

Dispelling a myth: developing world poverty, inequality, violence and social fragmentation are not good for outcome in schizophrenia

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Abstract

The WHO multi-site studies of schizophrenia concluded that course and outcome of the disorder was better in developing countries. This has become psychiatric lore. However, the reality is that significant political, social and economic ills that characterize many countries in Africa, Latin America and Asia constitute psychosocial stressors that mediate strongly against better outcome in individuals living with this disorder. Outcome studies of schizophrenia in developing countries are reviewed and concepts of poverty, inequality and violence in relation to the course of the illness in this context are debated. The generally poor state of mental health services and policies in these regions are discussed. The belief that community and family life in the developing world is widely intact and that it provides a nurturing environment that facilitates recovery and promotes social and economic empowerment of seriously mentally ill individuals is dispelled as a myth. Idealisation of the under-developed South as a haven for schizophrenia sufferers will only add to the already heavy burden experienced by these individuals, their families and these societies in coping with this disabling disease.

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Introduction

Beginning in the late 1960s, the World Health Organization (WHO) began a series of studies of schizophrenia at multiple sites in both 'developed' and 'developing' countries. The International Pilot Study of Schizophrenia (IPSS)¹, the Determinants of Outcome of Severe Mental Disorders (DOSMeD) or Ten-Country Study² and the International Study of Schizophrenia (ISoS)³ have found consistently that the outcome of schizophrenia is better in developing countries than in developed countries. These studies have been hailed as epidemiological triumphs and this result

described as "the single most important finding of cultural differences in cross-cultural research on mental illness."⁴

While the finding of improved outcome has been critiqued on the basis of definitions of 'developed' versus 'developing', diagnostic ambiguities and methodological biases^{5,6,7}, it has withstood three decades of scrutiny and is regarded as something of an 'axiom' in psychiatric lore. However, recent reviews and analyses of other (non-WHO) studies of outcome have questioned the axiom and suggested that this issue be revisited.⁷

Interestingly this doubt is occurring in the context of another challenge to established epidemiological beliefs about schizophrenia – a belief also emanating from the WHO studies – namely that the incidence of schizophrenia is constant worldwide. McGrath and colleagues have reviewed new data that points to significant variability in incidence rates in relation to variables such as geographical site, urban

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versus rural location, immigrant status and socio-economic status.⁸ Other studies have reported variability in incidence in relation to ecological measures of income inequality.^{9,10} In the face of such findings, McGrath has argued that we should be "slaves to the data" rather than ideologically clinging to old dogma and that the new epidemiology of schizophrenia "is fertile ground for the generation of new hypotheses."¹¹

The purpose of this paper therefore is to revisit the issue of 'better outcome' by 'looking at the data' in the context of the significant political, social and economic ills that we know characterize many countries in the so-called 'developing world.' The paper debates concepts of poverty, inequality, violence and 'under-development' in relation to the course of the illness. It argues that the commonly held belief that community and family life in the developing world is widely intact and that it provides a nurturing environment that facilitates recovery and promotes social and economic empowerment of seriously mentally ill individuals cannot be supported. Finally the paper maintains that holding onto beliefs such as these will only add to the already heavy burden experienced by these individuals, their families and these societies in coping with this disabling disease.

The WHO studies

The International Pilot Study of Schizophrenia (IPSS) was initiated in 9 countries and included a total of 1202 patients recruited from consecutive admissions to psychiatric facilities.¹ In this sense it was not a truly representative sample. Follow-up at 2 years¹, 5 years¹² and 10 years^{13,14} indicated better clinical and social outcomes for patients living in developing countries (as compared with those in developed countries.)

The Ten-Country Study or the Determinants of Outcome of Severe Mental Disorders (DOSMeD) was a first-episode incidence study conducted by the WHO at 12 sites.² The authors concluded their report by stating that DOSMeD "replicated in a clear and, possibly, conclusive way the major finding of the IPSS, that of 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

Finally, the International Study of Schizophrenia (ISoS) included 1633 patients comprising 14 treated incidence cohorts and 4 prevalence cohorts from culturally diverse sites in 12 countries.^{15,16} At 15 years, Hopper and Wanderling showed that the finding of a consistent outcome differential favouring the developing countries remained robust and remained significant when strict ICD criteria were applied as well as when 'broad' versus 'narrow' definitions of schizophrenia were used.¹⁶ These authors argue that the ISoS analyses dealt adequately with various possible sources of bias in the previous studies and that such bias could not account for the differences in outcome.

