Translating genomic research into care for people with schizophrenia in China

Raymond CK Chan^{1,*}, Jehannine C Austin^{2,3,*}, Veronica J Pearson⁴, Qi-yong Gong⁵, and William G Honer²

¹Key Laboratory of Mental Health, Institute of Psychology, Chinese Academy of Sciences; Neuropsychology and Applied Cognitive Neuroscience Laboratory, Institute of Psychology, Chinese Academy of Sciences, Beijing 100101, China

²BC Mental Health and Addictions Research Institute, and Department of Psychiatry, University of British Columbia, Vancouver, Canada

³Department of Medical Genetics, University of British Columbia, Vancouver, Canada

⁴Department of Social Work and Social Administration, University of Hong Kong, Hong Kong SAR, China

⁵Huaxi MR Research Centre, Department of Radiology, West China Hospital/West China School of Medicine, Sichuan University, Chengdu, China

Abstract

The implications of increased understanding of the genetic contribution to schizophrenia for patients and their families remain unclear. We carried out a study of Chinese patients' (n = 118) and relatives' (n = 78) views of illness severity, attribution of cause, concern about developing illness, and effect of schizophrenia on family planning. A comparison sample of English-survey respondents was also obtained, using the same series of questions (n = 42 patients, n = 127 relatives). Fewer Chinese patients and family members rated schizophrenia as very severe (33%) than did the predominantly North American respondents (67%, $p < 0.0001$). The pattern of attribution of cause differed between samples ($p < 0.0001$), favouring environmental alone in the Chinese sample (52%), with a low frequency of genetics alone (9%). Although comparatively fewer Chinese respondents were very concerned about developing schizophrenia themselves or about the risk of illness in their families (21%), this high level of concern was more common in family members (28%). Finally, Chinese respondents were somewhat less likely to indicate that schizophrenia impacted on family planning decisions (31%) than were English-survey respondents (45%, $p = 0.02$). The descriptive findings contribute to understanding schizophrenia in China. The comparative findings must be regarded as preliminary, since differences in demographics could influence results. The present findings suggest that understanding patients' and families' attributions of cause of schizophrenia may be important for developing a shared model of illness in order to decrease stigmatization, and improve therapeutic alliances.

Correspondence should be addressed to: Raymond Chan, Institute of Psychology, Chinese Academy of Sciences, 4A Datun Road, Beijing 100101, China; rckchan@psych.ac.cn or Jehannine Austin, BC Mental Health and Addictions Research Institute, Rm A3-112, CFRI Translational Lab Building, 938 W28th Ave, Vancouver, BC, Canada, V5Z 4H4 ; jehannine.austin@ubc.ca. Both the first and second authors contribute equally to the writing of the paper.

Keywords

schizophrenia; genetics; stigma; causal attributions

1. Introduction

Genomic research is making great strides in understanding the biological substrates for developing schizophrenia. Applying the knowledge obtained through research to practice will depend on both the beliefs of patients and their families concerning schizophrenia, and the sophistication of understanding of psychiatrists. Beliefs about the nature of schizophrenia may be shared, or may differ across cultures (Fosu, 1981, Phillips et al., 2000). Acute psychosis is a phase of illness in schizophrenia, and was consistently ranked across the globe as one of the most disabling health conditions (Ustun et al., 1999). In this WHO-sponsored study, Chinese key informants ranked acute psychosis as less disabling than did Canadians.

Beliefs in causal attribution can play a powerful role in individual adaptation to illness, engagement with treatment, and interactions with family members (Kelly et al., 1987, Phillips et al., 2000, Fosu, 1981, Yang et al., 2004). Different types of attribution may also influence stigma and discrimination at multiple levels, from social or institutional to personal. A term used to describe schizophrenia in Chinese is *jing shen fen lie zheng* (精神分裂症), meaning “mind-split-disease”. This terminology continues to be widely used, although less stigma-laden alternatives are proposed in Mandarin (*xiang tai duo* 想太多 “excessive thinking”) and in Cantonese (*shi-jue shi-diao* “dysregulation in thinking and perception”) (Yang et al., 2010, Wong et al., 2008).

