Perspectives and experiences of the process of mental health diagnosis: a systematic review

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Introduction

Receiving a formal diagnosis can have a powerful impact.[1,2] It can be of great value for people to make sense of their experiences, provide a sense of relief and containment, offer a springboard for recovery and direct service provision.[2,3] Nonetheless, diagnosis has also been associated with unintended negative consequences, including feelings of fear and hopelessness, stigma, loss of identity and treatment avoidance.[1-4]

Evidence suggests that the impact is influenced by how diagnoses are decided and communicated (e.g. whether the diagnosis is framed as enduring or malleable, as well as the timing and medium of communication).[4-7] It is important to collate this evidence due to its high relevance to understanding and informing the diagnostic process.
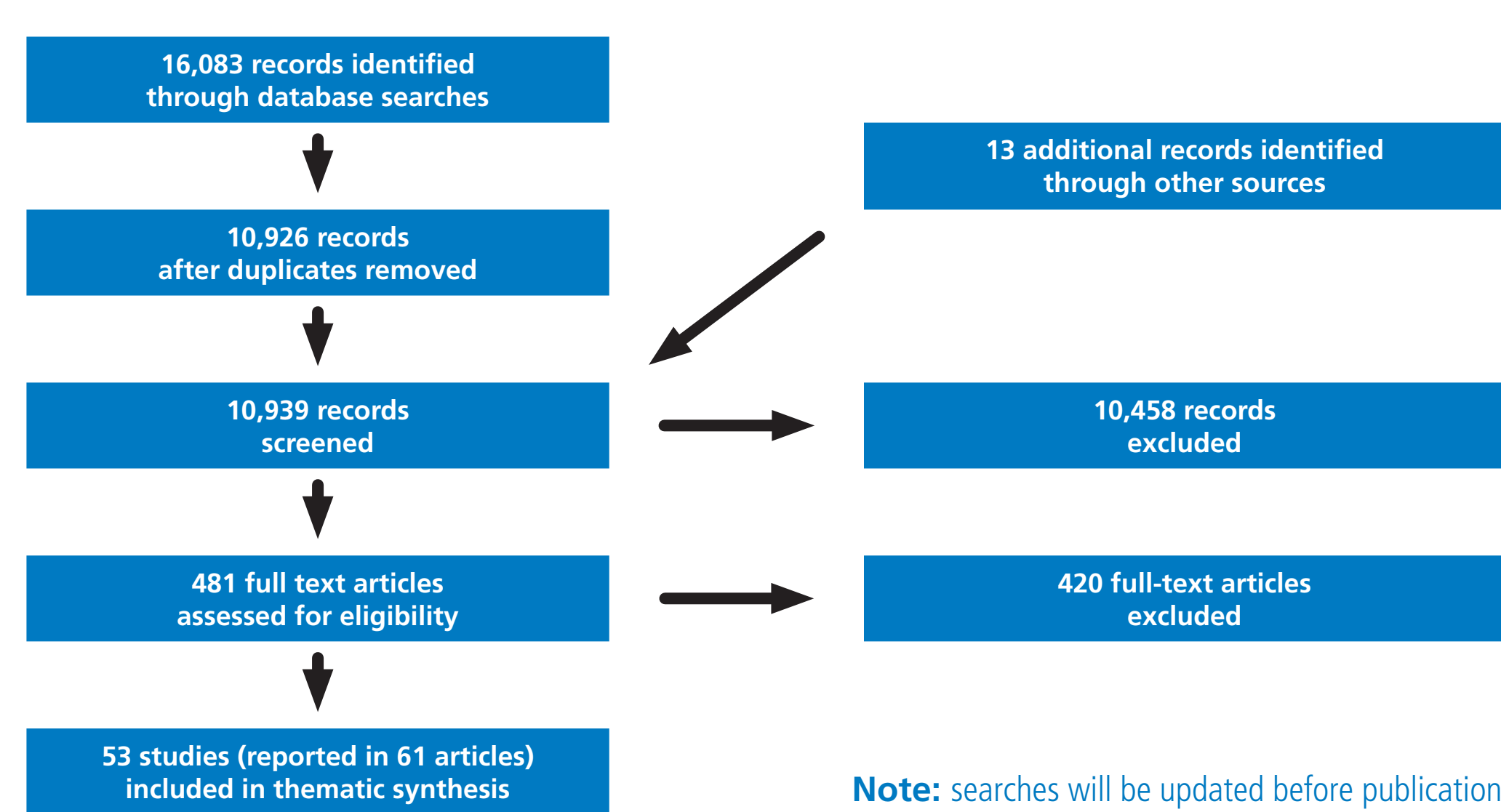
Research aims

