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Subjective experience and meaning of delusions in psychosis: a systematic review and qualitative evidence synthesis

Rosa Ritunnano, Joshua Kleinman, Danniella Whyte Oshodi, Maria Michail, Barnaby Nelson, Clara S Humpston, Matthew R Broome



Summary

Background Delusions are a common transdiagnostic feature of psychotic disorders, and their treatment remains suboptimal. Despite the pressing need to better understand the nature, meaning, and course of these symptoms, research into the lived experience of delusional phenomena in psychosis is scarce. Thus, we aimed to explore the lived experience and subjective apprehension of delusions in help-seeking individuals with psychosis, regardless of diagnosis and thematic content of the delusion.

Methods In our systematic review and qualitative evidence synthesis, we searched MEDLINE, Embase, PsycINFO, CINAHL, and Web of Science for qualitative studies published in English from database inception, with the last search on Sept 9, 2021. Grey literature search and hand-searching of relevant journals were also done. Studies were eligible if they provided an analysis of lived experience of delusions or pre-delusional phenomena presented from the perspective of individuals (age 14–65 years) who had developed a clinical high-risk stage of psychosis, or a diagnosable affective or non-affective psychotic disorder (as clinically defined, self-reported, or assessed within the primary study). Studies with only a subset of relevant participants were eligible only if data for the population of interest were reported separately. Studies that did not discriminate between the experience of delusion and other positive symptoms (eg, hallucinations) were included only if data for delusions were reported separately or could be extracted. First-person accounts (and author interpretations) discussing changes in the sense of self, lived world, and meaning in relation to delusions were extracted and synthesised using a novel thematic synthesis approach informed by a critical realist stance and a phenomenological theoretical framework. Analytic themes were developed into a new overarching framework for understanding the emergence of delusional phenomena. The study was registered with PROSPERO, CRD42020222104.

Findings Of the 3265 records screened, 2115 were identified after duplicate removal. Of these, 1982 were excluded after title and abstract screening and 106 after full-text eligibility assessment. Of the 27 studies entering quality assessment, 24 eligible studies were included in the qualitative evidence synthesis, representing the perspectives of 373 help-seeking individuals with lived experience of delusions in the context of psychosis. Gender was reported as male (n=210), female (n=110), transgender (n=1), or not reported (n=52). Only 13 studies reported ethnicity, with White being predominant. The age of most participants ranged from 15 to 65 years. We found no eligible studies investigating subclinical or pre-delusional experiences in at-risk mental state populations through qualitative methods. Most studies were undertaken in western, educated, industrialised, rich, and democratic (WEIRD) societies, and most included participants had received or self-reported a diagnosis within the schizophrenia spectrum. Studies differed in relation to whether they focused on one kind or theme of delusion or delusional phenomena more generally as a unified category. Three superordinate themes relating to experiential changes and meanings in delusion were identified: (1) a radical rearrangement of the lived world dominated by intense emotions; (2) doubting, losing, and finding oneself again within delusional realities; and (3) searching for meaning, belonging, and coherence beyond mere dysfunction. Based on the review findings and thematic synthesis, we propose the Emergence Model of Delusion to advance understanding of delusional phenomena in psychosis.

Interpretation Delusions are best understood as strongly individualised and inherently complex phenomena emerging from a dynamic interplay between interdependent subpersonal, personal, interpersonal, and sociocultural processes. Integrative approaches to research on delusion, which consider their potential adaptiveness and favour explanatory pluralism, might be advantageous. Effective clinical care for individuals with psychosis might need adapting to match more closely, and take account of, the subjective experience and meaning of delusions as they are lived through, which might also help redress power imbalances and enduring epistemic injustices in mental health.

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Research in context

Evidence before this study

Previous systematic reviews into cognitive and affective processes linked with delusional psychopathology have said little about any potential contribution of phenomenological models to explaining delusions. Following the Sample, Phenomenon of Interest, Design, Evaluation, Research framework, we used both text words and controlled vocabulary to describe the sample of interest (eg, "Schizophrenia Spectrum and Other Psychotic Disorders"/"Bipolar and Related Disorders"/"psychosis"/"at risk mental state" or "ultra-high risk" or "clinical high risk") and the phenomenon of interest (eg, "delusion"/"grandios*" or "paranoi*" or "delusional mood" or "delusional belief*" or "delusional idea*" or "delusional experience*"), in combination with methodological terms such as "questionnaire*" OR "survey*" OR "interview*" OR "focus group*" OR "case stud*" OR "observ*" "view*" OR "experien*" OR "opinion*" OR "attitude*" OR "perce*" OR "belie*" OR "feel*" OR "know*" OR "understand*". We searched MEDLINE, Embase, PsycINFO, CINAHL, and Web of Science for qualitative studies published in English from database inception, with the latest search update on Sept 9, 2021. We manually searched the reference lists of all retrieved full-text articles. Additionally, searches were run on OpenGrey and Google Scholar, relevant journals were searched by hand, and experts in the field were contacted where suitable but unpublished data were thought to exist. We found a small body of qualitative studies, of which 24 were deemed eligible for inclusion in the qualitative evidence synthesis after quality appraisal, and provided evidence for the potential role of subjectivity, agency, emotions, insight experiences, metaphorical thinking, life experiences, and social and cultural factors in the onset and maintenance of delusions in psychosis. We found no systematic reviews or qualitative evidence syntheses of the findings from multiple primary qualitative studies on the experience and meaning of delusions in psychosis.

Added value of this study

By bringing together evidence on the views of 373 individuals with psychosis, this study provides rich data about the lived experience of a broad range of delusional phenomena, and allows for the identification of similarities and differences across delusional themes and transdiagnostically. Our new interpretive model, the Emergence Model of Delusion, adds depth, nuance, and complexity to previous cognitive and phenomenological theories of delusion by providing a multilayered and empirically sound account of how delusions emerge and are shaped by social, relational, and emotional contexts. It also highlights the role of communicative dynamics and trust in the clinical encounter with people with delusions, underscoring the epistemic value of first-person accounts as crucial sources of knowledge that can inform therapeutic interventions. Our study contributes to filling conceptual and therapeutic gaps in dominant theories of delusions that are built on the so-called faculty psychology approach, which is based on the idea that mental processes such as belief and perception can be easily demarcated and studied as separate faculties or abilities.

Implications of all the available evidence

A deeper knowledge of what people with delusions experience and might find meaningful can help guide clinical practice and improve communication within the clinical encounter. Improved communication is likely to ameliorate the quality of the therapeutic relationship and trust in individual clinicians and services, contributing to better clinical outcomes and benefitting services users and clinicians. Our findings can inform future theoretical and causal research, and potentially contribute to the refinement of existing and development of new psychological interventions for people with psychosis.

Introduction

Formal attempts to understand and explain delusional psychopathology have been pursued since the early 20th century, with classical phenomenological work by Jaspers, Bleuler, Minkowski, Blankenburg, and Conrad, among others.¹ As this heritage is revived and critically revisited by contemporary phenomenologists,^{2,3} moves are made towards cross-disciplinary and pluralistic approaches that can account for the inherent complexity of delusions beyond purely understanding them as erroneous beliefs.⁴ In 2021, Feyaerts and colleagues⁵ used intensive qualitative research methods, but literature directly investigating the lived experience and subjective apprehension of delusional phenomena in psychosis is still scarce and, to our knowledge, no systematic review on this literature has been done.

Typically, psychopathological research on delusion is quantitative⁶ and deficit oriented, focusing on the search for a putative cognitive dysfunction invariably located in the person's mind or brain.⁴ Within psychiatry, delusion

research often relies on clinician-administered interviews or self-rating scales for assessing the severity of positive symptoms, and aims to detect causal factors involved in the development and persistence of delusions, such as reasoning biases (eg, jumping to conclusions),⁷ low self-esteem and negative self-schemas,⁸ and maladaptive appraisal processes driven by anxiety, worry, and depression.⁹ Such work has led to significant advances, particularly in cognitive-behavioural treatment for patients with persecutory delusions and understanding of the role of affect and anxiety.¹⁰ Yet, by implicitly assuming that delusions are harmful and dysfunctional beliefs, current approaches miss the full range and breadth of the lived experience and potential adaptiveness of delusional phenomena across cultural, social, historical, and linguistic contexts. These approaches might overlook the clinical significance and meaning of other experiential dimensions of delusions, and hence any potential benefits of their adoption. This neglect contributes to a widening conceptual mismatch between

the operational constructs used to study delusions and the experience lived by the person with psychosis, who might feel seen but not heard—thus increasing the risk of testimonial and hermeneutical injustices (appendix p 2).¹¹ In addition, while the real-world efficacy of cognitive behavioural therapies is still debated,¹² psychological treatments for psychosis remain suboptimal.¹³

A growing body of literature in philosophy of psychiatry emphasises the potential psychological adaptiveness and epistemic benefits of delusions,^{14,15} wherein being adaptive means delivering a psychological or biological advantage—eg, by temporarily increasing one's wellbeing or enhancing genetic fitness. Few, but consistent, empirical observations suggest that elaborated delusions can enhance a person's experience of meaning and purpose in life,¹⁶ contribute positively to one's sense of coherence,¹⁷ and provide a sense of purpose, belonging, and self-identity.¹⁸ But research in this area is scarce. Phenomenological accounts, while recognising the importance of subjectivity (particularly, the role of self-disturbances)¹⁹ and personal meanings,²⁰ have traditionally neglected qualitative research, and their conceptualisations are mostly based on clinical experience or on the re-analysis of classical case studies and theoretical elaboration.

By using a novel qualitative method integrated with a phenomenological theoretical framework and underpinned by a critical realist epistemology, this systematic review sets out to synthesise the available qualitative research on the experience and meaning of delusional phenomena as reported by individuals with psychosis, transdiagnostically and irrespective of the delusional theme. The synthesis remains agnostic as to the belief or other nature of delusions, conceiving of them as occurrent experiential states that have a specific phenomenology—ie, there is a characteristic what-it-is-likeness to be in a certain delusional state. We assume that this what-it-is-likeness can be investigated in phenomenological terms by gaining access to a person's experience of the self, as situated and embedded within their lived world.