Work carried out in China suggests family members attribute schizophrenia predominantly to the social environment, to personal characteristics, and much less to biological factors including heredity. The reverse is true of medical professionals (Pearson, 1993, Phillips et al., 2000). Research from Australia and Canada suggests attributing mental illness to genetic origins may contribute to family members’ concern about their own risk of illness, and may also influence decisions about childbearing for patients and family members (Austin et al., 2006, Meiser et al., 2007). There are few studies of Chinese samples with reference information from non-Chinese samples. In the present study, we asked patients with schizophrenia and relatives having a family member with schizophrenia to rate the severity of mental illness and the seriousness of the impact on families. The same instrument was used in the Chinese and English-speaking samples, allowing examination of concepts of severity of illness, attributions, and concern about developing schizophrenia in a Chinese sample with a comparison non-Chinese sample.

2. Methods

2.1 Survey

We used a previously described survey instrument that was developed to investigate relationships between attitudes towards psychosis, understanding of the origins of illness,

concerns about developing mental illness, and reproductive decisions (Austin et al., 2006). This was translated into Mandarin, and back-translated into English to ensure fidelity with the original intent of the questions. The English version of the survey was designed for studies of psychosis in general, with specific inquiry into the diagnosis that was associated with the participant (relative or patient). For the translation into Mandarin, the emphasis was on schizophrenia. Where questions in English used the term psychosis, in the Mandarin version this was substituted with the term *jing shen fen lie zheng* (精神分裂症) meaning “mind-split disease” commonly used for schizophrenia in China.

2.1.1 View of psychosis—Participants were asked to select one of five options describing their view of psychosis, ranging from “I think psychosis is a very severe condition, it has serious negative effects on individuals and families” to “I think psychosis is a very mild condition, it has no negative effects on individuals or families”.

2.1.2 Causes of psychosis—Participants were asked the question: “In my opinion, psychosis is probably caused by” and were asked to check as many options as they felt applied; the options were: “genetic/hereditary factors”, “drug use”, “head injuries”, “stressful life events”, and “birth trauma”.

2.1.3 Concern about developing psychosis—Participants were asked the question “How concerned are you about the chance of yourself or other family members developing psychosis?” Five options were provided, ranging from “Very concerned” to “Not at all concerned”.

2.1.4 Impact on family planning—Participants were asked the question: “Has the diagnosis of psychosis in your family affected your decision-making regarding family planning?” The options for response were yes, no, or don’t know.

2.2 Sites and participants

For logistic reasons, the survey was administered in China in a paper and pencil format. In- and outpatients, and their family members participated in three centers: Shantou – Guangdong Province, Chengdu – Sichuan Province, and Hangzhou – Zhejiang Province.) The English version of the survey was implemented on the website www.psychosissucks.ca. This website was established in 2003 as part of the Early Psychosis Intervention Program in the Fraser Health Region of British Columbia, Canada. The site provides information for patients, families and the general public about psychosis, and schizophrenia in particular. All visitors to the site had the option to complete the survey, additional details concerning visits to the site are reported in a previous publication using survey data (Austin et al., 2006). For the purposes of the present report, data was restricted to participants who indicated they had schizophrenia, or were the relative of a patient with schizophrenia. Respondents to the English survey were from Canada (58%), USA (30%), UK (8%) and Australia (4%).

The study was approved by the Research Ethics Committees of the Institute of Psychology, Chinese Academy of Sciences, and the Fraser Health Authority, British Columbia.

2.3 Statistical analysis

Responses were grouped for descriptive analyses. For the 'view of mental illness', responses were dichotomized to very severe, or quite severe or less. For 'causes of psychosis,' participants had multiple options, and each participant's response was categorized as genetic alone, genetic + environment, or environment alone. For 'concern about psychosis', responses were dichotomized to very concerned, or quite concerned or less. For 'impact on family planning', only yes or no responses were included. Relatives reporting a child with schizophrenia were also excluded, since the impact on family planning was expected to be less relevant in this older age group. Exploratory analyses comparing responses between samples were carried out using logistic regression with predictors source (China, English-survey), affected status (relative, patient), and a source-by-affected status interaction term.