To develop an understanding of service user, carer / family, and clinician views and experiences of the diagnostic process, including what might be helpful or unhelpful within current practice.

To collate service user, carer / family, clinician, and researcher recommendations for the process of mental health diagnosis.

Methods

A systematic review and thematic synthesis of qualitative research

Databases searched	PsycINFO, Embase, Medline and CINAHL (database inception to October 2016).
Inclusion criteria	Adults (18+) who have received a mental health diagnosis in a western health setting, their carers or family, or clinicians involved in giving mental health diagnoses.
Exclusion criteria	Developmental disorders, substance abuse disorders, somatic disorders, dementia and brain injury.
Eligible study designs	Formal qualitative methodology, with primary data on service user / carer / family / clinician views, experiences or recommendations for adult mental health diagnosis.
Critical appraisal	Quality was critically assessed with reference to the CASP qualitative assessment checklist[8], supplemented with a narrative appraisal.
Analysis	A standardised form was used to extract demographic information. Qualitative data extraction involved line by line coding using NVIVO-11. Codes were used to develop descriptive and analytical themes, accounting for the number of times a code occurred, alongside relevancy, usefulness, and transferability. Data extraction and thematic synthesis are still ongoing.

16,083 records identified through database searches

13 additional records identified through other sources

10,926 records after duplicates removed

10,939 records screened

10,458 records excluded

481 full text articles assessed for eligibility

420 full-text articles excluded

53 studies (reported in 61 articles) included in thematic synthesis

Note: searches will be updated before publication

Results

Of the 53 studies, 38 involved service user participants, 17 involved clinicians, and seven involved carers and family members. The most frequent diagnoses included in these studies were Mood Disorders, Personality Disorders, and Psychotic Disorders.

Preliminary analyses identified emerging themes regarding views and experiences of current diagnostic practice. Critical components were highlighted; for each, examples are given of helpful and unhelpful practice, as well as participant concerns and suggestions for improvement.

1. Deciding diagnosis

Unhelpful practice and participant concerns	Helpful practice and participant recommendations
• Limited focus when deriving diagnoses (e.g. current presentation, neglecting history and culture). • Pressure to diagnose for reasons outside service user interest (e.g. financial). • Clinician uncertainty about deciding diagnoses (e.g. normality vs disorder; limitations of diagnostic tools). • Using time as a tool to accurately diagnose vs taking too long.	• Utilising a holistic approach, driven by service user interests. • Training and further development of diagnostic tools. • Needs-centred, individualistic approach; working collaboratively to decide diagnoses based upon severity, burden, and service user needs / preferences. • Transparency, including acknowledgement that diagnostic decisions are on-going and under review.

2. Disclosure and timing

Unhelpful practice and participant concerns	Helpful practice and participant recommendations
• Reluctance to disclose due to fear of negative impacts. • Avoidance of specific diagnoses in favour of general diagnoses (e.g. schizophrenia vs psychosis). • Discovering diagnosis indirectly (e.g. via referral letter). • Concern about service user being 'ready' for diagnosis, and negative implications of both premature disclosure and withholding diagnosis.	• Evaluating reluctance to disclose to ensure service user interests are priority, considering the negative impacts of non-specific diagnoses (e.g. limited sense of containment and understanding; trust and transparency). • Clear and sensitive disclosure with follow-up, via a medium tailored to individual needs and preferences. • Agreements between service user and clinician can be made regarding timing and gradation of disclosure, allowing service user to decide when to go into detail.

