

Patient Perspectives on Learning of a Psychosis Diagnosis

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Abstract

Background: The experience of receiving psychiatric diagnoses is under researched. The impact of how an individual receives a diagnosis of psychosis, as used in early intervention services is particularly lacking in empirical understanding.

Method: Participants were recruited from an early intervention for psychosis team in the south-east of England. Semi-structured interviews were carried out with 10 participants who were selected using a random sampling methodology, participants were aged between 21 and 61. Interviews were analysed using reflexive thematic analysis.

Findings: Analysis of the interviews created four themes: *“No easy way to say”*, *“Setting the tone”*, *“Power”* and *“Changing perspective”*. The themes illustrate the individualised nature of what makes for a good experience of diagnosis, the impact that the diagnostic meeting has on the early beliefs and understanding that individuals form about their diagnosis, the awareness and impact of power dynamics within services and the ways individuals go on to make sense of their diagnosis.

Conclusions: Individual perceptions of the diagnostic experience are unique, influenced by individual characteristics, level of prior knowledge and individual context. Diagnosis should be approached by clinicians in a person-centred way that aims to meet the information and communication needs of each individual as early as possible. It should be assumed that internalised stigma will result from the diagnosis and steps taken to mitigate for this as the early negative impacts of the diagnosis can be processed and addressed, ideally with a network of support.

Introduction

General Introduction

This research project aims to explore the process of receiving a diagnosis of psychosis within an early intervention for psychosis (EIP) team, and the impact this process has on the individuals receiving it. Through this introduction, I will set out the rationale for undertaking this research, from the historical context of psychosis in the United Kingdom to the present difficulties associated with the diagnosis. I will outline the current understanding of the diagnostic process for mental health conditions from the perspective of both patients and clinicians. I will define relevant terms used throughout the thesis, my relationship to the research, and my epistemological position.

Use of Language

Diagnoses: In this thesis, diagnostic labels like psychosis are central, but this should not be taken as an endorsement. Michael White observed that for diagnosis, 'the issue is not whether people are given diagnoses or medications, but how they are used, whether they are enabling to human agency and freedom' (Larner, 2003, p. 212). Diagnoses achieve their utility by providing an efficient way for clinicians to cluster symptoms of mental distress and from this, assign clinical interventions (Perkins et al., 2018). This is because interventions are based on guidance from the National Institute of Health Care Excellence (NICE), who base recommendations on research evidence that is in turn based on diagnostic criteria (NICE, 2023). Diagnosis is a requirement for individuals to access treatment within the early intervention services that exist in the United Kingdom, and access to services is a benefit regularly cited by individuals who receive diagnoses (Pitt et al., 2009). Research into

the impact of these labels on the individual, however, regularly points to the damage they can cause (Pitt et al., 2009; Howe et al., 2014; Moritz et al., 2019). This thesis will use diagnostic terms when discussing the relevant disorders or the impact of the diagnostic label. On other occasions, mental or psychological distress will be used to describe individual experience.

Psychosis: Refers to what has become an extremely broad term used to describe features of a number of mental health conditions. Psychosis is characterised in literature as an experience that disrupts an individual's thoughts, feelings and behaviours, distorting their reality. Typically, this is described through hallucinations (seeing, hearing, smelling, or tasting things that others cannot) or delusions (fixed, unevidenced beliefs that are not culturally bound). People experiencing psychosis are described as having difficulty engaging in everyday activities and communicating with others (Arciniegas, 2015). Psychosis is characterised by the Diagnostic and Statistical Manual (American Psychiatric Association, 2013) as:

“Two or more of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated): 1 delusions, 2 hallucinations, 3 disorganized speech (e.g. frequent derailment or incoherence), 4 grossly disorganized or catatonic behaviour”.

Psychosis itself has only recently become a diagnostic label with the growth of early intervention services where the diagnosis of First Episode Psychosis (FEP) is used routinely. These services aim to provide psychological and psychiatric support to individuals when they first experience symptoms (IRIS, 2012). The diagnosis of psychosis reflects that their experiences have not progressed to the stage of meeting one of psychosis' other closely associated conditions, such as Schizophrenia or Schizoid Personality Disorder, which feature

psychosis as part of their diagnostic criteria. As this thesis explores the impact of being given the diagnostic label of psychosis as part of treatment within an early intervention team, I will use the term throughout when discussing the experience of hallucinations or delusions.

Western: The term Western is used in this thesis to make clear that there is no universality to the experience of psychological distress. Ferris et al. (2017) describe Western countries as countries whose cultural background can be said to be European in origin and that are highly industrialised. Therefore, in this thesis, western is a shorthand means of describing countries that meet this description and all the associated ontologies and epistemologies arising from scientific practice in these societies. The research takes place in an early intervention service in the United Kingdom. Therefore, all understanding and experience of psychosis and diagnostic practice reported by the participants in this study is culturally bound to, and shaped by, the mainstream Western epistemology, traditionally, positivism.

Patient: The term patient is used throughout the project when referring to individuals within the treatment team or when describing an interaction with a doctor. How to refer to people who are using health services is a subject of much debate, patient, service user, and client are all commonly used across different settings. In the host service this research was conducted in, patient is the term used. Simmons et al, (2010) investigated which term is preferred by people using secondary mental health services finding that in relation to working with nurses or psychiatrists, the term patient was preferred, while when working with therapists or social workers the term preferred was client. As the reported study is investigating the diagnostic process that occurs between a psychiatrist and patient, therefore, the term patient will be used throughout.

Researchers Position

Research of all forms seeks to increase understanding of an aspect of ontology. Essential to conducting qualitative research is the researcher recognising that as the individual carrying out the work, they strongly influence what results are produced. Positionality in qualitative research can be seen as the recognition of the place where this objective aim at ontological understanding and the subjective reality of conducting research meet (Godley & Smailes., 2012). When conducting qualitative research, the researcher themselves can be seen as the research instrument (Dodgson, 2019). This necessarily means that the individual carrying out the research will bring their own subjective influence onto the research design and the subsequent interpretation of its findings (Bourke, 2014). It is, therefore, essential that the researcher engages in the process of research in a reflective way, understanding their own influence on the research and where this comes from. Throughout this study, I kept a reflective log of the experience, recording thoughts and feelings after interactions with supervisors, participants, and consultants. An extract of this log is contained in Appendix A.

The individual characteristics of the researcher do not just dictate positionality but also the way the researcher stands in relation to the subjects of their research, leading to the insider/ outsider researcher dichotomy (Breen, 2007). My positionality at first seems obvious, I am a white male, someone who has never experienced psychosis, middle class, credentialed and an NHS professional. These characteristics have shaped how I experience and interact with the world around me and, apart from my gender, all position me as different demographically from those likely to experience psychosis (Kendler, 1996).

Therefore, I positioned myself as an outsider researcher and expected that the participants would see me that way.

During my placement in the early intervention team, I became very aware of the impact diagnosis had had on the individuals I was working with and how the stigma added to their difficulties. Upon reflecting on my position and why this area of research was important to me, however, I came to recognise some limited similarities. My own experience of being diagnosed with a mental health condition that I did not feel accurately reflected what I was experiencing, is what started me towards my career in mental health work and now psychology. The condition was not psychosis, however, I experienced similar feelings of self-stigma and shame that are reported by those diagnosed with psychosis or related conditions (Pitt et al, 2009; Howe et al., 2014; Moritz et al., 2019). The final similarity is geographical, I grew up in the same area that this research is being conducted in and had a very typical childhood for the area. The participants in this study likely went to similar schools, maybe played in the same sports teams, and hung out on the same high streets as I did growing up. All these factors influence not only how I interpret what participants say to me, but also how they will perceive me, having a huge bearing on the research outcomes. Rather than trying to deny or minimise these differences and similarities, I have endeavoured to recognise my position and factor this into the conducting and analysing of this research project.

Epistemological Position

Epistemology is the theory of knowledge, the investigation of what it is possible to know and how to determine whether that knowledge is reliable and valid (Willig, 2013).

There are many varied epistemological approaches a researcher can take, and the decision will significantly impact the research. From the methodology selected to the understanding of the information created, and what conclusions can eventually be drawn from the work, epistemology shapes the research. Defining an individual epistemological position is therefore critical to any research and is a personal as well as academic exercise. In this research, I have adopted a critical realist (CR) stance, which both fits my philosophy as well as the aims of the research. The realist element of CR has the explicit understanding that there is an objective reality of cause and effect that is separate from subjective individual experience, and that this reality can be explored through research. The CR approach stands in contrast to both positivist and constructionist epistemologies in viewing reality as existing beyond what can be measured by, or created with, human endeavour and interaction (Fletcher, 2017). The critical element of the CR stance allows for the researcher to draw conclusions about the reality of experience, while acknowledging that what is described by each participant is only one of many possible ways of understanding the reality of their experience. In this project, with the aim being to understand individual perspectives about how they learned of their diagnosis, using a critical realist stance allows for the exploration of the individuals' reality in being diagnosed, while understanding that this reality can only be understood when viewed in the wider context of diagnosis in the UK.

In the context of the current project, a CR stance also allows the researcher to go beyond simply reporting on experience, allowing for causative links to be drawn (Fryer, 2022). This benefits the study as, beyond simply learning about the experience of individuals receiving diagnoses, I hope to explore how these experiences potentially influence the development of difficulties such as self-stigma and other negative outcomes associated with the diagnostic label of psychosis. The information will hopefully allow for recommendations

to be hypothesised and then further tested to benefit the experience of individuals receiving these diagnoses. This is based on the assumption, arising from CR, that the data collected can tell us about the reality of the experience of being diagnosed, while acknowledging the influence of broader cultural, sociological and historical influences on this experience. The CR epistemology also acknowledges the impact of the researcher and my characteristics on shaping the reality that I can access within the interview and following analysis.

Diagnosis in context

History of Mental Illness

Mental illness, as the medical model currently labels psychological distress, is a modern construct. To understand the impact these labels have today, it is important to understand how they came to prominence.

Historically, from the Middle Ages in Europe, there began to be written evidence of forms of psychological distress. European society at this time was a much more spiritual and mystical form of society (Foerschner, 2010). This has led to assumptions and stereotypes that in the era before the advent of science, aberrant behaviours or beliefs were attributed to spiritual concepts such as possession or divine punishment (Kemp & Williams, 1987). This stereotype has however been challenged, with reviews of medieval literature demonstrating a much more nuanced understanding of mental distress. Kroll & Bachrach (1984), explored accounts of mental illness from medieval sources and were able to attribute supernatural causes to only 16% of the descriptions. The authors argue that from

the medieval perspective, what we would now see as a biopsychosocial model of mental health was implicitly understood. Records refer to factors like; humoral imbalances, head injuries or physical illness (Bio), grief, shame and guilt (Psycho), and fasting or alcohol use (social). All these factors are given more prominence than the supernatural as an understanding of the causes of psychological distress. Another prominent trope is the idea of mental illness being attributed to demonic or nefarious causes. In a similarly critical review of this literature, Schoeneman (1977) argues that the traditional view of the witch hunts being driven by symptoms of mental illness in women has been exaggerated. Furthermore, he argues that this exaggeration is due to the dominance of the current medical model, historians assuming that prior to modern scientific knowledge, people throughout history must have looked to the mystical to explain what we now view as bizarre.

One interesting aspect of the historical interpretations of psychological distress, is that both see psychological problems as external to the individual rather than intrinsic to them. This can be seen as more fitting with modern systemic approaches to mental distress which attempt to move beyond the traditional positivist medical model (Carey & Russel, 2002). The externalising and the understanding of wider contextual factors paint a far less stigmatised picture of pre-scientific views on psychological distress than traditional assumptions. This raises the question of where exactly the well-established modern stigma around psychological distress arises from.

Development of modern Diagnostic Practice

Psychiatric diagnosis can be traced back to the ideas of asylums, assigning a label to individuals suffering psychological distress to imprison and remove them from society (Jarret, 2020). Until the passing of the Lunacy Act (UK) in 1845, mental illness was dealt with through punitive action, ostracising those who behaved or thought in a non-normative way. While the act changed the focus from incarceration to treatment, the stigma attached to mental illness in Western cultures began here.

Diagnosis as we know it today was first attempted by Kraepelin in 1883. He described a series of psychological disorders with shared symptomology which he suggested had an underlying biological or physical cause, a positivist stance that psychiatry has remained in ever since (Jablensky, 2007). The first attempt at codifying psychological distress into formal psychiatric diseases was in the 6th edition of the International Statistical Classification of Diseases Injuries and Causes of Death (World Health Organisation, 1948), commonly referred to as the ICD. This was the first edition of the ICD to include psychiatric diagnosis as well as physical and was quickly followed by the first Diagnostic and Statistical Manual (DSM) published in 1952 by the American Psychiatric Association. The DSM was designed specifically as a reference for all known mental disorders. It is still used, in its 5th edition. It was designed to categorise different mental health conditions by attaching diagnostic labels to clusters of behavioural, cognitive, and emotional experiences. The ICD is now into its 11th edition (World Health Organisation, 2019) and is the primary classification system used outside of the United States of America. However, the two systems continue to operate in parallel due to the sustained dominance of the DSM in research and academic

publishing (Katschnig, 2010), and in the United Kingdom and Europe, the use of ICD classifications in clinical settings.

Questions of Validity

The validity of this system of categorisation has been challenged throughout its use, when describing individual psychiatric disorders (Kendell & Jablensky, 2003) and what is contained within it has changed significantly over the years. This is most famously illustrated by the inclusion of homosexuality as a disorder within the DSM I and DSM II, with the removal of homosexuality only occurring in late editions of DSM II in 1974 (Drescher, 2015), demonstrating how terms can enter and leave the classifications on the basis of changes to societal norms as well as any scientific developments. DSM III was the first edition to embrace the medical model as the dominant paradigm to view psychological distress, having previously been grounded in more psychodynamic conceptualisations (Suris et al., 2016). Since the shift towards a medical framework, the criticisms of the DSM and the ICD classifications have grown. The categories have struggled to achieve the validity and reliability that is expected of diagnostic categories within physical medicine, most clearly demonstrated by the inability to establish any biological markers or tests that can distinguish or identify individual psychiatric diagnoses (Katschnig 2010; Kendell & Jablensky, 2003). A further criticism of the current diagnostic categorisation within mental health is the process by which decisions are made on what to include or remove from the DSM and the ICD. The process is self-fulfilling, with diagnostic categories serving as the basis for research that can be used to further justify the diagnoses (Kraemer, 2007).

Despite the ongoing criticism of the lack of reliability and validity, since the DSM III was published, the positivist medical model of mental illness has become ubiquitous across Western healthcare systems and has influenced the wider public understanding across Europe and North America. It has been argued that a large factor in the dominance of a medical approach has been the influence of corporate interests, primarily from the pharmaceutical industry, in promulgating the medical model of psychiatric disorders (Pilecki et al. 2011). The growth of psychopharmacology has represented an enormous source of revenue for the pharmaceutical industry. In 2022, the total global pharma industry was estimated to be worth 1.48 trillion US Dollars, with psychopharmacology representing the third largest drug class for pharmaceutical companies (Mickulic, 2023). Clearly there is an enormous economic imperative for the industry to continue to promote a medical understanding of psychological distress and maintain the status quo.

Psychosis

Diagnosis and Treatment in the UK

Psychosis care in the NHS has been through a large upheaval in diagnosis and management over the last 20 years. Individuals experiencing psychosis are currently advised to seek support from their GP to obtain a referral to a specialist service, with treatment options including antipsychotic medication, psychological support, and social support (National Health Service, 2019). The United Kingdom, alongside many other Western nations, has, since 1999, begun to adopt an early intervention treatment programme specifically for individuals experiencing psychosis (Neale & Kinnair, 2017). The National Institute for Health and Care Excellence (NICE) recommends that all adults experiencing a

first episode of psychosis should have access to early intervention services. Early intervention services aim to offer treatment to individuals experiencing an episode of psychosis, to prevent the development of more chronic difficulties that could arise if left untreated. The advice from NICE is based on the utility of early intervention when compared to traditional treatment within community mental health teams (CMHT), demonstrated through a randomised controlled trial (Craig et al., 2004).

Early intervention services differ slightly according to local service provision but typically consist of psychiatric, psychological, and social support provided within a multidisciplinary team approach (IRIS, 2012). The emphasis on psychological and social support to treat individuals with a first episode of psychosis demonstrates the increasing recognition of the limitations of the medical model within NHS mental health services, evident in the five year forward view for mental health services (NHS England, 2016). This gradual shift towards more holistic approaches can be seen in the increase in emphasis on using EIP teams alongside the growth of talking therapy provision through national programmes like the Improving Access to Psychological Therapy (IAPT) services (NCCMH, 2018).

Stigma

There is a large body of evidence that individuals diagnosed with psychosis in the UK experience significant stigma. Both internal stigma, negative beliefs about themselves, and external stigma, the experience of prejudice from others due to the label are commonly reported. (Degnan et al., 2021; Wood et al., 2014; Holzinger et al., 2003). It is thought that 0.5 - 0.7% of the population have experiences that could be labelled as psychosis at any given time (Public Health England, 2016). The lifetime prevalence of psychosis has been

established at 3% (Perala, et al., 2007). When extrapolated out to a population figure, this means that in the U.K, approximately 2 million people have experienced symptoms that could be labelled as psychosis. Psychosis, therefore, is not an uncommon experience yet it still attracts significant stigma, to a greater degree than other mental health conditions (Holzinger et al., 2003). This could be due to the improved public understanding of other common mental health diagnoses, such as depression and anxiety, which have seen significant public information campaigns launched, such as the recent “Help!” campaign by the NHS. These aim to normalise the experience of these forms of psychological distress, reduce stigma and decrease barriers to seeking support. For diagnoses like psychosis, however, no such campaigns exist. There are also very few public personalities willing to speak openly about psychosis, notable exceptions such as David Harewood exist (Harewood & Ottewill 2019; Harewood, 2021), but the stigma around experiences such as voice hearing or delusional beliefs still holds very firm throughout society.

The root cause of the stigma is not clearly understood. In a review of the root causes of stigma across mental illness, Hayward & Bright (1997) conclude that there are four main drivers when considering external stigma; the idea that individuals with mental illness are dangerous and therefore should be feared. Secondly, individuals with mental health difficulties are responsible for their problems and therefore less deserving of sympathy than individuals with other difficulties. Thirdly, there is no hope for getting change for individuals with mental health conditions. Furthermore, the belief that individuals with mental health difficulties will disrupt normal social order, that they are, even if not considered dangerous, still difficult to be around. This review was conducted in 1997 and it is likely that since then, thanks to public information campaigns and a cultural shift towards openness about common mental health conditions, these attitudes would not be so prevalent for depression

and anxiety disorders. When it comes to psychosis however, with no equivalent public awareness campaigns or general attitudinal shifts, it is likely that all these factors continue to play a large role in public stigma towards people diagnosed with psychosis. As a result of these societal beliefs, individuals who receive this diagnosis likely hold some, or all, of the beliefs themselves, leading to self-stigma and an assumption of external stigma in others.

Cross-cultural understanding of psychosis

The ubiquity of this positivist understanding of mental distress in Western cultures is firmly established. This has shaped the Western cultural understanding of psychosis symptoms and, as a result, appears to shape how individuals who experience these symptoms perceive them. The impact of this can be seen by comparing how individuals brought up within different cultures make sense of their psychosis symptoms (Luhmann et al., 2015a, 2015b). These two papers demonstrate that across cultures the same experience of voice hearing is given very different meanings and, therefore, have very different responses from the individual experiencing them. Individuals outside of a Western cultural context (Chennai, India and Accra, Ghana) experienced less distress because of their experiences and reported them to be significantly less violent than the participants from a Western context (San Matteo, USA). The Western participants were much more likely not to like the voices they heard compared to the Indian and Ghanaian participants, who were more likely to report that the voices were positive, often representing family or ancestors, or interpreting them as representing a positive religious experience. The research highlights the power of society and cultural narratives in how individuals perceive their own internal experiences. The authors highlight that despite all participants demonstrating a similar level

of personal religious faith, those from the Western society did not seem to have the same positive religious perceptions of the voices as the individuals in non-western countries.

One key difference found between the groups was knowledge of psychiatric diagnosis. In the Ghanaian and Indian participants, awareness of psychiatric labels was very low, with only 10% and 20% respectively reporting knowledge of psychiatric labels. In the US sample however, 85% of participants were aware of the psychiatric labels associated with their experiences. This can be seen as demonstrating how individual perception of their own subjective experience can be shaped by the context in which they have those experiences. This finding has been replicated when analysing psychosis cross-culturally (Laroi et al., 2014). This review concluded that culture affects the meaning and characteristics of the hallucination experienced and that experiencing them as positive or as a person-to-person phenomenon can improve patient outcomes. The pathologizing nature of the use of diagnostic labels appears to contribute to negative experiences of psychosis symptoms.

The cross-cultural analysis demonstrates that there is not necessarily anything inherently distressing or disabling about experiences that we have come to label psychotic. The research suggests that the diagnostic labels themselves can contribute to the individual who receives them feeling stigmatised. Several factors could contribute to the experience of stigma from the diagnosis itself. One area that is under-researched in mental health, but better understood in physical health, is the communication of diagnoses and the impact of how an individual learns of the news.

Communication of Diagnosis

How are patients currently told about diagnoses?

Medical professionals overwhelmingly conduct diagnosis in the UK. Disclosure of diagnosis is at its core, an issue of medical ethics. Guidance produced by the General Medical Council (GMC) explains that medicine operates under an informed consent model, with patients having the right to refuse treatment or seek an alternative explanation. With knowledge of the condition, a clinician believes the patient to have, informed consent is possible (GMC, 2020). The need for clinicians to accurately inform their patients of their diagnosis should only be ignored if it would counter another core tenet of medical ethics, the need for medics to do no harm. Sullivan et al., 2001 explore this justification by examining ethical decision making behind the imparting or withholding of diagnostic information by medical professionals. The research demonstrated that clinicians underestimated the amount of information patients wanted to receive regarding their illness. It concluded that more patient involvement was warranted in decision making around diagnosis. The clinicians reported that they withheld information only when they believed doing so was in the patient's best interests, with the aim to minimise potential distress. There is evidence to suggest that this practice also occurs in the context of mental health; clinicians regularly withhold diagnostic information (Outram et al., 2014).

There is a surprising lack of clarity on how diagnosis should be communicated to patients within mental health settings. For example, no formal guidance for how diagnostic information should be imparted to patients within mental health settings has been issued by the Royal College of Psychiatrists or the British Medical Association, the two foremost professional bodies representing the psychiatric and medical professions. For such an important aspect of the patients' experience of illness, it is an interaction that needs to be

improved in evidence-based practice. This lack of guidance has led to inconsistency of approach between clinicians (Outram et al., 2015; Moran et al., 2014; Amidi Naeini et al., 2020). These studies all demonstrate that clinicians use clinical judgement to make decisions about disclosure of psychiatric diagnosis, rather than evidence-based practice. From the clinician's perspective, more help in this area would be welcomed. In a study exploring psychosis diagnosis specifically, clinicians working in early intervention services in the UK were surveyed on the issue of disclosure of diagnosis with 76% of the clinicians surveyed believing that greater guidance on the communication of diagnostic information would be welcome and beneficial to patients (Farooq et al., 2018).

Comparison with other branches of medicine

The lack of research into the diagnosis process in mental health settings can be contrasted with physical health and neurology literature. Best practice for delivering a diagnosis of cancer for example, has been extensively researched both from the patient's perspective (Bryant et al., 2018; Anderson et al., 2021) and from the clinicians' perspective (Bennet & Alison., 1996; Ellis & Tattershall., 1999). In both studies exploring the patient's perspective, the primary communication needs identified were the sharing of accurate information about the disease that is personalised to their circumstances by clinicians but also the power to control the amount of information they received (Bryant et al., 2018; Anderson et al., 2021). Anderson et al (2021) explored differences in the experience of diagnosis between white and black patients, identifying that black patients were less likely to have their communication needs met and to feel disempowered by the process. In the context of psychoses diagnosis and the lack of research into its communication, evidence

suggests that non-white individuals are up to five times more likely to receive a diagnosis of a psychotic disorder in Western societies than white individuals (Jongsma et al., 2021).

A similar picture exists for neurological conditions such as dementia and Parkinson's Disease, where the clinician's perspective (Bailey et al., 2019; Anestis et al., 2020) as well as the patient's perspective (Peek, 2017; Nielson & Boenink, 2021; van Gils et al., 2022) have been studied. These conditions represent very different, but comparable, diagnoses to psychosis in terms of the emotional response they will likely elicit in the receiver of this news. Neurology and oncology have therefore endeavoured to understand this process from the patient's perspective to improve the experience. These papers all make recommendations for how to adapt communication of the diagnosis in question, with a strong emphasis placed on how the diagnosis is initially imparted as potentially having a strong impact on how the individual perceives their condition (Peek, 2017).

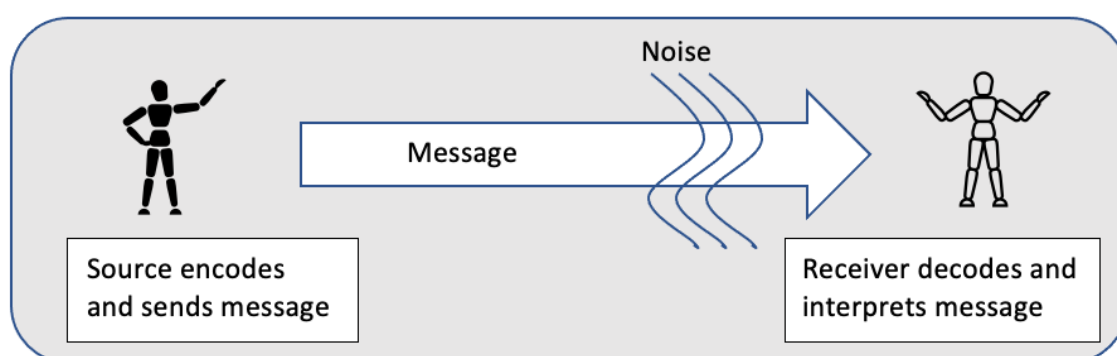
Models of Communication

The relationship and roles of patient and doctor within Western healthcare systems have slowly undergone quite a radical shift over the second half of the 20th century (Beisecker & Beisecker, 1993). The doctor's role was traditionally seen as paternalistic, with patients cast as passive receivers of the orders from an authority or expert figure. This has slowly moved towards a consumerist relationship, emphasising collaboration and engaged decision making between the two parties (Reuben, 2016). This shift can be seen in guidance published by the NHS on increasing patient involvement (NHS England, 2017), highlighting the legal obligations that Trusts operate under to involve patients and carers in decision making following the Health and Social Care Act 2012.