One broad review question was formulated collaboratively within a multidisciplinary research group, including an expert with experience of psychosis: how do individuals with delusions, in the context of psychosis, experience and interpret changes in their sense of self, world and meaning? (appendix p 2).

Methods

Search strategy and selection criteria

We followed the updated Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement guidelines (appendix pp 3–4).²¹ A protocol was developed and registered with PROSPERO (CRD42020222104), and the qualitative evidence synthesis was conducted in accordance with the Enhancing Transparency in Reporting the

Synthesis of Qualitative Research guidelines (appendix pp 5–6).²² Our method was embedded within a critical realist philosophical stance (appendix p 2).

We conducted a comprehensive literature search, combining the use of bibliographic database searching and supplementary search methods (appendix pp 7–13). Given the specific problems associated with poor indexing of qualitative literature, the Sample, Phenomenon of Interest, Design, Evaluation, Research framework was adapted and used for the search strategy.²³ MEDLINE, Embase, PsycINFO, CINAHL, and Web of Science were searched by RR (in consultation with an information-specialist librarian) from database inception, with the last search on Sept 9, 2021, for English-language reports.

All search results were downloaded into a reference management programme and imported into a screening and data extraction tool (Covidence). Covidence was used for the deduplication of citations, abstract, and full-text screening. Studies were eligible if they were qualitative and if participants ($n \geq 3$) were aged 14–65 years, had a clinically assessed or self-reported diagnosis of any psychotic disorder, or were eligible for Early Intervention in Psychosis clinical service provision, had past or present experience of delusions, delusion-like ideas, or pre-delusional phenomena (eg, delusional mood or atmosphere) reported from the first-person perspective. Studies were excluded if they reported experiences of people who used mental health services for reasons other than symptoms of psychosis, did not have delusion or pre-delusional experiences as their main outcome, or where data relating to delusional themes or experiences could not be extracted, reported exclusively clinical-descriptive data, third-person data, or no primary data (appendix pp 14–17). Titles and abstracts were screened independently by RR and DWO, or RR and JK. Disagreements were either resolved by discussion until consensus, or the full-text report was independently assessed (by RR and DWO, or RR and JK). Where disagreements could still not be resolved, a third member (MM, CSH, or MRB) of the research team was involved in the final decision.

Overall study quality was assessed using the Critical Appraisal Skills Programme (CASP),²⁴ and the National Institute for Health and Care Excellence (NICE)²⁵ methodology checklist for qualitative studies (appendix pp 18–19). RR and JK first appraised each study independently, then compared assessments and discussed any discrepancies. Although there is no consensus as to the role of quality criteria and their application in qualitative evidence syntheses,²⁶ we took the view that the quality of primary studies should be rigorously assessed to avoid drawing unreliable conclusions at the synthesis stage. Thus, based on the combined outcome of the CASP and NICE checklist appraisals, a decision to include or exclude based on quality was made through discussion and consensus with all authors (appendix pp 20–31).

See Online for appendix

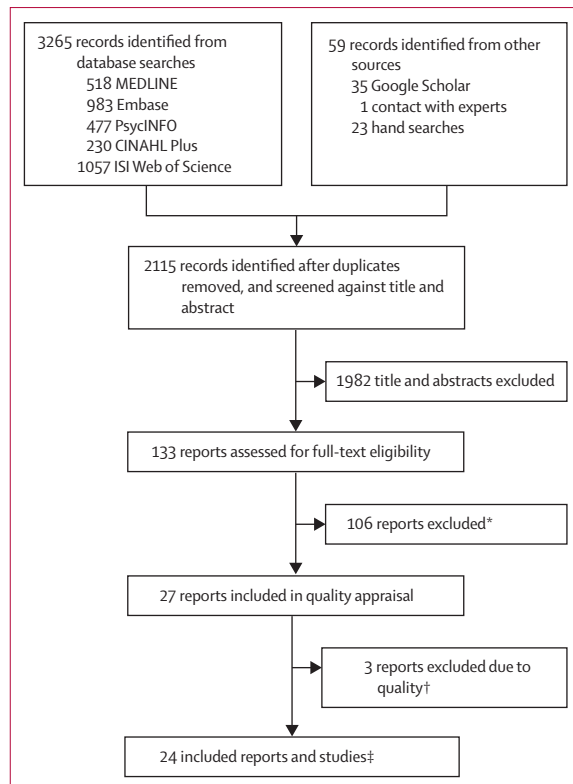


Figure 1: Selection of studies

*Further information is provided in the appendix (pp 14–17). †Further information is provided in the appendix (pp 20–31). ‡Reference lists of included studies were screened. 43 were identified against title screening, and none were deemed eligible.

Data analysis and QES

All included full-text articles were uploaded verbatim to NVivo software, version 12, to manage data and apply codes across the dataset. A thematic synthesis approach was deemed most appropriate for this qualitative evidence synthesis based on Cochrane guidance,²⁷ and application of the RETREAT criteria²⁸ (appendix p 32). Thematic synthesis allowed us to flexibly and rigorously combine, and synthesise, individuals' views and experiences across primary studies using different epistemological frameworks. We followed three main stages (appendix p 34):^{29,30} (1) line-by-line coding; (2) generation of descriptive themes; and (3) development of analytical themes supported by codes and descriptive themes and informed by a phenomenological theoretical framework. For each article, all text under the headings of results or findings was coded by RR, and JK independently coded one-third of the articles to encourage reflexivity and improve rigour. An inductive and iterative approach to analysis was privileged throughout to allow important themes, topics, or models to develop directly from the raw data, while a deductive phase was implemented in the last stage of synthesis to address the review question. We aimed to enhance rigour and quality through a process of critical dialogue between coders and reviewers:

each member voiced their interpretations and offered critical feedback, thus providing a theoretical sounding board, which encouraged reflection and exploration of alternative explanations and interpretations. A reflexivity statement is provided in the appendix (p 35).

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Results

We identified 2115 records after duplicate removal (figure 1). 1982 records were excluded following title and abstract screening. Of 133 reports assessed for full-text eligibility, 106 were excluded (appendix pp 14–17). Of the 27 studies entering quality assessment, three studies were excluded; two were deemed unsatisfactory based on the CASP and NICE checklists^{31,32} and one with uncertain global quality score on the CASP³³ was excluded based on the NICE checklist (appendix pp 20–31). 24 studies were included in the final synthesis (table), representing the views of 373 individuals with lived experience of delusions in the context of psychosis. No eligible studies were found specifically investigating delusions in clinical high-risk for psychosis populations. The 24 studies were conducted in the UK (n=14), UK and Australia (n=2), USA (n=2), Belgium (n=2), Denmark (n=1), Poland (n=1), Switzerland and Canada (n=1), and Sweden (n=1). Participants were recruited from a range of settings, including community mental health teams, Early Intervention in Psychosis teams, inpatient units, hospital-based psychology departments, mental health charities, and service-users' advocacy services. Gender was reported as male (n=210), female (n=110), transgender (n=1), or not reported (n=52). Ethnicity was only reported in 13 of 24 studies, being predominantly White.

Six of these studies (48 [13%] participants) did not specify diagnosis beyond psychotic disorder. In the remaining 18 studies (325 participants), classification system criteria were not used consistently, limiting our ability to reliably discriminate participants based on diagnosis. Of these 18 studies, two^{58,60} confirmed diagnosis through a diagnostic interview based on ICD or DSM criteria, one⁴⁹ confirmed diagnosis through consensus, and 15^{5,18,37,39,45–48,51,53,54,56,57,59,62} relied on self-reported or clinically established diagnosis collected at point of recruitment (table). 271 (73%) of 373 participants had received or self-reported a diagnosis within the schizophrenia spectrum; 41 (11%) participants had received or self-reported a diagnosis of bipolar disorder with psychotic symptoms or psychotic depression, four (1%) reported psychosis not otherwise specified, two (<1%) reported personality disorder, not specified, and one (<1%) reported obsessive-compulsive disorder and previously paranoid schizophrenia.

Most studies did not specify the clinical stage of the illness, or the timing of the active delusional symptomatology in relation to the interviews. Only four studies^{42,49,53,56} interviewed participants who were currently manifesting delusional experiences or ideation as a criterion for inclusion. Participants with either

