

Is the outcome of schizophrenia really better in developing countries?

O prognóstico da esquizofrenia é realmente mais favorável nos países em desenvolvimento?

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Abstract

That schizophrenia has a better prognosis in non-industrialized societies has become an axiom in international psychiatry; the evidence most often cited comes from three World Health Organization (WHO) cross-national studies. Although a host of socio-cultural factors have been considered as contributing to variation in the course of schizophrenia in different settings, we have little evidence from low-income countries that clearly demonstrates the beneficial influence of these variables. In this article, we suggest that the finding of better outcomes in developing countries needs re-examination for five reasons: methodological limitations of the World Health Organization studies; the lack of evidence on the specific socio-cultural factors which apparently contribute to the better outcomes; increasing anecdotal evidence describing the abuse of basic human rights of people with schizophrenia in developing countries; new evidence from cohorts in developing countries depicting a much gloomier picture than originally believed; and, rapid social and economic changes are undermining family care systems for people with schizophrenia in developing countries. We argue that the study of the long-term course of this mental disorder in developing countries is a major research question and believe it is time to thoroughly and systematically explore cross-cultural variation in the course and outcome of schizophrenia.

Keywords: Schizophrenia; Cross-cultural comparison; Developing countries; Human rights abuses; Prognosis

Resumo

O fato de que a esquizofrenia possui um melhor prognóstico em sociedades não industrializadas tornou-se um axioma na psiquiatria internacional; as evidências mais comumente citadas provêm de três estudos trans-nacionais da Organização Mundial da Saúde (OMS). Ainda que um conjunto de fatores socioculturais tenha sido considerado como contribuinte para o curso da esquizofrenia em diferentes ambientes, possuímos poucas evidências de países de baixa renda que demonstrem claramente a influência benéfica dessas variáveis. Neste artigo, sugerimos que o achado de melhores desfechos em países em desenvolvimento necessita ser reexaminado por cinco razões: falhas fundamentais nos estudos da Organização Mundial da Saúde; a falta de evidências sobre os fatores socioculturais específicos que contribuem aparentemente para os melhores desfechos; as crescentes evidências incidentais que descrevem o abuso dos direitos humanos das pessoas portadoras de esquizofrenia nos países em desenvolvimento; novas evidências de coortes em países em desenvolvimento descrevendo um quadro muito mais sombrio do que se pensava originalmente; e as rápidas transformações sociais e econômicas estão enfraquecendo os sistemas de atenção familiares para pessoas com esquizofrenia nos países em desenvolvimento. Afirmamos que o estudo do curso de longo prazo desse transtorno mental é fundamental e acreditamos que é tempo de explorar completa e sistematicamente a variação transcultural no curso e no desfecho da esquizofrenia.

Descritores: Esquizofrenia; Comparação transcultural; Países em desenvolvimento; Violações dos direitos humanos; Prognóstico

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Financing: None

Conflict of interests: None declared

Submitted: 9 November 2005

Accepted: 9 November 2005

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That schizophrenia has a better prognosis in non-industrialized societies has become an axiom in international psychiatry. The most compelling evidence for this comes from three cross-national studies conducted by the World Health Organization: the International Pilot Study of Schizophrenia (IPSS),¹ the Determinants of Outcome of Severe Mental Disorder (DOSMeD),² and their successor, the International Study of Schizophrenia (ISoS).³⁻⁴ The DOSMeD project, in particular, represented the most ambitious and methodologically sophisticated of these efforts in that the investigators attempted to identify, over a period of two years, all persons suffering from the first onset of schizophrenia in 13 catchment areas located in 10 different countries. The most striking finding in all of this research was 'the existence of consistent and marked differences in the prognosis of schizophrenia between the centres in developed countries and the centres in developing countries'.² The DOSMeD investigators then went on to note that the greatest contribution of their research was 'not in providing the answer[s]' but in delineating questions about how 'societies and cultures shape the process of illness'.²

This is the DOSMeD challenge,⁵ but it has not been taken up. Although a host of sociocultural factors have been cited as contributing to variation in the course of schizophrenia in different settings: family support and styles of interaction, industrialization, and urbanization, in particular,⁶ we have little evidence from low-income countries that clearly demonstrates the beneficent influence of these variables. Indeed, the DOSMeD research did not provide any direct sociocultural evidence to support its conclusions.⁵ Yet, its findings and the evidence on which they were based, have hardly been questioned.