This shift in patient and doctor roles can be seen from a communications theory perspective as a transition from a linear to a transactional model of interpersonal communication (Gamble & Gamble, 2013). A linear model (Figure 1) represents an interpersonal interaction, where one party imparts a message and the other receives and decodes it, making meaning from their decoding. This communication model is limited in that it does not consider context and reciprocity, however, it can be used to represent the paternalistic imparting of expertise as described in Beisecker and Beisecker (1993).

Figure 1

Linear Model of Interpersonal Communication

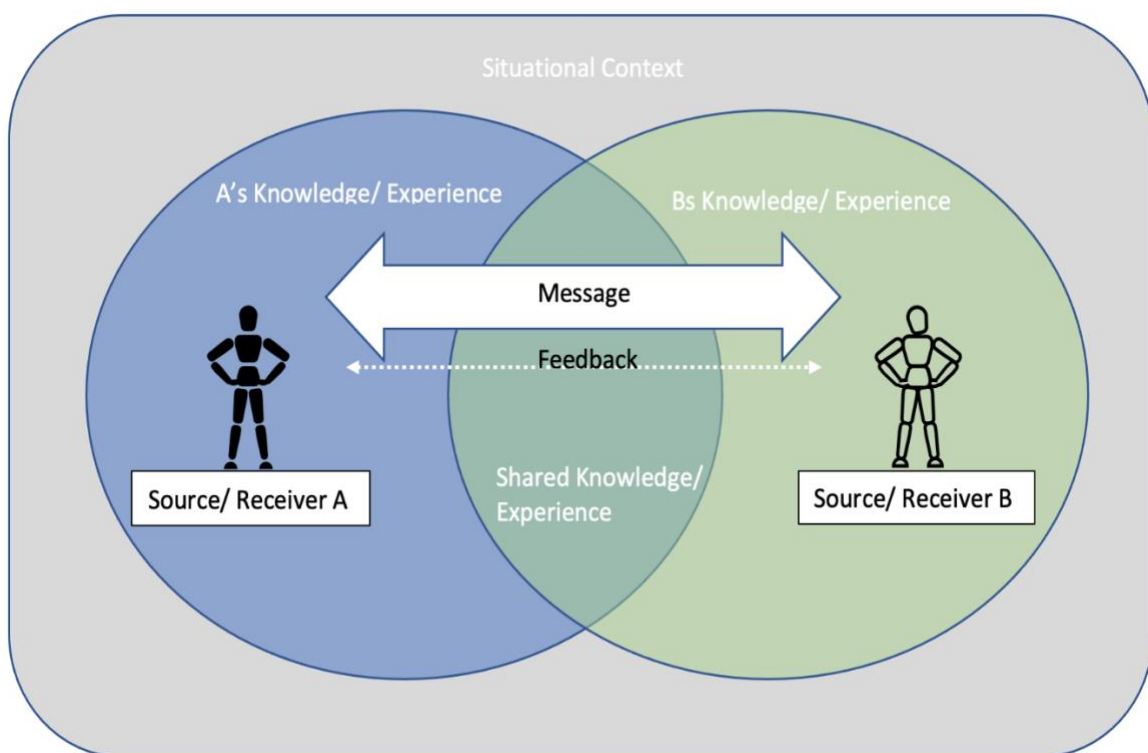


A transactional model (Figure 2), can be compared to the more consumerist patient doctor relationship, demonstrating how the two parties involved in communication dynamically interact. Feedback occurs from both individuals simultaneously through verbal and non-verbal means. The model also accounts for how each individual brings relevant experience and knowledge that will be very different from each other but share some overlapping elements. Furthermore, the model incorporates the impact of the context in

which the communication occurs as key in each individual's understanding and what meaning they each take from the communication. The model illustrates what could happen in a diagnosis communication using the collaborative decision-making paradigm described by Reuben (2016).

Figure 2

Transactional Model of Interpersonal Communication



The rationale for Systemic Literature Review

Overall, the literature suggests that being diagnosed with psychosis is a likely cause of stigma. We know that this has not always been the case throughout the history of the United Kingdom but has developed to be distressing since the late Victorian era and the introduction of psychiatric practice and that this is not a pattern that has been replicated in

non-western societies. From physical health research we know that how someone learns of their diagnosis impacts their perception of their illness and themselves and that in a mental health context, there is very little guidance for how this should be done. Where the evidence is lacking is an enquiry from the patient's perspective. Therefore, the following systematic literature review will explore what existing literature exists regarding patients' beliefs about their own diagnosis of psychosis.

Systematic Literature Review

Overview

A systematic literature review is a process that aims to synthesise the current understanding of a particular topic from the existing literature (Siddaway, Wood & Hedges, 2019). Through the process it is possible to establish areas of the literature where there are gaps and make recommendations for future research that may be required. They can also be used to collate information around clinical work and establish best practice. This systematic literature review will aim to answer the question:

“What beliefs do individuals diagnosed with psychosis and related conditions hold about their diagnosis”.

Method

A scoping search on patient perspectives on the diagnosis of psychosis was carried out using Cochrane Library and PROSPERO to check for existing or planned reviews that cover this area. This search revealed an absence of reviews in the area looking specifically at the patient perspective on the diagnosis of psychosis.

Once originality was established, a metasynthesis approach was taken to integrate the findings of different qualitative studies. Sandelewski, Docherty & Emden (1997) outline the method used to integrate the information generated by qualitative studies. Qualitative research was used in this systematic literature review due to the aim of the question, to investigate the beliefs of individuals. Belief is a complex construct and therefore qualitative studies utilising interview methodologies were used, while studies using questionnaires or other restrictive instruments were excluded, quantitative studies were also excluded. The

studies reviewed explored individuals who had a diagnosis of psychosis or related diagnoses, as well as those involving individuals who had been given a label of being “at risk mental state” (ARMS) of psychosis. Studies were restricted to those occurring in the western world due to the greater cultural homogeneity of these countries, allowing for consistent comparisons of findings to be made. Other exclusion criteria applied were those studies investigating perceptions of those under the age of 18 and any that reported findings in any language other than English, due to time and budgetary constraints not allowing for the use of translation services. The full inclusion and exclusion criteria are listed in Table 1

Table 1

Systematic Literature Review Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • The study must include data from the perspective of the individual diagnosed with psychosis or related conditions 	<ul style="list-style-type: none"> • Quantitative research
<ul style="list-style-type: none"> • The study must contain a reference to the patients’ belief about their diagnosis 	<ul style="list-style-type: none"> • Qualitative research utilising only questionnaire design • The study participants were non adults (under 18)
<ul style="list-style-type: none"> • The study must use a qualitative interview methodology 	<ul style="list-style-type: none"> • The study is only available in non-English language • The study was conducted in a non-Western country
<ul style="list-style-type: none"> • The study must be available in English (published or translated) 	<ul style="list-style-type: none"> • Study is related to physical health, disability, or autism

-
- Study must have been conducted in a western country
 - The study must be published in a peer reviewed journal
 - The study must be empirical
-

Search Strategy

To carry out the search, 3 databases were searched; PubMed (15.09.22); Scopus (15.09.22) and ProQuest (15.09.22). These were chosen as they provide a broad range of literature from medical, psychological, and other health science journals. The search terms used in the search are detailed in Table 2, with 4 concepts from the initial search question used to generate the overall search terms.

Table 2

Search Terms Used in Literature Search

Search Terms			
Patient*	AND Belief*	AND Psychosis	AND Diagnosis
OR Client*	OR Perspective*	OR Psychoses	OR Diagnosed
OR "Service user"	OR Impact*	OR "Psychotic Disorder"	OR Label

OR Effect***OR "First Episode****Psychosis"**

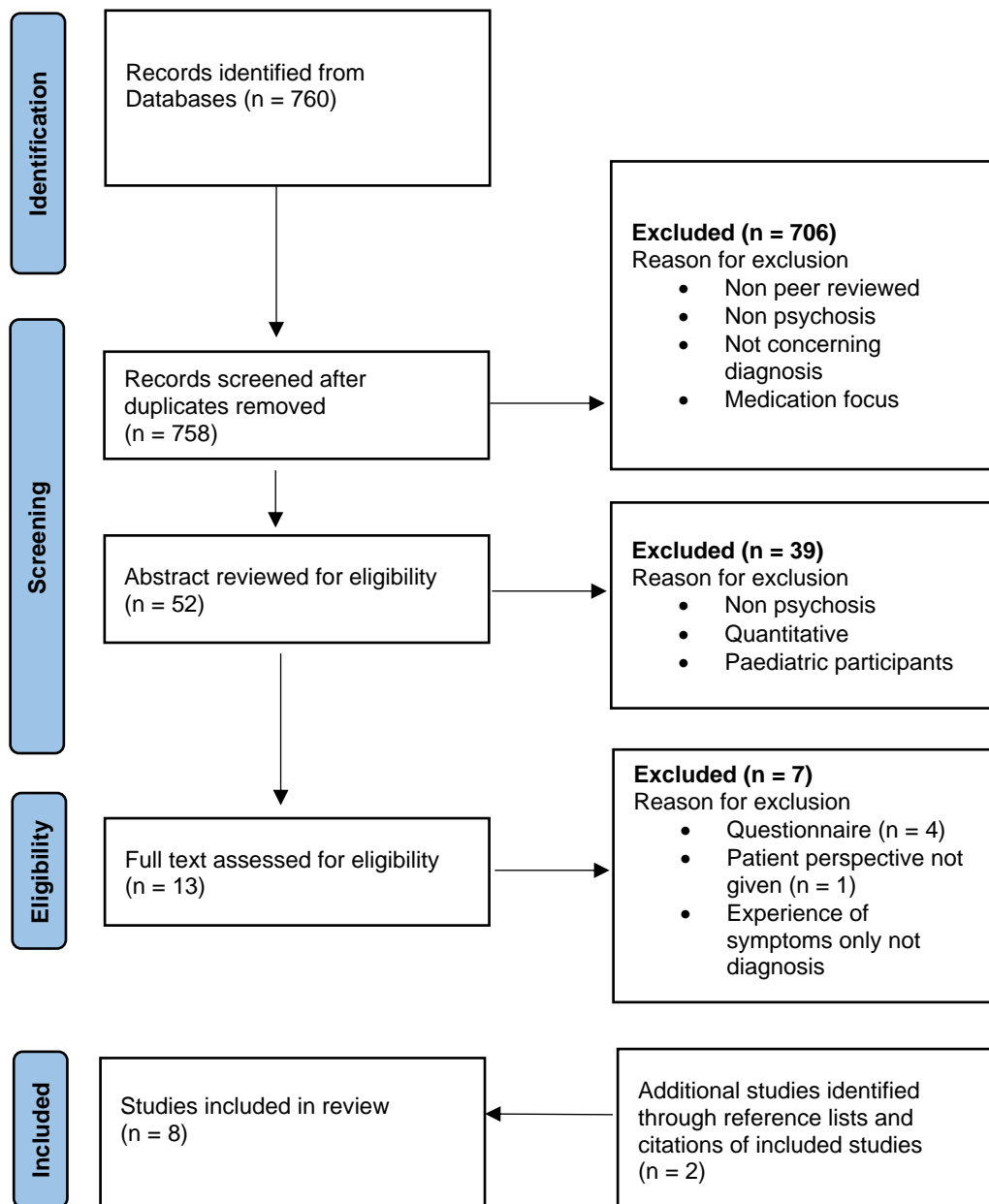
OR FEP

Following this search, 760 studies were returned. These were firstly screened by title, with irrelevant studies removed from the process. Any studies with titles that were unclear were put forward to the next stage, abstract review. For studies in which the relevance was still unclear from the abstract, a review of the full text was undertaken to ascertain suitability. Finally, the articles were reviewed against the inclusion and exclusion criteria to establish the final sample from the database search. Further relevant literature was sourced by exploring the reference lists of relevant studies. Finally, studies that had gone on to cite relevant papers were sourced using PubMed and Google Scholar.

From this process 760 papers were identified from the database searches, 52 proceeded to abstract review and 15 went on to have the full text reviewed. A further 2 studies were identified from the exploration of reference lists and articles in which relevant studies were cited. Following the full text review, a total of 8 Papers were suitable for inclusion in the final review. This process is outlined in Figure 3.

Figure 3

Systematic Literature Review Flowchart



Results

The systematic literature review yielded 8 suitable papers. Seven of the papers utilised an interview methodology while one used a mixed methodology, utilising questionnaire data alongside the interview. All papers featured a reporting of the patients' beliefs about their diagnosis and its impact on them. The majority of the studies (n = 6) occurred in Europe (Denmark - 2, UK - 2, Norway - 1 Poland - 1), with the remaining taking place in Canada (n=1) and Australia (n=1). Four of the studies investigated the impact of, or beliefs about, the diagnosis directly (Loughland et al., 2015; Pitt et al., 2009; Tranulis et al., 2013; Dinos et al., 2004), while three explored the experience of services and treatment and beliefs about diagnosis were discussed. (Jansen et al., 2015; Jansen et al., 2018; Odegaarde et al., 2020). Finally, one paper investigated the impact of the diagnosis on love and relationships (Budziszewska, Babiuch-Hall & Wielebska 2020), with themes relevant to beliefs about diagnosis explored. A summary of the final eight studies can be found in table 3.

Table 3*Summary of Studies*

Title, Author, Country	Aim	Sample Details	Data Collection	Data Analysis	Summary of findings	Strengths and Limitations
“It means so much for me, to have a choice.” First person perspectives on medication free treatment in mental health care: a qualitative interview study Oedegaard et al. (2020) Norway	To investigate the experience of recovery for patients with psychosis following new medication free treatment options.	10 participants undergoing treatment for psychosis in Norway	Semi structured in depth interview.	Thematic network approach	Participants reported some positive beliefs around their diagnosis. Contrastingly a narrative of personal responsibility and requirement to "do the work" in order to recover, indicated a more negative appraisal of the condition.	Strengths: Designed and carried out in collaboration with service users. In depth interviews conducted, focus on psychosis and related conditions, reports on strengths and weaknesses and offers suggested areas of future research and clinical implications, incorporation of experts by experience in the design of the study. Limitations: small sample (10 participants).
Changing the Name of Schizophrenia: Patient Perspectives and Implications for DSM-V,	To investigate how patients in a first episode psychosis clinic	19 patients in a first episode psychosis	Semi structure interviews and self-report questionnaire	Qualitative analysis with specific	Identified that patients in the first episode psychosis clinic reported positive beliefs about the name change away	Strengths: mixed methods allow for interesting conclusions to be drawn, large sample of 19. Acknowledges limitations of the

Tranulis et al. (2013) Canada	would perceive a change in diagnostic term from schizophrenia to a more ambiguous name would be perceived.	clinic in Canada		method not specified.	from the diagnostic label. The main reason for this was the avoidance of perceived societal stigma associated with the existing term.	study, proposes further research and clinical implications. Contrasts study results with existing literature. Limitations: Half of the sample were individuals diagnosed with Schizophrenia, rather than psychosis.
Important first encounter: Service user experience of pathways to care and early detection in first-episode psychosis Jansen et al. (2018) Denmark	To explore service users experience of an early intervention for psychosis service.	10 patients in a first episode psychosis service.	In depth interview	Thematic analysis	Participants reported significant stigma towards the condition as well as the psychiatric system in general. Concern about implications of the label were indicated. Contrastingly comfort was found in being given a diagnosis and knowing there was an accompanying pathway to treatment.	Strengths: In depth interview, well explained analysis, good discussion of clinical implications. Strong service user involvement. Limitations: small sample, self-selecting, and narrow age range, 5 diagnoses met inclusion criteria without stating the numbers of participants who had each diagnosis.
Service user perspectives on the experience of illness and pathway to care in first-episode psychosis:	To explore service user experience of seeking help and entering treatment for	11 participants in a first episode psychosis service.	Semi structured interview	Thematic analysis	Fear of stigma from others was identified as arising from self-stigma in participants. This led to a lack of disclosure due to beliefs about the	Strengths: good clinical implications discussed, acknowledges limitations of study Limitations: only 9 participants, very homogenous sample,

a qualitative study within the TOP project	first episode psychosis.				societal impact of the diagnosis.	
Jansen et al. (2015)						
Denmark						
Stigma: the feelings and experiences of 46 people with mental illness. Qualitative study,	To describe the relationship of stigma with mental illness	46 participants in community mental health services, sourced from services around north London	Narrative interview	Qualitative analysis with specific method not specified.	Stigma was most likely to be reported by participants with psychosis and were more significantly affected by the stigma than other diagnoses.	<p>Strengths:</p> <p>Strengths: coding performed by multiple researchers and then inter-rater reliability assessed. Clinical implications discussed as well as limitations of study, good discussion of forms of stigma, specifying internal related to the diagnosis and external.</p> <p>Limitations: Unclear description of analysis, other mental health disorders intermixed.</p>
Dinos et al. (2004)						
UK						
Love and Romantic Relationships in the Voices of Patients Who Experience Psychosis: An Interpretive Phenomenological Analysis	To explore the impact of serious mental health on the forming of romantic relationships	10 participants sourced from outpatient clinics or patient groups in Warsaw.	Semi structured interview	IPA	Participants reported a sense of lowered social status after being diagnosed and this had a strong impact on their perception of themselves as worthy of love or possibility of being attractive to others.	Strengths: In depth interviews, centre patient perspective clearly throughout, acknowledge their own position as psychologists and practitioners and the influence this will have had on the

Budziszewska, Babiuch-Hall & Wielebska (2020)	and beliefs about love.					outcome, acknowledge limitations. Limitations: self-selection likely to exclude those who are experiencing negative symptoms
Impact of a diagnosis of psychosis: User-led qualitative study. Pitt et al. (2009) UK	To explore the impact of a psychosis diagnosis	8 participants with diagnosis of psychosis or related condition. from the UK	Semi structured interview	IPA	Found that the diagnosis is perceived in both negative and positive ways. Individuals diagnosed were generally able to hold a both and position recognising that there were positive aspects to the label (clarity and access to services) but also noting that they suffered from negative beliefs that it brings about for them in themselves and others.	Strengths: Study involves a large amount of service user involvement, particularly in the design of the research. Good discussion of clinical and social implications Limitations: small sample size of only 8 participants, use of IPA mean results are not generalisable.
Communication of a schizophrenia diagnosis: A qualitative study of patients' perspectives.	To explore the impact of diagnostic communication practices.	14 patients in community mental health services in Australia.	Semi structured interview	Thematic analysis	Participants reported a sense of disbelief regarding their diagnosis when familiar with the term. Participants also reported a sense of comfort and control building from the diagnosis. Some reported	Strengths: Very novel study topic. Clinical implications discussed. Limitations: Length of time since the diagnosis was made likely impacted the recall accuracy of participants.

Loughland et al. (2015)	high levels of fear of experiencing symptoms they had never experienced due to the negative beliefs they held about the diagnosis.
Australia	

Assessment of Study Quality

An important aspect of conducting a systematic literature review is the appraisal of quality of the included research studies. Aspects of the research such as the appropriateness of the design, ethical considerations, and the relationship between researcher and participants should all be assessed (Sandelowski et al., 1997). To carry out a critical appraisal of the final eight studies a quality appraisal tool was used. The Critical Appraisal Programme (CASP) offers a tool specifically for assessing qualitative studies (CASP, 2018) against ten metrics. It is a widely used tool within health science literature and has been endorsed by bodies such as the Cochrane Review (Noyes et al., 2018). A summary of the CASP appraisal can be found in Table 4.

Table 4*CASP Appraisal of Study Quality*

Study	Was there a clear statement of the aims of the research	Is the qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research	Was the recruitment strategy appropriate to the aims of the research	Was the data collected in a way that addressed the research issue	Has the relationship between the researcher and participants been adequately considered	Have ethical issues been taken into consideration	Was the data analysis sufficiently rigorous	Is there a clear statement of findings	How valuable is the research
Oedegaard et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The research is valuable in exploring the impact of broadening choice of interventions and treatment planning to include more patient involvement.
Tranulis et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	A novel methodology was utilised which contributed to existing understanding of

the stigmatising nature of the exiting diagnostic terms. Limitations are acknowledged and both clinical and research implications are discussed.

Jansen et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The research discussion recommends a number of clinical implications and situates the research within existing knowledge.
Jansen et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	A number of clinical implications are discussed and recommendations made while acknowledging the limitations of the design in drawing wide conclusions.
Dinos et al. (2004)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Article explores the different forms of stigma that are possibilities for

											those diagnosed with serious mental health conditions and makes a number of clinical recommendations.
Budziszewska, Babiuch-Hall & Wielebska (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Researchers discuss findings well in the context of existing literature and centre the participant experience throughout the research and discussion.
Pitt et al. (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Cannot Determine	Yes	Yes	Yes	Article discusses both the clinical and social implications of the findings in the context of existing literature. Acknowledges lack of generalisability of the design.
Loughland et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Strong discussion of clinical implications and practical

recommendations
for clinicians.

Quality Evaluation Outcome

The research included in the systematic review was generally of good quality, two studies were assessed to be of medium quality and the remainder were all categorised as high quality. All the studies had clearly stated aims which allowed for the assessment of the appropriateness of their choices with regard to their design and evaluation. All but one of the studies utilised a purposive sampling methodology to recruit participants from relevant community services and many acknowledged the limitations of this approach such as the sampling method excluding those who have relevant diagnoses but who are not engaged in services. All studies used an appropriate interview method to obtain the data and all stated the form of interview used. Semi-structured interviews were the most popular but in depth and narrative interviews were also used. Utilising interview methodologies allowed each of the studies to obtain rich accounts of the participants' experiences, in line with their respective research aims.

Most of the studies made specific reference to the positioning of the researcher in contrast to the participants, recognising the role of researcher or practitioner and how this influenced the results obtained, however in only one of the papers, Budziszewska et al (2020) was the question of positionality explored in any significant depth. It is challenging when using quality assessment tools such as CASP to accurately assess how much a researcher has genuinely considered their own position. Journal articles rarely allow for extensive consideration of these kinds of questions in the way that a thesis does due to limitations such as word count or a lack of recognition in journals of the importance of questions of positionality. Similarly, there is no consistent standard between journals of how much detail, if any at all, they would like included regarding positionality. This means that some studies where only a brief reference was made in the write-up, could have gone

through extensive consideration at the design stage without the reader being aware of this. For the purpose of the review the decision was therefore made to be generous in the assessment of positionality considerations where they are mentioned in only a small amount of detail, allowing for all the limitations described above.

Regarding ethics, a formal ethical review of the research was confirmed as having been conducted in all of the studies except one (Pitt et al., 2009). In each of the papers relevant safeguarding steps that had been carried out were acknowledged, such as maintaining anonymity and confidentiality of the participants through the use of pseudonyms for quotations in all papers, inclusion of a debrief following the interviews was also mentioned. None of the included studies discussed ethical considerations in detail. For the purposes of the review assessment of ethical issues was interpreted generously for the CASP assessment. The reasoning for this was similar to that used for the assessment of the quality of relationship between the researcher and participant discussed in the previous paragraph. Journals have strict word limits, and the purpose of the included research was not to discuss ethics. The fact they have achieved formal ethical approval from an ethics board means it is fair to assume that ethical risks have been considered and accounted for to a reasonable level.

For the majority of the studies included in the final review, the choice of analysis was appropriate, sufficiently rigorous and justifiable within the context of the overall research aims. For two studies the specific qualitative methodology used to analyse the transcripts was unclear (Dinos et al., 2004; Tranulis et al., 2013). The validity of the findings in these studies would have been improved had their specific method been stated, although from their descriptions of the process of analysis, there were common practices employed, such as the use of coding and inter-rater reliability assessments in Dinos et al. (2004). Tranulis et

al. (2013) employed a mixed methods approach with the interview forming one half of the overall research study, this enhanced the validity of their findings despite the lack of stated analysis method for the transcripts, as the conclusions drawn from the analysis of the interview was supported by the outcomes from the questionnaire data. Two studies, both by the same research team (Jansen et al., 2015; Jansen et al., 2018) utilised Thematic Analysis with only 10 and 11 participants respectively. There is no set rule for the minimum required number of participants to perform thematic analysis, however, studies have demonstrated that to achieve saturation of themes, at least twelve participants should take part (Ando, Cousins & Young 2014). The study analysed themes from 37 transcripts and established that 92% of the codes identified could have been established from any combination of 12 of the overall 37 studies. The validity of the findings from both Jansen et al. (2015) and Jansen et al. (2018) could have been increased with the recruitment of more participants, or the use of an analysis method more suited to smaller sample sizes, such as IPA (Smith and Osborne 1999).

Findings were clearly described in all the included studies and appropriate conclusions were drawn from these and discussed. Discussions were well centred within the usual clinical context in which the studies were taking place with valuable recommendations offered in each. All studies centred the voices of the patient participants, and their needs were primary within the discussions. This could, however, have been aided through increased service user involvement. In two of the studies no service user involvement in the design or dissemination was reported (Tranulis et al., 2013; 2005 & Loughland et al., 2015), while for most it was not discussed in any detail. The majority of the studies would have benefitted from greater discussion of dissemination plans in order to make use of the

information gained to achieve change for the population groups studied. Also useful would have been information around dissemination to the participants who were involved.