	Aim of primary study	Design and methods	Country and recruitment setting	Participants (number, gender, ethnicity, age*)	Diagnosis (if not assessed, descriptive information is reported as extracted from the primary study)	Delusional psychopathology (as reported in the primary study, subtypes of delusion, and timing of active delusions)	Main themes (as reported in the study findings)
Bögle and Boden (2019) ^{34*}	To gain an in-depth understanding of the lived, felt experiences of a first crisis in psychosis	Semi-structured interview; drawing or images for visual data collection; multimodal approach based on IPA	UK; mental health charities	N=7 (male n=4, female n=2, transgender n=1; White British n=3, White other European n=2, Black British n=1, White American n=1); age range 15–70 years	Diagnosis not reported; all patients "had recently experienced a first crisis in psychosis"	Unusual beliefs (n=7), voices (n=6), and visions (n=4); delusion subtype was not differentiated; timing was recent (no further specification)	(1) Feeling shattered; (2) an all-enveloping strangeness and lingering threat; (3) lacking a sense of belonging
Boyd and Gumley (2007) ³⁵	To develop an experiential perspective on developing paranoia using grounded theory	Semi-structured interview; social constructionist version of grounded theory	UK; two community mental health teams, a rehabilitation unit, and a psychiatric hospital	N=10 (male n=9, female n=1; ethnicity not reported); age range 27–54 years	Diagnosis not reported; all participants displayed positive symptoms of psychosis ("as evident at interview")	Persecutory delusion identified based on Freeman and Garety's criteria ³⁶ ; delusional subtypes at interview: persecution (n=10), reference (n=8), grandiose (n=4), hearing voices (n=7); timing was current (n=5) or past (n=5)	Core category was fear and vulnerability; subcategories were (1) confusion and uncertainty, (2) self under attack, (3) engaging in safety systems
Campbell and Morrison (2007) ^{37†}	To examine the subjective experience of paranoia by comparing patients' and non-patients' discourse on the topic	Semi-structured interview; IPA	UK; patient group: community mental health teams (n=5), previous research (n=1); non-patient group: University of Manchester	N=12 (all White British; age range 18–57 years (mean 30.9); patient group n=6 (male n=5, female n=1; mean age 37.7 years); non-patient group n=6 (male n=1, female n=5; mean age 24.2 years)	Clinically established diagnosis (criteria not specified); schizophrenia-spectrum disorder (n=6)	All participants "had experienced paranoid thoughts"; Peters Delusions Inventory (PDI brief form ³⁸): non-patient group only; no criteria specified for the patient group; delusion subtype: persecutory; timing was unspecified	(1) Content and nature of paranoia and insight into paranoia; (2) positive and negative beliefs about paranoia; (3) factors that influence paranoia: unusual perceptual experiences, biased information processing, past experience, factors that alleviate; (4) consequences of paranoia: emotions, the self, behaviour
Dickson et al (2016) ³⁹	To explore participants' interpretations of early interpersonal experiences and how these interpretations might be meaningfully related to the onset of persecutory delusions	Semi-structured interview; IPA	UK (northern England); one early intervention in psychosis team and two community mental health teams	N=7 (male n=6, female n=1; ethnicity not reported); age range 18–43 years (mean 34)	Diagnosis reported as chart diagnosis (criteria not specified); paranoid schizophrenia (n=4); delusional disorder (n=2); psychosis NOS (n=2)	Persecution and deservedness scale ⁴⁰ ; participants completed the measure for the time they were most distressed and were included if they listed at least seven out of ten items as possibly or certainly true; subtype was persecutory delusions; for timing, absence of delusions for the preceding 8 months was required	(1) Early experiences: early relationship problems, victimisation experiences, not all bad; (2) impact of early experiences: inconsistent sense of self, negative sense of others, disturbed social functioning; (3) coping with adversity, avoidant coping, proactive coping
Dinnan and Lavender (2006) ⁴¹	To explore the relationship between religious belief and beliefs regarded as delusional (including exploring experiences, events, and beliefs around the time when the participant encountered psychological difficulties)	Semi-structured interview; grounded theory	UK; community mental health teams and an assertive outreach team	N=7 (male n=6, female n=1; White English n=4, White English-Spanish n=1, Afro-Caribbean n=1, White Scottish n=1); age range 30–54 years	Diagnosis not reported; all participants reported symptoms of psychosis and "having been diagnosed as delusional" was part of the inclusion criteria	Unusual beliefs that had been diagnosed as delusional; subtypes were (1) beliefs about the power of religious figures, eg, that God was running all radio stations; (2) persecutory religious beliefs, eg, about being spoken to by demons; (3) grandiose religious beliefs, eg, believing oneself to be Jesus; (4) meta-beliefs, or beliefs about the nature of the relationship between religious beliefs and delusions, eg, believing one could not discriminate between reality and delusions; timing was unspecified	Overarching theme was negotiating identity, with four processes: (1) social context and triggers for psychological difficulties; (2) personal-identity development; (3) religious-identity development; (4) negotiating identity

(Table continues on next page)

Aim of primary study	Design and methods	Country and recruitment setting	Participants (number, gender, ethnicity, age ^a)	Diagnosis (if not assessed, descriptive information is reported as extracted from the primary study)	Delusional psychopathology (as reported in the primary study, subtypes of delusion, and timing of active delusions)	Main themes (as reported in the study findings)	
(Continued from previous page)							
Feyaerts et al (2021) ⁵	To investigate the nature of delusional reality experience, and its subjective apprehension, in individuals with lived experience of delusions and a schizophrenia-spectrum diagnosis	Semi-structured interview; IPA	Belgium; two psychiatric hospital services	N=18 (male n=13, female n=5; White Flemish n=15, Russian Flemish n=1, Indian Flemish n=1, Asian American n=1); age range 19–62 years	Clinical diagnosis “ascertained through clinical interview by the attending psychiatrist upon admission”; schizophrenia (n=15), schizotypal disorder (n=2), schizoaffective disorder (n=1)	Delusional symptoms in the context of at least one psychotic episode (present at least 1 year before participation) assessed on the basis of clinical notes; delusion subtype was not differentiated; timing was unspecified (average duration of illness 16 years)	(1) Psychosis as an ontological transformation; (2) psychosis as a state of hypo-reality; (3) psychosis as a state of hyper-reality; (4) the complexity of delusional belief; (5) aftermath: the enduring impact and value of delusional experience
Gunn and Larkin (2019) ⁴²	To describe the lived experience of people with active delusions and present an interpretative account based on the Enactive Approach	Semi-structured interview; IPA	UK; local NHS mental health services	N=4 (male n=1, female n=3; ethnicity not reported); age range not reported (recruited within Adults Mental Health Services)	Diagnosis not reported; all participants self-reported symptoms of psychosis	All participants had been clinically assessed as “having active delusions”; delusion subtype was not differentiated; timing was current (n=4)	(1) Context; (2) injustice, unfairness and a radical alteration in lived experience
Hutchins et al (2016) ⁴³	To examine how individuals with psychosis make sense of their emotional and delusional experiences	Semi-structured interview; IPA	UK; local EIP service	N=8 (male n=6, female n=2; White British n=6, White Italian n=1, White Hungarian n=1); age range 19–35 years	Diagnosis not reported; all participants had experienced psychosis within the previous 5 years (n=8); most participants described delusional experiences	Self-reported delusions; delusion subtype was not differentiated; timing was unspecified (within the past 5 years)	(1) Struggling with life distress; (2) transformed world and intense emotions; (3) blame and guilt after the breakdown; (4) confusion, despair, and hope
Isham et al (2019) ³⁸	To discover from patients whether grandiose delusions have harmful consequences, the psychological mechanisms that maintain them, and what help patients might want from clinical services	Semi-structured interview; thematic analysis and grounded theory	UK; EIP team, adult mental health team, and inpatient	N=15 (male n=7, female n=8; White British n=12, Indian n=1, Black British Caribbean n=1, mixed White and Black British n=1); age range 16–65 years	Diagnosis “identified at point of referral”; schizophrenia (n=4), schizoaffective disorder (n=4), bipolar affective disorder (n=6), non-organic psychotic disorder (n=1)	Grandiose delusions held for at least 1 month with at least 50% conviction; subtype was grandiose (Schedules for Clinical Assessment in Neuropsychiatry ⁴⁴); timing was current (n=10) or past (n=5)	(1) Harm (physical, sexual, social, emotional); (2) maintenance mechanisms (meaning-making, anomalous experiences, mania, fantasy elaboration, reasoning biases, immersive behaviours); (3) experience of service-use and help-seeking
Jones et al (2016) ^{45*}	To explore the ways in which individuals with a psychotic spectrum diagnosis negotiate both cultural and clinical tensions between the real and delusional, and the sacred and secular	Unstructured interviews (part of a larger mixed-methods fieldwork); the analytic strategy was “loosely derived from constructivist-grounded theory”	USA; diverse community mental health and service user advocacy settings	N=19 (male n=9, female n=10; Caucasian n=13, African American n=3, Latino/a n=1, Asian or Asian American n=1, Multiracial n=1); age range 19–78 years	Self-reported diagnosis; schizophrenia spectrum (n=14), bipolar disorder with psychotic features (n=4), obsessive-compulsive disorder (previously paranoid schizophrenia; n=1)	Self-reported delusions: some participants were reported as being clearly symptomatic during interviews (eg, demonstrating tangentiality, association clanging, disorganisation, or active conviction in unusual beliefs), and others were not; delusion subtype was not differentiated; timing was unspecified	(1) Participant’s self-conscious engagement with both secular and clinical doubts; (2) explanatory migration, ie, a tendency to use secular and nonsecular figures, logics, and explanatory strategies in narratives
Jones et al (2016) ^{46*}	To investigate the phenomenology of subjective agency in relation to the onset and development of psychotic symptoms (primarily delusions and hallucinations)	Semi-structured interview; service-user-led, including multiple participatory techniques; grounded theory and qualitative phenomenology	USA; recruitment via flyers, internet, community field sites, word of mouth, and clinician referral	N=19 (male n=10, female n=9; Caucasian n=14, African-American n=3, Latino/a n=1, Asian n=1); age range 18–40 years (n=11), 41–60 years (n=5), ≥61 years (n=4)	Self-reported diagnosis: “All participants reported a schizophrenia spectrum diagnosis and/or bipolar with psychotic features”	Self-reported delusions and hallucinations; delusion subtype was not differentiated; timing was current or past	(1) Experiences of agency leading up to and during initial onset of psychosis; (2) experiences of agency involved in subsequent production and elaboration of positive symptoms

(Table continues on next page)

current or past experience of delusions were included in nine studies,^{18,35,46,48,51,54,58,59,61} one study³⁴ specified that psychotic symptoms were recent, and the remaining eight studies^{5,37,41,43,45,47,60,62} did not provide information on timing. Two remaining studies specified that delusions were past^{39,57} (table).

Interpretative Phenomenological Analysis was the most common methodological approach (n=14; appendix p 33). Studies differed in whether they focused specifically on one kind or theme of delusion (eg, persecutory) or investigated delusional phenomena more generally as a unified category (table). 13 studies^{5,34,42,43,45–47,51,53,54,56,59,62} did not differentiate delusion subtype, six studies^{35,37,39,48,57,60} investigated specifically the experience of participants with persecutory delusions or paranoia, one study¹⁸ investigated experiences of

grandiose delusions, and another⁶¹ had a subtheme discussing grandiose content. One study⁴⁹ investigated delusional experiences of possession, and two studies^{41,58} focused on religious content, where religious content was intertwined with persecutory, grandiose, and referential themes.

