REVIEW ARTICLE

Ethics in Research Related to Schizophrenia: Past Research and Future Implications

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ABSTRACT

Ethics holds an important place in research related to any field. Hence, the scientific community related to the field of psychology has its own sets of principles and ethical standards set by American Psychological Association (2024), that are deemed necessary for any research conducted in present times. However, in the past it was not always the case. The ethical standards for research in psychology have been built up from examples that helped in shaping principles and standards, with one such example are series of experiments conducted on the patients of schizophrenia in a University in USA. The article will shed light on the research, how it violated ethical principles of research and what the future concerns can be considering the research conducted on vulnerable population such as of patients of schizophrenia.

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Introduction

Research with vulnerable groups has several ethical, legal, and practical problems. Ethical issues frequently emerge in the pursuit of obtaining informed consent. Individuals may experience coercion to engage owing to perceived authority figures, or they may lack a comprehensive understanding of the implications of engagement. This necessitates that researchers devise novel methods to guarantee that consent is really informed (Hiltz, 1994). In 1980's, a series of high-risk research projects began at the University in USA. In the initial phase, the parents who were seeking help from psychiatric clinic for their adolescents having behavioral issues became a part of the study.

The initial and one of the goals of the series of research experiment was to understand the development of disorder in the patient who came from a family with negative affective and communication pattern. Hence the first goal of the researchers was to identify the development of disorders in teenagers (Goldstine, 1987). The principal investigators in the project were carrying out multiple studies in which they wanted to identify if patients with schizophrenia can do better without medication, development of disorder, effectiveness of psychotherapy amongst others (Hiltz, 1994). The study followed the research participants for an astounding 15 years. However, they were blindly diagnosed (Goldstine, 1987).

Further, 23 out of 50 patients under the treatment suffered relapses after their medication was stopped. Not just that many patients had more than one relapse including paranoia and hallucination. Informed consent is the process by which a healthcare provider explains the risks, benefits, and alternatives related to a certain procedure or intervention to a patient. The history

of informed consent in medicine is grounded in the larger development of ethical norms and legal requirements concerning patient autonomy. In the early 20th century, medical practice was predominantly paternalistic, with physicians making judgments for patients without necessarily disclosing the specifics. The notion of informed consent originated in reaction to significant legal cases, notably the 1914 case of Schloendorff v. Society of New York Hospital, in which the court determined that every human being of adult years and sound mind has a right to determine what shall be done with his own body (Bazzano et al. 2021). This case established the notion that patients must consent to medical interventions. During the mid-20th century, unethical medical experiments, such the Tuskegee Study of Untreated Syphilis in African American men and Nazi human experimentation during World War II, underscored the necessity for stringent consent standards (Paul & Brookes, 2015).

These events, in conjunction with the formulation of the Nuremberg Code as well as Declaration of Helsinki, established informed consent as a fundamental ethical prerequisite in both research and clinical practice. Informed consent has grown to encompass not just a patient's signature but also the necessity of transparent communication, guaranteeing that patients comprehend the risks, benefits, and choices associated with medical procedures, so establishing it as a fundamental principle of patient-centered care and medical ethics (Schenker et al., 2011).

The patients did sign “informed consent” while understanding the fact that their condition might improve or get worse. However, a few important issues remained unchecked regarding the fact that the relapse can be severe, medication withdrawal can worsen the patient’s conditions amongst other. Families of two patients approached the Federal Government regarding improper care provided to the patients and lack of information regarding the study’s implication on the subjects, one of those patient Antonio Lamadrid committed suicide after jumping from the building of U.C.L.A and other Gregory Allen had a severe Relapse, who dropped out of college and threatened to kill his parents (Hiltz, 1994).

Historical Background of Ethics in Research

In the past there has been considerable debate over the research conducted on the protection of human subjects from harm, especially when it comes to the vulnerable population such as people with severe mental illness, pregnant women, children and mentally disabled. The history is filled with several examples of poor implementation and lack of ethical standards in research (Ryan, 1995). In the past few decades, there has been considerable debate over the ethical issues involved in the research carried out on patients with schizophrenia. The new era of scientific developments opens new challenges in ethics in research, however, there has been continuous progress made in the direction to protect the participants, but (Wilson & Stanley, 2005). The Nuremberg Code 1947 after World War II was the first landmark document that addressed the ethics involved in medical and research. The document heavily focused on the protection of human subjects and the responsibility of investigator in protecting the research subject in their study. The documents were devised keeping in view the inhumane treatment the research subjects endured in Nazi Camps (Ghooi, 2011).

The basic principles addressed in the documents were informed consent, protection from harm, and freedom to withdraw from the research (Wilson & Stanley, 2005). The Nuremberg code was followed by the Declaration of Helsinki in 1964, that focused on ethical principles related to medical research involving human participants and materials related to humans. The declaration further added the provision of confidentiality, importance of research protocol, professional integrity while conducting the research, and result publications. Although amendments started to appear in the documents of American Medical Association and American Psychiatric Association with research

related to human subjects, however the first broad set of principles were outlined in Belmont Report in 1981 (Goodyear, et al. 2007).

