

## Details



## ARTICLE

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Psychosis is the most ineffable experience of mental disorder. We provide here the first co-written bottom-up review of the lived experience of psychosis, whereby experts by experience primarily selected the subjective themes, that were subsequently enriched by phenomenologically-informed perspectives. First-person accounts within and outside the medical field were screened and discussed in collaborative workshops involving numerous individuals with lived experience of psychosis as well as family members and carers, representing a global network of organizations. The material was complemented by semantic analyses and shared across all collaborators in a cloud-based system.

## SPECIAL ARTICLE

## The lived experience of psychosis: a bottom-up review co-written by experts by experience and academics

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*Psychosis is the most ineffable experience of mental disorder. We provide here the first co-written bottom-up review of the lived experience of psychosis, whereby experts by experience primarily selected the subjective themes, that were subsequently enriched by phenomenologically-informed perspectives. First-person accounts within and outside the medical field were screened and discussed in collaborative workshops involving numerous individuals with lived experience of psychosis as well as family members and carers, representing a global network of organizations. The material was complemented by semantic analyses and shared across all collaborators in a cloud-based system. The early phases of psychosis (i.e., premorbid and prodromal stages) were found to be characterized by core existential themes including loss of common sense, perplexity and lack of immersion in the world with compromised vital contact with reality, heightened salience and a feeling that something important is about to happen, perturbation of the sense of self, and need to hide the tumultuous inner experiences. The first episode stage was found to be denoted by some transitory relief associated with the onset of delusions, intense self-referentiality and permeated self-world boundaries, tumultuous internal noise, and dissolution of the sense of self with social withdrawal. Core lived experiences of the later stages (i.e., relapsing and chronic) involved grieving personal losses, feeling split, and struggling to accept the constant inner chaos, the new self, the diagnosis and an uncertain future. The experience of receiving psychiatric treatments, such as inpatient and outpatient care, social interventions, psychological treatments and medications, included both positive and negative aspects, and was determined by the hope of achieving recovery, understood as an enduring journey of reconstructing the sense of personhood and re-establishing the lost bonds with others towards meaningful goals. These findings can inform clinical practice, research and education. Psychosis is one of the most painful and upsetting existential experiences, so dizzyingly alien to our usual patterns of life and so unspeakably enigmatic and human.*

**Key words:** Psychosis, lived experience, experts by experience, bottom-up approach, phenomenology, premorbid stage, prodromal stage, first-episode stage, relapsing stage, chronic stage, recovery, psychiatric treatment

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Psychotic disorders have a lifetime prevalence of 1%<sup>1</sup>, with a young onset age (peak age at onset: 20.5 years)<sup>2</sup>. They are associated with an enormous disease burden<sup>3</sup>, with about 73% of healthy life lost per year<sup>4</sup>.

Psychosis is characterized by symptoms such as hallucinations (perceptions in the absence of stimuli) and delusions (erroneous judgments held with extraordinary conviction and

*will be lost to the depths of chaos forever*<sup>5</sup>.

K. Jaspers often refers to the paradigm of "incomprehensibility" with respect to the primary symptoms of psychosis that cannot be "empathically" understood in terms of meaningful psychological connections, motivation, or prior experiences<sup>6</sup>. However, psychotic disorders – especially schizophrenia – have, more than any other mental condition, inspired repeated at-