Most studies (22 [81%]) were judged to be of high methodological quality for most items on the CASP checklist and were rated as meeting all or most ($\geq 10/15$) of the NICE checklist criteria by two independent reviewers (RR and JK). Among the studies included in the final synthesis, the most frequent methodological weakness concerned items 5, 6, or 7 (trustworthiness) on the NICE checklist (appendix pp 20–31). Studies with ratings of “unsure” or “item not fulfilled” did not discuss the reflexive position of the researcher and the influence of the context

	Aim of primary study	Design and methods	Country and recruitment setting	Participants (number, gender, ethnicity, age*)	Diagnosis (if not assessed, descriptive information is reported as extracted from the primary study)	Delusional psychopathology (as reported in the primary study, subtypes of delusion, and timing of active delusions)	Main themes (as reported in the study findings)
(Continued from previous page)							
Larsen (2004) ⁴⁷	To examine individuals' attempts to generate meaning after their psychotic experiences (including delusions)	Multi-method approach including documentary analysis, individual and focus group interviews, surveys, time registration forms, and written narratives; person-centred ethnographic approach using existential anthropological perspective	Denmark; experimental early intervention programme in Copenhagen, Denmark (OPUS)	N=15; ethnicity not reported; no gender or age reported (“young people”)	Clinically established diagnosis within “the schizophrenic spectrum” based on ICD-10 criteria	Self-reported delusions; delusion subtype was not differentiated; timing was unspecified (“from shortly after they were included in OPUS until half a year after they had been discharged from this service”)	(1) Experiences with psychosis: Frank's story; (2) agency and systems of explanation: the search for meaning; (3) bricolage and the cultural repertoire
Marshall et al (2020) ⁴⁸	To explore body image from the first-person perspective of patients with persecutory delusions	Semi-structured interview; IPA	UK; community mental health teams	N=12 (male n=6, female n=6; White British n=11, Chinese n=1); age range 19–58 years (mean 43)	Clinically established diagnosis of non-affective psychosis; paranoid schizophrenia (n=7), schizoaffective disorder (n=4), psychosis NOS (n=1)	Experience of persecutory delusions as identified by a clinician; subtype was persecutory; timing was current or past	(1) Appearance as a source threat; (2) impact of uncontrollable and unwanted weight gain; (3) feeling stuck; (4) looking well symbolises feeling well
Pietkiewicz et al (2021) ⁴⁹	To investigate experiences of possession (ie, “a distorted perception of having one's mental processes or actions controlled by demons or spirits associated with local religion”) in patients diagnosed with schizophrenia, including how they concluded that they were possessed, how they reported their symptoms, and their coping strategies	Semi-structured interview; IPA	Poland; recruitment via dedicated website, health-care providers, and pastoral counsellors	N=4 (male n=2, female n=2; ethnicity not reported); age range 21–30 years	Diagnosis was established consensually based on ICD-10 criteria; schizophrenia (n=4)	Delusions of possession identified through in-depth clinical assessment and PANSS ⁵⁰ ; Kathy: delusions of influence, grandiose and religious delusions, and thought broadcasting; Alice: delusions of possession, influence, and grandeur; Charles: delusions of possession, reference, persecutory, and grandeur, thoughts broadcasting; Greg: persecutory delusions and delusions of reference and possession, thoughts broadcasting; timing was current	(1) Links between traumatic experiences and psychotic symptoms; subthemes: (1a) insecure and unpredictable environment, (1b) deprived of close relationships and attention; (2) emergence of religious themes in delusional contents; (3) reluctance for medical treatment, and seeking exorcism

(Table continues on next page)

in which the research was conducted, or they lacked information (on triangulation or other reliability checks) to enable reviewers to judge the reliability of the original data.

Three superordinate (analytical) themes relating to experiential changes and meanings, as described by

individuals with psychosis in relation to their delusions, were identified: (1) a radical rearrangement of the lived world dominated by intense emotions; (2) doubting, losing, and finding oneself again within delusional realities; (3) searching for meaning, belonging, and

Aim of primary study	Design and methods	Country and recruitment setting	Participants (number, gender, ethnicity, age ^a)	Diagnosis (if not assessed, descriptive information is reported as extracted from the primary study)	Delusional psychopathology (as reported in the primary study, subtypes of delusion, and timing of active delusions)	Main themes (as reported in the study findings)	
(Continued from previous page)							
Rhodes and Jakes (2000) ⁵¹	To explore the correspondence between delusional themes and life-history themes, in particular goals and long-term problems, which are supposedly expressions of motivational concerns	Semi-structured interview; IPA and category-led thematic analysis	UK; unspecified	N=14; gender not reported; age range not reported	Clinically established diagnosis (criteria not specified): "The majority had been diagnosed as having some form of schizophrenia, some with manic-depression, and others with delusional disorder. Three of the cases reported here were diagnosed as schizophrenic and the fourth had received a diagnosis of 'depressive psychosis'; psychotic disorder (n=14)	Clinically established delusions, using Oltmanns' proposal ⁵² of an open list of features; subtype was not specified, but the "core delusion" was presented for four selected case illustrations: (A) "I can communicate with aliens and have special powers, for example, I can change my character"; (B) "The demons will come to test me on what I am reading. If I get it wrong, I'll go to Hell. If right, I'll go to Heaven"; (C) "I believe that in 1995, insects and spiders were crawling through my body. I heard their voices, they were trying to drive me mad"; (D) "I drove two people mad, one when I was 11 and one at 14. I was hypnotized to forget at 15 years of age. The Ministry of Defence (MoD) are trying to drive me mad by chemicals in my room, animals irritating me, pains in the neck, and stooges in the street"; timing was current or past	Superordinate categories: (1) social; (2) competence; (3) experiential base; (4) material base; (5) direction; (6) evaluation
Rhodes and Jakes (2004) ⁵³	To describe and understand the types of reason or evidence given by deluded patients to support their beliefs when questioned in the context of CBT	Therapeutic interviews in the context of CBT sessions; IPA (detailed notes and extra set of taped interviews)	UK and Australia; referred by psychiatrists	N=23; gender not reported; ethnicity not reported; age range 18–65 years	Clinically established diagnosis of psychosis (criteria not specified); schizophrenia (n=15), delusional disorder (n=4), personality disorder (n=2), schizoaffective (n=1), depressive psychosis (n=1)	Delusions as identified in the context of CBT; delusion subtype was not differentiated; timing was current ("All delusions were of at least one year's duration, but most had been held for several years")	Evidence typology: (1) object perception, (2) sensation-analogy, (3) global perception, (4) thought transfer, (5) volition, (6) social perception, (7) eruptive ideas, (8) narrow-focus accounting, (9) assumptive accounting, (10) prejudicial accounting; relationship to evidence: (1) reference to the real, (2) reference to the perceiver, (3) appeal to motivations, (4) appeal to self-awareness, (5) avoidance and ambivalence
Rhodes and Jakes (2004) ⁵⁴	To investigate the possible role of metaphorical thinking in psychotic delusions, with the aim of better understanding the content of delusions	Semi-structured interview; qualitative data analysis ⁵⁵	UK and Australia; community mental health setting	N=25 (male n=15, female n=10; ethnicity not reported); age range 25–66 years	Clinically established diagnosis of psychosis (criteria not specified); schizophrenia (n=15), schizoaffective disorder (n=1), manic-depression (n=2), psychotic depression (n=3), delusional disorder (n=4)	Delusions as identified in the context of routine clinical assessments; delusion subtype was not differentiated; timing was current and long term (ie, at least 1 year's duration, often many years' duration; median 6.5 years)	(1) Figurative thinking in pre-delusional period; (2) contribution during psychotic episode; (3) contribution to maintenance

(Table continues on next page)

coherence beyond mere dysfunction. Each theme contains three descriptive subthemes (figure 2; appendix pp 36–40).

The first superordinate theme specifies the embeddedness of delusions within a radically altered or unfamiliar world, often loaded with overwhelming emotions and characterised by incessant mental struggle

(eg, repetitive thinking). Although emotional distress was common, some described these changes in positive terms.

In the first subtheme, alterations of basic reality experience, and other unusual sensory or extrasensory perceptions were often reported by participants as strongly intertwined and entangled with their delusions in complex

Aim of primary study	Design and methods	Country and recruitment setting	Participants (number, gender, ethnicity, age*)	Diagnosis (if not assessed, descriptive information is reported as extracted from the primary study)	Delusional psychopathology (as reported in the primary study, subtypes of delusion, and timing of active delusions)	Main themes (as reported in the study findings)	
(Continued from previous page)							
Rhodes and Jakes (2010) ⁵⁶	To explore the beginning and development of delusions from the perspective of those with lived experience	Semi-structured interview; IPA	UK; community mental health teams (two inner-urban areas)	N=28 (male n=16, female n=12; White n=11, Black Mixed Race n=2, Black British n=10, Asian n=3, and Middle-Eastern n=3); age range: not reported (mean 37 years 10 months)	Clinically established diagnosis of psychosis (criteria not specified); paranoid schizophrenia (n=12), schizophrenia (n=3), schizoaffective disorder (n=1), bipolar disorder (n=2), delusional disorder (n=4), psychotic depression (n=3)	All participants had developed delusions based on clinical assessment; delusion subtype was not differentiated; timing was current	(1) Styles of onset, eruptive multi-episode emergent onset in childhood; (2) social and emotional problems
Rhodes and Healey (2017) ⁵⁷	To investigate the experience of adults with a diagnosis of psychosis (including delusional experiences) and who have survived childhood physical abuse	Semi-structured interview; IPA	UK; hospital-based psychology department	N=8 (male n=5, female n=3; White British n=4, British n=1, White Irish n=2, Asian British n=1, Nigerian British n=1, Black Mixed Race n=1; age range 23–53 years)	Clinically established diagnosis of psychosis (criteria not specified); schizoaffective disorder (n=2), bipolar disorder (n=1), paranoid schizophrenia (n=4), drug-induced psychotic episodes (n=1)	Self-reported delusional experiences; subtype was paranoia; timing was past ("participants positioned themselves at present as not being under the sway of these ideas and feelings; however, it was clear that sometimes they were prone to succumb to what appears to be a sort of force")	The fluctuating thread of meaning and identity transformation; other themes (not relevant to this qualitative evidence synthesis) were not included
Rieben et al (2013) ⁵⁸	To elicit how patients with delusions with religious contents conceptualised or experienced their spirituality and religiousness	Semi-structured interview (as part of a larger study including qualitative and quantitative methods); grounded theory	Geneva, Switzerland and Trois-Rivieres, Quebec; four public ambulatory psychiatric facilities (Geneva), Assertive Community Treatment programme (Trois-Rivieres)	N=62 (male 77%, female 33%; White 92%, other 8%); mean age 42 years (SD 11)	Diagnoses were established with the Mini-International Neuropsychiatric Interview and ICD-10 criteria; axis I diagnoses were schizophrenia (82%) and schizoaffective disorder (18%), with a comorbidity of substance misuse of 24%	Delusions identified using qualitative content analysis of the interview transcripts: "delusions of persecution, delusions of self-significance, and delusions of influence were categorized as delusions with religious contents when the agents of persecution, of power, or of control were spiritual entities"; subtype was religious content; timing was current (n=38) or past (n=24); average duration of illness 19 years (SD 12)	Higher-order concept: structure of beliefs (open, closed, or mixed dynamics); major themes: (1) spiritual identity (single or plural, stable or unstable, permeability); (2) meaning of the illness (spiritual nature, "empty envelope", identification with a spiritual figure, possession, spiritual mission or role); (3) spiritual or religious figures (subcategories: unique divinity, spiritual force, religious authorities, dead family members, supernatural beings, aliens)
Sips et al (2021) ⁵⁹	To investigate whether and how insight experiences (in particular aha experiences, anti-aha experiences, and the dialectic between them) play a role in psychosis as reflected in reports of people with experience of psychosis	Semi-structured interview, focus group; IPA	Belgium; two psychiatric wards and a patient organisation	N=21 (male n=15, female n=6; ethnicity not reported); age range 19–59 years (mean 39)	Diagnosis within the schizophrenic spectrum; no information on how the diagnosis was obtained	Comprehensive Assessment of Symptoms and History Interview (CASH) delusions present (0–5): mean 1 (SD 2); delusion subtype was not differentiated; timing was present (n=4) or past	(1) Aha-experiences: sudden and abrupt insight experience; new associations and connections; (2) dialectic of aha and anti-aha experiences: shifting from insight to shock; (3) anti-aha experiences: fear of possibility and realisation; seeing the past in a new light; identity and self-awareness (Table continues on next page)

