JADE VARNEY BSc Hons

INVESTIGATION INTO ALTERNATIVES TO PSYCHIATRIC DIAGNOSIS

Section A: A review of alternatives to psychiatric diagnosis.

Word Count: 7456 (55)

Section B: Service users' perspectives on psychiatric diagnosis and the use of ICD-11 experiential codes as an alternative.

Word Count: 7985 (605)

Overall Word Count: 15,496 (660)

A thesis submitted in partial fulfilment of the requirements of

Canterbury Christ Church University for the degree of

Doctor of Clinical Psychology

MAY 2021

SALOMONS INSTITUTE FOR APPLIED PSYCHOLOGY

CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgments

I want to firstly thank the participants who kindly took part in the study. It was a privilege to write about your experiences.

Thank you to my supervisors, Peter Kinderman and Anne Cooke, for your support, passion, and enthusiasm for this project.

To Ryan, who supported me the whole way through – I couldn’t have done it without you.

Summary

Section A

The first part of the review explored what the literature suggests should be the key characteristics of an alternative to diagnosis. It found that an alternative should attempt to de-emphasise biological causation, classify problems, attend to individual experience, be developed in line with the evidence-base and the views of key stakeholders, and serve practical functions. The second part of the review presented six alternative models that have been proposed so far. To identify possible ways forward, the review explored how the proposals might fulfil the various functions currently fulfilled by diagnosis. The review concluded by outlining clinical and research implications.

Section B

The empirical paper explored participants' experiences of receiving a psychiatric diagnosis and their views about utilising the ICD-11 experiential codes as a possible alternative. Thirteen participants were interviewed, and the data were analysed using thematic analysis. The results outlined six themes, including identifying and characterising the problem, communication with professionals, personal impact, support and recovery, response from others, and implementation. The findings were discussed in the context of current research, and the clinical and research implications were highlighted.

Table of Contents

Section A

Section B

List of Tables and Figures

Section A

Section B

List of Appendices

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Abstract

Psychiatric diagnosis continues to be a topic of controversy. In recent years, many have called for reform to clinical practice, suggesting the need for an alternative. However, there is a lack of clarity about what an alternative should look like. This review, therefore, firstly explored what the literature suggests should be the key characteristics of an alternative to psychiatric diagnosis. It also highlighted the proposed alternative models with respect to how they intend to fulfil the functions currently fulfilled by diagnosis.

The review adopted a scoping methodology which aims to systematically map the literature on a topic, identifying key concepts and gaps in the research. An electronic search of PsychINFO, Web of Science, and Medline was carried out from January 2013 to January 2021. There were 20 papers included in the review, 14 of those proposed key characteristics of an alternative, and 6 outlined an alternative model. All papers were from peer reviewed journals or written by professional bodies. Data were extracted and grouped according to subject matter and presented qualitatively.

This review found that an alternative should attempt to de-emphasise biological causation, classify problems, attend to individual experience, be developed in line with the evidence-base and in consultation with key stakeholders, and serve practical functions. The review found six alternative models, all of which had considered the ways in which they could fulfil the functions currently fulfilled by diagnosis.

There was relative agreement in the literature about what characteristics a non-diagnostic alternative should possess. The review demonstrated a variety of possible ways to work beyond diagnosis and outlined the relevant clinical implications. However, in order to take these ideas forward, future research should consider the wider systemic issues potentially at play in preventing change.

Key words: Psychiatric diagnosis, alternative to diagnosis, non-diagnosis.

Introduction

Diagnosis has been defined as “a medical concept which covers both the process of identifying a disease, and the designation of that disease” (Moncrieff, 2010). The use of diagnosis in mental health began in the United States in the 1920’s (Suris, Holiday & North, 2016). Many suggest that psychiatric diagnosis is useful in offering service-users an explanation of their problems (Maung, 2016) and assisting decisions about clinical care (Craddock & Mynors-Wallis, 2014). However, controversy concerning the usefulness and appropriateness of psychiatric diagnosis dates back to as early as the 1960s (Cooper, 2019) and every new release of the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM) has been met with increased controversy (Robbins, Kamens & Elkins, 2017).

The functions and benefits of psychiatric diagnosis

It is important to clarify the functions which diagnosis fulfils within the current system. Firstly, as a classification system, diagnostic manuals provide clinicians with a means to allocate difficulties to different categories (e.g. depression or anxiety). Appropriate classification gives people who use mental health services clarity about how clinicians understand their difficulties, and professionals a common language to communicate (Craddock & Mynors-Wallis, 2014). Furthermore, diagnosis is used to plan and guide appropriate support. For instance, the NICE guidelines (e.g. NICE, 2017) are largely organised according to diagnostic categories, with the intention of allowing clinicians to identify the most appropriate evidence-based interventions.

Moreover, some claim that diagnosis is fundamental to how most conventional mental health services are organised, informing decisions about the most suitable support to meet people’s needs (Pitt et al., 2009). It offers a system for recording and organising information across different contexts, for instance, for recording service-user information, or for research purposes. It also provides a conceptual rationale (i.e. a medical one) and an administrative mechanism for controlling access to wider systems of support (Strong, 2019).

Lastly, some service-users report benefits from receiving a diagnosis. For example, some experience a sense of relief at having their experiences recognised and validated by a mental health professional (Pitt et al., 2009). The latter can reduce fear and worry about the possibility of something being uniquely different or potentially ‘odd’ about their experiences (Craddock & Mynors-Wallis, 2014). Perkins et al. (2018) also suggest that a diagnosis helps people understand their experiences and seek appropriate support.

Criticisms of psychiatric diagnosis

A number of criticisms have been levelled at psychiatric diagnosis. Firstly, critics argue that diagnosis is reductionistic, reducing complex human experiences to ‘illness’ with putative biological causes (e.g. neurotransmitter abnormalities or genetics) and fails to account for the complex interplay of life, social, and cultural factors (Boyle, 2007; Deacon, 2013). There is increasing evidence demonstrating the major role of adverse social circumstances (e.g. poverty or unemployment), life events (e.g. bereavement or loss of job), abuse (e.g. childhood abuse or domestic violence) or cultural factors (e.g. racism) in the development of mental health problems (Anakwenze & Zuberi, 2013; Larkin & Read, 2008; Miller, Yang, Farrell & Lin, 2011; Williams & Williams-Morris, 2000).

Secondly, there are problems with categorising complex behaviour into discrete and measurable concepts. Each phenomenon may have multiple causes, and each casual factor may be related to many possible outcomes. Thus, the issues of validity and reliability have been long contested (Kendell & Jablensky, 2003; Vanheule et al., 2014). Failure to identify valid concepts also raises questions about empirical research based on those concepts (Boyle, 2007). Furthermore, some have argued (e.g. Moncrieff, 2008) that psychiatric diagnoses convey little useful information from which clinicians can infer appropriate interventions.

There is evidence that receiving a diagnosis can negatively impact service-users. Research over recent years has demonstrated that service-users experience stigma (Dinos et al., 2004; Ring & Lawn, 2019), identity changes (Honos-Webb & Leitner, 2001; Horn, Johnstone & Brooke, 2007), poor recovery outcomes (Yanos, Roe & Lysaker, 2010) and social isolation (Stalker, Ferguson & Barclay, 2005). There is evidence that these negative outcomes are often related to the label rather than to the original difficulties (Cooke, 2008). A recent systematic review (Perkins et al., 2018) found that psychiatric diagnoses can be experienced as labelling and lead to hostility, exclusion, and marginalisation from others.

Time for a paradigm shift

The release of the latest edition of the DSM-5 (American Psychiatric Association, 2013) was met with widespread controversy. Some of the most prominent concerns included the lowering of diagnostic thresholds, increased medicalisation of distress, and lack of empirical evidence for the proposed changes (Robins, Kamens & Elkins, 2017). Many professionals called for a reform in practice. The Society of Humanistic Psychology, Division 32 of the American Psychological Association published an *Open Letter to the DSM 5* which received widespread support (Kamens, Elkins & Robins, 2017). During the same year, the British Psychological Society (BPS) Division of Clinical Psychology (DCP) released a position statement openly criticising diagnosis and the medical model (BPS DCP, 2013).

> "The DCP is of the view that it is timely and appropriate to affirm publicly that the current classification system as outlined in DSM and ICD[1], in respect of the functional psychiatric diagnoses, has significant conceptual and empirical limitations.

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[1] International Classification of Diseases (ICD; World Health Organisation, 2018)

> Consequently, there is a need for a paradigm shift in relation to the experiences that these diagnoses refer to, towards a conceptual system which is no longer based on a ‘disease’ model.” (BPS DCP, 2013, p. 1)

Since then, a variety of possible ways forward have been suggested. *The Research Domain Criteria* (RDoC; Cuthbert & Insel, 2013) is a framework which aims to better identify and understand the ‘biological origins and mechanisms’ of mental health difficulties. However, as argued by some, RDoC “does nothing to revisit the underlying assumptions of diagnosis and psychopathology” (Russell, 2019, p. 430). Other approaches, such as *The Power Threat Meaning Framework* (Johnstone & Boyle, 2018) adopt a different ethos, proposing that it is vital to understand distress within the context of people’s lives. The framework openly rejects psychiatric diagnosis and instead outlines patterns of potential responses to life events and circumstances.

On a wider level, there has been international networking between mental health professionals interested in alternatives to diagnosis. For instance, in 2013 the *Global Summit on Diagnostic Alternatives* was formed with the aim to “develop, evaluate, advocate, and disseminate alternatives to current diagnostic systems” (Society of Humanistic Psychology, 2015, para. 3). One of the recent outputs of this group was the *Standards and Guidelines for the Development of Diagnostic Nomenclatures and Alternatives in Mental Health Research and Practice* (Kamens et al., 2019) to inform ‘best practice’ when developing alternatives to diagnosis.

However, it has been eight years since the BPS called for a paradigm shift (BPS DCP, 2013) and diagnosis remains dominant in clinical practice. Revolutionising this system is not an easy task, nor is this the first time it has been attempted. As documented by Cooper (2019), attempts to change diagnosis have surfaced since the 1960s, when critiques of, and the ideas for reform of the DSM were strikingly like those seen today. Some think that any attempt to standardise descriptions of complex human experiences is misguided: Bervoets et al. (2019, p. 894) suggests that “there is nothing worse than a clear, sharp image of a fuzzy concept”.

Rationale for the current review

Despite the move towards developing alternative practice, there remains a lack of clarity about what an appropriate alternative might be. For example, the BPS position statement (BPS DCP, 2013) did not describe any possible alternatives. Nor was any guidance given about how an alternative could be implemented in practice. Therefore, it seems timely to review the literature to examine the various suggestions.

As per the BPS statement (BPS DCP, 2013) this review will explore approaches that are not based on a ‘disease model’ and intend to replace psychiatric diagnosis. Therefore, alternatives that are designed to work alongside psychiatric diagnosis (e.g. Cuthbert & Insel, 2013; Kotov et al., 2017) are outside the scope of this review.

Aims

The aim of this paper is to explore the literature concerning alternatives intending to replace psychiatric diagnosis in mental health practice. This paper firstly explores what the literature suggests should be the key characteristics of an alternative to diagnosis, and then outlines the approaches which have been suggested. In order to explore possible ways forward, each of the alternatives is then discussed in terms of how it proposes to fulfil the various functions currently fulfilled by diagnosis. The review addresses the following research questions:

- What does the literature suggest should be the key characteristics of a non-diagnostic alternative?

- What alternatives have been proposed so far?
- How well does each proposed alternative fulfil the functions currently fulfilled by diagnosis?

Methodology

This study used a scoping methodology as outlined by Peters et al. (2020). A scoping review systematically maps the literature on a topic, identifying key concepts and gaps in the research. One of the most common reasons for conducting this type of review is to explore the breadth of the literature and summarise the evidence (Peters et al., 2020), aligning with the aims of this study. As is usual for this type of review, no formal critical appraisal was undertaken (Grant & Booth, 2009).

Methodological guidance was taken from Peters et al. (2020). Firstly, ‘data charting’ was used to develop a summary of the key details of each paper. In terms of data analysis, the authors state that qualitative data should be mostly descriptive, such as basic coding of data to particular categories. For the first part of the review, the data extracted from each paper were grouped according to subject matter (e.g. diagnosis implies biological causation) which was used to organise and inform the results section. This information, and evidence of this process, can be seen in Appendix A.

The second part of the review presents alternative models that have been proposed so far. A similar process was undertaken where data were ‘charted’ and subsequently categorised with respect to how each model attempts to fulfil the current functions of diagnosis (e.g. classification, guiding practice, recognising service-user experiences, providing access to support, and administrative and research purposes). The data for both parts are presented in tabular and narrative summaries.

Search terms

An electronic search of PsychINFO, Web of Science, and Medline was carried out using the following search terms: (“Psychiatric diagnosis” OR “diagnos*” OR “DSM” OR “ICD” OR OR “psychiat*” OR “mental health” OR “disorder” OR “disease” OR “classif*” OR “psychol*”) AND (“alternative” OR “non-diagnos*” OR “beyond” OR “reform” OR “non-medicalis*” OR “non-DSM” or “non-ICD” OR “paradigm”). The search was carried out in January 2021.

A manual search of reference lists was also undertaken. Relevant issues of the *Journal of Humanistic Psychology* were screened to identify several special issues on the topic of alternatives to diagnosis. A final search of Google Scholar ensured that no other relevant papers had been missed. The literature search strategy and how the papers were selected is displayed in Figure 1.

Inclusion and exclusion criteria

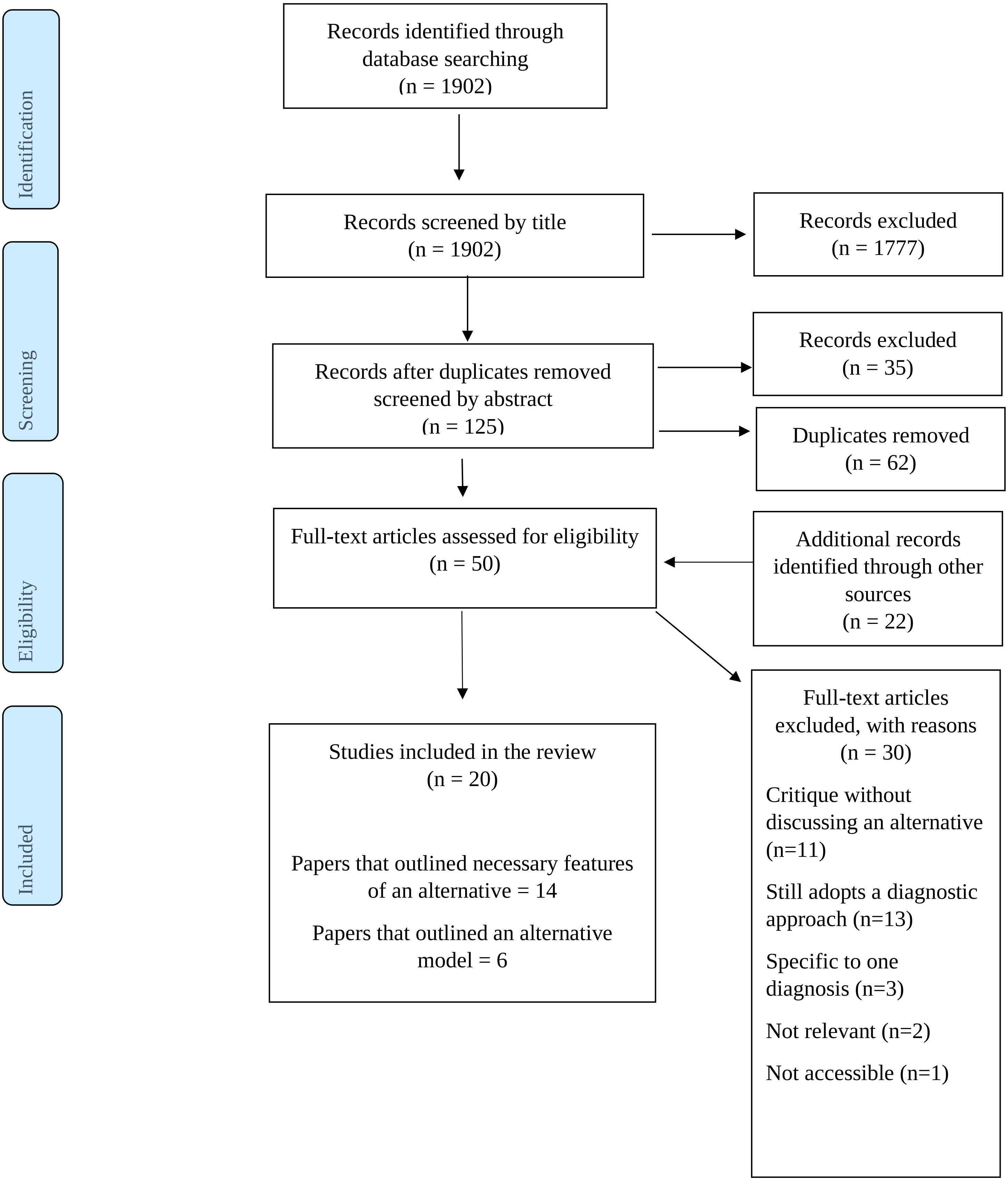
This study seeks to review the literature concerning alternatives to psychiatric diagnosis which has been published since the BPS position statement (BPS DCP, 2013). Therefore, the search was limited in scope to those written after 2013. To be included in the review, papers needed to explicitly discuss the components of an alternative to diagnosis, or outline an alternative conceptual model. Both empirical and theoretical papers were included.

As is common practice for scoping reviews, no formal quality assessment of the literature was undertaken (Grant & Booth, 2009). However, to ensure quality assurance all papers were all published in peer-reviewed journals or by professional bodies.

Papers were not included when only serving to critique psychiatric diagnosis. Similarly, any alternatives that were specific to one particular diagnosis (e.g. gender dysphoria) were not included. Papers were also excluded if the proposed alternative was complementary to, or to be used alongside diagnostic practice (i.e. it was not proposed as an alternative per se). Non-English language papers were excluded on the grounds of practicality.

Figure 1

Prisma Diagram



The Review

The review is organised in three sections according to the research questions. The first part explores what the literature suggests should be the key characteristics of an alternative to diagnosis. Next is a summary of the alternative frameworks and models that have been proposed. Lastly, the review examines how each model serves the functions currently fulfilled by diagnosis.

What does the literature suggest should be the key characteristics of a non-diagnostic alternative?

The literature suggests that an alternative should de-emphasise biological causation, classify problems, attend to individual experience, be developed in collaboration with key stakeholders and in line with the evidence-base, and meet certain practical needs (e.g. administrative purposes).

De-emphasises biological causation

A unanimous finding in the literature was the importance of any alternative providing a framework for understanding distress outside of the current ‘medical model’: the latter was seen as over-emphasising the contribution of biological abnormality or dysfunction (Boyle & Johnstone, 2014; Efran & Cohen, 2019; Elkins, 2017; Johnstone & Boyle, 2018; Kamens et al., 2019; Kinderman et al., 2013; Raskin, 2019; Schneider, 2019; Strong, 2019). The authors argue, and outline evidence that most mental distress can be understood as a response to the contexts of people’s lives. For example, Boyle and Johnstone (2014) emphasise the interplay between life events (e.g. poverty, childhood adversity, and discrimination) and specific mental health difficulties (e.g. hearing voices). Moreover, many authors suggest the need to look beyond the individual, and include, for example, the socio-political and historical context (Schneider, 2019; Strong, 2019).

Elkins (2017) proposes that any alternative must be informed by an understanding of the problems with the medical model. He claims that in order to move forward there needs to be "a nonmedical system for describing patterns of emotional distress… as an alternative to the DSM and other medical diagnostic systems" (Elkins, 2017, p. 672). This position is consistent with that outlined in the BPS statement that "there is a need for a paradigm shift in relation to the experiences that these diagnoses refer to, towards a conceptual system which is no longer based on a 'disease' model" (BPS DCP, 2013, p.1)

Classifies problems, not people

Several authors suggest that an alternative should classify problems or concerns rather than people (Efran & Cohen, 2019; Kinderman et al., 2013; Raskin, 2019). There appear to be a number of aspects to this. Firstly, addressing specific concerns (e.g. anxiety or relationship difficulties) avoids the detrimental impact of classifying people as 'disordered' and 'ill'. Some therefore argue that this change is imperative in any alternative conceptualisation (e.g. Johnstone & Boyle, 2018). Secondly, some suggest that changing language is an important part of changing the focus from what is wrong with the person to what they are concerned about, thus we 'drop the language of disorder' (Kinderman et al., 2013). The BPS has released guidance on changes to language (BPS DCP, 2015) which also suggests that behaviour should be described in non-medical terms. For instance, it suggests referring to someone as 'hearing voices' or 'holding unusual beliefs' instead of 'having schizophrenia'.

Moreover, according to several authors (e.g. Kinderman et al., 2013; Kinderman, Allsopp & Cooke, 2017), an alternative should acknowledge that distress lies on a continuum and should avoid making a distinction between 'normal' and 'abnormal' experiences. For many (e.g. Boyle & Johnstone, 2014; Johnstone & Boyle, 2018; Kinderman et al., 2013;

Strong, 2019), distress should be viewed as a normal part of life and consequently of what it means to be human. As put by Strong (2019) the effect of medicalisation has been "encroaching on normal sadness and fear" (p. 396). Lastly, many authors propose that people's responses to distress are largely adaptive in the face of adverse circumstances (Boyle & Johnstone, 2014; Johnstone & Boyle, 2018) and any alternative should, therefore, acknowledge this.

Attends to individual experience

A consistent suggestion in the literature is for close attention to be given to individual experiences (Kamens et al., 2019; Kinderman et al., 2013; Kinderman, Allsopp & Cooke, 2017; Russell, 2019) rather than putative 'syndromes' or 'disorders'. Similarly, some authors suggest that an alternative should be more inclusive of the range of concerns that clients bring to therapy, some of which are beyond the usual purview of psychiatry, for example, relationship difficulties (Strong, 2019).

Finally, several authors argue that the most important function of any alternative is to restore the meaning in people's lives (Boyle & Johnstone, 2014; Johnstone, 2018; Johnstone & Boyle, 2018, Kinderman, 2015; Russell, 2019; Strong; 2019). The latter is, of course, a subjective and individual endeavour. Russell (2019) acknowledges the tension between attending to each person's experiences on the one hand and the need for a common language on the other.

Developed in collaboration with key stakeholders

Several papers highlight that key stakeholders, particularly service-users, should be extensively involved in the development of any alternative system (Kamens et al., 2019; Raskin, 2019; Russell, 2019). As put by Raskin (2019), key stakeholders should be guaranteed a "seat at the table" (p. 373) in any discussion about an alternative. Similarly, Russell (2019) proposes that developing a shared language is an important aspect of a new system, which can only be achieved by working with service-users.

As a counterargument, Efran and Cohen (2019) suggest that the full responsibility for any new system should rest with professionals. They suggest that the ‘nonexpert stance’ can be potentially problematic in promoting ‘professional powerlessness’. Therefore, they argue that collaboration need not involve collapsing of roles, and that there should be a distinction between ‘self- knowledge’ and ‘professional-knowledge’.

Developed in accordance with the evidence-base

Kamens et al. (2019) outline the importance of any alternative reflecting the best available scientific evidence, and the need for alternatives to be based on empirical evidence as well as theory. As described above, many authors propose that this should include the evidence demonstrating the psychosocial origins of distress (Boyle & Johnstone, 2014; Kinderman, 2015; Raskin, 2019). However, Keeley (2019) argues that no system is purely scientific as systems reflect societal norms and values at any given time.