Overall, the studies selected for this systematic review represent a generally high quality of qualitative research as assessed using the CASP methodology. The small samples mean that wide generalisation of the findings is not possible individually. Through analysis of the studies using a meta-synthesis approach, themes will be created to describe common beliefs about a psychosis diagnosis reported by patients across the selected studies.

Meta-synthesis of Findings

A thematic analysis approach was used to synthesize the findings of the included studies. The approach was guided by Braun and Clarke (2006). The process begins with a familiarisation of the literature through reading and note taking, before extracting all passages specifically referring to patient beliefs about diagnosis. This data included direct quotes from the participants in the studies as well as researcher interpretations of their data. The outcome of the critical appraisal process also informs how each study is interpreted within the overall analysis. From this, initial codes were created followed by clustering the codes into themes that best represented the patient perceptions of their diagnoses across the literature. Following this process, three themes were created to represent these beliefs. The themes can be divided into two categories: positive beliefs about the diagnosis (theme three) and negative beliefs about diagnosis (theme one and two)

Theme 1: Diagnosis changes who I am

All of the papers in the included study featured reports from individuals diagnosed with psychosis indicating a belief that the diagnosis had changed their sense of self (Budziszewska et al., 2020; Dinos et al., 2004; Jansen et al., 2015; Jansen et al., 2018; Loughland et al., 2015; Oedegaard et al., 2020; Pitt et al., 2005; Tranulis et al., 2013). Consistent throughout all the reported studies was a belief that as a result of their diagnosis the participants had undergone a change for the worse. Participants' beliefs about psychosis prior to being diagnosed were highly stigmatised and upon diagnosis these beliefs were transferred onto themselves. As a result of these negative attitudes, participants reported a shift in their ideas about what was possible for them as a person with psychosis, often reporting a significant narrowing of their horizons in terms of hopes, expectations and ambitions for the future.

“Alice, a woman in her late twenties, notices and expresses the change in herself and the resulting need for identity work the following way: I seem to be completely new to myself in many ways. After illness onset, she feels she has to learn anew who she is.” (Budziszewska et al., 2020. P.4)

Two of the papers (Loughland et al., 2015; Tranulis et al., 2013) feature participants directly reporting a sense of shock they felt at first learning of the diagnosis and the distress that it caused for them:

“The psychiatrist put it on a paper, he did not tell it in person. Luckily, because I would have cried in front of him. But when I saw it on the welfare certificate, I cried, I

went to the washroom, in the hospital, and I cried a lot. I didn't like it" (Tranulis et al. 2013. P.3)

The above quote demonstrates a reluctance to disclose the diagnosis directly to the participant by their psychiatrist and this was reported in Loughland et al. (2015) also. The concept of benevolent stigma is discussed in Howe et al. (2013) and describes the idea that because of stigmatised attitudes that clinicians hold about mental health diagnoses, they attempt to withhold diagnoses or information about their diagnoses from the patients they are working with. This is described as benevolent because it is an attempt to minimize the distress that they expect the information to cause, however, it increases the stigma felt by the patient as it leads to an anticipation of negative reactions in others. Withholding of information inevitably leads to an understanding gap for patients which can cause unhelpful ideas about themselves to take hold:

This participant also experienced significant anxiety about having a 'split personality' and the risk of harming others. He believed that the years he had lived in fear could have been avoided had adequate information been communicated about the nature of his illness:

... I lived for years in fear that I had a split personality; that I was going to break out and do something terrible. So I would've appreciated a dialogue that would've calmed me down and made me understand what was really going on instead of just giving me medication. (Loughland et al., 2015 p.731)

This quote illustrates the high levels of fear and anxiety that were reported when there was a lack of understanding about a diagnosis. This is increased through unhelpful media representations such as reports of infamous people who share the same diagnoses:

I think I still had Breivik in my head, you know, and the guy is nuts, and then I'm sitting there thinking, 'shit, I don't want to be in the same category as such a bastard'. (Jansen et al., 2018, p.172).

The shock and distress at learning of the diagnosis was followed by anxiety about what such a label meant for the participants as individuals. All reported fear regarding the future because of the negative expectations they had regarding the label of psychosis:

"I was certain that I would be admitted and not let out again . . . and get a straight-jacket and a box over my head or things like that." (Jansen et al., 2018, p.172).

These quotes represent the fear that participants reported due to their own negative beliefs about the nature of psychosis. Throughout the papers these negative expectations are consistently reported. There is a sense of individuals withdrawing from life following their diagnosis, their worlds shrinking in response to the news: *"participants' hopes for the future evolved around managing one day at a time"* (Odegaard et al. 2020. p.8). The negative beliefs held about the diagnosis and of what can be expected of people who have such a diagnosis severely diminished participants hopes for themselves. When asked where they expect themselves to be in five years' time one participant responded:

“I hope I’m not dead ... No, I hope I’m alive, that’s the only thing I hope for. I can’t say I have any ... I hope I’m ok. I would have loved to have a husband and family, but that’s kind of distant to me...

Now, I just want to figure out everyday life and how to be around myself and be ... in my own company ... And have a good time with myself, be happy with who I am, and sort of ... get a self-image that fits with reality and ... not be so hard on myself as I have been.” (Odegaard et al. 2020. p.8).

It is difficult to determine how much of this lack of hope is as a direct result of the diagnosis. The participants will all have been through difficult or confusing experiences leading up to diagnosis and these may well be influencing the reported hopes for the future. However, it is clear that the diagnosis brings with it a great deal of stigma which recipients of the diagnosis internalise, shifting beliefs about themselves and their hopes for the future.

Theme 2: Diagnosis will lead to negative reactions from others.

The second theme identified through the analysis was also present in all eight studies (Budziszewska.,2020; Dinos et al., 2004; Jansen et al., 2015; Jansen et al., 2018; Loughland et al., 2015; Oedegaard et al., 2020; Pitt et al., 2005; Tranulis et al., 2013). Participants in these papers reported that because of their diagnosis they believed they would receive negative responses from others. This belief was reported in a number of contexts and lead to understandable reactions like avoidance of people and places as well as

denial of or failure to disclose the diagnosis to the people around them. This belief is most directly outlined in Pitt et al. (2013):

“Many participants noted they were wary of telling new people they met about their diagnosis due to stigma and discrimination. Most participants were also concerned about being open about their diagnosis to potential employers for fear of discrimination.” (Pitt et al., 2013. p.421)

The belief that employers would discriminate against the participants based on their diagnosis was stated in three of the studies (Oedegaard et al., 2020; Dinos et al., 2004; Pitt et al., 2013).

‘Basically, what I told them at work was that I'd got severe depression and most of them are ok with that... Well, I've only told them an edited version... if anybody at work or my professional body knew that I'd got schizo-anything I wouldn't be allowed to practise.’ (Pitt et al., 2013. P421)

Budzisewska et al (2020) directly explored the impact of diagnosis on participants relationships and romantic life. The participants’ beliefs about how the diagnosis would impact them were not hopeful: *“He clearly made his point that, in his experience, a mentally ill man cannot expect much from women.” (Budziszewska et al., 2020. p.6)*. Participants believed that their diagnosis made them undesirable to potential romantic partners and as a result they had stopped trying to form relationships or felt that to maintain them, hiding their diagnosis was a necessary step:

“The study participants often expressed an understanding that the illness can pose a great challenge for potential partners but that understanding does not make the rejection any less painful. Informing potential partners about the illness was an important issue, where the problem was in choosing an appropriate moment to confess to it. The perceived risk of rejection is very high.” (Budziszewska et al., 2020. p.6)

A similar experience was reported regarding friendships in all studies except for Loughland et al. (2015), with participants believing that their diagnosis meant they were less likely to be able to maintain existing friends or to form new friendships.

“It was found to be a potential cause of social exclusion for all. Participants talked about the social stigma of having a diagnosis. Some participants had lost friends as a result of their experience of mental health problems and diagnosis.” (Pitt et al., 2013. P.421)

The main response to the perceived stigma was to try to hide their diagnosis and the symptoms associated with it:

“So you’re just kind of afraid of being stigmatised by other people ... you just know there are prejudices about all these things; I used to be like that myself ... and so in order to avoid that people were thinking badly of me, I thought I’d better put on a façade” (Jansen et al, 2015. P.8).

“What I was most nervous about . . . to be labelled as crazy, afraid of being locked up, and not being let out again. It took a lot of courage to tell my general practitioner.” (Jansen et al., 2018, p.172).

It is hard to tease apart the root cause of the stigma that individuals expect to experience, it is possible it is because of their symptoms or diagnosis or a mixture of both. A direct link to diagnosis reported by Dinos et al., (2018) who reported that stigma was expected from others, even in participants who have never experienced direct stigma as a result of their symptoms *“reported feelings of stigma in the absence of any direct discrimination. The participants' feelings of stigma were often related to the psychiatric diagnosis.” (Dinos et al. 2018 p.177)*

Media representations of people with these kinds of diagnosis were cited in several studies as influencing the participants beliefs about the diagnosis that they had been given:

“If it's on the news or TV it's usually because they've brandished a sword on the high street or attacked someone. There's never a story about a schizophrenic who saves life of granny who falls in canal.’ (Dinos et al. 2018 p.178)

Tranulis et al., (2013) directly tested the perception of societal stigma arising from diagnosis through asking individuals about how they would feel given the possibility of using an alternative name:

“While the power of words and of stereotypes was acknowledged, often reasons for preferring one label over the other were more pragmatically motivated... social acceptance of symptoms (“...because no one wants to live with someone who hears voices” (Tranulis et al. 2013. P.4)

With individuals in early phases of treatment, the reasons to prefer one name over the other was mostly related to the capacity of the label to avoid societal stigma, either by completely rejecting any diagnosis, or by being able to conceal the mental illness under an obscure term.

Theme 3: Diagnosis brings relief

In four of the eight studies (Dinos et al., 2004; Jansen et al., 2018; Loughland et al., 2015; Pitt et al., 2005) participants reported positive beliefs about diagnosis with the sense of relief that it brought being mentioned by participants in all four studies. The sense of relief was brought about primarily from the belief that diagnosis had increased the participants understanding of their experiences and that through having a label to attach to their previously unexplained symptoms this legitimised their distress.

The clarity that a diagnosis can provide was referenced throughout the four studies (Dinos et al., 2004; Jansen et al., 2018; Loughland et al., 2015; Pitt et al., 2005). At its most basic level, participants found relief from their diagnosis through simply having a label that they could attach to their experiences:

“I thought it was great to receive a diagnosis. Then you know ‘okay, this is what’s wrong with you’, instead of being left in the dark.” (Jansen et al., 2018, p.173).

Themes one and two make clear that receiving a diagnosis of psychosis has the potential to have a negative impact, there is a clear sense of shock illustrated following the diagnosis in Loughland et al. (2018). However, participants were able to move beyond the initial shock at learning of their diagnosis to find comfort from this increased understanding.

“The majority of participants (n=13) believed it beneficial to receive a diagnosis. Although all experienced an initial ‘sense of disbelief’ following diagnosis, many participants also experienced a sense of relief that they finally had a medical diagnosis for their illness:

Yeah, it was a relief; for the initial couple of days it was a relief to actually have a diagnosis. And I had known, I had enough insight to know that I was a bit cracked in the head. That was my only term; I wasn’t sure what psychotic meant, but I knew, like looking back on it, I was having psychotic episodes.” (Loughland et al., 2015 p.731)

The above quote demonstrates the pre diagnosed position, where participants are aware that the symptoms they had been experiencing are unusual. The use of the harsh term, cracked in the head, displays an understanding of their being something wrong or different about the psychotic experiences, but prior to learning of the diagnosis a lack of understanding of what they were or why they were happening.

“I got a better understanding of why I had been through the things I had been through – seen and heard the things I had seen and heard – why I had that depression, the stress and all these problems.” (Jansen et al., 2018, p.173)

This quote illustrates the importance of being able to put a label on previously unexplained symptoms. In the case of psychosis, where the confusing nature of the symptoms experienced, participants experienced their diagnosis as offering them an explanation as to why these unusual experiences had occurred.

Receiving a diagnosis was also reported as legitimising previously unexplained symptoms in four of the reviewed studies (Dinos et al., 2004; Jansen et al., 2018; Loughland et al., 2015; Pitt et al., 2005). Participants reported that having been given a diagnosis they were relieved because it meant that their problems would be better supported in health care settings *“It was very nice, you know, that someone knew what was wrong with you. I was relieved because then, in a way, I was taken more seriously.” (Jansen et al., 2018, p.173)*. The relief felt is clear in the participants wording. They describe how the label itself provided the participant with the belief that this was a problem that had a name and was understood, resulting in a sense of containment and hope for the future, indicated by the belief that they would now be taken seriously.

In contrast to the legitimising of experience that came from diagnosis, participants reported a sense that without it they were left confused, knowing something was wrong but without knowing what. The lack of explanation understandably led to frustration in some participants:

'I always knew I had a mental illness so I knew something was wrong with me. It was just the diagnosis that — it's just a name, I knew I'd got a mental illness so I always felt quite fed up about that. They just diagnosed it. It didn't surprise me at all.' (Dinos et al. 2018 p.179)

Conclusions

This literature review is the first to review patient beliefs about their diagnosis of psychosis and related conditions. There is a lack of investigation in this area reflected in only eight papers ultimately featuring in the review and only two of those directly investigating the question of the review. The papers featured were all effective at giving a voice to those who receive these labels, and the findings highlight the complex nature of the issue of diagnosis, particularly when you add in the consideration of systemic factors like the role of diagnosis in accessing treatment that did not feature in this review of patient beliefs. It is clear from the papers that patients can maintain a “both and” position when it comes to their diagnosis, recognising the potential positive aspects, while having to live with the negative consequences. This is well illustrated by a participant in Jansen et al. (2018) who articulates the challenge that even when diagnosis brings comfort and understanding to the individual, it comes with a knowledge that others will not feel the same:

“I understand it better and better. I still find it difficult to accept that I have it, more because I'm worried that when I tell people about it, they label me crazy – because that's what I used to do – but now I know it's because people lack knowledge of the illness.” (Jansen et al., 2018, p.173).

Clinical Implications

The review must acknowledge that the small number of studies and the small number of participants used within the studies make it hard to draw any definite conclusions. This is a result of the lack of research focussing on the patient's perspective around diagnosis and reflects a general lack of curiosity on the part of mental health care professionals about the impact of the labels that are given to patients.

The review has highlighted several considerations for clinicians when working with individuals who have received a diagnosis of psychosis or a related condition and particularly those who impart these diagnoses. Pitt et al, (2009) discusses the implications for psychiatrists at the point of imparting a diagnosis, discussing how an understanding of the possible harms but also the potential benefits of the label can be used to support patients in processing the diagnosis. The review clearly demonstrates the impact of societal narratives that exist around diagnosis on the patients in the formation of their beliefs about the diagnosis. Clinicians should use this knowledge to help patients gain a clear understanding of the implications of their diagnosis to counteract the prevailing societal narratives that patients are already aware of.

Gaps in the literature

The review has highlighted a general lack of research exploring the perspective of the patient themselves towards their diagnosis of psychosis or related conditions. As a result of this, there is a large gap in the literature in exploring what it is about a diagnosis that results in both the negative and positive beliefs that can be formed as a result. Clearly being diagnosed with psychosis or related conditions has an impact on the individual

receiving it, however it is not clear why. The existing research is often unable to detach the impacts of the diagnosis from the impacts of the symptoms, this would benefit from being further researched. Similarly, in terms of the impact of the diagnosis, there is a gap in understanding what can be done to mitigate the negative consequences and to promote the positive. This gap provides an opportunity for this project to attempt to close the gap in understanding the impact of how someone learns about their diagnosis, not simply the diagnosis itself.

Rationale and aims of the current project

The contrasting themes identified in the systematic literature review, that participants believe their diagnosis will increase stigma while also bringing a sense of relief, reflects the very individual nature of responses to diagnosis. Such polarised findings indicate that there are factors outside of simply having or not having a diagnosis that dictate the individual's response to the label. One factor that could have a large bearing on individual perceptions of diagnosis is how the individual learns about their diagnosis. The experience of the diagnostic process featured in a number of the included studies and was directly explored in Loughland et al. (2015) where it is highlighted as an area needing further exploration in the discussion. Loughland et al. (2015) was conducted with individuals in community settings who had learned of their diagnosis a long time prior to the research and as such could have been vulnerable to changes in memory over time. To determine the impact of how the individual learns of a diagnosis, the current research project will utilise individuals who have learned of their diagnosis more recently and will explore what impact the process by which they were diagnosed had on the formation of beliefs about the nature of the diagnosis and what it means for them as an individual.

The question the current research will seek to examine:

How do individuals with a diagnosis of psychosis experience learning of their psychosis diagnosis and how does this impact them?

Methods

Overview

This chapter sets out the methodology used in this study. It begins with a discussion of qualitative design, its application in the study and a justification for the use of this approach. Following this, the steps taken in conducting the study are detailed including the planning, recruitment and conducting of the interviews and the analysis of the data that came from them. Finally, a discussion of the ethical issues arising from the study and the quality of the reported study is considered.

Design

The study utilised a qualitative design consisting of semi-structured interviews, conducted either in person or using video call software. The decision to offer both face-to-face and video call options was made to broaden accessibility for participation. In the interviews, participants were asked to explore their experience of learning about their diagnosis and how this impacted them.

Qualitative research

Willig (2013) describes qualitative research as a branch of research that seeks to understand and explain human experiences, behaviours, and social phenomena. It is used to study complex, sensitive, or subjective topics that cannot be easily measured or quantified using quantitative research methods. Qualitative research typically involves collecting and analysing rich, in-depth data from a variety of sources, such as interviews, focus groups, observation, and document analysis. This data can be unstructured and open-ended, requiring a variety of techniques to analyse such as coding, thematic analysis, and content

analysis. Qualitative research is often used to explore and understand the perspectives, experiences, and meanings of participants, and to develop a deep, nuanced understanding of the research topic. It can provide insights into the lived experiences and subjective realities of participants, and can shed light on the social, cultural, and historical factors that shape human behaviour and social phenomena (Willig, 2013). The systematic literature review reported previously, demonstrated that the body of evidence regarding patients' beliefs around diagnosis of psychosis is limited. This lack of research may be reflective of a prevailing dogma concerning diagnosis within medicine, that it is simply something attached to a patient by a professional (Johnston, 2000). Such an attitude may have contributed to the views of the receiver of the diagnoses being underexplored when compared to the professionals involved in the process.

The rationale for Qualitative Design

Initial searches of literature during the planning stage of the research project had identified that there was a distinct lack of research into the experience of being diagnosed with psychosis, particularly from the patient's perspective. The systematic literature review conducted as part of the overall project went on to confirm this. This literature gap provided an opportunity to explore directly with patients, how they experienced the process of learning about their diagnosis. The aim was to increase understanding of the factors that drive distress and stigma around receiving a psychosis diagnosis and what strategies may help to mitigate this. The study's focus, on understanding the participants' experiences, lends itself to the use of a qualitative design. Using a qualitative methodology does have certain drawbacks, including a lack of generalisability to a wider population due to the small sample sizes used (Willig, 2013). When exploring topics such as individual experience

however, to obtain as accurate understanding as possible (while acknowledging the interpretative nature and influence of the researcher on any results) a qualitative approach offers a level of detail in the exploration that is difficult to replicate with quantitative methods which are by nature reductive and lead to restrictions on the accuracy of expression or the possibility of surprise or creativity in responses.

Analysis Method

Reflexive Thematic Analysis

Thematic analysis (TA) is a method of analysing qualitative data, such as interview transcripts, focus group discussions, and open-ended survey responses. It involves identifying and coding recurring themes in the data, and then using those themes to develop a broader understanding of the subject being studied (Braun & Clarke, 2006, 2013). The approach has been clarified recently with a greater emphasis placed on reflexivity (Braun & Clarke, 2019). Braun and Clark observe how the method has come to be used in ways they did not intend and advocate for the explicit acknowledgement of the researcher's position and influence on the findings, renaming the method Reflexive Thematic Analysis (Braun & Clarke, 2019). Reflexive TA is flexible and can be approached from both an inductive or deductive position, or a mixture of both, depending on the research aim and epistemology (Braun & Clarke 2019). Themes are created by the researcher to represent the story that is being told across the data set and can be drawn from both latent meaning and manifest statements, contained within the transcripts.

Appropriateness of Reflexive Thematic Analysis

The aim of this research is to attempt to understand the participants' experience of receiving a diagnosis of psychosis and the broader impact this has on them. The experience does not occur in a vacuum, participants' understanding will be influenced by their own context and will be subject to change over time. A CR approach acknowledges this, seeing knowledge as subjective rather than objective, recognising it as contextually bound. Language from the perspective of CR serves as a medium that provides a best attempt at both conveying and then understanding, internal experience and meaning made by another individual. Reflexive TA allows for the consideration of wider societal context as well as individual context when creating themes, all while holding the influence of the researcher at the forefront of the analysis (Braun & Clarke., 2019). All of this fits with the current research aims as well as the overall epistemological position.

The theoretical flexibility offered by the use of reflexive TA, in terms of adopting both an inductive and deductive position where appropriate is another useful element for this study. There is much that is novel in this research project which invites an inductive approach, however, factors such as the stigma caused by diagnoses are well-researched topics and therefore utilising a deductive approach when focussing on these elements during both coding and theme creation, is appropriate. Similarly, when coding and interpreting the data the use of reflexive TA allows for a mix of both latent as well as semantic meaning to be drawn from the document by the researcher. In this research, primarily latent meaning was used to create the codes and themes as the research was focussed on identifying meaning from the participants' language, however, there were also times when a semantic coding approach was preferable in determining meaning, making the flexibility of reflexive TA a useful tool. (Braun & Clarke., 2021b)

Alternative approaches considered

The two most suitable alternative analysis methods to reflexive TA considered were Content Analysis (CA) and Interpretive Phenomenological Analysis (IPA). Both have their respective strengths and weaknesses. CA offers theoretical flexibility similarly to TA, however, it requires the researcher to use a more standardised method of coding through the development of a framework. This allows for reliability to be assessed through inter-rater coding (Kleinheksel et al., 2020), enhancing the reliability of the method. CA is limited in that it offers a mainly descriptive rather than interpretative output making it less suited to the aims of this research study, to increase understanding of the role played by how an individual learns of their diagnosis and the meaning they made from the experience, rather than to simply describe it. The fact that there is no existing literature on the impact of the process of diagnosis in EIP services means that building an understanding of patient experiences is key in this exploratory stage of the investigation, which is difficult to achieve with CA.

IPA in contrast has a much stronger theoretical rigidity than CA or TA, being rooted in phenomenology, the study of conscious individual experience (Smith et al., 1999). As a result, the method focuses to a much greater degree on the idiographic data within each individual participant transcript, drawing themes from the personal experience of the individual participants before considering all participants together as a wider dataset. For this research study, the primary aim was to create a shared meaning across the dataset, in order to build a more generalisable understanding that spans across the different participants, something that IPA does not lend itself to as well as reflexive TA (Braun & Clarke., 2021a). Similarly, the study is also not aiming for a homogenous sample of participants, utilising a random sampling method in order to achieve a heterogenous

representation of the patients within the host service, again making IPA a less suitable method (Braun & Clarke., 2021a). Overall, therefore, reflexive TA fits the epistemology and aims of this research project and offers the flexibility required to investigate the novel research area, making it the most suitable approach.

Data collection

Participation criteria

The inclusion and exclusion criteria for the research project were developed in consultation with the research team as well as with experts by experience. It was decided to recruit exclusively from the EIP team rather than the wider public as this would ensure that individuals had been given a diagnosis within the last three years. The service accepts individuals from the age of 16 but we sought to only include individuals over 18 due to the different ethical requirements and complexities of conducting research with children. Participants were required to be able to communicate in English. This was not a requirement for access to the service, where the use of interpreters to engage patients who cannot communicate in English is an option, so this decision did exclude some potential participants. This was an unfortunate result of the constraints upon the research, lacking the budget to employ interpreters. One area of debate for the research team consisted of whether to include participants who were in the midst of a psychotic episode or not. The conclusion reached in consultation with the experts by experience was that if the participant had the capacity to fully understand and consent to the research while deemed to be psychotic, it would be unfair to restrict them from participating on this basis alone.

Table 5*Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
Under the care of the early intervention for psychosis team.	Participants who do not speak English or would require an interpreter to conduct the research.
Have been given a diagnosis of psychosis or related condition.	Participants under the age of 18.
Age 18 and over.	Participants who have not been given a diagnosis.
Have capacity to consent to participate in the research.	Participants lacking in capacity to consent at the time of the study.
Able to communicate in and understand English	Participants within the first or last 6 months of their 3 year treatment pathway within the EIP Team.

Sample Size

There is no clearly established number of participants required for thematic analysis, as the appropriate sample size will depend on the specific research question and goals of

the study. In general, however, thematic analysis is often used in small-scale, in-depth studies that involve a relatively small number of participants.

The number of participants needed for a thematic analysis study will depend on a variety of factors including the complexity of the research question, the amount and diversity of the data collected, and the goals of the study. For example, if the goal is to explore a broad and complex research question in depth, a larger sample size may be needed to capture a diverse range of perspectives and experiences. On the other hand, if the goal is to study a specific, narrowly defined topic with a homogenous sample, a smaller sample size may be sufficient.

Researchers, therefore, are required to carefully consider these factors and aim to collect a sample that is large enough to provide a rich and nuanced understanding of the research topic, while also being manageable and feasible to analyse. For the purpose of this research, 12 participants were set as the minimum level. This was based on research into the concept of saturation that points to 12 as the point at which data saturation is achieved (Ando et al., 2014). This figure has however been criticised as the method used to establish it was retrospective and saturation was set at 92% of themes, meaning that the use of 12 participants alone was likely to have resulted in some missed data. Similarly, the concept of saturation as applied to reflexive TA has been questioned (Braun & Clarke, 2021). There is too much variation between individual research aims to be able to state that a specific number can achieve saturation across all qualitative studies. The aim of reflexive TA as interpreting meaning rather than simply pulling themes from data in an objective way, also makes it difficult to predict, ahead of time, how many participants will be required to achieve saturation. The true saturation level is likely to only become apparent once the data set has been analysed. Nonetheless, due to the time restrictions in place for the completion

of this research project, twelve participants were set as the minimum, with an aim of fifteen.

