

## ABSTRACT

**Background:** *Schizophrenia, a profound mental health disorder, has been a focal point of research for its intricate etiology and treatment complexities. Amidst scientific advancements, ethical considerations have gained prominence, emphasizing the need to safeguard the rights and well-being of participants. The evolving ethical landscape in schizophrenia research encompasses challenges such as informed consent, decision-making capacity, and protection of vulnerable populations. We examined how empirical studies in each of these domains address specific inquiries. Ultimately, we underscored significant gaps in our comprehension of ethically significant facets of schizophrenia research and provided certain recommendations.*

**Objective:** *To analyze and map the ethical issues identified in schizophrenia research from the literature and understand research ethical committee members' perspectives on this topic.*

**Methods:** *This study used mixed methods consisting of a scoping review and semi-structured qualitative interviews with members of the research ethics committee. Five databases (PubMed, ScienceDirect, Wiley Online Library, PsycINFO, and Google Scholar) were systematically searched for studies related to ethical issues in schizophrenia research. All data were analyzed using thematic analysis and synthesized using a narrative approach.*

**Results:** *35 of 5,222 records were included in this review. Eight ethical issue themes were identified through the scoping review and interview process with three ethical committee members, including: informed consent and decision-making capacity; willingness to participate and compensation in research; risk-benefit consideration and perception; therapeutic misconception; participants safeguard; ethical issue in various study design; research guidelines; and recommendations.*

**Conclusions:** *Individuals diagnosed with schizophrenia should actively participate in decision-making processes related to research, ensuring dignity and respect are maintained throughout the research journey. Researchers have a responsibility to balance autonomy, participant well-being, and the rights of individuals, carefully considering the potential benefits and risks of the research. Despite this, there is currently a lack of guidelines specifically addressing ethical considerations in research involving individuals with schizophrenia.*

**Keywords:** *ethical issue, bioethics, schizophrenia research, research ethics*

## INTISARI PENELITIAN

**Latar Belakang:** Skizofrenia, gangguan kesehatan mental berat, telah menjadi titik fokus penelitian karena kompleksitas etiologi dan pengobatannya. Di tengah kemajuan ilmu pengetahuan, pertimbangan etis semakin menjadi sorotan, menekankan perlunya menjaga hak dan kesejahteraan peserta. Pembahasan etika yang berkembang dalam penelitian skizofrenia mencakup tantangan dalam persetujuan penelitian, kapasitas pengambilan keputusan, dan perlindungan populasi rentan. Penelitian ini melihat bagaimana studi empiris di masing-masing domain menjawab pertanyaan terkait isu etika penelitian. Pada akhirnya, penelitian ini menggarisbawahi kesenjangan dalam pengetahuan tentang aspek-aspek isu etika penelitian skizofrenia dan memberikan rekomendasi bagi pihak yang terlibat dalam penelitian skizofrenia.

**Tujuan:** Menganalisis dan memetakan isu etika yang teridentifikasi terkait penelitian yang melibatkan partisipan dengan skizofrenia berdasarkan literatur dan memahami perspektif anggota komite etik penelitian mengenai topik tersebut.

**Metode:** Penelitian ini menggunakan metode campuran yang terdiri dari *scoping review* dan wawancara kualitatif semi terstruktur dengan anggota komite etik penelitian. Pencarian dilakukan pada lima *database* (PubMed, ScienceDirect, Wiley Online Library, PsycINFO, dan Google Scholar) secara sistematis untuk mendapatkan studi terkait isu etika dalam penelitian skizofrenia. Seluruh data dianalisis menggunakan analisis tematik dan disintesis menggunakan pendekatan naratif.

**Hasil:** 35 dari 5.222 artikel dianalisis dalam tinjauan ini. Delapan tema isu etika diidentifikasi melalui proses *scoping review* dan wawancara dengan tiga anggota komite etik, termasuk: *informed consent* dan kapasitas pengambilan keputusan; kesiapan untuk berpartisipasi dan kompensasi dalam penelitian; pertimbangan dan persepsi risiko-manfaat; kesalahpahaman terapeutik; perlindungan partisipan; permasalahan etika dalam berbagai desain penelitian; pedoman penelitian; dan rekomendasi.

**Kesimpulan:** Individu dengan skizofrenia harus dilibatkan dalam pengambilan keputusan penelitian menjunjung tinggi martabat dan rasa hormat selama proses penelitian. Menyeimbangkan otonomi, kesejahteraan, hak peserta, dan menimbang potensi manfaat dan risiko penelitian merupakan kewajiban bagi peneliti. Hingga saat ini belum ada pedoman yang membahas etika penelitian yang melibatkan orang dengan skizofrenia maupun gangguan mental lainnya.

**Kata Kunci:** isu etika, bioetika, penelitian skizofrenia, etika penelitian