Revisiting the incidence of schizophrenia: learning about the other half

Hogerzeil, S.J.

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Learning about the *other* half

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Mr. J. from The Hague was treated for posttraumatic stress disorder as a young man, later treated for alcohol abuse, and then, at age 39, diagnosed as having schizophrenia. He would probably not be counted in a *First Contact (FC)* study, the gold standard for measuring incidence of (treated) schizophrenia and other psychoses. In fact, many people who develop psychoses are missed by first contact studies. Precise estimates are premature, but recent studies indicate that about half can be missed. How could this happen, and what are the implications?

The first contact design was introduced in the 1970s by the World Health Organization . The crucial innovation was the attempt to identify and then assess all people in a defined population over a specified period who initially contacted a helping agency and reported symptoms suggestive of psychosis. The range of helping agencies was wide and context specific, including, for example, traditional healers in India. The first contact design has since been the gold standard for measuring incidence of schizophrenia and other psychoses.

The first contact design requires all care providers to identify and refer to the research team any suspected case of psychosis. This is difficult to achieve. Accumulating evidence ranging from studies of traditional healers to studies using *electronic Psychiatric Case Registers (ePCR)* suggests that first contact studies struggle to monitor all people at all agency entry points and to ascertain first onsets of psychosis among people who previously sought help for a nonpsychotic mental disorder. Here we focus on what we have learned from high-quality ePCRs.

What is the impact of incomplete monitoring of entry points? In this issue, Simon et al. (2017) report that when using an ePCR constructed from health insurance records, they found that the incidence of psychosis and the proportion with a late onset were higher than reported previously from first contact studies. Other ePCRs, such as in Denmark and The Hague, have reported similar findings. Because ePCR studies have included methods to validate the first onsets detected, misclassification does not explain a discrepancy of this magnitude. We concur with Simon et al. (2017) that *the discrepancy is partly due to more complete monitoring of entry points*, resulting in detection of first onsets that would be missed in first contact studies, especially in older age groups.

What is the impact of incomplete detection of cases previously treated for a nonpsychotic disorder? In The Hague, Hogerzeil et al. (2014) directly compared the results from an ePCR with those from an excellent first contact study done in the same population over the same period. The ePCR identified large numbers of people like Mr J, who had been missed in the first contact study. We suggest that the *more complete detection of first*

onsets among people already treated for other mental disorders explains another part of the discrepancy.

What are the implications for researchers? In the evolution of psychiatric epidemiology, initially first-admission studies and later first contact studies replaced previous methods for incidence studies of (treated) psychosis. We propose that in contexts where ePCRs can be constructed, a new gold standard could now be considered: a *hybrid design that combines the strengths of ePCRs with those of first contact studies*. ePCRs offer the best approach to detect suspected first onsets seen by the health system. First contact studies offer the best approach to evaluate these potential first onsets, using well trained clinical interviewers and standardized instruments for both initial and follow-up assessments. First contact studies also encompass people seen by helping agencies outside the formal health system. Although a hybrid design will present new practical problems, such as ethical issues pertaining to use of registry data for referral to a research study, we think that in many contexts these problems can be solved. The next step is to test the hybrid design in the field.

What are the implications for clinicians? We need to revise prevailing views about the syndrome of schizophrenia as currently defined. The incidence is higher, the age of onset is often much later, and many (perhaps most) people with an ultimate diagnosis of schizophrenia have been treated for other mental disorders. We need not curb the enthusiasm generated by early intervention studies focusing on early-onset psychoses. Nor should we dismiss the wide range of important results from first contact studies, many of which will remain valid. But *it is time to get to know the other half*—the people with schizophrenia or other psychotic illnesses who tend to be undercounted and overlooked. We do not know whether their illnesses have different causes or whether they would respond to early interventions, but we need to find out.