Is Prognosis in the Individual, the Environment, the Disease, or What?

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This wonderful title was suggested by Will Carpenter. It provides a perfect context for considering the problem of prognosis in general, and more specifically, the report by Cohen et al. on the question of cultural differences in prognosis.

Often unrecognized currently, prognosis has for centuries been one of the foundations of scientific medicine. Hippocrates, Sydenham, and in psychiatry, Kraepelin, utilized prognosis as the basis for identifying disease processes. This contrasted strongly with the tendency to use the clinical picture or “syndrome” at one moment in time as the basis for defining various diseases. In fact, Kraepelin put together 3 very different syndromes, considering them one disease (dementia praecox) because of what he believed to be their common inexorable downhill course. Aside from its use for identifying disease processes, prognosis also serves as a basis against which treatment effectiveness can be measured and for identifying healing processes. In fact, prognosis demonstrates how the use of a longitudinal perspective can provide one of the major ways of understanding many major aspects of disease and disorder.

And what a neat idea that is. In the medical world where the striking syndrome “dropsy” (generalized bodily swelling) was shown over time actually to represent several very different pathological processes involving the kidney, heart, or other organs, the dependence on syndromes alone to identify separate diseases was shown to be grossly inadequate and often misleading. Perhaps, it is because of the power of prognosis and its serving as a base for so many of our medical concepts that there has been so much resistance to recognizing that ‘schizophrenia’ (derived from Kraepelin’s original concept of dementia praecox) in fact has a diverse range of courses and outcomes. Since our early report on this diversity over 30 years ago using measures of demonstrated reliability, there have been well over 20 studies carried out in many different centers showing the prognostic diversity of schizophrenia no matter the choice of diagnostic criteria, the measurement techniques for defining outcome, or the length of follow-up. Even Kraepelin who was an excellent observer raised a question about his theory at one point. Nevertheless, many mental health professionals continue to be taught and to believe that schizophrenia is invariably chronic and very often involves an inevitable deterioration. Incredible!

No, the desire for a simple model of prognosis in schizophrenia, as laudable as that might be in the abstract, has not been confirmed by scientific study. So, where did we go wrong? And, more specifically regarding the report of Cohen et al., what can we learn from cross-cultural studies about the determinants of and the issues involved in understanding the course and outcome of schizophrenia?

To begin at the beginning, what might account for the diversity of outcome that has been found? Biological factors such as genetic differences of course may play a role. But there is little data to suggest exactly how that might operate. Environmental factors perhaps? And this is where the international studies have been particularly important with their suggestions regarding cultural differences. Of course, once we let in cultural factors, the way is open for other environmental factors, social class as well as suggested in the 1950s and 1960s, and another variable that became politically incorrect in the 1970s, family environmental factors. There are other potential environmental factors as well, such as the availability and efficacy of treatment and rehabilitation, programs focusing on “recovery” and reinsertion into the community, employment, and housing possibilities, etc.

One variable strikingly lacking from these more traditional biological and social considerations is the possible role of the individual in affecting the course and outcome of disorder. This variable too can be “politically incorrect” either from the point of view of the danger of “blaming the patient” for example if he or she does not improve or from the deviation involved in considering the patient’s role from a narrow, sometimes considered “more rigorous,” version of the medical model. That narrow version suggests that the disease, and perhaps treatment and environment, more or less alone are the key factors in determining prognosis. My own unrecognized acceptance of such a narrow version of the medical model was first severely challenged when a patient who was a subject in a longitudinal study we were conducting suddenly said to me, “Why don’t you ever ask me what I do to help myself?” Subsequently Alan Breier and
Strauss began to try to answer that question, and it continues to be a focus of my efforts (eg, ) because it appears to me to be such an important part of understanding of the processes of disorder and their prognosis.

In considering the possibility of cross-cultural factors in the report by Cohen et al., we focus on the social realm of the triad, biologic, social, and personal. The report demonstrates that in understanding social factors, the problem begins with measurement and the interpretation of that measurement. In the International Pilot Study of Schizophrenia (IPSS) which marked one of the earliest systematic cross-cultural investigations, anthropologists who consulted to the study such as William Caudill were concerned that we were not paying sufficient attention to the assessment of cultural variations even at the syndrome level. The primary goal of the IPSS, however, was to discover whether we could identify “similar” manifestations of a disorder schizophrenia suggesting that such a disorder actually existed in different cultures. For the organizers led by the principle investigator Tsung-yi Lin, it seemed reasonable to focus on that goal and to recognize that one could not do everything in one project. Thus, the exploration of diversity would have to await other research efforts.

Even in that project, however, certain problems in comparing clinical status across cultures signaled potential difficulties for future research attempting to reach specific cross-cultural conclusions about epidemiology and the status of patient functioning. In terms of comparing prognosis, there were issues of sampling (eg, do the less florid [the more “process”] patients who also tend to have poorer prognosis, tend not to come to the attention of mental health professionals in developing countries?). There were also issues of interpretation of longitudinal functional status. For example, there was a patient in a developing country who at follow-up was “working full time” guarding the cattle. When we asked a person from the village what that meant in terms of work, the response was that it was not real work because that was usually a job reserved for young children. In another developing country, there was the statement that there was less stigma around mental illness than in developed countries. When we inquired in more detail, however, we were told that of course family members would not let it be known that one of the sons had mental illness because it would then be impossible for the daughters to get married. These are only anecdotes of course but they suggested that making certain cross-cultural comparisons may need a sophisticated approach to sampling and inquiry to assure the validity of conclusions.

These considerations, here focusing on one aspect of the social domain, indicate the complex context within which an understanding of the diversity of prognosis in schizophrenia exists. But even the recognition of issues in each of the 3 individual domains, the biological, environmental, and personal, is incomplete. More than likely, interactions between 2 or all 3 of these domains will be important influences on course and outcome, for example, the interaction between the efforts of a person to get better, a case worker who assists him in that process, the availability of a helpful job and of useful medication.

Often in medical research, we try to focus on one variable that can account for a huge amount of the variance in a certain problem. Occasionally, we meet with relative success, as with the pneumococcus for example as a major variable in one type of pneumonia. For schizophrenia, however, as is seen in the report by Cohen et al., even a focus on only 1 of the 3 domains involves considerable complexity in research design, data collection, data analysis, and interpretation. Such complexity is nothing new of course for medical research. Very often, the crucial factors involved in aspects of illness are extremely complex. In the study of schizophrenia, there is increasing evidence that the diversity of prognosis is the result of a complex interaction between the disorder, the environment including the culture, and the characteristics of the person afflicted. Only by considering such a model are we likely to develop an accurate picture of the prognostic processes.

References