> “We are placing all kinds of values on the nature of the person’s condition. We do not want someone to endure chronic feelings of sadness; we do not tolerate someone who harms others for their own benefit. These social values are integral to our definitions of mental disorders, and they must be taken into consideration in the development of any classification system... A purely “scientific” approach would be hard pressed to easily incorporate the implications such decisions would have on the social world” (Keeley, 2019, p. 449).

Elkins (2017) argues that any new approach must be based on the longstanding evidence that common factors in therapy (e.g. therapeutic alliance, collaboration, and empathy) are the key agents of change. He concludes that “the new paradigm, in order to reflect this perspective and the evidence that supports it, must place the human and relational elements at the center of psychotherapy and consign theories and techniques to the margins" (Elkins, 2017, p. 670). This has also been echoed elsewhere (e.g. Raskin, 2019).

Practicalities

Some authors address the practical issues relevant to the development of an alternative, for instance, the necessity of working in conjunction with systems of support, including benefits, insurance, and funding (Cooper; 2019; Kinderman, Allsopp & Cooke, 2017) and the need for clinicians to be reimbursed for their work. Raskin (2019) recommends that this could be achieved with a system where clinicians code individual concerns and provide evidence regarding how each of those concerns have been met.

There are contrasting views regarding whether an alternative should apply across different professional groups (e.g. to psychiatrists as well as psychologists). Raskin (2019) proposes that an alternative should be applicable across different therapeutic orientations and professions. This would ensure a single and unified system that is widely recognised. However, Efran and Cohen (2019) acknowledge the complexity of this task, proposing that psychologists should adopt a system based entirely on psychological principles, regardless of whether it is adopted by other professions (Efran & Cohen, 2019).

Kamens et al. (2019) is the only paper that considers the process by which an alternative should be developed. The authors suggest that "a necessary first step in improving the delivery of mental health care services is to ensure that guidelines are developed free of industry influence and are based on unbiased and uncensored scientific evidence" (Kamens et al., 2019, p. 410). Therefore, they suggest that anyone developing an alternative should be transparent about any potential conflicts of interest (e.g. financial or institutional) and minimise the likelihood of these occurring as much as possible. Moreover, they suggest that any proposals should be independently reviewed by multi-disciplinary professionals and other key stakeholders.

What alternatives have been proposed so far?

To date, there appear to have been six proposals for a system to replace psychiatric diagnosis in mental health settings. A brief summary of each is outlined below and in Table 1.

Listing problems (Kinderman, 2015)

Instead of giving someone a diagnosis, Kinderman (2015) suggests listing a person's problems using 'operationally defined' terms. This might involve recording that someone is experiencing 'low mood', 'intrusive thoughts' or 'performs compulsive behaviours'.

The Partners for Change Outcome Management System (PCOMS; Duncan, Sparks & Timimi, 2018)

The authors propose that a solution to the limitations of psychiatric diagnosis might be found in using systematic client feedback. They suggest that clients can 'self-diagnose' using validated outcome measures to capture their level of current functioning and the concerns with which they need help.

The PCOMS employs two scales. The first is the *Outcome Rating Scale* (ORS; Miller et al., 2003) a measure to capture self-rated client functioning across four domains (individual, interpersonal, social, and overall). The ORS can be scored to show current functioning and identify areas for support. The second measure is the *Session Rating Scale* (SRS; Duncan et al., 2013), a measure of the therapeutic alliance.

Psychological Formulation (Johnstone, 2018)

Psychological formulation has been described as "the process of co-constructing a hypothesis or "best guess" about the origins of a person's difficulties in the context of their relationships, social circumstances, life events, and the sense that they have made of them" (Johnstone, 2018, p.32). The approach is applicable across therapeutic orientations and considers people's strengths and resources as well as their difficulties.

The Power Threat Meaning Framework (Johnstone & Boyle, 2018)

This framework was developed by the BPS DCP in 2018 and shifts the focus from the question of what is *wrong* with people to what has *happened* to them that has led to distress. The emphasis is on understanding a person's problems in the context of their experiences. The framework describes how through the impress of power, people experience difficult life events (e.g. abuse) or circumstances (e.g. poverty), leading to 'threat responses' (e.g. 'fear' or 'hearing voices'). The authors also emphasise that people's experiences of distress are largely shaped by personal meaning and agency. The framework moves away from diagnosis by outlining provisional patterns of distress into which responses to these events and circumstances tend to fall.

Non-diagnostic recording of mental health difficulties using the ICD-11 (Kinderman & Allsopp, 2018)

These authors propose to use existing structures in the International Classification of Diseases (ICD-11), a global classification system developed by the World Health Organisation (2018). The latest edition includes numbered codes (referred to from here as 'experiential codes') pertaining to different possible complaints (e.g. MB29.1 Binge eating, MB28.9 Low self-esteem) and life experiences (e.g. QE83 Personal frightening experience in childhood, QD71 Problems associated with housing). The authors propose that instead of assigning a diagnosis, clinicians could instead assign a particular combination of experiential codes depending on the person's circumstances.

The Classification and Statistical Manual of Mental Health Concerns (CSM; Rubin, 2018)

The CSM is based on the concept of classifying concerns (e.g. emotion, mood, sleep, or relationships) rather than disorders or syndromes. Concerns are recorded using a numerical coding system, enabling them to be used by third party payers and organisations. Psychological formulation can then be used to expand on the list of concerns, allowing people to understand and address these experiences.

All these papers have been written in the last six years, and some by the same authors (e.g. Johnstone, 2018; Johnstone & Boyle, 2018; Kinderman, 2015; Kinderman & Allsopp, 2018). All mention the importance of service-users' perspectives on their difficulties being prioritised, and all suggest a similar approach to clinical care. For instance, five include a role for psychological formulation (Johnstone, 2018; Johnstone & Boyle, 2018; Kinderman, 2015; Kinderman & Allsopp, 2018; Rubin, 2018) and emphasise the role of understanding and finding meaning in people's experiences. There are also significant differences between the proposed approaches. For instance, some suggest using outcome measures (Duncan, Sparks and Timimi, 2018), others utilising existing experiential codes within the ICD-11 (Kinderman and Allsopp, 2018), and some comprised entirely new frameworks (Johnstone & Boyle, 2018; Rubin, 2018).

Table 1

Summary of the proposed alternatives to psychiatric diagnosis

Author	Proposed Alternative	Key Features
Duncan, Sparks & Timimi (2018)	The Partners for Change Outcome Management System (PCOMS)	• Utilises the ORS, a measure of client functioning, and the SRS, a measure of the therapeutic alliance. Both measures produce scores that can be tracked over time to review therapeutic change. • Provides a system record the problems clients are experiencing and their progress (or lack of it) over the course of therapy. • Claims that approaches such as formulation are expert driven, whereas the PCOMS focuses on reducing the power imbalance and privileging client expertise. • Emphasis is on the centrality of the therapeutic relationship, on the basis that common factors in therapy are the key agents for change.

Johnstone (2018)	Psychological Formulation	• A co-developed and individualised understanding of the client's presenting problem based upon the unique circumstances in their lives (e.g. social factors and/or life events). • Draws upon a range of psychological theories to explain presenting problems (e.g. the idea that voice hearing can be product of early abusive experiences). • Problem-focused, rather than illness-focused, and includes a consideration of strengths and resources. • Applicable across theoretical approaches. • Does not include an administrative or recording element.
Johnstone & Boyle (2018)	The Power Threat Meaning Framework (PTMF)	• A framework to identify patterns of distress in response to life events and circumstances. • Emphasis is on the social, psychological, historical, and cultural context of the development of distress (e.g. the impact of poverty, unemployment, marginalisation) and the individual meaning that people make from their experiences. • Shifts the focus from 'What's wrong with you?' to 'What's happened to you?'
Kinderman (2015)	Listing problems	• Recording a list of client problems using 'operationally defined' terms (e.g. hearing voices, experiencing auditory hallucinations)

Kinderman & Allsopp (2018)	Non-diagnostic recording of difficulties utilising ICD-11 codes.	• Utilises experiential codes in the ICD-11 to record client experiences (e.g. low mood) and social circumstances (e.g. unemployed). • The codes can be used in wider clinical practice (e.g. to help inform a shared formulation).
Rubin (2018)	The Classification and Statistical Manual of Mental Health Concerns.	• Classifies mental health concerns which are grouped around the following topics: behaviour, emotion, mood, addictions, meaning of life, death, dying, managing chronic pain, work, relationships, education, eating, cognition, sleep, and challenging life situations. • Provides an administrative system to record concerns (using a corresponding numerical code) which can be communicated to wider systems of support. • Includes the use of psychological formulation.

How well does each proposed alternatives fulfil the functions currently fulfilled by diagnosis?

The current functions of psychiatric diagnosis were outlined in the introduction. In summary, these include:

- Classifying
- Guiding practice
- Recognising service-user experiences
- Providing access to services and wider support
- Research and administrative purposes

This section includes an account of how successfully the various alternatives are likely to fulfil the current functions of diagnosis.

Classifying

The dominant message across all approaches was the drive to preserve individuality and avoid basing responses to people on allocation to categories. Several authors explicitly addressed this, stating, for example, that "human suffering does not come in neat parcels" (Johnstone, 2018, p. 37) and "[client opinion] trumps those of manuals and professional helpers" (Duncan, Sparks & Timimi, 2018, p. 19). More specifically, Johnstone (2018) proposes avoiding classification entirely and suggests that a formulation should reflect the unique experiences of each person. By contrast, Duncan, Sparks and Timimi (2018) argue that formulation is still expert-driven, and the onus should instead be on clients to "self-diagnose".

However, there is a difference between medicalised classification (i.e. you have X disorder), versus problem classification (i.e. you are experiencing X concern). Several authors attempt to draw on the latter suggesting that classification can still be achieved outside of ‘illness’ and ‘disease’ based models (e.g. Johnstone & Boyle, 2018; Rubin, 2018). Rubin (2018) proposes a ‘scientifically based’ manual listing ‘expressed concerns’ in everyday language (e.g. sleep, eating, mood), which can also be represented numerically (e.g. expressed concern number 2). Furthermore, Rubin suggests that the person’s current functioning of each concern could be measured by rating each on a scale of -5 to +5, with -5 representing ‘very much below average’ for the general population and +5 being ‘very much above average’. However, there was no further suggestion of relevant norms to guide such ratings.

Some authors (e.g. Kinderman, 2015) suggest that using common and accessible language (e.g. low mood, self-harm, irritability) will improve communication between professionals. They argue that people’s experiences of the same diagnosis (e.g. obsessive-compulsive disorder) vary and so the term does not always carry sufficient information. Kinderman (2015) suggests that recording more detailed information about people’s experiences could avoid some of these associated challenges and reflect the complexity of lived experience. In a later proposal, Kinderman and Allsopp (2018) suggests that a system based on existing codes within the ICD-11 would ensure consistency of these ideas across clinical practice.

The *Power Threat Meaning Framework* (Johnstone & Boyle, 2018) addresses classification by proposing seven common patterns of distress. Each pattern represents general regularities in response to social and contextual influences, leading to “meaning-based threat responses to power” (p. 213). Most patterns begin with the word “surviving” (e.g. surviving disrupted attachments and adversities as a child/young person) to imply that these responses are driven by the need to meet core human needs.

Guiding practice

The DCP *Good Practice Guidelines on the use of psychological formulation* (2011) state that the main purpose of formulation is to identify the “best way forward and informing the intervention” (p. 8). Many authors suggest that a formulation leads to an individualised and tailored plan, appropriately guiding support for each person (Johnstone, 2018; Kinderman & Allsopp, 2018; Rubin, 2018). However, this approach is at odds with the idea of categorising and then applying a standardised ‘evidence-based treatment’ for a particular category.

Johnstone and Boyle (2018) summarise the extensive literature outlining the causal link between social factors and mental health difficulties, challenging the dominant discourse of biological determination. Given this context, they argue that support need not be entirely focused on the individual, and should, instead, consider wider community approaches that deal with immediate concerns in people’s lives (e.g. poverty or lack of social support). Moreover, they emphasise the importance of trauma-informed care as an effective principle guiding evidence-based practice. An approach like this has wider implications for how we might respond to, or prevent, such difficulties and assumes that psychological interventions might not be the sole focus.

The *Partners for Change Outcome Management System* (Duncan, Sparks & Timimi, 2018) suggests that interventions should be informed by the specific areas that people rate on the outcome measure. Moreover, they argue that common factors in therapy have consistently been shown to be the key components of therapeutic change. Therefore, they suggest that using the *Session Rating Scale* ensures that the therapeutic relationship is prioritised. The paper reviews the research demonstrating the efficacy of using the PCOMS in this way in individual, couple, and group therapy.

Recognising service-user experiences

All papers emphasise the importance of privileging service-user voices. The *Classification and Statistical Manual of Mental Health Concerns* (Rubin, 2018) allows service-users to have a choice about which expressed concerns are recorded and addressed, positioning them as experts in their own lives. Taking this approach one step further, Duncan, Sparks and Timimi (2018) describe the PCOMS as “client-defined” and “egalitarian”: an attempt to transform power relations in clinical practice. Similarly, the remaining models (Johnstone, 2018; Kinderman, 2015; Kinderman & Allsopp, 2018; Johnstone & Boyle, 2018) centralise the role of collaboration in developing a shared understanding of the presenting concerns.

There is a move towards using everyday language to capture experiences (Kinderman, 2015). Kinderman and Allsopp (2018) suggest creating coded lists, capturing both experiences and social circumstances. They argue that recording social circumstances promotes clearer links to social inequality and a ‘rights-based approach’ to care. Furthermore, Duncan, Sparks and Timimi (2018) suggest that using outcome measures puts the “richness of real life” (p. 19) back on the agenda of clinical practice.

Formulation-based approaches emphasise the central role of “restor(ing) the meaning in madness” (Johnstone, 2018, p 31). For example, Johnstone (2018) outlines a case study where voice hearing is formulated in the context of traumatic experiences. Instead of a label of ‘schizophrenia’, a psychological formulation provided the client with a non-pathologising perspective their presenting difficulties. Furthermore, approaches such as these focus on strength and survival and view problems as a product of adaptive coping (Johnstone & Boyle, 2018). Lastly, Rubin (2018) suggests that moving away from labelling people as ‘disordered’ could potentially reduce stigma.

Providing access to services and wider support

Any system that moves away from recognised terms runs the risk of creating barriers to support. As acknowledged by Johnstone (2018), individualised approaches are difficult to translate to wider systems of support (e.g. the benefits system) and risk requiring sensitive information to be shared with others. Moreover, most of the suggestions did not include a measure of severity, which has implications for service organisation and provision of support.

Kinderman and Allsopp (2018) suggest that recording ICD-11 experiential would allow for better early intervention pathways that target particular trajectories of distress (e.g. childhood sexual abuse and voice hearing). Similarly, Johnstone and Boyle (2018) propose that services should be based upon interventions for specific presenting complaints, including mental health difficulties (e.g. low mood) and social factors (e.g. financial support). Furthermore, Duncan, Sparks and Timimi (2018) address the challenges of recognising severity. The use of validated measures ensures that severity of ‘symptoms’ is regularly measured and reviewed. Thus, clinicians have a clear account of their client’s current level of functioning.

In terms of wider support, Kinderman (2015) argues that other systems (e.g. justice, education, social services) do not rely on people needing a diagnosis to access support. He therefore questions the assumption that this is needed in mental health. Rubin (2018) argues that the solution can be found in small changes to the way mental health difficulties are recorded. For instance, he proposes that benefits forms could change from ‘diagnosis’ to ‘mental health concern’. Furthermore, in order to omit personal and sensitive details, he suggests that individual mental health concerns could be represented by numerical codes (e.g. expressed concern number 2).

Research and administrative purposes

Formulation-based approaches prioritise understanding and working with each person's experiences. Therefore, approaches such as these not intended to capture or classify experiences across groups of people. They are also difficult to summarise and therefore record in administrative systems. Although they are often beneficial for service-users, this presents challenges for the purposes of admin or research. Several authors suggest that including numerical data (e.g. validated outcome measures, Duncan, Sparks & Timimi, 2018) or codes (Rubin, 2018; Kinderman & Allsopp, 2018), would allow for services to collect data which can be used for research or to help organise services. More specifically, Kinderman and Allsopp (2018) state that recording experiential codes would advance the understanding of the impact of particular adversities on the occurrence of particular mental health difficulties. Similarly, Rubin (2018) builds on this approach by suggesting that recording specific, numbered mental health concerns would allow research to advance by better identifying the correlations between mental health and physical health.

Discussion

This review explored the literature to determine what key characteristics of a non-diagnostic alternative should possess. It identified six alternative models which have been suggested as possible replacements for psychiatric diagnosis, and explored how each model could potentially fulfil the functions currently fulfilled by diagnosis.

Summary of the findings

What does the literature say about what the key characteristics of a non-diagnostic alternative should be?

There was much agreement between authors about the key characteristics that a non-diagnostic alternative should possess. All papers advocate for a non-medical understanding of distress: that is, the suggestion that most mental health difficulties are not solely caused by biological mechanisms, and that social and psychological factors are often the main reason. Similarly, they suggest that distress should be normalised, rather than pathologised, as a product of a ‘disorder’ or ‘illness’ and attend to individual experience. Many propose that an alternative should, therefore, classify concerns or problems.

Many authors suggest that an alternative should revisit the business of psychotherapy and prioritise relational and common factors that are known to be effective in driving change. Furthermore, it is importance for any new system to be able to work in conjunction with wider systems of support and consider the views of all key stakeholders.

What alternatives have been proposed so far?

This review also explored the various alternatives which have been suggested as replacements for psychiatric diagnosis. Six models were identified and summarised (Duncan, Sparks & Timimi, 2018; Johnstone, 2018; Johnstone & Boyle, 2018; Kinderman, 2015; Kinderman & Allsopp, 2018, Rubin, 2018). Indeed, it appears that the models included many of the characteristics that were outlined in the first part of the review.

Although this review focused on alternatives designed to replace psychiatric diagnosis, there are, of course, other possible approaches. Examples include, dimensional approaches such as *The Hierarchical Taxonomy of Psychopathology* (HiTOP; Kotov et al., 2017) or those that aim to identify the ‘biological mechanisms’ of distress (e.g. RDoC; Cuthbert & Insel, 2013). Approaches such as these are designed to be used in conjunction with psychiatric diagnosis and were outside the scope of this review.

How well do the proposed models fulfil the functions currently fulfilled by diagnosis?

The last part of the review explored how each of the alternative models might fulfil the functions currently fulfilled by diagnosis. This is important because any move away from the status quo requires careful consideration as to how the functions that are served by the current system will be fulfilled under any alternative. Most of the authors had considered the ways in which their proposals could fulfil the current need for classification, guiding interventions, recognising service-user experiences, providing access to support, and serving practical functions.

However, it appears that there is a tension between the need for classification on the one hand and for individualisation on the other. Many suggest that classification importantly guides practice, service organisation and provision (McCutcheon, 2014). However, one of the major criticisms of diagnosis is that human behaviour is complex and cannot be classified into discrete categories (Johnstone, 2018). Authors promoting alternative approaches suggest that individual experience should be prioritised. This presents a dilemma, as the current function of classification is at odds with attending to individual experience. However, several authors (e.g. Kinderman & Allsopp, 2018; Rubin, 2018) argue that common categorisation and individualisation can be achieved through classifying experiences, not ‘disorders’ or ‘illnesses’.

Furthermore, the drive to ‘drop the language of disorder’ (Kinderman et al., 2013) has the potential to benefit service-users by preventing them from being labelled in ways that can be harmful. However, another possible dilemma that appears not to be addressed sufficiently in the literature, is the balance between normalising experience on one hand, and on the other acknowledging the severity of people’s difficulties. Within our current system, severity is demonstrated by receiving a diagnosis and the associated ideas of ‘illness’. An alternative that promotes the idea that distress is ‘normal’ and ‘part of life’ potentially run the risk of people’s needs not being met. This is particularly concerning in the context of austerity (Kinderman, Allsopp & Cooke, 2017).

On a similar note, some of the suggestions are beyond the remit of health services to change. For instance, the importance to work alongside wider systems of support, particularly the benefits system. Arguably, in order for these alternatives to be implemented in practice, other wider, social, and political changes need to happen alongside. Moreover, an approach that incorporates a way of categorising service-user difficulties (either recording codes or concerns) is likely to overcome some of the potential barriers.

Clinical Implications

Research by Randall-James and Coles (2018) found that clinical psychologists strive to find ways to work beyond psychiatric diagnosis but are often met with challenges, for example, feeling ‘othered’ by colleagues, or working with the reality that diagnosis is embedded within systems. One of the conclusions from the study was that there is still uncertainty about what alternatives to offer and how to implement them in practice. This review found that there are a variety of ways to work beyond diagnosis in clinical practice, some of which are already widely used (e.g. psychological formulation; DCP, 2011), and others that present clinicians with new ways of working (e.g. PTMF; Johnstone & Boyle, 2018; PCOMS; Duncan, Sparks & Timini, 2018).

It appears that some of the changes that can be implemented in practice are small but could make a big difference. One of the findings from this review was the ways in which language could be changed to describe experiences in non-medical terms, for example, from ‘having schizophrenia’ to ‘hearing voices’ or ‘holding unusual beliefs’. Moreover, the change in language could also be applied more broadly so that instead of using terms such as ‘disorder’, we could adopt the language of ‘concern’. Changing to a concern-based approach has the potential to shift the focus from expert-driven manuals to one that attends to each person’s unique experiences.

It is important for professionals to ask about people’s experiences of adversity, life events and social factors as it could lead to a better understanding of the reasons why people seek help, leading to more meaningful formulations and interventions. Furthermore, some argue (e.g. Kinderman, 2015) that recording problems (i.e. ‘real world’ data) could help services to be based on an assessment of needs, that is, knowing how many people experience certain problems and the recommended interventions.

In terms of the challenges related to developing a common framework, some suggest that the answers can be found in using existing systems (e.g. using ICD-11 experiential codes, Kinderman & Allsopp, 2018). However, as noted in this review and elsewhere (Randall-James & Coles, 2018), more work is needed to translate these changes to wider systems of support. Although, some have already started to explore possible ideas that could compliment structures that are already in place (e.g. CSM; Rubin, 2018).

Future Research

Most of the authors outline the potential impact that alternative approaches could have on service-users and clinical care. However, there was little empirical evidence to support these claims. As stated by Johnstone (2018), more needs to be known about the effect of these new developments in practice and the true impact on service-users. Moreover, although there has been progress in developing these approaches, it would be beneficial to explore how to implement these changes, and the potential barriers and enablers to change. Lastly, one of the areas identified in the review is the challenges in translating these ideas to wider systems of support. Therefore, future research could consult key stakeholders.

Limitations

As is common practice for scoping reviews, no formal quality assessment of the literature was undertaken (Grant & Booth, 2009). Therefore, there may be variability in the quality of the literature. However, the papers that were included were all published in peer-reviewed journals or by professional bodies. This review did not plan to be an exhaustive summary of the literature in this area. Best efforts were taken to ensure that all relevant material was included (Appendix A). However, there is inevitably some subjectivity in this endeavour.

Furthermore, it would be unfair to assume that the views represented in the review are fully representative of alternatives to diagnosis. For example, many of the authors were clinical psychologists who are longstanding advocates of non-medical approaches (e.g. Lucy Johnstone, Mary Boyle & Peter Kinderman). As noted elsewhere, there are other ways in which diagnosis could be improved or changed (e.g. dimensional categorisation, Kotov et al., 2017).

