

# Phenomenology as a resource for translational research in mental health

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## Editorial

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# Phenomenology as a resource for translational research in mental health: methodological trends, challenges and new directions

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## Abstract

This editorial reflects on current methodological trends in translational research in mental health. It aims to build a bridge between two fields that are frequently siloed off from each other: interventional research and phenomenologically informed research. Recent years have witnessed a revival of phenomenological approaches in mental health, often – but not only – as a means of connecting the subjective character of experience with neurobiological explanatory accounts of illness. Rich phenomenological knowledge accrued in schizophrenia, and wider psychosis research, has opened up new opportunities for improving prediction, early detection, diagnosis, prognostic stratification, treatment and ethics of care. Novel qualitative studies of delusions and hallucinations have challenged longstanding assumptions about their nature and meaning, uncovering highly complex subjective dimensions that are not adequately captured by quantitative methodologies. Interdisciplinary and participatory research efforts, informed by phenomenological insights, have prompted revisions of pre-established narratives of mental disorder dominated by a dysfunction framework and by researcher-centric outcome measures. Despite these recent advances, there has been relatively little effort to integrate and translate phenomenological insights across applied clinical research, with the goal of producing more meaningful, patient-valued results. It is our contention that phenomenological psychopathology – as the basic science of psychiatry – represents an important methodology for advancing evidence-based practices in mental health, and ultimately improving real-world outcomes. Setting this project into motion requires a greater emphasis on subjectivity and the structures of experience, more attention to the quality and patient-centredness of outcome measures, and the identification of treatment targets that matter most to patients.

## Introduction: why do we need phenomenology in psychiatry?

Recent years have witnessed a gradual accretion of knowledge about mental disorders, as well as incremental advances in evidence-based treatments. Nevertheless, few new treatments have been developed, and clinical research has fallen short of its promise to deliver better mental healthcare for all (Thornicroft, 2007; Leichsenring *et al.*, 2022). Despite an ever-increasing, evidence-based body of knowledge to aid clinical and policy decision-making, considerable research-practice and treatment gaps remain (Stein *et al.*, 2022). The heaviest burden, in terms of years lived with disability, falls upon children and adolescents, with significant implications for young people's ability to participate in education, family and occupational life (Gustavson *et al.*, 2018; Dalsgaard *et al.*, 2020).

While there is reason to hope that neuroscience and genetics will deliver the kind of hard-science certainties that psychiatry – as a medical discipline – aspires to, much work is still required to develop a genuinely personalised and ethically responsive practice. To this end, psychiatry – as the discipline that strives to make sense of abnormal human subjectivity – needs a pluralistic methodological and ethical framework that can connect explaining with understanding and caring (Stanghellini and Broome, 2014). Such a knowledge is integral to the very practice of medicine and clinical care, regardless of perceived scientific maturity. This tension, between the human and the biological sciences, lies at the very core of phenomenological psychiatry and, arguably, of psychiatry generally as a discipline. But this should not be regarded as misfortune. Rather, it points to the strength, complexity and excitement of our field. The challenge is, then, to create an integrative framework that can accommodate – within psychiatry – both sides of the same coin.

Emerging from the philosophical tradition of phenomenology (with its central figures of Husserl, Heidegger, Merleau-Ponty, Sartre and Stein among others), phenomenological

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psychiatry has a history dating back to Karl Jaspers's founding text *General Psychopathology* (Jaspers, 1963; originally published 1913). Jaspers was well aware of the aforementioned methodological challenges, and tensions, inherent to the study of psychopathological syndromes. Finding himself in a historical moment – after the 'first biological psychiatry' – conceptually not dissimilar to the present terrain laid out by the 'decade of the brain', Jaspers reflects critically on the obscurity and lack of common theoretical language in psychiatric discourse (Broome, 2013). While acknowledging the need for 'certain general concepts and laws' (Jaspers, 1963, p. 1) and thus for reliable classifications, Jaspers is also clear that 'psychopathology is limited, in that there can be no final analysis of human beings as such'. The more we reduce them to what is typical and normative, the more we realise there is something hidden in every individual that defies recognition: 'We have to be content with partial knowledge of an infinity which we cannot exhaust' (*ibid.*, p. 1). Psychopathology, he continues 'is concerned with every psychic reality which we can render intelligible by a concept of constant significance. The phenomenon studied may also be a matter of aesthetic, ethical or historical interest, but we can still examine it psychopathologically' (*ibid.*, p. 2).

