Exploring the experiences of receiving the label ‘treatment resistant’ for people with a diagnosis of schizophrenia

Jen Richards

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ABSTRACT

There is a wealth of research which focuses on the impact a diagnosis of schizophrenia or schizoaffective disorder can have on people's lives. Less common is research which explores how the additional label of treatment resistant has affected this cohort of people. Previous literature is overwhelmingly quantitative and indicates the label is synonymous with a biogenetic approach to causality and treatment, with little hope given for recovery. The aim of the current study was to explore the experiences of those who have been diagnosed with schizophrenia and schizoaffective disorder and received the label of treatment resistant. Participant perspectives on the explanations for them receiving the label were sought, along with the effects it had on treatment, their perspectives and the perspectives of others.

The study utilised a qualitative design and conducted semi-structured interviews with seven participants, six of whom had a diagnosis of schizophrenia and one of whom had a diagnosis of schizoaffective disorder. The resulting data was analysed using Thematic Analysis. Six themes were constructed: 'Effects of a psychosis diagnosis', 'Antipsychotic medication in the treatment resistant context', 'Explanatory models of distress and treatment resistance', 'Effects of the treatment resistant label on service user's perceptions', 'Effects of the treatment resistant label on others' and 'Sources of meaning and support'. The study found that the treatment resistant label can have a damaging effect on those who receive it, particularly in the context of participants' pre-existing psychosis diagnosis which is already highly stigmatised. The label was reported to be associated with reduced hope for recovery from both mental health staff and participants themselves, underpinned by ideas around personal responsibility and chronicity. The treatment resistant label was linked to severe medication side effects and shaped which treatment was offered, or not, to participants. Implications of the study are considered at policy, research, practitioner and service user level.

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1. INTRODUCTION

1.1 Introduction Overview

This research study aims to shed light on the experience of people who have been diagnosed with schizophrenia [1] and received the label of treatment resistant[2] (TR). The study consists of semi-structured interviews with seven participants and employs thematic analysis to analyse the resulting data. The study aims to capture rich qualitative data and begin to address the absence of literature which focuses on the subjective experience of being described in this way.

The thesis introduction consists of four main sections. The first will begin by exploring the concept of schizophrenia. A brief outline of the history of the concept will lead into debate around the diagnosis. Models of causal explanations will be interrogated, along with associated treatment options. Perspectives from the service user movement will be discussed before an explanation of terminology used in the present research study. Next, the introduction will focus on the TR label, noting the history of the term before addressing debates around definition, development and clinical application. A content analysis of recent research on TR in the context of a schizophrenia and schizoaffective disorder[3] diagnosis makes up the third section. This examines

[1] Schizophrenia is a diagnosis which sits under the broad category of ‘‘Schizophrenia and other primary psychotic disorders’’ in the International Classification of Diseases 11th edition (ICD-11; World Health Organisation, 2021). The ICD-11 notes that people who receive this diagnosis experience alterations in their perception of reality such as seeing visions, hearing voices and speaking or thinking in a way which appears confused to others, an experience commonly termed psychosis (Boyle, 2006), alongside presenting with other emotional experiences such as reduced emotional expression, all of which differ from cultural norms in their intensity and frequency (ICD-11 for Mortality and Morbidity Statistics, 2021). These experiences may cause the person, and/or others, distress.

[2] In their document ‘’Psychosis and schizophrenia in adults: The NICE guidelines on treatment and management’’, the National Institute for Health and Care Excellence (NICE) note that label of TR describes the experiences of people who have been diagnosed with schizophrenia but who continue to experience poor community or psychosocial functioning despite treatment with multiple trials of medication (NICE, 2014).

[3] Schizoaffective disorder sits under the same broad category as the schizophrenia diagnosis (see above). Discussion of why the former diagnosis was included in the content analysis can be found in the Methods chapter.

the aims of contemporary research around the concept and reveals a heavy focus on biogenetic explanations of distress. These findings will be discussed before the introduction concludes by presenting a clear rationale for the current study.

The introduction is approached in this way in the hope that it becomes apparent that a biogenetic lens dominates the literature on the TR label. As a result, subjective experience is largely ignored. Therefore, I contend that consideration of the psychological and social impact of the TR concept for those diagnosed with schizophrenia, via qualitative explorations of the subjective experience of this diagnosis, deserve attention and are vital additions to the literature. This argument underpins the introduction and aims to illustrate that an alternative perspective on people labelled in this way is overdue, hence providing rationale for the present study.

1.2 The Schizophrenia Diagnosis

1.2.1 History of Conception

The European Enlightenment period fostered hopes of discovering specific brain pathology and attempts to categorise people's distress (Outram, 2019; Read, 2013a). These efforts extended into the late 19th Century, when Emil Kraepelin suggested aetiology and symptomology held the key to disease classification (Cromby et al., 2013). However, aetiology was difficult to determine, therefore observed behaviors and expressions became disease indicators (Bentall, 2004). In 1893, Kraepelin claimed to have discovered 'dementia praecox', a condition associated with early deterioration of the brain leading to dementia and began to use this term as a catch all for a wide range of experiences (McNally, 2016; Read, 2004). The flaws of this approach were outlined by another psychiatrist, Eugene Bleuler, in his 1911 publication ''Dementia Praecox or The Group of Schizophrenias'', which argued that Kraepelin had erroneously collected wide ranging problems under the guise of a single classification (Bleuler, 1911).

Nonetheless, Bleuler did not dispute the existence of dementia praecox. Furthermore, his critique was soon forgotten as Kraepelin proceeded to detail over fifty symptoms which fell under the umbrella of a schizophrenia diagnosis (Bleuler, 1911; Kraepelin, 1913). Indeed, these were added to over time by both

Kraepelin and Bleuler as the term schizophrenia came to replace that of dementia praecox (Bleuler & Brill, 1924). Those diagnosed were typically placed in asylums, routinely sedated and restrained, and, beginning in the 1930s, subject to procedures such as electroconvulsive therapy (ECT) [4] and insulin coma therapy [5] (Hoenig et al., 1956).

In contemporary literature and mental health services, the concept of schizophrenia endures, thanks to social support elevating its institutional usage (McNally, 2016). Moreno-Küstner et al. (2018) suggest a median worldwide prevalence of 4.6 per 1,000 people, whilst both UK mental health charity Mind and the Royal College of Psychiatrists (RCP) suggest 1 in a 100 people will receive this diagnosis at some point in their life (Mind, 2020; RCP, 2015). Those who receive the diagnosis are thought to be split equally between men and women and are typically between 15 and 35 years old (RCP, 2015). However, the schizophrenia diagnosis is subject to extensive debate, which this introduction will now outline.

1.2.2 Association with Social Control

Western society in the early 20th century was discriminatory to large groups of people, including women, queer people and those deemed to be too intellectual (Batchelor, 2002; Mccormack & Anderson, 2014; McNally, 2016). Reviewing the wide range of behaviours Kraepelin and Bleuler believed warranted a schizophrenia diagnosis reveals a direct reflection of these discriminations, for example being homosexual (Kraepelin, 1913). Furthermore, the demographic of those diagnosed with schizophrenia were largely White middleclass women unhappy in their marriage, poets and White immigrants (Metzl, 2009).This suggests that who was deemed to be mad was a direct reflection of social and cultural norms (McNally, 2016).

Adherence to such norms was central to the Eugenics movement, which sought to destroy so-called undesirable genes and achieved legal compulsory sterilisation for those with the schizophrenia diagnosis across Europe in the

[4] Electroconvulsive therapy consists of an electrical stimulus being briefly applied to the brain to produce a seizure which is believed to result in the alleviation of behaviours associated with the schizophrenia diagnosis (Bini, 1939).

[5] Insulin coma therapy, often administered several times a day, consisted of medically inducing a coma for around 20 minutes by administering large amounts of insulin to a person before waking them up (Sakel, 1935).

1930s (Kallmann, 1938). This ideology was heavily promoted by psychiatrists as making financial, moral and ethical sense for those with a schizophrenia diagnosis and their families (Lifton, 1986). In promoting Eugenics, psychiatry gave legitimacy to the idea that certain types of life, or people, were genetically less valuable or desirable than others (Lifton, 1986). As Hitler's Nazi party gained popularity around the same time, such ideas facilitated racist ideology around racial purity which benefitted from association with the medical establishment (Read & Masson, 2013). Indeed, psychiatrists were heavily represented amongst the members of the Nazi party (Dudley & Gale, 2002; Strous, 2006). Horrifically, it was not long until sterilisation was replaced with murder. In 1938, the mass extermination of people with a schizophrenia diagnosis began through starvation and later gas chambers, all supervised by psychiatrists (Muller-Hill, 1988; Read & Masson, 2013). Such atrocities, legitimised by biogenetic understandings of the schizophrenia diagnosis, reveals the dark history the diagnosis has as a means of social control (Read, 2004).

Further evidence for this argument comes from the shift in the concept's demographic during the American Civil Rights (ACR) movement of the 1950s. During the ACR movement, racialised people[6] campaigned to end widespread racial segregation and discrimination (Bloom, 2019). As racial tensions were exacerbated, institutional, structural and individual racism in the medical profession strengthened in response (Metzl, 2009). Consequently, the diagnosis became associated with men racialised as Black, accompanied by a change in language from docility to hostility (American Psychiatric Association, 1968; Metzl, 2009). This shift has left its mark on the diagnosis today; men racialised as Black are consistently overrepresented in populations with a schizophrenia diagnosis across much of the Western world, including America and Britain (Chen et al., 2021; Edge et al., 2020). This is unsurprising given the persistence of racism in contemporary society which positions racialised people as outside (White) societal and cultural norms (Fernando, 2017). This suggests that those who are positioned on the margins of society often have their experiences

[6] The term racialised people is used in favour of other terms such as people of colour or British, Asian and minority ethnic to reflect an anti-racist stance which exposes how race, although purely a social construct, is used as a means to perceive and treat people who are not White differently from those who are (Hopson, 2013).

viewed through a biogenetic lens. Research from a number of communities, such as that which notes that queer people often have their gender and sexual identity dismissed as a symptom of this diagnosis (Origgi & Vial, 2013; Peta, 2020), supports this claim.

1.2.3 Reliability and Validity

There has been much debate over the reliability and validity of the concept of schizophrenia. Early critique of the diagnosis argued that it led to the circular logic of diagnosis being led by both outcome, whereby those who got better were claimed to be misdiagnosed whilst those who didn't were accurately diagnosed, and symptom, where people who were exhibiting behaviours from a wide-ranging selection could be diagnosed on that alone (Sullivan, 1927). Over time, numerous researchers have noted that the tenets required for the diagnosis to be classed as a scientific category, namely reliability, which is concerned with replicating results across different samples, and validity, which is concerned with predicting these results, are not fulfilled (Bentall et al., 1988; Read, 2013b). For example, research suggests test-retest reliability sits at under fifty percent (Read, 2004), whilst the cross-cultural inconsistency of the diagnosis reveals it as unreliable (Copeland et al., 1971; Metzl, 2009; Savage et al., 2019). In worldwide field trials for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association & DSM-5 Task Force, 2013), the schizophrenia diagnosis was found to have a kappa statistic of 0.46 (Freedman et al., 2013). Freedman et al. (2013) claim that such a statistic, which measures interrater reliability, effectively dismisses any critique of discrepancy over who receives the schizophrenia diagnosis. However, McHugh (2012) argues that any kappa statistic below 0.60 indicates there should be little confidence placed in the agreement between raters.

Schizophrenia can be additionally critiqued as being a disjunctive category, whereby people whose distress manifests in completely different ways nonetheless receive the same diagnosis (Bannister, 1971; Bola & Pitts, 2005; Read, 2013b). For example, Read (2013b) notes that if one person were to experience hearing voices and unusual beliefs, and another disorganised speech and reduced emotional expression, both would qualify for a schizophrenia diagnosis. Boyle's (2002) hypothesis that there appear to be

distinct similarities in the populations studied by Kraepelin and Bleuler and what is now termed post-encephalitic Parkinsonism, a degenerative condition which effects the nervous system, suggesting that schizophrenia as a diagnostic category fails to demonstrate stability over time. Indeed, recent research investigating the DSM-5 (American Psychiatric Association & DSM-5 Task Force, 2013) highlights the heterogenic nature of the diagnosis both within and across categories, undermining claims of schizophrenia being a credible scientific construct (Allsopp et al., 2019).

Furthermore, there is a plethora of research which implicates a lack of validity, such as the frequency with which those with a schizophrenia diagnosis are given an additional diagnosis such as depression and obsessive-compulsive disorder (Postolache et al., 2019; Sharma & Reddy, 2019). Poor predictive validity in terms of outcomes is evidenced via claims of improvement which range from 14% to 50% of people (Ciompi et al., 2010; Zipursky, 2014). In clinical practice, Guloksuz & van Os (2018) suggest that those who have a schizophrenia diagnosis but experience little distress are absent, leading to bias in what is deemed to constitute the category's population. Some researchers claim that the difference between historical and contemporary understanding of the diagnosis obstruct research progression (Kendler, 2016). Consequently, it appears that the classification system designed by Kraepelin and Bleuler ultimately failed to discover a disease; rather, as Read (2013a) notes, it had created one. Nonetheless, there continues to be intense debate around this diagnosis, not least in the search for causal explanations of the experiences associated with it, for example that of psychosis.

1.2. 4 Models of Causality

Despite a plethora of research into causal explanations of experiences such as hearing voices, there remains a lack of agreement whether the biogenetic, psychosocial and biopsychosocial model is the best fit. The first of these, the biogenetic model, also known as the medical or psychiatric model, suggests that biogenetic abnormalities result in a predisposition for, and later diagnosis of, a disease called schizophrenia (Pavon & Vaes, 2017). Evidence for this theory has historically come in the form of twin studies, which argue that any schizophrenia diagnosis must have a genetic basis due to the assumption of equal environment (Fosse et al., 2016). Such an assumption suggests that both

monozygotic and dizygotic sets of twins experience similar environments, therefore any difference in the diagnosis of schizophrenia between the pairs can be taken as evidence of genetic causal factors (Joseph, 1998). One such study, a meta-analysis of twelve twin studies, concluded that heritability led to an 81% chance of receiving a schizophrenia diagnosis (Sullivan et al., 2003). Additionally, research has attempted to find genetic specificity with varying success. Whilst it is widely accepted that investigations into a 'schizophrenia gene' failed, finding no association between a diagnosis and fourteen candidate genes (Sanders et al., 2008), recent research on factors such as differences in grey matter volume, gene mutation and gene variation leading to dopamine dysfunction claim success (Ji et al., 2021; McCutcheon et al., 2019; Rees et al., 2014; Ripke et al., 2014). However, it should be noted that such findings are rarely, if ever, replicated and often refer to minor gene variation (Joseph, 2004).

Indeed, many are sceptical of biogenetic causal explanations, citing over-inflated results and poor study methodologies in research which may often be biased by pharmaceutical company funding (Fosse et al., 2016; Mosher et al., 2013; Woo et al., 2020). As Kingdon and Young (2007) note, research into biological mechanisms underpinning the schizophrenia diagnosis have contributed little to contemporary understandings. Furthermore, the assumption of equal environment, much lauded as the key to proving heritability, has been widely rejected as both impossible to achieve and ignoring of childhood adversity, increasingly linked to experiences labelled as psychosis (Fosse et al., 2015).

The relationship between adverse life experiences and instances of psychological distress forms the basis of the psychosocial model. Evidence for this causal explanation is found in a plethora of research which links higher social inequalities to an increase in psychological distress (Wilkinson & Pickett, 2020). A multitude of relational, environmental and social factors, such as neglect, lower socio-economic status, racism and sexual violence, are linked specifically to receiving a schizophrenia diagnosis (Anderson et al., 2016; Cromby et al., 2019; Xanthos, 2008). Varese et al. (2012) found that people with a psychosis diagnosis were 2.72 times more likely to have experienced adversity in childhood. Despite this, the psychosocial model is often overlooked

in favour of more medicalised thinking. As Johnstone et al. (2018) note, the biogenetic model dismisses the role of adverse experiences in favour of biology, therefore obscuring experiences such as racism. Consequently, in the context of pervasive institutional racism in Western mental health services (Fernando, 2017), there is arguable utility in the continued use of biogenetic causal explanations of the schizophrenia diagnosis.