Reflexivity is an important when conducting research, including reviews (Mortari, 2015). By documenting the challenges to psychiatric diagnosis, and suggested alternatives, this review inevitably reflects a critical stance on the concept of diagnosis. Both members of the supervising research team have written about these issues (e.g. Cooke & Kinderman, 2018, Kinderman, 2015). Therefore, it was important to have overt discussions in supervision to minimise the effects of potential effects of bias when writing this paper.

Conclusions

This review explored what might constitute an alternative to psychiatric diagnosis and identified possible models to use in practice. Six models were proposed and included a variety of possible changes that could be made. Examples included classifying concerns or experiences (e.g. Johnstone & Boyle, 2018; Kinderman, 2018; Rubin, 2018) or utilising systematic client feedback (Duncan, Sparks & Timimi, 2018). Many authors discussed the importance for any new approach to describe experiences in non-medical terms and include the various reasons that people experience mental health problems (e.g. social factors, or life events). These ideas would benefit from further research scrutiny, especially from the perspective of service-users, to investigate the likely utility and impact of these approaches. On wider level, more work needs to be done to explore how these changes could translate to other systems of support, particularly those that provide welfare.

There are several potentially problematic tensions in non-diagnostic practice and the functions that are currently served by diagnosis. This is particularly apparent in the drive to normalise people's experiences on the one hand and acknowledge the severity of people's difficulties on the other. If practice is to change, greater exploration of these issues is needed, considering the potential implications to access to care and service organisation.

This review highlighted the widespread efforts to reform diagnosis in mental health settings. However, it has been eight years since the BPS called for a paradigm shift (BPS DCP, 2013) and diagnosis remains dominant in clinical practice. Some have suggested that barriers to change can be seen in the interests of those in power:

> "Power and decision-making in mental health policy, services, and care structures is concentrated in the hands of biomedical gatekeepers, particularly biological psychiatry. These gatekeepers, reinforced by the pharmaceutical industry, maintain this power based on two outdated and scientifically unsound concepts: that people experiencing mental distress and diagnosed with "mental disorders" are dangerous, and that biomedical interventions in most cases are medically necessary." (Pūras, 2017, para. 6).

On a similar note, research by Randall-James and Coles (2018) outlines the concept of 'playing the diagnostic game', that is, the idea that clinical psychologists implement alternative ideas in practice, whilst also collaborating with diagnosis where there was felt to be client need or to protect relationships with colleagues. The authors explore the role of interpersonal and organisational power that could be at play in preventing clinicians overtly asserting their position on alternatives to diagnosis. Issues such as these are complex and suggest that there are wider systemic issues at play in preventing change. Future work, should, therefore, continue to explore these barriers in hope of finding ways to overcome them and to implement some of the ideas proposed in this review.

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Section B: Service users' perspectives on psychiatric diagnosis and the use of ICD-11 experiential codes as an alternative.

Word Count: 7985 (605)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

MAY 2021

SALOMONS INSTITUTE FOR APPLIED PSYCHOLOGY
CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

There is a growing body of evidence that service users can experience harmful effects from receiving a psychiatric diagnosis. Many have suggested alternatives to replace psychiatric diagnosis. One recent suggestion is to use the existing ICD-11 experiential codes to record complaints (e.g. ‘anxiety’) and life experiences (e.g. ‘experience of abuse’). Service-user perspectives on the likely impact of alternative approaches is sparse. This study, therefore, explored participants’ experiences of receiving a psychiatric diagnosis and their views about utilising the ICD-11 experiential codes as a possible alternative.

Thirteen participants were interviewed, and data were analysed using thematic analysis. The results presented six themes, including identifying and characterising the problem, communication with professionals, personal impact, support and recovery, response from others, and implementation.

The study found that participants experienced some benefits from receiving a diagnosis. The negative effects were similar to those outlined in previous research, namely that labelling people as ‘disordered’ can lead to stigma and identity changes. The alternative was viewed positively by participants in it’s potential to reduce the negative effects of diagnosis. This study concluded that recording experiential codes, regardless of whether a diagnosis is received, could lead to better person-centred care.

Key words: Psychiatric diagnosis, alternative to diagnosis, service user experience, ICD-11, experiential codes.

Introduction

Psychiatric diagnosis can be defined as “a medical term used to describe patterns of experiences or behaviours that may be causing distress” (BPS DCP, n.d. p. 2). According to a report published by the Mental Health Foundation (2016) one in six adults in England met the diagnostic criteria for at least one common mental health problem. However, there is debate about whether, or at least when, the concept of diagnosis is appropriate in mental health. The debate largely pertains to diagnoses that are ‘functional’, a term used to describe problems that lack a distinct biological cause (e.g. ‘depression’ or ‘bipolar disorder’) (Bell et al., 2020).

Critique of psychiatric diagnosis

Psychiatric diagnosis is part of the medical model, which Deacon (2013) defines as the idea that mental health difficulties are caused by biological abnormalities in the brain and require medical treatment. Reaching a diagnosis involves observation of various patterns of distress that help to identify the nature of the underlying disease that is causing the symptoms (Moncrieff, 2010). However, research has failed credibly to show that a biological cause exists for most mental health problems and that psychiatric drugs work by correcting abnormalities (e.g. Mathalon & Ford, 2012). This is particularly concerning given the sharp increase in medication prescribing in the NHS (Iacobucci, 2019). Furthermore, Read and Harper (2020) argue that many of the diagnostic concepts are ‘scientifically meaningless’ in their failure to demonstrate validity (Jablensky, 2016) and reliability (Vanheule et al., 2014).

A frequent criticism of the medical model, and consequently of psychiatric diagnosis, is its de-emphasising of other factors that are associated with distress, for example, adverse experiences or social circumstances (Anakwenze & Zuberi, 2013; Larkin & Read, 2008; Trotta, Murray, Fisher, 2015). Critics argue that the language of ‘disorder’ is misplaced, and that many experiences are better conceptualised as understandable responses to distressing circumstances (Kinderman et al., 2013).

Lastly, research exploring service-user perspectives has found that receiving a diagnosis, whilst it can bring certain benefits (Pitt et al., 2009), can lead to a range of negative outcomes. For instance, diagnoses have been criticised for inflicting blame, failing to account for adverse experiences, and leading to changes in how people view themselves (Allman et al., 2018; Horn, Johnstone & Brooke, 2007; Howe, Tickle, & Brown, 2014). A recent systematic review highlighted many of these issues and further emphasised the role of service-related factors (e.g., communication of the diagnosis and poor information giving) on service-user experience.

Service-users also report experiences of stigma (Dinos et al., 2004) which often arise in the context of negative stereotypes about what it means to be labelled as ‘mentally ill’ (Huggett et al., 2018). According to modified labelling theory (Link et al., 1989) people who receive diagnoses are likely to internalise these narratives and are therefore at risk of seeing themselves in a more negative light. Our understanding of this process is also extended by Conneely et al., (2021), who propose that identity change can be a consequence of internalised stigma related to pre-existing negative societal beliefs. Such beliefs can be attached to specific diagnoses (e.g., schizophrenia) and can lead people to feel ‘tainted’ and different to others.

The quest for an alternative

The implications of the issues outlined above are extensive and suggest that our dominant model of working is, in many ways, flawed. Many have advocated the need for alternative ways to conceptualise mental health problems (e.g. Boyle, 2007; Cooke & Kinderman, 2018). This was publicly affirmed in a position statement by the British

Psychological Society (BPS) Division of Clinical Psychology (DCP) (BPS DCP, 2013), criticising the use of psychiatric diagnosis and stating the need for an alternative.

Some authors have attempted to define the key features of a non-diagnostic alternative. Raskin (2019) has proposed that an alternative must place psychosocial factors on equal footing with biological factors, categorise problems rather than people, be scientifically sound, and be developed in collaboration with service-users.

A variety of non-diagnostic alternatives have been proposed (e.g. Duncan, Sparks, & Timimi, 2018; Rubin, 2018;). Perhaps the most well-known is the *Power Threat Meaning Framework* (Johnstone & Boyle, 2018), a comprehensive model that places psychosocial factors at the forefront of understanding mental health difficulties. Indeed, in terms of the criteria proposed by Raskin (2019), the framework embodies what an alternative ‘should’ look like. However, it is not without criticism (e.g. Salkovskis, 2018) and its use is not, or not yet, widespread.

A mainstream alternative that is supported by the BPS (BPS DCP, 2011) is psychological formulation. Endorsed as a core skill for clinical psychologists (BPS DCP, 2011), formulation can be described as “the process of co-constructing a hypothesis or “best guess” about the origins of a person’s difficulties in the context of their relationships, social circumstances, life events, and the sense that they have made of them” (Johnstone, 2018, p. 32). Research has shown the benefits of formulation for service-users (Gibbs, Griffiths & Dilks, 2020). However, critics argue that the approach lacks scientific grounding (Bieling & Kuyken, 2006).

Despite recent work to suggest alternatives to psychiatric diagnosis, there is very little empirical research exploring service-user perspectives on their applicability and utility. This is most surprising given that one of the key drivers for change was the negative impact diagnosis has on many service-users (BPS, DCP, 2013). Many have advocated that service-users should be involved in the process of developing an alternative:

> "People with lived experience of diagnosis must be at the heart of any discussions about alternatives to the current system. People who use services are the true experts on how those services could be developed and delivered; they are the ones that know exactly what they need, what works well and what improvements need to be made." (Hearing Voices Network, n.d. para. 3)

Experiential Codes

Many practitioners argue that a classification system is necessary or even essential (e.g. McCutcheon, 2014). Within our current system, diagnoses guide service organisation, communication between professionals, and access to support (Craddock & Mynors-Wallis, 2014). One recent suggestion made by Kinderman and Allsopp (2018) is to use existing structures in the International Classification of Diseases (ICD-11), a global classification system developed by the World Health Organisation (2018). The latest edition includes as a list of possible diagnosable disorders as well as numbered codes pertaining to different possible complaints (e.g. 'MB29.1 Binge eating', 'MB28.9 Low self-esteem', 'MB23.H Panic attack') and life experiences (e.g. 'QE83 Personal frightening experience in childhood', 'QD71 Problems associated with housing'). For this paper, the term 'experiential codes' will be used to refer to both of the 'compliant' and 'life experience' codes.

Kinderman and Allsopp (2018) suggest that instead of assigning a diagnosis, clinicians could instead assign a particular combination of experiential codes depending on the person's circumstances. An example of the difference between the two approaches is outlined in Table 1.

Table 1

The Difference Between Psychiatric Diagnosis and Experiential Codes

Psychiatric Diagnosis	ICD-11 Experiential Codes
Major Depressive Disorder	History of spouse or partner violence (QE51.1) Low income (QD51) Problem associated with interpersonal interactions (QE50) Non-suicidal self-injury (MB23.E) Depressed mood (MB24.5) Feelings of guilt (MB24.B) Poor concentration (MB21.A)

Note. This is an example. The list of codes would be based on the person's circumstances and experiences.

Kinderman and Allsopp (2018) suggest that this approach would allow for people's mental health problems to be recorded accurately, without unnecessary pathologisation, within a system that already exists in mental health practice. As noted by linguistic relativity theory (Kay & Kempton, 1984) language influences our thinking, behaviour, and interactions with one another and society. Therefore, it is possible that the change in language in this approach (i.e., away from 'disorder' and 'illness') may lead to changes in how people relate to their mental health. Furthermore, removing the psychiatric label could reduce the opportunities for 'othering', internalised stigma, and identity changes (Conneely et al., 2021; Link et al., 1989)

However, these proposals have not been subjected to research scrutiny. We do not know, for instance, how this approach might impact various stakeholder groups. The most important stakeholder group is clearly that of service users. Few studies have examined service-user perspectives on either diagnosis or its alternatives (Perkins et al., 2018; Johnstone, 2018) and some argue that their views remain under-represented in the literature

(Russo & Beresford, 2015). To our knowledge, this study is one of the first empirical papers to explore service-user perspectives on non-diagnostic alternatives.

Research aims and questions

This study aims to address the gap in the literature by exploring service-user experiences of receiving a diagnosis, and their perspectives on the use of experiential codes. This study aimed to answer the following research questions:

- What are service users' experiences of receiving a psychiatric diagnosis?
- What are service users' views on the likely utility and impact of the use of the experiential codes in the ICD-11 as an alternative to psychiatric diagnosis?

Methodology

Design

This study used a qualitative methodology. Participants were interviewed individually using a semi-structured interview schedule. The data were analysed by Braun and Clarke's (2006) thematic analysis.

The epistemological position adopted was one of critical realism, which sits between the two poles of essentialism and constructivism. It is an approach that acknowledges "the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of 'reality' (Braun & Clarke, 2006, p. 81).

Participants

Thirteen participants took part in the study. Demographic information can be seen in Table 2. Participants were invited to take part if they had received a psychiatric diagnosis and were able to give informed consent. The intention was to speak to people with a range of diagnoses. No limits were set on the time since the diagnosis had been received. No other inclusion or exclusion criteria were set.

Participants were recruited through local mental health organisations, support groups, and via social media platforms (a list of which can be seen in Appendix B). Recruitment took place largely in south east England. A copy of the advertisement and the email inviting people to take part is in Appendix C. Most of these forums provided community support for people with mental health difficulties and did not take a particular stance on psychiatric diagnosis. Three participants were recruited via a social media group that took a critical stance towards psychiatric diagnosis: the implications of this are discussed below in the limitations section.

Table 2

Participant demographics

Pseudonym	Gender	Age Range	Ethnicity	Diagnoses received	Year diagnosis was received
Claire	Female	55-60	White British	Postnatal Depression Recurrent Depressive Disorder Emotional Unstable Personality Disorder Major Depressive Disorder Complex Post Traumatic Stress Disorder	Between 1992-2020
Robert	Male	60-65	White Other	Bipolar Disorder Post Traumatic Stress Disorder	1987
Emily	Female	30-35	White British	Bipolar Disorder & Psychosis	2011
Lucy	Female	25-30	White British	Depression & Anxiety	2008
Paula	Female	25-30	White British	Post Traumatic Stress Disorder Schizoaffective Disorder	2005 2015
Amy	Female	25-30	White British	Depression & Anxiety	2018
Holly	Female	30-35	White British	Bipolar Disorder	2016
Dave	Male	60-65	White British	Emotional Unstable Personality Disorder	2015
Amani	Female	25-30	Asian - Indian	Borderline Personality Disorder	2011
Julie	Female	45-50	White British	Depression Anxiety & Emotional Unstable Personality Disorder	1986 2015
Tony	Male	70-75	White British	Paranoid Schizophrenia Depression & Anxiety	1999
Jess	Female	25-30	White British	Post Traumatic Stress Disorder Anxiety Disorder Obsessive Compulsive Disorder & Depression	2009 2017 2019
Amanda	Female	60-65	White British	Manic Depression Bipolar Disorder Schizoaffective Disorder	1984 2000 2001

Measures

A short video clip was shown to participants during the interview. It provided information about how the experiential codes could be used in practice (Appendix D). This approach was used because it ensured a controlled presentation of information for each participant, in a clear and accessible way. It also allowed the researcher to be independent of the process and to adopt a stance of neutrality, minimising the likelihood of demand characteristics.

The video was developed in collaboration with service-users. An initial draft of the video was presented by the lead researcher to a panel of nine lived-experience practitioners. The feedback from the panel included ideas about how to simplify the language and ensure that the ideas were communicated sensitively and accessibly. All the proposed changes were implemented in the final video.

The interview topic guide can be seen in Appendix E. To ensure a flexible and participant-driven approach, the interviewer adopted an open and curious stance, holding in mind key topics without imposing a fixed structure. When discussing the use of experiential codes, the interviewer revisited the areas discussed by participants about their experience of diagnosis, to prompt participants to compare the two approaches.

Procedure

An advertisement for the study (Appendix C) was circulated to mental health organisations, support groups, and via social media platforms. Any participants who were interested in taking part were sent the information sheet (Appendix F) and consent form (Appendix G). At the start of the interview, participants were reminded about the information on both forms and could ask any questions. Demographic information was collected, and participants self-reported their psychiatric diagnoses.

Three participants were interviewed face-to-face. Given the restrictions imposed in response to the covid-19 pandemic, the remaining interviews took place via video or telephone call. In these instances, verbal consent was obtained. A member of the supervising research team provided an authorising signature on each consent form as evidence of this process.

Participants were interviewed about their experience of receiving a psychiatric diagnosis. Participants were then shown the video and could ask any questions. They were then asked about their views about the experiential coding approach. All interviews were audio recorded and ranged between 33 and 77 minutes long. The average length of the interviews was 57 minutes. The shortest interview did not include the video as the participant had watched it beforehand.

All participants were asked whether they wanted to receive a summary report outlining the key findings from the study (Appendix H). All participants agreed.

Data Analysis

Interviews were individually transcribed by the lead researcher. The data were analysed using Braun and Clarke's (2006) thematic analysis which is a method for "identifying, analysing and reporting patterns (themes) within data" (p.79). This method of analysis was chosen as the topic is under-represented in the research and would therefore benefit from a rich description of the main themes. An outline of the approach can be found in Table 3.

The data were analysed inductively (Kiger & Varpio, 2020), to ensure that the breadth of experiences were captured, without assuming pre-existing ideas. Initially, separate thematic maps for diagnosis and experiential codes were generated. However, upon a closer exploration of the data and discussion in supervision, there was considerable overlap between the participants' discussion of the concepts, suggesting that it might be clearer to present them together.

Table 3

The thematic analysis process as proposed by Braun and Clark (2006)

Step	Process	Description of the process
1	Familiarising yourself with the data	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.
2	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3	Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4	Reviewing the themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5	Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6	Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Quality Assurance

In order to ensure high quality analysis, the researcher followed procedures suggested by Castleberry and Nolen (2018). Examples of each recommendation and how it was used can be seen in Appendix I. A bracketing interview (Tufford & Newman, 2010) was conducted between the lead researcher and a colleague, to consider pre-existing beliefs about the topic which could influence data interpretation. A research diary (Appendix J) was used throughout the study to ensure transparency in decision making and to promote ongoing reflection.

Research supervision was beneficial in all aspects of the study, particularly when identifying themes. After the first interview had been conducted it was listened to in full by the lead research supervisor, who provided feedback on the interview technique. Further evidence of codes, themes and subthemes are presented in Appendix K.

Ethics

Ethical approval was granted by Canterbury Christ Church University Salomons Institute for Applied Psychology Ethics Panel (Appendix L). Throughout the research process, the researcher adhered to the relevant professional research frameworks (BPS, 2018; NHS Health Research Authority, 2020).

The interviews addressed sensitive themes. Participants were therefore advised only to talk about experiences which they were happy to discuss in this context. Participants were given the option to stop at any time and were all asked halfway through how they were finding it. Notably, no participants became distressed during the interviews.

All relevant ethical issues that were outlined in the information sheet were discussed with participants. Participants were reminded that they could withdraw at any time without giving a reason. Participants were advised that they could contact the lead researcher or the research team with any queries or concerns, although none were raised by any of the participants.

Results

This study explored two areas of enquiry: participants' experiences of receiving a diagnosis and their views about experiential codes as an alternative. Participants' statements fell into six broad themes. The first related to the ability of each approach to identify problems and the second to the extent to which they were, or might be, useful in communicating with professionals. The third related to the personal impact of being described in each of the two ways, and the fourth to the way in which each might facilitate or hinder recovery. The fifth related to usefulness in terms of communication with others, and the sixth to how the experiential coding approach could be used and disseminated. Table 4 outlines the main themes and subthemes.

Table 4

Themes, subthemes, and description

Theme	Subtheme	Description
Identifying and characterising the problem	Recognition	Diagnosis: Identifies the problem and provides reassurance that it is one that is recognised by a professional: “It’s not all in my head”. Experiential Codes: Could severity go unrecognised?
	Accuracy	Diagnosis: Fails to capture lived experience. Experiential Codes: Foreground individual experience.
	Understanding	Diagnosis: Provides an explanation. Experiential Codes: Non-medicalised language is easier to understand.
Communication with professionals	-	Diagnosis: The way in which diagnoses are decided and communicated is key. Experiential Codes: An aid for more collaborative care. Could the process become lengthy and how to prioritise the codes?
Personal impact	Emotional Impact	Diagnosis: Being labelled is an emotional experience. Experiential Codes: Reduce blame and the emotions associated with diagnosis.

	Self-perception	Diagnosis: Receiving a diagnosis can lead to changes in the way people view themselves. Experiential codes: Less likely to negatively impact identity: “It’s more human”.
Support & recovery	Access to support	Diagnosis: Does not always lead to appropriate support. Experiential Codes: Opens up options for help and support. Would support be difficult to access without recognised terms?
	Sense of recovery	Diagnosis: Implies that you’ll never get better. Experiential Codes: Promote recovery through the ability to change and remove codes over time.
Response from others	Disclosure	Diagnosis: Difficult to disclose to people. Experiential Codes: A lot of personal information to share with others.
	Stigma	Diagnosis: People do not understand and make assumptions. Experiential Codes: Normalises experiences.
Implementation	Experiential codes as an addition to current practice	Experiential Codes: A tool which could facilitate person-centred care.
	Consideration of the wider context	How to disseminate these approaches to wider systems of support?

Themes and subthemes will now be described in turn and illustrated by quotes from participants.

Identifying and characterising the problem

Participants felt that the two approaches varied in the extent to which they helped (or might help) them to identify, understand, and describe their experiences.

Recognition: *Diagnosis*

Some participants reported that receiving a diagnosis had been helpful in that it represented a recognition of their experiences and reassured that their difficulties were not unique or unusual.

> "It just felt like a huge relief that someone who you know was obviously very experienced and knowledgeable would say to me 'It's okay, you're not going mad, you're actually suffering with depression and it can be treated." (Lucy)

> "This is actually something that is recognised. I'm not just inventing this in my head." (Amy)

Recognition: *Experiential Codes*

Participants felt that the detail afforded by the experiential codes could help people to characterise their difficulties and seek appropriate help.

> "It could help the individual to process what's happened to them as well. You might need someone to ask those questions to get that information and highlight it even to you." (Emily)

> "People [might] look at the descriptions and are like: 'Actually I tick a lot of these boxes I should probably go and talk to someone about this'." (Amy).

Conversely, participants were concerned that the severity of people’s experiences could go unrecognised without the use of diagnostic terms, meaning that they would not get the understanding and help they needed.

> “I do also worry about the lack of understanding of the severity. I’m all for normalising it but the compound of all those experiences is severe. I think if you normalise it too much you can maybe feel like it’s not that big a deal, and people cope with this all the time, and they should be able to cope.” (Emily)

> “I would also worry that for people who are quite dismissive of mental illness, taking away the medical words might make it a bit easier for them to dismiss the problem. You talk about it as ‘She’s not sleeping and she’s sad’ it has less of an impact when describing it to other people than ‘She was diagnosed with depression’.” (Paula)

Accuracy***:*** *Diagnosis*

Many participants felt that diagnosis failed accurately or adequately to capture the nature of their problems. Some described feeling “pigeonholed” into diagnostic categories and felt that professionals failed to adopt a person-centred approach. Many felt that their diagnosis did not reflect their lived experiences.