Critiques of the WHO studies

As early as the first publication of outcome results from the IPSS, the WHO schizophrenia studies have drawn criticism.^{5,17,18} These critiques were responded to vigorously in print.^{19,20} As Williams states, "the organization [WHO] and

its investigators have always been sufficiently empowered to meet any challenge to their reputation as leaders in the field of international research."⁶

Early criticisms concerned issues of methodology, essentially arguing that some patients recruited in developing country sites did not necessarily have schizophrenia.²¹ For example, it has been argued that there is a 10-times higher rate of an acute psychotic illness with rapid complete remission termed 'nonaffective remitting psychosis' (NARP) in developing countries²², and that cases of NARP were misdiagnosed in the WHO studies as schizophrenia. Furthermore, in the IPSS cohort, a 'broad' definition of schizophrenia was used; and it is quite possible that individuals with affective psychoses may have been included in developing countries. The IPSS was also criticized for relying on hospital admissions for recruitment as it was argued that a sample bias would exist when many patients in developing countries may not have easy access to services.⁵ Other problems included high attrition rates and loss to follow-up (especially at developing sites) as well as differences in severity, chronicity and mode of onset of illness across the sites. Regarding the DOSMeD, Edgerton and Cohen expressed major skepticism about the representativeness of the so-called 'developing country' sites – they state: "But one thing is obvious. These five centres do not begin to represent the full range of social or cultural diversity in what might be called the developing world, nor can they be said to be typical of that world."⁵ They also point out the significant social, economic and cultural variability among the so-called 'developed country' sites. Finally they question the very distinction of 'developing' and 'developed' countries – an issue that has been debated greatly during the ensuing two decades.

Hopper and Wanderling¹⁶ maintain that ISoS addressed these methodological issues and eliminated six potential sources of bias. They conclude that "none of these potential confounds explains away the differential in course and outcome" and that the robustness of the differential "is generally taken as *prima facie* evidence for the relevance of "culture" in influencing course and outcome of schizophrenia."

The issue of 'culture' certainly came to the fore as a means of explaining the apparent better outcome in developing countries. Bresnahan and colleagues write "It appears, therefore, that some aspect of the economic or cultural circumstance in developing countries may provide a more therapeutic context for recovery."²³ According to these authors, the most commonly proposed explanations fall into four categories:

1. Family relationships may be more conducive to recovery in developing countries.²³⁻²⁵
2. In developing countries informal subsistence economies may provide diverse opportunities for reintegration of patients into work roles.²⁶
3. Individuals with mental illness are less likely to be segregated within institutions in developing countries and the mentally ill are less stigmatized in developing countries.
4. There is better community cohesion in developing countries creating opportunities for greater social integration and less isolation.

Non-WHO data on outcome

One of the criticisms of the WHO studies and the seemingly unchallengeable belief in 'better outcome' is that the sites regarded as representative of 'developing countries' were few and were hardly representative of the 'developing world.' Only one African country and one Latin American country featured in the IPSS and the DOSMeD, while the ISoS relied solely on Indian sites and Hong Kong as representative of developing countries. Cohen and colleagues addressed this obvious problem in a review of 23 longitudinal studies of schizophrenia from 11 countries defined as low- and middle-income by the World Bank.⁷ These countries included 3 in Africa (Nigeria, Ethiopia and South Africa), 2 in South America (Brazil and Colombia), 2 in the Caribbean (Jamaica and Trinidad), 3 in Asia (India, China and Indonesia) and 1 in Eastern Europe (Bulgaria.) To provide a basis for comparison, these authors included developing world sites from both the DOSMeD and the ISoS. Studies were both prospective and retrospective, included first-episode and prevalent cases, had follow-up periods ranging from 1 to 20 years and drew samples from a variety of settings (outpatient clinics, hospital samples and communities.) Thus, the review by Cohen and colleagues provided evidence from a much wider range of countries than the ISoS and took a more critical stance in regard to the evidence. In a comment on this review, Bromet expresses concern that methodological variability between studies included in the review may account for the various outcomes described.²⁷

