Advancing Our Understanding of the Ethics of Schizophrenia Research: The Contribution of Conceptual Analyses and Empirical Evidence

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Schizophrenia is a devastating illness affecting millions of people throughout the world. The suffering associated with this neuropsychiatric disorder creates a tremendous need for scientific inquiry: to understand the nature of schizophrenia; to learn about its prevention and treatment; and to address its effects on ill individuals, families, communities, and society as a whole. Nevertheless, as a disorder of the mind that disrupts cognitive abilities and erodes personal strengths, relationships, and societal roles of ill individuals, schizophrenia produces potential vulnerabilities that may be exploited in the context of human research.

For this reason, scientific investigation of schizophrenia naturally raises important ethical questions. How do we diminish the burden of schizophrenia without ever diminishing the dignity of the people living with this illness? More positively, how do we strive to help people with schizophrenia, now and in the future, while fully honoring their personhood, value, and importance in our society? How may schizophrenia research be conducted respectfully, beneficently, and justly? More concretely, how do we conduct research involving people with schizophrenia with correct procedures and adequate safeguards?

People with good will, good hearts, and good minds will disagree on the answers to these questions. Some individuals will place greater importance on pushing the science forward in an effort to help others in the future; other individuals will place greater importance on the need to protect potentially vulnerable research volunteers. People living with these illnesses may hold different perspectives from those who do not know what it is like to “walk in the shoes” of a person with schizophrenia. People whose focus is on historical examples of scientific exploitation may disagree with people whose focus is more forward-looking. People with different life experiences and values will view things differently. Yet, just as schizophrenia affects our society as a whole, all of us have a stake in finding a positive resolution to these questions.

It will take all of the skills and strengths we possess in our society to address these concerns constructively and in a manner that is not dismissive of other points of view. The scientific community will need to bring valuable approaches to the investigation of schizophrenia in pursuit of meritorious scientific questions that may be translated into genuine benefit for people living with serious mental illness. The professions will need to bring clearly defined values, guidelines, and standards to the task. Government leaders, policy makers, and advocates will need to bring a commitment to progressive and unbiased positions, policies, regulations, and laws to the task. The general public will need to bring a willingness to examine attitudes toward mental illness and to commit resources to the scientific study of this major public health problem. The scholarly community will need to bring rigorous conceptual analyses and empirical evidence to the task of building an authentic, shared understanding of the ethics of schizophrenia research.

This special feature of Schizophrenia Bulletin seeks to advance the field of schizophrenia research ethics by fulfilling this last aim—of bringing rigorous conceptual analyses and empirical evidence to bear upon the complex and challenging ethics questions that arise in the study of schizophrenia. The collection is filled with commentaries, reviews, and data-based papers that, taken together, help illuminate and clarify key questions in schizophrenia research ethics. Insights from the literature, as well as landmark papers and historical documents, are articulated and appraised. Data derived from people with schizophrenia, people with prodromal schizophrenia, clinical trial participants, psychiatrists, healthy comparison volunteers, and the general public are included. The manuscripts are informed by the expertise of multiple disciplines, and they are enriched by the experiences and perspectives of diverse “stakeholders.”

The collection marks a milestone in the development of this new and important field of schizophrenia research ethics. It is my hope, and I imagine the hope of all of my colleagues whose contributions populate this issue of Schizophrenia Bulletin, that this collection will serve as the platform for common understanding and future dialogue in our field.
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