> “I previously had a psychiatrist that told me that I don’t feel a certain way because the textbook says this about this illness, or tablet, or disorder, or whatever. That makes me feel like I’m wrong for feeling the way I am.” (Amani)

> “You kind of feel like a square peg going into a round hole.” (Julie)

> “I think the EUPD diagnosis just made me feel awful because I looked it up and it didn’t fit. I didn’t fit the descriptors. They wouldn’t listen to me when I said that.” (Claire)

More specifically, several participants who received diagnoses of Bipolar Disorder or Personality Disorder reported that they had never been asked about their previous experiences of trauma. Some believed that their early histories had shaped their current difficulties and that their diagnosis failed to account for this. Vitally, these participants reported that they were left feeling blamed.

> "Without acknowledging the trauma - knowing now that the trauma caused it, it's not my fault. None of it's my fault and when you get a diagnosis you feel as if it is... Everything is always my fault, and that's what I've been told throughout my life, and that is reinforced in the mental health system so much, that you're the problem." (Claire)

Other participants had lost faith in diagnosis when they had it changed or compared themselves to other people with the same diagnosis.

> "When did I stop becoming Manic-Depressive and then become Schizoaffective Disorder? I don't remember a change looking back." (Amanda)

> "My cousin has got Bipolar but she's working. She's in a completely different place to me. It confuses me because it makes me think that I should be like that, and I'm not doing it right. Yet obviously I'm an individual with different experiences." (Holly)

***Accuracy**: Experiential Codes*

Some participants stated that adopting this approach would promote a "more accurate representation" (Holly) of their problems. They saw benefits in being able to have a tailored list of codes that reflect their experiences.

> “It’s switching from something that doesn’t quite fit, doesn’t feel right or is stigmatising you, to something that’s yeah, that’s how I’m feeling…They would see the person, not the label.” (Claire)

> “You’re not just like labelling everyone under one umbrella… you’re looking at the individual, and person in front of you, and addressing every single thing that they are going through.” (Lucy)

> “I think it’s a massive thing to be able to describe what you’re feeling and having that, rather than trying to put it under the umbrella term.” (Amy)

Understanding: *Diagnosis*

Most participants reported that receiving a diagnosis provided them with an understanding of their difficulties.

> “I was always looking for a reason why I was so volatile, why I was so emotional, so erratic, and once I got that I could then understand why I was.” (Dave)

> “I felt a little bit relieved because it gave me a reason obviously for my changes in behaviour, and personality, and everything else.” (Robert)

However, others felt that their diagnosis did not account for all their experiences or adequately explain their mental health problems.

> “It’s been over a 10-year period [after receiving a diagnosis] that I finally feel like I have fully understood what I’ve experienced.” (Jess)

***Understanding**: Experiential Codes*

Participants felt that the language used in the experiential codes was accessible, descriptive, and non-medicalised, and would therefore make it easier for people to understand their experiences.

> "It helps me to understand as well because you know, 'paranoid schizophrenic': I had to read up about it, whatever it meant. Whereas if you just say 'voice hearer' or 'depressive' you instantly know that what is." (Tony).

> "So I think using quite simple language like 'hearing voices' or 'having strange thoughts' - they make they make it more accessible, I think, to people who might not have an understanding of their own condition, or have a good language ability, particularly if English isn't their sort of primary language." (Paula).

However, several participants were concerned that other people might not understand the nature or severity of their difficulties without recognised terms.

> "It was maybe only obvious to people who live with us how poorly I was, and how much I couldn't do. I think if it was just listed symptoms, some of that might not be recognised as much, and I think would make it harder for people to understand." (Emily)

A few participants were concerned that moving away from diagnosis would mean that their experiences might be left unexplained. For instance, some felt that merely listing problems was inadequate.

> "If someone's got depression, I know it means that they're feeling really sad, or that they might be to the point of being suicidal. [People] would understand that, rather than just 'low mood'." (Amy)

> "People would probably be like, but what is actually wrong with you though?" (Lucy)

Communication with professionals

Participants reflected on the process of receiving a diagnosis, including how the decision was made and communicated by professionals. In terms of experiential codes, participants discussed how they envisioned the approach working in practice.

Communication with professionals: *Diagnosis*

Participants expressed the importance of professionals tasking the time to understand and listen to their experiences. Some had negative experiences, often when decisions had been made based on brief interviews.

> "They saw a few behaviours, and they gave me like a brief, very brief interview and then they made me have a diagnosis that is like awful…and life changing." (Holly)

> "How can you make that assumption like so quickly when you don't really know me? I've literally said a few keywords and you've linked them to bipolar." (Lucy)

Several participants commented on the way that diagnoses are sometimes delivered. Some had first been made aware of their diagnosis through seeing it in documents addressed to others (e.g. discharge letters). Many had received little information about what their diagnosis meant and had received no support to understand it, or to discuss their diagnosis with a professional. Most took to online platforms to educate themselves about the diagnosis.

> "I didn't know I'd been diagnosed with EUPD until about six months after I was. It came out - I think I saw it written down and I was shocked." (Claire)

> "With bipolar I had to actually go and research what bipolar was, which is crazy because I have it, I should know." (Holly)

***Communication with professionals**: Experiential codes*

Several participants commented that the change to non-medicalised language may promote greater collaboration and communication between clients and professionals. For instance, some felt that they might more inclined to seek help and discuss their experiences if they were described in this way.

> “I would open up to you a lot more if you use those words with me, rather than use diagnoses like schizophrenia and what have you.” (Amanda)

Participants thought a benefit of the experiential codes was the level of detail that would be recorded in their notes. An advantage of this meant that it could prevent people from having to repeat the same information to different professionals.

> “I think it just it would be so much easier if that was in my records. Then I wouldn’t have to explain it all the time.” (Jess).

Participants also saw some disadvantages. There was uncertainty about which codes professionals would prioritise and worry that the process might become lengthy.

> “Have professionals got the time to actually list off the different codes and allow you to explain how you associate with all the different codes?” (Julie).

Participants were also concerned about having personal and sensitive information on their records.

> “People might not want that to be so open.” (Jess)

Personal Impact

Participants reported the emotional impact of receiving a diagnosis and how it had led to changes in how they viewed themselves. With respect to the alternative, participants speculated about how the approach might affect them personally.

Emotional impact: *Diagnosis*

For many participants, receiving a diagnosis had been an emotional experience. A few had found it beneficial, comforting, or "a relief" (Dave). However, most participants described a range of distressing emotions including, shock, denial, confusion, devastation, anger, and fear. Some participants said this was due to a lack of information about their diagnosis.

> "It was also quite frightening because I didn't know what it was" (Paula)

However, many experienced these emotions because of being 'labelled'. In some circumstances, receiving a diagnosis had a profound impact on mental health.

> "Nasty labels…it's like if you're gonna bully someone what a way to do it. You realise like it's a horrendous, horrendous thing to be labelled… and it's life changing. When they gave me the diagnosis 'Oh you've got bipolar' it was just like 'Oh great, so my life's always been hard and now it's just gonna be forever like the same'… and it made me feel really suicidal, like it made me feel like I didn't want to live like this." (Holly)

Emotional impact: *Experiential Codes*

Participants did not anticipate any negative effects of using the experiential codes. Several participants felt that this approach was less "frightening" and could prevent people experiencing the negative emotions associated with being assigned a diagnosis.

> "I think it's better and less frightening. I really believe that actually, less frightening…and I [would have] been actually much more compassionate with myself, because I would have realised that I was struggling with certain things that some people do struggle with." (Amanda)

> "Just talking about them as experiences, as things that are difficult, makes it more accessible to people, and less frightening to them if they don't have to go in and hear that they have X problem or X diagnosis, they can just talk about the experiences and the things they struggle with." (Paula)

Several reported the potential for this approach to remove the sense of blame that they felt was inherent in psychiatric diagnosis.

> "That would have been massive because I would have realised that it wasn't my fault necessarily, it was you know, something that was happening to me, rather than it happen because of me." (Amy)

Self-perception: *Diagnosis*

The final subtheme in participants' responses was differences in how they viewed (or might view) themselves. Many said that receiving a diagnosis had led to negative, in some cases devastating, changes in self-concept.

> "Devastating. I went through a period of grieving for myself… you go through mourning who you were, or you thought you were." (Amanda)

> "It almost feels like you've got that label and you're walking around, and it's like you think that people can see the label and that's all that they see." (Lucy)

> "That's one thing that is taken away from me, because bipolar [has] made me mad, and bipolar has like taken away my humanity." (Holly)

In contrast, some participants said that their diagnosis did not define them as a person.

> "I've got schizophrenia I suffer from it. I'm not a 'schizophrenic'." (Tony)

***Self-perception**: Experiential Codes*

Many felt that the experiential codes better reflect real life experiences and have the potential to normalise mental health problems. Several felt that the approach was more "human" and might be less likely to negatively impact identity.

> "It's really interesting that you take away that loaded, loaded label, and you're just replacing it with something that is just human and that anyone could be." (Holly)

> "There's nothing particularly unhuman about all those other issues that make up bipolar and schizophrenia. [If the experiential coding approach was used] people would be able to relate to all those other issues - obviously a lot more acceptingly than these harsh medical terms." (Robert)

> "I think it would make the experiences more normal." (Emily)

Support and Recovery

This theme covered participants' experiences of, and thoughts on, access to appropriate support. With respect to diagnosis, participants described their experiences of receiving negative messages about the possibility of recovery. It was felt that the experiential codes could promote a better message for recovery.

***Access to support:** Diagnosis*

Participants had had a range of experiences in relation to access to support. Some reported that their diagnosis had led to appropriate support.

> “It was quite reassuring to have a doctor come to me and say, ‘This is what I think the problem is, and this is like the game plan of how we’re going to treat it’.” (Paula)

> “[Having a diagnosis] makes it easier to get support.” (Tony)

However, most participants felt dissatisfied with the lack of support following their diagnosis. Many had been presented with medicalised treatment plans with no offer of therapy, and felt that the diagnostic approach seemed to have led professionals to see their role as limited to labelling and medicating.

> “It’s, you know, ‘You’ve got your label, you’ve got tablets, we don’t care now’.” (Julie)

> “Nothing was done about it… I didn’t really receive much treatment. It was more like ‘Oh you’ll be fine, here’s some tablets’.” (Jess)

> “For someone who had been to the point of suicidal thoughts before, that was like ‘Oh right, you’re just gonna leave me to do this by myself while I’m this vulnerable’.” (Amy)

***Access to support**: Experiential Codes*

Several participants suggested that the experiential codes could promote better access to support beyond medication and even beyond therapy. Recording life events and circumstances was deemed a positive step towards offering support for the variety of circumstances that lead people to seek help.

> “You avoid the whole ‘You’re bipolar we’ll stick you on lithium’. They have to actually think about it.” (Holly)

> “Going to a talking therapist group when you’ve got no money to put food on the table because you haven’t been able to claim benefits… If it’s on your medical

> records…it's something that is there that they can check with you when they see you." (Julie)

Conversely, some participants said that the absence of recognised medical terms that everyone understands could make it harder to access support.

> "There is a risk that people might not receive the right treatment because it might sort of be not acknowledged, or seen as less important or less significant, than it actually is." (Lucy)

> "Seeing a list of problems and then seeing an actual diagnosis would be massively different. It would feel like [diagnosis] is going to get me somewhere and [experiential codes] is you just listing what is wrong with me." (Amy)

Sense of recovery: *Diagnosis*

The next subtheme includes participants' experiences of recovery. Many participants had encountered negative messages from services about recovery. For instance, diagnoses had been described as being lifelong, incurable, and permanent. As a result, many had been left feeling that recovery was unreachable.

> "The opinion of my psychiatrist was that this was the kind of lifelong illness that I wasn't going to recover from, and I needed to adjust my expectations and learn that I was living with this condition." (Emily)

> "I was told 'You probably won't hold down a job that involves thinking'. So, that had an impact on me for many, many years…I didn't do certain things because I was told I wouldn't be able to." (Amanda)

> "Change was not part of the process at all… I'm really angry at the system because it's not talking about optimism, there is no optimism about it" (Holly)

Sense of recovery: *Codes*

Participants thought that the fact that the experiential codes could change, be removed, and be edited, could have a positive influence on recovery.

> "What's really optimistic about this list is that certain things can be scribbled out after a period of time." (Holly)

> "You wouldn't necessarily have a diagnostic label that follows you everywhere that reminded you of that period of time in your life…I think it would be a better message for recovery." (Emily)

Moreover, participants reported that they might feel more able to seek help and to cope better with their difficulties.

> "[With diagnosis] your outlook is automatically like – 'I'm depressed, I feel helpless', and all the things you associate with depression. Whereas I guess if you've got the other approach maybe you're not as consumed by that thought, and the outlook going forward might be a bit more positive." (Lucy)

> "Because you can recover from those individually, I feel like people would feel more likely that they can recover from your own list of symptoms, one step at a time." (Emily)

Response from others

This next theme includes two subthemes: disclosing mental health difficulties and experiences of stigma.

Disclosure: *Diagnosis*

Participants felt that receiving a diagnosis enabled them to locate and receive support from people with similar experiences. Most participants had joined service-user forums or support groups, sometimes based around particular diagnoses. However, a downside of diagnoses was the prejudice and discrimination often associated with them, which had left many participants to avoid disclosing theirs.

> "I felt I had to keep it quiet and hide it that I was schizophrenic." (Tony)

> "I didn't tell work… because I wanted everyone to see me as someone who was normal and had no issues." (Lucy)

***Disclosure**: Codes*

Some participants suggested that experiential codes could promote greater and more relaxed communication with others.

> "Easier to communicate and easier to tell someone how I'm feeling without using the term." (Amani)

However, one of the possible disadvantages of the approach was the sharing of detailed personal information, which some felt could be exposing.

> "It's a lot easier to say to somebody 'I have a diagnosis of EUPD', rather than 'I suffer from all of this'." (Julie)

***Stigma:** Diagnosis*

Participants shared a range of experiences they had with friends, family, or employers that they felt had been driven by the stigma associated with receiving a diagnosis. Some described having been mocked, disbelieved, or avoided by others.

> "My extended family don't believe me. They think I make it all up which is very difficult." (Amani)

> "There were certain friends afterwards didn't speak to me again." (Emily)

Most participants felt that other people, particularly those who have not suffered from mental health difficulties, do not understand what it is like to live with a diagnosis. They had encountered people making assumptions about how they would behave. Although many felt that it was helpful that diagnoses were recognised by others, there was a danger of people misunderstanding or misusing them, which was harmful.

> "Well a lot of people associate, yeah because of the media, they associate paranoid schizophrenia… with violence." (Tony)

> "Sometimes there's this mantra that I'm dangerous and kind of unstable, and, you know, that I need to be wrapped up in cotton wool." (Emily)

> "When you put like 'borderline personality disorder' people probably think of going through Jekyll and Hyde" (Amani)

***Stigma**: Experiential Codes*

Participants felt that using experiential codes might normalise people's experiences and potentially reduce stigma.

> "It would reduce stigma to a degree because they're not using these words that people are scared of." (Robert)

> "A lot of the symptoms of bipolar, on their own, other people will have experienced in their life, and so even for the people that experienced it it's more normal and there's less things to be stigmatised for it." (Emily)

However, others felt that stigma is part of more general prejudice, (i.e. about mental health problems in general rather than just the diagnostic terms) and felt that changing the language of diagnosis was unlikely to make a difference.

> "If you start to then use lots of different words and lots of different terms, and telling people in-depth information about you and how you are feeling, that's when people become uncomfortable and don't really want to hear it. I think it could make the stigma worse." (Lucy)

Implementation

Experiential codes as a helpful addition to current practice

Participants discussed changes they would like to see in practice, and how perhaps the two approaches could work together.

Two participants felt that a diagnosis "had to be made" (Dave) and thought that it should continue to be used. By contrast, several participants fully endorsed the approach as its own system that should replace diagnosis.

> "I'd prefer it if that's how things were and how it was approached rather than what it is right now… I think it would work best." (Jess)

> "I would like to see it replaced. Just because the wording, the language, and the optimism, which is so important." (Holly)

However, most participants felt that the approaches complemented one another and could be used together. Some thought that people should be given the choice between the two approaches.

> "I think both can work together to sort of provide quite unique experiences for people, which is what I think there should be more of - more personalised experiences and more personalised treatment plans that involve all aspects of their life." (Paula)

Wider Context

Finally, participants felt that a diagnosis provided access to wider systems of support, such as benefits or sick leave. One of the concerns regarding experiential codes was the potential for this to be negatively impacted. However, some reported that having more detail on their medical notes could better guide provision of support.

> "Benefits people have only just started to get round to understanding mental illness, and so if you then say to them 'Forget all those diagnoses, we're looking at [experiential codes] now', I can see there being a bit of a problem. But I don't think that should be a problem that stops us going forward with losing the diagnosis." (Amanda)

Discussion

Summary of the findings

This study explored service-users' experiences of receiving a psychiatric diagnosis and their views about the use of ICD-11 experiential codes as a possible alternative. The main findings are summarised below.

What are service users' experiences of receiving a psychiatric diagnosis?

Participants shared a variety of experiences concerning their diagnosis. They reported that diagnoses are useful terms to communicate to systems of support (e.g. access to mental health services or welfare support), employers, and people in their lives. Furthermore, participants felt that having a diagnosis helped both them and others to recognise the seriousness of their difficulties. Lastly, like participants in other studies (O'Connor et al., 2018) many felt that diagnoses explained their difficulties.

However, the psychological impact of receiving a diagnosis was far-reaching. Many experienced distress in response to being labelled as ‘disordered’. This was particularly the case for diagnoses of bipolar, schizophrenia, and personality disorder. Furthermore, many participants reported that their diagnosis was impersonal and failed to account for the unique experiences in their lives, particularly the impact of adverse circumstances. In these instances, diagnoses were experienced as not quite ‘fitting’ and sometimes as blaming and pathologising. This finding is not new and is reported elsewhere in the literature (Horn, Johnstone & Brooke, 2007; Perkins et al., 2018; Stalker, Ferguson & Barclay, 2005).

Moreover, this study was like others in demonstrating that receiving a diagnosis can lead to changes in how people view themselves (Allman et al., 2018). As stated in the identity literature, people can maintain well-being after an important life change (i.e., receiving a diagnosis) if they keep their old social group membership or gain new social group membership (Conneely et al., 2021). The literature also suggests that people are less likely to identify with a group that is stigmatised and belonging to such groups can negatively impact on mental health (Conneely et al., 2021). This study highlighted that participants felt different from others and some felt that they had become “mad” or had lost a part of themselves since receiving their diagnosis. Importantly, some spoke about the negative impact that this change had on their mental health and relationships with others.

Furthermore, changes were also discussed in the context of internalised stigma and what it means to be ‘mentally ill’. For instance, the idea that schizophrenia is associated with violence, or that people with mental health difficulties are unable to “do a job that involves thinking”. These findings relate to the ideas proposed by modified labelling theory (Link et al., 1989) in highlighting how those labelled with a psychiatric diagnosis can see themselves differently in the context of societal beliefs about mental ‘illness’. This study, therefore, was like others in demonstrating the link between psychiatric diagnosis and stigma (Dinos et al., 2004; Perkins et al., 2018) and affirms the need for alternative ways of naming and communicating mental health distress.

There were many incidences where participants had been told by professionals that their diagnosis was permeant, incurable and lifelong. Most received medicalised treatments (e.g. medication and ECT) without the offer of therapy. Although diagnoses should lead to appropriate support (Craddock & Mynors-Wallis, 2014), many participants felt that this was not the case.

What are service users' views on the use of experiential codes in the ICD-11 as an alternative to psychiatric diagnosis?

Participants reflected on the advantages and disadvantages of the use of experiential codes. In terms of advantages, most participants viewed the change to non-medicalised, accessible language as beneficial. Indeed, this approach is in line with the guidance released by the BPS (2015) who advocate for experiences to be described in non-medical terms. This study found that this idea was viewed favourably by participants. Many suggested that it could promote a better understanding of mental health difficulties, collaboration with service-users, accuracy in recording problems, and potentially reduce stigma.

Furthermore, an important finding was the potential for the use of experiential codes to have less of a psychological impact on service-users. For example, many felt that the approach was more relatable to everyday experiences and consequently more "human". In the context of identity literature, it is possible, therefore, that people may be less likely to experience identity changes with this alternative approach (Conneely et al., 2021). This may be largely due to people perceiving less of a change to their pre-existing social groups (i.e.

codes are more relatable to everyone’s experiences) or the removal of the associated stigma from psychiatric terms.

However, participants were concerned that normalising experiences and moving away from official terms could also have negative implications. Firstly, they worried that the severity of mental health difficulties could go unrecognised, and therefore untreated. Consequently, participants were concerned that people might be unsure about when to seek help and that they ‘should’ be able to cope with these ‘normal’ experiences. These findings are important and highlight an interesting tension between normalising experiences on the one hand and recognising the severity on the other.

Clinical Implications

Experiential codes as a helpful addition to practice

Participants held different views about whether the experiential coding approach should replace the current diagnostic one. Some fully endorsed the alternative, while others believed that both should be used or that service users should be able to choose. One suggestion was to record experiential codes regardless of whether a diagnosis is also given. Participants reported that this approach would lead to more detailed information on people’s records, increase communication between professionals, and lead to more person-centred care.

Furthermore, this study also highlights that the most appropriate approach depends on the context in which it is used. For instance, one of the benefits of receiving a psychiatric diagnosis was seen to be that these are recognised medical terms, which participants used to communicate the severity of their difficulties and appropriately access support. However, diagnoses were seen to be less helpful when communicating with family or friends, or when thinking about how these terms best represent themselves. Therefore, the combination of both approaches might provide a way forward in meeting these conflicting needs.

Balancing the tensions

However, the participants presented a dilemma between normalising experiences on the one hand and capturing the severity of their difficulties on the other. Previous research has also highlighted that clinicians experience a similar dilemma in wanting to move away from diagnoses but also ensure that service-users can access appropriate support (Randall-James & Coles, 2018). Arguably, one of the barriers to moving forward is the fact that a diagnosis can help to communicate a need within wider systems (e.g., access to sick leave). In order to manage this tension, it is important to be transparent with service users about our current context. So, for instance, explaining that in some contexts (i.e., applying for benefits) medicalised diagnostic language may be beneficial to ensure people get their needs met. However, in clinical practice we should adjust our language and approach to one that is more tailored to the individual and non-pathologising of their difficulties. Approaches such as experiential codes and formulation-based approaches are helpful here (e.g., Johnstone, 2018; Johnstone & Boyle, 2018)

Furthermore, a problem can still be taken seriously without the need for a diagnosis (i.e., debt) (Kinderman, 2015). We should communicate to clients that ‘illness’ is only one way of communicating difficulty and that they can still have a serious problem outside of the medical frame and need help. It is our responsibility to ensure that clients know that there are alternative ways of conceptualising, communicating, and understanding their distress.

Improving the process

Regardless of the approach employed, something that emerged that was noteworthy was the willingness of participants to engage in these discussions about the classification of their mental health problems. Therefore, in line with NHS guidance (NHS England, 2017) clinicians should involve service-users in their care and provide opportunities for these discussions.

This study highlighted that some participants had found out about their diagnosis indirectly (e.g., through discharge letters) and many had not been given the appropriate information about it. These findings are highlighted elsewhere (Perkins et al., 2018) and suggest that better care needs to be taken in the process of deciding and communicating diagnoses. The experiential approach potentially provides a helpful tool for practice, by slowing down the process and collating an individually tailored list of people's experiences. Participants felt that this could promote collaboration and avoid the inaccuracy of fitting people into expert-driven diagnostic categories.