This lack of critical assessment is curious, particularly when later analyses of the DOSMeD and ISoS data have pointed to a number of problems. For example, and true to earlier critiques of the developing/developed world categories,^{5,7} one set of secondary analyses of data from DOSMeD revealed that although location, in general, was associated with patterns of course, two sites in the developed world (Prague and Nottingham) had outcomes that were similar to those in the developing world, and outcomes in one developing world site (Cali) were similar to those found in the developed world sites.⁸ A 15-year follow-up of subjects in the DOSMeD sites confirmed the anomalous outcomes in Prague and Nottingham.³ The most robust finding from these later analyses was that long-term outcome was best predicted by 'measures of early course,' and while setting was associated with better chances of recovery the 'precise nature of these setting- or culture-specific effects remains to be unraveled'.³

Thus, one is left with only questions about the 'better outcomes' hypothesis. Following the cautions of Edgerton and Cohen,^{5,7} the DOSMeD and ISoS investigators readily admitted that the 'black box' of culture remained closed, and that the socio-cultural factors which may influence outcome in schizophrenia had not been revealed.^{3,8-9}

We suggest that the apparent finding of a better outcome in developing countries needs further re-examination for five major reasons: 1) methodological limitations of the DOSMeD study; 2) the lack of evidence on the specific socio-cultural factors which apparently contribute to the better outcomes; 3) increasing anecdotal evidence describing the abuse of basic human rights of people with schizophrenia in developing countries; 4) new evidence from cohorts in developing countries depicting a much gloomier picture than originally

believed; and, 5) rapid social and economic changes are undermining family care systems for people with schizophrenia in developing countries.

Even though DOSMeD has been cited as the 'single most important...finding' in cross-cultural psychiatry,¹⁰ it suffered a host of methodological problems: 1) while pointing to differences in outcome as significant, the investigators downplayed significant cross-national variation in the incidence of broadly-defined schizophrenia or cultural differences in subtypes of the disorder, and chose to place an overwhelming emphasis on universal aspects of schizophrenia, i.e., the lack of variation in the incidence of narrowly-defined schizophrenia and the stability of the disorder at the syndrome level;¹¹ 2) the multidimensional measures of outcome and course lacked validity as variables such as percentage of the follow-up period spent in the hospital or on psychotropic medication reflected differences in socioeconomic environments rather than variations in course of illness; 3) the failure to account for the much higher attrition rates in the developing country sites; and, 4) the unfounded claim that case ascertainment problems at five of the sites (Ibadan, Moscow, Rochester, Agra, and Prague) would have been 'of little consequence' regarding 'the clinical...characteristics of the patients'.² Because the validity of schizophrenia research depends, to a large extent, on whether all cases are identified in a defined population over a fixed period of time,¹² this last point suggests a key limitation of the DOSMeD findings.⁷

At the same time, we have a great amount of evidence that would make us expect that course and prognosis for schizophrenia might be *worse* in low-income countries. We know, for example, that severe stigma, lack of treatment, and human rights abuses in large custodial asylums – all of which are well-documented in many low-income countries – are associated with poor course and outcome. Even though landmark reports on the state of mental hospitals in South and East Asia¹³⁻¹⁴ have described grotesque conditions of care and violations of human rights, there has been little movement to reform many of the hospitals. Nor are human rights abuses restricted to mental hospitals. The Erwadi tragedy in South India in 2001, in which more than 20 persons with mental illness were burned to death when a fire swept one of the treatment shelters near the healing mosque where they were chained to their beds, is an example of the rights abuses which take place under the guise of local medicine.¹⁵

In contrast to any notions of better outcomes, recent investigations have reported unusually high mortality rates in developing countries among persons with schizophrenia. In the 15- to 25-year outcome studies of schizophrenia across different countries, the proportion of subjects who died or were lost to follow up ranged from 23% in Chennai to over 50% in the Chandigarh and Agra centres in India; it is worrying that such a large number of persons could not be traced in the two Indian centres.³ In a 20-year study in South India, mortality for the cohort was high, (17%) and the average age at death was only 34.2 years compared to 60.5 years, the average life span in India at that time. Suicides – all by persons younger than 35 years – accounted for nearly half of all deaths (7 of 16).¹⁶ The paradox of a better symptomatic outcome in developing countries was also exemplified in the results of the earlier IPSS.¹⁷ Even though a better 2-year clinical outcome was reported for patients from developing countries, at the 5-year follow-up, the percentages of patients in Agra (India) and Ibadan (Nigeria)

who had died were 9.0 and 7.1, respectively, compared with 4.9% for the entire study cohort. A recent epidemiological study from Ethiopia confirmed high rates of mortality for persons with schizophrenia: over 10% of subjects with schizophrenia died during a follow up period of 1 to 4 years.¹⁸