Jaspers' lesson remains highly relevant in the contemporary culture of categorical classifications and standardised quantitative data collection, dominated by a frantic search for the neurobiological cause that will explain psychopathological experiences once and for all. For instance, there are – within clinical research – a number of widespread but questionable assumptions such as: (1) that specific categories of signs and symptoms (e.g., delusions or hallucinations) will translate directly, relate meaningfully and reduce smoothly, to the lived experience of mental disorders and their neural correlates (i.e., a particular symptom or experience can be redescribed in the language of cognitive neuroscience, without loss of any richness of the phenomena); (2) that 'statistically significant evidence' for or against the effectiveness of a certain treatment in controlled conditions can be treated equally to 'personally significant evidence' in clinical practice; (3) that patient-centredness and shared decision-making can be unproblematically achieved through a mathematical weighing of patient preferences, research evidence and clinical expertise. But just as the reduction of consciousness to a mere product of neurophysiological events has proven difficult (Levine, 1983; Chalmers, 1996), the bio-reductionist research agenda of the past 40 years in psychiatry has failed to close the explanatory gaps between a given psychopathological phenotype, its modular neuro-cognitive substrates or processes, its proposed pharmacological or psychological intervention, and their translation into meaningful and effective treatment for those in need.

As others have already argued on phenomenological grounds (Schwartz and Wiggins, 1985; Mullen, 2007; Parnas *et al.*, 2012; Nordgaard *et al.*, 2013; Sass, 2022), we believe that psychiatry's enduring tendency to conform to a philosophy of operationalism, at the expense of more genuinely pluralistic and multi-layered methodological enquiries into the person's subjectivity, may have become a self-sustaining form of stagnation and impediment to the generation of new knowledge. In line with other recent calls for more phenomenology in psychiatry (Larsen *et al.*, 2022), we believe that phenomenological concepts and methods can act as a fruitful corrective for contemporary psychiatry – with the proviso that a stance of openness, provisionality and humility is adopted (Ritunnano *et al.*, 2022a). Phenomenological psychiatry is specifically aimed at grasping the existential structures (and alterations thereof) that give formal coherence and meaning to our experience of world.

As such, it is not just illness-oriented, but also person-oriented; it makes room for symptoms both as a source of distress and meaning-making process. Thus, phenomenology offers a way to develop an enriched, person-centred, evidence-based psychiatry that takes subjectivity seriously when selecting the object of enquiry, targets of treatment and preferred outcomes (Stanghellini and Broome, 2014).

Our proposal bears significant ethical implications for both research and practice in mental healthcare, where the alleged value-neutrality of operational epistemologies has often led to the dismissal of the perspectives of people who live with mental disorders. In the past, this has led to localised and structural forms of epistemic injustice (Box 1) derived from differential power relations (e.g., patient/physician; participant/researcher; policymakers/communities) across healthcare research and services, where many have voiced feelings of being persistently ignored, dismissed or marginalised by health professionals (Carel and Kidd, 2017; Harris *et al.*, 2022; Ritunnano, 2022). While there is now (at least in high-income countries) a growing recognition of the importance of patient and public involvement within the field of mental health research and service improvement, it is still the case that meaningful participation of service-users and carers as active collaborators in the research process is not yet systematically sought (Montori *et al.*, 2013; Schünemann *et al.*, 2014; Zhang *et al.*, 2019).

Therefore, as we move closer to a fuller understanding of subjective life with the potential to improve psychiatric interventions, a new integrative framework is needed that acknowledges and values the role of subjectivity, personhood and existential meanings, alongside traditional research data. By drawing on a range of different value perspectives, this framework can aid decision-making processes in mental health research. Here, we focus on three key actionable areas where we see possibilities for engagement between phenomenology and mainstream psychiatric research: (1) defining the object of interest or 'caseness'; (2) integrating phenomenological methods: promises and challenges; (3) identifying meaningful outcomes and new targets for psychological treatment. In Box 1 below, we provide accessible definitions of relevant technical terms.