3. Results

3.1 Sample composition and demographics

The composition of samples is described in Table 1. Women were in a majority in both samples. The magnitude of the majority was statistically greater in the English-survey sample, particularly in the relatives' group. In both samples, patients were younger than relatives. Education level was statistically greater in the English-survey sample, predominantly due to higher levels of education in the relatives.

3.2 View of schizophrenia

The descriptive results for this and subsequent findings appear in Figure 1. Fewer in the Chinese sample (63/188, 33%) endorsed schizophrenia as being a very severe type of illness compared with the English-survey sample (128/168, 67%, Chi-square = 41.08, $p < 0.0001$). Across both samples, the view of schizophrenia being a very severe illness was more common in family members (133/201, 70%) than patients (58/155, 30%, Chi-square = 9.30, $p = 0.002$). There was no interaction between sample source and affected status in relation to the view of schizophrenia.

3.3 Causes of schizophrenia

Causal attributions were classified into the groupings: genetics alone, genetics + environment, and environment alone. Differences in attribution of cause of schizophrenia were seen in the groups selected by sample source (Chi-square = 38.51, $p < 0.0001$), and by affected status (Chi-square = 11.54, $p = 0.003$). More of the Chinese sample attributed schizophrenia to environment alone (98/187, 52%) than did the English-survey sample (28/168, 17%). In contrast, more of the English-survey sample attributed illness to genetics alone (53/168, 32%) compared with the Chinese sample (16/187, 9%). There was no interaction between sample source and affected status in attribution.

3.4 Concern about developing schizophrenia

This analysis revealed an overall difference between Chinese and English-survey respondents, and an interaction between sample source and affected status in concern about developing schizophrenia. Fewer in the Chinese sample (40/195, 21%) were very concerned

about developing psychosis than in the English-survey sample (75/166, 45%, Chi-square = 28.09, $p < 0.0001$). In the Chinese sample, the very concerned response was more common in relatives (22/78, 28%) than patients (18/117, 15%). In contrast, in the English-survey sample the very concerned response was more frequent in patients (24/40, 60%) than relatives (51/126, 40%). This distribution profile was different in the two sample groups (interaction Chi-square = 9.30, $p = 0.002$).

3.5 Impact on family planning

Only one statistically significant difference emerged in this comparison. Chinese respondents were less likely to endorse an effect of schizophrenia on family planning (yes response 42/135, 31%) than English-survey respondents (49/108, 45%, Chi-square = 5.63, $p = 0.02$).

4. Discussion

The study adds to our understanding of how schizophrenia is perceived in China, and provides four preliminary findings in comparing responses from a Chinese sample with a predominantly North American sample. Chinese patients and family members rated schizophrenia as less severe. Chinese patients and families frequently attribute schizophrenia to environmental rather than genetic causes. Although comparatively fewer Chinese respondents were very concerned about developing schizophrenia themselves, or risk in their families, this high level of concern was more common in family members. Finally, Chinese respondents were less likely to indicate that schizophrenia impacted on family planning decisions than were English-survey respondents.

The observation of fewer Chinese respondents rating schizophrenia at the highest level of illness severity is consistent with a WHO-sponsored study on the perceived disability associated with acute psychosis (Ustun et al., 1999). As is commonly observed in studies of disability, patients scored illness as being less severe than did family members (Briggs et al., 2008).