Interestingly, marked variation in outcome was demonstrated and patterns of course were noted to change over time. Specifically, although relatively few individuals experienced chronic symptoms, over time the majority experienced relapse, especially in the Chennai sample. Disability and social outcomes tended to be better in India and Indonesia and worse in China, Brazil and Ethiopia. Marital failure was high in Brazil, Ethiopia and Nigeria while unemployment was highest in Brazil, Ethiopia and Indonesia. Studies from China, Ethiopia, India (Chennai) and Indonesia reported high percentages of subjects who had never received biomedical treatment (with long duration of untreated psychosis) and this was associated with poor outcome. Cohen and colleagues⁷ argue that this evidence suggest that good outcome cannot be assumed for schizophrenia in low- and middle-income (LMI) countries – a belief popularized by the WHO studies. These authors also address the issue of mortality and show markedly higher mortality rates in people with schizophrenia in LMI countries compared with the general population.^{28,29,30} High attrition due to mortality is likely to distort measures of long-term outcome in these contexts, as Ran and colleagues³⁰ suggested in China. Cohen and colleagues⁷ also express their skepticism about the perceived positive role of family and the relative lack of stigma in 'developing countries' as is usually assumed. In African and Asian sites particularly research has identified a breakdown of family support and high levels of stigma which are believed to be associated with the risk of families abandoning mentally ill members.^{31,32}

Finally, Cohen and colleagues criticize the case-finding methods of the WHO studies that focused exclusively on help-seeking agencies, pointing out that, in the absence of community surveys, these studies are likely to have missed

large proportions of seriously ill, poor prognosis individuals. This omission of poor outcome subjects is likely to have been a critical flaw that may well have skewed the perception of outcome in 'developing world' contexts. Cohen and colleagues⁷ conclude their review by arguing that it is time to revisit the 'better outcome' hypothesis and that clinical, epidemiological and ethnographic research are required to resolve this question. A close understanding of how sociocultural and psychiatric processes interact is necessary if we are to truly understand outcome in low- and middle-income countries and limit the potential damage of expanding globalization.

A skeptical view of 'better outcome'

It seems then that a healthy dose of skepticism is called for in judging the validity of this axiom of psychiatric knowledge. Gureje has reminded us that much of the psychiatric literature of Africa is inescapably influenced by colonial stereotypes and political agendas.³¹ Importantly these political agendas did not disappear with the end of colonialism – indeed many would argue that 'western' interests and agendas within the 'developing world' are as vigorous now as they were during the colonial era.³³ Many a myth about psychiatry in Africa – built on little data and lots of prejudice – has been dispelled within recent decades. As Gureje writes: "The short but impressive path that psychiatry has traversed in Africa is littered with the splinters of broken myths."³⁴ And so, in re-examining the evidence for 'better outcome' in 'developing countries', it is important that we consider the part played – consciously or unconsciously – by political agenda and underlying prejudice. The attribution of the 'better outcome' finding to 'cultural' factors such as family cohesion, social integration and a relative absence of stigma is, superficially, complimentary of 'developing world' socio-cultural practices. However, one could argue that the unstated opinion of the WHO authors regarding such societies is that these nations are simple, unsophisticated and exist as some sort of idyllic paradises for the optimal recovery of the mentally ill. And so, rather than being complimentary, these assertions are in fact patronizing and, as Williams argues, "this dichotomy has served largely to reinforce the sophistication of the outsiders and to justify power relations currently in place."³⁶

In the absence of truly culture-sensitive epidemiological research that is relevant to context, flexible so as to accommodate variability, and 'deep' enough to measure and describe all aspects of outcome, it seems reasonable to speculate and to draw on anecdotal evidence in attempting to judge true outcome of schizophrenia in low- and middle-income country contexts. It also seems reasonable to draw on data which could be described as parallel to the main subject of focus – that is not specifically focused on outcome – but nevertheless informative to the question at hand. Some of these include:

- Low- and middle-income (LMI) countries are largely characterized by high levels of poverty, income inequality and violence, all of which have been associated with increased incidence and worsened prognosis of serious mental disorders.^{35,36} Living in poverty is associated with lack of education, lack of financial resources, inability to access health services, high levels of co-morbid disease and substance abuse and exposure to multiple stressors.

Income inequality is significantly associated with poor health outcomes³⁷ and has been associated with increased incidence of psychosis.¹⁰ These factors all bear relevance on the issue of outcome of schizophrenia in LMI countries and one would assume that together, these social ills militate against favourable outcome.