Lastly, diagnoses were often seen as permanent and associated with negative messages about the possibility of recovery. In contrast, participants felt that experiential codes promoted more recovery focused care as they could be changed and removed over time. In the context of recovery theory, Jacob (2015) states that it is important for people to feel that recovery is an ongoing process whereby it is possible to regain a meaningful life. Many have proposed guiding principles, such as self-management, choice, autonomy, and hope (Bonney & Stickley, 2008). Recording experiential codes could, therefore, be in line with recovery-focused care.

Research Implications

As advocated by service-user groups, the development of any alternative should involve the perspective of the "true experts" (Hearing Voices Network, n.d.). To our knowledge, the experiential coding approach is one of the first non-diagnostic alternatives to be subjected to research scrutiny from a service-user perspective. Thus, filling an important gap in our understanding in this area. However, this area of enquiry remains still in its infancy. How these ideas could be implemented and evaluated in practice remain unknown. We also need to explore the perceived impact on other key stakeholders, such as clinicians or those working in wider systems of support.

Moreover, this research largely represented the views of White British individuals from rural parts of England. Therefore, these results may not be generalisable to other groups of people (e.g., black and minority groups, faith groups etc.). It is vital that future research should continue to be employed with larger, more diverse, samples of participants to enhance our understanding in this area.

Limitations

This was a relatively small sample of participants. Although it was not the intention to be fully representative of all diagnostic groups, some experiences were under-represented in the data (e.g. obsessional thoughts and compulsions). This could also be said in terms of population diversity, as most participants were White British.

Participants might have been attracted to take part in the study if they held stronger views, either positively or negatively, about their diagnosis experience. For instance, three participants were recruited via a social media group that took a critical stance towards diagnosis. It is possible, therefore, that some participants may have had particularly negative views about diagnosis and therefore may have had a particularly positive response to the alternative.

Although quality assurance measures were put in place to ensure transparency qualitative research inevitably reflects a degree of subjectivity. In order to show transparency of the results, a reflexivity statement can be seen in Appendix L.

The video that was shown to participants included a voice over of the material from Peter Kinderman, who is a keen advocate for change to psychiatric diagnosis and allied to the experiential approach. It is possible, therefore, that there was an issue of bias in the interview materials. However, it is important to note that none of the participants raised this in the interviews.

Conclusion

This study explored participants' experiences of receiving a psychiatric diagnosis and their views about experiential codes as a potential alternative. It was one of the first to be subject to research scrutiny by service-users and provided interesting highlights on possible ways forward. A noteworthy contribution was using experiential codes as default in clinical practice, with the option of giving people a diagnosis if required for other purposes (e.g. legal systems or welfare support).

Although this was a small sample, there were similar findings to other research that demonstrates the negative impact of receiving a diagnosis. Some of these harmful experiences could be negated by improving the collaboration and communication between services and service-users. However, adjusting our approach to use experiential codes might, as participants stated, promote more person-centred, individualistic, and recovery-focused care.

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JADE VARNEY BSc Hons

Section C: Appendices of supporting material

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

MAY 2021

SALOMONS INSTITUTE FOR APPLIED PSYCHOLOGY
CANTERBURY CHRIST CHURCH UNIVERSITY

Appendix A - Summary of the papers included and evidence of each of the key characteristics.

Author	Title of paper	Key features of an alternative	Theme
1. Keeley (2019)	Accounting for Social Processes in the Development of Diagnostic Classification Systems: Commentary on the "Standards and Guidelines for the Development of Diagnostic Nomenclatures and Alternatives in Mental Health Research and Practice".	• Suggests that no new alternative conceptualisation is 'purely scientific' because it inevitably reflects the social norms and processes at any given time.	Developed in accordance with the evidence base
2. Boyle & Johnstone (2014)	Alternatives to psychiatric diagnosis.	• People actively make sense of the experiences in their lives. • Even extreme distress can be understood in the context of adversity. • Need to consider the experiences and circumstances in people's lives.	De-emphasise biological causation
		• Mental health difficulties can be understood as normal, and adaptive response to the circumstances in people's lives. • It is 'human' to want to avoid unpleasant experiences.	Classifies problems, not people
		• Draw upon research and theory (i.e. that experiences can be understood in the context of people's lives) to make sense of people's problems	Developed in line with the evidence base
		• People's responses to difficulties are shaped by the meaning they attribute to their experiences.	Attending to individual experience

3. British Psychological Society Division of Clinical Psychology (2013)	Classification of behaviour and experience in relation to functional psychiatric diagnoses: Time for a paradigm shift. DCP Position Statement.	• Proposes that a new model should no longer be 'disease based' and acknowledge the role of psychosocial factors in the development of distress. • Biology plays a role but should not be assumed as the primary cause for mental health difficulties.	De-emphasises biological causation
4. Cooper. (2019)	Commentary on Jonathan Raskin's "What Might an Alternative to the DSM Suitable for Psychotherapists Look Like?"	• Cannot discount the importance of needing an administrative system to record mental health problems for the basis of insurance, funding, and welfare support.	Practicalities
5. Russell. (2019)	Developing a Common Vocabulary: Questions of Purpose and Priority.	• Argues that moving away from classification systems allows people to share their experiences in their own words and develop a personal and meaningful narrative. • Discusses the context of service-user organisations (e.g. Hearing Voices Network) that embrace lived experience and making sense of individual experiences. • Argues that we should switch focus from developing a common language to attending to people's lived experience.	Attending to individual experience
		• Must include people with lived experience in developing new approaches. • Allow service-users to develop a shared language of mental health problems. • Ensuring these two points are addressed would reduce the power imbalance in clinical practice.	Developed in collaboration with service-users

6. Kinderman et al. (2013)	Drop the language of disorder.	• Argues that distress is a normal part of life and typically in response to distressing circumstances. • Any new system should use language that reflects this position (i.e. ‘drop the language of disorder’). • Experience lies on a continuum – there is no easy cut off between ‘normality’ and ‘illness’	Classifies problems, not people.
		• Respond to individual difficulties.	Attending to individual experience.
		• Use operationally defined and recognised terms. • Include some measure of severity.	Practicalities
		• Psychosocial factors are ‘strongly evidenced’ as causal factors of distress. • Genetics and biology play a role in distress. However, evidence suggests that this is a complex interplay of biology and the environment.	De-emphasises biological causation
7. British Psychological Society Division of Clinical Psychology (2015)	Guidelines on Language in Relation to Functional Psychiatric Diagnosis.	• Experiences are better understood as a response to psychosocial factors. • Move away from ‘disease model’ and use language that reflects this (e.g. from ‘schizophrenia’ to ‘hearing voices’) or (e.g. from ‘patient’ to ‘client’). • Should describe behaviour and experiences in non-medical terms.	De-emphasises biological causation
		• Should describe behaviour and experiences within personal context.	Attend to individual experience

8. Efran & Cohen (2019)	Not So Fast: A Response to Raskin.	• A system should neither rule out or directly address biological determinants.	De-emphasises biological causation
		• The responsibility for any new system should rely on professionals, not with service-users. There is a role for consultation and collaboration, but this should not be equal to professional input. • Distinguishes between ‘self-knowledge’ and ‘professional knowledge’.	Collaboration with service-users
		• Should adopt a ‘concern centred system’	Classifies problems, not people
		• Complicated task which can’t achieve everything (e.g. improve life-satisfaction, explore neurobiological correlates, strengthen community bonds, foster social justice). • Psychologists should adopt a system based entirely on psychological concepts. • No one size fits all for all professional groups.	Practicalities
9. Strong (2019)	Reconciling Conversational Handles with Scientific and Administrative Classifications? A Response to Jon Raskin	• Need to look beyond the individual and consider the wider context of the causes of mental health difficulties.	De-emphasise biological causation
		• ‘Medicalisation has been encroaching on normal sadness and fear’. • Expert-driven, medicalised language constrains and determines how mental health is spoken about. Discusses the need to move away from this and create new ways to talk about problems.	Classifies problems, not people.

		• Needs to be inclusive of the range of concerns that clients bring to therapy (e.g. relationship difficulties), not just those that can be 'diagnosed'. • Emphasises the role of making meaning in experiences, which is hard to do when working within diagnostic categories. • Needs to align with the work in therapy, that is, finding meaning in experiences.	Attending to individual experience
		• Discusses the challenges of developing a new system that would fit into existing systems of support.	Practicalities
10. Kinderman, Allsopp & Cooke (2017)	Responses to the Publication of the American Psychiatric Association's DSM-5.	• No easy cut off between 'disorder' and 'normal'. • Distress is a normal part of life.	Classifies problems, not people
		• Tailor the approach to help individual need	Attending to individual experience
		• Should consider the impact on access to support, especially in the context of austerity.	Practicalities
11. Kamens et al. (2019)	Standards and Guidelines for the Development of Diagnostic Nomenclatures and Alternatives in Mental Health Research and Practice.	• An alternative should consider not just biopsychosocial factors, but the socio-political context.	De-emphasises biological causation
		• Should value lived experience in the development in any alternative. • Reflect diversity of experiences. • Should include first person accounts of experiences, which would enhance face validity.	Developed in collaboration with service-users
		• Adhere to external standards and guidelines. • Prioritise empirical over hypothetical or theoretical evidence. • Include the 'best scientifically available' evidence.	Developed in line with the evidence-base

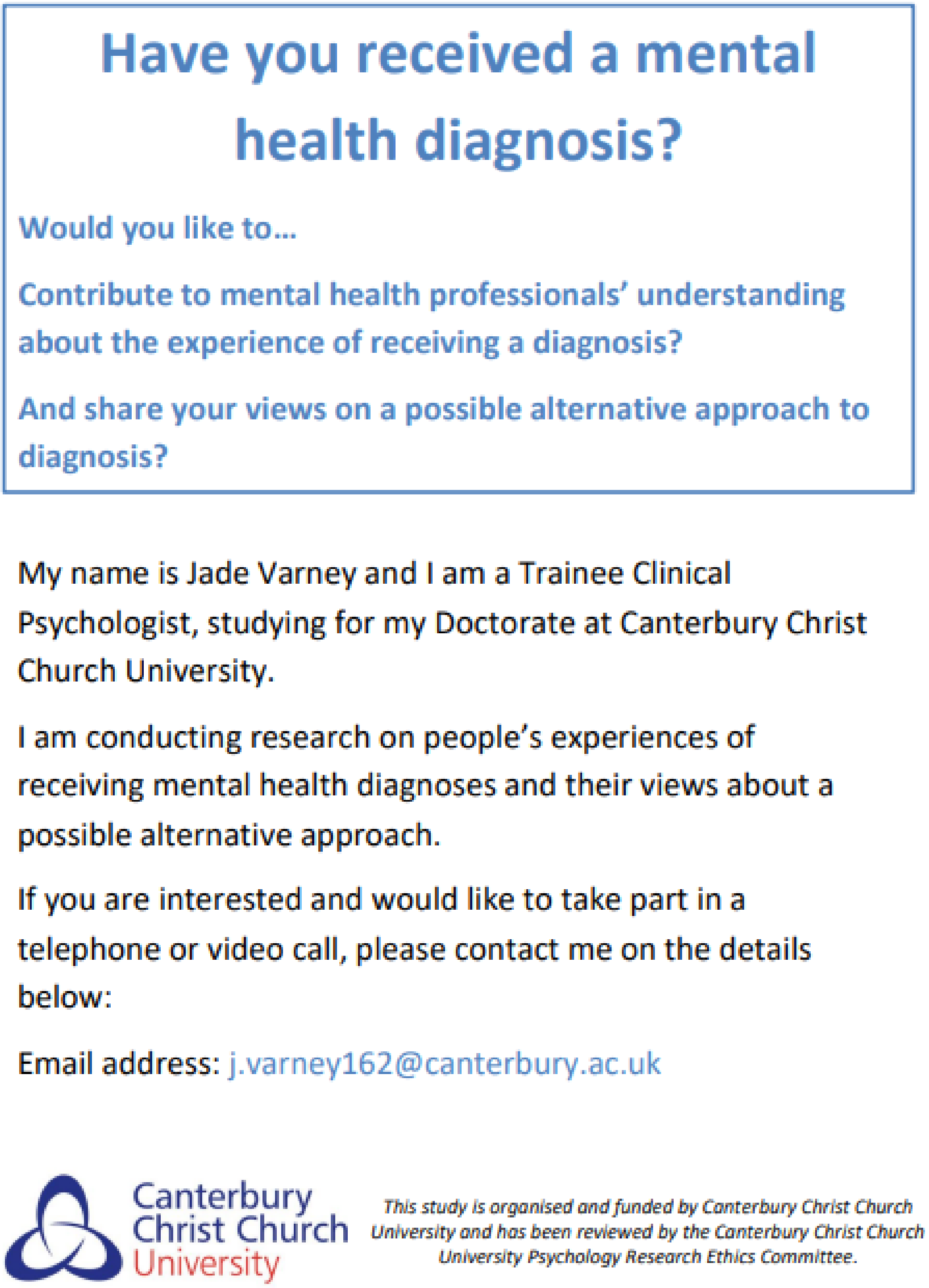
		• Be based on qualitative and quantitative evidence, systematic literature reviews, and multiple types of evidence. • Based on unbiased scientific evidence.	
		• Create a common vocabulary that facilitates communication between service-user and professionals. • Monitors the impact on marginalised groups. • Avoid and/or minimise harm and benefiting the communities it serves.	Classifies problems, not people
		• Valuing the whole person and recognising the richness and complexity of lived experience.	Attending to individual experience
		• Developed free of industry influence. • Subject to independent evaluation. • Made publicly available. • Transparency regarding any potential conflict of interest.	Practicalities
12. Schneider (2019).	The Chief Peril Is Not a DSM Diagnosis but the Polarized Mind.	• Looks beyond the individual. • Considers the socio-political context.	De-emphasises biological causation
13. Elkins. (2017)	The Paradigm Shift in Psychotherapy: Implications for the DSM	• The evidence showing that common factors in therapy are effective in promoting change undermines the medical model. • Any new approach should reflect the power of human and relational factors. • An alternative should be informed by an understanding of the nature of the ‘paradigm shift’ (i.e. away from the medical model’.	De-emphasises biological causation

		- Move from medical to non-medical understanding of distress. - Develop a non-medical approach to describe experiences.	
		- Should be developed in accordance with the evidence that common factors in therapy are key agents for change. - New approach must place relational factors at the centre. - Science has 'long undermined' the medical model.	Developed in line with the evidence-base
14. Raskin. (2019)	What Might an Alternative to the DSM Suitable for Psychotherapists Look Like?	- Biology is not a unidirectional determinant of behaviour. - Need to acknowledge the role of psychological, social, and contextual factors. - An alternative should account for the complex interplay of these factors.	De-emphasises biological causation
		- Prioritise service-user voices in the development of any new system. - Key stakeholders must "have a seat at the table".	Developed in collaboration with service-users
		- Rely on the best scientifically available evidence. - Consider the evidence of the psychosocial factors influencing the development of distress.	Developed in line with the evidence-base
		- Discuss concerns (e.g. feeling anxious, unhappy etc.)	Classifies concerns, not people
		- Applicable across therapeutic orientations and professional groups. - Provide a practical way for professionals to record concerns and provide evidence that they are effectively meeting those needs. This is vital for insurance purposes.	Practicalities

Appendix B - List of social media platforms

- Facebook
- Instagram

Appendix C – Advert and email correspondence



Have you received a mental health diagnosis?

Would you like to…

Contribute to mental health professionals' understanding about the experience of receiving a diagnosis?

And share your views on a possible alternative approach to diagnosis?

My name is Jade Varney and I am a Trainee Clinical Psychologist, studying for my Doctorate at Canterbury Christ Church University.

I am conducting research on people's experiences of receiving mental health diagnoses and their views about a possible alternative approach.

If you are interested and would like to take part in a telephone or video call, please contact me on the details below:

Email address: j.varney162@canterbury.ac.uk

Canterbury
Christ Church
University

This study is organised and funded by Canterbury Christ Church University and has been reviewed by the Canterbury Christ Church University Psychology Research Ethics Committee.

Example email correspondence

Good Afternoon,

Thank you for taking the time to read this email.

My name is Jade Varney, and I am a Trainee Clinical Psychologist studying my Doctorate at Canterbury Christ Church University. I am undertaking research on people's experiences of receiving a mental health diagnosis and their views about a possible alternative approach to diagnosis.

I was wondering if there were any opportunities to seek interest for this study at your organisation. Perhaps by attending the end of one of your groups, or circulating the information to people who access your service?

I have attached an advert and information sheet about the research but would be happy to discuss further over the phone.

I look forward to hearing from you.

Warm Wishes,

Jade

Jade Varney

Trainee Clinical Psychologist

Salomons Institute for Applied Psychology | Canterbury Christ Church University | 1 Meadow Rd | Tunbridge Wells | TN1 2YG

T: 01227 92 7166

Appendix D – Video

Link to the video: https://www.youtube.com/watch?v=MM-NCyGfAV4

Information outlined in the video in written form:

Views about diagnosis and about a possible alternative way to describing problems

Mental health services typically assign a medical label or diagnosis to problems using criteria described in a manual such as the World Health Organisation's ICD-11 (International Classification of Diseases, Version 11). Examples of these diagnoses include ‘major depressive disorder’, ‘schizophrenia’ or ‘personality disorder’. These diagnoses are used in various ways within services including treatment planning and record keeping. They can also be used in other contexts, for example when applying for benefits.

Recently, however, psychiatric diagnoses have been criticized. Critics suggest, for example, that diagnoses risk unhelpfully medicalising what might be normal responses to stressful situations, that they give a misleading impression of being explanations when they are actually just descriptions, and that they can lead to prejudice and discrimination.

Psychologists Dr Kate Allsopp and Professor Peter Kinderman have suggested other ways of thinking about and describing problems within mental health services. One suggestion is just to describe the experiences someone has had or is having, rather than calling them symptoms of one or other ‘disorder’.

As well as lists of conventional diagnoses, manuals such as the ICD 11 (explained above) also include ‘phenomenological’ codes, which describe experiences in more straightforward terms. Examples include:

Hopelessness

Hearing voices

Believing things that other people find strange

Worry

Anger

Avoidant or restrictive eating

The suggestion is that instead of, or in addition to, assigning experiences to a diagnostic category, a mental health professional could record the codes that best represent the problems that someone may be experiencing. These problems could also be wider factors, such as being homeless, having experienced abuse or been in foster care.

Here is a pretend example to illustrate the difference between the two approaches. The codes presented in the alternative are all things that the person would have described to the professional.

Current Diagnosis System	**The alternative**
Major Depressive Disorder	Low mood Difficulty concentrating Poor sleep Tiredness Thoughts of suicide Recent bereavement Inadequate family support

Some of the advantages of this approach include:

- A system based on experiences (not diagnoses) could avoid labelling people with ‘illnesses’
- Help professionals communicate more clearly, understand the nature of the problems better, and lead to better plans for care.

Some of the possible disadvantages could include:

- A system such as this may result in very personal information included in records,
- Any move away from ‘recognised medical conditions’ might make it hard for people to access benefits.

The original paper that outlines this approach can be found at:

Kinderman, P., & Allsopp, K. (2018). Non-diagnostic recording of mental health difficulties in ICD-11. The Lancet Psychiatry, 5(12), 966.

https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(18)30394-8/fulltext

Appendix E- Interview topic guide

NB: Questions are examples that will guide the interview

PRE VIDEO

“This is a conversation about mental health diagnoses... do you have any thoughts on the topic?”

- “Can you start by telling me about your experience of receiving a mental health diagnosis?” *(Explore the positive and negative effects)*

  Potential areas to explore:
  - Personal impact
  - Receiving support from services
  - Impact on self-concept
    “For some people, after receiving a diagnosis, they have viewed themselves differently – either positively or negatively – do you have thoughts about this?”
  - Recovery
    “Do you think receiving a diagnosis have any impact on your feelings about recovery?”
  - Process of receiving the diagnosis (e.g. collaboration, choice)
  - Stigma

- Possible purposes of traditional mental health diagnoses
    - “Are there reasons for approaching things this way, would you say?”

  Potential areas to explore:
  - Service level (Managing care)
    - Medication / treatment
    - Access to services
    - Other services – benefits/welfare, employment, education, law,
  - Communication
    - Between professionals
    - With service users
    - With the public / media.
  - Research
  - Sense of understanding of difficulties

- Possible benefits of this (traditional / diagnostic) approach
  “In your view, are there benefits of approaching things this way?”

- Potential problems with this (traditional / diagnostic) approach
  “In your view, are there problems with approaching things this way?”

  Potential areas to explore:
  - Society factors
    Stigma
    Culture
  - Engagement and accessibility

- “Do you think the language used to describe mental health difficulties is important? If so, in what way?”

- “Do you have any other thoughts or views that you would like to share?”

POST VIDEO

“So; what do you think?...”

Make sure explore both the non-diagnostic element and recording the social determinants

- Possible benefits of this alternative approach
  “In your view, are there benefits of approaching things this way?”

- Potential problems with this alternative approach
  “In your view, are there problems with approaching things this way?”

- Addition to, or an alternative – “In your view, does this approach fit in with the current system?” (explore pros and cons to this, and if they think that this is complementary or an alternative to diagnosis.”

Mention points raised by the participant earlier. Points below are examples / guides

- **Understanding**
  “We talked earlier about the impact a psychiatric diagnosis can influence how you might affect your understanding of your own mental health. ... How might this approach alter the way you understand your mental health?”
    - Advantages
        - “Are there any ways in which it could be helpful for how you understand...?
    - *Disadvantages*
        - “Are there any ways in which it could be harmful for how you understand...?

- **Self-concept**
  We talked earlier *about the impact a psychiatric diagnosis can alter how people think about themselves, their self concept...*
    - Do you think that this approach would be similar or different?
    - Advantages / Disadvantages

- **Recovery**
  We talked earlier about the impact a psychiatric diagnosis can have on our thoughts about recovery...
    - Do you think that this approach would be similar or different?
    - Advantages / Disadvantages

- “Do you have any other thoughts or views that you would like to share?”

Appendix F – Participant information sheet

Participant Information Sheet

A study about people's views on psychiatric diagnosis and an alternative approach

Thank you for your interest in this study. My name is Jade Varney and I am currently undertaking a Doctorate in Clinical Psychology at Canterbury Christ Church University. I am being supervised by Professor Peter Kinderman, and Ms Anne Cooke, who are both experienced in undertaking research and have worked as mental health professionals. As part of the course I undertaking this research project, and would like to invite you to take part.

Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything that is not clear or if you would like more information, please contact me on the details given below.

Purpose of the study

The aim of this study is to seek people's views about diagnosis in mental health and a proposed alternative approach.

Do I have to take part?

No - Taking part is entirely voluntary. You can refuse or withdraw your participation from the study, at no penalty or loss, now or in the future.

What will happen to me if I take part?

If you agree to take part in this study, you will be invited to an interview with the researcher, Jade Varney. The researcher will ask you questions about your views on psychiatric diagnosis will then show a short video which outlines an alternative approach. The researcher will then ask you your views about this approach. The interview will last approximately 1 hour and will be audio recorded.

Are there possible disadvantages and/or risks in taking part?

We do not foresee that taking part in this study would be distressing to participants. However, talking about mental health problems and care can sometimes bring up difficult memories and experiences. I am happy to talk to participants both before and after the interviews if any support is needed. Should you wish to talk to someone else, Anne Cooke (my supervisor) who works at the university and is an experienced mental health professional has agreed to make herself available. We can both point you to sources of additional help if necessary.

What are the possible benefits of taking part?

There are many conversations in our society about mental health, particularly regarding people's experiences of diagnosis. Taking part in this study would give voice to your views in this area, and further contribute to our understanding about helpful ways to support people who are struggling with a mental health difficulty.