The Belmont Report identified three major principles of research which were respect for participant, beneficence, and justice. It was in this document that focused on risk benefit assessment, importance of informed consent and distinction between research and treatment. Further it highlighted research related to vulnerable population such as children, pregnant women, fetuses, mentally disabled most relevant to schizophrenia patients as they do not have the capacity to give informed consent while ignoring the fact that non-psychiatric people can also have impaired capacity to give informed consent (Wilson & Stanley, 2005).

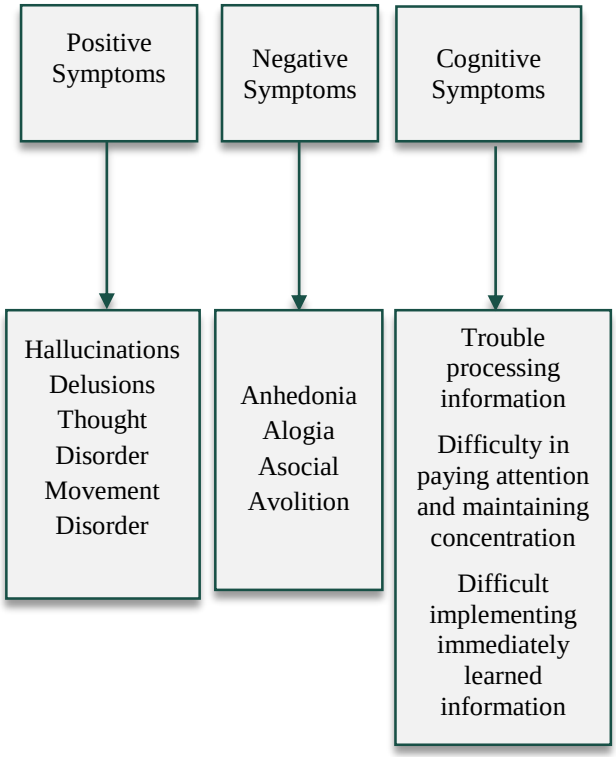
Ethical Principles in Research Related to Psychology

Ethics are a set of standards governing the conduct of a person (American Heritage Dictionary, 1992). The important question is why do we need to follow the ethics in research related to psychology? The answer is that just as research related to atomic physics can lead to the development of destructive weapons such as atom bombs. The methods uncovered by research in psychology can also lead to manipulation, create artificial wants etc. The truth is that the discoveries in the scientific world hold double-edge potentiality for all scientists (American Psychological Association, 1992). Failure to conduct research in an ethical manner can undermine the entire scientific process (Shaughnessy, et al. 2003).

The five general principles of American Psychological Association are Beneficence and Non-Malfeasance, Fidelity and responsibility, Integrity, Justice and Respect for People's Right and Dignity (Goodwin, 2005). Before indulging further into the principles, it is important to understand schizophrenia research in detail and why it becomes tedious to carry out a research with patient of schizophrenia.

Understanding Schizophrenia

Being a complex neurological disorder, the symptoms of schizophrenia are divided into four broad categories: negative symptoms, positive symptoms, mood disturbances as well as cognitive impairment. These four major categories involve manifestation in the form of hallucination, delusion, agitation, flat effect, impaired thinking, bizarre speech patterns including other (Nawaz, et al. 2020).



Keeping in view of the symptoms it is clear that the research related to patients of schizophrenia is a very sensitive matter, as they have limited ability to think clearly and understand along with other symptoms that make it difficult to think logically and rationally. Hence it is important to direct attention to the meticulously devised ethical standards by American Psychological Association (APA, 2013) that are necessary to be followed by researchers in the field of psychology.

Are the Patients of Schizophrenia Competent Enough to Understand Research Protocol?

In the early research, the patients of schizophrenia and other mental illnesses were undertaken in a similar manner as non-psychiatric patients. Schizophrenia is a serious mental health condition that can render individuals vulnerable. Lack of insight makes it difficult for patients of schizophrenia to make informed decision about their own care, and this is true for psychiatric and medical treatment as well (Dunn, 2007). Researchers must take extra precautions to protect the rights and well-being of participants, especially given the potential for cognitive impairment and difficulties in understanding the research.

Ethical Concerns in U.C.L.A Schizophrenia Study

It is an established fact that the patients of schizophrenia have impaired cognitive ability, and their thinking patterns are compromised. The following are ethical issues raised in the schizophrenia study that are still highlighted and have opened debate for future research.