- LMI countries are amongst the most deprived countries in the world in terms of the state of development of their mental health services.³⁸ In general these countries fall far below recommended international norms for all categories of mental health professional; they lack decentralized mental health services; they have few specialist services such as child and adolescent mental health programmes; most of them cannot afford new generation antipsychotic drugs; in many cases they lack truly patient-centered mental health legislation; and they are weak on health prevention and education initiatives. In this context it is unlikely that individuals with incipient schizophrenia are likely to receive early detection and intervention, broad biopsychosocial treatment (including optimal psychotropic medication), timely management of co-morbid substance abuse³⁹; adequate follow-up and healthy reintegration into occupational and social roles.
- The belief that community and family life in the developing world is widely intact and that it provides a nurturing environment that facilitates recovery and promotes social and economic empowerment of seriously mentally ill individuals must be questioned. We have seen that longitudinal studies of schizophrenia in LIM countries suggest a significant degree of social disintegration, alienation of the mentally ill, stigma and even abuse.^{7,40} Within the last decade, major human rights enquiries have revealed appalling human rights abuses within psychiatric institutions in both India⁴¹ and South Africa.⁴² Furthermore, in these same countries, abuse of the mentally ill continues to occur within community settings.^{43,44} In a special report for TIME Magazine in November 2003, the plight of the mentally ill in Asian countries such as China, Cambodia, Indonesia, Pakistan and Japan is addressed.⁴⁵ In this region of the 'developing world', psychiatric facilities are very often inadequate, large numbers of patients remain hidden away at home due to stigma and most cannot afford treatments due to high costs. Suicide rates are high and psychiatry and mental illness are taboo concepts. Finally, the burden on families within the 'developing world', already struggling with basic survival needs, is great⁴⁶ – support for families and caregivers is generally non-existent.
- It could be argued that tardive dyskinesia (TD) is a proxy 'marker' of outcome in patients with schizophrenia. TD has many risk factors but it is clear that the injudicious chronic use of classic high-potency antipsychotics is one of the major causes of TD. This unfortunate syndrome can largely be avoided where early intervention, accurate diagnosis, adequate management of comorbidity and good follow-up are provided. A large analysis of outpatients with schizophrenia in Africa, the Middle East, Asia, Eastern Europe and Latin America (including a total of 6981 patients) found a point prevalence of TD of 9%.⁴⁷ This is significantly higher than rates reported for patients on atypical antipsychotics in developed world contexts.⁴⁸

While it is well recognized that there is less risk of TD with the use of atypical antipsychotics, this complication is also not an inevitable outcome of classic antipsychotic therapy. A high prevalence of TD in LMI countries does not just reflect the widespread use of classic antipsychotics in these patients – rather it reflects poor management and mental health care provision at all stages of the course of the illness.

- As discussed earlier, mortality rates for patients with schizophrenia have been shown to be higher in developing countries as compared with developed countries^{29,30} (although the meta-analysis by Saha and colleagues²⁸ did not confirm this finding.) Nevertheless, this fact is starkly in contrast to notions of 'better outcome' as one can assume that the same conditions that give rise to increased death in patients living with schizophrenia in the community are likely to contribute to poorer general health status.

Discussion

A lesson that might be learnt from the re-examination of 'established facts' and axiomatic truths within psychiatry is that all research – no matter how rigorous and objective the methods – is contextual and is vulnerable to biases, conscious and unconscious. No scientist operates in a social, political and cultural vacuum. The very formation of an hypothesis is a value-laden process and every objective hides an agenda. And conducting research in a 'cross-cultural' landscape is an exercise particularly prone to these kinds of risks. Concerning the WHO studies of schizophrenia, there is no question that the entire project spanning 3 decades was an impressive and ground-breaking step in epidemiological research. However, when a specific finding acquires the status of axiom or textbook fact, it must be scrutinized in an uncompromising fashion – as McGrath states, we must leave the dogma and return again and again to the facts.¹¹ The difficulty with this question of outcome in 'developing countries' is of course the reality that we do not have much data to work with. This in itself is an indication of the difficulties of delivering good psychiatry and mental health care in these contexts. The dearth of reliable evidence from LMI countries is a reflection of a whole array of deficiencies that characterize psychiatric service provision in the 'developing world.' There are too few psychiatrists and other mental health professionals, there are outdated and sparsely resourced facilities and there is little money dedicated to mental health care. It is no surprise then that there is little research relative to the 'developed' nations of the North.