Joseph (2004) notes that popular consensus on causality has landed on the biopsychosocial model, otherwise known as the diathesis-stress model. On the surface, this model appears pluralistic, including biological, psychological and social causal explanations of distress. Studies of epigenetics, a process whereby gene expression changes in response to environmental influence (Cromby et al., 2019), add weight to this model. For example, research which links changes in the hypothalamic-pituitary-adrenal axis to adversity appears to widen out biological models by considering social and psychological aspects of distress without suggesting that such changes are the result of genetic deficiency (Barker et al., 2015; Read et al., 2014). Yet, in practice, the biopsychosocial model is frequently interpreted as an inherent genetic vulnerability for mental distress that is suddenly triggered by life experiences such as poverty or childhood abuse, rather than holding these as causal factors in themselves (Porter, 2020). This places adversity as a mere risk factor to the foundational biogenetic make-up of a person which is promoted as the real cause of their distress (Boyle, 2013; Cromby et al., 2019; Harper et al., 2021). Indeed, Cromby et al. (2019) note that much of the research around epigenetics prioritises genetic factors as the site of inquiry rather than the psychosocial factors that have precipitated any changes. Consequently, despite the existence of alternative models such as psychosocial and biopsychosocial, the schizophrenia diagnosis is consistently associated with biogenetic explanations of causality (Fosse et al., 2015). This is illustrated by a study which examined articles in the national psychiatry journals of America, Britain and Canada between 2005-2007, finding that over 75% of them attributed biology as the primary cause of a person being labelled with psychosis (Jarvis et al., 2015). In addition, Ingleby (2014) suggests the influence of the pharmaceutical industry, with its focus on biological mechanisms and medication, is a contributing factor.

1.2.5 Drugs as Treatment, Treatment as Drugs

The influence of the biogenetic model of causality is evident in what is promoted as the primary treatment for those who receive a diagnosis of schizophrenia, namely pharmacological intervention. Neuroleptic medications, typically called antipsychotics, began to be used in the 1950s and are considered the foundational treatment when the diagnosis is understood through a biogenetic lens (Boyle, 2013; Moncrieff, 2013a). Whilst advocates claim first-generation antipsychotics (FGAs) restore dopamine imbalance in the brain by blocking these receptors (Kapur & Mamo, 2003), second-generation antipsychotics (SGAs) work under a similar assumption for serotonin receptors (Meltzer et al., 2003). Both types of drug claim to stop or reduce experiences associated with the schizophrenia label (Stepnicki et al., 2018), such as seeing visions, hearing voices and having unusual beliefs. A recent meta-analysis of sixty-six studies concluded that antipsychotics are more effective than placebo, enjoying moderate to large effect sizes (McCutcheon et al., 2021). This echoes an earlier meta-analysis investigating both FGAs and SGAs (Leucht et al., 2013).

Yet, there are alternative studies which suggest that antipsychotics are only effective in around 30% or less of those who have a schizophrenia diagnosis (Adams et al., 2007; Hutton et al., 2013; Leucht et al., 2009). A worldwide five-year follow-up study found that people living in countries with a lower socio-economic status, such as India and Nigeria, achieved better outcomes that those living in countries with a higher socio-economic status, such as the United Kingdom and America, suggesting that social and cultural factors play a role in recovery over and above medication (Leff et al., 1992). Indeed, the dopamine hypothesis is widely discredited and therefore raises questions around the accuracy of the purported drug action of FGAs (Moncrieff, 2009). Despite this, antipsychotics are widely used, with UK guidance recommending these as long-term treatment (NICE, 2014). In addition to drugs, interest in treatment via electrical brain stimulation, such as transcranial magnetic stimulation [7], is hailed as an innovation in biological intervention (Freitas et al., 2009), whilst ECT, popularised in the time of Kraepelin and Bleuler, remains in use for those with a

[7] Transcranial magnetic stimulation consists of electrical stimulation of the brain for therapeutic effect (Udupa & Chen, 2010).

schizophrenia diagnosis despite well-known and dangerous side effects (Raising Doubts About ECT, 2021; Sanghani et al., 2018). Such interventions are almost always used in addition to, rather than instead of, medication and hence locate experiences of psychological distress firmly in the biological realm.

Recent interest in psychosocial factors of the schizophrenia diagnosis has grown, with moves towards psychological input via therapeutic models such as cognitive behavioural therapy (CBT) and family therapy claiming varying success in reducing experiences associated with the schizophrenia label (Carr, 2019; Jauhar et al., 2019). However, whilst a pioneering study compared CBT to antipsychotic medication for people with a schizophrenia diagnosis and found no difference in outcomes between the two (Morrison et al., 2018), such studies are a rarity. Indeed, as a recent meta-analysis demonstrates, when psychological therapy is offered, it is consistently as an adjunct, rather than primary, treatment option (Bighelli et al., 2018). The same applies for psychosocial interventions focused on rehabilitation, which typically require service users to take antipsychotics in order to participate (Buonocore et al., 2018). Consequently, a diagnosis of schizophrenia is consistently viewed through a biogenetic lens and requiring of medical treatment. This is despite research noting that 40% of people in the early stages of their psychological distress recover without the use of antipsychotics (Bola, 2006). Indeed, Higgs (2020) notes that outcomes associated with the label have failed to improve despite over fifty years of research into pharmaceutical drugs, suggestive of both the inadequacy and power of the biogenetic model.

1.2.6 Service User Perspectives

There is, however, an ever-growing movement of service users[8] who are vocal about the need for alternative ways of understanding experiences labelled as schizophrenia. Whilst critique can be traced back to the 18th century (Crossley, 2006), the contemporary movement emerged in late 1960s America as a response to personal experiences of mistreatment at the hands of the psychiatric system (Chamberlin, 1978; Oaks, 2006). Some service users use

[8] The term ‘service user’ has been chosen in place of alternatives such as survivor or consumer, however the researcher is aware of critiques of this term, not least that it identifies people in relation to services (Beresford, 2005). However, service user was chosen as it is most widely used in the UK literature (McLaughlin, 2009). Nonetheless, where possible, the term ‘people’ will be used instead.

the term survivor[9] to denote their survival of harmful psychiatric treatment (Crossley, 2006). One service user-led network formed in 1988, the Hearing Voices Network (HVN), is a pioneer in directly challenging biogenetic causal explanations of distress via encouraging a multiplicity of different causal explanations (Higgs, 2020). Indeed, the HVN cites the importance of curiosity to experiences; seeing them as meaningful and understandable responses to life events, rather than meaningless symptoms of a disease called schizophrenia (Dillon et al., 2013). The peer support groups run by the HVN act to remove taboo from experiences and support recovery through factors such as therapeutic relationships, space to be oneself and meaning making (Payne et al., 2017).

Another alternative to the biogenetic model is presented in the recovery movement, which came to the fore in the 1990s and called for personal recovery, marked by reclaiming a life which is personally fulfilling, to be privileged over clinical recovery, marked only by an absence of so-called symptoms (Repper & Perkins, 2003). The recovery model draws on service user testimony and rejects the assumption that experiences such as voice hearing are required to be removed for people to lead a fulling life (Slade et al., 2019). Other perspectives from service users note the negative impact of receiving the diagnosis of schizophrenia on self-esteem (Pitt et al., 2009), with a recent review citing a resulting sense of hopelessness (Perkins et al., 2018). This is perhaps unsurprising given widely held discriminatory views around danger and risk posed by those with a diagnosis which form pervasive and harmful stereotypes that are reproduced in the UK media (Li et al., 2021). Nonetheless, it is important to recognise the power a shared diagnosis represents for some service users (Rose & Novas, 2004). Indeed, Rose and Novas (2004) argue that collectives can be formed through such a shared identity which can then motivate lobbying for more research, funding and better treatment, despite often not fully ascribing to the biological model purported to underpin such diagnoses.

[9] The term ‘survivor’ is used briefly in the context of the specifically named survivor movement to denote someone who is involved in this movement and therefore has chosen this identity for themselves (Chamberlin, 1978). This is not used throughout this study to respect that not all those who use mental health services align with this movement.

In terms of treatment, service users report that professionals position drugs as the primary offering in response to their distress (Pitt et al., 2009; Wagstaff et al., 2018), despite extensive first-hand accounts of the unpleasant and harmful effects that antipsychotic use can have (Read & Williams, 2019). An international study with 650 participants found 58% of people experienced negative effects, such as cognitive dysfunction and suicidality, when taking antipsychotic medication (Read & Sacia, 2020). This presents a complex picture of antipsychotic experience and efficacy which is not reflected in the prescription increase of 100% between 2000 and 2014 (Shoham et al., 2021). Furthermore, a recent study found most psychiatrists interviewed about the schizophrenia diagnosis still held onto clinical ideas of recovery and all subscribed to the biogenetic model of causality (Sargent & Abela, 2021). This is despite those taking antipsychotics often drawing on psychosocial, rather than biogenetic, causal explanations for their difficulties (Read, 2020a). Consequently, although the conception of the schizophrenia diagnosis has benefitted from the perspectives of service users, there is arguably more work to be done.

1.2.7 What's in A Name?

There have been multiple efforts to move away from using the word ‘schizophrenia’ in recognition of the above critiques from both those who give and receive the diagnosis (Mesholam-Gately et al., 2021). In Western Europe and America, ‘psychosis’ has emerged as the most widely used alternative, aiming to embrace a more psychosocial understanding of psychological distress (Cromby et al., 2013). However, as Boyle (2006) notes, causality for psychosis is often associated with individual deficit via the biogenetic model, despite some progress being made around the link to adverse experience.

Despite these criticisms, much of the literature remains structured by the labels of schizophrenia and psychosis, presenting a dilemma for researchers who wish to use alternatives (Moncrieff, 2013b). Consequently, this thesis will employ this terminology but through a descriptive approach, for example ‘diagnosis of schizophrenia’, ‘label of psychosis’ and phrases such as ‘hearing voices’. This aims to acknowledge that these are phrases applied to people by others and may not be used by service users themselves. It is hoped that the reader

understands that this is not endorsement of these terms and that the researcher understands that experiences such as psychosis can be meaningful.

1.3 Treatment Resistant Schizophrenia

As outlined, the diagnosis of schizophrenia is consistently perceived through the lens of the biogenetic model, with the dominance of this model evident in the heavy emphasis on psychiatric medication as treatment. Yet, it is notable that these drugs fail to have the desired effect on a sizeable group of people (Nucifora et al., 2019). Consequently, these people often receive the label of treatment resistant by default of treatment equating primarily to pharmaceutical drugs. Those whose experiences are described in this way are often painted as having poorer outcomes by clinicians with little interrogation of the efficacy of the treatment they are offered. Thus, the label of TR for those with a schizophrenia diagnosis will now be examined to investigate if critiques levied at the schizophrenia diagnosis extend to the TR label.

1.3.1 History of The Treatment Resistant Schizophrenia Label

The notion of TR for those with a schizophrenia diagnosis hinges on the concept of chronicity, a concept which can be traced to the 15th century when failure to recover from physical illness was cast as individual moral failure and led to people being described as chronically unwell (Bynum, 2015; Galvin, 2002). It was not until the 18th century, when understandings of madness moved from a temporary to permanent state, that chronicity began to be associated with psychological distress (MacDonald, 1981). The rise of the asylum, where people were not observed to be getting better despite lengthy stays, supported this notion (Cromby et al., 2013). Furthermore, the emerging psychiatric profession, looking to establish its legitimacy in the early 20th Century (Read, 2004), linked the biogenetic model to madness and therefore it emerged as a chronic construct (Grob, 1983; Jimenez, 1988).

Interest in schizophrenia as a chronic diagnosis grew steadily in the 20th century and offered a receptive context for the dawn of FGAs in the 1950s (Moncrieff, 2013a). These drugs appeared to represent a solution to problems of persistent psychological distress, now more visible through the move to community care

after mass deinstitutionalisation (Jimenez, 1988). Yet Elkis (2010) notes that this hope fell short; some people who were given these drugs as treatment found little reduction in the experiences that had led to a schizophrenia diagnosis in the first place (Itil et al., 1966). Therefore, the notion of TR began to appear in the 1970s as a description for this lack of response (Molina et al., 2012). However, at the time, TR was used to describe those who stayed in hospital for more than two years and who continued to experience e.g., hearing voices (Schultz et al., 1995).

It was not until the early 1980s that literature began to link the notion of TR specifically to pharmacology (Molina et al., 2012). A landmark study by Kane et al. (1988) operationalised criteria, outlining historical, cross-sectional and prospective requirements for diagnosis (Appendix A) and found that 30% of people who were not responding to FGAs did respond with Clozapine, an SGA. This resulted in Clozapine being positioned as the gold-standard treatment for those with a diagnosis of schizophrenia who were classed as TR. Over time, the word ‘chronic’ has declined in use to be largely replaced with the phrase TR, or interchangeably, ‘treatment refractory’, schizophrenia (Vanelle, 1997). Contemporary research suggests that around 30% of those diagnosed with schizophrenia will go on to be labelled as TR (Kane et al., 2019), with this number thought to rise to 56% in UK community samples (Beck et al., 2019). Beck et al. (2019) found no difference in age, gender or ethnicity between those with a schizophrenia diagnosis and those who had subsequently been given the TR label.

1.3.2 Establishing The Treatment Resistant Label

Antipsychotics, namely Clozapine, played a key role in the development of the TR label (Molina et al., 2012). Clozapine is the only antipsychotic drug licensed for the treatment of this label in the UK (Barnes et al., 2020). However, upon first introduction in the early 1970s, Clozapine was discontinued due to its effects on white blood cells which caused the deaths of several people (Iqbal et al., 2003). Nonetheless, as FGAs were increasingly deemed to be ineffective for those with a schizophrenia diagnosis, there was a push to re-introduce Clozapine with additional monitoring (Hippius, 1999). Kane et al. (1988) are credited with establishing such a re-introduction and at first glance, their

research appears to demonstrate a clear-cut advantage of Clozapine over Chlorpromazine for people with a schizophrenia diagnosis who saw no improvement with the latter drug. However, Peuskens (1999) writes how the licencing of Clozapine was dependent on the development of accompanying criteria for the TR label. Further examination reveals that Kane et al. (1988) were funded by the pharmaceutical company Sandoz in an attempt to document Clozapine's superiority (Braslow & Marder, 2019). Commercial and professional interests of pharmaceutical companies invested in antipsychotic drugs are well documented (Moncrieff, 2013a), as is the positive bias that emerges in the results of studies that are funded by them (Goldacre, 2012). This raises the possibility that the TR label lent legitimacy to the use of SGAs, in particular Clozapine, for those with a schizophrenia diagnosis.

1.3.3 Establishing Definition

Despite Kane and colleagues presenting a landmark study, there are debates around the clarity of criteria for the TR label. Whilst some commend Kane et al. (1988) for a rigorous approach towards definition (Buckley, 2020), others complain of a lack agreement over the specifics of the criteria and the limitations it places over who can receive Clozapine (Peuskens, 1999; Seppälä et al., 2016). Nonetheless, a systematic review found Kane's criteria, namely the failure of two antipsychotics other than Clozapine, at adequate dose and duration, to achieve a reduction in experiences labelled as psychosis, is an enduring feature of a large majority of the research (Howes et al., 2017). However, there are suggestions of amendments to the criteria, such as positioning treatment response as dimensional rather than distinct and ensuring that adherence to medication is documented prior using the label of TR (Molina et al., 2012; Barnes et al., 2020). In the UK, current NICE guidelines state that ''poor psychosocial and community functioning'' (NICE, 2014, p. 327), necessary for the application of the TR label, can occur as a result of medication side effects and unusual behaviour in a departure from the sole focus on so-called symptoms outlined in the criteria of Kane et al. (1988). Whilst such revisions of the label criteria are useful in theory, in practice this leads to as little interrater reliability on what defines the TR concept for those with a schizophrenia diagnosis (Howes et al., 2017). Inconsistent guidelines around how to measure antipsychotic failure lead to lack of international consensus

which hinders research progress (Seppälä et al., 2016). As a result, study comparison, interpretation and replication are problematised, whilst calls for definition consensus, prevalent since the label's inception, continue (Howes et al., 2017).

1.3.4 Disease Model Versus Drug Model

Within this context of uncertainty around definition, claims made around mechanisms of drug action support the utility of the TR label. Indeed, the mechanisms through which drugs are understood to work sets the context for the initial development of the TR criteria for those with a schizophrenia diagnosis. Moncrieff (2008) writes that in the 1950s, when psychiatric drugs were introduced, they were viewed through the drug-model of drug action, which suggests that drugs create an altered chemical state which may support functioning. For example, an altered state marked by disinterest and sedation could be useful in instances of agitation or distress (Delay & Deniker, 1956; Whitaker, 2002). In line with this, the drugs were called neuroleptics due to the effect they had on the neurological system (Moncrieff, 2013). However, as the influence of the biogenetic model grew within psychiatry in the 1960s, the disease-centred model, which posits that the brain requires chemical altering via drugs in order to function, replaced the drug-model. This had the effect of rebranding 'neuroleptics' as 'antipsychotics' due to their supposed disease-specific, or anti psychosis, abilities (Moncrieff, 2008). This shift, which happened with relative ease and little opposition, was enabled by several factors; the established desire to find specific biogenetic causal explanations, psychiatry's attempts to align itself with general medicine and the influence of pharmaceutical companies striving to link their drugs to specific problems in drug advertising (Klerman, 1978; Moncrieff & Cohen, 2005; Valenstein, 1998).