Participant Selection

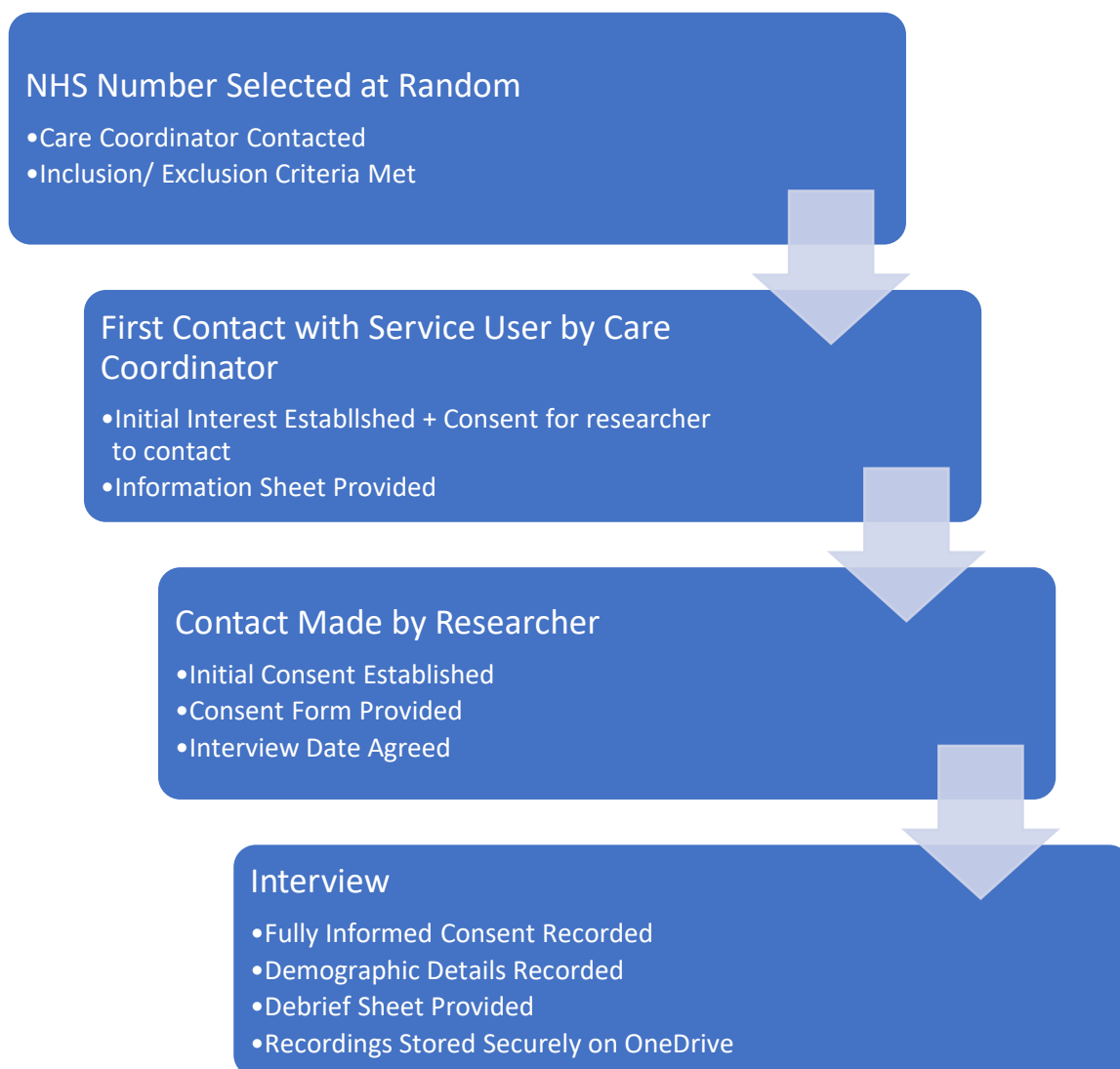
The design of the recruitment process was done by the research team in collaboration with experts by experience. This process led to the development of a three-stage recruitment process. Participants were first identified using an anonymised list of all patients that were under the care of the team at that time. This list was generated for the research team by administrators in the host service, using the Electronic Patient Records system (EPR). It contained no identifying information, simply the date of referral, patient ID number, and the care coordinator for the patient. This method of selection maintained anonymity and reduced any possibility of bias that could have arisen were demographic details to have been included. From the total list of 571 patients, outside of the first or last six months of their treatment within the team were removed. This left 350 potential participants. Individuals were then selected using a random number generator.

Following selection, the care coordinators for the individual patient were asked to provide information as to whether the potential participant met or breached any of the inclusion or exclusion criteria. If the potential participants passed this stage, the care coordinator or other associated clinicians were tasked with inviting the patient to participate in the research, providing them with all relevant information forms if they were interested. This approach to first communication of the invite was taken for two reasons. Firstly in order to maintain anonymity from the research team for participants who did not want to participate. Secondly, the advice from experts by experience was that hearing about the study from known clinicians would be less anxiety provoking than a stranger, this was

hoped therefore to allow a more considered response to the invitation. The final recruitment stage, once interest in taking part was established, was for the clinician to pass the patients' details on to the researcher who contacted them directly to obtain full consent and arrange a suitable time for the interview to take place. If the individual's preference was for an in-person interview, a local site was utilised. The service has sites spread throughout the area and any participant who opted for an in-person interview was given the option of using whichever of these sites was most convenient for them.

Figure 4

Recruitment Process Stages



Overall 83 potential participants were drawn at random and requests were sent to care coordinators. Of the 83 initial contacts, responses were received from care coordinators for 62 potential participants. Of the 62, 46 met inclusion and exclusion criteria and had invitations sent. 19 respondents consented to being contacted by the researcher to discuss the study and a total of 17 agreed to participate. 1 participant declined to participate following the initial meeting, and 6 did not attend the interview or respond to invitations to reschedule. This left a total of 10 participants who completed the interview and entered the sample.

Table 6*Participant Demographic Details*

Pseudonym (Randomly Generated)	Age	Gender ID	Ethnicity	Diagnosis	Date of Diagnosis	Location of Diagnosis	Method of diagnosis
Ivona	30	Female	Black British	FEP	2020	Hospital	Discharge Letter
Isa	32	Female	Black African	FEP, OCD, Anxiety	2021	GP Surgery	Face to face meeting
Diana	61	Female	White British	FEP	2020	Hospital	Face to face meeting
Theo	52	Male	White British	FEP	2020	Home visit	Face to face meeting
Ashlyn	21	Female	White British	FEP/ Bi Polar	2020	Hospital	Face to face meeting
Bojan	49	Male	Black African	Acute Psychosis	2021	A&E	Discharge Letter
Leyla	59	Female	White British	FEP LD	2022	Hospital	Face to face meeting

Niki	35	Female	Black African	FEP	2022	Early Intervention Team	Video Call
Ernest	30	Male	Black British Caribbean	FEP PTSD Social Anxiety	2022	Early Intervention Team	Face to face meeting
John	32	Male	White European	FEP	2022	Hospital	Discharge Letter

Semi Structured Interview

Data was generated using semi-structured interviews, conducted either through video calls or in person. A semi-structured interview format was chosen due to the flexibility of implementation it offers. Semi-structured schedules allow for the exploration of a minimum base level of information covered by the questions themselves, while leaving the participant, or researcher, free to delve into greater depth on certain points or areas of particular interest. They are also not so rigid as to remove the possibility of tangential discussion taking place that could potentially help to inform latent meaning from the overall dataset. (Runswick – Cole, 2012).

In order to carry out the interviews in a place participants felt comfortable, they were provided with the option of conducting them face-to-face or via video call. The embrace of video call technology since the Covid 19 pandemic has been a significant shift in how clinical contacts take place. Patients have adapted and are generally confident and comfortable in using the technology and often find it preferable to having to travel to meet a clinician (Nuffield Trust 2020). This is not a universal experience however and therefore, so as not to exclude potential participants, face-to-face was offered as well, conducted in the local EIP base for the participant. When participants opted for a video interview, care was

taken at the beginning of the interview that they were in a private space where they felt comfortable answering questions about their experience.

Creating the interview schedule

The interview schedule was developed through consultation with the research team and experts by experience. The first stage was to develop a list of questions related to the overall research question. Existing research related to the topic was also used to provide ideas for potential questions. Discussion of the potential questions was then conducted with the research team to ensure relevance to the research aim and overall question. Finally, the questions were shared with experts by experience in order to check the questions from the perspective of someone who may be answering them, as well as assessing their relevance to the topic and overall research question. This part of the process was key in considering the ethics of potentially building an understanding regarding the distress that could arise from participating in the research, as well as formulating mitigations for this as detailed in the ethics section.

Conducting the Interview

Prior to the interview, the participants had spoken with the researcher on the phone to establish that they fully understood the nature of their involvement, and formal consent obtained. At the start of the interviews, verbal consent was re-established and recorded and participants were reminded that they were free to leave for any reason. During the interview the semi-structured schedule was utilised as a framework for the conversation that took place, ensuring that nothing was missed while not sticking rigidly to the order of questions, allowing for flexibility where any particular interview required (Runswick – Cole,

2012). Following the completion of the interview schedule participants were asked if they had any questions or if they would like to return to any particular points prior to the recording being stopped and the interview finishing. Once the recording was stopped participants were offered the opportunity to reflect on their participation and debrief information was provided.

Ethical Issues Considered

The study received Health Research Authority (HRA) ethical approval from the Camden and Kings Cross REC on the 26th January 2023 (IRAS Protocol: 314311) (Appendix C). The following ethical issues were considered during the design stage of the research.

Informed Consent

The information sheet provided to participants (Appendix E) outlined the aims and intentions of the research, the potential benefits and risks of participation as well as detailing the processes that the research would follow in terms of participant involvement and maintenance of confidentiality, data security measures and data usage. This enabled participants to be fully informed of what their involvement would entail as well as what would happen to the information they shared through their involvement. Participant consent was recorded through the signing of a consent form (Appendix F). Furthermore, as the participants' reading level could not be ascertained prior to recruitment meetings an easy-read version of this information sheet was produced, to ensure that any participants whose reading level prevented them from fully understanding the information sheet, could still participate and give fully informed consent (Appendix G). Participants were aware of

their right to withdraw from the research at any time with no requirement to give a reason. Participants were reassured that their withdrawal would have no impact on their treatment within the early intervention team due to the separation of the research, conducted through the university, from the clinical team. Participants were also informed of their right to withdraw their data following the completion of the interview, within a reasonable timeframe, set at two weeks post-interview.

Confidentiality

The standard limits of confidentiality were in place for this research study and these were outlined in the information sheet, reiterated in the consent form and again reiterated verbally prior to the commencement of the interview. The confidentiality of information shared during the interview was to be maintained with only one exception; disclosure of any information that there was a risk of harm to the participant themselves or to anyone else.

Data Security

All data collected during the study were stored securely on the University of Hertfordshire OneDrive cloud storage system. The primary researcher was the only person with access to the online data storage system. The OneDrive features two-factor identification using the researcher's personal phone to identify themselves to the system at every login, as well as knowledge of the password that protects the account. In order to maintain anonymity even in the event of an unlikely data breach, all information that recorded any identifying details about the participant, i.e. their consent form, was stored separately from the research data, using the principle supervisors' university one drive account.

It was unavoidable that for short periods, prior to the data being transferred to the secure cloud system, data was stored on less secure devices such as the Dictaphone or the researcher's laptop. There were also physical records where interviews were conducted face to face, such as paper consent forms or contact details. To minimise the risk of any data breaches a policy was put in place that all data was transferred to the secure system the day it was collected and then deleted from the physical device, or securely shredded if in paper form.

Potential Distress

I was aware that due to the nature of the interview topic, there was a possibility that participants could experience some emotional distress as a result of their participation in the interview. For instance, if their experience of being diagnosed was negative, there was the possibility that recalling these memories could be emotionally triggering for the participant to discuss. In order to mitigate this risk, the interview schedule was first discussed with experts by experience who had received diagnoses of psychosis. The feedback from the experts by experience guided the formation of the final interview schedule. From the perspective of potential distress, experts by experience acknowledged the possibility of emotional distress but felt that the potential benefits of participation in the research would outweigh the risk of emotional distress. The experts by experience also felt that the nature of the questions could be beneficial to participants who were distressed by recalling the experience in that it may help them make sense of and also validate their emotions.

Nonetheless, the risk of emotional distress had to be mitigated against, and this was achieved in a number of ways. Firstly, ensuring that participants understood that they were

free to answer or not answer any of the questions asked and that they had the right to withdraw at any point of the interview, this was outlined in the information sheet and reiterated prior to commencing the interview. Secondly, the clinical skills that the interviewer has obtained as a trainee clinical psychologist, in creating safe and containing environments in which to discuss emotionally distressing topics, were also utilised. This ensured that the interviews could take place as safely as possible if there was emotional distress for the participant. Finally, a debrief following the interview was also carried out in order to allow the participants to ask any questions they had about the process or topic and offer their feedback. A further safeguard that was in place for this study was that both research supervisors are senior clinicians within the early intervention team that participants were recruited from, allowing for following up of any concerns that the researcher had in regard to individual participants and all individual participants would have a personalised risk management plan, as this is standards practice within the EIP team.

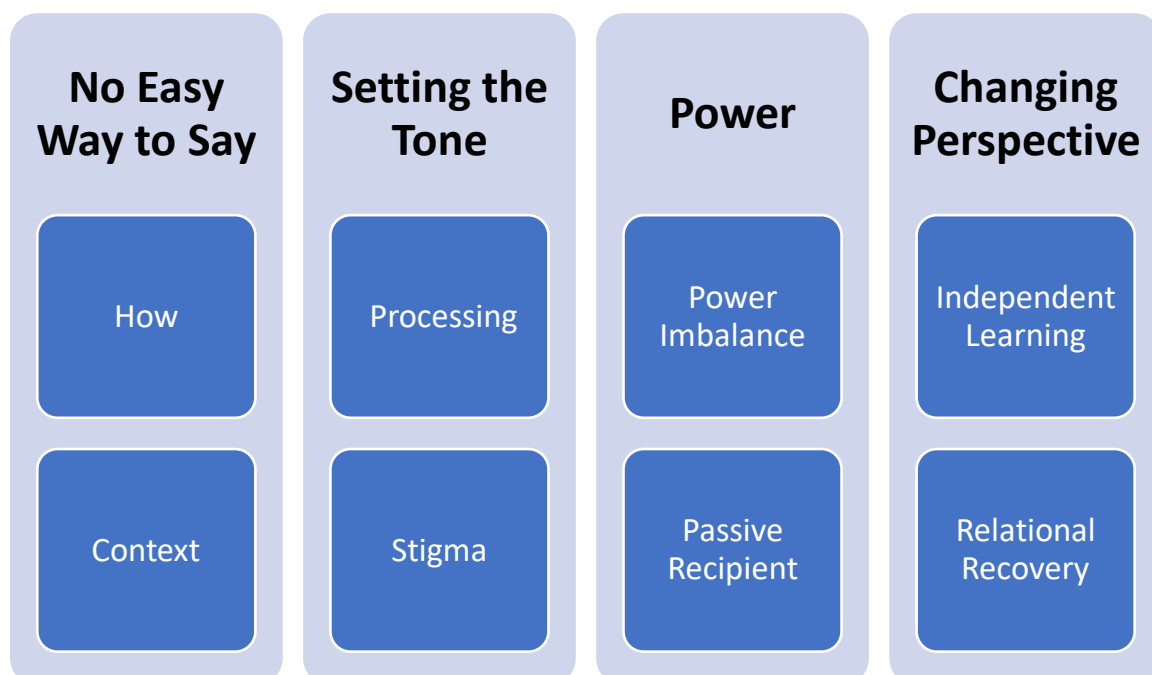
Findings

Overview

This chapter presents the results of the thematic analysis of 10 semi-structured interviews. Four main themes were created from the analysis using a reflexive TA methodology. The four primary themes and their respective subthemes are displayed in Figure 5 and together represent the participant's experiences of receiving a diagnosis of First Episode Psychosis. Each theme is described in detail, with selected quotations used to best illustrate the meaning of each theme and sub-theme. Selection of quotes has been made consciously to include all participants, to allow for all voices who contributed to the research to be heard, although inevitably, the use of quotations is not balanced perfectly across the participant pool. Within the quotes ... is used to indicate words being omitted, while [] is used to to add words to improve clarity and understanding.

Figure 5

Themes and Subthemes



Theme 1 – No Easy Way to Say

The first theme concerns the communication of a diagnosis from a service or doctor to a patient. From the interviews, it was clear that there are no simple rules to follow regarding what makes for “good” communication. Person-centred practice however may provide the best frame for meeting the needs of each individual. This theme goes beyond simply describing communication style, incorporating the participant’s experiences of the context in which the diagnosis is communicated and when the information is given or not given.

Sub Theme 1 – How

Seven participants had their diagnosis communicated directly through a verbal conversation with a professional, two learned through reading their discharge letter, and one was told by their wife after reading a letter. Where communication was verbal, two-way transactional communication was found by participants to help put them at ease. Five of the participants who were told verbally had positive communication experiences. Participants particularly valued the opportunity to tell their stories at the point at which they were diagnosed. Diana clearly describes this kind of interaction:

“[Interviewer] What was it about her [psychiatrist] that was very good?”

[Diana] Because she listened and explained it all well.

[Interviewer] So she explained it first; what was it you wanted her to listen to?

[Diana] She listened to how I felt about what she told me.

[Interviewer] Ok so that was really key, was it?

[Diana] Yeah, it was. Being listened to. And, somebody that actually understood you.

[Interviewer] So did you tell her that you felt a bit worried by the news?

[Diana] Yeah, of course.

[Interviewer] And how did she respond to that?

[Diana] Yeah, she was very supportive and told me that I wasn't on my own. And they've got other people there for support. And yeah, she sent to me for the tests and the brain scan that was very thorough." (Diana)

The first meeting or contact was important in establishing the relationship between the participants and the NHS services that they would go on to navigate and whether they felt they could trust them. In the case of bad first impressions, mistrust could develop, as well as negative ideas about how the services they were entering viewed them as patients.

"Well, Um. No one was telling me whatever stage what next or what is it that is going on with me. Even though amongst themselves they were talking about me. And I was thinking probably because they think maybe in my mind, I'm not right, I'm not OK." (Bojan)

"Well you know when I asked about the medication and it was just, and this was the true thing, they way it was told to me by the doctor then was that I would be on this medication for the long term. And like now they're looking, I've got an appointment next week cause they want to start reducing my meds, you know what I mean, and that's not what was told to me" (Theo)

For both Bojan and Theo, the communication was very linear, there was no opportunity to question or engage with the conversation. The opportunity, however was there for doctors at an early stage to mitigate concerns through compassionate communication. Normalising the patients' experiences was highlighted as a helpful aspect of the diagnostic process.

"Uh by talking to me about it and also making me understand that I am not alone, that they have other clients who have been in the same scenario as me." (Niki)

Compassion was regularly highlighted as being a factor in the perception that the communication had been good.

Yeah for sure they were kind, like kind and caring I would say, just the way he explained things and cause of the way I asked questions and that and then I got told that's what my diagnosis is, I don't know you know, he just gave off a good vibe and it was reassuring. (Ernest)

Umm the main thing I would say is caring, the way he listened to me, even when I was talking, talking he listened to me, he never cut me off, and I just felt like even before I opened my mouth to say a word he understood what I was trying to say." (Niki)

Niki was a participant who had been particularly distressed by her experiences before diagnosis and faced barriers in getting what she felt was an appropriate diagnosis.

For her, feeling heard for the first time was clearly an important factor in making the communication of the diagnosis a positive experience for her. Ernest's quote also demonstrates the back-and-forth nature of genuine transactional communication.

Being able to question the person providing the diagnosis was another key factor in participants feeling heard and experiencing the meeting as positive.

"Oh yeah I was free to ask any questions, I had questions about the medication, they changed it... It was really positive, they treated you like an adult not a child you know... They talked to you normal and like asked you how you were feeling. Not like a doctor-patient kind of chat." (Diana)

Diana's point about being treated like an adult and not feeling patronised was consistent amongst those who felt their diagnosis had been communicated well.

It could possibly be my background because the psychiatrist knew I was a medical student and so they spoke to me like they would a medical student. And so, it I felt less you know, like a patient." (Isa)

As well as communication style, participants highlighted how the information was conveyed positively in the meeting, there was no consistent preference for this, for some the diagnosis was made in a direct way

"So it was good. I had all the time I needed to ask questions and discuss. Everything was explained clearly. Um, I liked that. It was sort of, to the point." (Isa)

For others, however, the diagnosis was eased into the wider meeting.

“it was kind of like eased in, they didn't come in and say like, sorry, well, you have this! But I think it was a general like consensus, so like they told me, kind of like they just explained that [my symptoms] my general kind of like approach to people and like state of mind and also physically as well, they said with everything that we've gathered, like, this is what we believe you have” (Ashlyn)

From Ashlyn's quote, you really get a sense that the diagnosis was something they felt required building up to, discussing symptoms first before disclosing the diagnosis at the end. She was someone who found the diagnosis very distressing despite this.

Where individuals had a negative experience the communication was more linear, the participants described a meeting in which there was no room for discussion or questioning of the information they were being given.

“So then at all those appointments... there was not much for me to say. It was like, he's doing his job. You've been diagnosed. We are continuing the treatment.” (Bojan)

“There was no conversation” (Theo)

Both Theo and Bojan strongly disagreed with their diagnosis, and this view persisted through their course of treatment up to the point of the interview. The lack of discussion during the first meeting led to them forming negative opinions of the diagnosis and feeling like the clinicians they were working with also felt this way.

“Because acute psychosis is a mental health issue. So probably they were avoiding me or, that was what I thought.” (Bojan)

Another feature of the diagnoses was the variety in prior understanding of psychosis reported by the participants. It was important where there was confusion that the clinicians continue to repeat information, as it cannot be assumed that it has been understood or retained. When asking Leyla how she understood psychosis at the point at which she was told that was her diagnosis, this was her response:

“[Interviewer] and did you tell them that you felt confused by it?”

[Leyla] I probably did yeah, they sort of told me what it meant but, I'm struggling to remember what it was now... I'm not sure, I still feel quite confused about it” (Leyla)

Clearly, for her, there is a lack of genuine understanding of what the doctor explained psychosis to mean, she understands that she has a diagnosis but has no conception of what that actually means. This gap in ongoing communication about the diagnosis was something repeated by many of the participants. Once the diagnosis had been communicated, that was generally the end of the conversation about what it meant for them, this is an aspect of the diagnostic process that will be returned to in the final theme.

For three participants, communication and interpersonal style were irrelevant to their experience of finding out about their diagnosis because they discovered the news through a letter. For Bojan in particular, not being told significantly impacted his perception

of what was happening to him, because he was taken under section to a secure hospital, without any understanding of what the basis of that happening was.

“Probably those who diagnosed it themselves should have informed me. Being told directly, maybe, in A&E because, It was scary. I was like, where are we going? Where? Where? Where? And no one said, they were not talking.” (Bojan)

The story continues with Bojan painting a vivid picture of what it is like to arrive at a secure hospital without understanding why you have been taken there and the distress this caused him.

“They never spoke a word. And I was just praying. Where was I going? Where was that. We used the motorway. We went round and round, nothing. No one was saying anything. So we got to this huge place and they told me to get out you know, we are going there. I was resisting that, I wasn't going” (Bojan)

For Ivona, the experience of reading her diagnosis rather than being told was isolating, with her left to try to understand what it meant alone, without the support of a clinician.

“I was given a letter and there was a copy sent to me and a copy sent to my GP with my notes on there like my medication, personal details and on there was the diagnosis. I think it was some like the ICD10 or something like that and then it said first episode psychosis on there and that's the first time I remember seeing it written

down... But then it's also quite hard to see that sort of written down on paper about yourself. Umm, As I'm sure like you know in your line of work, there's still plenty of stigma, sadly, around mental health. Um and to see that written down on paper was quite hard hitting as well to have a look at that and think sort of like that is me."

(Ivona)

For John, however, despite learning of his diagnosis in a discharge letter in hospital, the process was still positive. On reading his discharge letter for the first time.

Yeah, I mean, it was informative. The situation which was reassuring for me. The doctors said that they were able to rule out an organic cause, they had done all the investigations, MRI, all the tests and the letter said there was nothing to indicate any significant organic cause. (John)

For John, the ruling out of any brain injury meant that being diagnosed with psychosis instead came as a relief. The overall picture is one of a need for a personalised approach to communicating a diagnosis, no simple rule will ever be appropriate for all individuals. The challenge that this presents was well summarised by Ashlyn.

"I said, im not sure if there is an easy or good way to project diagnosis on people.

Well, i'm sure there are, but, when it's with significant mental health or life-changing labels as such, it isn't easy." (Ashlyn)

Subtheme 2 – Context

Information communication is not simply a process of speaking and hearing, writing and reading. Subtheme 2 describes the various contextual factors that influenced how the participants experienced the diagnostic process. These include the environment in which they were told, their mental state at the time and what else was going on for them in their lives.

The environment in which the participants learned of their diagnosis impacted the early formation of beliefs about their condition, particularly for those hospitalised under section.

“these two ladies who would always go for this procedure and they'd always come back like absolutely different people after, just like very dismal... And I was like, Oh my God like is that what's gonna have to happen to me, like, is this what I'm going to have to live with for the rest of my life, a constant cycle of hospitalizations?” (Ashlyn)

“I know that I received a diagnosis on being discharged from hospital... I was just trying to make sense of what had happened to me again, I think I took a long time to completely process what I've been through and even to this day I still sometimes have random memories or like flashbacks to what happened.” (Ivona)

Witnessing others changing following treatment or going through a traumatic experience while in hospital left participants feeling distressed about what their futures might look like with their diagnosis.