Will my taking part in this project be kept confidential?

Yes- Your information will always be treated confidentially and with respect. All data will be anonymised and will identifiable by a code (e.g. a letter or number). All data will be stored securely in a locked filing cabinet at Canterbury Christ Church University for up to ten years, before being destroyed securely. The data will only be accessible to the research team (myself and two other colleagues, Ms Anne Cooke and Professor Peter Kinderman).

Audio recordings will be identified only by a code and will not be used or made available for any purposes other than the research project. These recordings will be stored electronically on an encrypted and password protected devise. The audio data will be securely deleted after completion of the course (end of 2021).

Anything you say during the interview will be kept private and confidential. However, if the researcher is worried about your safety in any way, then the researcher may need to discuss this further with the clinical supervisors of the project (Ms Anne Cooke and Professor Peter Kinderman), after discussing it with you first.

What if I change my mind and want to withdraw from the study?

If you do not want to carry on with the study, you can withdraw up to 1 month after the interview without needing to give a reason. If you withdraw from the study you can ask for data (e.g. details, interview answers) to be removed.

What will happen to the results of the research project?

The project will be written up as part of a doctorate project (completed 2019-2021) and will also be submitted to an academic journal for publication. The project will also be available on the university institutional repository for student and public use. All data included in the write up will be completely anonymised to ensure that no participants can be identified.

An information sheet outlining the outcome of the study will be made available to participants on completion of the project. If you do not wish to receive this please tick the box below to opt-out

☐

Who is organising and funding the research?

This study is organised and funded by Canterbury Christ Church University.

Ethical review of the study

The project has been reviewed by the Canterbury Christ Chruch University Psychology Research Ethics Committee.

Complaints and feedback

If you have concerns about any aspect of this study or would like to give feedback, please either tell me in person or you can contact on the details below, and I will do my best to address your concerns and feedback.

If you remain unhappy and wish to complain formally, you can do this by contacting Ms Anne Cooke on anne.cooke@canterbury.ac.uk

Contact for further information

If you have any further questions, please do not hesitate to contact me: Jade Varney on j.varney162@canterbury.ac.uk

Appendix G – Consent form

Canterbury
Christ Church
University

Consent Form

A study about people's views on psychiatric diagnosis and an alternative approach

Please read each statement and sign your initials.

- I confirm that I have read and understand the Participant Information Sheet ____________
- I have had the opportunity to ask questions and have them answered ____________
- I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified ____________
- I agree that data gathered in this study may be stored anonymously and securely. I am aware that all data will be stored securely in a locked filing cabinet at Canterbury Christ Church University and password-protected computer for up to ten years, before being destroyed securely ___________
- I give my consent for the researcher to audio record the session and understand that the data will be stored on an encrypted device which is only accessible to the research team. The audio data will be deleted on completion of the course (end of 2021) _____________
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. In this instance, any data or information I have given to the researcher will not be retained ___________
- I understand that the project will be written up as part of a doctorate project (completed 2019-2021) and will also be submitted to an academic journal for publication. The project will also be available on the university institutional repository for student and public use All data included in the write up will be completely anonymised to ensure that no participants can be identified __________
- I agree to take part in this study ____________

Participant's name	***Participant's signature***	***Date***
Researcher's name	***Researcher's signature***	***Date***

Appendix H – Report to service users and ethics panel

Service-user experiences of receiving a psychiatric diagnosis and the use of the ICD-11 experiential codes as an alternative.

Background

Psychiatric diagnosis guides practice, service organisation, and access to support. Some service-users find it helpful to receive a diagnosis. However, research has shown that receiving a diagnosis can also be harmful. Over recent years, there have been suggestions to look at things differently, and develop new ways of recording mental health problems without necessarily giving people a diagnosis.

A suggested alternative approach

One potential way forward, is to use existing structures in the International Classification of Diseases (ICD-11), a global classification system developed by the World Health Organisation.

The latest edition includes as a list of possible diagnosable disorders as well as numbered codes pertaining to different possible complaints (e.g. 'Binge eating', 'Low self-esteem', 'Worry') and life experiences (e.g. 'Personal frightening experience in childhood', 'Problems associated with housing').

Instead of assigning a diagnosis, clinicians could instead assign a particular combination of these codes depending on the person's circumstances. An example of the difference between the two approaches is outlined below.

Psychiatric Diagnosis	**ICD-11 Experiential Codes**
Major Depressive Disorder	History of spouse or partner violence (QE51.1)
	Low income (QD51)
	Problem associated with interpersonal interactions (QE50)
	Non-suicidal self-injury (MB23.E)
	Depressed mood (MB24.5)
	Feelings of guilt (MB24.B)
	Poor concentration (MB21.A)

(This is an example. The list of codes would be based on the person's circumstances and experiences).

Study aims

This study had two aims:

1. What are service users' experiences of receiving a psychiatric diagnosis?
2. What are service users' views on the use of the experiential codes in the ICD-11 as an alternative to psychiatric diagnosis?

Method

Thirteen people were interviewed. The data were recorded and transcribed by the lead researcher. The data were analysed using a thematic analysis, whereby the transcripts were coded, and themes and sub-themes were generated from the data.

Findings

The findings are summarised in both tables below. Participants shared both positive and negative aspects of either approaches. Participants thought that the two approaches could, in fact, work well together, or that people should be given the choice between which they would prefer.

1. What are service users' experiences of receiving a psychiatric diagnosis?

Theme	**Subtheme**	**Description**	**Example Quotes**
Identifying the problem	Recognition	Diagnosis identifies the problem and provides reassurance that its one that is recognised by a professional	"This is actually something that is recognised. I'm not just inventing this in my head." (Amy)
	Accuracy	Fails to capture lived experience	"I think the EUPD diagnosis just made me feel awful because I looked it up and it didn't fit. I didn't fit the descriptors. They wouldn't listen to me when I said that." (Claire)
	Understanding	Provides an explanation	"I was always looking for a reason why I was so volatile, why I was so emotional, so erratic, and once I got [the diagnosis] I could then understand why I was." (Dave)
Communication with professionals	-	The way in which diagnoses are decided and communicated is key	"With bipolar I had to actually go and research what bipolar was, which is crazy because I have it, I should know." (Holly)
Personal Impact	Emotional Impact	Being labelled is an emotional experience	"Nasty labels…it's like if you're gonna bully someone what a way to do it. You realise like it's a horrendous, horrendous thing to be labelled… and it's life changing. (Holly)

	Self-perception	Receiving a diagnosis can lead to changes in the way people view themselves	"Devastating. I went through a period of grieving for myself… you go through mourning who you were, or you thought you were." (Amanda)
Support and recovery	Access to support	Diagnosis does not always lead to appropriate support	"It's, you know, 'You've got your label, you've got tablets, we don't care now'." (Julie) "It was quite reassuring to have a doctor come to me and say, 'This is what I think the problem is, and this is like the game plan of how we're going to treat it'." (Paula)
	Sense of recovery	Implies that you'll never get better	"The opinion of my psychiatrist was that this was the kind of lifelong illness that I wasn't going to recover from, and I needed to adjust my expectations and learn that I was living with this condition." (Emily)
Response from others	Disclosure	Difficult to disclose to others	"I felt I had to keep it quiet and hide it that I was schizophrenic." (Tony)
	Stigma	People do not understand and make assumptions	"Well a lot of people associate, yeah because of the media, they associate paranoid schizophrenia… with violence." (Tony)

2. What are service users' views on the use of the experiential codes in the ICD-11 as an alternative to psychiatric diagnosis?

Theme	Subtheme	Description	Example Quotes
Identifying the problem	Recognition	Could the severity of people's difficulties go unrecognised?	"I would also worry that for people who are quite dismissive of mental illness, taking away the medical words might make it a bit easier for them to dismiss the problem. You talk about it as 'She's not sleeping and she's sad' it has less of an impact when describing it to other people than 'She was diagnosed with depression'." (Paula)
	Accuracy	Foreground individual experience	"It's switching from something that doesn't quite fit, doesn't feel right or is stigmatising you, to something that's yeah, that's how I'm feeling…They would see the person, not the label." (Claire)
	Understanding	Non-medicalised language is easier to understand	"So I think using quite simple language like 'hearing voices' or 'having strange thoughts' - they make they make it more accessible I think to people who might not have an understanding of their own condition, or have a good language ability, particularly if English isn't their sort of primary language." (Paula)
Communication with professionals	-	An aid for more collaborative care. Could the process become lengthy and how to prioritise codes?	"I would open up to you a lot more if you use those words with me, rather than use diagnoses like schizophrenia and what have you." (Amanda) "Have professionals got the time to actually list off the different codes and allow you to explain how you associate with all the different codes?" (Julie)
Personal Impact	Emotional Impact	Reduce blame and the emotions associated with diagnosis	"That would have been massive because I would have realised that it wasn't my fault necessarily, it was you know, something that was happening to me, rather than it happen because of me." (Amy)
	Self-perception	Less likely to negatively impact identity	"It's really interesting that you take away that loaded, loaded label, and you're just replacing it with something that is just human and that anyone could be." (Holly)

Support and recovery	Access to support	Opens up options for help and support	“You avoid the whole ‘You’re bipolar we’ll stick you on lithium’. They have to actually think about it.” (Holly)
		Would support be available without recognised terms?	“Seeing a list of problems and then seeing an actual diagnosis would be massively different. It would feel like [diagnosis] is going to get me somewhere and [experiential codes] is you just listing what is wrong with me.” (Amy)
	Sense of recovery	Promote recovery through the ability to change and remove codes over time	“Because you can recover from those individually, I feel like people would feel more likely that they can recover from your own list of symptoms, one step at a time.” (Emily)
Response from others	Disclosure	A lot of personal information to share with others	“It’s a lot easier to say to somebody ‘I have a diagnosis of EUPD’, rather than ‘I suffer from all of this’.” (Julie)
	Stigma	Normalises experiences	“It would reduce stigma to a degree because they’re not using these words that people are scared of.” (Robert)

Implications and recommendations

- Participants were willing to engage in these discussions about the classification of their mental health problems. Therefore, clinicians should involve service-users in their care and provide opportunities to have these discussions.
- A noteworthy contribution was using experiential codes as default in clinical practice, with the option of giving people a diagnosis if required for other purposes (e.g. legal systems or welfare support). Participants reported that this approach would lead to more detailed information on people’s records, increase communication between professionals, and lead to more person-centred care.
- Experiential codes were considered to be less ‘fixed’ as they could be changed and removed over time. Recording experiential codes could, therefore, promote more recovery-focused care.
- Some participants experienced their diagnosis as stigmatising, pathologising, and noticed changes in how they viewed themselves. A benefit of the alternative was the potential to reduce the likelihood of these experiences, and consequently reflect a “more human” approach to clinical care.

Appendix I – Use of quality assurance recommendations

Quality assurance recommendation (as outlined in Castleberry & Nolen, 2018)	**How this was applied to the research**
Know your own biases and report these openly in your manuscripts.	Please see Appendix M for reflectivity statement to aid transparency of the researcher and position in the work.
When reporting, include direct quotations from your data that are brief and targeted to show readers the quality of your coding, theme generation, and subsequent conclusions.	Consistent throughout the results section. Additional table of evidence of themes and subthemes can be found in Appendix K.
Answer your research questions.	The data collected was applied directly to the research questions. Results also correlate to previous research findings.
Take your time when coding for it is foundational to the data analysis process and should not be rushed.	The coding process happened across several weeks. This allowed sufficient time for breaks, avoided fatigue and the possibility of this phase being rushed.

Appendix J - Research diary extracts

30th November 2018 – I attended the research fair today. I only spoke with two people, one of them was Anne Cooke. I was quite keen to think about a potential project with her because I'm interested in critical psychology. I wondered about something relating to the Power Threat Meaning Framework, and how that could be implemented in practice / people's experiences of implementing in practice.

Anne discussed a potential idea with me that she was thinking about with another colleague, (Peter). She told me about the experiential codes in the ICD-11 as an alternative to diagnosis. Referenced the paper and said to let her know if I was interested.

I went away and read the ideas and was keen to think about this more as a project.

Email I sent to Anne following:

I have read both articles and found their ideas interesting. From looking at the ICD-11 I was able to see in more detail how it could be used in terms of capturing a range of adversities and contributing factors which influencing wellbeing and distress, as well as using the codes to show symptoms of distress instead of a diagnosis for example:

'Symptoms and signs or clinical findings not else where classified' - Includes a range of mental and behavioural signs categorised into areas, for example; 'Symptoms or signs involving mood or affect' - Euphoria, elevated mood, irritability, depression, anger etc.

'External causes' or 'Factors influencing health' codes includes many social factors such as low income, insufficient social welfare support, victim of crime etc.

A further benefit of using the codes this way is that it would provide accessible information as to potential patterns of adversities and types of distress.

I would feel quite excited to take this project forward - Firstly, because I feel passionately about being able to contribute to alternative approaches to diagnosis and the medical model, both on a personal and professional level. The experience that I had pre-training was in CAMHS, mainly doing assessments of children where ADHD was queried - it definitely used to raise questions for me around ethics in diagnosis because there was a pattern often observed in particular adversities such as poverty, witnessing DV etc. So for me I feel drawn to how we can raise awareness of these factors that contribute to distress in everyday practice, as well as alternatives to diagnosis. I am keen to do an MRP which provides an opportunity to hear service user / survivors voices (although I also wondered if it would be an opportunity to gain clinician's perspectives on this approach also).

7th February 2019 – Met with Anne and Peter for the first time

- Discussed the approach together in more detail and key details for the proposal
- Decision between focus groups or individual interviews – I thought individual interviews would be better because they are easier to arrange and allow people to talk more freely about their experiences.
- Discussed number of p's, sampling, data analysis etc.
- Agreed to take the project forward and write up a 'nutshell proposal'

5th June 2019 – Submitted proposal

20th June 2019 – Proposal review

Was an interesting process, and helped me to think about other potential ideas for the project

- How to present the information? (Likely a video – ensures reliability of the information)
- Consultation with service-users on the development of the information – probably attend a SAGE meeting if possible.
- Good to discuss the ideas out loud, consult with other people – good opportunity to do this.

22nd July 2019 – Proposal approved

25th July 2019 – Dyslexia diagnosis

I had been struggling completing my first-year deadline and noticed in particular that it was difficult to form my thoughts on paper and organise things clearly. I didn't think too much of it at the time, but after speaking to a course tutor they suggested that I should get tested for dyslexia. I was quite surprised because I hadn't thought this was something that I struggled with. However, looking into it more made me realise that it could be possible.

I had the assessment today and was given the diagnosis of dyslexia. Reflections:

- Shock
- Upset
- Knew something was wrong!
- Noticed afterwards that it had knocked my confidence a little – the next day in teaching I paused and took a while to get out what I wanted to say, I had the thought "but you have dyslexia now!"
- Need to discuss in supervision in order to stay reflective on my position when researching experiences of diagnosis.

It's interesting because I can connect with a lot of what is discussed in the literature

- Provided access to support
- Ensures other people understand the things that I find difficult (then I don't feel so bad when I get feedback about my writing style)
- However, it made me feel not great about myself – especially the age that I am and getting a learning difficulty diagnosis.
- Although it does make a lot of sense – I always got feedback during my undergraduate that my writing style was poor.

What I did

- Reminded myself it doesn't define my academic abilities
- Can still achieve a lot with this diagnosis – I've got this far already
- Encourage myself to keep speaking out in teaching because it won't help to avoid doing it.
- Discussion in supervision to reflect on these experiences, bracketing the likelihood of impacting on the results.

20th September 2019 Attending SAGE meeting for the materials

This was a difficult meeting but essential in moving forward the project. I presented my research idea to a group of 9 service users at the university. I gave the handout that included the ideas to everyone at the meeting. I have a few comments initially about the size, font, and some jargon that had been used.

One service user said that she was offended by the material and said that the information implied that low income leads to anger. This was totally not what I had intended to imply. I tried to explain myself as best as I could and really wanted to understand her experience of the material. Its really important that if something comes across in a way that is offensive, we need to understand and definitely adjust the material.

This experience really made me also think about how sensitive this topic is. It's also quite political, in exploring systems and, for example, whose interest is it in to change or not change the current system?

What happened next

- I discussed how I felt with the lead service-user rep at the meeting and provided some feedback.
- Discussion with Anne and Peter. They were really interested in what happened and they felt that this feedback was vital in our research process. It reminded us of the upmost importance of the careful use of language in describing people's experiences.
- I made the changes on to the material.

Old version, that was presented to the meeting (this is only an extract of a whole form – but relates to the contentious issue). On reflection, I can see how this could be misinterpreted. It doesn't make it clear that this is an example. Instead, I can see how this could assume that we, as professionals, have made this assumption.

Current Diagnosis System	The alternative
Moderate Personality Disorder (6D10.1)	For example, personal history of sexual abuse (QE82.1), history of spouse or partner violence (QE51.1), and low income (QD51) leading (understandably) to anger (MB24.1), depressed mood (MB24.5), feelings of guilt (MB24.B), and non-suicidal self-injury (MB23.E)

The revised version, taking into account the service-user feedback. We changed the example to include something less personal and potentially triggering and added the text above to make it clear the context of deciding the codes.

Here is a pretend example to illustrate the difference between the two approaches. The codes presented in the alternative are all things that the person would have described to the professional

Current Diagnosis System	The alternative
Major Depressive Disorder	Low mood Difficulty concentrating Poor sleep Tiredness Thoughts of suicide Recent bereavement Inadequate family support

October 2019 - Reflections on the process of the proposal

Initially I thought that after I had a research idea that I would be close to submitting the proposal. However, I soon realised that developing a research idea is not as linear as I thought. For example, we spent a lot of time changing our thoughts about the theoretical underpinnings and even now (October

19) this is still developing. I have learnt that research development is an adaptive and flowing process, whereby ideas from the team are evolving and change over time.

4th October 2019 – Ethics proposal submitted

14th November 2019 – Ethics approved

Excited to get going!

January 2020 – I've started recruiting people for the study. Thinking about making sure I have a variety of organisations that I contact.

6th February 2020 - I've done my first 2 interviews today at a mental health support charity. I spoke to 2 people with very different experiences of diagnosis. One found it really hard to get the help that she needed and wanted a diagnosis to prove how difficult things were for her. And the other person was diagnosed with Bipolar which she experienced as very stigmatising and damaging to her mental health. She spoke about how the experiential approach could promote a better message for recovery, namely the fact that the codes could be moved and changed. This point really interested me as I hadn't thought about this before. These perspectives remind me of why I think asking people with lived experience is so vital in our understanding of what services should look like.

March 2020 – Covid-19 is prominent and has meant that I am working from home. I'm hoping that recruitment won't be an issue – especially as most people can use online platforms or telephone. Plan to revise my ethics form to ensure that it is okay to recruit people solely online/via telephone interviews.

27th March 2020 – I discussed with Peter in supervision today how I have felt about interviewing people about their experiences. I spoke about how it is difficult when one half of the week I am a psychologist, attending to and helping people make sense of their experiences, and the other half putting a research hat on and responding differently. There were many times where I noticed that I could easily discusses people's experiences in a different way, or make summarising statements etc… although I recognise that this is not ideal for research purposes! Supervision helped me to be able to step back and notice this. Going forward I am going to ensure I keep changing statements to questions and remember that I can still use many of my skills – just in a different way!

Plan – Peter to listen to one of the interviews and provide feedback on technique.

June 2020 – Recruitment is still going well, dispute the covid restrictions. Most people are available on online platforms.

Reflections after interviews this week

- People are keen to discuss their experiences
- Many haven't received support after their diagnosis, which is surprising given that this should be one of the primary functions?
- There isn't a one size fits all – so many different experiences, and positives and negatives to diagnosis/changes that we make
- Process of receiving – little information, how it's communicated to people (e.g. through discharge letters!)

July 2020 – I started transcribing the interviews. Initial thoughts

- People's experiences of more 'severe' diagnoses have tended to be more negative (e.g. PD, Bipolar, Schizophrenia)

- Managed to get a variety of people's experiences – really is mixed which shows balance in perspectives.

August 2020 – Spent most of this month transcribing interviews and thinking about the potential themes in the data. It seems like there is a variety in people's responses to the alternative. Some like the idea, and think that it could compliment practice, while others find diagnosis beneficial. I think it's helpful that there are different views from participants and will likely make the paper more balanced.

September 2020 – I've decided to do one last recruitment push. Bit worried about timing and making sure that I don't overstretch, but I think it would be beneficial for the analysis that I am doing to get some more participants if I can.

October 2020 – I've had 4 more people want to take part! Which is great and means that there will be more data. I have also thought about my interviewing technique and making sure that I slow down, ask single questions and avoid giving statements. I also think, sometimes, that it is difficult spending half of the week being a psychologist, and the other half with a research hat on – mainly because the approach you take to how you respond to people's experiences is so different.

10th October 2020 – I started coding the data – it definitely takes a long time! Need to stay patient and not rush this process because it's important. I'm noticing some initial ideas already – particularly around the fact that the alternative doesn't seem to capture the severity of people's experiences in the way that a diagnosis does. Most people say that their diagnosis helped them understand their experiences and validated that something is wrong.

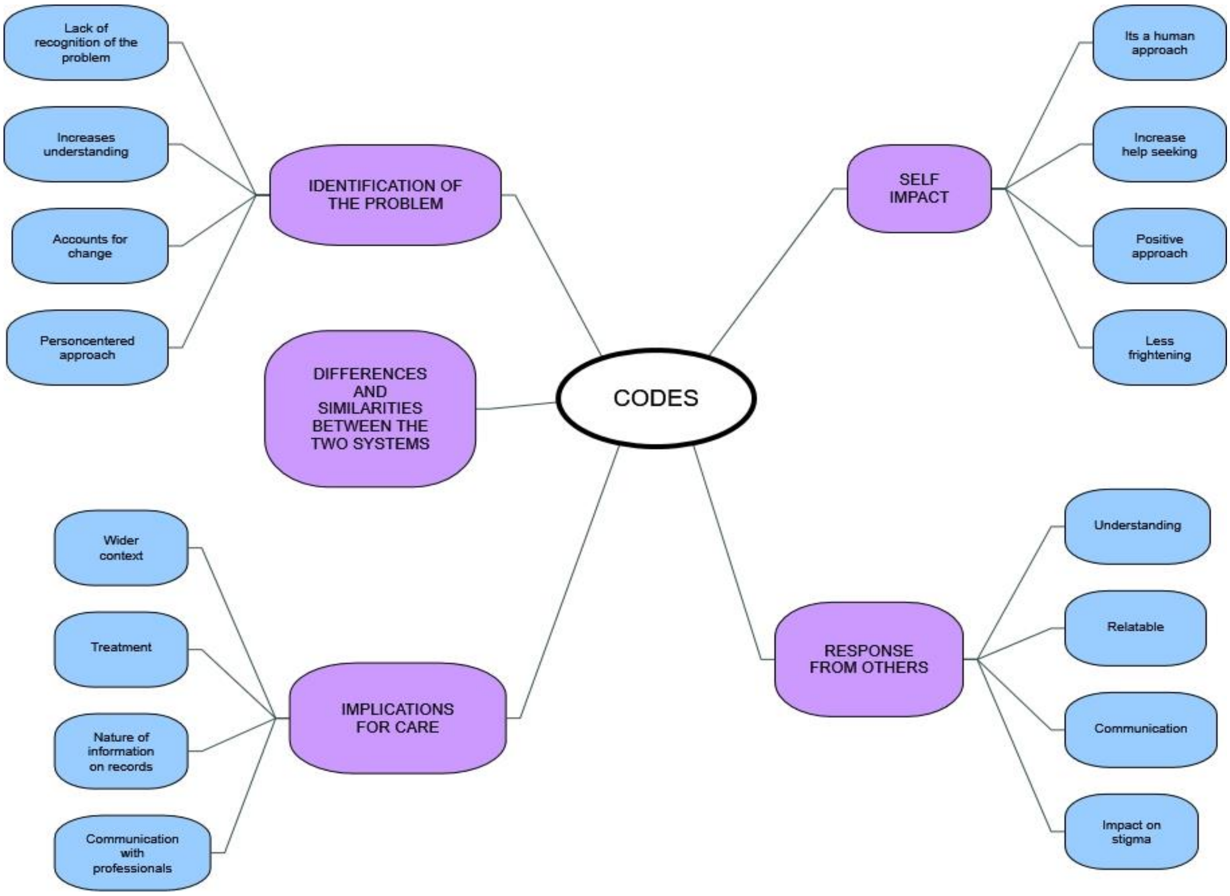
I have also decided to code the discussion about diagnosis separately from the coding approach. This will help me to organise the data according to these separate topics. I can always bring the ideas together at the end. I'm not sure how different or similar they will be.