Within this context, Clozapine came to be framed as acting on the specific chemical imbalances which cause experiences linked to the label of TR for those with a schizophrenia diagnosis (Meltzer, 1989). This is despite the artificial separation of drug effects in the disease model which equates any improvement as the intended effect and all others as side effects (Moncrieff, 2013). Consequently, experiences such as unwanted sedation, lethargy and loss of agency (Angermeyer et al., 2001; Thompson et al., 2020) are framed as

inconvenient aspects of the drug, rather than as effects in their own right. Moncrieff and Cohen (2005) note the lack of evidence for the accuracy of the disease model, as the effects of other sedatives mirror that of supposed disease specific ones, whilst people with and without psychiatric diagnoses experience similar drug effects. For example, a study found that Diazepam was an effective treatment for those with an early schizophrenia diagnosis (Carpenter Jr et al., 1999), whilst antipsychotics such as Chlorpromazine have been found to cause sedation and impaired cognitive performance in those without a diagnosis of schizophrenia (McClelland et al., 1990). Such debunking of the disease model undermines claims of antipsychotic efficacy via the specific actions of the serotonin and dopamine hypothesises. As a result, the efficacy of the treatment being given to those with a diagnosis of schizophrenia is called into question, and therefore, by proxy, the notion of TR.

1.3.5 Treatment and Outcomes

Consequently, it follows that the evidence for the efficacy of Clozapine is mixed. Some studies suggest the drug is effective for people with a schizophrenia diagnosis who have received the TR label and call for earlier usage (Lally et al., 2018). However others, including Kane et al. (1988), lament the 40-70% of people who fail to experience any improvement (Meltzer et al., 2008; Siskind et al., 2017). The lack of efficacy contributes to a well-documented hesitancy in both clinicians and those taking the drug to begin the prescribing process (Weickert et al., 2018). However, the perceived chronicity of the TR label arguably dictates that drugs are rarely reduced. This means people with this label are perfect candidates for strategies such as medication dosage being prescribed over and above the levels recommended or multiple antipsychotics being prescribed at the same time (Hellewell, 1999; Thompson et al., 2016), despite the dangers of these approaches (Latimer et al., 2014). Furthermore, Moncrieff (2006) suggests that stopping antipsychotics can cause experiences such as seeing visions associated with a schizophrenia diagnosis, thereby confirming the apparent need for them. As Harper (2021) notes, the term treatment resistance deflects criticism of the drugs themselves and suggests their lack of efficacy is related to individual factors.

Alternative treatments for those who have a schizophrenia diagnosis and have received the TR label echo those for people without the label, such as ECT as an augmentation to Clozapine (Lally & Gaughran, 2018). In terms of psychotherapy, both NICE and the American Psychological Association (APA) endorse CBT, with the former additionally suggesting family therapy (APA, 2020; National Collaborating Centre for Mental Health, 2013). Indeed, evidence is beginning to grow which supports the use of psychotherapeutic intervention for those who have received the TR label. A recent 25 year systematic review and meta-analysis found that psychotherapy, including CBT, was effective in reducing experiences such as voice hearing for those with the TR label (Polese et al., 2019). However, as Polese et al. (2019) note, there is a distinct lack of studies which propose psychological treatment as an alternative, rather than adjunct, to pharmaceutical drugs in the context of TR. In addition, research around outcomes paints a pessimistic picture for those with a schizophrenia diagnosis who have received the TR label, pulling largely on clinical notions of recovery and lamenting chronicity (Iasevoli et al., 2016; Suzuki et al., 2011).

Consequently, similarities can be drawn between the dominant presence, and effect, of the biogenetic model for both the schizophrenia diagnosis and the diagnosis with the addition of the TR label. Furthermore, research appears to suggest that the latter of these experiences has yet to benefit from any service user input and hence remains fully shaped by the biogenetic lens.

1.4 Content Analysis

1.4.1 Introduction

In order to gain a better understanding of current research around the concept of TR for those with a schizophrenia diagnosis and to explore if alternatives to the biogenetic model are available, initial plans for this introduction included a systematic review of the literature. However, pilot searches with terms such as ‘qualitative’, ‘subjective experience’ or ‘service user’ produced few results. This seemed to be due to the taken for granted nature of the concept of TR in the context of a schizophrenia diagnosis which has yet to be explored through any lens other than biogenetic or as anything other than a category, with a predominate focus on pharmacological intervention.

In order to investigate this further, a content analysis (CA; Berelson, 1952) of contemporary literature around the concept was carried out. CA is a method of analysis used to analyse written communication (Cole, 1988). CA was appropriate for this introduction due to its ability to systematically categorise data in order to describe a focused yet wide-ranging picture of a phenomena (Elo & Kyngäs, 2008; Vaismoradi et al., 2013). The aim of this CA was to identify the themes of the research on the TR label for those who have been diagnosed with schizophrenia and schizoaffective disorder, along with the proportions of these different themes.

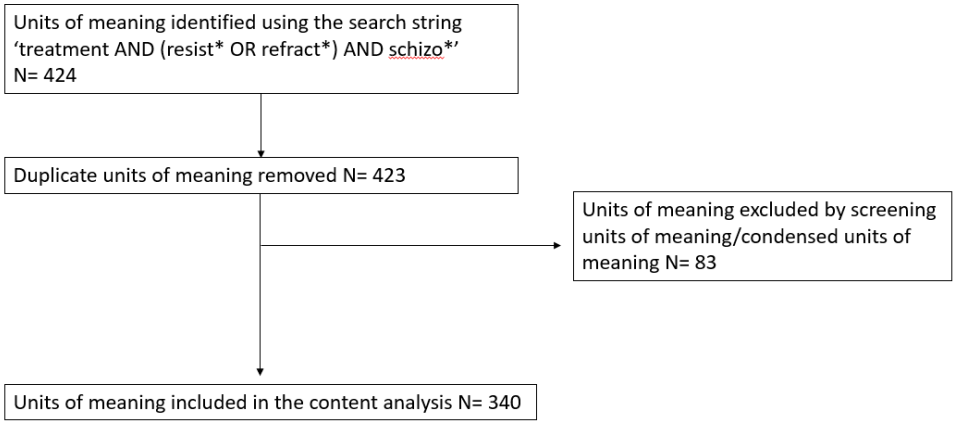
1.4.2 Method

The current study utilised guidelines which outline three main stages of CA: preparation, organisation and reporting (Elo & Kyngäs, 2008). As there was no pre-existing theory against which to analyse the data, an inductive analysis of manifest content was conducted (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). In line with this, the research question was 'What are the aims of research around the TR label for those with a diagnosis of schizophrenia or schizoaffective disorder?'. The search was carried out on 5th January 2022 using the search term 'treatment AND (resist* OR refract*) AND schizo*'. This allowed for variation such as resistance/resistant/resisting/refractory/refractive and schizophrenia/schizophrenias, along with the schizoaffective disorder diagnosis.

The search results were filtered for papers in the English language and limited to publication in the year 2021. After rejecting one duplicate and 83 results on the basis of irrelevancy, 340 papers remained which made up the unit of analysis as shown below (Figure 1). Following Elo & Kyngäs (2008) the individual papers, or meaning units, were individually analysed against the research question by hand via a process of reading each abstract, or the condensed meaning units, before being grouped into overarching codes and refined into categories. The author keywords were also considered. At times it was necessary to read the full article after reading the abstract to allow through analysis. As Vaismoradi et al. (2013) write, both the content of articles and the frequency of codes can contribute to the formation of categories.

Figure 1

Content Analysis Process (N= Number of Units of Meaning)



1.4.3 Results

Analysis of the articles against the research question, 'What are the aims of research around the TR label for those with a diagnosis of schizophrenia or schizoaffective disorder?', resulted in four generic categories; investigating treatment, investigating causality, investigating subjective experience and investigating progression. These categories were broken down into several subcategories. A category map is shown below (Figure 2), along with a table showing the number and percentage of articles that were ascribed to the generic categories (Table 1).

Figure 2

Content Analysis for Category Map

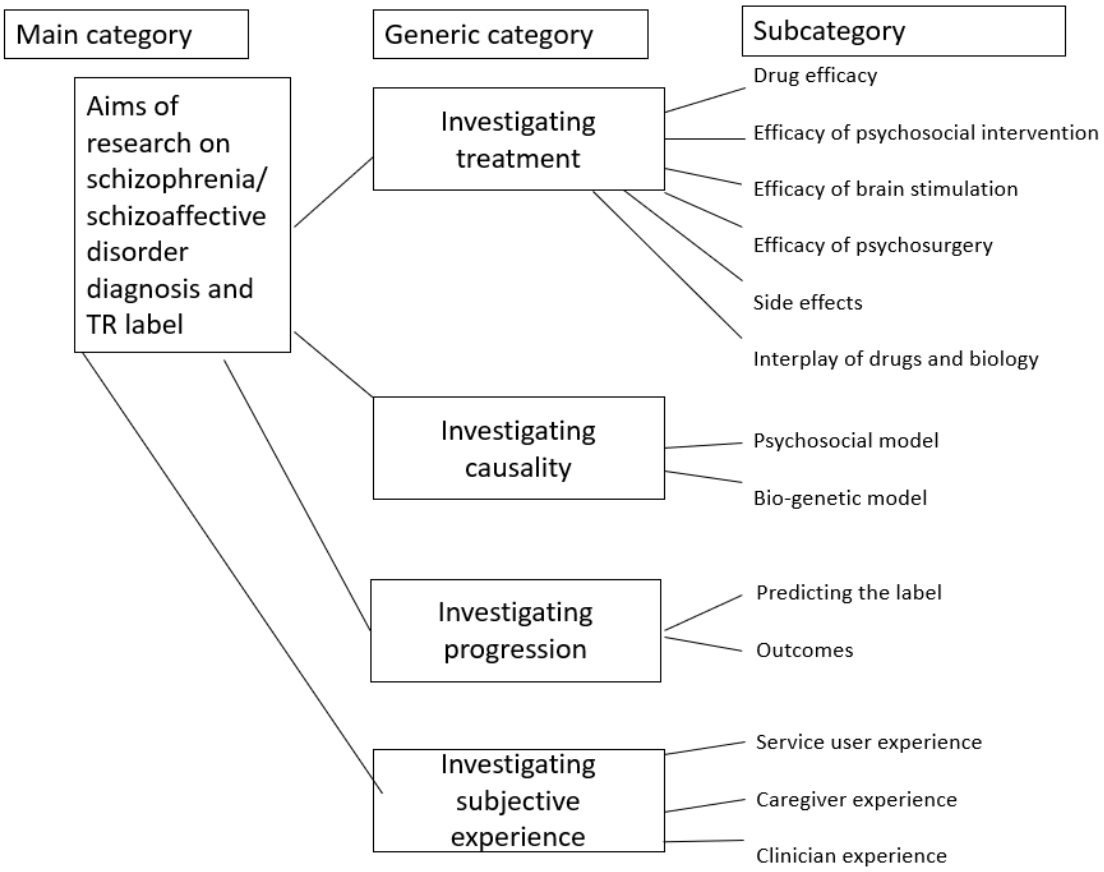


Table 1

Number and Percentage of Articles Ascribed To Generic Categories in The Content Analysis

Category type	Category name	Number of search results	Percentage of main category
Generic category	Investigating treatment	246	72.4%
	Investigating causality	58	17.1%
	Investigating progression	27	7.9%
	Investigating lived experience	9	2.6%

1.4.3.1 Generic category 1: Investigating treatment: This category includes the articles which were primarily concerned with investigating different treatment options and their effects for people diagnosed with schizophrenia or schizoaffective disorder (S/SAD) who had received the TR label. This was the most populated generic category, comprising 72.4% of the articles in the analysis. There were six subcategories: drug efficacy, efficacy of psychosocial intervention, efficacy of brain stimulation, efficacy of psychosurgery, side effects and interplay of drugs and biology. Of these six, side effects emerged as the most populated, followed by drug efficacy, whilst the efficacy of psychosurgery was least represented in the articles, as shown below (Table 2).

Table 2

Generic Category 1: Investigating Treatment

Investigating treatment				
Category type	Category name	Number of papers	Percentage of 'investigating treatment'	Percentage of main category
Subcategory	Drug efficacy	73	29.7%	21.5%
	Side effects	78	31.7%	22.9%
	Interplay of drugs and biology	45	18.3%	13.2%
	Efficacy of brain stimulation	33	13.4%	9.7%
	Efficacy of psychosocial intervention	16	6.5%	4.7%
	Efficacy of psychosurgery	1	0.4%	0.3%
Total		246	100%	72.4%

In the largest subcategory of side effects, all articles bar one referred to adverse effects such as weight gain and even death (e.g., Barbosa & Fernandes, 2021; George et al., 2021; Hillow et al., 2021; Sahyouni & Hefazi, 2021).The anomaly spoke of the potential for antipsychotics to offer some protection from Covid-19 via effects such as antioxidant drug properties (Tendilla-Beltrán & Flores, 2021). Yet even this article noted that these drugs may additionally increase the likelihood of survivors becoming dangerously unwell if they contract Covid-19 in the first place (Tendilla-Beltrán & Flores, 2021). Drug efficacy concerned the usefulness of pharmaceutical intervention, focusing on Clozapine, or pharmaceutical alternatives such as Olanzapine (e.g., Okeya et al., 2021; Siskind et al., 2021; Wagner et al., 2021). Many of these articles were written by researchers who are advisors to and/or receive personal fees from pharmaceutical companies themselves (e.g., Gammon et al., 2021; Iruretagoyena et al., 2021).

The third most populated subcategory, the interplay of drugs and biology, revealed a focus on understanding how mechanisms of drug action affect

biology, and vice versa, in the hope of increasing overall drug efficacy (e.g., McQueen et al., 2021; Shad, 2021; Werner & Coveñas, 2021). Finally, in the subcategories of efficacy of psychosurgery, efficacy of psychosocial intervention and efficacy of brain stimulation, interventions such as subcaudate tractotomy[10], CBT and ECT were described respectively (e.g., Dellazizzo et al., 2021; Tan et al., 2021; Vilela-Filho et al., 2021). Of note is that such interventions were only ever discussed as adjunct to drugs (e.g., Dellazizzo et al., 2014; Moulier et al., 2021; Vilela-Filho et al., 2021).

1.4.3.2 Generic category 2: Investigating causality: This was the second most populated generic category, comprising 17.1% of the articles. This generic category was concerned with investigating causal explanations for people receiving the TR label. There were two subcategories; psychosocial model and biogenetic model, which comprised 1.7% and 98.3% of this generic category respectively as shown below (Table 3).

Table 3

Generic Category 2: Investigating Causality

Investigating causality				
Category type	Category name	Number of papers	Percentage of 'investigating causality'	Percentage of main category
Subcategory	Biogenetic model	57	98.3%	16.8%
	Psychosocial model	1	1.7%	0.3%
Total		58	100%	17.1%

In the biogenetic subcategory, attempts to identify biomarkers were prevalent (e.g., Assunção-Leme et al., 2021; Saleh et al., 2021; Veronese et al., 2020). In addition, the subcategory featured articles which drew on the disproven

[10] Subcaudate tractotomy is a neurosurgical operation where two probes are inserted into the brain and the caudate nucleus destroyed via an electric current. It is typically carried out for people whose psychiatric diagnosis is deemed to be resistant to treatment (Malizia et al., 1993).

dopamine hypothesis, along with persistent medicalised language around causality (e.g., Badrlou et al., 2021; Miyazawa et al., 2021). The single article focused on psychosocial explanations of distress linked childhood adversity, such as physical and sexual abuse, to an increased likelihood of receiving the TR label due to the poorer outcomes associated with this experience (Chaiyachati & Gur, 2021). The study authors call for these experiences to be explored in psychotherapeutic interventions, raising questions about why such interventions are largely missing from this CA.

1.4.3.3 Generic category 3: Investigating progression: This generic category was concerned with predicting who would receive the TR label, along with their possible outcomes and made 7.9% of articles. There were two subcategories, predicting diagnosis and outcomes, which made up 51.9% and 48.1% of the articles respectively as demonstrated below (Table 4).

Table 4

Generic Category 3: Investigating Progression

Investigating progression				
Category type	Category name	Number of papers	Percentage of 'investigating progression'	Percentage of main category
Subcategory	Predicting the label	14	51.9%	4.1%
	Outcomes	13	48.1%	3.8%
Total		27	100%	7.9%

The subcategory of predicting the label noted that factors such as early onset and increased duration of experiences such as seeing visions were associated with people with a schizophrenia diagnosis receiving the TR label (e.g., Chan et al., 2021; Griffiths et al., 2021). In addition, there was consistent reference to biogenetic explanations of distress in the search to find characteristics which would lead to better prediction of who may receive the TR label (Bernardo et al.,

2021). Often this was in order to facilitate better treatment through antipsychotics.