### Defining the object of interest or 'caseness'

Perhaps the one area where phenomenology has the greatest potential to be swiftly employed, to improve the quality of interventional and outcomes research in mental health, is that of 'caseness'. In this context, we use the term caseness to refer to the degree to which accepted standardised diagnostic criteria, or psychometric tools for a given condition, can validly and reliably distinguish cases as cases rather than controls, or distinguish between different clinical groups within a study (for instance on the basis of severity or risk stratification), and define the boundaries between such groups.

Depending on the study design, caseness is a key research strategy required to ensure diagnostic and prognostic homogeneity, and draw reliable conclusions. For example, in randomised controlled trials, failure to assemble participants into groups which are (as much as possible) prognostically similar may lead to biased findings that cannot reliably or meaningfully guide practice. In non-interventional cohort studies, poor caseness may lead to erroneously identifying participants as having developed a certain pathological condition, again leading to biased findings about its aetiology. Without being able to identify who is or is not

**Box 1.** Key terms

Epistemic injustice	Epistemic injustice occurs when a person's capacity as a giver of knowledge is wrongfully denied (Fricker, 2007). This denial can manifest in two ways, which are relevant for mental health researchers and practitioners (Kidd <i>et al.</i> , 2022): <ul style="list-style-type: none"> <li>• Testimonial injustice: when a person's credibility or authority is challenged because of prejudice (including assumptions of irrationality linked with mental health diagnoses), so that the person is not believed or trusted.</li> <li>• Hermeneutical injustice: when someone is rendered unable to understand or express some important aspect of their own experience due to the person belonging to a stigmatised and vulnerable group.</li> </ul>
Phenomenological psychopathology	Emerging from the philosophical tradition of phenomenology, phenomenological psychopathology is an interdisciplinary research programme that aims to describe and classify experiential alterations in mental disorders (i.e., characteristic features of the experience and expression of mental disorders). Phenomenological investigations usually go beyond both 'objective' symptoms and narrative descriptions, to explore the existential structures (and alterations thereof) that give formal coherence and meaning to our experience of world. These may include selfhood, embodiment, temporality, spatiality, affectivity, understanding, intersubjectivity, etc. (Broome <i>et al.</i> , 2012; Fernandez and Køster, 2019; Køster and Fernandez, 2021).
Phenomenological interviews	There are a number of semi-structured psychometric checklists, inspired by phenomenology, designed to examine anomalies of various dimensions of experience: the Examination of Anomalous Self-Experience (EASE) by Parnas <i>et al.</i> (2005); the Examination of Anomalous World Experience (EAWWE) by Sass <i>et al.</i> (2017), the Examination of Anomalous Fantasy and Imagination (EAFI) by Rasmussen <i>et al.</i> (2018). For an overview see Sholokhova (2022). Phenomenological methods are also widely used in qualitative research (e.g., Giorgi, 2009; Smith <i>et al.</i> , 2022).
Self-disturbance	Disturbance or instability of the basic self (aka minimal self or ipseity) can manifest in a variety of anomalous subjective experiences. The term 'basic self' refers, in this context, to the pre-reflective and immediate awareness of being the subject of one's own experiences, thoughts and actions (Nelson <i>et al.</i> , 2014).
Subjectivity	The ongoing first-personal manifestation of experiential life as immediate consciousness of action, experience and thought. In phenomenology, this refers to the person's experience of various aspects of their self (e.g., sense of agency and embodiment) and their lived world (e.g., space, time, intersubjectivity and atmosphere) and represents the implicit foundational background against which our experience of the world is constituted.

affected, whom is to treat and what is most likely to work, clinicians may also struggle to make informed clinical decisions.

By providing a more detailed psychopathological characterisation of the individual case, we believe that phenomenology may help clinical researchers with the task of assembling prognostically homogeneous patient groups, for the purpose of investigating the effectiveness of a new intervention. It may also help guide aetiological and prediction research within non-interventional study designs. A tangible example of this potential is provided by the application of phenomenological insights for the purpose of early identification and prediction of psychotic disorders, holding potential for translation into early treatment and prevention of deleterious outcomes.

