basis of available medical records, approximate the age-adjusted prevalence in the Iban community within the catchment area. This question turns on two issues.

(1) *Documentation.* Although the medical records were of reasonable quality, it is well recognized that the lack of documentation of psychopathology in records that are made for clinical purposes limit diagnostic claims. Furthermore, age at onset has been defined as the age at initial assessment as consistently documented by medical records, which rarely contain a reliable history detailing earliest onset of psychotic symptoms. Thus our age at onset is not

only biased upwards but is also dependent on the reliability of the medical records. Moreover, for late age at onset, the records do not permit a distinction between genuine onset and delay of treatment. Hence we base the estimated rates of our diagnoses on persons up to age 55 years, as well as giving the crude rates based on the entire age range.

We anticipated that if the records were more accurate in relation to the age of onset and longitudinal course of illness, the number of cases with a diagnosis of schizophrenia and schizoaffective disorder would be higher with a corresponding decrease in the number of cases with schizophreniform disorder and brief psychotic disorder. We also anticipated that if the records were to provide more detailed reports of presenting symptoms, many cases with a suspected diagnosis of schizophrenia would have this diagnosis confirmed. We derived some support for these predictions by examining a subset of 50 of the 405 cases (12.3%), where we correlated the ICD diagnoses based on case-record data with the ICD diagnoses that R.B. had previously determined using PSE 10 research interviews. The diagnoses were concordant in 30 (60%) of cases (schizophrenia in 27 of them, schizoaffective disorder in 3). Three reasons accounted for the 20 cases in which diagnoses were discrepant. In 13 of them it was a matter of unrecorded clinical phenomenology; case-record data only permitted the diagnosis of unspecified non-organic psychosis, whereas on interview it was possible to make a diagnosis of schizophrenia (12) or schizoaffective disorder (1). In four cases it was a matter of insufficient information about the length of illness; case-record data only permitted the diagnosis of various subcategories of acute and transient psychotic disorder, whereas on interview it was possible to make a diagnosis of schizophrenia (3) or schizoaffective disorder (1). In the three remaining cases there was disagreement over the presence of an affective component. In two of these the record-based diagnosis was schizophrenia and the interview-based diagnosis was schizoaffective disorder, whereas in the last case it was the reverse. Notwithstanding these discrepancies, it is notable that there was no case record-based research diagnosis of broadly defined schizophrenia that was not confirmed on interview. If these findings held true for the entire series of

405 cases, we would expect to find higher rates of narrowly defined schizophrenia but similar to the rates of schizophrenia as broadly defined. More credence can therefore be accorded the latter rates.

(2) *Undetected cases.* The more substantive issue that affects the relationship between treated rates and population prevalence is the number of cases that may be undetected by their own longhouse communities, or that may not have come to the attention of the treating facilities. With respect to community detection, it is notable that behavioural manifestations rank highly among presenting clinical features in this series. Aggression in its various forms (denoted as global aggression) is the second most frequent presenting symptom after insomnia, occurring in 219 of 405 cases (54%) of psychosis. Particularly alarming to the Iban is the behaviour of running away, ranked ninth and occurring in 20% of cases. It represents a significant danger to the patient because it usually involves running away into the forest. It is possible that the cultural constellation of aggression and assertiveness *versus* fear and flight, outlined above, provides the background context in which aggression and running away assume prominence as presenting features of psychosis. Restlessness and aimless wandering rank fourth (39%) and fifth (36%) respectively. It is not surprising, in view of the tightly regulated norms that apply to longhouse life, that the Iban are quick to detect such changes in motor behaviour. Given that overt behavioural symptoms are such a salient feature of these clinical presentations, it is likely that most cases of psychosis will rapidly come to the attention of members of their own community. However, it is possible that there are individuals that escape community attention altogether, most likely those suffering from forms of psychotic illness with predominantly negative symptoms.

Then there is that group of cases who may have been identified by their longhouse community as ill but who have never sought medical treatment. We suspect, for several reasons, that the size of this group will be less than expected for a traditional, small-scale society. The first reason is the aforementioned cultural tendency to seek treatment frequently and from many sources, traditional and modern, even for minor symptoms. The second is the ready availability

of government-funded treatment for all. The reach of the community health clinics is impressive, extending far into the interior, such that to get there by longboat may take up to 2 days. Those who staff these clinics develop a close working knowledge of these remote communities. Given a people who are characteristically anxious to seek treatment, and a government health service capable of providing it, even in remote regions, it could be argued that the number of untreated cases is unlikely to be large. A measure of support for this position comes from the observation by R.B. that there were no such cases throughout the river systems in which he lived and worked for 21 months in all.

Furthermore, preliminary evidence is now to hand from the recruitment phase of our genetic study currently in progress. A number of field trips have been undertaken by R.B. in which he works with the principal recruiter (E.J.) who has a personal knowledge of the great majority of individuals with psychosis and their families, having worked in the mental health services for many years. As an Iban person, he also brings to the project an extensive knowledge of traditional culture, a native fluency with the language, and family connections throughout the catchment area. Recruitment proceeds by identifying all recorded cases in one river system before proceeding to the next. At each longhouse visited, an attempt is made to locate as yet untreated cases, working principally through headmen and other senior people with a knowledge of the population in that longhouse and the surrounding longhouses. With the first 96 cases to hand, and with extended periods of time spent in two river systems thus far, visiting a third of the longhouses in each, it is notable that only one untreated case has been uncovered. While this falls short of complete epidemiological evidence, it provides solid support for the notion that untreated cases are uncommon. Where we lack confidence however, is in the ability to detect untreated cases of predominantly negative schizophrenia and brief psychotic disorder, particularly if the latter occurred in the remote past.

In sum, we suggest first that the rates of broadly defined schizophrenia derived from these case-record data are similar to the rates that would be ascertained on diagnostic interview, and secondly, that in view of the highly

distinctive Iban culture of treatment seeking and the highly effective penetration of the Malaysian district health service, these rates closely approximate population prevalence. While it would be epidemiologically naive to suggest that we are reporting prevalence figures, we argue that our rates are highly indicative of the prevalence of schizophrenia in the Iban.

Gender differences

We found higher rates for narrowly defined schizophrenia for males than females, consistent with our finding that males have a higher mean number of admissions and a slightly higher mean length of illness than females. This finding is lower than the 2:1 male/female ratio in Palau (Myles-Worsley *et al.* 1999) and somewhat higher than other studies finding the same lifetime prevalence for males and females (Hafner & an der Heiden, 1997). In addition, we found no significant difference between males and females in age of onset, defined as the age at initial assessment. Our age of onset results are consistent with other genetic (DeLisi, 1992) and epidemiological (Murthy *et al.* 1998) studies. It must be noted that a more accurate age of onset will be available once the genetic investigation of this population is available.

Conclusion

In sum, the limitations of working on the basis of case records determine that the rates reported here probably underestimate the true population prevalence among the Iban, especially in relation to briefer forms of psychotic illness, but the extent of this underestimate may not be large. More weight should be placed on the prevalence figures for schizophrenia as it is broadly defined. However, within this category we anticipate that with increasing accuracy, a higher percentage would be identified as suffering from schizophrenia as narrowly defined. While important in themselves, these data also provide an epidemiological framework for our molecular genetic study. This framework will contribute to our understanding of the phenotype and inform our genetic analyses of this population.

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DECLARATION OF INTEREST

None.

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