Aim of primary study	Design and methods	Country and recruitment setting	Participants (number, gender, ethnicity, age*)	Diagnosis (if not assessed, descriptive information is reported as extracted from the primary study)	Delusional psychopathology (as reported in the primary study, subtypes of delusion, and timing of active delusions)	Main themes (as reported in the study findings)	
(Continued from previous page)							
Stopa et al (2013) ^{60†}	To explore threat experiences in people with social phobia and persecutory delusions (particularly how they encounter, engage, and live through these distressing situations)	Semi-structured interview (adapted version of the Cognitive Profiling Interview); thematic analysis	UK; recruitment through consultant psychiatrists	N=18 (schizophrenia with persecutory delusions n=9 [male n=5, female n=4; age range 29–57 years]; social phobia n=9 [male n=2, female n=7; age range 20–58 years]); ethnicity not reported	Diagnosis was confirmed through the Structured Clinical Interview for DSM-IV-TR Axis I disorders; schizophrenia (n=9)	All participants in the schizophrenia group had persecutory delusions based on clinical assessment (criteria not specified); subtype was persecutory; timing was unspecified	Superordinate theme: narrative coherence; major themes: (1) experience of threat (threat and safety; affective, sensory, and perceptual experiences); (2) reaction (trapped in thinking; control and escape); (3) reflection (lost or decentred; judgements of self; parallel understanding)
Strand et al (2015) ⁶¹	To provide a deeper understanding of how individuals with psychosis make sense of the content of their psychotic symptoms, including delusions	Semi-structured interview; IPA	Sweden (outskirts of an urban area); outpatient unit specialising in psychosis	N=12 (male n=7, female n=5; ethnicity not reported, but authors report on country of birth: Sweden n=8, another European country n=2, Middle East n=1, South America n=1); age range 29–63 years	Diagnosis not reported; patients either had active psychotic symptoms at the time of interview or reported symptoms within the past year	Descriptions of grandiose beliefs as self-report by four participants; subtype was grandiose content; timing was current (n=9) or within the past 12 months (n=3)	Narratives about (1) grandiosity; (2) harassing voices; (3) commanding voices; (4) supportive voices (themes 2–4 did not contribute to the synthesis)
Taylor et al (2020) ⁶²	To explore core schematic beliefs (strongly held beliefs about the self and others) in individuals with psychosis and their relation to hallucinations and delusions	Semi-structured interview; thematic analysis	UK; early intervention services and community mental health teams	N=20 (male n=15, female n=5; White British n=16, any other White n=1, White Irish n=1, Pakistani n=2); age range 18–47 years (mean 31.49)	Clinically established diagnosis based on ICD-10 criteria; schizophrenia-spectrum (n=20)	Participants had a score of 3 or more on the PANSS P1 Delusions or P3 Hallucinations subscales; delusion subtype was not differentiated; timing was unspecified	(1) The solidity and permanency of core beliefs (this theme did not contribute to the synthesis); (2) the causes and development of core beliefs; (3) the synergistic relationship between core beliefs and symptoms; (4) core beliefs, images and their influence on symptoms

IPA=interpretative phenomenological analysis. NHS=national health service. CBT=cognitive behaviour therapy. NOS=not otherwise specified. EIP=Early Intervention in Psychosis. OPUS=Danish mental health community programme for early intervention in schizophrenia. PANSS=Positive and Negative Syndrome Scales. *Although our pre-established inclusion criteria for participants and population specified an age range of 14–65 years, these studies were considered eligible as the majority of the population was within the pre-established age range, thus contributing relatively more to the main themes identified by the authors of the primary study. †Only the group with persecutory delusions was included in the thematic synthesis.

Table: Summary of characteristics of included studies

ways. For some, the reported subjective changes represented a novel, unexpected and all-encompassing transformation of their overall reality.

“It was like a lightning bolt hitting my world [...] It was like I couldn’t escape from it. I didn’t know what was happening as well. There was a psychology added to it, abuse added to it, and I didn’t know what was happening. It never happened to me before.”³⁴

Others described a radical alteration of their lived world resulting from unusual sensory, extrasensory, or bodily perceptions, such as hearing voices, painful bodily sensations, mental intrusions, vivid dreams, or dissociative experiences. Although seemingly limited to one or few perceptual or cognitive modalities, such alterations appeared to contribute similarly to a profound

change in the individual’s experience of reality by eroding trust in oneself, increasing uncertainty, and inducing intense emotions.

“T: What do you think about those voices now? P6: Well I was hearing people plotting against me. Saying my name and I would hear people shouting my name at night. But then when I was taken into hospital and I was in a quiet ward at the back of the hospital and there was no activity outside, I was hearing all these things, and that was the first time I realised that what I thought was everyday life wasn’t real. (right, ok). I’d been hearing things for years. T: What did you think at that moment then when you realised? P6: It shook me deeply actually because I couldn’t trust my mind anymore.”³⁵

For many, particularly in the case of delusions of reference or persecution, the surrounding environment

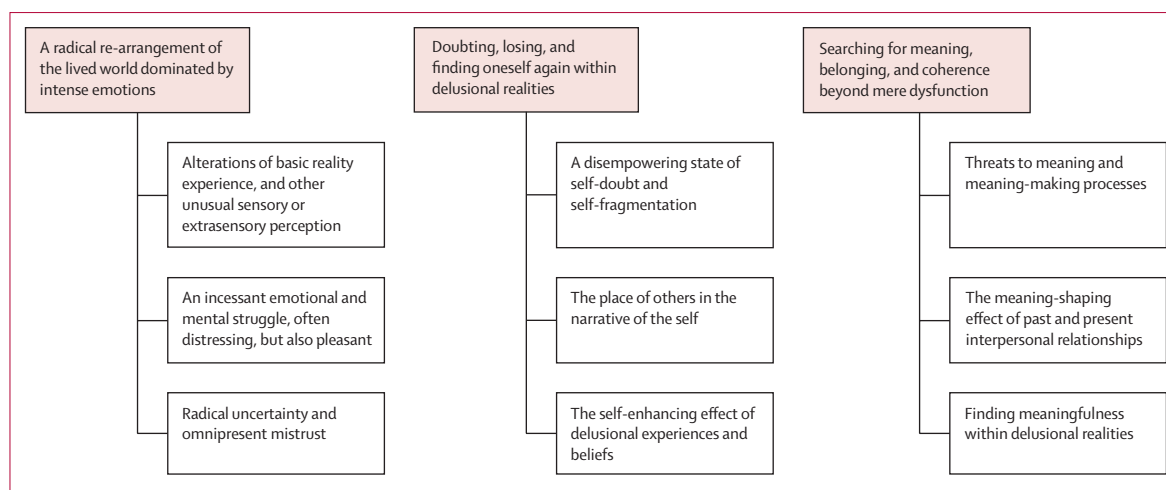


Figure 2: Overview of superordinate (analytic) and subordinate (descriptive) themes

turned into a hostile, threatening, or apocalyptic world where participants felt frightened, vulnerable and in constant anticipation of threat. Threat was often predicted as coming from other people, but it could also be referred to specific hyper-salient objects or felt as an all-encompassing atmospheric experience embedded within one's surroundings.

"Yes, it just felt like you're being watched and perhaps people are following your every moves, so you have to be careful and very...I guess there's also a feeling of...like I was always a bit scared and frightened of everything that I encountered."³⁴

Reality changes were not always distressing. Some participants reported positive changes, which they likened to the experience of accessing heaven, entering the spiritual world, or establishing a cosmic union with the universe.

"At that moment, I believe you are in contact with the universe. Every step that I took was rhythmical, and after a while, everything I did was rhythmical, every step, every eye movement. You have a better feeling for timing in which you master each moment, a moment in which you lose time and space, hour and time."³⁵

In the second subtheme, participants described an incessant emotional and mental struggle, often distressing but also pleasant. Distressing emotions, such as fear, shame, and guilt were often described in overwhelming terms, leading to varying internal or behavioural responses, including attempts to control, avoid, or suppress the experience, or to a state of inertia.

"Especially the feelings of guilt, the guilt was the worst part of it, you know, I'd felt, I literally felt guilty for all the problems in the world and that was too much of a burden for me to take on and that guilt was so overwhelming and overpowering, it just overtook my

every thought and that at the time I was probably crying up to ten times a day, you know, and it just completely disabled me, I just couldn't do anything."⁴³

In many cases, overwhelming feelings appeared to drive repetitive thinking, which in turn intensified the emotional experience and the sense of losing control, leaving no possibility for the individual to relax or think of anything else.