Other research provides evidence that contradicts the 'better prognosis' hypothesis. In Nigeria, a study looked at long-term social outcomes among a group of persons with schizophrenia who were receiving outpatient care. Contrary to the expectation that traditional family networks and supports would buffer these patients against drifting down in socioeconomic status, these patients continued to experience severe social disabilities in multiple domains.¹⁹ Investigations in a rural district of Ethiopia have also suggested that the course of schizophrenia may not be particularly benign in the developing world. While functional status was found to be relatively high in persons with schizophrenia, this was primarily because they had full-time employment working in the fields. At the same time, however, most were actively psychotic and had experienced continuous symptoms since the onset of illness.²⁰ These initial findings were later supported by a prospective study which found persistently high levels of symptomatology and disability after an average of 2.5 years.¹⁸

In Chennai (Madras), India, a 20 year prospective study of 90 persons with schizophrenia also provides evidence that undermines the 'better prognosis' hypothesis. While a 10-year follow-up revealed a 'steep decline' in both positive and negative symptoms in the cohort, and that families were supportive and caring, the 'predominant pattern' of course was repeated psychotic episodes which were not always followed by remission.²¹ This same pattern was found at the 20-year follow-up.¹⁶ Furthermore, as noted above, this cohort was subjected to high rates of mortality and suicide.

Ethnographic evidence from Chennai also provides evidence that is at variance with the view that 'traditional' societies in developing countries are necessarily tolerant and supportive of persons with severe mental disorders. A study of women with schizophrenia whose marriages had broken revealed a number of disturbing aspects about their lives.²²⁻²³ They were the objects of 'hostile and very negative attitudes' of other family members, held no jobs, and received no support from their husbands.²³ Furthermore, the women were 'ridiculed and ostracized' for both being mentally ill and divorced or separated.²²

Evidence from surveys also suggests that persons with psychosis do not live in societies that necessarily promote recovery. In the late 1970's, research revealed widespread stigma toward persons with severe mental illness, and conjectured that such attitudes were responsible for the 'not uncommon' sight of 'mentally ill people roaming the streets in tattered dresses or even naked'.²⁴ More than 25 years later, another survey of community attitudes found that a broad cross section of the population held extremely negative views of mental illness, believing that mentally ill persons were dangerous.²⁵

Thus, we are left with the DOSMeD Challenge⁵ to investigate the social and cultural factors that may influence both the short- and long-term course and prognosis of schizophrenia. The question of the course and outcome of schizophrenia in developing countries is profoundly important for two reasons. First, it helps generate vital information regarding the health needs of people, and families, affected by this disorder which, in turn, may influence health policies. Secondly, such data

can help illuminate the role of sociocultural factors in influencing the prognosis of this severe mental disorder and, thereby, offer insights into possible intervention strategies of potential universal applicability. Furthermore, developing countries are undergoing enormous sociocultural and health status changes that may be of relevance to the occurrence and outcome of psychotic disorders. Migration, urbanization, changes in family structure and supportive networks, increasing economic insecurity, increasing global competitiveness in employment opportunities, widening social inequalities, and growing privatization of health care may profoundly influence the course and outcome of schizophrenia.

During the last 30 years, cross-cultural psychiatry has embraced, almost without question, the notion that the prognosis for schizophrenia is better in low-income countries than in the wealthy countries of the West. Close examination of the evidence, however, suggests a surprising, collective willingness to accept what must be considered, at least by us, unconfirmed beliefs about the perniciousness of the modern and the beneficence of the traditional. Those beliefs notwithstanding, we believe it is time to investigate these questions systematically. Echoing a sentiment that one of us expressed some years ago,⁷ McGrath²⁶ has suggested, 'variations (in the incidence) should be seen as valuable opportunities to generate and test novel candidate exposures'. We think the same applies to the study of the long-term course of outcome of this mental disorder and believe it is time to thoroughly and systematically explore cross-cultural variation in the course and outcome of schizophrenia.

Acknowledgements

The first author is supported by a Wellcome Trust Senior Clinical Research Fellowship in Tropical Medicine.

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