- Risks exceeded the benefits
- Compromised integrity
- Poorly constructed informed consent
- Participants had difficulty withdrawing from research
- No protection from harm

Conducting a thorough risk-benefit analysis is essential. Researchers must weigh the potential benefits of the study against the potential risks, ensuring that the research contributes to knowledge without causing undue harm to participants. Attempted suicide and suicide occur at a high rate in patients of schizophrenia. The research at the U.C.L.A did not give enough thought to the fact that the participants will be at risk of attempting suicide. The research had opened up a debate regarding a prominent issue of involvement of suicidal patients in the research, an important factor is that there is a lack of literature in understanding the validated treatment of patients with suicide. This led to exclusion of at-risk suicidal patients in the research leading to poor generalizability of study on targeted population (Wilson & Stanley, 2005).

Schizophrenia is a disorder that requires medication, the debate ensued during the research regarding the lack of information provided by the researcher regarding the serious relapse due to medication withdrawal. The case of two participants was widely publicized when one committed suicide and the other threatened to kill his parents. The issue not only raised concerns during the research project but also opened avenue of discussion regarding inclusion of patients with serious mental disorder with medication in research study and protection of participants who are included in the research. In 2001, ICH issued guidelines on the use of placebo use in clinical trials, these guidelines addressed the practices of development of new drugs as well as addressed relevance of drug-free clinical trials (Wilson & Stanley, 2005). The past decade has seen an increase in interest in early intervention studies.

The studies have again opened up debate over the ethics involved in these studies. The following are the debates that have been raised related to ethics as follow.

- Defining the at-risk population
- The issue of false positives and the consequences of intervention for these individuals
- Problems with stigma and loss of autonomy
- Type and duration of intervention/treatment (Wilson & Stanley, 2005)

Informed consent holds an important place in research. It is usually the first document that is presented to the participants which ensures their voluntarism in research. The document not only serves as entry in the research but also provides information regarding the fact that the person will have full right to withdraw from the research, will be ensured of confidentiality and impact of research

(Farooqi, 2010). Hence ensuring that participants provide informed consent is a fundamental ethical requirement. Individuals with schizophrenia mostly have impaired decision-making capacity, and obtaining true informed consent can be challenging (Wilson & Stanley, 2005). Until the documents were revisited by the Federal agency and the research team was communicated to revise inform consent (Rovner, 1992), the participants were recruited on ill-constructed document in which they were poorly informed about the implications of being recruited into the study.

Navigating in the World of Artificial Intelligence, Genetic Testing and Future Ethical Standards

As we progress further into the 21st century, science is making tremendous progress in the field of genetic testing related to various diseases and disorders. It is evident that genetic testing related to mental illnesses is taking center stage and science behind is refined (Applebaum & Benston, 2017). Progress made in genetics has also raised great interest of molecular genetics in identifying genes related to schizophrenia. As suggested, the heritability of the disorder is 81%, however, till yet there is still no gene identified that is related to the disorder other than few candidate genes. The interest in psychiatric genetics have recently raised several debates over the major ethical issues that the research will open. The issues might fall into three main categories such as

- Genetic testing and screening
- Discrimination is based on genetic information.
- Sharing of information collected for research purposes (Wilson & Stanley, 2005)

It is important to understand that the fact that the responsibility falls on the shoulder of the researchers and professionals equally while communicating the implications of genetic testing to the patient while understanding his capacity to fully comprehend the process and implication of testing and interpreting results as well as filling the gaps in knowledge (Applebaum & Benston, 2017).

In this era, Artificial Intelligence AI is widely used in different domains such as finance, banking, agriculture, education, and even health care. The use of AI in healthcare helps to diagnose medical conditions such as heart diseases, cancer, and neurological disorders. AI algorithms can also detect skin cancer through thermoscopic images. AI has also played its role in pediatric healthcare. AI is able to make a prediction models for children with cleft lip and cleft palate as these children faced eating and breathing problems so AI can make a treatment plan for them. Furthermore, healthcare professionals also play their role by checking AI algorithms before implementing them to the desired population. However, it is an issue that who will be responsible for the outcomes of the AI algorithm such as if it cause an error or disasters. So, proper guidelines and policies should be made which will enhance the security of patients and protect the healthcare professionals from legal actions. It has wide access of patient's data including patient's sensitive information. To protect the patient's personal data is very crucial to gain trust of patients. Few researches were conducted in Pakistan which revealed the positive attitude of AI in medical field such as helps in improving diagnosis and helps in predicting treatment. Other research shows that AI training programs can help medical students gain knowledge and help develop their skills related to AI in healthcare (Sharif & Hajira, 2025).

Conclusion

The ethical issues in schizophrenia research are longstanding (inclusion and exclusion criteria and competency) and new (involving suicidal patients and early intervention). With advancements in new research avenues ethical issues related to severe disorders will continue to evolve, raise debates, and prepare researchers for future dilemmas. The experiments allowed the research community to dig deep into one of the most sensitive populations and prepared us for future dilemmas. Moreover, the main task of the

researcher is to find a fine line between scientific progress and the rights and well-being of the surveyed, ensuring that consent procedures are solid enough and that vulnerable populations are thoroughly cared for.

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