Outcomes documented how recovery was progressing for those with the TR label and evaluated the financial implications of this recovery (Jin et al., 2021; Moges et al., 2021; Verma et al., 2021b). The risks of long-term antipsychotic use are outlined in an article from Harrow et al. (2021), who found that those who were no longer taking antipsychotics after two years experienced higher likelihood of recovery and less hospital readmissions than those who continued to take them.

1.4.3.4 Generic category 4: Investigating subjective experience: This generic category concerned articles which investigated aspects of subjective experience related to the TR label. This was the smallest category, comprised 2.7% of the articles and resulted in three subcategories: service user experience, caregiver experience and clinician experience. Of these subcategories, service user experience made up 66.7%, whilst the other two were calculated at 22.2% for clinician and 11.1% for caregiver experience (Table 5). Further details of these papers, such as results and location, can be found in Appendix B.

Table 5

Generic Category 4: Investigating Subjective Experience

Investigating subjective experience				
Category type	Category name	Number of papers	Percentage of 'investigating subjective experience'	Percentage of main category
Subcategory	Service user experience	6	66.7%	1.8%
	Clinician experience	2	22.2%	0.6%
	Caregiver experience	1	11.1%	0.3%
Total		9	100%	2.7%

Service user experience made up the largest proportion of the articles. One paper aimed to explore the difference in experience of being in the mental health system for White British/non-British and Black Caribbean people with long-standing labels of psychosis and antipsychotic use (Lawrence et al., 2021). One aimed to develop a scoping review on service user perspective on Clozapine treatment (Jakobsen et al., 2021) and investigated the effect of Covid-19 on people with the TR label (Fahy et al., 2021). The remaining articles aimed to document the nature of the psychosis experience for those with the TR label or whose psychosis experiences were described as chronic, namely the association of paranoia with uncertainty (Lebert et al., 2021), the effect of command voices on violent behaviour (Salim et al., 2021) and any heterogeneity in service users' beliefs about their voices (Zanello & Dugré, 2021)

The clinician experience and caregiver experience subcategories were concerned with reporting the experience of mental health staff and of caregivers. The aims of these articles, namely to outline a framework to improve Clozapine adherence (Ahluwalia et al., 2021), to assess psychiatrist willingness to carry out coercive treatment (Stoll et al., 2021) and to explore the effect of Clozapine in relation to caregiver burden (Verma et al., 2021a), document the biogenetic model's influence on clinical practice and on the treatments promoted as effective to caregivers.

1.4.3.5 Quality of Generic category 4 studies: The current study is similarly concerned with investigating the subjective experience of those who have been diagnosed with the S/SAD diagnosis and received the TR label. Therefore, the quality of existing papers on this topic which came to light through the CA was assessed. This was done using the Critical Appraisal Tools developed by the Joanna Briggs Institute (Bilotta et al., 2020), which have been found to demonstrate face validity and include a range checklists for different study methodologies, including qualitative studies which is a rarity amongst other tools (Katrak et al., 2004; Munn et al., 2020). Ratings of quality were developed by answering the questions on the checklists for each study design, where responses were rated either 'Yes' or 'No'. A percentage of quality criteria met

was then assigned to each study, along with additional comments around study quality (see Appendix C).

Quality criteria met ranged from 55% to 100%, with five of the nine studies scoring 100% of quality criteria met and showing methodological strengths such as clearly defined inclusion criteria, participant demographics and thoughtful consideration of the influence of researchers on the study (Jakobsen et al., 2021; Lawrence et al., 2021; Lebert et al., 2021; Stoll et al., 2021; Zanello & Dugré, 2021). Failing to offer sufficient detail for post-intervention clinical presentation, not naming confounding variables and not having a control group were areas where the remaining studies could improve (Fahy et al., 2021; Salim et al., 2021; Verma et al., 2021a).

1.4.4 Discussion

Overall, articles in the CA perceived those who have received the label of TR and who have a S/SAD diagnosis through a biogenetic lens which shapes research around treatment, causal models and progression. Articles investigating treatment were most prevalent. This reveals a reactive rather than preventative approach to the label of TR, where focus is on how to treat rather than how to prevent people becoming distressed in the first place. It is striking that articles looking into drug efficacy were outnumbered by those investigating side effects of these drugs. This highlights the dangers posed by drug treatments for those diagnosed with S/SAD who have received the TR label, something which is echoed in the research for those with a S/SAD diagnosis (Tandon et al., 2020).

Yet despite this, psychiatric drugs emerge as a given in the treatment of the TR label. There were consistent references to clinical notions of recovery (e.g., Shimomura et al., 2021), whilst articles concerned with the interplay of drugs and biology all focused on how this could be harnessed in order to augment the efficacy of drug intervention. This ensures people's experiences are firmly located in a biogenetic context, despite the documented negative effects those treatments have on the bodies of survivors and the intensely personal nature of their experiences (Dillon & Longden, 2013; Read & Sacia, 2020; Read & Williams, 2019). Indeed, support for the biogenetic model is found in the

plethora of articles around causality at the expense of the psychosocial model. This reflects the state of play for those with a schizophrenia diagnosis, despite service users themselves often disagreeing and amplifying psychosocial factors (Dillon & Longden, 2013). Furthermore, articles predicting the label and possible outcomes leaned heavily on the biogenetic model, promoting antipsychotic use by identifying ways to maximise their efficacy through earlier and continued prescription (e.g., Jin et al., 2021; Verma et al., 2021b; Yasui-Furukori et al., 2021).

Of the nine articles concerned with subjective experience related to the TR label, six were concerned with aspects of service user experience. However, it is notable that four of these used quantitative data collection methods (Jakobsen et al., 2021; Lebert et al., 2021; Salim et al., 2021; Zanello & Dugré, 2021). Whilst such a methodology can present a wide-ranging perspective on the topic at hand, it fails to offer the explanation or detail behind this perspective (Krawczyk et al., 2017). Indeed, the PANSS utilised by Lebert et al. (2020) and Salim et al. (2021) in the CA, has been critiqued as lacking nuance in capturing the complexities of the psychosis experience (Barnes et al., 2020). In contrast, qualitative methods allow a rich exploration of subjective experience which can give voice to those who are frequently marginalised in research (Willig, 2008). These voices are notably absent in both the CA and the wider context of literature around the TR label.

Of the two articles which utilised qualitative data collection methods, it is notable that one of these, Fahy et al. (2021), used these methods alongside quantitative measurements. Furthermore, the study consistently referred to the TR label from a biogenetic perspective. Whilst this was common across the majority of the studies concerned with the subjective experience of service users, research shows such explanations of distress increase stigma, a process of labelling and discrimination where power is wielded over others (Link & Phelan, 2001), as they feed into harmful stereotypes which paint service users as unpredictable and dangerous (Kvaale et al., 2013). Furthermore, the study suggested that those with the TR label are more isolated than those with only a schizophrenia diagnosis, however failed to explore possible interaction between this and service users receiving such a label (Fahy et al., 2021). This exemplifies the taken for granted nature of the TR label across the CA literature.

The only article exploring service user experience via purely qualitative methods found that the biogenetic model failed to honour personal meaning making and reduced hope service users had around recovery (Lawrence et al., 2021). Such an article in theory gives insight into the impact of receiving a label such as TR for those with a diagnosis of S/SAD and echoes findings from earlier research around the S/SAD diagnosis (Perkins et al., 2018; Pitt et al., 2009). However, a caveat needs to be placed around the generalisability of these findings as the article only refers to people with a diagnosis under the broad category of schizophrenia who have been using mental health services for over ten years and are described as 'chronic' (Lawrence et al., 2021). Therefore, whilst assumptions can be made given research which puts the percentage of those with a schizophrenia diagnosis who receive the TR label as high as 56% (Beck et al., 2019), further research specifically around the impact of this label is needed.

1.5 Thesis Rationale

Research concerning the label of TR for those with a diagnosis of S/SAD is dominated by the biogenetic lens. The impact and influence of this lens is demonstrated in literature around causal models, treatment and ideas around prediction and outcomes. Unlike the diagnosis of S/SAD, studies around the label of TR have yet to include service user perspectives around alternative explanations or the effect of receiving such a label itself. Whilst assumptions can be made that findings around the adverse effect on factors such as self-perception, stigma and available treatments experienced by those with a S/SAD diagnosis are transferable to those with the additional TR label, there is an absence of these voices in the literature. Even the small number of articles exploring service user experience in relation to the TR label largely drew on the biogenetic model, used quantitative methodology and failed to consider the impact receiving such a label could have on people.

Therefore, there is a need for a study which takes a qualitative approach to data collection and explores the effect receiving the TR label has on the lives of those with a diagnosis of S/SAD, for example on how they see themselves. In addition, service user perspectives on why they received the label are vital in order to explore if these fit with the overwhelmingly biogenetic frame of the pre-existing literature.

1.6 Research Questions

The aim of the present study is to capture meaningful, exploratory data on the experiences of people who have been diagnosed with S/SAD and received the label of TR. As such, the primary Research Questions are:

1) What do people report being told about the treatment resistant label and the reasons for being given it?
2) How do people describe the effects of the treatment resistant label on how they view themselves and how others view them?

2. METHOD

2.1 Rationale For Methodology

The study employed semi-structured qualitative interviews to explore the experiences of people who had received a diagnosis of S/SAD and been told that their experiences were TR. Harper and Thompson (2011) write that qualitative research is best placed to facilitate a through and meaningful understanding of processes and participant experience, whilst Willig (2012) notes that it highlights the rich texture of these experiences.

2.1.1 Epistemological and Ontological Considerations

It is vital to ascertain the theoretical and philosophical assumptions which are generated by the research questions prior to beginning the planning, collection and analysis of data (Willig, 2013). After reviewing the research questions, it was apparent that the study should take a Critical Realist position (Bhaskar, 1998). Critical realism is built on three assumptions: namely ontological realism, epistemological relativism and judgemental rationality (Pilgrim, 2019). The first of these tenets holds that the world is independent of us, it existed before us and will exist after us and therefore reality is not dependent on our existence, whilst the second holds that all research methods are limited (Pilgrim, 2019; Willig, 2013). The third factor, judgemental rationality, notes that drawing on the assumptions outlined above, judgements about the plausibility of different claims can be made (Pilgrim, 2019).

Critical realism acknowledges the subjective nature of such interpretation, shaped by the different lenses with which both researcher and participant see the world (Banister et al., 1994). For example, in the current study, interviews are carried out with people who have been diagnosed with S/SAD and later been told that their experiences are resistant to treatment. The data collected from these interviews mirrors participant perspectives, whilst the subsequent analysis relies on the perspective of the researcher for interpretation. As Willig (2012) notes, participants may not be aware of the underlying structures which shape their perspectives.

2.1.2 Critical Realist Thematic Analysis: Rationale

Thematic analysis (TA) is a popular qualitative analysis method which focuses on patterns, or themes, within a data set (Braun & Clarke, 2006). Braun and Clarke (2006) outline how TA is not constrained to any one epistemological position. This flexibility, additionally noted by Willig (2013), contributed to it being chosen for the current study, aligned as it is with a critical realist perspective. Furthermore, TA facilitates the structuring of unstructured data, highlighting meanings which appear the most pertinent and thereby shedding light on how participants conceptualise the study phenomena (Joffe, 2012). This fits with the aims of the current study to explore participant experiences of receiving the label of TR. Indeed, TA offers a nuanced analysis, one that presents both differences and similarities and an overarching picture of participant experience (Blacker, 2009; Joffe & Yardley, 2003).

TA suggests two approaches to data analysis: inductive or deductive/theoretical (Braun & Clarke, 2006). An inductive approach was taken in this analysis which ensures that the themes are data-driven and hence maintain a strong connection to the data (Braun & Clarke, 2006; Patton, 2014). However, it is important to note that themes are explicitly shaped by the epistemological position of the researcher, along with their own assumptions and beliefs, and as such are constructed rather than simply awaiting discovery (Braun & Clarke, 2006; Taylor & Ussher, 2001).

There were several other methods of analysis considered as alternatives to TA, one of which was Grounded Theory (GT; Glaser & Strauss, 1967). GT is a useful tool in drawing up a theoretical framework (Glaser & Strauss, 1967). However, as there is a sparsity of research around those who have been diagnosed with S/SAD and received the label of TR, it was considered that aiming for a theoretical model was premature. Interpretative Phenomenological Analysis (IPA; Smith, 1996), which aims to develop a rich subjective account, was another analysis method considered. However, again, the lack of established research around the topic of the TR label drew the researcher to TA rather than IPA, as the study aimed to gain a broader picture rather than focus on features shared across participants. Similarly, Discourse analysis was not used due to its focus on language which would have narrowed the scope of the research and failed to relate to the research questions.

2.1.3 Researcher Reflexivity

As discussed, a critical realist position recognises that the researchers own beliefs, experiences and assumptions will shape how they interact with and analyse the data (Willig, 2013). Willig (2013) notes that personal reflexivity on these factors, along with pre-existing relationships to the research, is helpful when conducting qualitative research to increase credibility. Such reflexivity is encouraged by a critical realist position; indeed, it may even act to deepen the interpretation of the data (Clarke & Braun, 2013; Pilgrim, 2019).

2.1.3.1 Researcher's Position: Prior to clinical psychology training, I worked for a small team teaching on courses which took a non-medicalising stance to mental distress. I was drawn to this topic of study due to having previously worked alongside people who had received a diagnosis of schizophrenia and the TR label. We had many conversations about the effect of the label on their lives. I was interested in whether the adverse impact it appeared to have was experienced by others. I was additionally aware of the growing research examining the impact of the schizophrenia diagnosis as a phenomenon in its own right, yet could find little literature which explored the label of TR. Therefore, I was motivated to focus on this topic area as a means to widen my perspective.

I am a White woman, who is able-bodied, middle class and completing a doctorate degree. These visible aspects of my identity will have undoubtedly shaped how participants experienced me during interviews and how they interacted with me as a result. Whilst I have my own experience of mental distress, I did not include this in the study advert. Therefore, a combination of these factors could have led to people having concerns around not being understood. In a sense this would have been correct, as I have never received a diagnosis of S/SAD or the label of TR, therefore there are limitations to my understanding of their experiences. Supervision with the study supervisor was helpful to discuss these dilemmas. In addition, I aimed to be transparent with participants over what the study consisted of and how their data would be used.

2.2 Ethical Considerations

2.2.1 Ethical Approval

The study was granted ethical approval by the University of East London's School of Psychology Research Ethics Sub-Committee (Appendix D). Recruitment was not via the NHS and therefore did not require further ethical approval.

2.2.2 Informed Consent

Prior to agreeing to take part in the study, participants were sent a link to the study website (ABOUT ME | My Site (u1945526.wixsite.com)) which contained the Participant Information Sheet (Appendix E) via email from the researcher's university email address. On the day of the interview, participants were re-sent the Participant Information Sheet directly, along with an electronic copy of the Consent Form (Appendix F) to digitally sign after reviewing the Participant Information Sheet. Interviews were not started until this form had been completed and any questions answered. Data management and the process of recording and transcription on Microsoft Teams was explained prior to beginning the interviews. Participants were aware that they could stop the study at any point and that post data collection, they had three weeks in which to state that they no longer wished for their data to be used. No participants chose to withdraw their data or stop their participation in the study.

2.2.3 Confidentiality and Anonymity

Participants were all given a pseudonym in the original transcripts and extracts used in the thesis, which will remain for future publications. All references to features which could identify participants were removed, along with references to service names or other people. The researcher, study supervisor and examiners are the only people with access to the full anonymised transcripts. As the interviews were conducted via Microsoft Teams video-call, the researcher conducted the interviews in a confidential, secure space.

2.2.4 Data Protection

A comprehensive and detailed Data Management Plan (Appendix G) was completed which adheres to the principles of the Data Protection Act 2018 (U.K). This covered all the data generated by the research study. For example, consent forms were saved directly to the UEL OneDrive for Business and any

local copies of the forms deleted, whilst audio recordings were downloaded and uploaded onto UEL OneDrive for Business, with any local copies destroyed. Following examination of the doctoral thesis and acceptance, consent forms and audio recordings will be destroyed. Anonymised transcripts and demographic information will be kept for three years or until thesis publication and then destroyed.

2.2.5 Participant Wellbeing and Debrief

Prior to the interview beginning, the researcher outlined to participants that they were not required to answer any questions with which they felt uncomfortable. Participants were encouraged to think of something they could do after the interview as a personal debrief, for example go for a walk. During the interviews, the interviewer checked in at various points to check that participants felt comfortable with how the interview was progressing. After the interview, participants were sent the Debrief letter (Appendix H) which the interviewer then checked their understanding of. None of the participants indicated that taking part in the study had caused them any distress.