Overall, we observed less concern about developing schizophrenia in the Chinese compared with the predominantly North American sample. Combined with a more frequent attribution of illness to environmental causes among Chinese people, these findings are consistent with a less “genocentric” or biomedical model in China. Lack of health insurance or financial support is likely the greatest single obstacle to care for schizophrenia in China (Phillips et al., 2009). If this can be overcome, awareness of a mismatch between patients’, families’ and medical professionals’ causal explanations for schizophrenia may be an important consideration to encourage engagement with treatment (Phillips et al., 2000). In the relative absence of endorsement of biomedical models of illness among patients and family members, care provided by physicians could benefit from inquiring into the patients’ and families’ ideas about the causes of schizophrenia. This approach could support the development of a mutual understanding that facilitates engagement with treatment and adherence to medication regimes (Kelly et al., 1987).

For those with schizophrenia, or with a sibling or parent with schizophrenia, there was less of an influence of mental illness/psychosis on childbearing decisions in the Chinese sample. These findings must be interpreted with caution. A spouse and child are necessary to provide care after parents die, given the scarcity of alternatives, and the options for family size may be limited by governmental policies in the Chinese sample.

The present study has several limitations. For pragmatic reasons, the data was gathered through direct recruitment in China, and through the internet for the English-survey. This limitation must be balanced against the strength of using the same instrument in both samples, and the moderately large numbers of participants at the different sites. Demographic differences between subgroups in the samples could also influence results. Patients were younger than relatives. The China sample was relatively gender balanced, while the English-survey sample was contained more women, particularly in the relatives group. The latter group also had more members with greater than 12 years of education. Further research involving considerably larger, more homogeneous samples will be needed to clarify if these factors interact with judgments about severity of illness, attributions of cause, and implications for family planning.

In summary, health care in China is undergoing a period of dynamic change (Dong and Phillips, 2008). In a large-scale study carried out in four Chinese provinces, patients with psychotic disorders reported receiving professional help at some time in 70% or more of cases (Phillips et al., 2009). However, ongoing care may not be provided as efficiently (Wang et al., 2007). Continuing engagement with care may be more feasible if patients, the families they almost universally live with, and physicians share a common model of illness. Avoiding deterministic genetic models may be important in preventing worsening of the already high levels of stigma experienced by people with schizophrenia in China (Yang and Kleinman, 2008). The need for long-term psychiatric treatment, involving medication and psychosocial interventions, may be best understood in the context of evidence-based etiological models for schizophrenia that involve individual differences in genetic factors that result in different risk thresholds for environmental influences to precipitate episodes of illness. Better training of primary health-care workers, general physicians, and psychiatrists to provide integrated care, sensitive to the causal attributions of patients and their families will be important to improve treatment of schizophrenia in China.

References

- Austin JC, Smith GN, Honer WG. The genomic era and perceptions of psychotic disorders: genetic risk estimation, associations with reproductive decisions and views about predictive testing. *Am J Med Genet B Neuropsychiatr Genet.* 2006; 1418:926–928.
- Briggs A, Wild D, Lees M, Reaney M, Dursun S, Parry D, Mukherjee J. Impact of schizophrenia and schizophrenia treatment-related adverse events on quality of life: direct utility elicitation. *Health Qual Life Outcomes.* 2008; 6:105. [PubMed: 19040721]
- Dong Z, Phillips MR. Evolution of China's health-care system. *Lancet.* 2008; 372:1715–1716. [PubMed: 18930524]
- Fosu GB. Disease classification in rural Ghana: framework and implications for health behaviour. *Soc Sci Med B.* 1981; 15:471–482. [PubMed: 7323856]
- Kelly GR, Mamon JA, Scott JE. Utility of the health belief model in examining medication compliance among psychiatric outpatients. *Soc Sci Med.* 1987; 25:1205–1211. [PubMed: 2893455]