As well as experiences in the hospital, the participants often referenced how their own state of mind at the point of diagnosis impacted how they understood or reacted to the information. Ashlyn, for instance described herself at the time which she was diagnosed as:

“I was very elated, very excited, having a great time in the hospital setting. Um, I don't really know the timeline of it cause I was so high at that point.” (Ashlyn)

This meant that when she was told about the diagnosis, she was not in a position to consider the alternative perspective that the doctors were offering her.

“My delusions were still very convincing to me, like, I registered them as facts, so I didn't really see the need to be put into this category of having a significant mental health issue. Because I didn't think I needed it, I didn't think that's what I required or what, how my brain works. (Ashlyn)

Isa paints a similar picture of the impact of her pre-existing beliefs on what meaning she made from the diagnostic process.

“...even when I joined the [treatment] team, I thought this was all part of some big surprise and I'm just waiting for it to end and for everybody to say, you know, this is what's really happening. This was all not true.” (Isa)

The quote demonstrates how little understanding there was for Isa about what was happening to her. An ongoing conversation around the diagnosis and what it means to each

individual could be important in countering potential unhelpful beliefs forming. What participants took from the early diagnostic meetings when they were still actively experiencing the positive symptoms of psychosis, was very different from the meaning the doctors intended to impart to them. The importance of this aspect of diagnosis is made acutely clear by Terence.

“I was like trying to think about it like, man, that’s mad. That’s what I’ve got [psychosis]. So that was on one level, but then, it was also like reassuring. But a couple of days after that, I took an overdose of medication like, and that was due to like not believing what they told me.”

For Terence, whose experiences that led to being diagnosed were primarily paranoid thoughts, the confusion around the meaning of what he had been told had such an impact on him that he attempted suicide. This was the most extreme reaction reported by any participant and was not remotely typical, however, it demonstrates the potential outcomes of not considering the interaction between diagnosis and pre-existing beliefs.

“Obviously it’s good to let people know their diagnosis as early as they can, so they have time to like process it and make sure they can come to terms with it, but I believe. Waiting until people appear more, a bit more coherent might be a bit more favourable” (Ashlyn)

As well as their internal context, participants also referenced the impact of their external context. What was happening for them in their general lives around the time of

their diagnosis and how this impacted their understanding or importance on the diagnostic information. Just prior to experiencing psychosis, Diana's husband had nearly died following a car crash.

"Well no, he was out of hospital but they were saying well you better come over because he's not going to survive so it was a hugely stressful time. I mean, that was a lot of I think, what did it. Yeah. It might have a lot to do with that." (Diana)

She was, therefore, understandably distressed to be sent to a hospital 400 miles away in the north of England. Her geographical separation only enhanced the guilt she was already feeling at not being able to support him in his recovery:

"But at the time I felt like I should be there to support John, be looking after him. So that didn't make me feel great either. Yeah because, we've been together like nearly 15 years. We do everything together. You know, at that point I felt guilty." (Diana)

Similarly, Niki, who at the time she received her diagnosis was living in a refuge, having escaped a violent relationship with her children, found that what was happening in her life outside of the psychosis had a huge bearing on her ability to engage with and understand the information she was being given.

'Umm to be honest with you it was at that particular time I was at my lowest, I was almost unable to talk, especially about my scenario I could not do so without

breaking down. Like if I was talking to you as we are now back then I wouldn't have been able to talk to you" (Niki)

And finally, Ernest, who described arriving at the meeting in a state of high anxiety due to what he believed was happening to him at the time.

"I remember, being very shaken for the few days leading up to it, I was really panicky and when I got there I was super panicky, like really stressed you know." (Ernest)

Theme 2: Setting the Tone

This theme captures the importance of how individuals first hear about their diagnosis on the formation of beliefs about; the condition, themselves and the services they are navigating. This effect can go both ways, with positive initial interactions key in mitigating pre-existing negative ideas or setting up positive relationships to treatment.

Sub Theme 1: Processing

This first subtheme represents the struggle participants experienced to make sense of the fact they were diagnosed with psychosis. There was a wide range of responses to the news but all participants sought to make sense in their own way. Some were combatting a sense of extreme confusion or lack of understanding about what the diagnosis meant; others felt fearful or anxious, while some felt a sense of relief and questions having been answered. All responded by seeking out information about the condition, this was almost always self-driven in the first instance, with barriers to accessing information resulting in unnecessary difficulties for some who could not conduct their research. Across the

participant pool, there was a consistent desire for information around the meaning of their diagnosis.

“It felt good to have a label put on it and to be able to do a little bit more research about what that was and what I had experienced and to sort of understand what I'd been through” (Ivona)

This desire to discuss their experiences and the labels that may be attached to them often predated receiving the diagnosis of psychosis.

“I had um had done some research. Um, I'd. I'd always been kind of looking things up ever since I was able to, about what was going on in my mind.” (Isa)

“Umm. I knew there was something wrong with me, I had been reaching out since 2021 but nobody was taking me seriously, they just kept giving me more medication for depression and anxiety.” (Niki)

The desire to understand more about what the participants had been diagnosed with was often not responded to during the early stages of being given the diagnosis. Participants consistently reported, regardless of setting, that the focus of early conversations was very medicalised, focussing on discussing treatment or justifying the diagnostic decision by describing the relevant symptoms.

“from what I can remember I believe they gave me advice. They gave me the general kind of symptoms of what this condition is...” (Ashlyn)

I don't remember there being like a lengthy explanation [of psychosis], but I already knew what that meant. I'd been having the symptoms for quite some time, and I myself suspected that I might have psychosis. (Isa)

The second quote from Isa demonstrates the impact of mental health literacy and pre-existing knowledge on the individuals' perception of what they are being told. For Isa, a medical student, she understood the condition well and had already begun to diagnose herself. For many others, however, the lack of discussion of what having psychosis meant for them, beyond simply a collection of symptoms, proved unsatisfying.

The importance of each individual's understanding of the information they have been given can be seen in the different emotional responses reported. For some, their diagnosis led to a sense of relief.

“I was hearing voices, I was so embarrassed to share it with anyone because they will think that I am going insane, so I never opened up to anyone, and when the doctor told me that there were other people going through it, other people had the same thing and that it wasn't just me... It made me feel so comfortable and happy that I am not going insane or crazy.” (Niki)

Niki's relief at being given a diagnosis was palpable during the interview and demonstrates the importance of the preconceptions each individual has about psychosis

prior to their diagnosis. Niki had no mental health awareness and had not heard of psychosis prior to diagnosis. The news that her experiences had a medical label that could be attached to and explained, led to a positive shift in her perception of herself.

“I guess maybe a bit of relief because I have a diagnosis, somebody understands what's happening to me, I don't feel, I guess, as alone. People know what's happening to me.” (Isa)

The relief reported by Isa was similar in her sense of normalisation, but for her, having a medical label gave her a sense that her experiences are understood, ‘*People know what's happening to me*’ really demonstrates how when what you are experiencing is confusing or uncertain, being told that Doctors understand what is happening can bring a sense of calm.

For eight of the ten participants, however, their diagnosis did not bring about relief but more negative emotions. A sense of confusion was often reported about what had happened and what the diagnosis meant for them

“I dunno whether I really understood what was going on at the time” (Theo)

“I didn't understand what it meant really, when they said psychosis it felt yeah, quite confusing” (Leyla)

This sense of confusion could translate into a mistrust of their thoughts or beliefs. When an experience that the participants had perceived as real was explained from a

medical perspective, they were forced to reassess their experience. This led to both a reappraisal of past events and questioning of their beliefs in the present.

“There are days where I think, yeah, it's definitely just psychosis and there's nothing else going on. I guess I'm always looking for things in my environment to prove one hypothesis over another.” (Isa)

For the majority of participants, the process of being diagnosed with psychosis produced a sense of fear or anxiety.

“Interviewer - OK, So what do you remember about that first meeting you had in [City in the North of England]?”

Diana - Frightening. Very frightening... She just said it's like I had a psychotic breakdown” (Diana)

“I thought it meant there was something wrong with me but there was something wrong with my mind it made me worry about the future, like I just wanted to go back to normal.” (Leyla)

“It was absolutely shocking. It was like the biggest thing that I've had to deal with in my life so far.” (Ivona)

Leyla's idea of there being something wrong with her mind was a consistent concern, the idea that something had broken within them. An initial attempt at denial sometimes

accompanied this worry. Participants would jump ahead and begin worrying about the consequences of diagnosis for their lives.

“You hear that [psychosis] and like it's just like a little switch goes off in your brain. For me, personally, It was just a complete like denial, disbelief shock all the crazy words you want to say... I didn't wanna be put on this pedestal or put into a section of having such a stigmatised or like, fearful mental health condition” (Ashlyn)

“The sort of worry on my part, cause I was worried, I was really worried, was about losing my job.” (Theo)

“It's not just as simple like. You have a cold, but we'll give you some medication and you'll be fine in two weeks, as it's a lifelong thing, you know, and it's a big thing” (Ashlyn)

The anxiety associated with receiving the diagnosis was clear throughout, with many participants reporting leaving the initial meeting, unsure about what the diagnosis meant for them also in terms of their health and wider consequences for their life.

Subtheme 2: Stigma

Linked closely to the emotional reactions seen in subtheme one, subtheme two, Stigma, represents the beliefs about psychosis that individuals took with them into the meeting, as well as those formed due to the diagnosis. There are also some examples of

mitigations of stigma experienced as a result of the actions of clinicians, family or the participants themselves.

For those who had heard of psychosis prior to their diagnosis, the perception was universally negative.

“Umm, like, mad basically yeah. It’s mad innit, like I didn’t fully understand what psychosis was but I just knew its like when someone loses their mind.” (Ernest)

The quote from Ernest most directly summarises the perception of psychosis at the point of diagnosis. These beliefs could be driven by their perception of what was happening to them prior to diagnosis.

“I felt like I was going insane and that nobody could understand me so it was something that I was scared of” (Niki)

And sometimes driven by the reaction of those around them.

“people tend to use words like psychopath and he or she is psycho or going psycho for generally quite angry behaviour, whereas in reality it's not really anything to do with anger... The word has kind of been. Hmm. Perjurised, bastardised... it's kind of been taken and it's used in general society in a different way than it is in the medical field.” (Ivona)

“felt embarrassed to tell even anyone close to me... when you have something that you want to talk about but don't have anyone to talk about it with, like, I am going through this I need help, it is really hard when they look at you like there is something wrong with you so it was kind of embarrassing at first to be honest.” (Nikki)

Nikki's quote illustrates the isolating impact that stigma had on the participants, the belief that psychosis is something that they needed to hide, stopping them from reaching out to friends and family for support, or from seeking help with services.

At the point of learning they had received a diagnosis of psychosis, many participants experienced stigmatised feelings. Whether they accepted the diagnosis or not, there was a belief forming that this was a negative development for them as an individual.

“I wasn't happy with this diagnosis, generally feeling like I don't agree with this diagnosis, like it was too harsh for myself, like due to like the stigma surrounding mental health and surrounding bigger diagnoses such as psychosis or bipolar, I think I didn't wanna be labelled as someone who had that.” (Ashlyn).

“I kind of I hang on to that [that as a first episode, it may never recur]. It's possible, but it's not definite. Because then it seems almost like it's stamped and imprinted on me. And there's nothing I can do about it. And it's with me for the rest of my life. Like it's going to have a big impact on my life, just like it did on my mum's life.” (Ivona)

Ivona's phrase “imprinted on me” demonstrates the strong internalisation that occurred for many of the participants due to the diagnosis. It shows the comfort she took

from the fact that the *first episode* means it may not be permanent, may not be “*with me for the rest of my life*”. This demonstrates the negative beliefs that many participants felt at the point of diagnosis.

The perception of stigma was for some participants further enhanced by the behaviour of clinicians, particularly for those who received a diagnosis after being admitted to the hospital under the mental health act. Here the label of psychosis was experienced as bringing about negative reactions from staff.

“Whilst I was there, because of whatever diagnosis they've been told I had. All those who came to take care of me, were talking to me as if I was off... like I couldn't understand what they were saying” (Bojan)

Stigma experienced by clinicians could also be more subtle. Clinicians, without meaning harm, could give the impression that the label of psychosis was something to be avoided.

“I couldn't help but feel she was being professionally vague on what she was saying.”
(Ivona)

One of the most striking aspects of the descriptions of stigma was the persistence with which these beliefs were held. Ashlyn and Ivona both explained, in strong terms, how months on from the diagnosis they still have to challenge negative, stigmatised conceptions of psychosis that exist within them.

"I still have like thoughts that people like me, should just be like locked away or like people like me, should just kind of like not be present in society." (Ashlyn)

"...perhaps I shouldn't even be here. I know it's quite a bleak thought, but I'm being as honest with you. I want your research to be sort of my honest opinions and sometimes I genuinely did think like if my mum hadn't have had me, it would be one less person with a mental disorder in the world." (Ivona)

Theme 3: Power

Theme three concerns the awareness the participants reported of the power in the diagnostic process. Participants' experiences of the imbalance of power between the giver and recipient of a diagnosis were reported in several different ways. The feeling of being a passive recipient rather than an active participant in the process particularly enhanced the negative feelings of power.

Subtheme 1: Power Imbalance

Participants have yet to talk about power directly; however their awareness of the power that was wielded by doctors and services and the impact on them as individuals featured in all of the interviews. Use of power was perceived negatively for the most part, but there was an exception where a psychosis diagnosis was perceived as having the power to open doors to particular treatments or support services.

"I think going back to like the ward round situation and the diagnosis being done in the way that they kind of planned it out was very daunting. To me, like, learning that

I would be taking pills every night for the rest of my life was very daunting. Like, I didn't want that.” (Ashlyn)

Ashlyn’s quote provides a sense that the diagnosis she had received meant that she would have no choice other than doing something she did not want to, taking medication, and that this was akin to a life sentence. Ashlyn’s diagnosis was made while she was involuntarily being held in the hospital under section. This context contributed to her acute sense of power being wielded against her, with no hope of change. However, even for those who were not being held under the mental health act at the point of their diagnosis, the sense of the power held over their lives by the doctors was evident.

“Cause if you sort of, ask for a change like when I asked about the medication, cause this makes me feel shit, they were sort of like, there was no conversation.” (Theo)

“they were giving me more medication but I knew there was something else wrong, but each time when I was reaching out, I feel like they didn’t really care that there was something else bothering me” (Nikki)

For both participants, the sense that they have no control over their treatment is clear; for Theo, it did not matter that the medication was causing him to have negative side effects, there was “no conversation” when it came to decisions about changing it, leaving him feeling like this was a permanent, unchangeable state. For Nikki, it is clear that all she wanted was to be taken seriously rather than dismissed. The impact of the sense of

powerlessness can be seen in Theo's later resignation to the fact that there is no point in challenging decisions made about him, resulting in him giving up in trying.

"And then after that, all you can do is play the game, if you know what I mean. Just go along with it, yes sir, no sir, three bags full sir. Just to push things along as quick as you can. That's how I felt about it." (Theo)

In some instances, however, the diagnosis enacted power positively, allowing them to access treatment.

"Because I had that diagnosis, I was also given medication which really helped during the episode." (Isa)

"Back when my mental health was simply labelled as depression or, like severe depression, and I was on antidepressants and it just was not working at all. But with this diagnosis, through medication that is incredible and that keeps me happy and stable, which is just lovely. I also did six months of therapy and that literally changed my life." (Ivona)

The participants were very aware of the power conveyed by credentials and titles and how this related to their status as a patient.

"I don't accept that I should use that word. I don't accept it, but then it's their [the doctors] diagnosis, and I have to follow." (Bojan)

Bojan's sense that he had to follow what he was told despite strongly disagreeing with the diagnosis he had been given was shared by many participants. This sense of qualifications being sacrosanct and the impact of this, was most eloquently described by Theo:

"No of course, cause, how can you challenge someone who's a qualified doctor, I dunno what are they psychiatrists or, I don't think you can, can you." (Theo)

The power imbalance the participants experienced led several to describe a sense that the diagnosis and subsequent treatment amounted to a punishment, not a treatment. Being detained under section enhanced the feeling that participants were in a punitive rather than curative system.

"You're in a place, on your own, you don't really know anybody, I didn't have [name of husband], I didn't have no support there. Yeah. Do you know what I mean? Like my family there. I'm sorry but the reality is it's lonely." (Diana)

"As soon as they say psychotic episode that's it, your life stops for 6 months minimum. Maybe more. I think that's the rules innit. It might even take longer if you know what I mean. So you think you'd be, like seen as difficult or whatever. In the end you know I thought you've just got to go with the flow and get on with it, and hopefully get out of here as quickly as you can." (Theo)

This perception of the system as being punitive led to half of the participants reporting that they became more guarded with the professionals they were working with. When discussing how she interacted with the team, Isa reported:

"I feel like I can't really be honest. Um, with anybody. It affects my relationships. I don't know what I can share, what I can't share, how people would react if I shared what was on my mind or what I was thinking" (Isa)

Participants were very aware of the imbalance of power between them as an individual and the NHS systems into which they were entering. This was represented for participants who learned of their diagnosis while an inpatient, simply by the number of clinicians present at the point of diagnosis.

"there were lots of other people, there was the doctor, a sister then probably three or four other people but I didn't really know who they were." (Leyla)

"I believe, there were other people in the room, there was at least a group of like at least four" (Ashlyn)

This imbalance of professionals to patients at the time participants learned of their diagnosis contributed to the sense that their opinions were irrelevant, the image of four professionals against one patient is a powerful one and it is easy to see how this situation could also contribute to the anxiety and stigma development described in theme one. The

imbalance of power experienced by participants could however be mitigated by support and engagement from family at the time of diagnosis:

It was all right but only because my sister was there and that put me at ease so that she made me feel safe and comfortable. Because, I didn't know anyone in the room I'd never met anyone before, I met them all for the first time for that meeting."

(Leyla)

Leyla's description of being diagnosed while in front of a whole panel of professionals seems particularly intimidating; however, for her the presence of her sister meant the experience was not distressing. Leyla also has been diagnosed with a learning disability. This may have been a factor in the service involving her sister, as none of the other participants reported having a family member present with them at the time of diagnosis.

Subtheme 2: Passive Recipient

The second subtheme describes the perception of participants that they were simply passive receivers of diagnosis, the process was non-collaborative and was something perceived as being done to them. This sense pervaded all aspects of their contact with services, from information provision:

"no one was telling me what stage, what next or what is it that is going on with me. Even though amongst themselves they were talking about me." (Bojan)

To the treatment they would be receiving:

“They would trial and test me on all medications that they believe would work for me and can help me live a fulfilled and happy life with this condition.” (Ashlyn)

To their beliefs about the diagnosis:

Um, but with regards to my confusion around the diagnosis, I just. I don't really talk about that anymore. And I don't really feel that there's much more that can be done. I guess I've kind of put up this wall where. Okay, let's pretend. All I have is psychosis and let's talk about that. (Isa)

Ashlyn's description of trial and testing of treatments evokes a sense of her seeing herself as a Guinea Pig, while Isa's "Let's pretend." seems to show a forced acceptance of something she doesn't believe, for want of an easy life.

The wider context of an overstretched NHS was not lost on the participants. This knowledge however enhanced the perception that they were just passively caught up in a system that was not really serving their needs. Sometimes this was presented compassionately, a sense that the staff are doing the best they can in difficult circumstances,

“I had something, but I don't think I had what they say I was. It's difficult to say innit, cause they're understaffed as well and they are just going through the motions as well ain't they, you know.” (Theo)

The distrust of services evident in Theo's quote gives us a sense of his belief that the diagnosis was not made primarily for his benefit. The description of staff "just going through the motions" suggests thoughtlessness and lack of personalised care. This was further increased by a sense that the decision making process was rushed.

"I don't see how you can make a decision, on one meeting. Just like that... Surely not." (Ernest)

"How can you see someone for an hour, half hour to an hour, and make a proper diagnosis in such a short space of time. I think they just do their thing and then have to move onto the next one... they shouldn't have gone as far as diagnosing straight away, they should just sign you off for a couple of weeks and then see how you are at that time... to do it on one visit I think a bit quick." (Theo)

Finally, the sense of diagnosis being done to, not with, was enhanced where participants felt their own beliefs or interpretations of their experiences were being dismissed by how they were diagnosed. Isa most clearly described this:

I felt like somebody had done something to my mind... as opposed to it being organic, just normal psychosis. And I guess a part of me would have liked that aspect of things to be explored before it was concluded that I had psychosis, because even to this day I still wonder whether that's the case." (Isa)

The diagnosing clinician may feel a need to simply dismiss these ideas, seeing them as bizarre, wrong or purely as a result of psychosis, however for the patient, these explanations are very real, and not exploring them alongside the medical perspective can leave patients with unanswered questions leading to long term distrust of the process they have been through.

Theme 4 – Changing Perspective

Theme four details how the participants' understanding of psychosis came to evolve and what they did in the weeks and months following to try to understand and come to terms with the diagnosis. The two subthemes, independent learning and relational recovery explore the helpful and the unhelpful ways in which belief's around the diagnosis can develop in the period after it has been made.

Subtheme 1 – Independent Learning

Participants consistently described how they were, initially lacking in support to process the diagnosis and it's meaning. As discussed in Setting The Tone, the participants had a general desire to talk about their diagnosis that mostly went unmet in services. Where there is an information vacuum, the participants all fill it in their own way. This led to a wide variety of information gathering strategies being reported, some very helpful and others damaging. For others however, they turned to other sources of information to inform themselves.

“Yeah. So I did a Freedom of Information request as I wanted to read all the notes that had been made from my time in hospital and my time with the [treatment] team.” (Ivona)

“Very broadly, but Google help me a lot” (Ashlyn)

“Yes, I read about it. I researched and. And read about it.” (Bojan)

Social media could potentially play a role in widening access to information for people from all backgrounds. Ashlyn, 21, was the youngest participant by 9 years and was the only one to mention social media as a source of information. The role social media plays in how patients make sense of their diagnosis could be good and bad; as such, clinicians should be aware of what is out there.

“I downloaded the social media app TikTok. And TikTok has that algorithm which gives you more and more of what you have watched. And, unfortunately, I'd kind of consumed the mental health side of TikTok, but not the one that tells you like how we can get better or positive tips. It was a lot of like sectioning and self-harm.” (Ashlyn)

It was clear from the reports of the participants that there was a lot of variability in their access to information. Ivona describes how the ability of participants to inform themselves about the condition they had been diagnosed with was very dependent upon the participants' backgrounds and access to information.

“if someone won't tell me I'll go and find out. If I'm not getting what I need from one source, I'll go and find out. And I think that makes me quite lucky that I've got the resources and the intellect to do so, as I know that not all people who suffer with mental health conditions can do what I do, can understand what I can, or have the educational level.” (Ivona)

For those participants who were not able to independently source information to help their processing of the diagnosis, as will be shown by subtheme 2, they went on to find people to process their diagnosis with either clinicians or in their personal lives. However, for some, the impact of the loss of trust discussed in theme 3 prevented this from happening. This was demonstrated by the fact that even at the point of the research interview some participants had still yet to find information to process the news, or anyone to discuss it openly with. Theo, for example reflected on his experience of participating in the research interview:

“Well, you know, it would have been good to have done this [research interview] earlier you know, cause like I think they made the decision too quick but like you don't wanna tell them in the team, cause you worry that would go against you, and you know the worry is that the process might take even longer you know.” (Theo)

Theo clearly did not feel safe to discuss his diagnosis with his clinicians because of concern that it could be received negatively.

Subtheme 2 – Relational Recovery

This subtheme describes the process of coming to terms with their diagnosis positively. All participants interviewed felt they were generally a lot better than at the point of diagnosis and discussed how, time, support from their families or the EIP team and therapy had contributed to this.

All participants' improvement did not come without a wide variety of support and highlighted the relational aspect of recovery.

"I was very shocked, but I think people help me kind of rationalise the fact that, like. I guess it's not as bad as you think it is like" (Ashlyn)

"The first thing you think is am I officially crazy or what? Am I gonna be on medication for the rest of my life? But... my mental health team have said to me that that's like probably not gonna happen, like they've told me that you can make a recovery." (Ernest)

For eight participants, it was support of family and their care team that were the biggest factors in starting to believe that recovery was possible the . Diana, however, described how meeting with others while in the hospital helped her to normalise what she was going through, while seeing people getting discharged helped her feel hopeful of recovery.

“You just felt that there was light at the end of the tunnel. You wasn’t always gonna stay in that psychotic state” (Diana)

Family support was key for participants initially in providing practical support, but later the foundation of hope for either recovery or for self-acceptance.

“My mum was there, which I was happy about, with me not trusting my mind and the things that I believe in, see and hear, it's quite helpful for me to have my mum there or just a member of my family there with me.” (Isa)

“She [sister] had to bring me clothes and stuff cause I didn't have anything with me and the clothes I was in that was all I had... She helped to put me at ease, she'd say to me like, you're not gonna be here forever you're not gonna be like this forever, we will get you back to normal, so she made me feel a bit hopeful” (Leyla)

For others, direct experience of familial mental health struggles and recovery, helped to provide tangible examples of recovery or sources of support who understood what they were going through.

“I sorta knew how bad my half brother is and how bad he can be at times and the way he goes into his own mind and stuff, and like knowing that he has got better you know, that helped. Cause I’ve seen like it before.” (Ernest)

"I would say probably just having family that had experienced poor mental health was something where I felt like. I wasn't completely alone with my diagnosis like I could talk to them." (Ivona)

Almost all participants cited the clinical or therapeutic support they had received as a factor in the progression of their beliefs about their diagnosis and recovery journeys.