2.3 Participants

2.3.1 Consultation

A member of the University of East London's People's Panel, a service user steering group, was consulted during the initial planning stages of the research. This person indicated that the area of study was currently underdeveloped and would benefit from further research. Further informal consultation was conducted with someone known to the researcher who had a schizophrenia diagnosis and had received the label of TR. They also indicated that there was little known research on the topic and flagged that recruitment may be difficult due to the fear people may have around other people's perceptions of them. This consultee additionally indicated that receiving the label had a detrimental impact on their life.

2.3.2 Inclusion Criteria

The inclusion criteria were: adults (18 years or older) living in the UK who have received the label of 'treatment resistant schizophrenia' or who have been given a diagnosis of schizophrenia and been told that their experiences were 'resistant to treatment' at any point in their life. The lack of time frame on when

this label/description was received was chosen to reflect the possibility that participant identification with the label may have changed over time, or that they may have recovered. Access to the internet on a computer, smartphone or other device was required due to the interviews taking place via Microsoft Teams video-call.

2.3.3 Recruitment

Participants were recruited via Twitter, where a brief outline of the study criteria was posted, along with a link to the study website, ABOUT ME | My Site (u1945526.wixsite.com). The website included the inclusion criteria, the researcher's university email address and the participant information sheet. The study advert was posted with a message asking Twitter users to retweet it and was re-posted by the researcher around once a week, beginning on 6th August 2021 until late December 2021 when recruitment stopped. The study advert was additionally posted on a Facebook group, Intervoice: The International Hearing Voices Movement | Facebook and on a Reddit forum, A subreddit for those interested in schizoaffective disorder. The study post was not accepted on a similar Reddit forum for those with a schizophrenia diagnosis.

The London Hearing Voices Network (London Hearing Voices Network | Mind In Camden) advertised the study in their monthly newsletter. The second consultee mentioned above is part of the National Paranoia Network (National Paranoia Network) and agreed that the study advert could be placed on their website. It should be noted that this consultee, along with a colleague of theirs also known to the researcher, both took part in the present research study. This will be discussed further in the Critical Review section of the Discussion chapter.

The researcher's university email address was visible on the social media posts and on the study website itself. Participants expressed interest via email and were sent a link to the study website to ensure that they had understood what the study entailed and met the inclusion criteria. If participants were eligible for the study and remained interested after reviewing the study website, a date and time for the Microsoft Teams video-call interview was arranged via email.

2.3.4 Sample

The sample consisted of six people who had been diagnosed with schizophrenia and had received the label of TR. A direct message was received via Twitter from the keyworker for someone with a diagnosis of schizoaffective disorder who had received the TR label asking if their unnamed client could take part. The researcher discussed this with the study supervisor and it was decided that as schizoaffective disorder sits under the umbrella of the 'Schizophrenia and other psychotic disorders' category in the ICD-11 (World Health Organisation, 2021), then the person would be eligible to partake in the study. An email from a person who had been given a diagnosis of schizoaffective disorder was then received, referencing their key worker as passing on the study details, however it is not certain as to whether this was the same person though it seems likely. Therefore, in total, seven participants were recruited and their demographics are reported below (see Table 6). Research suggests that as little as six participants is a sufficient sample size to construct codes and develop a meaningful TA analysis (Guest et al., 2016). In addition, the literature provides evidence that seven participants have provided a fruitful TA from a critical realist standpoint (Harper & Timmons, 2021). Sample size will be discussed further in the Critical Review section of the Discussion chapter of this thesis.

Table 6

Demographics of Participants

Participant pseudonym	Age	Gender	Ethnicity	Diagnosis received?
Cillian	34	Male	White Irish	Schizoaffective disorder
Rosie	33	Female	White British	Schizophrenia
Ian	34	Male	White British	Schizophrenia
George	52	Male	White British	Schizophrenia
Sarah	46	Female	White British	Schizophrenia
John	60	Male	White British	Schizophrenia
Lisa	35	Female	White British	Schizophrenia

2.4 Procedure

2.4.1 Developing The Interview Schedule

Semi-structured interviews are useful in capturing the subjective experience of the interviewee, whilst allowing the interviewer freedom to sensitively explore what participants say (Fylan, 2005; Wengraf, 2001). As a result, nuance can be captured within the data (Fylan, 2005). However, there are limitations to semi-structured interviews. Diefenbach (2009) notes that both interviewer and interviewee are likely to be shaped by unconscious bias in their interactions which will be reflected in the data collected, whilst Alvesson (2003) writes that data should be not taken as a direct reflection of reality, rather of a reflection of participants' cultural scripts. Nonetheless, semi-structured interviews provide the opportunity to reveal rich and detailed insights on the topic at hand that other data collection methods miss (Diefenbach, 2009). For this reason, the study employed this method, holding as it does a critical realist perspective which goes some way to guarding against the critiques outlined above.

Wengraf (2001) states the importance of planning and preparing for a semi-structured interview to avoid producing vague data which fails to answer the research questions. Therefore, the first draft of the interview schedule was drawn up after an initial review of the literature and the consultation outlined above (Appendix I). A colleague of the researcher assisted in conducting a pilot interview to check the flow of the questions and develop the skills and confidence of the researcher.

2.4.2 Data Collection

In total, seven interviews were conducted between August - December 2021. The interviews took no longer than one hour and thirty minutes and were conducted via video-call using Microsoft Teams. A date and time suitable for the participants was arranged via email prior to the interview and a digital invite sent out which had a link to the meeting within it. On the day, the researcher joined the call around ten minutes early and kept an eye on their emails for any problems interviewees were having with accessing Microsoft Teams.

When the interviewees had joined the video-call, and prior to the researcher beginning the semi-structured interview, participants were sent the Participant Information Sheet (Appendix E) and the Consent Form (Appendix F) to re-read

and sign respectively. These were discussed with the interviewer and any questions answered. The Consent Form was sent back and checked for completion before the interview began. A Demographic Information sheet (Appendix J) was additionally sent via email and returned by participants.

Prior to beginning digital recording, the interviewer confirmed consent with the interviewee. A plan was made should the internet connection of either the interviewer or interviewee drop out, namely to re-join the call or email if this was not possible. The interview then began following the interview schedule (Appendix I). Following the interview, participants were thanked for taking part in the study and sent the Debrief Letter (Appendix H). This was discussed and any questions answered before the interview ended.

2.4.3 Transcription

The interviews were recorded on Microsoft Teams which produces an automatic transcript of the interview. Braun & Clarke (2006) note that TA does not require the following of a complex transcription convention. Therefore, the transcript was checked for accuracy and corrected against the audio-recordings, before it was presented word for word with what participants said and punctuation added (Appendix K).

2.5 Analysis

The study followed the six-phase framework outlined by Braun and Clarke (2006) to complete a TA. Whilst the phases for analysis are presented here in a linear fashion, the process was applied flexibly and involved moving between the different steps until analysis was considered complete.

- Phase 1: Researcher familiarising self with data
    - The researcher reviewed the transcripts provided by Microsoft Teams, listening to the audio recordings simultaneously to ensure that the transcripts were correct. This began the process of the researcher familiarising themselves with the data and was followed by listening to each audio recording and reading each transcript multiple times whilst jotting down any initial ideas (Appendix L).

- Phase 2: Initial code generation
    - Codes highlight features of the data which appear important to the researcher completing the analysis. The entire data set was systematically coded by the researcher for features of interest, giving equal focus on each data item (see Appendix K). This formed a framework with codes and associated extracts (see Appendix K).

- Phase 3: Searching for themes
    - Collections of codes form themes, which give a broader perspective and identify patterns in the data set. The next phase of analysis saw the researcher actively collating codes into initial themes, however these were held lightly in anticipation of the next phase of analysis (Appendix N).

- Phase 4: Reviewing themes
    - The researcher reviewed the initial themes, a process which involved discarding and collapsing some into others (Appendix O). Initial themes were also shared with the study supervisor and refined further. These themes were additionally checked against both the whole data set and the coded extracts, before a thematic map was generated.

- Phase 5: Defining and naming themes
    - Following a further process of revision, this phase entailed the researcher naming and defining each theme (Appendix P). This aimed to capture both the character of the theme and the narrative it tells in relation to the research questions.

- Phase 6: Producing the report
    - The final phase of analysis involved the researcher producing a report which presented the final analysis. This report included data extracts to exemplify themes and analytic commentary.

2.6 Quality of Research

2.6.1 Evaluating Qualitative Research

Despite the importance of evaluating qualitative research to ensure that it is of a high quality, there are a number of different guidelines as to how to achieve this (Spencer & Ritchie, 2011). However, as Spencer & Ritchie (2011) note, there are several overarching quality principles which are vital to adhere to in qualitative research, namely, contribution, credibility and rigour. Below is an outline of the meaning of these principles. The study will be evaluated using these criteria in the Critical Review section of the Discussion chapter.

2.6.1.1 Contribution: The principle of contribution is concerned with the ability of the research to make inferences which are not limited to the study context or participants. To do so, a study must demonstrate that its evidence is both relevant and valuable to a wider context than that drawn from to gather the research evidence (Spencer & Ritchie, 2011).

2.6.1.2 Credibility: Credibility relates to how believable and plausible conclusions made in research are (Guba & Lincoln, 1989; Spencer & Ritchie, 2011). In order to demonstrate this principle, some transparency is required on behalf of the researcher to demonstrate how such claims have been reached, e.g., by providing the reader with raw data (Spencer & Ritchie, 2011).

2.6.1.3 Rigour: Rigour is held as an important factor in confirming validity in studies which employ qualitative methodologies (Yardley, 2008). As Spencer and Ritchie (2011) note, rigour requires consideration of multiple factors including the suitability of decisions made during the research, how dependable the evidence is and how safely the research itself was carried out.

3. RESULTS

3.1 Introduction to Themes

This chapter presents an analysis of the data collected during interviews with participants which focused on their experiences of receiving the label of TR. The data was analysed thematically following the steps outlined in the methodology. A network of themes, organised into a hierarchy of themes and subthemes, is outlined below (see Table 7). A table of which participants contributed to which themes and subthemes is provided (Appendix Q).

It became apparent when analysing the data that there were times when the participants did not always differentiate between the effects of being diagnosed with S/SAD and the effects of receiving the TR label. This is exemplified by an extract from the interview with Sarah.

> *The first label [schizophrenia] or the one that you're interested in [treatment resistant], whether I mean it's kind of quite difficult to extract from, you know the two, but they would. Yeah so. But they all had this effect of, you know my life going tits up […]*
>
> (Interview with Sarah, p.13-14)

The analysis sought to capture this variation. Therefore, themes one and five refer to the more general context of a psychosis diagnosis, whilst for themes two, three and four the analysis notes when specific reference to the TR label is made.

Table 7

Themes and Subthemes

Theme	**Subtheme**
1. Effects of a psychosis diagnosis	1.1: *'I'm immediately dismissed on the basis of my mental health'*: Altering interactions with others

	1.2: *'[…] The World Interacts Differently Cause You're Fat, You Know, So It's Just Like. It So Adds Insult.*': Physical Health Impacts 1.3 *'I generally felt I had no choice 'cause it would be forced on anyway.'*: Coercion in the mental health system
2. Treatment in the treatment resistant context	2.1 *'It's not just me, this these medications don't work on many, many people'*: Efficacy of antipsychotic medication 2.2: *'Why Would You Spend Money On A Lost Cause'*: Effects Of The Treatment Resistant Label On Treatments Offered 2.3 *'I don't know how you can say a human is treatment resistant. Like have you tried everything?'*: Experiences which led to questioning the label
3. Explanatory models of distress and treatment resistance	3.1 *'Things have got worse the less I've been listened to, the less I've been heard'*: Causal explanation for distress 3.2 *'I've so many medications just won't work with them, and that's the conclusion'*: Explanations for treatment resistance 3.3 *'It's not our drugs that are wrong, it's you'*: Locus of responsibility

4. Psychological impact of the treatment resistant label	4.1: *'I Didn't Have Another Child (.) Because I Felt That Would Be Too Risky'*: On Sense of Self 4.2: *'[…] Like A Poor Prognosis, Like A Terminal Illness In Many Ways'*: Hopelessness 4.3: *''Your Son's Got Treatment Resistant Schizophrenia. We Just Don't Know What To Do For Him Now''*: On Other's Perceptions
5. Sources of meaning and support	5.1 *''[…] Just looked at me and just treated me''*: Staff in the mental health system 5.2 '*At last I could take this mask off I'd been wearing for years'*: Chosen communities 5.3 *'Voices that have got messages that I need to listen to'*: Alternative meaning frameworks

3.2 Theme 1: Effects of a Psychosis Diagnosis

The first theme draws on the data from all seven participants. It refers to general effects of a psychosis diagnosis on participants, rather than focusing specifically on the TR label. The first subtheme, *altering interactions with others*, documents change in how participants interacted with others, and how others interacted with them, following their psychosis diagnosis. The second subtheme, *physical health impacts*, notes the varying impacts on physical health experienced as a result of participants' receiving a psychosis diagnosis. The final subtheme, *coercion in the mental health system*, explores the

oppressive practices experienced by participants after receiving a diagnosis of psychosis in the context of the mental health system.

Overall, this theme demonstrates that interactions with others, including mental health staff, were adversely impacted by a psychosis diagnosis. In addition, participants contended with harmful effects of the medications they were taking which caused substantial damage to their physical health.

3.2.1 Subtheme 1.1: *'I'm Immediately Dismissed On The Basis Of My Mental Health'*: Altering Interactions With Others

This subtheme exemplifies the effect a diagnosis of psychosis had on participants' interactions with others and included six of the seven participants. Several noted that a degree of secrecy was needed around their experiences.

> *Erm, I mean I didn't tell any of them [friends]. Erm, I told I told a few, a couple of times I've told people just the word schizophrenia was enough for them to stop talking to me.*
>
> (Interview with Ian, p.19)

> *Uhm, I have been quite cautious and who I've shared it with, so I don't have a lot of experience. But in general, people have been supportive.*
>
> (Interview with Lisa, p.7)

These extracts from Ian and Lisa demonstrate the different reactions participants received upon telling others about their psychosis diagnosis. However, a uniting factor was the hesitancy they expressed over sharing it.

Another factor was how other people's understanding of a psychosis diagnosis was shaped by the effects of harmful media stereotypes.

> *I suppose because you hear a lot in the news about people with mental health conditions, and they're they're usually portrayed quite negatively. Uh, so people think that people with schizophrenia are potentially violent and they tend to avoid them a bit.*
>
> (Interview with Lisa, p.5)

> *And I I read a survey that said you know people in my position, that public perception was that I shouldn't be allowed to decide what to spend my own money from my own bank account on.*
>
> (Interview with Sarah, p.5)

As Lisa says in the extract, stereotypes in the media linked a psychosis diagnosis with violence, whilst Sarah outlines public doubt around ability to make financial decisions.

Another aspect of this subtheme was a sense of otherness which pervaded interactions with mental health staff.

> *[…] if those people [mental health staff] who are able to get over that and kind of go 'this could be me in other circumstances'. 'I am not inherently different from this person' [..]*
>
> (Interview with Sarah, p.9)

As Sarah says in the extract, mental health staff reportedly ignored similarities between her and participants, dismissing the fact that they too could have received a psychosis diagnosis in different circumstances.

This subtheme additionally captured the power imbalance experienced by most participants because of interactions with the mental health system.

> *And what really got within the system, with been on psychiatric wards was there's a power difference. And I'm not saying that's what staff create. Maybe some do, some don't, but that's how I was perceiving it. These are in a position of power, and I can't be around them, unless they come and speak to me.*
>
> (Interview with John, p.7)

As John says in this extract, this perceived power difference was to the detriment of participants, shaping how participants related to staff. In addition, this extract raises questions over the deliberateness of the creation of such an imbalance.

3.2.2 Subtheme 1.2: *'[…] The World Interacts Differently Cause You're Fat, You Know, So It's Just Like. It So Adds Insult.'*: Physical Health Impacts

This subtheme included all seven participants and describes varying impacts on their physical health due to experiences related to their psychosis diagnosis. There was a range of experiences, with some sharing weight gain whilst taking antipsychotic medication.

> *I still haven't lost the weight, but I put on four stone. And so you know, all these things and you you think well, that's not really matter in one way. But actually the world interacts with again, the world interacts differently cause you're fat, you know, so it's just like. It so adds insult.*
>
> (Interview with Sarah, p.24)

In this extract, Sarah states this weight gain had an additional impact to that of receiving a diagnosis of psychosis as larger bodies face pre-existing societal discrimination.

Another aspect of this subtheme was lactation that some participants experienced after taking antipsychotics.

> *Like I would literally just start sprouting milk out my breasts. You know, like there was all this stuff like my body changed overnight.*
>
> (Interview with Rosie, p.19)

This presented participants with a rapidly changing body, as Rosie says.