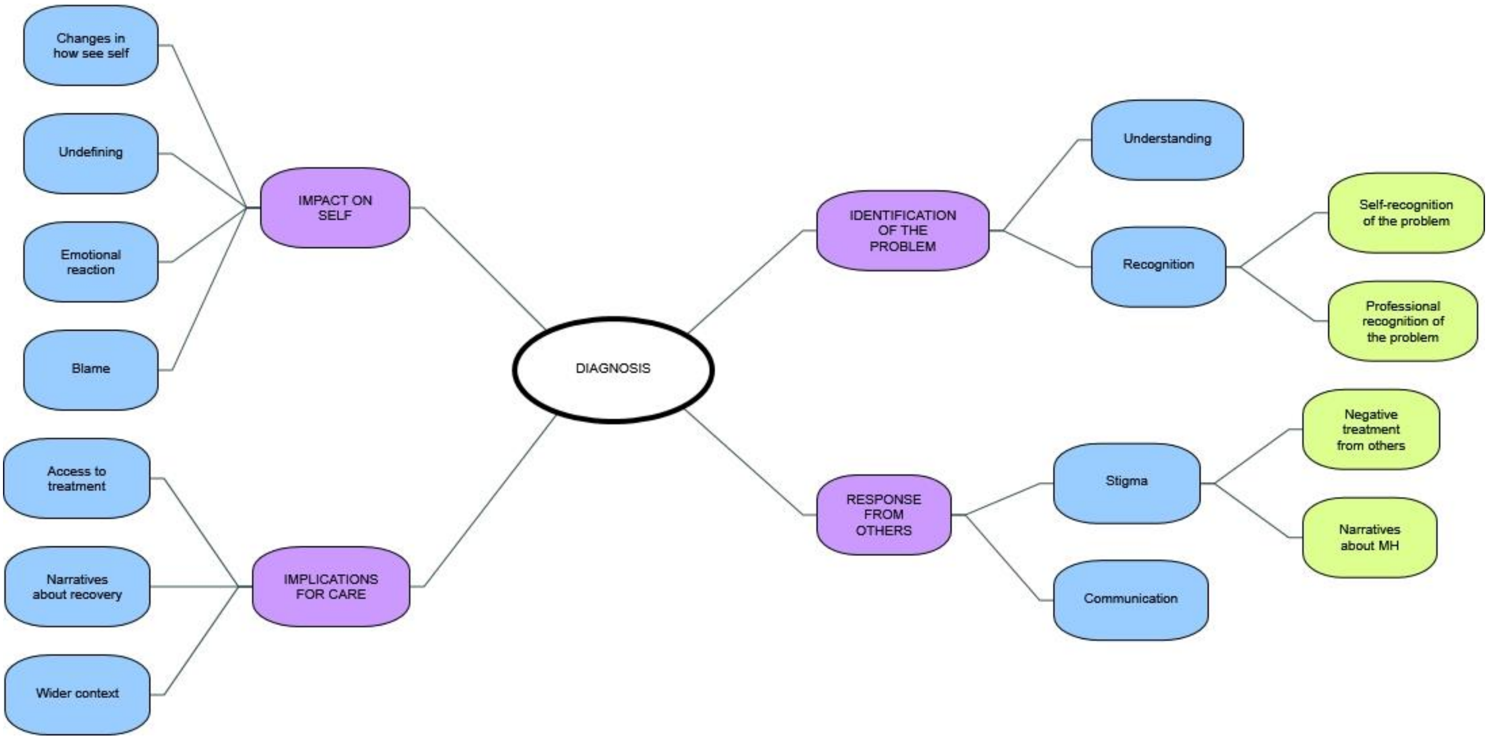
29th October 2020 - Another interesting idea from the data that I can see is around how much to normalise people's experiences. It's interesting, because as a professional and particularly on the course that I am on, there is always conversations about contextualising and trying to normalise people's responses as 'adaptive' and 'understandable' in the face of particular circumstances. However, from some of the participants points of view, this might not always necessarily be helpful. People sometimes want to be told that they are 'ill' and have a serious illness – this gets them support, recognition from other people, and understanding. Moving away from 'illness' and 'disorder' actually could have huge challenges for how we speak about mental health difficulties. As a participant said, 'there is nothing serious about low mood'.

12th November 2020 – I really struggle with Nvivo and seeing everything on the screen. So, I have decided to print off ALL of the codes and arrange them visually. Although it was pretty time consuming it really helped me to gather my thoughts and see a huge amount of data visually.

I've decided to keep all the codes about diagnosis, and those about codes/alternative separate still. Because I'm not sure how any of the ideas relate together at this point.

14th November 2020 – Still organising and some of the provisional themes are…


CODES
IDENTIFICATION OF THE PROBLEM
Lack of recognition of the problem
Increases understanding
Accounts for change
Personcentered approach
SELF IMPACT
Its a human approach
Increase help seeking
Positive approach
Less frightening
DIFFERENCES AND SIMILARITIES BETWEEN THE TWO SYSTEMS
IMPLICATIONS FOR CARE
Wider context
Treatment
Nature of information on records
Communication with professionals
RESPONSE FROM OTHERS
Understanding
Relatable
Communication
Impact on stigma


DIAGNOSIS
IMPACT ON SELF
Changes in how see self
Undefining
Emotional reaction
Blame
IMPLICATIONS FOR CARE
Access to treatment
Narratives about recovery
Wider context
IDENTIFICATION OF THE PROBLEM
Understanding
Recognition
Self-recognition of the problem
Professional recognition of the problem
RESPONSE FROM OTHERS
Stigma
Negative treatment from others
Narratives about MH
Communication

19th November 2020 – Discussion with Peter in supervision

We discussed the provisional maps in supervision. Key points included

- Whether the ideas overlap? And make one map with ideas according to both diagnosis and experiential codes?
- Initial thoughts from p's that codes AND diagnosis could work well together – discussion about how this was surprising and wasn't something that we had thought about. Brings up interesting points around choice of either approach and how to utilise in practice.
- Discussion about the difference between understanding the problem, and recognising the problem – are they the same/do these overlap – or should I keep separate?

Plan – Look at the maps again, and go back to the data to see if these ideas are matching the provisional maps

21st November 2020

Revision of the themes – started to look at each individual theme to check for internal consistency and external difference and realised that the separation between diagnosis and codes was perhaps an unhelpful distinction. Started to draw the data together to think about how the themes relate to one another, providing a better structure to the paper.

26th November 2020 - Progression of the ideas into one thematic map

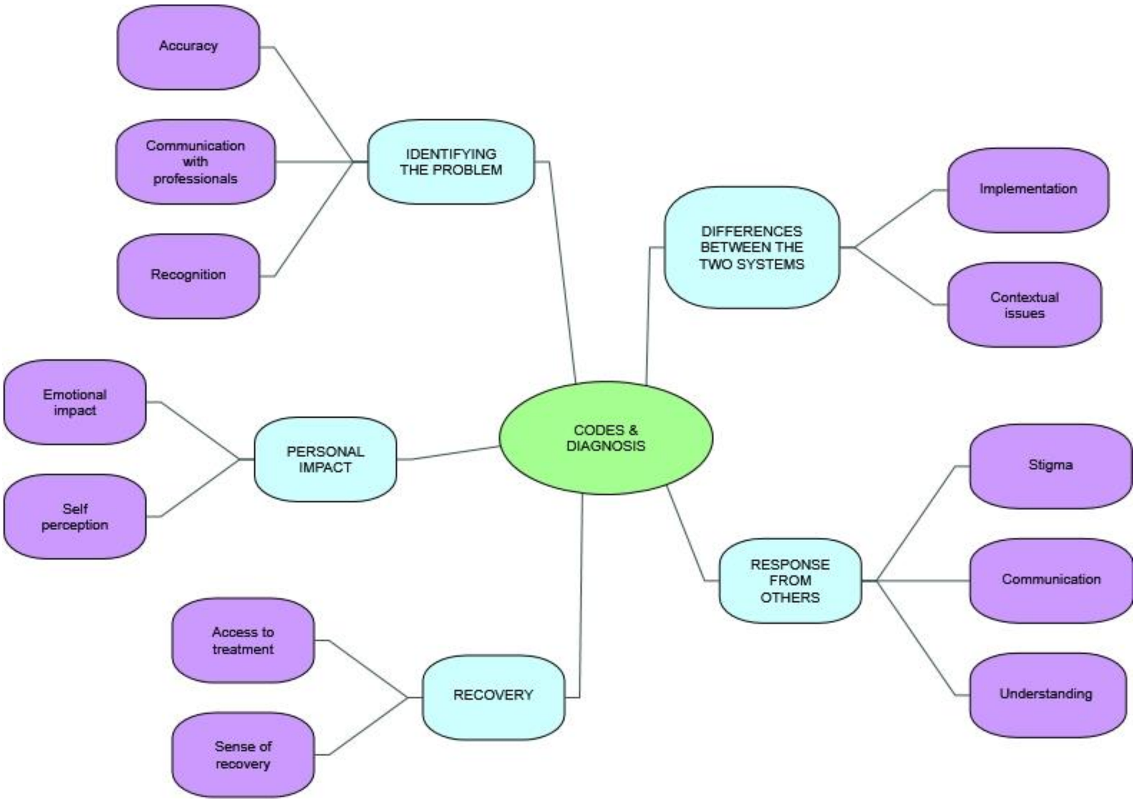
Created one thematic map that encompassed both diagnosis and codes. Did another check of internal consistency and external difference between the themes (process of checking each bit of coded data and seeing if it reflected the theme it was in and moving it if necessary, then looking to see if the themes overlapped in any way and moving around to ensure this wasn't the case)

I think where I had revisited certain topics with p's (e.g. if they said that diagnosis helped them access support, I'd ask how the coding approach might be similar or different), there was general overlap between the two approaches, and probably means that I could present the results as the following…

Accuracy

Diagnosis xxxxx

Codes xxxxx



There are still some ideas I'm thinking about

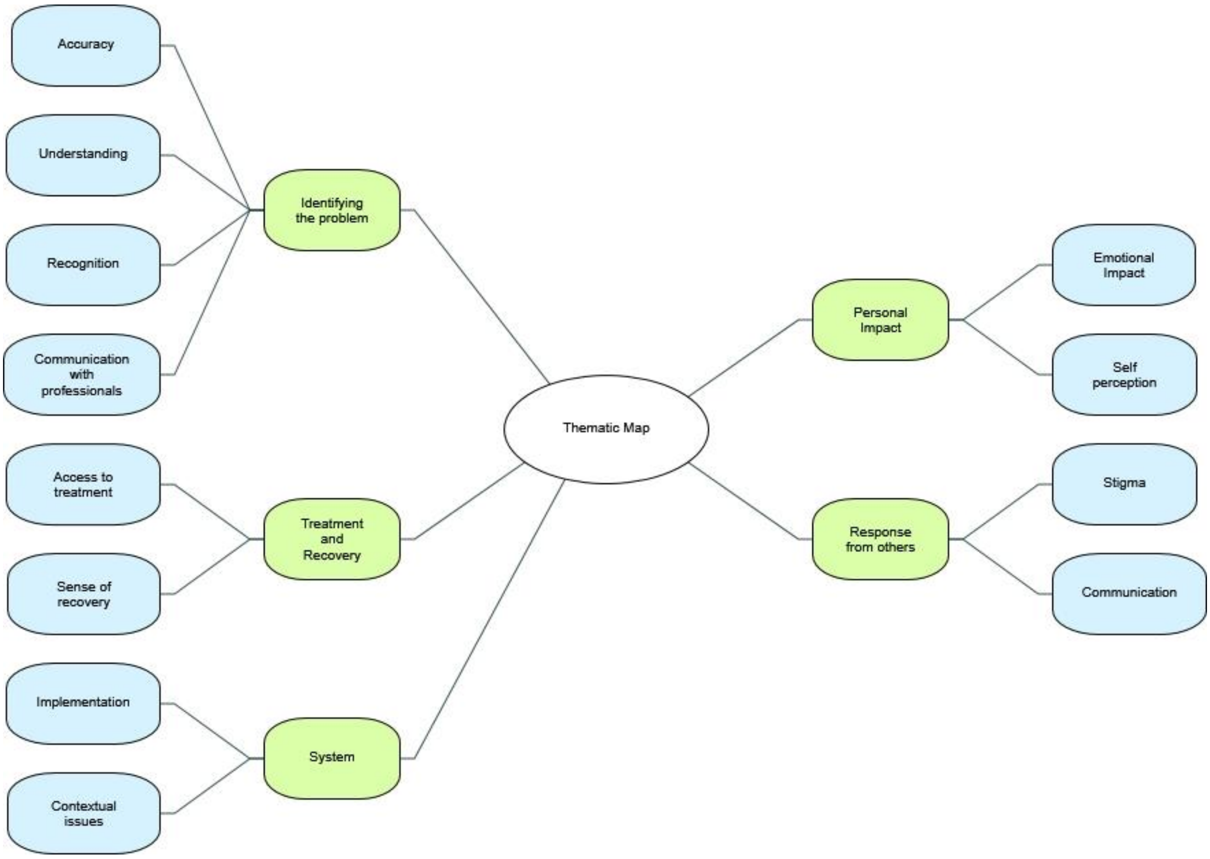
- How to position 'understanding' is it always about understanding for self? or about how others understand the concepts? Want to explore this further.
- I think recognition doesn't capture people's own understanding and explanation of the ideas.

Discussion with Peter again

- How the ideas come together and reflect differences and similarities in stages of people's journey.
- Some of the ideas around better message for recovery were interesting – when you adopt an approach that is less fixed and permanent to something that can change, p's seem to think this sends a much better message for recovery. This wasn't something that was specific about what we were going to ask people but came up from the data anyway!
- On the one hand diagnosis seems to better provide an 'answer' to people's problems, yet can have a negative impact (sometimes) to how they view themselves as a person?

3rd December 2020 – Final thematic map

- Supervision helped me to reflect and progress these ideas.
- Also having conversations with my partner and discussing these outload makes a difference.
- Went back over the data to see if the new draft map reflected the nature of the interviews and to code any additional data (I read all the interviews and often did some more coding and noticed that the thematic map was accurate).
- I then created a table evidencing the themes and subthemes with example codes and subsequent quotes.



Christmas break – started witing part B

- Amazing to see the work coming together, and forming ideas about what this would mean for practice and people's care
- So many quotes to choose from, some are quite powerful and shocking
- Hoping to get an initial draft by the start of Jan

8th Jan – Submitted draft of part B

Jan – March – Worked on part A

March – Revising drafts, seeing everything come together

- Such an intense and stressful process
- Struggling with organising my thoughts and writing a little – Anne has been helpful in how thorough her comments have been
- Feeling nervous to submit but very ready for this to be done

Appendix K – Table of themes, subthemes, and quotes

Theme	**Subtheme**	**Diagnosis or Experiential Codes**	**Code**	**Quotes**
Identifying the problem	Recognition	Diagnosis	Recognition of the problem	"At least you can put a name to it, so you know that you're not quite right or acting the right way… I think we all need to know what's wrong with us, or what's causing it." (Dave) "It does give you that reassurance and that you do get that like that confirmation that what you are going through is something and it's not just disregarded, and your feelings are valid." (Lucy) "It's comfort isn't it. Its comfort. It's it's knowing that you fit in somewhere." (Amy) "It kinda makes you feel like there is something wrong and it's not just you in your mind going crazy. Like there is actually is the diagnosis there." (Jess) "I think a diagnosis is important because it helps you to identify what's going on." (Paula) "For my benefit, I can accept that I have an illness." (Lucy) "Having a diagnosis for me so I knew what was wrong with me." (Amy)
		Experiential Codes	Aid recognition of the problem	"But to be able to google the descriptions of something, rather than just what it means might help people identify what and how they are feeling and what it is, making it a little bit easier." (Amy) "I also think it could help the individual to process what's happened to them as well because I think not until afterwards when I looked back, I don't think I realised how much was going on my life at the time. Where(as) if someone may be pointed all of

				this out at the start, because sometimes you can’t see for yourself, and you might need someone to ask those questions, to get that information and highlight even to you. Erm because you’re so involved in what’s happening that maybe you don’t recognise that, that you stop looking after yourself. Erm so I think you know having that conversation about it could actually help that person to process what’s going on, which would help them to deal with the symptoms better I suppose.” (Emily)
			Lack of recognition	“And it’s like if you list all these things, you’re recognising lots of different problems but for a person who is going through something we just need that recognition and that - yeah it’s weird it comes back to having that sense of like identity and like what’s actually going on rather than just throwing out all these different things. Because to me they’re symptoms. You can’t just say this is what you’re going through I feel like the symptoms of depression, there symptoms of anxiety, like you still have a mental illness it doesn’t matter how you go about wording it. And I just think as humans we need that validation that something is not right.” (Lucy) “So, like as someone that doesn’t know anything about medicine, having that term is like ‘right now are going somewhere, now we’re moving, now something is going to change’. Whereas having just a list of things that I’ve said that’s wrong with me feels like you’re still trying to find out what’s wrong with me. Even if they could be associated with depression or whatever, not having that term would feel like you don’t know what’s wrong with me.” (Amy) “I think people obviously need to know there’s something wrong.” (Dave) “The thing is if you sort said somebody suffering from that, what they suffering from?” (Julie) “I know for myself when I wasn’t eating very well people saying ‘Oh she just doesn’t eat very much’ didn’t make it seem very real to me and it wasn’t until I was diagnosed with anorexia, like however many years ago, it was then I thought oh actually yeah this is a problem and I need to do something about it.” (Paula)

			Downplay the seriousness of the problem	“Would it downplay…some of the seriousness that people are suffering?” (Julie) “It might seem like it’s playing it down a little bit and normalised, rather than actually acknowledging that something is wrong…So people that are going through the experiences, there might think oh you’re almost like not recognising how I’m really feeling. Like playing it down and making it not as important or significant.” (Lucy)
			Distinguishing between normality and illness	“Because for some people, some of those symptoms or experiences might be something that they experience now and again but they’re not necessarily mentally ill. We all go through things now and again. So, it’s like how do you differentiate to someone else that you’re not well? Because they might go ‘Oh but I feel like that and I’m fine’.” (Lucy) “I think perhaps if we did get rid of the diagnosis altogether I feel like maybe for serious and enduring mental health conditions where you actually can’t function, I think it could make it more difficult for people to for people to actually acknowledge how difficult life is for them.” (Emily)
	Accuracy	Diagnosis	Lack of fit	“To be honest I don’t think it fits at all. I honestly don’t struggle with my mood at all. Erm so I don’t think identify with it all and that’s why I’m so resentful towards it…So it doesn’t really feel like it’s a condition I have.” (Emily) “You go to appointments and they’re expecting you to be a certain way depending on what the list of criteria they have in the diagnostic manual is. And you turn up and your nothing like they’re expecting because not everybody you know presents the same way.” (Paula) “Because at the moment you either have one category or another. But many times you have a bit of everything and it’s not just black-and-white.” (Amani) “It’s like anxiety and depression whether you have got both of them is is a different thing. And I think that that possibly needs to be thought about because whether I’ve got anxiety and depression even now, I’m not sure you know. I still get anxious about

				things and I still have high low days, but whether I've got both of them permanently is a is a different thing." (Amy) "And I think again having that label it didn't it doesn't always help because you think that 'Oh I've got OCD' well so and so has got OCD but how they react is different but under the same title does that make sense? How they experience and my experience could be completely different, but we are the same category." (Jess)
			Failure to consider trauma	"Everybody was treating the Bipolar Disorder, which is a symptom of the cause, it's not the cause." (Robert) "So that was a really extended period of trauma. So, you can tell me I've got bipolar, and depression, and anxiety, and PTSD, and all the rest of it, but you also need to see that having been through that I'm not going to be… The person I want to be without a little bit help and that doesn't mean medication and ECT and CBT and all the rest of it, it means help. It means talking and listening and helping me work through all of that, you know. Which could have happened 30 years ago, but it didn't, no one offered no one suggested it. I didn't even think of it, I just thought that it was bipolar disorder and that was that." (Robert) "But, of course, all of this trauma has never been spoken about in mental health services, nobody had ever asked me about it. And I think that's terrible. I think when you first present to mental health services it should be one of the first things that people should be talking to about. Erm because that informs so much before you get to a diagnosis. It's not just how your feeling, it's why you're feeling. Not how you're feeling." (Claire) "I had a lot of things going on in my life that I think did contributed to that. Erm, but that probably wasn't given any significance really in terms of what happened and how people approached how - like my illness really." (Emily)
		Experiential Codes	More accurate description	"It describes me better really." (Tony)

				“Well for a start I would connect with it because I’d be thinking ‘Oh I spend lots of money’ or erm feeling really suicidal or whatever. I connect with it.” (Holly) “It makes you feel more of an individual because bipolar - like my cousin has a very different experience of bipolar than I do, yet we both have the same diagnosis - So this would be like my diagnosis. It would be personal to me; it would be a person-centred approach.” (Holly) “I think it’s because it’s got like your experience, I feel like it’s more like tailored to the individual.” (Jess) “The new approach I found promising, I guess, because then you’re not just like labelling everyone under one umbrella. You’re more, it’s looks like, you’re more looking at the individual and person in front of you and addressing like every single thing that they’re going through.” (Lucy) “They would see the person and not the label.” (Claire) “It opens up more conversations, I think. It’s more accepting of who they are.” (Amanda) “If you had a list of things, that you know a patient had said, it would be a lot harder to kind of pigeonhole one thing…. Because you’re looking at more than one thing, you’re looking at a multitude of descriptions rather than just one diagnosis.” (Amy) “Whereas if you changed it to what symptoms you’ve got, everything is actually what you are feeling and what you are experiencing, so nothing is incorrect.” (Claire) “Erm the list of symptoms would be accurate if you discuss them jointly decided on them.” (Claire) “It’s far more accurate, you know, and far more accepting.” (Amanda)