"I used to do private therapy as well, and I could. I could talk to my therapist about my diagnosis" (Ivona)

"Yeah, they've [treatment team] been pretty good... I feel like I understand it more than when I first heard it, I don't feel quite so frightened by it." (Diana)

"Obviously [treatment team] they came into play and they kind of reassured me in the fact that I would be taken care of up to, I believe, three years. To me then, that was a very long time... but now, I don't want it to end!" (Ashlyn)

For some, it was medication that helped to feel hope for change.

"It doesn't feel scary anymore actually, no, I think the tablets I've been taking have helped like, I'm going back to work and that has helped cause I'm not now sat at home just thinking about it." (Leyla)

Generally, the message was one of positivity for how the participants had developed in accepting their diagnoses and their recovery journey.

“Having mental illness isn’t an easy thing. Like when your brain is wired to not act or react normally it is quite difficult, but my learning how to manage it and learning how to be at peace with my diagnosis is really nice. It’s a lovely place to be in.”

(Ashlyn)

“Umm to be honest, I am just happy to feel back to myself at the moment, I do not really care much about anything else at the moment, like as long as I get my medication, I don’t want to take it forever but I am feeling good on it now, and I am talking to the therapist and I am doing so much better.” (Niki)

Niki’s reflection that she does not “really care that much about anything else at the moment” was typical of the participants. They had all moved beyond the initial shock of diagnosis to a place of acceptance and were focussed much more on the recovery and positive changes that had occurred in their lives. Finally, Ashlyn offered a reflection on her transition to feeling like she was more than her diagnosis which is reflective of the experience of the majority of participants.

“You’re not stuck anymore labelled as a single thing...To give the example like, if someone had lost a finger, like that’s not the only thing that they know you for because they don’t have ten fingers. I’m very comfortable in the fact that I do have this condition and it is a condition that I’ll have my entire life... The best way I can go

towards and go about it, is accepting it and living my life beside it, not just being a patient, not just being like an individual who suffers with mental health” (Ashlyn).

Discussion

Overview

This chapter summarises and situates the study's results within the context of existing theory and research. A critical appraisal of the study is made before finally discussing the implications of the research on clinical practice and future research.

Summary of findings

The research sought to investigate how individuals who had been given a diagnosis of psychosis experienced this and what impact the process had had on them. The research question was:

How do individuals with a diagnosis of psychosis experience learning of their psychosis diagnosis and how does this impact them?

Participants described an often challenging initial encounter, mitigated or worsened by the actions of the clinicians involved but also strongly influenced by their own prior beliefs and knowledge of psychosis. They spoke of a process of disempowerment and passivity in the face of services and clinicians. They generally left the experience confused with a lack of information provision at a time when they sought clarity and understanding, providing a space for unhelpful narratives to grow. They finally described a journey of acceptance with the support of others playing a key role in their coming to terms with their new identity, being able to hold their psychosis diagnosis in accordance with their earlier sense of self.

The four themes that were created through the use of reflexive thematic analysis were “No Easy Way to Say”, “Setting the Tone”, “Power”, and “Changing Perspective”. I will discuss these themes in the context of existing literature and theory.

Theme 1 – No Easy Way to Say

This theme concerned the participants’ perceptions of how they learned of their diagnosis in terms of both the communication style used by the clinicians and the other factors that influenced the experience. The stories shared by the participants highlighted the challenges that clinicians face in communicating difficult information, such as a diagnosis. The primary conclusion that can be drawn is that clinicians should approach a diagnostic meeting in a person-centred way to minimise the possible harm.

Patient preferences of communication factors

Despite inconsistencies between participants generally, some factors were universally appreciated when it came to communication. The ability for participants to ask questions of the diagnosing clinician, to explain themselves and tell their story was always appreciated. Similarly, the diagnosis being communicated by a figure that was perceived as caring was also positive. Factors that participants did not appreciate were communication being perceived as rushed or impersonal. The variation in preferences reported indicated that when communicating a diagnosis, a person-centred approach where the clinician aims to identify and then meet the needs and preferences of the individual patient would be most likely to reduce negative outcomes. As discussed in the introduction, there is a lack of

empirical evidence specific to mental health regarding what factors are deemed positive in a diagnosis disclosure from the patient's perspective.

The findings, however, conform with the evidence base established in other branches of medicine. In cancer care, the most important factors identified when communicating with patients were the provision of personalised information and the patient having some control over the level of information provided (Bryant et al., 2018). Similarly, general healthcare communication literature within medicine and nursing recommends using person-centred approaches when conveying bad news to patients (Harvey et al., 2007; Monden et al., 2016; Rosenzweig, 2012), and these findings have received further support in a systematic review (Dwamena et al., 2012).

The recommendations from the breaking bad news literature, in particular, are very much in line with the results of the reported study. Important factors include person-centred communication, conducted face to face, ensuring that the clinician understands the patient's understanding of the information given and their perception of the condition and the impact the news is having on them (Monden et al., 2016). When considering this theme in combination with the reported stigma experienced by participants because of their diagnosis, it is not surprising that the results of this study concur with the existing breaking bad news literature.

Interpersonal communication models

The participants' experiences in the reported study demonstrated the impact of linear and transactional communication on diagnosis (Gamble & Gamble, 2013). Four participants experienced a diagnosis that was more in line with a linear communication strategy (Ivona et al.). The model suggests that in linear communication, the message being

communicated is subject to distortion by “noise” before the receiver interprets it. Noise can be verbal, non-verbal, and contextual information that distorts the message being sent and how it is then interpreted. Bojan and Theo, in particular struggled with the impact of noise distorting the message the clinicians aimed to convey and experienced more distrust of the clinicians and their motives as a result. Linear communication, therefore, will likely increase the risk of negative outcomes as it leads to greater miscommunication or misinterpretation. When utilised in a context, such as a patient in a hospital under section, the contextual “noise” in particular could further enhance the feelings of threat and punitiveness, rather than treatment or care.

In contrast, those who experienced communication more in line with the transactional communication model reported better relationships to treatment, despite all experiencing initial confusion or distress upon hearing the diagnosis. The transactional model offers a useful framework for thinking about how information can be conveyed and received well in the context of diagnosis. It takes account of the wide variety of individual characteristics, prior understanding, and the context in which the communication is occurring while emphasising the importance of ‘back and forth’ between the two parties in generating understanding. This approach can work in harmony with person-centred communication that recognises the huge variation between patients in terms of prior understanding, beliefs, communication preferences, and the variety of settings in which diagnosis can be conveyed.

The Right Time

The reported study highlights the complexity of when to tell someone about their diagnosis. As discussed in the introduction, the medical model operates based on informed consent for patients when consenting to treatment. As a result, communicating a diagnosis is essential for patients to be truly informed (GMC, 2020). The exception to the expectation of disclosure is where information would cause harm to the person receiving the diagnosis. The description by participants of the distress caused by being diagnosed while still experiencing the positive symptoms of psychosis raises a question of whether doctors should consider withholding a diagnosis until symptoms have reduced, to minimise the harm from diagnosis. It is worth recognising that participants in the reported study generally experienced distress regardless of the extent of symptoms at the time of diagnosis. However, applying a person-centred approach could be beneficial where a diagnosis would severely counter the patients' perception of reality, which could be withheld until a later point. This could help to reduce the distress of such a challenge to the patient's sense of reality. The impact of the diagnosis on Ernest in particular, whose confusion at the diagnosis contradicting his beliefs led to him taking an overdose, demonstrates the potential benefit of delaying a diagnosis in certain cases.

Theme 2 - Setting the Tone

Information Provision

Sullivan et al., (2001) found that medical professionals underestimated the amount of information that patients wanted to receive about their conditions. The results of the reported study were consistent with this finding, highlighting that for most participants,

there was a desire for greater information provision at the time of diagnosis than they had been given. As well as information provision, participants were consistent in their desire for more discussion of what the diagnosis meant for them, beyond simply a collection of symptoms, again this is consistent with other studies (Howe et al., 2014)

Emotional Response

The range of emotional responses to the diagnosis, including shock, anxiety and relief, were in line with existing literature. The immediate impacts described by participants following the diagnostic meeting replicate the findings of several studies featured in the systematic literature review reported in this thesis (Jansen et al., 2018; Loughland et al., 2015; Tranulis et al., 2013). This reaffirms that the confusion or shock experienced by most participants is present from the first meeting and can continue through treatment. Recognising this and taking steps to minimise this as early as possible could mitigate negative beliefs about a diagnosis.

For the minority of participants who experienced relief at the news of their diagnosis, the key factor appears to have been prior knowledge of psychosis and the absence of any strong negative beliefs about the condition. Two of the participants in the reported study who experienced relief had never heard of the condition before (John and Niki), while the third had a high level of knowledge due to her study area. In the systematic literature review, the available evidence suggested that the relief felt due to a diagnosis of psychosis generally appeared following an initial sense of shock or disbelief. The three participants in the reported study who experienced immediate relief, represented the two poles of the spectrum of understanding, from total lack of awareness to having studied the condition. This further supports the idea that unhelpful narratives about psychosis that exist

in the public consciousness contribute to the fear and anxiety experienced at the point of diagnosis (Luhmann et al., 2015a, 2015b). Individuals who had no awareness of psychosis in the reported study experienced it as no different to any other diagnosis, while the individual with a very high level of knowledge had a greater understanding of the medical model and a more nuanced view of how she perceived her experience to fit within this. Both naivety and high levels of knowledge appear to have reduced initial anxiety felt at diagnosis and promoted a positive, relieving experience of diagnosis.

Stigma

Participants generally viewed their psychosis diagnosis, understandably and expectedly, through the lens of the medical model. This appears to contribute to their distress, reporting initial fears that the condition is untreatable, narratives around madness and a fear that the diagnosis would result in perpetual medication use to manage their symptoms. The reported study did not investigate the participant's experience of the symptoms of their psychosis, only the diagnosis itself, but the results are in concordance with the findings of a cross-cultural analysis of the impact of voice hearing and delusional beliefs (Laroi et al., 2015; Luhmann et al., 2015a; 2015b). In the cross-cultural analysis, the negative beliefs about the experience were generally reported by participants from the USA, while participants from India and Ghana experienced them as more benign. Pertinent to the reported study, one of the key differences in participants beyond geographical location was their awareness of psychiatric labels for their experiences, conceiving them as representing a disease rather than a spiritual experience. The results of the reported study support this finding in that the participants who did not report any prior knowledge of the condition also did not experience distress or internalised stigma at the point of diagnosis. This could

provide further support for the idea that the meaning attached to the experience of delusions and hallucinations is qualitatively different due to knowledge of the medical explanation of their experiences as a disease.

Theme 3 – Power

The impact of power on the experience of receiving a diagnosis was clear throughout the interviews. The participants described a clear awareness of the power held by doctors and services and the impact that they could have on their lives. This had the potential to make the experience feel punitive rather than curative. This finding contributes to the debate around the purpose of diagnosis generally and the use of involuntary detention under the mental health act; for whose benefit are these measures taken, is it the patient or for society? The NHS guidance on patient involvement in care (NHS, 2017) clearly states that when individuals are involved in the decision-making process about their care, this leads to better outcomes and increased engagement in services. This is not simply an ideal but a legal duty under the Health and Social Care Act 2012. The reported study demonstrates how the participants did not feel involved in decision making. Participants consistently reported that their diagnosis felt disempowering and that they were passive recipients rather than active participants. Whether it is possible to deliver a diagnosis collaboratively, in line with the 2017 guidance, is a question worthy of more exploration. One alternative to diagnosis that directly acknowledges power within the clinician patient relationship is provided by the Power Threat Meaning Framework (PTMF). PTMF could provide a framework for having less stigmatising conversations avoiding the use of diagnostic labels (Johnston & Boyle 2018). Rather than asking the question of “what is wrong with you” and providing a diagnosis as the answer, PTMF asks four questions; “what has happened to you”, “how did it affect you”,

“what sense did you make of it”, “what did you have to do to survive” (Johnstone et al., 2018). Through the use of PTMF, clinicians would not only be mitigating for stigma by having more person centred conversations but would also be invited to discuss and reflect on the role of their own power as clinicians within the NHS. This would allow for the potential alleviation of the negative effects of the doctor patient power imbalance. As seen from the results of the reported study, patients are aware of the power held over them by clinicians and services. When this is not discussed it is likely that patients are more inclined to interpret decisions made or labels given, as being punitive rather than curative, leading to distrust of clinicians and services.

The participants’ perception of powerlessness is not surprising when 6 of the 10 received their diagnosis in a hospital setting. The evidence for a feeling of powerlessness and loss of control within a hospital setting is well established (Wood & Alsawy, 2016). In a comparison of procedures involved in involuntary hospitalisation in the UK and Germany, it can be seen how few protections the patient has in the UK compared to Germany. In Germany, a doctor must obtain a court order for an involuntary hospitalisation or treatment. In the UK, there is comparably little protection, with no requirement for court involvement and a wider range of risks included as reasons for hospitalisation (Rottgers & Lepping, 1999). The number of patients being hospitalised involuntarily in the UK is high compared to other European nations, and the rate is increasing (Bonnet & Moran, 2020; Conlan et al., 2022; Keown et al., 2011). Bonnet & Moran (2020) explore the factors behind the high hospitalisation rate, arguing that overstretched and under-resourced services resulted in patients being admitted due to a lack of alternatives. Participants in the reported study were aware of the pressures on the NHS, and this knowledge further contributed to their sense of being passive rather than active in their treatment and diagnostic process.

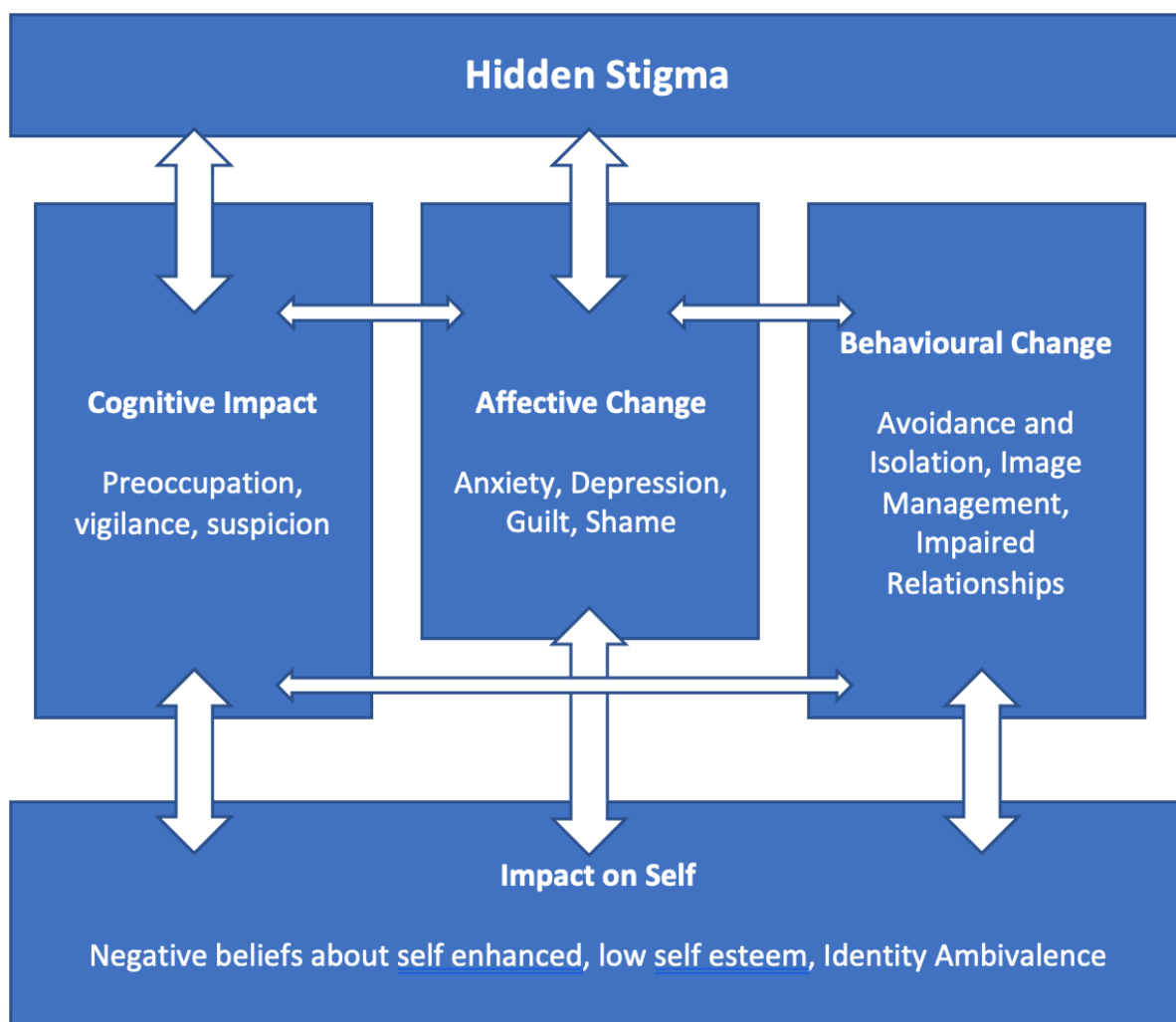
Theme 4 – Changing Perspective

Relational Recovery

The participants' reports demonstrated the importance of the relational aspect of recovery. Disclosure of their diagnosis and discussion of it was one of the key factors in the shift in perspective from a negative, stigmatised view of psychosis to a more balanced, accepting position. The relational aspect of recovery supports the idea of disclosure as key to challenging and reducing self-stigma. Pachankis (2007) describes a model of internalised stigma that applies to stigmatised parts of individuals' identity that can be hidden, such as diagnoses, sexuality, or religion and the impact that concealment of this aspect of identity can have on individuals.

Figure 6.

Cognitive Affective Behavioural Model of Concealed Stigma



The Pachankis (2007) model of concealed stigma demonstrates the impact of concealment of the stigmatised aspect of identity on cognitive, affective, and behavioural functioning and their sense of self. Attempting to hide the stigmatised identity creates feedback loops across these domains that entrench the negative outcomes described. Pachankis discusses the necessity of disclosure of the stigmatised aspect of individual identity in order to break this cycle; however, also acknowledges the difficulty of doing so in societies that stigmatise. This change process can be seen in the descriptions of participants in the reported study being based on relational support; their own acceptance of the diagnosis and reduction in negative beliefs about psychosis came through relational safety

in discussing it, whether that was with their care team, family, or friends, the disclosure of the diagnosis in a safe environment was key.

Empirical support for the disclosure as key to recovery can be seen in Corrigan et al. (2010), who found that being open about diagnosis helps to reduce self-stigma experienced following a diagnosis of a severe mental health condition. The use of interventions that directly address the fear of disclosure have also shown to reduce stress and improve self-esteem in individuals with mood disorders (Modelli, 2021). Safe disclosure is also a method of addressing shame in Dialectical Behavioural Therapy (Linehan, 2014). There it is described in the context of opposite actions; a feeling of shame can be countered by disclosing the source of shame to a trusted individual, reducing the degree of shame felt when the negative reaction that had been anticipated does not come to pass. The principle has also been supported by empirical studies (Rizvi & Linehan, 2006).

It is important to recognise that families and friends of individuals diagnosed with psychosis may not always be in a position themselves to offer support. Families of individuals diagnosed with psychosis have been shown to experience feelings of stigma towards the family member diagnosed (Kuipers et al., 2010). Similarly, families and carers of individuals diagnosed with psychosis have been shown to struggle to understand the experiences of their loved one which can put strain on relationships and family dynamics (Wainwright et al., 2015). Finally, the impact of the new role as a carer, particularly in an emotional sense, is high (Onwumere et al., 2016). These studies demonstrate the challenges faced by families of those diagnosed with psychosis and so it should not be assumed that families will be able or willing to offer emotional support that could lead to the acceptance of a diagnosis of psychosis and could even hamper this process. This further emphasises the importance of services in providing a safe space for discussion of what diagnosis means for

the individual, in order to help promote relational processing as well as providing support for the families of patients through providing psychoeducation and offering family intervention (FI).

Clinical Implications

It is important to acknowledge that the results of the reported study are specific to the context and time in which the research was conducted. However, as discussed prior, the findings correlate with other available research in various ways. As such, some further clinical implications of the reported study are discussed at the levels of clinicians, services, and wider policy.

Clinicians who Diagnose

One of the primary conclusions from the reported study is 'patients' preference for a transactional rather than linear communication style. One easy win for improving the proportion of patients who receive their diagnosis in this way would be to cease the practice of disclosing diagnosis for the first time through written communication methods. When communicating a diagnosis face to face, to best adhere to a transactional communication standard, when disclosing diagnoses to patients, clinicians should consider adopting the principles of person-centred communication as a basis for communicating the information. This is due to the variation in individual responses to the news due to individual characteristics and context. NICE provides guidance for tailoring healthcare services to individual patients (NICE, 2021). Section 1.3 of the guidance provides a good summary of factors that support tailoring healthcare to the individual and corresponds well with the

principle of patient centred care identified as a key feature of positive communication in this study. The results of this study also supports research from other areas of medicine that when delivering news that is likely to be perceived as negative by the receiver, the principles of person centred communication allow the clinician to respond best to the recipient's needs. A five-phase protocol (Fine, 1991) developed for communicating critical illness, which matches well the principles of person centred communication, could be utilised to help scaffold the conversation for the clinician. The five phases are:

1. Preparation – taking time to understand the context of the patient, their life situation, their cultural and spiritual beliefs, and their individual needs, and preparing an appropriate setting to communicate the diagnosis.
2. Information Acquisition – Building an understanding of the patient's prior knowledge level, their beliefs about their symptoms, and how much information they would like to know from the meeting.
3. Information Sharing – Disclosing the information to the patient in a clear, empathic way.
4. Information Reception – Assess the impact of the information on the patient, space for discussion, clarification, and questions.
5. Response – Acknowledge the impact of the information on the patient and conclude the meeting.

As well as how the diagnosis is communicated, clinicians should continue to check in with patients regarding their understanding of the diagnosis and provide as much information as the patient desires. This allows for a better understanding of the condition and minimises the risk of patients seeking information from unhelpful, potentially damaging

sources. Clinicians underestimate the amount of information patients want regarding a difficult diagnosis (Sullivan et al., 2001), and there is evidence from research on schizophrenia that mirrors the reports from the participants in this study that they would have appreciated more information about the condition (Howe et al., 2014).

Provision of information at the initial meeting is important but continued checking in on understanding and discussion of the diagnosis and what it means for the patient should be considered as part of the ongoing care package. The progressive self-stigma model (Corrigan et al., 2011) considers self-stigma to progress from an initial stage of awareness of the stigma followed by agreement with the stigma and finally application of the stigma to the self. Applying this model to the diagnostic process indicates a need to challenge stigmatised beliefs early on and the importance of ongoing work to prevent the stigmatised beliefs from taking hold. Stigmatised beliefs could be assessed at the first meeting, and measures put in place to address this with the patient. Clinicians could incorporate self-stigma specific measures (Corrigan et al., 2006 & Corrigan et al., 2012) into their initial assessment and diagnostic meetings to help scaffold conversations about self-stigma.

Services

One aspect services should consider, highlighted by the reported study, is the potential for iatrogenic harm to be inflicted on patients through the perception of powerlessness experienced while navigating services. A feeling of powerlessness is a key element of trauma, and the link between trauma in early psychosis is well established (Dean & Murray 2022; Schafer & Fisher, 2022). Navigating services in this context could pose a risk of re-traumatising patients. Indeed, it has long been a subject of debate whether psychosis and PTSD are simply two formations of the same spectrum of distress (Morrison et al.,

2003), and there is growing evidence for the use of EMDR and other trauma therapy protocols when working with psychosis (Adams et al., 2020; de Bont et al., 2019). The results of the reported study demonstrate the perception of both clinicians and services as wielding power over the participants through their care journey and how difficult this was for them. In light of this and the extensive evidence of trauma influencing psychosis, it is likely that patients' experience of diagnosis within services would improve if services operated under a trauma informed care model (Office for Health Improvement and Disparities, 2022). This recommendation aligns with a growing call for greater trauma informed care being applied in EIP services (Mitchell et al., 2021; Wood et al., 2023).

The impact of power in the reported study was even more acutely felt by participants diagnosed in hospital settings under the mental health act. This is unsurprising as this is a situation where power is very clearly being used to override the patient's wishes. Services could consider shifting towards greater use of less stigmatising more collaborative explanations of psychological distress such as PTMF, discussed previously. Such changes would however take significant adaptation within services across the NHS, quick wins however that would be implementable in the short term could include changes such as; applying the same trauma-informed principles discussed above to a ward setting to bring about a less distressing diagnosis experience from the patient's perspective. Making time for a specific diagnostic meeting while the patient is staying on the ward, rather than diagnosing patients as a part of a ward round where the priority is managing symptoms and setting up treatment plans rather than fully understanding the patient and their context. Addressing the high ratio of staff to patients while the diagnostic conversation is happening could also help reduce distress felt by patients at the time of diagnosis. Greater inclusion of families or support networks in the process, only one participant in the reported study could

involve their family in the diagnosis process while admitted. Being open to involving family while the patient stays on the ward would likely help them process the diagnosis. There is no direct research into family support at psychiatric diagnosis; however, from other branches of medicine, research suggests that involving a family member in the meetings with doctors was beneficial (Bryant et al., 2018). It is important to recognise that participants in the reported study received their diagnosis during the time of the Covid 19 pandemic, and therefore the restrictions on family access may have been more limited for the participants than is typical.

For a more inclusive approach to diagnosis and service provision generally, services could increase the use of Open dialogue. Open dialogue is an approach to treating psychosis that was pioneered in Finland and has since spread across the world. Open dialogue involves services working directly with the patient, their family, and their support networks in a totally transparent way. All decisions are taken collaboratively and in an individualised, person-centred way that promotes recovery within the unique circumstances that each patient comes with (Seikkula et al., 2001). Such an approach would correspond well with the person-centred communication for disclosure of diagnosis preferred by the participants in the reported study. In a systematic review of the evidence for open dialogues effectiveness the use of this treatment model was concluded to have promising empirical results (Freeman et al., 2019). The study was cautious not to draw firm conclusions due to the risk of bias present in the included studies and the lack of any randomized controlled trials, but the review is still supportive of the use of open dialogue in the treatment of psychosis. Even if services were to stop short of complete reform to run in concordance with an open dialogue approach, when considered with the results of the reported study, incorporating

the principles of open dialogue into the early stages of contact with services such as diagnosis and treatment planning could have positive impacts for patients.