Several of the participants felt the medication presented other risks to their physical health, such as diabetes and high cholesterol.

> *Many people I talk to who are diabetic now because of antipsychotic drugs, so it's not nice.*
>
> (Interview with Ian, p.4)

> *Uhm, and certainly with my cholesterol last time it was measured it was slightly high and I think that was to do with the [antipsychotic] tablets cause my family, not many people have high cholesterol.*
>
> (Interview with Lisa, p.12)

As highlighted by Ian and Lisa, these additional physical health risks were directly linked to taking antipsychotic medication by the participants.

Indeed, some participants specifically named Clozapine when outlining physical health impacts.

> *At which point, and they said, well, you probably can't work to start with, you know your white cells will crash possibly. I mean, it's like this, litany of horrific-ness. And. And so essentially what I did then pretty much was disengage services, 'cause I was absolutely terrified […]*
>
> (Interview with Sarah, p.3)

> *When when they offered me the Clozapine, I said no to start with because I was worried about the side effects. [..] Uhm, and I was working and I was worried about the drowsiness and the weight gain.*
>
> (Interview with Lisa, p.3)

For these participants, side effects such as weight gain and its effect on white blood cells were sufficient to make them refuse to take it or even stop their engagement with mental health services altogether.

Another aspect of this subtheme was the dismissal of physical health difficulties that participants experienced due to diagnostic overshadowing from their mental health diagnosis.

> *It's it's not just psychiatric care. It tips over into general care as well, because when I was 40 years of age. (.) I had a [physical health issue]. And because of my diagnosis, they refused to treat me.*
>
> (Interview with John, p.9)

This diagnostic overshadowing, exemplified by what John says, led to consistent refusal of physical health treatment, often years after participants' initial psychosis diagnosis. This highlights the detrimental and wide-ranging impact a psychosis diagnosis can have on the physical health of those who receive it.

3.2.3 Subtheme 1.3: *'I Generally Felt I Had No Choice 'Cause It Would Be Forced On Anyway.'*: Coercion In The Mental Health System

This subtheme, which includes six of the seven participants, outlines coercion experienced by participants after receiving their psychosis diagnosis. For all of these participants, an exacerbation of their mental distress occurred as a result of this coercion.

> *So if you detain me. If I'm detained in a location now I can't escape who are trying to kill me. I can't get away from them because if they find out where I am. Then they can harm me. […] Has it it it actually, it kind of it distresses me more as a result.*
>
> (Interview with Cillian, p.8-9)

> *And it's never been, and I think I think also the NHS the the structure currently in the NHS is always about how sick you can be. So that in itself is a very negative 'cause like you have to to get any help you have to be really unwell. And then but then, that doesn't. But then if you need the help, it's almost like a double-edged sword because any, like if you get marginally better then they then take that away, you then relapse, you're back to square one.*
>
> (Interview with Rosie, p,9)

As exemplified in this extract from Cillian, being detained against his will served to heighten the impact of distressing thoughts he was experiencing, whilst Rosie outlines a cycle whereby people are forced to act in certain ways in order to gain support. This seemingly leads to a lack of meaningful recovery for those in distress and highlights the power of the mental health system to decide who does or doesn't receive treatment.

Indeed, several participants experienced a lack of choice and control over their treatment following their diagnosis with psychosis.

> *I was getting serious side effects. You know which then they say, 'well, we'll just add another drug to stop to the side [effects]', you know you so it's just erm. […] To have then they control over what's going into your body. I mean, that's quite. Ah. (.) It's it's just yeah, it's just it then that threat, fear.*

(Interview with Sarah, p.7)

> *Because of the setting as well, I was an inpatient at that time on an acute ward, I generally felt I had no choice 'cause it would be forced on anyway.*

(Interview with George, p.3)

As these extracts exemplify, the lack of choice around medication was experienced as a frightening reduction in agency over bodily autonomy and resulted in coercive practices, such as being forced to take medication.

Furthermore, for some of the participants in this subtheme, being given the label of 'treatment resistant' began to actively obscure pre-existing personal understandings of distress and replace them with medical explanations.

> *I also I also did worry if I'm treatment resistant because it, after a while for so long, I was beginning to believe that this was a medical issue then, there's you know my other sort of beliefs [around reasons for distress] were being eroded away […]*

(Interview with George, p.11)

In this extract, George, who prior to contact with mental health services had firmly believed in childhood adversity as a causal factor for distress, evokes an image of gradual pressure destroying these beliefs over time.

Indeed, the apparent lack of choice over how the experiences of participants' are described appears to have wide-ranging consequences, as outlined in the extract from John.

> *If I went to the the benefit system said I hear voices. (.) Don't don't get a penny. If I say I've got treatment resistance schizophrenia, they give you loads of money. You get DLA, you get benefits and this and other. So it's it's a trap. You trapped. I've got to be this just survive 'cause I've been told I can't work, even though I don't want to carry this label.*

(Interview with John, p.12)

As John states, he felt coerced into labelling himself in a certain way in order to access financial assistance, despite this not being aligned with how he wishes

to describe his experiences. This indicates that the control the mental health system has over how the TR label is perceived is far-reaching, extending into wider socio-economic and political contexts.

3.3 Theme 2: Treatment in The Treatment Resistant Context

All seven participants spoke about their experiences of taking and being prescribed psychiatric medication in the context of receiving the TR label. This data formed the second theme which had three subthemes. The first of these, *efficacy of antipsychotic medication*, demonstrates the varying perceptions participants had on whether the antipsychotic medication they were prescribed was working or not. The next theme, *effects of the treatment resistant label on treatments offered*, documents how the TR label appeared to influence the treatment participants received or were offered by mental health staff. The final theme, *experiences which led to questioning the label*, exemplifies how participants' responses to psychiatric medication fuelled debate over the continued accuracy of the TR label.

Overall, a picture emerged where the prescribing of antipsychotics never resulted in a straightforward reduction of the experiences they aimed to diminish, leading to all participants debating the efficacy of medication and, for the majority, by proxy the appropriateness of the TR label. Despite this, the label of TR appeared to shape the treatments offered to participants from clinicians.

3.3.1 Subtheme 2.1: *'It's Not Just Me, This These Medications Don't Work On Many, Many People'*: Efficacy Of Antipsychotic Medication

This subtheme highlights the breadth of participants' experiences with antipsychotic medication in terms of their efficacy at producing the intended results. All seven participants were included in this subtheme. Some of the participants found antipsychotic medication to be ineffective.

> *And again, as I've learned that many years later from various other ways that it's not just me, this these medications don't work on many, many people.*
>
> (Interview with George, p.11).

I mean, it did nothing. I'm as well have been, you know, taking placebo or something and then they put me on to Aripiprazole. And I was probably very lucky to get that in some ways, but then it didn't really work all that well.

(Interview with Sarah, p.3).

As George and Sarah state in these extracts, some participants found antipsychotics as not being particularly helpful.

For others, there was a partial effectiveness which left participants with residual experiences of a varying nature.

The Quetiapine was put up to 600 milligrams and that did take me out of psychosis. But it replaced the visual hallucinations and delusional thinking and paranoid, extreme paranoid thinking, with chronic depression.

(Interview with Cillian, p.5).

[…] I was started on Lurasidone and that's actually worked really well, although I have a few residual symptoms.

(Interview with Lisa, p.2).

The extracts from Cillian and Lisa present different perspectives, implying a range of severity and impact to their residual experiences.

Another aspect of this subtheme was a period of trial and error with multiple antipsychotics that was useful for some participants but less so for others.

It took nearly five years to erm (.) to finally, I think I switched six times before I found a medication that actually did something useful.

(Interview with Ian, p.17)

I went through every antipsychotic in nine months. So, they trialled every antipsychotic in nine months, then labelled me treatment resistant. But how did they give medication even a time to work in nine months?

(Interview with Rosie, p.18)

As outlined by Ian and Rosie, there were different time frames to these trial periods, which appear to mitigate the end result of finding the medication to be effective or not.

Some of the participants found that the antipsychotic medication obscured their attempts at addressing their problems.

> *Now I'm not saying they don't suppress the voices if you hear voices. What happens when you stop the drugs, the problem comes back. Let's respect that, stop covering [them up].*
>
> (Interview with John, p.22-23).

As John says, antipsychotics covered up the difficulties underlying voice hearing. However, there was a sense that such experiences were to be respected rather than obscured.

3.3.2 Subtheme 2.2: *'Why Would You Spend Money On A Lost Cause'*: Effects Of The Treatment Resistant Label On Treatments Offered

This subtheme includes six of the seven participants and exemplifies how the TR label appeared to shape the treatments offered to participants by mental health staff. For all of these participants, medication was seen as the primary offering.

> *[…] when there was a you know a bit of a dip I'll be taken to see my psychiatrist and my medication would be increased so just again reinforces this, the the importance of medication. That's the sole thing that you need to get yourself better.*
>
> (Interview with George, p.15)

As George says, the context of being labelled TR led to him being offered only medication whenever his distress appeared to worsen. Indeed, this was a common sentiment across many of the participant experiences.

Some participants spoke of alternative treatments, such as talking therapies.

> *It's medication primarily. Yeah, yeah. I mean. The treatments they have are either medication, talking therapy and then all these sorts of things that I choose to do with my every day, you know.*

(Interview with Cillian, p.14)

However, as Cillian states, these alternatives were seen as secondary to medication. These extracts suggest that experiences related to the TR label were firmly viewed through a medicalised lens which demanded treatment by medication take priority over alternatives.

Some participants highlighted how the label of TR appeared to bar access to alterative medications.

> *And really my doctor's of the opinion that of the current medications they have, there's no real point in even trying anymore, because (.) I think there's something like 27 anti-depressants available in the NHS. I've probably been on about 20 of those.*

(Interview with Cillian, p.2)

> *Erm so my first care coordinator used it against me as a weapon to stop me from getting treatment, because why would you spend money on a lost cause basically is the crux of it.*

(Interview with Ian, p.28)

As Cillian states, the failure of medication to produce the desired results led to no further treatment being offered by staff. In the extract from Ian, he expresses his sense that this had been weaponised to his cost. Both these extracts suggest a rigidity of medicalised perspectives around the TR label and treatment, which appears to be underlined by medication efficacy being held as the primary treatment outcome.

Indeed, despite supposed resistance to medication, several participants noted that they still continued to be offered it.

> *[…] to be told your like treatment resistant, but yet they wouldn't take me off the medication being treatment resistant. I'm still on clozapine, still on all these massive drugs. And having the associated side effects when actually the benefit was err very little.*

(Interview with Rosie, p.2)

This led to continuing to experience side effects, as Rosie states in this extract, whilst experiencing little benefit from taking the medication. This can be taken as further evidence of the medicalisation of experiences related to the TR label, whereby a lack of alternative treatment being offered leads to medication being prescribed despite its known inefficacy.

3.3.3. Subtheme 2.3: *'I Don't Know How You Can Say A Human Is Treatment Resistant. Like Have You Tried Everything?'*: Experiences Which Led To Questioning The Label

This subtheme captures how doubts were raised about the appropriateness of the TR label in relation to their response to receiving it and their experiences with medication. This subtheme included six of the seven participants. For some, the current efficacy of these medications led to them questioning the accuracy of the label.

> *Well, I can tell you now they're wrong, 'cause with years of just dealing with stuff it seems to have gotten better (.). And erm now I'm on Amisulpride that seems to help.*
>
> (Interview with Ian, p.9)

As Ian says in this extract, treatment working, along with his own efforts, threw doubt on the appropriateness of the label of TR.

Another aspect of this subtheme outlines how for some it was the blame associated with treatment failure which led them to question the label.

> *But maybe it's the treatment I think, but I think now is on its calling, we shouldn't really call people treatment resistant. Yeah we we should be looking at the treatment, that's the problem, it not the person.*
>
> (Interview with George, p.19)

> *I don't know how you can say a human is treatment resistant. Like have you tried everything? Like what constitutes as everything? Like they don't respond in the way that you think to a couple of medications. Well that's not treatment resistant, there is a whole world of opportunities and possibilities […]*
>
> (Interview with Rosie, p.36)

As exemplified by George and Rosie, the inefficacy and lack of variety of treatment offered was felt to be to blame for treatment failure, rather than participants themselves, and these factors led them to debate the accuracy of the label.

For another participant, recovery despite absence of medication raised questions over the label's accuracy in the first place.

> *[…] but it was very interesting because I have now been fine without any medication err for four years, so whether that was a realistic diagnosis or not, you know, isn't it.*
>
> (Interview with Sarah, p.2)

For others, the utility of TR label was questioned in relation to outcomes and meaning.

> *Yeah, I just don't and I don't even know like what any like the diagnosis of treatment resistant schizophrenia. What did it actually achieve? […] Like it, it kind of. And what does it? What does it actually mean?*
>
> (Interview with Rosie, p.24)

As exemplified by Rosie, the label was felt to lack purpose and offered little in the way of explaining or aiding understanding of her experiences.

3.4 Theme 3: Explanatory Models of Distress and Treatment Resistance

This theme describes what explanations participants hold about the experiences that brought them to services, along with explanations for why they received the label of TR. This theme includes all seven participants. A subtheme of *causal explanations for distress* explores the different models participants ascribed to the experiences which caused sufficient distress to bring them to the attention of mental health services. A further subtheme of *explanations for treatment resistance* tracks reasons given to participants for why they received the label, whilst *locus of responsibility* notes where participants felt the responsibility was placed for treatment resistance by both themselves and staff members.

This theme revealed variation in participants' causal explanations for distress, whilst medication failure was a unifying factor in the application of the TR label, the responsibility of which was perceived to be attributed to different factors.

3.4.1 Subtheme 3.1: *'Things Have Got Worse The Less I've Been Listened To, The Less I've Been Heard'*: Causal Explanations For Distress

This subtheme exemplifies the explanations that participants shared for what caused the initial distress that brought them to mental health services. All seven of the participants are included in this subtheme. For some, causal explanations drew on the biogenic model.

> *I think the biological explanations are much more convincing than the sort of psychological, environmental explanations. I find them more convincing.*
>
> (Interview with Cillian, p.10)

> *And I don't think it [referring to sexual assault] was sufficiently traumatic that it would have made the difference uhm on its own, but I think the fact that I had that family history probably was the main thing.*
>
> (Interview with Lisa, p.13)

As these extracts demonstrate, biogenic explanations appeared to hold more weight for participants than other explanations, such as the impact of their surroundings or adverse experiences.

For others, a psychosocial causal explanation of distress seemed to be a better fit.

> *It's not an illness, it's a reaction to perfectly, to difficult things in your life, you know.*
>
> (Interview with John, p.19)

As demonstrated in John's extract, it was adversity, not a biomedical explanation, which he believed caused his distress.

For some of the participants, a biopsychosocial model appeared to explain their experiences.

I had these beliefs for probably a whole whole whole host of reasons. Some biological, some because actually, although I think it's key to note that actually being in, the [mental health system] system has accelerated, accelerated my experiences, so I think. Things have got worse the less I've been listened to, the less I've been heard, the more ostracised I felt.

(Interview with Rosie, p.25)

So there was that side of things [diagnosis of post-natal depression]. There was this side of things that was uh, this psychotherapist and hypnotherapist [reference to adverse experience with therapist]. Uh, so that was, uh, not good and then. I've got an ACE [Adverse Life Experiences] score of seven. You know so. […] I think there's probably a genetic, some sort of genetic or epigenetic component to that […]

(Interview with Sarah, p.19)

As Rosie and Sarah say in these extracts, participants noted that there was a multitude of reasons as to why they had accessed mental health services, citing a combination of biology, childhood adversity and negative experiences within the mental health system itself.

3.4.2 Subtheme 3.2: *'I've so many medications just won't work with them, and that's the conclusion'*: Explanations for treatment resistance

This subtheme exemplifies the explanations that participants were given for them receiving the TR label. All seven participants were included in this subtheme. For the vast majority, participants experiencing little effect from antipsychotic medication facilitated this label being given by clinicians.

Um and then they tried various treatments and they hadn't been totally effective. And so a few years after that was when uhm they sort of said, 'well, I think we'd class you as treatment resistant'.

(Interview with Lisa, p.2)

As the extracts from Lisa demonstrates, for most participants, receiving the label happened after they had been prescribed antipsychotics for a period of time.

Uniquely, for one participant who was diagnosed with schizoaffective disorder, it was their experience with antidepressant medication which had led to them receiving the label of TR.

> *But it's the other side of the condition, it's the (.) erm (.) the depression side of the illness or the or the negative symptoms of the illness which are treatment resistant. Erm (.). […] Just cause they're I've so many medications just won't work with them, and that's the conclusion.*
>
> (Interview with Cillian, p.1-2)

For Cillian, it was multiple antidepressant medications which failed to produce the desired effect and hence led to them receiving the TR label.