	Understanding	Diagnosis	Provides an explanation	“I think it helps you make sense of it.” (Emily) “I can sort of understand the points of it rather than feeling lost and not knowing.” (Amani) “It also gives me greater understanding of myself, because if I study about schizophrenia and if I hear anything, you know, hear a voice I can say to myself ‘Well that’s the delusion, that’s the hallucination’.” (Tony) “It’s understanding - knowing that there is something causing that, made (my) life easier, to make me know why I was different, or what might of caused me to be like that.” (Dave) “Understanding what’s wrong with you I think.” (Amy) “It does help me because I feel like I’ve got an answer.” (Amani) “I think it’s quite an important thing for people to get, it gives them answers.” (Paula)
			Didn’t explain experiences	“But it was also quite frightening because I didn’t know what it was.” (Paula) “But understanding it is the hardest thing. Trying to find a reason why. That sometimes makes the struggle worse when I start feeling low.” (Dave)
		Experiential Codes	Aids understanding	“I think that gives a better description.” (Amanda) “If you had your alternative and you had it like this is what you’ve got, and then that person will understand it better as well because they will be like ‘Oh actually I can see well it’s not just OCD could be this could be that’. (Jess) “I think it would be very different because people can understand symptoms.” (Amanda)

				“It would make mental illness more accessible in terms of understanding the people who don’t have that sort of language understanding or haven’t had any training, or research or education in erm in mental health. I think it’s quite an accessible way especially for younger people talking about their feelings in a way that everybody can understand. I think it’s quite good thing.” (Paula) “This actually intrigues me and increases my understanding then it’s got to increase everybody else’s understanding.” (Holly) “People would understand it more, from both myself and my experiences, and the wider community, because I wouldn’t have to keep explaining what I’ve got.” (Jess) “It might actually help people understand a bit more.” (Lucy)
			Hard to understand	“Having all of your issues laid out but not having a reason for them.” (Amy) “But I think people like having that label so rather than saying ‘Oh I’ve got a low mood’, they like being able to say, ‘I’ve got anxiety’. I think that makes it easier for some people to understand because low mood could just be like ‘Oh just in a bit of a bad mood today, I’m just feeling a bit sad today’.” (Amy) “Not having a clear understanding of what is.” (Amani)
Communication with professionals	-	Diagnosis	How the diagnosis was communicated	“I can’t remember to be honest, because I was so poorly, I don’t really remember - maybe I was told, and I don’t remember.” (Emily) “I think it would have helped if they hadn’t given labels until they were sure. So, you know, bipolar is now down on my medical records and there is no mention of the other diagnosis, but they were definitely mentioned to my family. I think that until they’d like determined exactly what it was, there wasn’t the need, in my opinion, to be

				upsetting my mum and getting her to go and look at all these different options. Erm so I think it would have been helpful to have not mentioned anything until it was agreed upon." (Emily) "I was just given a title and that's what I had." (Jess) "I wasn't told about it previously" (Amani) "I don't actually remember a person sitting me down the saying well this was your diagnosis this is now your diagnosis because of this I don't think I actually had that." (Amanda) "I don't think anyone told me that I was schizophrenic. I just I just picked it up and I mean medical certificates that I had to get then it did say schizophrenic illness and sometimes it said anxiety and depression." (Tony)
			Process of receiving the diagnosis	"It took a very very long time for me to get diagnosed. I've been unwell since I was about seven. Erm and I've been through a variety of 'It could be this. it could be that', and lots of different people saying 'I think it's this' and somebody else disagreeing. So, it took I think a really really bad hospital admission and a really really involved psychiatrist to actually get the diagnosis and when I did." (Paula) "They made me made me have a diagnosis" (Holly) "Erm all of which been very friendly very nice but just a million people involved in the process." (Holly) "It takes too long." (Julie) "I just didn't believe it because I just thought 'Well they don't know me'." (Claire)

			Lack of information	“My mum sort of said that they would just say it and she would come home and kind of have to Google it and find out what it was. And Dr Google is probably like the worst idea for those sorts of things. Erm she said there wasn’t a lot of explanation that came with what it would mean... May be actually given my mum some information from a reliable source at that point rather than her having to go in Google it.” (Emily) “I don’t remember anybody ever kind of sitting down and explaining what it would mean or what you know why - I mean, I knew why I’d been given the diagnosis, but I don’t think anyone ever kind of told me officially that that’s what it was.” (Emily) “I think erm as soon as I received the diagnosis, I went scouting every little piece of information I could about it, so I guess I taught myself everything. I read all the books, erm I read all the books, as well as all the clinical books that I could get my hands on. I watched videos that I found on YouTube and anything I could get my hands on to understand this thing that I was supposed to have.” (Amanda)
		Experiential Codes	Nature of information on records	“It’s more personal and I would be happy with that. I personally wouldn’t mind having that on my record” (Jess) “It’s strange to think that somebody is reading something written down that you wouldn’t ordinarily share with them in real life. Even if I know, you know, it was done for the good of my care or whatever, but it does feel a little intrusive to not be able to control who has access to your personal information and personal experiences.” (Paula) “I think in a roundabout way there be more information about that person” (Julie) “I think it’s a better like… It’s more information for everybody, not just for yourself.” (Jess) “And I do think [social determinant codes] need to be… be considered.” (Julie)

			Process of recording codes	“My thing is you only get 10 minutes in a doctor’s appointment. You can’t access mental health services that easily as it is, and then even those appointments are only 15 minutes 20 minutes. If you’ve got to break it down into all these little codes umm is it going to mean that people aren’t going to get the help?” (Julie) “There is not time. Like it’s just like in the interview with three questions, [so I] wouldn’t have time to talk [about] whether I felt help helpless, or whether I felt this, weather I felt that. There just wasn’t time.” (Holly) “It can be frustrating when you have to keep repeating yourself about things. You almost want people to just know the facts and know like what’s happened to you. Erm so maybe more information on your record is actually more beneficial I would say.” (Lucy) “And I would probably be able to avoid having to repeat that go over again.” (Emily) “You don’t have to keep repeating yourself” (Jess) “When you’ve got depression, you don’t want to talk about it. You know when you’re that low, you don’t want to have to recount why your feeling so rubbish. So, to have that information already passed along would be a lot better for someone with that you know, with depression so they didn’t have to talk about it all the time.” (Amy) “I think it would make it less difficult on the patient, or the client, or the user, because you don’t have to re- explain yourself 27 million times every time you meet a new person. You waste so much of their time and your time explaining your history. It would be a lot easier I think if they had sort of a list of the main symptoms that your experience, and then they can get an idea of how things are by asking you about each of them.” (Paula) “I think it would make more people who have sort of stigma about mental health, and a stigma about getting diagnosed, or don’t want to seek help, I think it would make it

				easier for those people to access help. If they know that it's going to be sort of a welcoming experience, where they can talk that they feel sad, or that they're starting to get anxious in the evenings, rather than having to come in and go 'You have this, and you know this is the problem with you'." (Paula)
Personal Impact	Emotional Impact	Diagnosis	Positive emotions	"It was a very enlightening experience." (Tony) "But yes, it was enlightening, but possibly er a bit of a millstone." (Dave) "It made me feel less alone" (Amani)
			Negative emotions	"Erm so I probably had about 15 to 20-ish years of doubt, and pain, and distress, around the diagnosis." (Amanda) "Paranoid schizophrenia is sort of quite a loaded term" (Tony) "Yeah, I mean the diagnoses I really hate them, hate them all." (Claire) "I just didn't believe it because I just thought 'Well they don't know me'." (Holly) "I think when I was first diagnosed it came as quite a shock." (Emily)
			Feeling blamed	"Erm so getting that diagnosis is so damaging. Really damaging because you're treated like scum really, and like you're the problem, your attention seeking." (Claire) "But it also you know is you're trying to fight your own mind every day. It's also like 'Oh well maybe it's all just my fault, maybe this is all just my fault, rather than it being something happening to me it was something I was causing if that makes sense." (Amy)

		Experiential Codes	Potential emotional impact	“Take away some of the guilt that you felt and some of the difficult feelings that perhaps got you in that situation in the first place.” (Emily) “It just feels better, just feels better.” (Robert) “I think I would have been more supportive of myself actually and not been so hard.” (Amanda) “That would have been massive, because I would of realise that it wasn’t just it wasn’t my fault necessarily. It was something that was happening to me, rather than it happen because of me.” (Amy) “So, its human rather than medical.” (Robert) “Because they’re just a list of symptoms, it’s just what you are experiencing. If you’ve got a headache you don’t think it’s your fault, do you? It’s just a symptom. So, symptoms aren’t your fault.” (Claire) “Everyone has poor sleep from time to time, tired or difficulty concentrating. I think a lot of people have thoughts of suicide at one point. It makes you human. So yeah, I like it.” (Holly) “It would not have been so devastating is what I’m thinking” (Amanda)
	Self-perception	Diagnosis	Changes in how view self	“Once you’ve got the diagnosis, it’s almost like it can consume you a bit. Because then you start to think about it too much and think ‘Oh I’m just a depressed person and I’m never going to feel better.” (Lucy) “Placebo effect – it’s like knowing that you’re gonna be suicidal so you let yourself.” (Holly)

				“When I had a diagnosis of manic-depressive, you know, it almost felt it was a huge big sign on your head saying that’s what you were.” (Amanda) “When you get a diagnosis it’s easy to sort of wallow in that, I mean I’m guilty of it. I do sort of wallow in my own self-pity sometimes and it’s really hard to snap out of that - it’s like I’ve got depression and I’ve got anxiety, and this is who I am.” (Lucy) “I’m constantly trying to just think of ways that I just don’t look mad.” (Holly)
			Un-defining	“Normally you’d say something like ‘I am a schizophrenic’, whereas really it’s ‘I suffer from schizophrenia’. I’ve got one leg you can’t say ‘I am only one leg’. There’s more to me than mental illness. ‘I’ve got schizophrenia I suffer from it,’ I’m not a schizophrenic sort of thing, yeah.” (Tony) “Whereas myself many years ago I realised that I wasn’t my diagnosis, I have a diagnosis but it’s not me. It’s just a diagnosis, it’s just a label... And I feel very strongly about that, I’m not my label and not my diagnosis. I have difficulties but so do a lot of people.” (Amanda)
		Experiential Codes	Self-perception	“The approach might be a bit better because you’re not saying I am depression, you’re going through these things, you’re not defined by it.” (Lucy) “It’s getting rid of the mad word.” (Holly) “I feel like if you say you’ve got depression and it is like a label, whereas the other approach is like ‘This is what I’m going through, and this is me’. Whereas I guess if you say to people ‘I’ve got depression’, yeah, you’ve subconsciously just put a label on yourself anyway because they may think of you is that depressed person. Whereas if you’ve got all of these different things that you’re feeling, it’s like ‘Oh she’s going through that, as opposed to she’s got depression’.” (Lucy)

Support and Recovery	Access to support	Diagnosis	Positive aspects	"It's useful to have a diagnosis because it gives you a cluster of things that you can focus on, to deal with, and you might have likes specific ways of dealing with things depending on the diagnosis." (Paula) "I suppose it then allowed me to reach out to particular support groups and charities, because I knew what it was." (Emily)
			Negative aspects	"I saw this chap at (mental health service) and he just went "Oh it's just depression, the GP has already put you on antidepressants, go away". (Julie) "We've given him his diagnosis, give him his medication, will have a review in a year, bosh he's gone, that's it." (Dave) "If you get told that you've got depression, and it's like but you've got to wait four months before there is anything that we can offer you - it's like, that's not gonna help." (Amy) "Once you've got that diagnosis, your turned away at the door, you're not allowed, you know, if you ask for help your pushed away… that is the care that you get when you've got EUPD diagnosis." (Claire) "I wasn't given any support" (Holly) "There was no support from this person. It was just like 'Off you go see you later" (Amy)
		Experiential Codes	Aid access to support	"It would be more informative and properly would be able to give you a more accurate treatment plan" (Julie) " I think if you had it on my record that I was waking up screaming, and my experience of why I have, that it might make the doctors think actually you do need more help than what I received." (Jess)

				"That would then saved so much time, so much money, because you're getting help from the start. Rather than not really knowing what path you're going to go down, because you don't fully know what's wrong with you." (Claire) "Maybe I wouldn't have been pumped so full of medication." (Emily)
	Sense of recovery	Diagnosis	Negative narratives about recovery	"Change was not part of the process at all, and that's what I find really really angry, I'm really angry at the system because it's not talking about optimism there is no optimism about it." (Holly) "Bipolar and schizophrenia and everything else is incurable that's what they say." (Robert) "It's like a limitation and an expectation that I can't live a full life because of this." (Emily) "The most annoying, frustrating, angry thing about it is that they've given me this label, and this is for life" (Holly) "People have this horrible horrible impression from the past that if you have such and such you could never work, or you would never get anywhere in your life, you would be completely feet stuck in quicksand and not able to proceed." (Amanda)
		Experiential Codes	More hope for recovery	"Whereas I guess if you've got all of these other things laid out about what you're going through, your almost like 'Ok this is what I'm going through, but some of the things can be quite normal'…Your outlook going forward might be a bit more positive." (Lucy) "I think it would be a better message recovery overall because, you know, people recover from insomnia, people recover from a bereavement, people recover from a low mood. So, you know because you can recover from those individually, I feel like people would feel more likely that they can recover from your own list of symptoms, one step at a time. Erm so I think overall it probably would give a better message for recovery." (Emily)

Response from others	Disclosure	Diagnosis	Connect with similar others	“Feeling like you can connect with others that have a similar sort of thought processes or past experiences.” (Amani) “When I attended a group, and that was the first group I went to for support, and for me it was amazing. There was this room filled with people with the same diagnosis, and I started then to accept that actually I am okay, and you know you’re not a weak person and all of that.” (Amanda)
			Difficult to share with others	“When I do let people know, it’s often after they’ve gotten to know me for a long time that I’ll then bring up, because I then kinda trust what their response is going to be.” (Paula) “I felt I had to keep it quiet and hide it that I was schizophrenic.” (Tony) “A lot of people don’t know what to say or how to act when you talk about mental health, you know it’s still such a taboo subject…People don’t want to talk about it.” (Amy) “I think I was worried about the judgement, and that they would think that I wouldn’t be able to do my job effectively. And that they may use it against me in a negative way, like in the future if I went for jobs, or if I wanted to progress.” (Lucy)
		Experiential Codes	Personal information to share with others	“Where you can just write one thing, you know this lady has EUPD. That’s one sentence. This lady has mood swings, depression, anxiety, umm you know lack.. it starts going into all the [detail]” (Julie) “I think it almost exposes you a bit more, and like tells them everything you’re going through. Whereas you may only want to sort of selectively tell them a few things that you think are important. You don’t always want people to know everything and they don’t have to know everything.” (Lucy)

			Aids communication with others	"Easier to communicate, and easier to tell someone how I'm feeling, without using the term…I think it would be a lot easier. I think I could communicate better with them if I had it like this rather than going to them 'I've got borderline personality disorder'. Because that's quite scary in itself, let alone saying it to someone that doesn't get it." (Amani) "I definitely think that it would help communicate problems clearly." (Amy) "It also makes it a lot easier to share experiences with people I think." (Paula)
	Stigma	Diagnosis	Negative treatment from others	"What we mustn't do is give you attention, however bad your feeling, oh dear you're feeling suicidal well go home, you know. Erm it's really naff (Claire) "I actually told one of my friends and she said she thought that I was being erm attention seeking. She was like 'I think you're just being attention seeking'. Then after that I didn't tell anyone again because I felt like I couldn't, because I was made to feel like… My feelings weren't valid by anyone." (Lucy) "My extended family don't believe me they think I make it all up, which is very difficult." (Amani) "It had the word like schizo in the title, which I immediately puts you in the sort of stereotypes that you hear on the news and stuff. [People] hear schizophrenia. or schizoaffective, or something that involves the mind sort of bending reality, I think people get quite scared, and I was worried about how other people would treat me I think." (Paula)
			Narratives about people with mental health diagnoses	"Control, loss of control, you really see a manic-depressive with an axe, or that's a schizophrenic as well with an axe." (Amanda) "I said that OCD everyone thought it was about cleaning". (Jess)

				"I think it's quite useful to use the correct language but also in the correct context. Like a lot of people will say 'Oh I'm really OCD' about my table or something, and they don't mean it in the diagnostic criteria kind of way, which kind of it can undermine the experiences of people who really do have obsessive-compulsive issues. Erm I think it's nice that that language is becoming more normalised by also thinks it's important to use it in the right way." (Paula) "Because when you put like borderline personality disorder they probably think of going through Dr Jekyll and Hyde" (Amani)
		Experiential Codes	Normalises experiences	" I think it would make the experiences more normal and more talked about, and perhaps reduce stigma because they're all things – everyone [would] of had a couple of things on that list at one point in the life, but people would relate to them." (Paula) "I think it would reduce stigma because of that sense of normalisation… A lot of the symptoms of bipolar on their own other people will have experienced in their life, and so for the people that experienced it it's more normal, and there's less things to be stigmatised for." (Emily) "People would look at everything as a whole, because as soon as people hear the word depression or anxiety or whatever - I guess people have a preconceived judgement of what that is, without knowing the facts and without knowing what it's like for you… Whereas if you list it like the [experiential coding approach] its listing everything that you're going through. So, I guess yeah they might not make the same judgements." (Lucy)
			Wouldn't make a difference to stigma	"I don't think it'll make a difference, because if you put different label on it people will take that label and they will eventually find out what it stands for… Trying to change the diagnosis doesn't help it's still what it is. It's understanding that I think we need" (Dave)

				“The stigma comes as much from behaviour as it does from diagnosis. In the fact that they know you’ve been in hospital and that sort of thing. It’s the behaviour that enhances the stigma.” (Robert)
Implementation	Differences between the two approaches		A diagnosis needs to be made	“It’s almost like we’re trying to overcomplicate things or normalise things.” (Lucy) “Erm but changing the diagnosis, or relabelling the diagnosis, I don’t think will work because you still - that then becomes the diagnosis. Whether it’s got a different label, or a different way you approach diagnosis, it is still the diagnosis it is still given that label.” (Dave) “I do think that will mean a lot more words that mean the same thing, on a system kind of thing.” (Amani)
			Codes as its own approach	“I prefer it if that’s how things were and how it was approached, rather than what it is right now… I think like having it down as what you’re experiencing I think would work best” (Jess) “It’s, very, it’s right though.” (Julie) “I like it. I like the idea, especially the descriptions rather than diagnoses.” (Amy)
			Codes in addition to diagnosis	“The alternatives need to be included but I don’t think you can lose the actual label.” (Julie) “The thing with the diagnosis though if you just give someone a diagnosis, like I say you don’t know it doesn’t give you that background it just tells you what they’re going through. Whereas with the codes it’s like it’s almost like adding to that. You’re adding to the information that you’ve already got. Because to me it just looks like an add on or like the diagnosis and the symptoms.” (Lucy) “I think they’re quite different but that means that they complement each other, because it gives more of a broader way of making the whole process individual to each

				person. Erm like if there's multiple ways of discussing things and talking about things you can talk about them in the way that suitable for that person." (Paula) "I think if they want to diagnosis - if they really would prefer to have a diagnosis, then give them one. But not everybody wants that. So, its maybe a choice between having a diagnosis, or not have the diagnosis. Having a diagnosis or having symptoms. Maybe it is a matter of choice." (Amanda)
	Consideration of the wider context	Diagnosis	Access to support	"It did help, erm in terms of accessing sick leave. Because I was not able to work for a while. Erm and I found it was much easier for me to access the support I needed than other people in similar situations who didn't have the diagnosis. Erm so that was a helpful thing about it." (Emily) "Well it was about being diagnosed with paranoid schizophrenia that was a help with my benefit saying that you know welfare benefit. Also erm… Yeah being diagnosed schizophrenic helps me with my benefits." (Tony) "But I do think there are benefits of it and I don't think it should necessarily be abolished. I think you know a diagnosis is there for a reason and it did have benefits for me in terms of accessing the support to allow me to be on long-term sick leave until I was ready to go back to work." (Emily)
		Codes	Lots of information to send to others	"Umm I mean it would certainly put me off and changing GP, the thought of them having to send it all." (Julie) "I think that would be a lot more difficult with this rather than generic terms." (Amani)
			Dependent on the context	"I think you could use both you know both paranoid schizophrenia and voice hearer depending on the situation. Because on a benefit form, I would put down paranoid schizophrenic, erm and then you know if someone stranger says or what's up with you I would say a voice hearer, or something like that." (Tony)

			Make it harder to access support	“It’s to airy fairy for the system. You can’t go to Social Security and say I’m tired all the time, homeless at the moment, and I have suicidal ideation or whatever can I please have the disability allowance. The system doesn’t work that way.” (Robert) “When I applied for benefits - if you’re not at work I can see being you know, it’s difficult enough as it is… yeah yeah I mean it’s hard enough as it is with the full diagnosis.” (Julie) “Erm you know it is possible that it might have a negative impact on benefits. So I just think it’s a possible negative but I don’t think it’s necessarily a definite negative, it might not happen. It’s unproven.” (Claire) “I suppose like it shouldn’t be… but like if you’re going from a system to a different system, like the benefit system for example, and you list the things instead of saying bipolar, it could influence benefits like because... Because the benefit people want to hear you’ve got bipolar, they don’t want you to hear that you feel hopeless and all the rest of it.” (Holly)

Appendix L – Ethics approval

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Appendix M - Reflectivity statement

Before I started the doctorate, I had a few supervisors who took a critical stance towards psychiatric diagnosis and were interested in community and critical psychology approaches. I spent some time working in an ADHD assessment service in CAMHS, and witnessed many conversations where professionals debated the appropriateness and ethics of giving this (quite contested) diagnosis to children. Therefore, I already started the course with an awareness of the critiques of diagnosis and an interest in thinking about this further.

One of my first assignments on the course was to critically review the Power Threat Meaning Framework – an alternative to psychiatric diagnosis. I was inspired by the ideas but wondered what the barriers were that meant that the approach hadn't become more mainstream in services.

When I went to the research fair, I was keen to speak with Anne Cooke, someone I felt who positioned herself as a critical thinker and interested in similar topics as myself. The idea of this project was shared to me by Anne at the research fair. She said that she had a colleague who had an idea for a project which involved exploring a possible alternative to diagnosis. I went away and did some reading on the approach and was keen to take the project further.

I think the three of us, Anne, Peter, and I held slightly different views on the approach and hopes for the research. Peter, as the person who had developed the idea, was obviously invested in exploring the potential of the approach. He brought excitement, enthusiasm to each stage. Anne and I were both critical of the idea of diagnosis, although could see its place within our current context (e.g. access to support in the context of austerity). I think we all hoped to develop knowledge in this area, particularly from a service-user perspective, and remained curious about the potential outcome.

I was open to what service-users would think about the alternative that we proposed. I think it helped to have the material disseminated in the video (although on reflection I think it would have been better to have someone else do the voice over on the material, instead of Peter). I anticipated that we would probably find positive and negative aspects of either approach.

What surprised me in the interviews and the data analysis was that so many people did not receive appropriate support following their diagnosis, and many experienced the process as uncollaborative and ‘expert-driven’. In terms of the coding approach, I didn’t anticipate the potential impact the approach could have on recovery, and how it could make people feel more hopeful and more likely to see help.

I think another interesting tension that was demonstrated in part A and B was the drive for alternatives to normalise experiences yet fail to consider how to communicate the severity of people’s difficulties when necessary. I was surprised that this came up in both parts of the thesis, and it wasn’t something that I had thought about beforehand. It’s interesting because the course that I am on really emphasises the importance to normalise people’s experiences, particularly in the context of their life circumstances. However, perhaps for service-users this might not always be helpful, particularly when they need to communicate their difficulties to wider systems of support (e.g. to their employers, family members, or welfare applications) – sometimes people might want to be referred to as ‘ill’.

Overall, I am pleased with how this research has been conducted and feel excited to share the results more broadly.

Appendix N - Samples of annotated transcripts

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