Over the last 25 years, advances have been made in identifying young people at heightened risk of schizophrenia and other psychoses (see, for instance, Fusar-Poli *et al.*, 2013; McGorry *et al.*, 2018). However, we are still unable to identify which individual patients are most likely to progress to full-threshold psychosis. While this is inherently a complex task involving several methodological challenges, part of the problem may be ascribed to the oversimplified nature of current psychopathological descriptions incorporated into many of the rating scales used to measure psychopathology. The use of yes/no self-report instruments in research studies seems to be particularly detrimental for the identification or delineation of 'caseness'. For instance, Nordgaard *et al.* (2019) investigated the validity of self-rated questionnaires for 'psychosis-like' symptoms in the general population. They found that the use of self-rating scales resulted in 82.5% of the cases being false positives when re-tested against a semi-structured interview conducted by staff trained in psychopathology. Phenomenology has been suggested as a useful corrective to these research trends, by way of adding depth,

richness and nuance to standard clinical data (Nordgaard *et al.*, 2013; Nelson *et al.*, 2018).

Nelson *et al.* (2021) have suggested a way to take this forward. For instance, in psychosis research, phenomenology could be integrated with the clinical staging approach to add depth and nuance to stage-based clinical phenotypes. Importantly, this approach promotes a multi-layered understanding of the unique (i.e., idiosyncratic) as well as shared (i.e., nomothetic) features of the experience of mental disorders. The integration of phenomenological insights could also open new research paths for clinical studies of delusions: here, it can help capture widely neglected areas of mental and experiential life beyond simple clinical severity, without lumping together forms of delusions that may only be loosely linked (Ritunnano *et al.*, 2021). When combined with standard clinical data, such as symptom severity or clinical stage, the integration of a phenomenologically informed framework allows us to increase the granular resolution of the psychopathological phenotype, thus contributing to improved, more accurate identification of caseness.

In this way, researchers may be able to better demarcate the diagnostic, prognostic and therapeutic subgroups in a way that is relevant, for instance, for the translation of findings from clinical trials to aid decision-making in clinical practice. In fact, when evaluating a patient's complaints and choosing treatments, the clinicians may not only consider the diagnosis or the severity of symptoms, but also their experiential quality, the meanings they bear for the person experiencing them, the social and cultural context in which they are embedded, the interactional dynamics that shape them and their consequences for the person's sense of identity.

In the context of data analysis, phenomenological variables may also provide potentially useful information for moderation, mediation or path analyses by foregrounding previously

unacknowledged *experience-based* variables with a significant effect on illness onset or recovery processes. They may also inform the iterative development and validation of new tools and measures grounded in the lived experience of the person. More accurate measures, and thresholds for caseness, informed by phenomenology may eventually improve our ability to diagnose, treat and potentially prevent serious mental disorders.

Importantly, phenomenology should not necessarily be constrained by existing taxonomies, but can aid scientific openness and the discovery of new knowledge by virtue of its rejection of strong theoretical assumptions, including that of our current classifications. This may be relevant for instances where psychopathological phenomena show an underappreciated transdiagnostic potential as an investigational and therapeutic target. For the case of mood instability, see Broome *et al.* (2015).

### Integrating phenomenological methods: promises and challenges

Phenomenology offers sound empirical methods for exploring and describing the patient's subjectivity (Box 1). The use of these methods is not, however, without challenges. Phenomenological practice has often been accused of requiring too much in-depth training, or of being too time consuming for it to be effectively embedded in mainstream psychiatric research – and therefore being unable to deliver on its promise. There is no denying that phenomenological interviews are lengthy processes, taking up a great deal of resources both in terms of training researchers, and conducting the necessary fieldwork. However, there is also no denying the fact that massive financial investments have been made in the past to support costly genetic testing and functional brain imaging studies, with relatively minimal or modest gains in terms of patient benefit.

We believe that the time has come to reflect on the assumptions and guiding principles that shape editorial and funding policies in mental health research. The 'hard' kind of scientific evidence, supposedly delivered by neuro-centric and bio-oriented research, may well seem reassuringly objective – with its allure of certainty and its promise of unshakeable empirical foundations – but does it deliver valuable, actionable information when it comes to understanding troubled human existence? There is an unjustified optimism in the faith that a narrow biomedical conception of mental ill health will deliver improved outcomes, echoing the criticisms of the 'neuromythology' of late 19th century German psychiatry made by Jaspers and his contemporaries. Is this approach as 'neutral' or 'objective' as it purports to be? Does it provide us with useful, effective tools to make sense of mental suffering? Does it challenge the forms of epistemic injustice that affect many people with mental disabilities? Does it provide psychiatry with the tools required to deliver improved care? As Bilsbury and Richman note, 'a quest for statistical psychometric virtue is futile if the instrument is so ill-focused that it is irrelevant to the individual' (Bilsbury and Richman, 2002, p. 10).