"It changed my thinking like that (hands clicked), with in a matter of, once something happened I started thinking, and once you start thinking you can't stop, you can't get rid of it, everywhere you go, you can't control your mind, and then the paranoia comes on and it gets worse and worse and specially when you're not sleeping it gets even worse."³⁵

In the case of persecutory delusions, participants often described ruminating on the perceived or hypothesised origins of the threat, overdwelling on possible future threats, or imagining possible plots and links with people involved in interpersonal fallouts in real life. Thinking was often described as having a particular, compelling draw similar to a compulsion: a sense of having grasped something that is so clear and so persuasive, that it is very difficult to resist, despite the negative and distressing content.

"it's like a sort of torture, but thriving off it...and putting yourself down by these thoughts...you know it's, nothing you, nothing to do with you in that sense, but it's just this compulsion to draw in and you know poke the fire and keep it burning."³⁷

In the case of positive emotional experiences, such as those linked with grandiose delusions, repetitive thinking was also described, but this was experienced by some as a pleasant escape from boredom.

“It fills my time. I’m always busy [...]. In the past without doing that I’d be just feeling bored, sitting in my flat, listening to the radio, watching TV, sitting on my computer, bored, drinking alcohol. [...]. But with this situation I am busy thinking all the time.”¹⁸

In these cases, and for short periods of time, positive emotions associated with delusional experiences could be deliberately sought out rather than avoided or suppressed, especially when laden with excitement and exaltation. Even in cases of persecutory delusions, some participants reported enjoying the attention received from others, despite concurrent feelings of threat.

“T: You say there that you like paranoia, what are the good things about paranoia? P9: It gives you eh...a funny, a funny feeling, like, if you’re not getting attention you’re like, you can feel like you’re getting attention, know. (mmmh). See if you’ve got a lack of attention (yeh) you can enjoy it. You know, they’re all looking at me and all that.”¹⁵

In the third subtheme, participants described their experiences of delusion as involving radical feelings of uncertainty and omnipresent mistrust.

“I was just staring at a blank white paper. I really didn’t know what was happening anymore. My consciousness and subconscious had been drawn close to each other, dream and reality blended into one another and I just wasn’t sure anymore.”⁵

This often led to a disempowering state of confusion and disorientation, which in some cases fostered feelings of hopelessness and despair. People reported feeling deeply shaken in their basic assumptions about themselves, the world, and other people—to the point that they could no longer trust their own judgment.

“Yes, you are afraid, but it is much bigger than fear. [...] Nothing is right anymore. The entire world...seems to implode upon you...Nothing is as you thought it was anymore [...] You can’t trust anything anymore. Is this a table? It might seem so, but is it really the case? Probably not (laughs). These people are sitting here, but are they really people or is it my imagination, or...? Pff... everything is possible...everything is possible.”⁵⁹

Across some of the studies, the sense of mistrust and abandonment stood in contrast with a deep desire for connection and belonging. Being respected, complimented, and supported by others were needed to regain a sense of safety, stability, and order. This is linked to and partly overlaps with theme three.

“I’ve been hungry...for life, for hope, recovery, to find my place in the world, hungry for love. I mean hunger is a basic need that needs to be...it’s to be...everybody needs... hungry for attention, everything.”³⁴

The second superordinate theme is concerned with the complex and dynamic processes of intrapersonal and interpersonal identity negotiation and self-constitution, arising in response to the alterations of the lived world,

and concurrently shaping the content and course of delusional phenomena. Self-constitution refers here to the ways the self as a dynamical structure becomes stable through adaptation and negotiation of its relationship with the world over time (appendix p 2).

Within the first subtheme of the second theme, intertwined with feelings of confusion and radical uncertainty, many described a disempowering state of self-doubt and self-fragmentation, which could lead to completely losing one’s sense of diachronic self-identity.

“At a certain moment, nothing remained. I did not even know who I was anymore, I still have problems with that sometimes. Like, who I was, it wasn’t there anymore. Or who I was 20 years ago, it was gone. And what was there, was sometimes difficult to determine [...].”⁵⁹

Self-instability and inconsistencies were salient as a perpetual sense of self-doubt accompanied the shifts in perspective driven by altered or multiple reality experiences. For persecutory delusions, people talked about holding conflicting beliefs about reality and about others, and explained how this contributed to a sense of being “in pieces” or “divided in two”.³⁷ This was often described as a disempowering state, similar to “hanging in a limbo”³⁴ or to a condition of liminality.⁴⁵ For some, a sense of losing their former self was accompanied by a desire for “normality” (eg, “Am I ever going to be normal again?”)⁴³ and by perpetual questioning.⁵

“It was like I wasn’t part of this world anymore, that I didn’t have a self-experience, and a lot of suspicion towards others. If others told me ‘you’re doing well’, then I thought to myself ‘what is this?’ Perpetual questioning and analysis.”⁵

Often, voice hearing and disturbed agency contributed to feelings of vulnerability and to a sense of “self-under-attack”,³⁵ whereby anomalous experience seems to contribute to the internally generated evidence for persecutory ideas, such as for auditory verbal hallucinations in which the persecutory content of the voices is endorsed in delusional expressions. Concurrently, some participants spontaneously linked their feelings of uncertainty with fallouts with an individual or a group with whom they were close (interpersonal rupture), or other social difficulties involving isolation or violence.^{35,54} In these cases, real-life interpersonal stress further contributed to the externally generated body of evidence in support of the idea of being vulnerable and under threat. Here, contingent life events appeared to be woven into the delusional narrative.

“Andrew described his workplace as a ‘hellhole’. He found it very difficult to talk about this, resorting to analogy and generalisation: It’s that awful. You’ve seen the original *Planet of the Apes*...film, 1964 I think it is with Charlton Heston...and you know how he’s treated during it? Management treat you the...similar to that. That’s how it felt.”⁴²

In the second subtheme, when describing their self-perception, participants stressed the place of others in the narrative of the self. They often talked about perceived self-discrepancies either in relation to an ideal or ought self, or in relation to an ideal state they believed significant others wished for them. Often, self-discrepancies contributed to feelings of guilt or self-contempt and to rejection-related emotions (eg, shame or embarrassment). Early experiences of victimisation or bullying were often mentioned in relation to self-discrepancies and reinforced negative self-evaluations.

“She reported being somehow different in her family and that even her younger siblings made her ‘feel small’, and her friends at school treated her ‘like their kid sister’. P-C stated that she had been criticized and rejected by her siblings throughout her childhood. Furthermore, they were all the children of her mother’s husband, she from an affair; she never knew her biological father.”⁵¹

Negative interactions with others in daily life (current, remembered, or imagined) often appeared to confirm participants’ negative self-evaluations, further increasing distressing emotions and maintaining a sense of self-under-attack, in studies of persecutory and grandiose delusions.

“(T)hey treat you with absolute contempt [...] I almost feel like I have to apologise for myself [...] But now, virtually nobody talks to me. I don’t know if that’s my body language. I think maybe it’s because I’m avoiding eye contact and sort of keeping myself to myself and I do it subconsciously [...] or whether it’s because I’ve got a scary face.”⁴⁸

As the third subtheme, participants across more than half of included studies reported a positive, self-enhancing effect of certain delusional experiences and beliefs. This was particularly, but not uniquely, evident in the context of grandiose delusions,¹⁸ where self-attributions of special powers and unique abilities were often lived as mood-elevating and as a preferred reality when compared with the memory of a premorbid state. Concurrently, the gaining of clinical insight appeared to be associated with severe depressive feelings.

“[It made] me feel strong and powerful and sort of able to do anything. The sort of feeling you get, it makes you feel like you become the person you’ve always wanted to be or better.” [...] “(Y)ou slip into quite a deep depression after you realise [...] it’s not like you go from a feeling of being really important back to where you were before, you go from really important to really unimportant.”¹⁸

The third superordinate theme is concerned with the individual and intersubjective processes of meaning-making driven by a fundamental human need for coherence, significance, and belonging. These processes were described both as pre-predicative (ie, non-propositional), referring to, for example, sudden aha or

eureka experiences, and as reflective sense-making attempts taking a narrative form. Across most studies, participants encountering unexpected changes in the lived world and identity often expressed a clear and motivated need to maintain a sense of coherence, purpose, and meaning in life. Delusional experiences, irrespective of their level of strangeness, bizarreness, and salience, all demanded personal understanding (accounting for teleological relations of meaning linked to questions such as “why is this happening to me?” or “what significance does it have?”), beyond a simple problem-solving approach to remedying a dysfunction or a symptom of illness.

In the first subtheme of the third theme, threats to meaning and meaning-making processes were evident in participants’ descriptions of their interpretive and communicative struggles as they experienced something literally indescribable.

“I mean, even now, even though I’ve experienced it, because it’s, it’s my mind coming back together. It’s like, that, that’s no...I can’t really, I can’t really understand it anymore. I mean, I can understand the bits that are still relating to some of what I’m experiencing now, but the bits that were so surreal and bizarre, I can’t, I can’t really understand them anymore, even if I ever could.”⁴³

As a consequence, people engaged in various meaning-making efforts aimed at finding a suitable explanation for, and a fitting understanding of, their unusual experiences. Notably, these processes did not merely involve an isolated instance of atypical mental reasoning. Although sudden “insight experiences”⁵⁹ were reported by some, people more often engaged in dynamic and temporally evolving processes of searching for meaning, giving meaning and co-constructing meaning by drawing on private and shared hermeneutical resources (eg, interweaving personal stories and experiences with culturally available and widely shared meanings). These social epistemological aspects and interactions were more easily detected by approaches such as meta-ethnography, where the situational context and the effects of interpersonal exchange are also considered.⁴⁷

“Hence, a variety of systems of explanations were available to my informants, depending on their social positioning: influences from institutions, public media, and social networks. Informants had different strategies of rejecting, accepting, and combining these systems of explanation to create an individual explanation that was subject to continuous renegotiation. As mentioned earlier, at her fourth interview Eva told me that she had given up attempts to discover a unified explanation of her psychosis. Instead, she had realized that various perspectives prevailed and that the thinking advocated within psychiatric institutions was just one of many: ‘When you leave the hospital psychiatry then it is just an institution in the society, with the worldviews and understandings they have there.’”⁵¹

In some cases, the person's ideas of exceptional knowledge and ability (eg, in the case of grandiose delusions) could lead to discounting others' testimony or feedback.