With the data that we do have on outcome – data emanating not just from India, but also from Africa, Latin America and Asia – we see that the facts (when scrutinized carefully) do not actually support the 'better outcome' hypothesis. While the investigators of the ISoS are strenuous in their contention that this study redressed all the methodological flaws and possible sources of bias attributed to the earlier WHO studies, it is fair to argue that even the ISoS was not water-tight. For example, this author remains skeptical as to the truly representative nature of the sample. It is well recognized by psychiatrists working in LMI countries that in contexts of scarce resource, it is very often only the

acutely psychotic and socially disruptive patients that access the health services. Those individuals with an insidious onset, often characterized by a long duration of untreated illness, marked social and occupational decline, prominent negative symptoms and a dependence on traditional sources of health care, very often fail to access formal medical services. For example, a community study in Bali revealed that patients with schizophrenia who had never received treatment were far less likely to have a history of violent behaviour.⁴⁹ These authors state that "the motivation for seeking help from psychiatric treatment in schizophrenic patients arose only after violent behaviour was observed." They further note the higher percentage of assaultive behaviour observed in first-contact patients in developing countries (compared with developed countries)⁵⁰ and suggest that this difference reflects the relative lack of non-violent patients with less severe symptoms gaining access to psychiatric services. Further evidence from China and India confirms the association between a never-treated status among people with schizophrenia and their poor clinical condition.^{51,52}

Furthermore, where psychiatric services are so often centralized far from the communities in which patients live, follow-up is difficult and many patients are lost to ongoing care. Cohen and colleagues⁷ stressed the significance of this reality and observed that mortality is high in patients with schizophrenia in LMI countries. In regions of high HIV infection and AIDS (where only a minority of those infected receives anti-retroviral therapy) patients with schizophrenia are at enhanced risk of contracting this disease.⁵³ The impact of the HIV-AIDS pandemic in Sub-Saharan Africa on outcome in individuals living with schizophrenia has not been measured to a great extent (but see Collins and colleagues⁵⁴ for an exception.) But it is likely to be a major factor that adds to the already pessimistic view on outcome in this particular context.

Finally, this discussion would not be complete without giving some consideration to an argument that might be phrased as follows: 'The benevolent worlds in which these studies were conducted have been destroyed in the past 25 years by economic changes and globalization – thus accounting for a more pessimistic view of outcome in the present age.' This possibility cannot easily be discounted as it represents an hypothesis that cannot be tested. We know that LMI countries have undergone considerable social and economic change since the first WHO study was conducted and outcome now may differ from outcome then. Nevertheless, even if this is the case, the questioning of the axiom of 'better outcome' remains a valid exercise in search of scientific truth.

Conclusion

It may have been somewhat reassuring for the psychiatric profession to believe that somehow the fantasy of the simple, unsophisticated, tranquil nature of life in the 'developing world' is a haven in which patients with schizophrenia are nurtured and achieve levels of recovery unheard of in the 'developed world.' The truth however is likely to be very different. We lack real facts to be conclusive on this issue. Further research in a diverse array of contexts that are truly representative of the 'developing world' (if such an entity really exists) is required to clarify this matter. Such research

must be firmly located and 'owned' by local investigators familiar with their own communities and sensitive to local social and cultural patterns of life, idioms of distress and realities of mental health service provision. 'Deep' ethnographic and qualitative longitudinal observation must accompany the standard quantitative measurement of data. Without this, this vexing question is unlikely to be answered and myths will continue to hold the status of facts. Finally, the perpetuation of this particular myth is arguably damaging for people living with schizophrenia in the 'developing world.' Idealization of the under-developed South as a haven for schizophrenia sufferers will only add to the already heavy burden experienced by these individuals, their families and these societies in coping with this disabling disease. The widespread acceptance of the 'better outcome' axiom could quite feasibly lead to complacency and become ammunition for those who might argue that the expansion and development of psychiatric services are not urgently necessary in developing countries. Given the desperate need for better mental health care in these regions of the world, such misperceptions and manipulations of the truth undoubtedly would have devastating consequences for all those suffering mental disorder.

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