Ultimately, to expect that quantitative, bio-psychiatric research alone is going to lead to better mental healthcare for all is probably unrealistic: we are currently lacking in strong evidence for such optimism. Joining forces may be a better way forward. But how? Echoing Jaspers once again, we believe that psychiatry should be concerned with the 'human being as a whole' (*ibid.*, p. 1) as its main object of investigation, including the environmental and social contexts in which altered experiences may occur (Pienkos, 2020).

Various phenomenologically informed methodologies, and forms of phenomenological interviewing, have been developed and used worldwide across qualitative and quantitative research designs. For instance, in qualitative research, Interpretative Phenomenological Analysis (IPA) is a widely used approach, informed by phenomenology, hermeneutics and idiography, committed to the investigation of how people experience and make sense of major life experiences (Smith *et al.*, 2022). In quantitative designs, the use of the Examination of Anomalous Self-Experience (EASE) scale (Parnas *et al.*, 2005) is a good example of how a phenomenologically informed approach can enrich translational research in psychiatry. The EASE is a semi-structured phenomenologically informed psychometric instrument, providing both qualitative and quantitative data on subjective anomalies that may indicate a disorder of self-awareness or self-disturbance (Box 1) – see also Nelson *et al.* (2014) for a clarification of the concept. The EASE has been used in empirical studies to explore both psychotic and non-psychotic self-disorders, and their association with clinical variables and diagnostic outcomes. Notably, a recent systematic review of 53 empirical studies using the EASE scale by Henriksen *et al.* (2021) supports the notion that self-disorders hyper-aggregate in schizophrenia spectrum disorders, but are less prevalent in other mental disorders or healthy controls. The results also show that self-disorders are far more prominent in first-episode psychosis and ultra-high-risk (UHR) groups compared to non-psychotic and health controls, and that they are a strong independent predictor of future schizophrenia onset in UHR patients (Nelson *et al.*, 2012), non-psychotic adults (Parnas *et al.*, 2011) and youth clinical populations (Koren *et al.*, 2020).

While larger observational studies are still ongoing (e.g., Krcmar *et al.*, in preparation), this knowledge holds promise as a powerful diagnostic and predictive tool in clinical settings. It is also particularly valuable to research investigating the pathogenic mechanisms of onset of schizophrenia and related disorders. In this context, for instance, phenomenological data on self-disorders are being used alongside neurocognitive and neurophysiological measures (e.g., source monitoring deficits and aberrant salience) with the aim of developing more accurate predictive models for the identification of UHR patients who are most likely to progress to full-threshold psychosis (Nelson *et al.*, 2019). If validated, such models could be translated into tools for use in clinical practice to inform diagnostic, prognostic and treatment decision-making. It is notable that despite the phenomenological knowledge accumulated in this area, the effect of pharmacological or psychotherapeutic interventions on self-disorders has not yet been investigated. Notwithstanding the high levels of distress, often reported by patients with psychosis, in relation to alterations in the sense of self and identity (Griffiths *et al.*, 2019; Bögle and Boden, 2022), the specific treatment of self-disorders remains, to our knowledge, unexplored.

### Identifying meaningful outcomes and new targets for psychological treatment

Identifying and selecting the appropriate outcome variables to assess healthcare interventions and services is one of the biggest challenges faced by researchers and providers today. Mental states are complex, fluctuating, strongly individualised experiences that often resist the kind of quantitative measurement pursued by standardised rating scales, and it is fortunate that many studies have now moved away from cross-sectional symptom reduction as a primary or sole outcome. Similarly, we know that recovery

is a deeply personal and unique process, which goes beyond a simple reduction in symptom severity as captured by a numerical score. Key dimensions of recovery in mental health include, for example, ‘connectedness, hope and optimism about the future, identity, meaning in life, and empowerment’ (CHIME) (Leamy *et al.*, 2011). For these and related reasons, there has been growing interest in the development of patient-centred approaches to assessing treatment outcomes (Thornicroft and Slade, 2014), and many calls to action have been made to build and deliver patient-centred care in collaboration with patients (Santana *et al.*, 2019; Schroeder *et al.*, 2022). To this end, patient-reported outcome measures (PROMs), measuring patients’ perspectives on health outcomes, are increasingly used in health care. However, the extent to which these measures are developed through a meaningful and systematic engagement with patients and lived experience researchers has been questioned (Trujols *et al.*, 2013; Wiering, de Boer and Delnoij, 2017).