"Interviewer: When you're in that mode of being God, how do you respond to advice or feedback from others?
Sophie: Completely dismiss and ignore it."¹⁸

In other interactions, the participant's epistemic agency appeared to be undermined, leaving the person isolated with their own evolving interpretive framework and reinforcing paranoid ideas.

"Well it's hard, because I become so convinced, I have become so convinced that something isn't right. To confront the last people about if there's any truth to what I'm experiencing and they say, 'No, it's ridiculous, it can't happen. You know you're just unwell, you need to rest. Get back on medication.' Makes you feel terrible, because you're so convinced that these things are happening and you feel you want a straight answer and that leads you to believe people are lying, cause you're so convinced yourself, which destroys any trust which burns bridges and you're sort of left on your own to ponder over the ideas in hospital while you're back on medication."⁴³

Testimonial isolation (eg, loss of communicative exchange) could also result from the secrecy of the delusional belief itself or from a lack of interaction on the part of mental health staff, potentially increasing the risk of epistemic injustice within the clinical encounter.

"I won't speak to them about it, thinking it's something that needs to be kept secret."¹⁸

"Nobody talked to me. I wanted to talk to them [...] I was alone and isolated."¹⁸

"You tell care staff, the medical staff and then they say, 'right, you have to go into hospital' and 'we're taking your driving licence away.'¹⁸

As participants interacted with other people (eg, family members or mental health staff) supporting a medical or illness narrative, they engaged in a process of appraisal or position taking, where they reflected and responded to their experiences and to others' narratives in different ways. Many appeared to hold different appraisals or attributions simultaneously and expressed multiple narrative voices by mixing terms conventionally associated with biomedical discourse alongside invocations of spiritual figures, possession and the paranormal.^{45,47,49}

"Charles's explanatory models of his unusual experiences changed over time. Initially, he was convinced he had a chip in his brain after reading on the Internet about alien civilizations controlling humans. He even saved money for a computed tomography (CT) scan to confirm his theory. "These voices convinced me that I had a chip installed in my brain. I had a sensation

in my head, like an electric current, an electronic impulse. I also read about it on the web. I had to find out if I was mentally ill or had an implant, but the tomography did not prove anything' (Charles). Because his voices and tactile symptoms persisted despite pharmacotherapy, he also refused to accept the medical diagnosis of schizophrenia, deciding instead that his problems could only be explained in terms of demonic possession. He believed that spirits could produce symptoms resembling mental illnesses and could also mess with his mind. 'I also read that some evil spirits can imitate mental illness. I don't know if that is the case because I never had problems with my faith. But I read that these spirits feed on human weakness.'^{7,49}

Participants also expressed a strong need for closure, and some highlighted dissatisfaction with current therapeutic approaches as they failed to promote narrative integration and understanding. A shared exploration of meanings appeared to positively impact therapeutic engagement, particularly where people did not accept that their experiences reflected a symptom of mental illness.

"I have done all sorts of therapy. And I found that it often offers common-or-garden tips in order to manage yourself. But that really doesn't suffice. You need to get insight into what happened, into the entire story that unrolled."⁵

Many described loneliness and isolation as the most troublesome experiences either in their current or past life and some understood their delusions as stemming from a lack of belonging. Within the primary studies, some found that these affiliative needs were a significant motivation for establishing and maintaining a relationship with a spiritual or religious figure in the context of participants' delusions.^{49,56,58,61}

"Loneliness is the most troublesome thing throughout my whole life. Perhaps one wants life to be different, yes. I have noticed that loneliness is the reason for my thoughts. Don't know. If that's a cause, then, yes."⁶¹

The second subtheme was the meaning-shaping effect of past and present interpersonal relationships, which became evident as memories of early adverse experiences with caregivers and peers appeared to significantly shape how participants made sense of their lived world, self-perception, and experience of mental illness.

"I think even at school I was paranoid because all my life I have just been like (pause), how can I say like a tree stump and every experience that I have had is like, something has driven a nail into me."³⁷

Although only one study specifically aimed to investigate the role of figurative language,⁵⁴ this analysis was able to detect thematic links between early adverse experiences and delusional content. These links appeared to be established, in some cases, through metaphorical and metonymic thinking.

“P1 described how she had attended a harsh religious school where she experienced social and academic difficulties. The children were obliged to attend the school’s church on a regular basis. The church contained small statues of ‘devils’. On one occasion P1 recalled noticing the way the nuns looked at her as if she were bad, and at the same time she began looking at a statue of a devil. She remembered wondering if she was like the devil. When in her early 20s, the patient went on to develop the idea that she was ‘possessed’ by a devil. She developed auditory hallucinations and heard a ‘devil’s voice’, and experienced other people as laughing at her. She was diagnosed as having paranoid schizophrenia.”⁵⁴

Interpersonal experiences of loss and rejection also appeared to directly affect participants’ sense of trust, belonging, and connectedness to the lived world. In the absence of the usual human connections providing people with a sense of belongingness and predictability, unpleasant emotions seemed to take over, accompanied by a heightened need for meaning and control. In some cases, religion appeared to act as a buffer, providing relief from this sense of meaninglessness.

“When Barbara’s husband finally left her, she became extremely depressed: ‘I was really depressed, really down, really miserable. So I prayed as you do...I just want this pain to go away. So...um...I’d already been through a bad time, took an overdose, everything and then all of a sudden...I felt better after I’d prayed.’ [...] Barbara prays for resolution and for the pain to go away. The breakdown of her marriage represented a significant alteration in Barbara’s lived experience. Her marriage gave her meaning and, although her husband was unreliable he had always returned to her in the past thus affording a form of stability.”⁴²

In the third subtheme, some participants described delusions as enhancing feelings of comprehensibility, coherence, and meaningfulness. Some reported a pleasurable feeling of meaning as they identified new meaningful connections in the context of a hyper-salient experience of the ordinary. This sense of heightened perceptions was described by some as having a compelling draw akin to aha or eureka experiences of “all-knowing”, “seeing through everything”, or of “the pieces of the puzzle falling together”.⁵⁹ Although often associated with predominantly positive emotions (eg, awe and wonder), often participants highlighted how these experiences could be at the same time frightening and how—in the long term—they could undermine self-trust.

“At that moment, everything is right, and is logical... and...reality is...completely clear for you. It is the pieces of the puzzle falling in place. You understand everything, you see everything, you grasp everything.”⁵⁹

Finally, some participants highlighted positive social meanings of delusions: they involved feelings of “fullness”, “overflowing with universal love”, a sense of “being part of a team”, and ideas of making a valuable contribution to society, helping others, having children,

and finding protection.¹⁸ In some cases, religious experiences in the context of delusions could provide strength and a way of coping with loneliness.

“Benefits in terms of relationships were described by participants, specifically participants valued the relationship with God which religion afforded them as well as belonging to a religious group providing membership of a community, and church/religious meetings providing a meeting place.”⁴¹

Going beyond each individual theme, we developed a novel integrative framework for understanding delusional phenomena (figure 3). In this emergence model of delusion, delusional phenomena are emergent in the sense that their meanings are rooted in and emergent from the person’s phenomenal consciousness, through an engagement with others and the sociocultural context that is mediated by language and affect. For example, early traumatic memories and difficult interactions in adulthood were essential aspects of some delusional narratives, such that they might be considered generative factors in the development or maintenance of those specific instances of delusion—as a strongly individualised phenomenon. Similarly, loneliness, isolation, and the need to belong all appeared as essential, constitutive aspects of other delusional experiences and narratives. Concurrently, other generative mechanisms working within the same stratum and across strata (figure 3), were identified in each theme and subthemes, which could contribute to shaping the form, structure, and meaning of a certain delusion for a particular individual and context.

Discussion

We found that delusions often involve a radical rearrangement of the lived world dominated by intense emotions, that they are embedded within complex and dynamic processes of intrapersonal and interpersonal identity negotiation and self-constitution, and that they are often driven by both individual and intersubjective processes of meaning-making, expressive of a fundamental human need to find coherence and meaning beyond a simple dysfunction framework. Thus, delusions in psychosis are best understood as strongly individualised and inherently complex phenomena resulting from a dynamic interplay between interdependent subpersonal, personal, interpersonal, and sociocultural processes (figure 3).

Our findings support the idea that individual processes of meaning-making and self-interpretation, and the social co-construction of meaning through testimonial exchanges, play a fundamental role in the acquisition and maintenance of delusions. In the initial stages of psychosis, these meaning-making processes might be central predictors of distress and the need for care,⁶³ suggesting that anomalous experiences alone do not always and necessarily indicate the presence of a clinical