Some participants said that they had received little explanation about why they had been given the label, leading to them doing their own research.

> *Erm but I just read out extracts, abstracts from journals and uh (.) just like treatment options [in reference to antipsychotic medication] and the Mind website or YouTube or Wikipedia and just click through links continuously, just find digging into more and more information.*
>
> (Interview with Ian, p.23)

> *So err, so, yeah, I don't think there was a huge amount of discussion about it [why the treatment resistant label was given and possible outcome] and obviously I did huge amounts of reading and stuff.*
>
> (Interview with Sarah, p.18)

As Ian and Sarah state, participants strived to become well informed about antipsychotic medications, explanations for why they had been given the TR label and what this might mean for the future.

3.4.3 Subtheme 3.3: *'It's Not Our Drugs That Are Wrong, It's You'*: Locus Of Responsibility

This subtheme demonstrates where responsibility for treatment failure appeared to be placed in relation to the TR label and includes five of the seven participants. For some, treatment failure was due to the simple fact of medication working for some but not others.

It's just one of those things where some people don't have a good response to medications.

(Interview with Cillian, p,17)

So yeah, I didn't feel like it was particularly anything I was doing. Uh, so. (.) I suppose. It was just the fact that I'd been on several medications and was still getting symptoms […].

(Interview with Lisa, p.22)

The extracts from Cillian and Lisa highlight how some participants understood medication not having the desired effect as the reason they received the TR label, rather than anything connected to themselves.

However, amongst the participants were reports of staff implying that participants were in some way responsible for treatment not working.

A nurse comes to speak. (2) Erm (2) she said something along lines 'well, you just started this new medication'. And I said 'I don't think it's going to work'. And she said 'well, if you think that, it's not going to work'.

(Interview with Cillian, p.19)

So basically, what they said. 'This is your fault. The drugs don't work 'cause you've got treatment resistant schizophrenia, so it's not our, it's not our drugs that are wrong, it's you, it's you as a human being individual, is that this is all your fault'.

(Interview with John, p.4)

These participants reported that staff appeared to hold them individually responsible for medication failing to have the desired outcome, either through their personal attitude influencing efficacy, as stated by Cillian, or through there being something innately wrong in their response to treatment, as stated by John.

This had led to participants feeling blamed for treatment not working.

But like it did feel quite damning, as in somehow blaming or this is my fault. 'Cause you're given these medications and they're not working so this must be my fault.

(Interview with George, p.2)

As George says, this perception of blame brought with it a sense of condemnation.

For some participants, this represented a shift in that responsibility was no longer located in either the treatment offered or the mental health system.

[…] if you describe somebody as being treatment resistant, what we should actually say is that this treatment doesn't work, not that that you know, 'cause we're passing the buck.

(Interview with George, p.18)

Like I, I almost feel like dressing mental illness up like that also takes away any responsibility to for anybody [in the mental health system] to try and help.

(Interview with Rosie, p.36)

Indeed, as exemplified in the extracts from George and Rosie, such a shift was perceived as allowing both the treatment offered, and the mental health system, to avoid taking responsibility for participants' recovery to their detriment.

3.5 Theme 4: Psychological Impact of The Treatment Resistant Label

This theme focused specifically on the psychological impact the label of TR had on those who received it and those who they interacted with. The theme included all seven participants and had three subthemes. The subtheme of *on sense of self* depicts how the TR label was hugely influential in shaping how participants saw themselves. The subtheme of *hopelessness* outlines the lack of hope participants experienced in the aftermath of them receiving the TR label. Finally, the subtheme *on others* exemplifies how the TR label changed how others saw and responded to the participants.

This theme suggests that receiving the label had an unanimously negative, frequently devastating, psychological impact.

3.5.1 Subtheme 4.1: *'I Didn't Have Another Child (.) Because I Felt That Would Be Too Risky'*: On Sense of Self

This subtheme exemplified the impact that the label of TR had on how participants saw themselves and includes five of the seven participants. For some participants, receiving the TR label was incorporated into their identity to a greater or lesser extent.

> *[…] uhm it is something that I kind of think I don't wanna make it my sole identity because my identity is as a Christian, but umm I think that umm it does affect your worldview.*
>
> (Interview with Lisa, p.11)

For Lisa, the TR label had an undeniable effect in shaping her perception of the world, however she was able to hold onto her primary identity as a Christian.

However, others reported that the label led to them perceiving themselves as flawed or deficient in some way.

> *Well then to say it's it's you being resistant to treatment as opposed in the treatment doesn't work. It becomes, you do feel, I think within, certainly an acute ward you're a bit of a second-class citizen.*
>
> (Interview with George, p.11)

As George states in the extract, receiving the TR label appeared to remove some humanity and resulted in him feeling less than other people.

A few of the participants saw themselves as losing credibility after receiving the label of TR.

> *I just I that's how I felt. Like because here I was. I'd got this label. Therefore you know nothing I say is credible.*
>
> (Interview with Sarah, p.9)

This extract from Sarah exemplifies how the mere fact of receiving the label appeared to legitimise her doubt in the trustworthiness of what she had to say.

For a few of the participants, the TR label had a direct impact on considerations about having children in the future.

> *And then also the other thing is it meant I I didn't have another child (.) because I felt that would be too risky [in relation to concerns over ability to look after a child].*
>
> (Interview with Sarah, p.6)

> *Erm well, I had some sessions with a psychologist and she told me that the reason erm that I got it was because my grandmother had it. […] And there was a family link. And that was that was quite hard in some ways because I thought, well, if I ever want to have kids then potentially I could pass it on.*
>
> (Interview with Lisa, p.13)

As Sarah states, adverse messages of recovery drove fears around caring abilities, whilst for Lisa, concerns about heritability led to consideration of the impact for future children. This demonstrates the extent of the psychological impact of negative associations around the TR label.

3.5.2 Subtheme 4.2: *'[…] Like A Poor Prognosis, Like A Terminal Illness In Many Ways'*: Hopelessness

This subtheme highlights the detrimental impact that receiving the label of TR had on participant hopes for the future and for recovery, and included six of the seven participants. For several, this impact was evident in the erosion of hope around living a 'normal' life.

> *Yeah, so I thought then that I wouldn't be able to have any sort of life. I think that's the thing it did to me. That you know what was the point really?*
>
> (Interview with Sarah, p.24)

> *Well. The erm effect has been a lot of despair. […] Uh. And a lot of fear that I'm never going to have anything approaching a normal life.*
>
> (Interview with Cillian, p.12)

As Sarah and Cillian state, the label brought with it distress and fears of an inability to live the life they wanted.

Common amongst the participants was a sense that the label imparted a permanency to their distress.

> *I kinda feel like it was when I was told treatment resistant. It was kind of, it felt like a sort of a negative prognosis, like a poor prognosis, like a terminal illness in many ways […]*
>
> (Interview with Rosie, p.36)

> *I'm almost worried that if I'm treatment resistant (.) then I'm never going to get any better and I was thinking this is going to be my life now forever.*
>
> (Interview with George, p.11)

As Rosie and George state in the extracts, there was a sense of finality accompanying the label which appeared to negate any hope of recovery.

This hopelessness was seen by some participants as something that profoundly impacted both staff and those who had received the TR label.

> *So not only does it [using the TR label] kind of give professionals a get out, oh we don't have try with that person they're a hopeless cause. It also that then translates to the patient, there's no point in me trying either uhm.*
>
> (Interview with Rosie, p.36-37)

As Rosie states, lack of hope from mental health staff was infectious and had a profound psychological impact on both parties.

3.5.3 Subtheme 4.3*: ''Your Son's Got Treatment Resistant Schizophrenia. We Just Don't Know What To Do For Him Now''*: On Other's Perceptions

This subtheme outlined how receiving the TR label appeared to impact how other people perceived and interacted with those who had received it. Five of the seven participants were included in this subtheme. One aspect of this subtheme was how the addition of the TR label to an existing psychosis

diagnosis served to exacerbate the stigma they experienced. For some, this was evident in the societal stigma they faced.

> *Well then then you're like you know you're in the bin [after receiving treatment resistant label]. So fuck you, 'cause not only are you the worst thing [reference to schizophrenia diagnosis] as far as society is concerned, but you're the worst of the worst thing if you see what I mean.*
>
> (Interview with Sarah, p.6)

As Sarah says, the addition of the TR label to a pre-existing psychosis diagnosis served to cement the already negative perceptions of others.

For several, these adverse perceptions, specifically from family members and friends, had devastating consequences.

> *Well it get it started to affect me really, well with my first wife. She, 'cause of this diagnosis and it's worse cause treatment resistant, she tried to stop me seeing the children and it was very very difficult at times.*
>
> (Interview with John, p.13)

As John states, the label of TR contributed to him having difficulties with arranging to see his children.

Some participants found that staff appeared to see the label as an end point and make no investment in their future.

> *So at no point did they say look, this is hopeful. We've got hope for you. We're gonna we can get this to work. Here's a plan. Let's sit down and do a plan how we can get you back into education.*
>
> (Interview with Rosie, p.12)

> *And then I tried loads and loads of drugs. At one point I was on 25 drugs a day. And and they weren't working and my parents were complaining about it. And that's when the psychiatrist told me parents, 'your son's got treatment resistant schizophrenia. We just don't know what to do for him now'.*
>
> (Interview with John, p.1)

As Rosie says, this lack of investment manifested as little attempt to hold hope or plan for her education. In the extract from John, a sense of finality to the treatment he was offered was coupled with no suggestion of exploring alternatives. Indeed, it appears that staff members had reduced their expectations for those who had received the TR label.

For several participants, low staff expectations were perceived as focusing on the maintenance of their current state, rather than attempts at improvement.

> *And I think they just wanted me to give up cause I was just being a pain for them because of obviously with trying to work and juggle the illness at the same time, I kept on relapsing […]*
>
> (Interview with Ian, p.15)

> *And I think again, this just ties into that thing that people just wanna maintain, that people don't want to move you forward, because you're treatment resistant. Don't rock the boat, there's like that sort of thing, so it fed in a lot of different ways.*
>
> (Interview with George, p.18)

As Ian says in the extract, he perceived himself as being discouraged from attempting to gain employment due to staff fear of him experiencing a setback, whilst George states how he felt like the status quo was privileged at the expense of him moving forwards.

The impact of mental health staff thinking in this way was outlined by several participants who reported that negative comments about recovery from mental health staff became self-fulling prophecies, defining their own perceptions around their future.

> *'Never ever work again'. So I can't. He's telling me I can't work again for a reason, so I've got this treatment resistant schizophrenia, I'll become unwell again. So I subconsciously I knew I could do it. But it's these words were so powerful, from this man in a position of authority, so I must I must not do it. And it's just it was silly little things like that. I knew I could have done it, but language is so strong and powerful.*
>
> (Interview with John, p.2)

In this extract, John demonstrates the devastating impact of adverse associations around the TR label on both the psychology of staff and, by proxy, those in their care.

3.6 Theme 5: Sources of Meaning and Support

Whilst previous themes have outlined aspects of the TR label which participants mentioned as detrimental to their recovery, it was clear during analysis that they additionally spoke about what factors they generally found supportive. Therefore, this theme outlines different factors which were, and continue to be, instrumental in participants moving forwards and finding hope. All seven of the participants contributed to this theme. In the subtheme of *mental health staff,* participants share what it was about certain staff within the mental health system which made them a source of support. *Chosen communities* exemplifies how this support was demonstrated in the participants' communities of choice, whilst *alternative meaning frameworks* explores different ways of understanding their experiences which participants found helpful.

In this theme, the importance of nurturing and accepting participants was clearly demonstrated, along with the value in alternative models to that of the biogenetic model.

3.6.1 Subtheme 6.1: *'[…] Just looked at me and just treated me'*: Mental Health Staff

In this subtheme, five of the seven participants spoke of individual staff who had been supportive to them throughout their journey in the mental health system. For some of these participants, staff advocating on their behalf was seen as vital in dictating the care they receive.

> *That's just yeah but my current CPN [community psychiatric nurse]. She's cool, she's refused when they told her to discharge me, she refused. She's refused to section me. Uhm, she's made it very clear that actually it provides no benefit for anybody.*
>
> (Interview with Rosie, p.28)

> *Well, he basically dedicated nearly five years worth of his very valuable limited clinic time with trying to get me onto a drug that actually worked.*

(Interview with Ian, p.16)

As Rosie says, a staff member acting on her behalf, even when in opposition to other professionals, was greatly appreciated, whilst Ian states that a staff member taking time to personalise treatment was valued.

For others, instilling hope was what marked these clinicians out as supportive in their journey through services.

> *So I suppose while he's saying I'm treatment resistant, he's he's referring to the, the treat the treatments that are currently available. Erm. He has given me some hope in the sense that he's saying there are new medications going to come out in the future. And the that they are different.*

(Interview with Cillian, p.14)

> *But it [reference to support worker encouraging George's future recovery] did begin to make you doubt, you know if somebody, you're completely hopeless, there's somebody still believes in you, it makes you begin to doubt your own sense of hopelessness.*

(Interview with George, p.16)

As Cillian says in the extract, this hope was encouraged through the promise of further treatment, whilst for George being championed by a staff member enabled him to begin to view the future in a more positive light.

Seeing participants as people first was noted to reduce stigma associated with the label.

> *He sort of took away all the stigma of that label and just looked at me and just treated me, he didn't keep on referring back to what had happened two, three, four years ago [referring to periods of medication not having desired effect].*

(Interview with Ian, p,14)

As Ian says, rather than focusing on the label of TR, staff who connected to him on a human level were greatly appreciated.

For several of the participants, staff who invested in their future outside of the mental health system were valued for the support they offered.

> *She got me a room at [place name], got us an office free of charge and I started to advertise the group. I got a purpose in life again and I wasn't relapsing every time I did this, she was giving me great support.*
>
> (Interview with John, p.20)

As John states, such encouragement brought with it a renewed sense of purpose which had a positive impact on his life.

An emphasis on facilitating meaning making from participants' experiences was additionally noted as a valued approach, and one which differed from other staff members.

> *But he began to ask me. You know, 'Are these voices men or are they women?'. 'Do they remind you of anybody you know?'. 'What sort of things do they actually say to you?'. And he took a real interest, and so on, and began to try and explore the connections. Nobody had done that up until that point.*
>
> (Interview with George, p,9)

As George says in this extract, questions around voices which focused on their meaning were beneficial.

3.6.2 Subtheme 6.2: *'At Last I Could Take This Mask Off I'd Been Wearing For Years'*: Chosen Communities

This subtheme, which includes four of the seven participants, exemplifies the benefit found in connection to communities outside of the context of traditional mental health services. One factor of benefit was the mutual support these communities offered several of the participants.

> *I've been a member of it [online forum for those with experience of psychosis/those who have received treatment resistant label] for five or six years now and erm. (.) Yeah, if you're ever having problems and stuff, you can at least talk to someone who's erm experienced it for themselves*

and you can. They can, sort of get you to stand down or whatever and just try and talk some sense into you when you're not making any.

(Interview with Ian, p.11)

I think uhm with [church group name], when people go along uhm the expectation is that you share things and people pray for you, and they help you.

(Interview with Lisa, p.21)

As Ian says, sharing experiences with those in a similar situation has been a vital support, particularly when distress has been heightened. For Lisa, the act of mutual sharing was itself a supportive experience.

For some of the participants, these chosen communities allowed a sense of freedom in being themselves.

Umm and God knowing everything about you and and still loving you and not, not needing to pretend before God.

(Interview with Lisa, p.18)

And they started to talk about their experiences and at last I could take this mask off I'd been wearing for years. It was such a liberating experience. So the starting point for me is knowing that I'm not alone with this anymore.

(Interview with John, p.6)

Whilst these extracts demonstrate difference in their audience, Lisa referring to God and John to a Hearing Voices Group, the significance of being able to remove pretence is a uniting factor in what both participants say.

For others, online support offered a useful space to begin to develop alternative perspectives.

Yeah, like I said the awakening or whatever you wanna call it didn't happen until a couple years later [after conducting own research] when I realised what the situation was and why it was so important to (.) fight against these medications as best as possible.

(Interview with Ian, p.25)

As Ian says, this was outlined as a process of realisation which occurred over a period of time.

3.6.3 Subtheme 6.3: *'Voices That Have Got Messages That I Need To Listen To':* Using Alternative Meaning Frameworks

This subtheme includes five of the seven participants and demonstrates the value found in ways of understanding experiences which differed from the explanations mental health services had given participants around the TR label. Some of these participants had formed their own language to describe their experiences.

> *I think I'm better at it [having own language]. Yeah, like. So like I categorise like certain sort of thoughts and experiences and I kind of so like I get a lot of I call them uneasy thoughts.*
>
> (Interview with Rosie, p.25)

As Rosie says, this alternative language was a useful exercise in developing personal categories for her experiences.