3. Explanation, education, and exploration, with awareness of personhood

Unhelpful practice and participant concerns	Helpful practice and participant recommendations
• Lack of information and explanation about the diagnosis and how it was derived. • Multiple or changing diagnoses not discussed, impacting confidence in clinicians. • Lack of time or resources to explore meanings attached to diagnosis (i.e. service user understanding, misconceptions) and address impacts (e.g. stigma). • Being labelled can have negative consequences.	• Clinicians providing psychoeducation via active discussion with service users, tailoring to communication needs (e.g. avoiding jargon). • Open and honest approach, acknowledging the dynamic nature of diagnosis and possibility of change. • Giving time and space to process, discuss and adjust to the diagnosis across multiple consultations. • Diagnosing not labelling; externalising the diagnosis.

4. Contextualisation within therapeutic relationships, teams, and systems

Unhelpful practice and participant concerns	Helpful practice and participant recommendations
• Service users feeling uncared for and dismissed by unfamiliar clinicians. • Power imbalance; clinicians as authoritative experts and service users as non-experts feeling unheard and uninvolved. • Clinician uncertainty regarding roles; some feel excluded. • Unplanned, inconsistent and chaotic diagnostic conversations.	• Diagnosing in a therapeutic relationship that is sensitive, supportive, empathic and non-judgemental, providing continuity of care. • Collaborative approach; listening and involving service users, recognising their opinions and expertise. • Team approach with clear roles. • Planned and structured diagnostic conversations, being mindful not to be overly formal or rigid.

5. Diagnosis as part of the service user journey; unification with treatment, social support and recovery

Unhelpful practice and participant concerns	Helpful practice and participant recommendations
• Providing diagnosis without purpose, treatment or meaning for recovery is experienced as disempowering. • Diagnosis being framed negatively as untreatable, inflexible or enduring, or unrealistically and flippantly positive. • Family and friends are excluded / included without consideration of service user needs and preferences. • Involvement of family and friends is ad hoc, causing them to feel ill-informed, excluded, unheard and unsupported.	• Combining discussion of diagnosis, treatment and recovery; using diagnosis as a meaningful tool and a foundation from which to take action. • Providing service users with realistic hope. • Working with service users to collaboratively decide upon the involvement of family and friends. • Education and sensitive support for family / friends to process the diagnosis and its impacts (e.g. feeling of blame / concerns about the future).

"I can't emphasize this enough... I would have accepted it more if they explained what schizophrenia was..."[5]
Service user p.731

"...provide some sort of hope... like letting someone know that there are a range of interventions... also without sort of providing false hope."[6]
Clinician p.743

Discussion and conclusion

Diagnosis is often a pivotal moment for service users, therefore the way it is decided and communicated warrants attention.[1-7] In this review, themes are emerging regarding particular aspects that are considered helpful and unhelpful.

They involve service user-clinician collaboration with regards to deciding and discussing diagnoses that are contextualised in the whole person, therapeutic relationships, teams, systems and recovery. Apparent in the data is the individual nature of diagnosis; there is not one 'right' way to diagnose, instead, an approach that is collaborative, flexible and sensitive to the individual's needs and preferences is suggested.

This review is still underway, and therefore the above data is considered preliminary and subject to revision through iterative analyses.

"... I lived for years in fear... So I would've appreciated a dialogue that would've calmed me down and made me understand what was really going on..."[5]
Service user p.731

"I am impressed by the number of people with schizophrenia who I meet who do not know their diagnosis and the largely positive effects telling the diagnosis has."[7]
Clinician p.338

Implications and further research

This review is part of a programme of research to support a better understanding of service user, carer / family and clinician needs and preferences regarding the diagnostic process. It will inform future qualitative research to develop recommendations for best practice.

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