With its focus on patients’ subjectivity and narratives, there is enormous potential for phenomenological knowledge and methods to be used to develop patient-focused healthcare systems and outcomes that are better tailored to, and centred around, patient experience. Indeed, phenomenology is by no means restricted to the description of psychopathological symptoms (Fuchs *et al.*, 2019). Insights from phenomenological studies can inform, for instance, the development of novel targets for treatment and care strategies, particularly in the field of psychotherapy (Nelson and Sass, 2009; Pérez-Álvarez *et al.*, 2011; Škodlar and Henriksen, 2019). Phenomenological knowledge and concepts can also help identify, refine or develop new PROMs that are based upon and truly incorporate the patient’s experiences and perspectives. This is especially important in the psychotherapy of schizophrenia and other psychoses, where the effectiveness of currently available, evidence-based treatments such as CBT has been repeatedly found to be sub-optimal against several standard outcomes (Jones *et al.*, 2012, 2018; Bighelli *et al.*, 2018; Jauhar *et al.*, 2019).

For instance, the anomalies of self-awareness described above as core clinical and vulnerability features of schizophrenia could be a potent *experience-based* target of psychological treatment – as they are purported to underly and generate a wide range of the disorder’s more obvious symptoms and signs (such as positive and negative symptomatology). This approach should begin from the patients’ subjective experiences (and not the researcher’s third-person interpretations of the patient’s behaviour or utterances) as the starting point for developing patient-centred interventions, and for identifying patient-focused outcomes. With the appropriate training and investment, the EASE and other phenomenologically informed instruments (Box 1) could be considered when selecting outcome variables for the evaluation of treatment in psychosis research. However, it is crucial to keep in mind that ‘phenomenologically informed’ does not always imply ‘patient-valued’ as there is always a risk that phenomenological measures, although based on experiential accounts, prioritise the values and concerns of clinicians and researchers over those of patients.

For this reason, a mixed-methods approach that integrates qualitative and participatory research techniques in study designs may be a better way forward to identify patient-centred outcome domains, develop patient-valued measures and select new treatment targets. A recent example of this is Sheaves *et al.* (2022)’s work using lived experience accounts to build a novel theoretical framework and developing two new measures of voice-related

distress (Sheaves *et al.*, 2022). In this study, qualitative interviews with people experiencing derogatory and threatening voices formed the basis for the generation of two psychometrically robust assessments, providing a new perspective on voice distress. This experience-based, patient-generated framework can then be translated into patient-valued targets for psychological intervention. Similarly, phenomenological insights gained from co-written bottom-up reviews of the lived experience of psychosis (Fusar-Poli *et al.*, 2022) or from systematic reviews and qualitative meta-syntheses (Ritunnano *et al.*, 2022b) could help create measures and develop treatments that are more faithful to the first-person perspective. Without this approach, the risk is that we continue to rely on outdated, researcher-generated constructs that may or may not reflect the real nature of the phenomena under investigation, and may or may not matter to patients.

## Conclusion

This paper shows that phenomenology can help psychiatry move forward. A phenomenologically informed framework may aid interventional and translational research in mental health by: (1) improving caseness; (2) providing valid and reliable methods that can capture the complexities of psychopathological phenomena from multiple perspectives; (3) contributing to the identification of meaningful, patient-valued outcomes and novel targets for psychological treatment. In addition to this initial proposal, other areas could be considered for phenomenological engagement on a larger scale. For example, natural language processing could be used to facilitate the analysis and management of large-scale phenomenological datasets (e.g., descriptive discourse in first-episode schizophrenia; Alonso-Sánchez *et al.*, 2022) and support early detection, prevention and treatment.

In conclusion, phenomenology enables psychiatry to address human subjectivity without losing sight of the human being as a whole. It can work in parallel with advances in neuroscience, providing a bridge between explanation, understanding and caring. By accepting the provisionality of knowledge, it can aid scientific openness and lead to unexpected discoveries. Translated into ethically responsive research and clinical practices, it can support a transformative process of knowledge co-creation that explicitly foregrounds the value of lived expertise.

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