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Estimating the incidence of psychosis in diverse settings

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In a recent paper, Anderson et al. (2019) demonstrated how, 'Case ascertainment strategies limited to specialized psychiatric services (in Ontario, Canada) may substantially underestimate the incidence of non-affective psychotic disorders, relative to population-based estimates.' This prompted correspondence in which Hogerzeil and van Hemert (2019) and Edwards, Rodrigues, and Anderson (2019) exchanged ideas about how the design of epidemiological research may influence incidence estimates. Furthermore, Edwards et al. (2019) proposed four types of incidence that reflect how estimates were derived: *true incidence* ('the theoretical incidence in the entire population'); *contact incidence* (those who have had contact with a health system); *diagnosed incidence* (those who have received a diagnosis of psychosis from a clinician); and *treated incidence* (those who have received treatment for a psychotic disorder).

Our primary concern is that the great majority of efforts to determine the incidence of psychosis have taken place in Western European countries (Jongsma et al., 2018; Jongsma, Turner, Kirkbride, & Jones, 2019) that have well-developed health systems and offer, to a broad cross-section of their populations, somewhat accessible psychiatric and social services. Given these contexts, it is somewhat safe to assume that individuals will, albeit after varying periods of time, seek medical care after beginning to experience symptoms of psychosis. However, this assumption is not valid in poorly resourced health systems and we would like to highlight the design strategies we have taken in INTernational REsearch Programme on Psychoses In Diverse Settings (INTREPID – https://www.intrepidresearch.org/) in an effort to reduce the gap between true and identified incidence. Moreover, this work suggests a more simplified, but universal, distinction between true and identified incidence, with researchers making explicit the precise detection strategies used to identify cases and the potential limitations of these.

Our research is being conducted in catchment areas south of Chennai, India, local government areas of Ibadan, Nigeria, and municipalities of Trinidad and Tobago. Our aim to identify truly representative samples of persons with psychosis, required us, during the pilot phase of the program, to develop comprehensive systems of case-finding in each of these sites that were diverse with regard to the nature of their health systems and sociocultural contexts. We approached this task in two ways. First, we conducted focus groups in each site to collect information about local concepts of psychotic illness (Cohen et al., 2016). An understanding of such concepts has been demonstrated to facilitate communication with informants about community members who might be experiencing a psychotic illness (Shibre, Teferra, Morgan, & Alem, 2010). Second, we used Kleinman's (1980) model of health systems – which posits 'three distinct but overlapping sectors in which illness is understood and managed…the professional (i.e. medical establishment), folk (i.e. spiritual and traditional healers), and popular (i.e. informal efforts to manage illness, e.g. self-medication, advice from friends and family, etc.)' – to create comprehensive lists of health providers and informants in each catchment area (Morgan et al., 2015). With this information we created more comprehensive structures for case-finding networks that extended beyond health professionals, public and private clinics and hospitals, to non-governmental organizations, traditional and spiritual healers, and key informants. For the site in India, we also hired several women who traveled the catchment area in search of individuals experiencing psychosis but who might not have ever come into contact with the professional or folk sectors.

Having completed this formative research, we conducted 6 months of case-finding in each of the catchment areas in India, Nigeria, and Trinidad (Morgan et al., 2016). This pilot study demonstrated that ascertainment of comparable cases in diverse settings was possible, but requires comprehensive coverage of the professional, folk, and popular health sectors in each setting with the understanding that the nature of local health systems would determine where and how cases would be found. Thus, in Trinidad 90% of cases were found through primary care and hospital-based mental health services, while in Nigeria about half of all cases were identified by monitoring alternative healers, and in India 90% of cases were found through key informants and community members.

At the same time, the detailed mapping of the mental health systems in each setting also made us aware that focusing case finding exclusively in the catchment areas would result in missing cases. For example, in Ibadan and Trinidad it was necessary to monitor psychiatric facilities that were outside the respective catchment areas. In addition, our mapping of the

mental health systems in the catchment areas made us aware that we did not have access to nor was it possible to monitor all points of possible help-seeking. Knowledge of what might have been missed informed adjustments to the case-finding networks and the extent to which we were confident of our estimates of incidence.

With funding from the UK Medical Research Council we initiated INTREPID II, a 5-year epidemiological study of affective and non-affective psychotic disorders in the same countries but in expanded catchment areas that would yield samples sizes of 240 cases and controls in each site. The design of the study follows that of the pilot study described above, i.e. efforts to conduct comprehensive case-finding in the professional, folk, and popular sectors and reliant on networks tailored specifically for the local health system. Thus, in April 2020, at the end of 2 years of case finding, we expect to have data that will allow us to estimate identified incidence in each of the catchment areas and, based on our detailed knowledge of the local mental health systems, to speculate about what the true incidence rates might be in each of the sites.

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