A final general consideration, primarily for community services, indicated by the reported study is group provision. The reported study suggests that disclosure and forming relationships with people who know the diagnosis is important in overcoming stigma and accepting the diagnosis. This was primarily reported as being a connection with family and people close to the participants. It is possible that individuals who are socially isolated or have limited family contact are less likely to experience the stigma reducing benefits of disclosing their diagnosis. In this situation, supportive non-therapeutic groups provided within early intervention teams, designed to connect individuals who share a diagnosis in a space where they can talk openly about it could be useful in reducing self-stigma.

Policy

At a policy level, the reported study contributes to the wider debate around diagnosis, particularly for whose benefit diagnosis is for. The results of the study demonstrate that for the participants interviewed, regardless of how the diagnosis was delivered, where there was a prior understanding of psychosis, distress was caused. It is plausible that moving away from the use of psychiatric diagnostic terms could reduce this distress and this could be done through moving towards alternative methods such as PTMF discussed earlier, or through increased use of formulation for the purposes of accessing and guiding treatment. As discussed in the introduction, the justification of whether to give diagnoses that we know to be stigmatising sits between two core principles of medicine. Firstly, that medics should do no harm and secondly, that treatment must be made based

on informed consent. The exception to this is when the patient has been deemed to be lacking in capacity and is being treated under the Mental Health Act. The general medical justification is that while diagnosis can do harm, this can be overridden by the need to achieve informed consent from individuals for treatment. For consent to be fully understood, the patient must know what they are being treated for; therefore, a diagnosis is necessary. However, it seems plausible that informed consent to treatment could be obtained without a diagnosis. For instance, using a formulation, as is common practice within a therapeutic process (Johnstone, 2018). Formulation is a more in depth description of the circumstances and experiences associated with psychological distress. They are created collaboratively between the clinician and patient and provide a much more personalised description of psychological distress than a diagnosis (Johnstone, 2018). Using a formulation as the basis of access and treatment to services would be another possible alternative to the current diagnostic based model. Even if a treatment plan was limited to pharmacology, this could still be prescribed based on a formulation, without an explicit need for diagnostic labels that can contribute to stigma and harm. With the limited validity of the various categories of mental health diagnoses, as discussed in the introduction, the continued use of stigmatising diagnostic labels should be questioned, and formulation could offer an alternative foundation for referral and accessing treatment within mental health services.

As a change of this magnitude is not likely to happen in even a medium-term timeframe, the Pachankis (2007) model can justify public level interventions to reduce the stigma felt due to the diagnosis. This could take the form of public awareness to allow individuals with stigmatised diagnoses to feel safer disclosing this aspect of their identity. Any such change from campaigns would also likely be minimal in the short-term, and

therefore organisations like the hearing voices network who provide support groups across the United Kingdom (National Hearing Voices Network, 2003) could provide important stigma reducing environments providing individuals diagnosed with psychosis the opportunity for interaction with others who share this stigmatised identity. This sense of group membership, Pachankis (2007) argues, can shift the stigma from an internalised position, as interaction with others who share the stigmatised identity helps to accept it as one part of an identity, rather than a global representation of the individual. This kind of shift was observed in Ashlyn's story of acceptance, who was exposed to others with similar diagnoses through social media. Her experience of mental health content on TikTok exposed her to dangerous and supportive content, so should be used with caution, but it could represent a potential normalising resource for individuals unable to access other group support.

Research Implications

In order to assess the generalisability of the finding's researchers could take the themes identified in this research and use them as a basis for a questionnaire exploring diagnostic experience for people diagnosed with psychosis. This would make it easier for a wider sample to be drawn to allow for an assessment of generalisability to be made. Such a questionnaire would enable researchers to perform many comparative studies; for example, it would be interesting to explore in more detail how the experience of being diagnosed within hospital and community settings differs and what impact this has. Future researchers could also look at the experience of diagnosis from the perspective of different groups of participants. For example, do individuals from racially minoritised backgrounds experience the diagnosis in the same way as white patients?

From the reported study, it appears that diagnosis led to some of the participants re-evaluating the experiences they had been through, changing their perceptions of the past. This aligns with the findings reported in a recent study into the development of first episode psychosis (Hansen et al., 2023). This likely makes it hard for participants to accurately recall the beliefs they held about diagnosis prior to the diagnosis being made, potentially impacting the accuracy of the account. Considering this, to further the understanding of the formation of stigma, a future area of research could be to explore patients' perceptions of their experiences before and after diagnosis.

The reported study contributes to the research base for the association of psychiatric labels with stigma formation. Stigma, however, is not driven simply by the changes brought about by diagnosis; further research into the mechanisms underpinning stigma formation is warranted. In order to isolate the impact of diagnosis, a service could trial an alternative method of access which used formulation rather than diagnosis as the basis for access to services and subsequent treatment. Formulation would need to be used prior to diagnosis rather than presented as an alternative understanding following diagnosis, and so would be challenging to establish in under current NHS service conditions. If created however such a study would allow for the exploration of stigma formation absent a diagnostic label to learn more about what other factors contribute to stigma formation. Such a trial could also examine how participants perceive the process of formulating their experiences without a prior diagnosis.

Strengths and Limitations

A primary strength of the reported study is that at the time of writing, it is believed to be the first exploration of diagnostic experience for individuals diagnosed with psychosis. As this is very under researched in mental health, the study provides some initial ideas for further research corroboration of the findings and several straightforward clinical practices that could improve the process for future patients. The study combines well with research conducted in other areas of medicine, where diagnostic communication from the receiver's perspective has a stronger evidence base. This raises questions as to why the field of psychiatric diagnosis has so far failed to take account of the patients' perspective.

The sample of participants, while smaller than is ideal for a thematic analysis, comprised of a diverse mixture of ages and ethnicity and a reasonable gender balance of 6 female to 4 male participants. This reflects well on the random sampling method used, which aimed to provide a broad range of participants that was representative of the patients within the service. As discussed in the introduction, a sample of 12 participants has been demonstrated as the minimum to achieve 90% saturation of themes when using a TA methodology, and this was the aim of the reported study. The final sample achieved was 10 participants, two short of the target. This is clearly a limitation of the reported study. The decision to end the recruitment at 10 participants was taken partly based on time due to the research being carried out as part of a doctoral thesis with a deadline. The decision was also based on guidance from the literature on sample size requirements. Braun & Clark (2006) discuss how the interaction between the homogeneity of the participant pool and how narrow or wide the subject of the research question and interview schedule. The question of homogeneity within a sample is a complex one. Homogeneity can be measured according to many aspects; age, gender, ethnicity and other individual factors, the source of the

participants, and the characteristics that unite them. In the reported study participants were all drawn from a single service in a single geographical region, indicating homogeneity.

However, they were also very diverse in terms of nationality, ethnicity, and age.

Furthermore, participants were informed of their diagnosis in a different ways - 3 received a letter while 7 received the news face to face. These different methods of delivery have been discussed previously, with a letter seen as comparable to a direct but linear communication style. This further source of heterogeneity within the participant pool, however, has reduced the homogeneity of the sample and as a result the study and its conclusions would have benefitted from more participants who were informed by letter. Overall, regarding the sample size, the aims and questions of the study were narrow, focussed on a single event, diagnosis, for a single psychiatric condition. The sample, while diverse in some respects, was drawn from a single service which treats a single group of participants. When considered together, the sample size of 10 can be justified, however, the study's results should be interpreted while taking account of these factors as they limit the generalisability of the findings.

The recruitment strategy was one of the biggest challenges of the reported project. The primary reason for this was the reliance it placed on the engagement of clinicians to pass on the invitations once the participants had been randomly drawn. The strain that the hosting service was under and the resultant pressure on the clinicians was not appreciated prior to the research taking place. Several of the clinicians I was working with were struggling with staff sickness as well as unfilled posts that were out for recruitment. This meant that some care coordinators were covering others' caseloads on top of their already highly demanding roles. As a result, the capacity of clinicians to help and their willingness to engage with the process was overestimated. While most care coordinators were very

generous with their time and engaged with the recruitment process, several did not engage with the recruitment requests. This created a difficult situation where participants were drawn but not contacted, as their care coordinator did not respond to requests to pass on the invitation. As a result, regrettably, some participants were drawn but never invited to participate. This reduced the true randomness of the final sample, as groups of potential participants under the care of the non-engaging care coordinators were effectively excluded. This limitation in the recruitment process also meant that the overall recruitment took far longer than anticipated and resulted in fewer participants recruited than was aimed for. In order to address this, greater work with the care co-ordinators prior to recruitment would be required to improve buy-in.

A further potential bias in the sample is that all participants who participated were progressing well with their treatment and progressing through their treatment pathway with the service at the time of the interviews. This is not wholly representative of the population of individuals recently diagnosed with psychosis. Early intervention services are not a panacea and not all patients will engage or progress through the service as hoped, the disengagement rate at 12 months has been measured in a UK EIP service at 24.6% (Turner et al., 2007). This makes it likely that participants affected by their diagnosis will have been discharged or dropped out of the service. This is a very difficult limitation to overcome, however, it is important to acknowledge that this factor likely means that alternative perspectives were missed from the sample in the sense that only individuals who are doing well participate.

Reflexivity

My personal and professional position on diagnosis and my prior personal and professional experiences have been reported throughout this study. They have been at the forefront of my mind when designing, conducting, and analysing the research, and I have used a reflexive log to help process my decision making. My professional experience of the negative impacts of psychosis diagnosis in my clients undoubtedly shaped the design, and what I was drawn to when analysing the interviews. I recognised this and, throughout tried to reflect on why I was focussing on one area over another, why I was seeing what I was seeing in the data, and to balance any areas of particular focus. The experience, however, has shown me that it is impossible to uncouple from my own perspective completely.

While carrying out the interviews, I was struck by the impact that participation had on many participants. The interview was often the first conversation they had ever had about their experience of the diagnostic process. This presented challenges for me as a researcher and also as a therapist. I had to keep in check my habitual response to offer a normalising or empathic statement when participants were discussing aspects they found distressing or from drifting into any kind of “therapy speak”. This felt both alien and impersonal at times during the interview, and I had to remind myself that the purpose was not therapeutic (although incidentally, many participants found it to be so) and that I did not need to think about building any kind of therapeutic alliance or relationship. I managed this by shifting position after the interview's conclusion, returning to a more familiar stance and offering reassurance or normalisation to participants where I felt it was required.

A similar adaptation was required in adhering to the process of conducting a semi-structured interview. At times, when participants would deviate on a tangential point unrelated to the interview, I felt uncomfortable at holding the balance between allowing

them to tell their story in the way they desired while also being conscious of time limitations and the need to obtain the information relevant to the study. This also impacted the number of follow up questions that I felt able to ask in some interviews.

Finally, I also often wondered how the participants were positioning me as the interviewer. I was clear throughout the process that I was not affiliated with their treatment team, and that the research was carried out as part of a university thesis; however, despite this, many seemed to regard me as a staff member of the service. I was concerned about the impact this could have on the answers they provided and the emotional impact this would have on the participants who positioned me this way. This was particularly acute for me as the interviews continued, and I became more aware of the influence of service and clinician power on the participants.

Critical Appraisal

A critical appraisal of the reported study was carried out using the “Big Tent” methodology (Tracey, 2010) reported in table 7.

Table 7

Critical Appraisal of Study

Criteria	Description of Criteria	Strengths	Limitations
Worthy Topic	The topic chosen for research is relevant, timely, significant and interesting.	<ul style="list-style-type: none"> The research topic is significant and novel, exploring an under researched area. The research is relevant and timely, coming at time where psychosis diagnoses are increasingly being used alongside the expansion of early intervention teams over the last decade. 	
Rich Rigour	Sufficient richness and abundance of data sources, samples. Rigorous data analysis procedure which is sufficiently complex and in-depth to be able to describe phenomena being studied.	<ul style="list-style-type: none"> Analysis was carried out following well established reflexive thematic analysis procedures, acknowledging the strong influence of the researcher on the final output, while attempting to still convey the experiences of individuals diagnosed with psychosis. The analysis process is reported in a transparent way with examples provided in the appendices. The research attempts to convey the experiences of individuals diagnosed with psychosis in a rich level of detail, supplemented with direct quotations. Sample contained individuals from a diverse range of backgrounds and ages. 	<ul style="list-style-type: none"> Final sample size of 10 participants was two fewer than originally sought. Due to challenges with the recruitment process, a portion of the overall population were artificially excluded from potential participation.
Sincerity	Self-reflexivity about researcher's biases, goals. Honesty, transparency about research process including challenges.	<ul style="list-style-type: none"> Reflexivity is present throughout the research. The researchers position is explicit and the impact of this discussed to place the results in context. A reflective log was kept throughout the process of carrying out the research and extracts are reported in the appendix. 	

Credibility	Study demonstrates trustworthiness and plausibility of research findings	<ul style="list-style-type: none"> • Quotations are offered throughout to support the themes reported in the findings. 	<ul style="list-style-type: none"> • Participants were recruited from a geographically limited area and a single treatment team. • Study did not investigate the impact of the experience of symptoms that likely influence belief formation.
Resonance	Study's ability to influence or move the reader by presenting text which is clear, evocative and promotes empathy and identification. Study's ability to generate knowledge resonance for different contexts, situations and audiences.	<ul style="list-style-type: none"> • Meaningfulness of study was enhanced by involvement of experts by experience in consultation to design the research and ensure relevance of the interview schedule. • Supervisory input in reviewing the study design, procedure and write up help to ensure clarity. • Numerous rich and detailed quotes are provided to enhance the empathy and identification that readers can achieve with the participants accounts. • Limitations are acknowledged and inform recommendations made for future research. 	<ul style="list-style-type: none"> • Generation of knowledge is reduced by the lack of generalisability of the study due to participant pool from a single host service.
Significant Contribution	Study makes important contribution to the field by improving/ extending knowledge, theoretical understandings, or clinical practice.	<ul style="list-style-type: none"> • Study is the first of its kind, exploring the perspective of the recipient of the diagnosis. • The research adds to the limited body of evidence for the impact of diagnostic process for psychiatric conditions. • Clinical and service level recommendations are offered. • Further research ideas to address study limitations are offered. • The research and the systematic literature review contained within will be submitted for publication to widen the access to the findings. 	<ul style="list-style-type: none"> • All conclusions have to be interpreted with the generalisability limitations of the study in mind.

Ethics	Adherence to professional/ research ethics guidelines, responding ethically to issues which arise in research process.	<ul style="list-style-type: none"> • Ethical approval to conduct the research was granted by the Health Research Authority after a thorough review process. • Ethical concerns are discussed and mitigation measures made clear. • Ethical issues were discussed with experts by experience as well as the supervisory team to allow for multiple perspectives to inform decisions taken.
Meaningful Coherence	Whether the study achieves its stated aims, coherence between epistemological position of the research design, data collection, and analysis.	<ul style="list-style-type: none"> • Epistemological position of the researcher and the impact this had on the design and analysis of the research are discussed. • Critical realism and the use of Reflexive Thematic Analysis are compatible and suitable to achieve the research aims. • The findings of the study correspond with existing literature, enhancing claims of coherence.

Conclusions

The study explored the experience of receiving a psychosis diagnosis. The findings demonstrate that person-centred communication is key to a positive experience that reduces the negative impact of the power imbalance between patient and clinician. The study suggests that services should expect patients to experience stigma due to the process and take greater steps to assess and address this at an early stage in their treatment pathway. Services should also take steps to support patients in accessing immediate and ongoing information about their diagnosis to a greater degree than is currently offered. The study also supports the idea that the diagnosis is not in and of itself stigmatising; it is the

awareness of the public perception, formed through the lens of the medical model, that drives the experience of stigma. In light of this, services could consider whether there is an inherent need to continue to base their access criteria on a diagnosis or if an alternative route is possible. The likelihood of a radical change of this kind is, however, slim. Therefore, greater efforts should be made to reduce the negative public perception of psychosis through increased public awareness campaigns aimed at normalising and uncoupling psychosis from its current harmful narratives.

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Appendices

Appendix A

Extracts from reflective research log

Extracts following two meetings with experts by experience

<p>12.06.22 ■ Meeting (experts by experience)</p>	<p><i>Met with ■ for the first time, came away struck by his generosity of disclosure and inspired by how passionate he was about the topic. Really affirmed my belief in the value of the research. The concept of diagnosis and its delivery felt a lot less theoretical throughout our conversation. The way ■ was treated stood in such contrast to the dignity with which he now described the experience and the actions he has since taken in joining the EBE panel. Really helpful advice given regarding the recruitment process and the design and structure of the interview schedule. His reflections about not being too rigid in sticking to the schedule and allowing participants to tell their story in the way they want will stick with me. Have to remember my agenda is only one part of this and what is important for me could be alienating to participants, have to allow enough time for them to tell me what they want in the way they want to.</i></p>
<p>■ Meeting</p>	<p><i>Meeting with ■ went well, reaffirmed a lot of what I had discussed with ■. Again I was struck by the intensity of her feelings when recalling how she learned of her diagnosis, despite the experience occurring 13 years ago. Another example of reading a diagnosis in a letter rather than ever being told by a clinician. Discussion with David and Nicola had prepared me for the fact that some participants would likely have read their diagnosis however now hearing from all the experts by experience that they had never been told their diagnosis still surprises me. It seems such a strange practice to withhold the information from someone while actively treating them according to the diagnosis. Again struck by the impressive character shown in using the anger from years of poor treatment experienced as a patient to try to make changes as part of the EBE panel.</i></p>

Extract following completion of an interview

<p>28.04.23. Interview with ■■■ Research interview</p>	<p><i>Really enjoyed that interview. ■■■ was so open and interesting to speak with. Such a shame the technical difficulties setting up his Teams lost us some time but such a useful interview nonetheless. He seemed to really feel really freed through the discussion, like he had been waiting to say all this for the last year but had no outlet. I found his cynicism around how decisions are made in a risk averse system like NHS mental health so insightful. I had to check myself on a couple of occasions from simply agreeing with his perspective as it was so similar to conversations we have had as a cohort about iatrogenic harm inflicted by service inflexibility and well intentioned yet overburdened clinicians. He was also really funny, a pleasure to talk too and his reflection at the end of how helpful the conversation had been was really satisfying. I have always hoped the research would be helpful for participants but in hindsight I underestimated the impact that it could have and just how novel these conversations are.</i></p>
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Extract during Reflexive Thematic Analysis Process

<p>15.06.23. Initial theme creation</p>	<p><i>I've been so engrossed now in the interviews for the last few weeks I think I may start dreaming about NVivo. I've had to transfer my working to paper as I'm struggling to order my thoughts using the NVivo system, it has been great for coding and keeping track of the codes across the data set but I think I've reached it's limit in terms of actually creating themes from the codes themselves. I keep returning to Braun and Clark to check my methods, constantly feel like I'm doing it "wrong" or not by the book enough. Sessions with Jen and the others have helped know I'm not alone in that but still finding it tough to commit to individual themes as a result. Almost feel like if its obvious I must be doing something wrong, but have to remember that I couldn't be more familiar with the dataset now, it really should be obvious at this stage!</i></p>
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Appendix B

Presentation For Hosting Service

Diagnosis Research Project

Tristan Neaves - Trainee Clinical Psychologist
(University of Hertfordshire)

Supervised by

David Chapman - Clinical Psychologist HPFT & UH
Nicola Green - Clinical Psychologist HPFT

Learning of a diagnosis of psychosis

Through the research we aim to explore how patients learned of their diagnosis of psychosis and what impact this had on them.

Aims

Discover more about diagnostic experience from the **perspective of patients**

How do individuals learn of their diagnosis?

How do they process that information?

Who supports them through this?

What makes for a good/ bad experience



Why Do This?

There is a huge gap in our understanding of what impact the way you learn about a diagnosis of psychosis has on a patient.

It is well established that a diagnosis of psychosis carries with it a large degree of societal stigma and this is often internalized by those who receive the diagnosis. What is less understood is what factors cause this stigma.

We know that the first meeting when you learn of any medical diagnosis has the potential to be distressing and have significant impacts on an individuals sense of self.

Working with people who are in treatment with the PATH team allows us to ask people who have recently experienced learning about their diagnosis, about this experience. Existing research is much more retrospective, this will be the first study of this kind done within a EIP team.

This research hopes to take the initial steps in establishing how diagnosis is delivered impacts patients and how this links with any stigma felt, allowing for improvement in delivery and in due course a reduction in stigma.

What will it involve for Service Users?

- One recorded interview, up to an hour long.
- We will talk about the experience of learning of this diagnosis and what this meant for them.
- Minimum of 12 participants required.

Potential Benefits

- Opportunity to talk about how they learned about their diagnosis and the impact it has had on them. Opportunity to be involved in research that could improve the experience of people in future in a similar position.

Potential Risks

- Could be discussing an emotionally difficult experience.

Payment?

Payment?

Unfortunately the project has no budget and therefore we cannot offer payment. Ideally interviews will be conducted over video call meaning there are no costs to participants beyond their time.



Recruitment

- Random selection using Paris ID in order to draw a representative sample of service users.
- Once number is selected, I will meet with clinicians involved with patient to make sure they meet inclusion and exclusion criteria.
- If they do, that patient will then be asked if they would like to participate by clinician they are familiar with.



Appendix C

Health Research Authority Ethical Approval



Dr David Chapman
 University of Hertfordshire
 College Lane Campus
 Hatfield
 AL10 9AB

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

26 January 2023

Dear Dr Chapman

**HRA and Health and Care
 Research Wales (HCRW)
 Approval Letter**

Study title:	Patient perspectives on the process of diagnosis in early intervention services for psychosis
IRAS project ID:	314311
Protocol number:	N/A
REC reference:	22/LO/0725
Sponsor	University of Hertfordshire

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Appendix D

Hosting Trust R&D Approval



Human Resources Department
The Colonnades
Beaconsfield Road
Hatfield Hertfordshire
AL10 8YE

Tristan Neaves
Trainee Clinical Psychologist
Cambridgeshire and Peterborough NHS Foundation Trust
University of Hertfordshire
College Lane
Hatfield Hertfordshire

02/02/2023

Dear Tristan Neaves

**Letter of access for research:
Patient perspectives on the process of diagnosis in early intervention services for
psychosis, IRAS: 314311**

As an existing NHS employee you do not require an additional honorary research contract with Hertfordshire Partnership University Foundation Trust (HPFT). We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in this organisation. Evidence of checks should be available on request to HPFT.

This letter confirms your right of access to conduct research through HPFT for the purpose and on the terms and conditions set out below. This right of access commences on **2/2/23** and ends on **1/6/23** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct research as per the emailed confirmation of Capacity and Capability for research from this NHS Organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received an email from us giving confirmation of our agreement to conduct the research.

You are considered to be a legal visitor to HPFT premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this organisation, in particular that of an employee.

While undertaking research through HPFT, you will remain accountable to your employer (**Cambridgeshire and Peterborough NHS Foundation Trust**) but you are required to follow the reasonable instructions of your nominated manager (**David Chapman**) in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with HPFT policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with HPFT in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on HPFT premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the HPFT Research Department (01707 253835) prior to commencing your research role at this Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 2018. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

HPFT will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend this organisation may be terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in this NHS organisation.

Yours sincerely

Amanda Donley
Recruitment Manager
Human Resources Department

cc: R&D office at HPFT (Thanusha.Balakumar@nhs.net)

Appendix E

Participant Information Sheet

Version 4
IRAS Project ID: 314311

27/10/22

PARTICIPANT INFORMATION SHEET

We are looking for participants to take part in a research study looking at the experiences of people who have received a diagnosis during or prior to their referral to and treatment with PATH.

Below is the information we think you will need to decide whether you would like to take part. If you are interested, please complete a registration of interest form at the back of this information sheet and pass to the member of the staff you are meeting with.

Project title (Draft): Patient perspectives on the process of diagnosis in an early intervention service.

You are being invited to take part in a research study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include.

Please take the time to read the following information carefully. Do not hesitate to ask about anything that is not clear or request further information you feel would be useful in helping you make your decision.

Why are we doing this research?

We hope that talking to people who have experienced being diagnosed with a mental health condition as part of, or before, their treatment with PATH, about their experiences of this process and what aspects they found helpful or unhelpful. We hope that this will allow us to better understand what steps can be taken by clinicians in order to best support people who are experiencing this.

Do I have to take part?

Taking part in this research is voluntary. It is completely up to you whether or not you decide to take part in this study and will not affect your care in PATH in any way. If you decide to take part you will be asked to sign a consent form. Even if you agree to the study you are free to withdraw at any time without giving a reason. Deciding to withdraw will also not affect your care in PATH in any way.

What will I need to do if I take part?

Taking part in the research will involve meeting for a one to one interview with a researcher. The interviews can take place in person or using video call, depending on your preference. If opting for in person, this will be arranged at a time and place that is easy for you to attend that you are familiar with from PATH. During this meeting you will be asked questions about how you experienced the process of being diagnosed and the impact this had on you. The meeting will last approximately one hour. With your consent, the meeting will be recorded using a Dictaphone and transcribed. A copy of the transcription can be made available to you once completed.

Version 4
IRAS Project ID: 314311

27/10/22

Who is the researcher I will meet with?

The primary investigator is Tristan Neaves, a Trainee Clinical Psychologist at the University of Hertfordshire. The research is being carried out as part of his doctoral training.

Who else is in the research team?

Tristan is supervised in conducting the research by two qualified clinical psychologists, Dr David Chapman (University of Hertfordshire) and Dr Nicola Green (Hertfordshire Partnership Foundation Trust) who are both Psychologists working in the PATH team.