- Meiser B, Mitchell PB, Kasparian NA, Strong K, Simpson JM, Mireskandari S, Tabassum L, Schofield PR. Attitudes towards childbearing, causal attributions for bipolar disorder and psychological distress: a study of families with multiple cases of bipolar disorder. *Psychol Med*. 2007; 37:1601–1611. [PubMed: 17537283]
- Pearson V. Families in China: an undervalued resource for mental health? *J Fam Ther*. 1993; 15:163–185.
- Phillips MR, Li Y, Stroup TS, Xin L. Causes of schizophrenia reported by patients' family members in China. *Brit J Psychiatry*. 2000; 177:20–25. [PubMed: 10945083]
- Phillips MR, Zhang J, Shi Q, Song Z, Ding Z, Pang S, Li X, Zhang Y, Wang Z. Prevalence, treatment, and associated disability of mental disorders in four provinces in China during 2001–05: an epidemiological survey. *Lancet*. 2009; 373:2041–2053. [PubMed: 19524780]
- Ustun TB, Rehm J, Chatterji S, Saxena S, Trotter R, Room R, Bickenbach J. Multiple-informant ranking of the disabling effects of different health conditions in 14 countries. *Lancet*. 1999; 354:111–115. [PubMed: 10408486]
- Wang PS, Aguilar-Gaxiola S, Alonso J, Angermeyer MC, Borges G, Bromet EJ, Bruffaerts, de Girolamo R, De Graaf R, Gureje O, Haro JM, Karam EG, Kessler RC, Kovess V, Lane MC, Lee S, Levinson D, Ono Y, Petukhova M, Posada-Villa J, Seedat S, Wells JE. Use of mental health services for anxiety, mood, and substance disorders in 17 countries in the WHO world mental health surveys. *Lancet*. 2007; 370:841–850. [PubMed: 17826169]
- Wong GH, Hui CL, Chu ICP, Lam M, Chung DW, Tso S, Chan K, Yip KC, Hung SF, Chen EY. Early detection and intervention of psychosis in Hong Kong: experience of a population-based intervention programme. *Clin Neuropsychiatry*. 2008; 5:286–289.
- Yang LH, Kleinman A. 'Face' and the embodiment of stigma in China: the cases of schizophrenia and AIDS. *Soc Sci Med*. 2008; 67:398–408. [PubMed: 18420325]
- Yang LH, Phillips MR, Licht DM, Hooley JM. Causal attributions about schizophrenia in families in China: expressed emotion and patient relapse. *J Abn Psychol*. 2004; 113:592–602.
- Yang LH, Phillips MR, Lo G, Chou Y, Zhang X, Hopper K. "Excessive thinking" as explanatory model for schizophrenia: impacts on stigma and "moral" status in Mainland China. *Schizophrenia Bull*. 2010; 36:836–845.

Figure 1. Comparison of Chinese and English-survey responses to inquiries concerning schizophrenia

(A) View of schizophrenia: Fewer in the Chinese sample responded “very severe” compared with the English-survey sample ($p < 0.0001$), and in both samples relatives endorsed greater severity than patients ($p = 0.002$). **(B) Causes of schizophrenia:** Differences in attribution of cause were seen in Chinese versus English-survey respondents ($p < 0.0001$) and in patients versus relatives ($p = 0.003$). **(C) Concern about developing schizophrenia:** Fewer in the Chinese sample were very concerned ($p < 0.0001$), and the pattern of concern between patients and relatives differed between the Chinese and English-survey samples ($p = 0.002$). **(D) Effect on childbearing decisions:** Fewer in the Chinese sample responded that the presence of schizophrenia had affected family planning decisions ($p = 0.02$).

Table 1

Demographics

	n	Gender		Age < 25		Age 25 – 50		Age > 50		Education 12 yr		Education > 12 yr	
		Female	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
China	196	115	(59)	66 (34)	104 (53)	25 (13)	86 (44)	109 (57)					
Patient	118	75	(64)	54 (46)	62 (53)	2 (2)	47 (40)	71 (60)					
Relative	78	40	(51)	12 (15)	42 (54)	23 (29)	39 (50)	38 (49)					
English-survey	169	123	(73)	35 (21)	102 (60)	26 (15)	43 (25)	119 (70)					
Patient	42	22	(56)	17 (40)	22 (52)	0 (0)	16 (38)	21 (50)					
Relative	127	101	(80)	18 (14)	80 (63)	26 (20)	27 (21)	98 (77)					