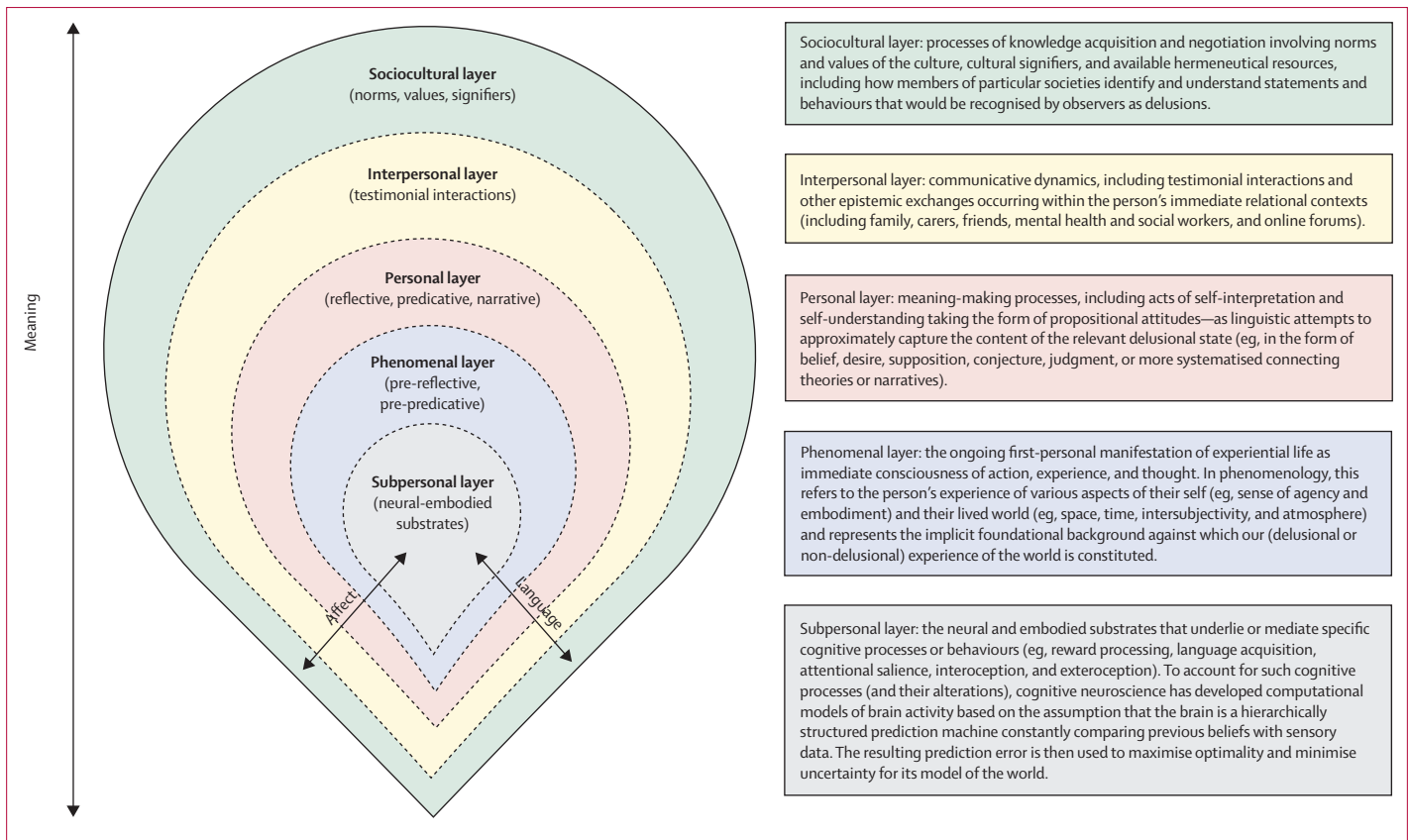


Figure 3: Emergence model of delusions

This model represents the emergence of meaning in delusions through interdependent layers or strata of increasing organisational complexity—each depending in part on the properties of the lower levels, but irreducible to it or them. The boundaries between layers are porous to indicate interdependence and reciprocal interactions. Each layer is autonomous, in the sense of being governed by its irreducible set of laws and mechanisms, which can be studied by different disciplines using different concepts. Delusions can thus be studied at each level (eg, by computational neuroscience, phenomenology, narrative psychology, anthropology, or sociology) in their different presenting forms, structures, and meanings (eg, as dysfunctional basins of attraction, altered reality experiences, dysfunctional beliefs, meaningful narratives, or the product of cultural signifiers). Potentially dysfunctional mechanisms at one level could therefore show adaptive properties at a higher or lower level. Here, language and affect are provisionally represented as arrows intersecting all strata due to their meaning-shaping effect at multiple levels, and their potential mediatory or causal role, or both, within and across layers.

disorder. This is particularly relevant for the assessment of attenuated or subclinical symptoms of psychosis, where in-depth phenomenological investigation and consideration of interpersonal and contextual meaning variables might allow for a more person-centred approach to care and decision-making beyond symptom reduction or predetermined functional goals. Similarly, in the aftermath of psychosis,⁶⁴ meaning-making might be central for understanding the process of recovery and improving long-term outcomes.

However, meaning is not always achieved through a reflective process easily mapped onto a specific cognitive or meta-cognitive function, such as those involving higher-order inferential processes. Our findings support the idea that a different pre-predicative, non-inferential sense of felt meaning or feeling of meaning might be involved in certain processes of delusional intuition or revelation. This affective dimension of meaning-making might be more appropriately framed as moods, atmospheres, or existential feelings,⁶⁵ providing an

explanatory framework for many psychopathological experiences frequently interpreted as pathologies of belief.

More strictly phenomenological models of delusions have emphasised the role of alterations of minimal selfhood as underlying and motivating delusional experiences.¹⁹ Descriptions of ipseity, or other phenomenal dimensions of experience such as time, space, or embodiment were not particularly frequent in our dataset. Possible reasons for this include a lack of dedicated qualitative research methodologically tailored to capture alterations of minimal selfhood, the inherent ineffability of self-disturbances, and their limited accessibility to language, and our caution not to impose a preconceived theoretical framework. This does not rule out a potential role for self-disturbances in the generation of some delusional experiences.

The important role of alterations in the experience of reality was confirmed by our data—in line with Feyaerts and colleagues⁵ and with an extensive phenomenological psychopathology literature. However, our findings also

suggest the need to look beyond the simple presence or absence of these experiential anomalies, and beyond the selective investigation of minimal dimensions of selfhood. Although these dimensions might play a significant role in the onset of certain types of delusions in schizophrenia, our multilayered and transdiagnostic model supports arguments for a contextual phenomenology of psychopathology—broadening the focus on self-disturbances to include the environmental and social contexts in which such disturbances occur.⁶⁶

Future research might benefit from a specific focus on the emotional background within which delusions are embedded and which gives them meaning. Epistemic emotions,⁶⁷ uncertain (ie, associated with uncertainty) emotions,⁶⁸ and existential feelings⁶⁵ are all appealing candidates for this interdisciplinary endeavour. The role of emotions in psychosis has been increasingly recognised, but research has focused on worry, depression, and anxiety in paranoia.⁶ Our results encourage a more in-depth examination of the role of different kinds of emotions across delusional themes, particularly for uncertain emotions (eg, surprise, fear, hope, and awe). For instance, awe (central in our dataset) has been found to increase supernatural belief and intentional-pattern perception,⁶⁹ which in turn have been linked to agency detection. Similarly, Whitson and colleagues⁶⁸ found that the uncertainty of emotions (more than their valence) increased belief in conspiracies and paranormal activity as forms of compensatory control—providing structure to the world.

Our model also allows us to speculate on possible avenues for integration with current computational models of delusion.⁷⁰ Approaches involving predictive coding constitute a promising framework, because of their emphasis on the role of uncertainty and its management, their modelling of individuals as agents who change the world, and their disavowal of strict conceptual separation between experience and belief. Predictive coding accounts of delusions also make room for their potential adaptiveness and recognise their epistemic benefits.^{71,72} Delusion formation thereby strategically reduces uncertainty through the provision of a new explanatory framework that allows re-engagement with an otherwise too-chaotic world. This is compatible with our findings, suggesting that some delusions were lived as enhancing feelings of comprehensibility and coherence, which provided new foundations for self-trust and hope for the future. In line with the feelings-as-information approach,⁷³ these feelings of meaning might be seen as providing adaptive information about the presence of reliable associations in the environment, thus directing cognitive processes in important ways.

The studies included were predominantly of high methodological quality. The main area of weakness across studies was a failure to address the role of the researchers' subjectivity and the research relationships,

including the social identity (and power relations) of individuals involved in the interviews and the effect of the context in which the research was conducted. Attending to the above methodological issues (eg, through reflexivity) is particularly important for delusion and psychosis research in clinical settings; a psychotherapeutic context might profoundly shape interview responses by indirectly affecting the language used by participants. The stage of illness and the length that participants spent under the care of mental health services, and the number and kinds of psychological interventions received, might also have influenced the results. Authors' interpretations (second-order constructs) originating from primary studies lacking in reflexivity should therefore be interpreted with caution. In our synthesis, these were coded separately from participants' quotations (first-order constructs) and none of the themes were based exclusively on second-order constructs.

As participation in in-depth qualitative interviews requires a willingness to cooperate and a degree of clinical insight, our findings might not be transferrable to all patients with delusions at all stages. In addition, due to the lack of information provided in the primary studies about diagnosis, potentially distinctive delusional phenotypes could not be discriminated in relation to different psychotic disorders. Given previous phenomenological research highlighting differential typologies of delusions in relation to diagnostic constructs,⁷⁴ qualitative empirical comparisons of their phenomenological features might also be considered in future investigations. Another methodological limitation is that delusional phenomena could not always be separated from other experiential alterations belonging to the broader psychosis phenotype. Finally, our search was limited to English-language studies and might have missed cross-cultural research, and most studies were in western, educated, industrialised, rich, and democratic (WEIRD) societies.⁷⁵

Our study adds depth, nuance, and complexity to previous psychopathological research on delusion. Within the clinical encounter, it might be helpful to think of delusions not as truths set in stone, but as a web of statements acting as expressive tools with a potentially adaptive function. Clinicians should be alert to and responsive to feelings of emptiness, hopelessness, and meaninglessness, which might arise in the post-delusional phase and might be aggravated by shame and self-stigmatising attitudes. The challenge now is for psychiatry to realise more of its complexity and come closer to the worlds of those directly affected. This will require a plurality of scientific efforts alongside a deeper and more genuine engagement with multiple forms of lived expertise.

Contributors

RR and MRB conceived the study, and MM and CSH contributed to the formulation of the study design. RR, JK, and DWO undertook the

literature searches, organised retrieval of articles, screened retrieved articles against eligibility criteria, and assessed quality. MM, BN, CSH, and MRB consulted in the literature searches and the selection of the studies, cross-checked the data and the quality assessments, consulted in the data analysis, and substantially contributed to the interpretation of the data. RR wrote the first draft of the manuscript and all authors contributed to the critical revision of the manuscript. MRB and BN acquired the financial support for the project leading to this publication. All authors read and approved the final manuscript. All authors had full access to all the data in the study. On agreement with all co-authors, RR had final responsibility for the decision to submit for publication.

Declaration of interests

We declare no competing interests.

Data sharing

Please contact the corresponding author if you would like to see any data that are not included in the Article or the Appendix.

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