If I take part in the research what happens to the information I tell you and the results of the study?

All research involving patient data must follow UK laws and information obtained during this research is subject to the Data Protection Act. The interview will be recorded and transcribed. Transcription will be conducted either by the researcher or by professional transcribers with appropriate confidentiality agreements in place. Once transcribed, the audio recording of your interview will be destroyed and the written transcription will be stored electronically and will be password protected. Only the research team will have access to this. The transcript will then be used in the write up of the research and selected quotes may be included in the text. These will be anonymised so as to make it impossible to link them to specific participants.

Confidentiality will be upheld at all times by the research team, no information given as part of the research will be shared with anyone outside of the research team. This includes the PATH team who are responsible for your care. They will be provided a copy of the research following its conclusion with all information anonymised, meaning nobody could identify the information you individually have provided.

The only exception we would make to this confidentiality would be if you shared information that indicated you or anyone else were at risk of harm. In this unlikely circumstance we would use the information to ensure the safety of whoever was involved.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your initials, NHS number, name, contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. All of this information will be stored on site or in the researchers secure storage system.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

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What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have if it is more than 2 weeks after the interview occurred.

Where can you find out more about how your information is used?

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/ or by asking one of the research team. Telephone and email details at the bottom of the form

What happens if I become distressed during the research interview?

The researcher, Tristan has over 5 years of experience working with people with mental health conditions. If you become distressed, upset or worried during your interview, he can support you to link in with the professionals you have been working with from the PATH team for support with this.

Will I get paid for taking part?

Participation is voluntary, unfortunately we are unable to pay however we will reimburse travel costs.

Who has approved the study?

The study has received ethical approval from the NHS research department, IRAS. If you would like to find out more about how your information is used in health research you can access information from the Health Research Authority (HRA) website at www.hra.nhs.uk/information-about-patients/

The research has been sponsored by the University of Hertfordshire.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers. If this does not resolve your concerns or you wish to complain formally, you can contact the Patient Advice and Liaison Service (PALS) at HPFT, this can be done using 01707 253916 or through email: hpft.complaints@nhs.net

Who do I contact if I need more information or have any questions?

If you would like further information or have any questions you can contact the researcher using the contact details below:

Researcher:
Tristan Neaves
Trainee Clinical Psychologist

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27/10/22

University of Hertfordshire
Tel: 01707 286 322
Email: tn15aap@herts.ac.uk

If you are interested in taking part in the study or would like to talk to a member of the research team to answer any questions you may have about the study, please contact Tristan on the above email.

Appendix F

Consent Form

IRAS Project ID: 314311

Participant Consent Form

Title of the Research: Patient perspectives on the process of diagnosis in an early intervention service

Researcher: Tristan Neaves (Trainee Clinical Psychologist)

Supervisors: Dr David Chapman (Clinical Psychologist), Dr Nicola Green (Clinical Psychologist)

**Please read each statement and circle Yes if you agree
(or delete as appropriate if completing electronic consent).
Please also write your initials in each check box as indicated.**

	Please write initials in the empty boxes below	
I have read the information sheet provided and have had the chance to ask any questions that I have, which were answered by the researcher.	Yes	No
I understand that I can withdraw at any time without giving a reason, until 2 weeks after the interview has been completed.	Yes	No
I understand that I can choose not to answer any questions asked during the interview.	Yes	No
I understand that my research interview will be audio recorded and that the audio recording of my interview will be destroyed once it has been transcribed.	Yes	No
I understand that taking part will not affect the treatment that I receive from the PATH team.	Yes	No
I understand that the information I provide will be stored confidentially and in accordance with data protection rules.	Yes	No
I understand that confidentiality may be broken only if there is any indication of a risk of harm to myself or others.	Yes	No
I understand that the information I provide will be used by Tristan Neaves for his doctoral thesis. The information will be anonymised (meaning that my name and other identifying details will be removed). Anonymised quotes from the interview may be used within the write up of the research, which may be published in an academic journal or another publication, or presented at a conference.	Yes	No
The researcher has provided contact information for if I need to ask further questions about the research.	Yes	No
I agree to take part in the research.	Yes	No

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I understand that I will not be paid but may have my travel costs reimbursed for taking part in the study.	Yes	No	
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**Please write your name and sign and date in the space provided below:
(if completing electronic consent, please type your name in both Participant name and signature spaces and date)**

Participant's name:

Participant's signature:

Date:

Researcher's name:

Researcher's signature:

Date:

Appendix G

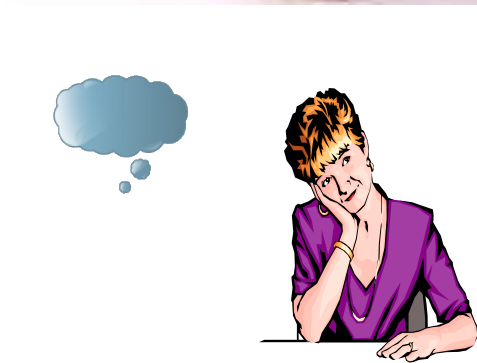
Easy Read Participant Information Sheet

Easy Read PIS
Version 2
25/10/22

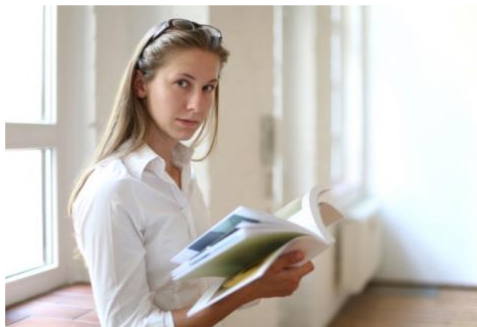
Participant Information Sheet



We want to talk to people in treatment with PATH who have been given a mental health diagnosis.



Before you decide to take part it is important that you understand what this will mean for you.



Why are we doing research?

We want to know how you were told about your diagnosis and What this was like for you.



Do I have to take part?

- *Taking part is up to you.*
- *Your decision will not impact your treatment in PATH.*
- *You can choose to stop at any time.*



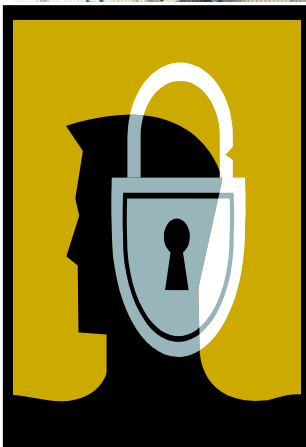
What will I do if I want to take part?

- *Meet with a researcher to talk about your diagnosis for up to an hour.*
- *This can happen in person or on video call.*
- *The interview will be recorded.*
- *You will be asked questions about how you were told about your diagnosis, and what this was like for you.*



Who will I speak to?

You will talk to Tristan Neaves who is a trainee clinical psychologist. He is supervised by Dr David Chapman and Dr Nicola Green who are both Clinical Psychologists.



What happens to the information you tell us?

- *The interview recording will be transcribed (written up) and then the recording file deleted.*
- *The text of the interview will be anonymised, (no names will be in it) saved securely and protected with a password.*
- *Only the research team will be able to see it.*



Will I be paid for taking part?

- *Unfortunately we are unable to pay.*



What If there is a problem?

- You can withdraw at any time for any reason
- You can contact the researchers with any concerns on the details below
- If this does not satisfy then you can speak for advice at hpft.complaints@nhs.net or with your mini team



Who will be told I am taking part?

- Your mini team will be aware and available to support you throughout your involvement.



Who has approved the research?

- The study has been approved by the NHS research department, called IRAS.
- You can find out more about IRAS on www.hra.nhs.uk/information-about-patients/
- It has been sponsored by the University of Hertfordshire

If you want to participate or have more questions, please contact -

Researcher:

Tristan Neaves

University of Hertfordshire

Tel: 01707 286 322

Email: tn15aap@herts.ac.uk

Principle Supervisor:

David Chapman

University of Hertfordshire

Tel: 01707 286 32

Email:

d.chapman4@herts.ac.uk

Appendix H

Participant Debrief Sheet

Debrief Sheet

Thank you for giving your time and taking part in the research study.

Project title:

Patient Perspectives on the Process of Learning of diagnosis in Early Intervention Teams.

Why are we doing this research?

We hope that talking to people who have experienced receiving a diagnosis through their referral and treatment with early intervention services about their experiences will help us to better understand this experience. We hope that this will allow us to gain further understanding of what enables people to have a good experience, allowing for promotion of good practice, that most benefits patients, in services.

What happens with the information I have provided?

The research interview with you will have been recorded. This recording will now be transcribed by the researcher. Any personally identifiable information such as your name will be removed so that the transcribed interviews will be anonymous. Once transcribed, the recording of your interview will be destroyed and the written transcription will be stored securely in the University of Hertfordshire OneDrive secure storage system. Only the research team will have access to this.

When the research has been completed, Tristan will write up the findings. The findings will also be published by the University of Hertfordshire and will be written for publication in an academic journal. These articles will include anonymised quotations to illustrate the findings, but no identifiable information will be included.

If during your interview you have said something which you do not want to be used, you can ask for this information to be removed from the transcript.

What if I've changed my mind?

Taking part in the study is completely voluntary. Now that you have completed the research interview you are still free to change your mind and withdraw from the study without giving a reason. There is a two-week period from the date of your interview in which you can withdraw your data from the research, after this point analysis of your data will take place. A decision to withdraw at any time, will not affect any treatment/care that you may receive.

Who do I contact if I have any further questions or wish to withdraw from the study?

If you would like further information or wish to withdraw from taking part in the study you can contact the researcher or their supervisor using the contact details below:

Researcher:

Tristan Neaves

Trainee Clinical Psychologist

Tel: 01707 286 322

Email: tn15aap@herts.ac.uk

Research Supervisor:

Dr David Chapman

Clinical Psychologist

Tel: 01707 286 322

Email: David.chapman6@herts.ac.uk

Where can I access further support?

We understand that it receiving a diagnosis can be difficult for some people and that people are likely to have had very different experiences both leading up to and after their diagnosis and that they might also have many different feelings about this.

Talking about your experiences or feelings during the research interview may have caused you to feel distressed, upset or worried about this experience. If you would like further support with this, we would recommend that you speak to the professionals you have been working with within the PATH Team about the interview.

If you feel so distressed that you are experiencing thoughts of wanting to hurt yourself or end your life and you feel that you are going to act on these thoughts and are unable to keep yourself safe please go to your nearest Accident and Emergency department.

Attached to this debrief sheet is a list of useful contact numbers and websites for further support.

Useful Websites and Contact Numbers

If you are experiencing difficulties with your mental health and wellbeing please speak to your Care Coordinator or GP as they will be able to refer you to the most appropriate service for support.

Mental Health Foundation

Provides information and support for anyone with mental health problems or learning disabilities.

Website: www.mentalhealth.org.uk

Mind

Mental Health charity who provide advice and support to empower anyone experiencing a mental health problem

Phone: 0300 123 3393 (Monday to Friday, 9am to 6pm)

Website: www.mind.org.uk

Rethink Mental Illness

Support and advice for people living with mental illness.

Phone: 0300 5000 927 (Monday to Friday, 9.30am to 4pm)

Website: www.rethink.org

Samaritans

Confidential support for people experiencing feelings of distress or despair.

Phone: 116 123 (free 24-hour helpline)

Website: www.samaritans.org.uk

SANE

Emotional support, information and guidance for people affected by mental illness, their families and carers.

SANEline: 0300 304 7000 (out of hours helpline daily, 4.30pm to 10.30pm)

Textcare: comfort and care via text message: www.sane.org.uk/textcare

Peer support forum: www.sane.org.uk/supportforum

Website: www.sane.org.uk/support

Anxiety UK

Charity providing support if you have been diagnosed with an anxiety condition.

Phone: 03444 775 774 (Monday to Friday, 9.30am to 5.30pm)

Website: www.anxietyuk.org.uk

Big White Wall

Anonymous online community to share troubles guided by trained professionals.

Website: www.bigwhitewall.com

CALM

CALM is the Campaign Against Living Miserably, for men aged 15 to 35.

Phone: 0800 58 58 58 (daily, 5pm to midnight)

Website: www.thecalmzone.net

Men's Health Forum

24/7 stress support for men by text, chat and email.

Website: www.menshealthforum.org.uk

No Panic

Voluntary charity offering support for sufferers of panic attacks and obsessive compulsive disorder (OCD). Offers a course to help overcome your phobia or OCD.

Phone: 0844 967 4848 (daily, 10am to 10pm)

Website: www.nopanic.org.uk

Information of Mental health support in Hertfordshire

<https://www.hpft.nhs.uk/get-help/>

Single Point of Access Tel: 0300 777 0707 Email: hpft.spa@nhs.net

The Mental Health Helpline: 01438 843 322 (out of hours support- 1700 and 0800 hours)

Hertfordshire NightLight is an out-of-hours weekend service for people in Hertfordshire who are feeling distressed or experiencing a crisis. Helpline available 6pm-12am and the centre is open until 2am, Friday to Monday. Tel: 01923 256 391 [www.turning-point.co.uk/hertfordshire-](http://www.turning-point.co.uk/hertfordshire-nightlight)

[nightlight](http://www.turning-point.co.uk/hertfordshire-nightlight)

Urgent Support

If you feel like you are in need of urgent help and want to talk to someone you have the following options:

- For urgent medical attention, you can call 999, visit Accident & Emergency (A&E) or make an Emergency GP appointments.
- For urgent medical advice you can call the NHS on 111 (England).
- You can talk to Samaritans anytime on 116 123, this isn't just for those who feel suicidal.

Appendix I

Interview Schedule

Version 4
IRAS Project ID: 314311

05/08/22

Appendix C - Interview Schedule

How does diagnostic delivery influence individuals experience of psychosis?

Are you aware of being given a diagnosis?

How did you learn of your diagnosis?

- Were you told/ did you read it?
- Who told you, how did they tell you?
- What do you recall of the experience?

How did you feel after hearing the news?

- What was your emotional response to being given the news?
- What if anything changed for you after hearing the news?

What did you find helpful about the meeting/ the way you learned about the diagnosis?

- Emotionally/ Understanding the information...

What did you find unhelpful about the meeting/ the way you learned about the diagnosis?

- Emotionally/ Understanding the information...

Had you heard of psychosis before?

- What was your perception of psychosis before diagnosis?
- And after diagnosis?

Do you talk about your diagnosis?

- Who with?
- What do you find helpful?
- What do you find unhelpful?

How do you feel about the diagnosis now?

- How does this compare to your feelings at the time?
- What factors led to any change?

If you were to imagine an ideal way to be told about your diagnosis, how do you think this would look?

Appendix J

NVivo Transcript Extracts

I
Um, OK, so do you remember how you were told? How did the meeting pan out?

P
I believe there was a team, so...
From memory, I believe there was either a psychiatrist or Doctor, who was like the main person who kind of spoke and said, these are the actions for like the next week or like, actions for you going home or the diagnosis, they led all of that.
I can't quite remember who else was there, but obviously this was in Covid times, so there wasn't actually that many people around and the majority of people who were involved were done by MS teams.
Because obviously, Covid. But yeah, I, I believe, there were other people in the room, there was at least a group of like at least four.

I
Thanks, do you remember how they told you about the diagnosis?

P
From what I remember, like I believe it was kind of like eased in, they didn't come in and say like, sorry, well, you have this, but I think it was a general like consensus. So like they told me, kind of like they just explained that... From the behaviour that I've been displaying and like my general attitude and demeanour. You know, my general kind of like approach to people and like state of mind and also physically as well, they said with everything that we've gathered, like, this is what we believe you have. And then obviously I went absolutely nuts, and started screaming
Like, I wasn't happy with this diagnosis, generally feeling like I don't agree with this diagnosis, like it was too harsh for myself, like due to like the stigma surrounding mental health and surrounding bigger diagnoses such as psychosis or bipolar, I think I didn't wanna be labelled as... Someone who has that, but yeah, like. They did it in as nice a way as possible, I think they did it in the best way they could regarding the state I was in, but obviously there's no easy way to kind of disclose that information to someone cause it is a lifelong illness. It's not just as simple like, you have a cold, but we'll give you some medication and you'll be fine in two weeks as it's a lifelong thing, you know, and it's a big thing. but honestlv. It's lovely to be at the position I am now. it's so different to when I was

I
OK.
And does that feed into the kind of confusion that you were talking about about around the diagnosis?

P
Yes, I think the fact that I didn't have fixed delusions, I wanted to clarify, I had this I guess self doubt.
Um, that made me think this isn't this doesn't feel like psychosis to me, although I could see why the the grandiosity and the delusions would be seen that way.

I
OK. And have you, has there have been a space either with the GP or with the [treatment team] team where you can discuss those questions about the diagnosis and about whether it fits for you?

P
There have been discussions, um, but the the conclusion is always that it it does fit psychosis. Um, and that what, what I describe about somebody having done something to my mind, or people being aware of my thoughts or people having been aware of what would happen in my life before it happened. That that would be very difficult to do and thus its very unlikely that those things occurred. Those have always been the conclusions

I
And what form of those discussions taken is that you and the care coordinator or you and the psychiatrist?

The image displays a transcript with NVivo coding bars on the right side. The coding bars are color-coded and labeled with various themes. The transcript text is on the left, and the coding bars are on the right, with some bars overlapping the text. The themes include:

- Intimidated by treatment
- Sense of numerical imbalance
- Relational Information Vacuum
- More than the label
- Family Support
- PATH Support
- Happily to
- Needs going unmet by care system
- Diagnosis as access to treatment
- Treatment ahead of diagnosis
- Internalising
- Treatment helped feel hope
- When as well as how
- Therapy to process
- Psychosis impacting processing
- The Ideal Scenario Question
- Coding Density
- Shock of diagnosis
- Awareness of stigma
- Worry about meaning
- Time to process
- gnosis as access to treatment
- ing up
- tily Shock
- Diagnosis
- icational privilege helps understand
- chosis impacting processing
- gnostic Uncertainty
- My opinions dismissed
- temic rigidity
- ry about meaning
- tily Support
- Medical Model Inflexibility
- Diagnosis Fit
- fusion or misunderstanding
- Ideal Scenario Question
- Ability to challenge
- ing Density
- No room for cultural beliefs or spirituality

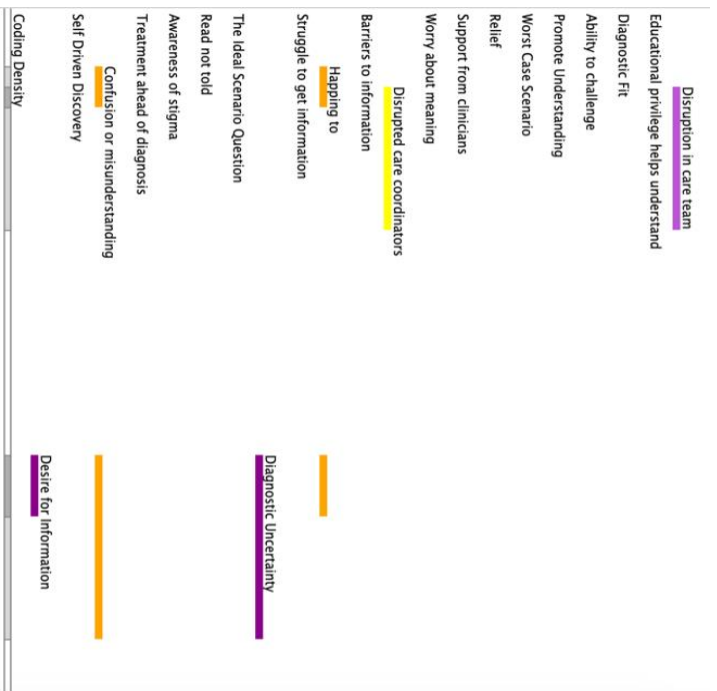
anything. Did any of them have a conversation with you about the diagnosis of psychosis?

P
Umm. I remember being asked a bit about what I could remember about what I'd experienced during my psychosis. Umm. And that's pretty much all I remember, but there's been like within my care team, there's been like some changes, like there was somebody called [male CC] who was in my team at the start, who then was like quite sick for a long time and wasn't in work and then there have been times when they've wanted to have trainee clinical. I'm guessing clinical, psychological students, I think to use a general term in on my appointments to sort of learn from what's going on, so I've I've never really felt like I've had a consistent small mini team around me. It always feels like ohh today it's gonna be so and so because of this reason can so and so be in your appointment. You know, I think the kind of the longest serving person that I worked with was somebody called [Feamle CC] who now has moved to the [City in SE England] branch of [Treatment team]. So to kind of get that report was quite difficult.

I
And do you remember if with [female CC], or with any of the other clinicians you work with in path, have you spoken to them about the diagnosis and what it means for you?

P
Um.
Not really. I think I've been more focused on like have I been diagnosed with this or not like almost, as in, there's this sheet of paper that says I've got it, but where's the, you know, chief person who's gonna actually tell me? Yes, you have. Because of this, this and this reason. And it still seems to be one of those things that's kind of, sometimes its there on my notes, sometimes its not like I went for an annual health check to my GP and she said Ohh you've been invited along to have this annual health screening because you have it. And I said hang on a minute. I've never been diagnosed and she said to me. Ohh yes sorry it says here possible. So there's always been this kind of ambiguity and this grey area around it.

I
Thank you for that. It's really interesting. So how does that feel to have that uncertainty



I
What made you think that?

P
Cause I didn't think there was any need for it, like I say, I was bad, probably really bad for a couple of weeks. But that was it. And then that medication they put you on that don't make you feel any better neither. So like I say, I was off work for 5 months and I thought I could go back well before then.

I
How did that feel?

P
It was. Yeah. It was frustrating. Feeling like you're well enough to be working, but because of the meds or because of the diagnosis, you can't drive and that means you can't go back to work and that sort of thing. Its like a vicious cycle...

I
Hmm. So I imagine that was quite difficult for you then at that time?

P
Yeah, I think they pulled the trigger too quick.

I
What do you mean by that?

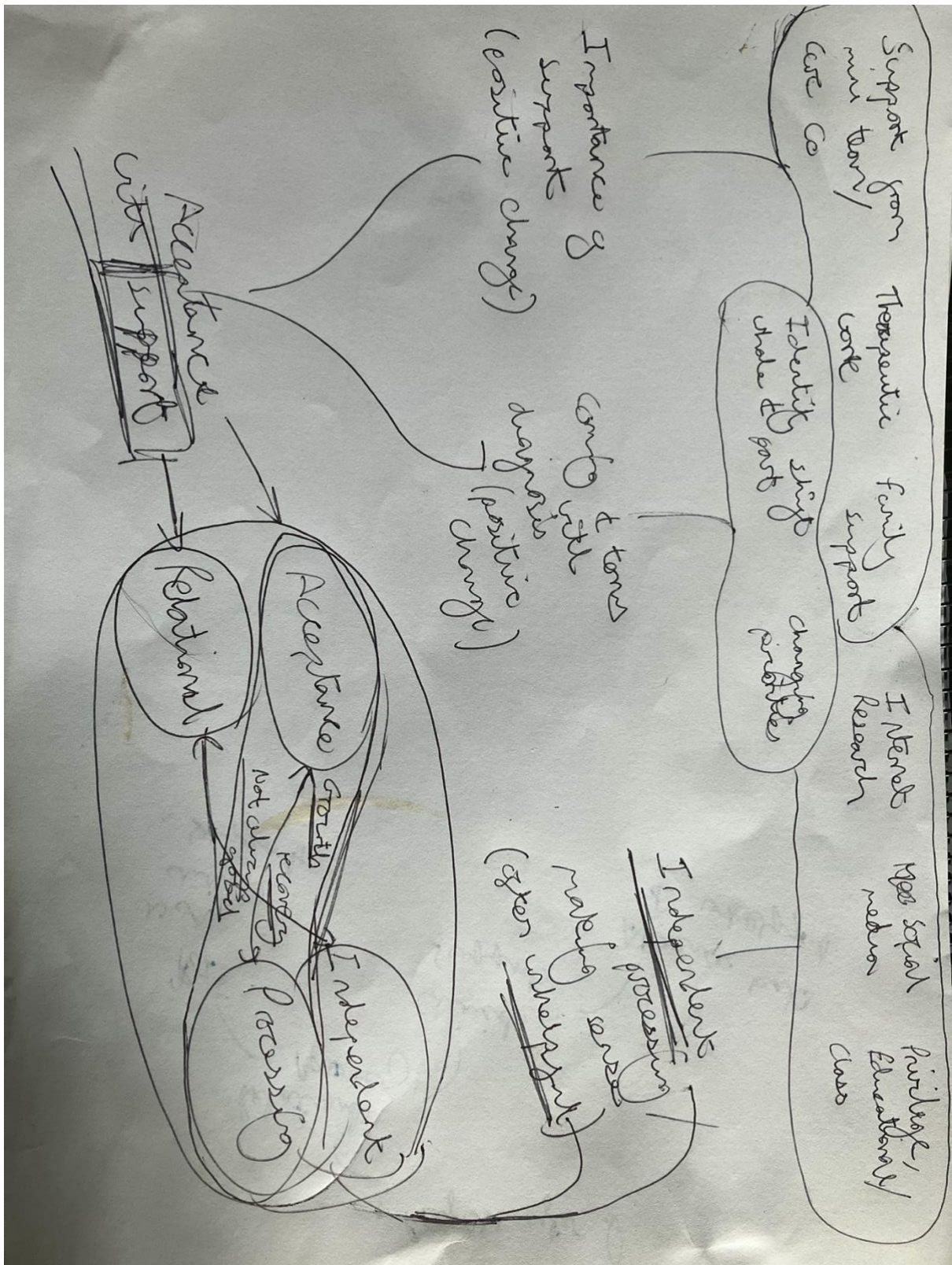
P
Hmm. Its difficult innit cause, how can you argue with a doctor, you can't can you.

T
Okay.
that's really interesting to hear. Can you tell me what made you think that?



Appendix M

Refinement of Themes



Appendix N

Final Thematic Map