Another aspect of this subtheme was participants' development of personal ways of being with their experiences.

> *So it's just a filtering mechanism [description of self-developed method of being with beliefs] that just takes a bit of time to get used to. 'Cause when I was unfiltered, we wouldn't be having this conversation right now so.*
>
> (Interview with Ian, p.22)

As Ian states, a self-developed way of filtering his beliefs over a period of time had been effective in making it possible for him to communicate with others.

For others, experiences such as voice hearing were firmly aligned with personal meanings which were to be respected.

> *Every time they predict something it comes true. So I've different experiences, so why would I want to take that away with antipsychotics? I wouldn't want. I would hate to get up tomorrow and not hear voices. My voices (.) are my emotions, so you take my emotions away I'm left blunted.*

(Interview with John, p,26)

> *[…] these have voices that have got messages that I need to listen to, these are voices that are trying to tell me things that are you know. The the methods might be questionable, but they're I think what they're in the intent is to help and you know, they certainly do help and I've realised that now.*

(Interview with George, p.19)

As John says, his experience of voice hearing enables him a breadth of emotional expression which is incredibly important, whilst George states the value in listening to what his voices have to say.

For several of the participants, considering alternatives to the biogenetic model was beneficial.

> *It was only in later life I realised I've got to stand up to these voices cause they're the people that hurt me. […] Then you kind of get a different fit on this. Have I got an illness that can't be treated? Or am I having a perfectly normal reaction to adverse life experiences?*

(Interview with John, p.17)

> *But I would say that whatever the cause, that kind of Eleanor Longden, Anne Cooke kinda thing going on is much more encourage- and John Read. It's much more encouraging for erm recovery. Than erm, than the alternative and less stigmatising.*

(Interview with Sarah, p.20)

As John says, psychosocial causal explanations provided a normalising alternative, whilst for Sarah, alternatives to the biogenetic model meant less stigma and more optimism for the future.

4. DISCUSSION

4.1 Overview

This study explored the experiences of people who have been diagnosed with S/SAD and received the label of TR. The study findings are examined in relation to the existing literature outlined in the Introduction, whilst additionally considering the research questions. A critical review evaluates the study and discusses limitations. Finally, suggestions for future research and study implications are explored.

4.2 Previous Literature and Findings

As noted in the Results chapter, participants did not always demarcate between experiences related to their diagnosis of S/SAD and those directly related to the label of TR. Nonetheless, whilst not directly addressing the research questions, participants' discussion of the former contributed useful findings which warrant discussion in relation to pre-existing literature. Following this, the remaining findings will be discussed in relation to the research questions.

4.2.1 Findings Related to The Experience of Psychosis

Consistent with previous research was the adverse effect receiving a diagnosis of S/SAD had on participants. The theme of 'Effects of a psychosis diagnosis' exemplifies how interactions with others were altered as a result as participants receiving a psychosis diagnosis, reflecting the findings of a wealth of literature (e.g., Degnan et al., 2021; Hampson et al., 2020; Valery & Prouteau, 2020). In particular, the subtheme 'Altering interactions with others' highlighted the caution participants reported over who to share their diagnosis with, and the varying responses experienced upon telling, is mirrored in research that positions secrecy as a survival strategy to shield oneself from the stigma, or experience of being othered, which accompanies the diagnosis of S/SAD (Jenkins & Carpenter-Song, 2008; St Jacques, 2004). In the present study, participants reported this sense of being othered, with particular reference to mental health staff, echoing a recent systematic review which found those working in mental health care to be a primary source of stigma for those who have experienced psychosis (Valery & Prouteau, 2020). In addition, participants

reported being privy to well-established harmful media stereotypes around violence in relation to their psychosis experience (Li et al., 2021).

The subtheme of ‘Physical health impacts’ outlined the substantial and detrimental impact a psychosis diagnosis had on the participants’ physical health. This was due to both the harmful effects of taking psychiatric medication, particularly antipsychotics, and instances of diagnostic overshadowing occurring long after initial reception of such a diagnosis. Both of these findings are well-supported in the literature (Molloy et al., 2021; Read & Sacia, 2020; Read & Williams, 2019; Üçok & Gaebel, 2008). Indeed the adverse effects of Clozapine, which was named by some participants as having particularly severe physical health impacts, were highlighted in the studies included in the earlier CA conducted for this study (e.g., Augustin & Maroules, 2021; Barbosa & Fernandes, 2021; George et al., 2021). In the current study these were so severe that they led to participants refusing to take Clozapine, hence providing some answers to the proposed scoping review around service user views on Clozapine analysed in the CA (Jakobsen et al., 2021).

Participants in the study reported the negative impact their diagnoses of S/SAD had on interactions with mental health staff, noting power imbalances to their detriment. Abuse of power underlines the subtheme of ‘Coercion in the mental health system’, which documents the restrictive practice and dismissal of agency reported by participants in the study. This coercion took many forms and had wide-ranging impacts, influencing how participants felt they should act and dictating that they employ a bio-genetic lens through which to view their experiences at the expense of personal understandings. Consistent with previous findings was the effect the TR label had on limiting the meaning that participants felt they could make from their experiences. Harper (2021) notes that labels such as these are often given as explanation for experiences, when they are mere descriptors. This can lead to a simplification which purposefully renders experiences meaningless (Sewell, 2018), as demonstrated in the study findings. In the current study there was the sense that the TR label, associated as it is with biogenetic understandings of distress, served to obscure alternative explanations. Such obscuring is reflected in the study CA, where the work of Chaiyachati and Gur (2021), which links childhood adversity to people receiving the label, was the sole paper investigating alternatives to the biogenetic model.

As the study suggests, this facilitates the sense of 'becoming' one's label at the expense of a pre-existing thoughts around causality, echoing the literature (Modrow, 2003; Pitt et al., 2009).

In addition, coercion dictated how participants presented themselves to wider systems, for example welfare agencies. Indeed, whilst the dominant perspective around distress continues to be primarily medicalised, people seeking support often feel forced to describe their experiences in such a way for fear of financial repercussions (Johnstone & Boyle, 2018). Such experiences add to the body of research which notes how interactions with the mental health system itself can both traumatise and re-traumatise through punitive treatment which fails to account for the personal histories of service users (Ådnanes et al., 2018; Sweeney et al., 2018). The study findings support the plethora of literature which calls for the reform of coercive practices in mental health systems (e.g., Bennetts et al., 2011; Nyttingnes et al., 2016; Sashidharan et al., 2019).

The theme of 'Explanatory models of distress and treatment resistance' found variety in the causal models used by participants to understand the experiences which brought them to services and reflects the literature around the topic (Magliano et al., 2009; Read, 2020a; Read et al., 2013b). In particular, as echoed by Read (2020), participants cited causes such as adversity or presented a more complex picture which included both biological and social factors. As Pavon and Vaes (2017) note, the overtly biogenetic lens of much of the research around causality works to increase rather than decrease stigma, adding context to the previously discussed study findings. Therefore, this study supports calls to widen this lens for those with S/SAD. However, the variety of causal models, represented in the study, which includes the biogenetic model, indicates that service user choice is paramount.

Participants who contributed to the theme 'Sources of meaning and support' spoke highly of mental health staff who instilled hope for recovery, acting as they did to encourage self-belief in their future. These factors fit with the principles of personal recovery, well-established in the literature as facilitating meaningful recovery for service users (Repper & Perkins, 2003; Slade, 2009; van Weeghel et al., 2019). Another aspect of support appreciated by participants was the advocacy shown by individual staff members, noted for its focus on championing their wishes for treatment and interacting with

participants on a human level. As Jugessur and Iles (2009) state, advocacy for service users by mental health staff can go some way to readdressing power imbalances, therefore it is not surprising that this was important to participants in the context of their reports of such imbalance in the mental health system.

Participants additionally found meaning and support outside of the mental health system, in the communities that they chose to connect with, namely online peer support, the Hearing Voices Network and the Christian community. Much has been written about the support these communities give to those in distress, providing safe places to begin to make sense of and share experiences, free of judgement (e.g., Highton-Williamson et al., 2015; Longden et al., 2018; Noordsy et al., 2002; Oakland & Berry, 2015; Roystonn et al., 2021). The findings of the current study support this literature. Additionally valued by participants, as exemplified in the subtheme 'Alternative meaning frameworks', were alternatives to the biogenetic model, which allowed participants to develop their own language and ways of being with their experiences. These aspects are echoed in work which draws on service user testimony and positions experiences such as voice hearing as meaningful phenomena (Slade et al., 2019). Indeed, it is apparent that the different factors outlined by participants as providing meaning and support fit with the framework of connectedness, hope, identity, meaning and empowerment (CHIME; Leamy et al., 2011). CHIME is promoted as a tool for both mental health staff and service users with S/SAD diagnoses to support recovery from distress (Apostolopoulou et al., 2020; Piat et al., 2017; Vogel et al., 2020). Consequently, the current study can be taken as further evidence of the value and utility of the CHIME model.

4.2.2 Research Question 1: What Do People Report Being Told About The Treatment Resistant Label and The Reasons For Being Given It?

As noted in the Results section, participants did not always differentiate between experiences related to receiving a S/SAD diagnosis and that of being labelled with TR. This suggests that a psychiatric diagnosis may have been an unhelpful starting point for the study research questions, creating an artificial distinction which does not translate to participant's lived experience of distress. As evidenced in the two qualitative studies from the earlier CA, service users themselves did not appear to make reference to the TR label when sharing their

experiences (Fahy et al., 2021; Lawrence et al., 2021). Nonetheless, this distinction was attempted in the present study, for example in interview questions around explanations given specifically for the TR label, in order to demarcate the unique contribution of the findings to pre-existing work around the psychosis experience more generally which remains largely structured by diagnostic categories.

In the subtheme of 'Explanations for treatment resistance', participants reported how their response to medication, either antipsychotics or antidepressants, led to them receiving the label of TR. These findings are unsurprising given the wealth of research around the label of TR which focuses exclusively on medication as the means of treatment and hence its failure as facilitating people receiving the label, along with little mention of non-clinical notions of recovery (Harper, 2021; Kane & Correll, 2016; Nielsen, 2021; Oloyede et al., 2021). In line with research which highlights the paucity of information with which mental health diagnoses are given (Pitt et al., 2009), participants found that little explanation was given about the TR label. These findings support literature which suggests that terms such as TR, themselves mere descriptions, are given by professionals as explanatory terms (Harper, 2021), requiring service users to shoulder the responsibility of education around treatment, cause and outcomes. This finding fits with the often inconclusive nature of much of the literature around causality and the relative absence of research which investigates outcomes. For example, whilst Kogure et al. (2021) firmly root the label in the biogenetic model, their conclusion around specific genes are speculative. Such uncertainty in the literature could feasibly underpin the limited explanations that participants of this study report receiving from staff.

Harper (2021) reported on the views of mental health staff and service users and suggested that notions of resistance implicitly locate the blame for treatment failure within the individual by virtue of the assumed biological cause of their distress. As exemplified in the subtheme 'Locus of responsibility', the current study found that for some of the participants, medication, both antidepressant and antipsychotic, was ascribed as responsible for them receiving the label with no association of blame on themselves for treatment failure. However, building on Harper (2021), there were more explicit

attributions of blame reported by participants, leading to them feeling individually responsible for the treatment not working. Service users feeling blamed for their distress is well-established in the mental health system (Beresford & Wilson, 2010). However, a systematic review found that when viewed through a biogenetic lens, personal responsibility for diagnoses such as S/SAD is seen as reduced (Angermeyer et al., 2011). Yet despite the large numbers of studies in the CA which ascribe treatment resistance to biogenetic causality (e.g., Assunção-Leme et al., 2021; Saleh et al., 2021; Veronese et al., 2020), the current study found strong indication that participants perceived themselves as being held individually responsible for treatment resistance.

A possible reason for these findings is the ties that the label of TR has to notions of chronicity which are underpinned by implications of personal moral failure (Bynum, 2015; Galvin, 2002; Harper, 2021). Furthermore, the current influence of neoliberalism in UK politics, which encourages individual responsibility for all areas of life rather than in relation to external factors, has infiltrated conceptualisations of mental distress (Cosgrove & Karter, 2018; Pearson, 2019). As a result, this provides fertile ground for the blame inherent in ideas around chronicity to thrive. Further findings from the study note that participants perceived responsibility for treatment failure shifting from the treatments offered or the mental health system to themselves, thereby removing scrutiny from these factors, are additionally supported by Harper (2021).

4.2.3 Research Question 2: What Are Some of The Effects of The Treatment Resistant Label Described by Participants (e.g., On Treatment, On Their Perceptions and How Others View Them)?

4.2.3.1 On treatment: As outlined above, treatment failure was the main explanation participants received for their TR label. Despite this, the subtheme 'Effect of the treatment resistant label on treatments offered' exemplifies how participants reported medication as the primary offering, even in the context of supposed resistance. Illich (2010) writes how the process of medicalisation of everyday experience, including distress, removes decisions over who is unwell and who requires treatment away from those who have these experiences into the hands of so-called expert medical professionals. As a result, people become reliant on powerful clinicians for their health care, which includes what treatment is deemed to be useful and necessary for their recovery (Illich, 2010). This

process is evident in the current study, as when alternatives to medication were offered, they were secondary to medication rather than treatments in their own right. These findings are reflective of the narrow definition of treatment, namely medication, found in the literature around the TR label which places alternatives such as psychotherapeutic interventions in a position of augmentation (NICE, 2014; Polese et al., 2019). Furthermore, such alternatives could arguably be framed as an extension of medicalisation, happening as they do in clinic and hospital settings and therefore removing power over recovery away from the hands of those in distress. Indeed, Illich (2010) calls for such power to be reclaimed by 'lay people' in order to bring about true recovery. In the current study, the meaning and facilitation of recovery found in avenues of support outside of the mental health system, and therefore away from the effects of medicalisation, add weight to this argument.

As Illich (2010) notes, medicalisation can often cause damage and harm. For some participants in this study, the continued prescription of medication led to little benefit but continued side effects. Such a strategy is reflective of the notion of 'maintenance medication', where medication is perceived as being necessary long term to manage a chronic problem (Harper, 2021). Unfortunately, moves towards medication reduction are problematised by dangerous withdrawal effects which can impact physical health and often lead to an increase in psychosis experiences due to the bodies reaction to less medication (Blackman & Oloyede, 2021). Despite this, there is a growth in literature which encourages withdrawal from psychiatric drugs for people with a psychosis diagnosis who have been taking them for prolonged periods of time in recognition of their harmful inefficacy and the possibility of recovery without medication (Aderhold, 2021; Bola, 2006). This raises questions around the notion of 'maintenance medication' deemed to be necessary for those who have received the TR label. Furthermore, such writings take as a starting point the idea that all people respond to all medications in different and unique ways as a matter of course, thereby throwing doubt on descriptions of people as being innately, chronically resistant to psychiatric medication and thereby labels such as TR (Aderhold, 2021).

In addition, this subtheme found that notions of chronicity appeared to limit the breadth of treatment offered due to reports that some mental health staff

believed it would have little effect. This suggests that once received, the label sends a powerful message to staff which casts doubt on service users' recovery and limits treatment offered. A possible explanation for this is that the combination of the perceived chronicity of the label and the pessimism over medication efficacy when distress is seen through a biogenetic lens (Phelan et al., 2006).

As evidenced in the subtheme 'Efficacy of antipsychotic medication', participants were keen to share their experiences taking antipsychotic medication in the context of them receiving the TR label. Whilst the varied findings around efficacy mirror those of research for people diagnosed with S/SAD (e.g., Adams et al., 2007; Hutton et al., 2013; Leucht et al., 2009; Lindenmayer & Kaur, 2016), of note is the apparent inefficacy of Clozapine for some participants which challenges research promoting its use (Lally & Gaughran, 2018; Shimomura et al., 2021b; Wagner et al., 2021). In addition, despite the original Kaneian criteria (Kane et al., 1988) being upheld in contemporary research, e.g., Howes et al. (2017), participants reported that multiple antipsychotics were trialled before the offer of Clozapine. This indicates a mismatch in how the TR label is operationalised in clinical practice and research.

Participants additionally reported how their responses to antipsychotics led them to question the accuracy of the TR label, for example finding a medication that worked and doubting their continued resistance or experiencing recovery without the need for medication. Indeed, the study findings demonstrate that four of the seven participants have been antipsychotic free for some time and despite having varying degrees of distressing experiences, feel better equipped to manage them. This mirrors the unique work of Harrow et al. (2021) outlined in the CA and suggests an alternative to the drug heavy focus of the remaining articles which make little mention of clinician responses to the TR label which don't involve medication (Barnes et al., 2020; NICE, 2014).

4.2.3.2 On service user perceptions: Overall, the label of TR had an adverse impact on the psychology of participants and those who they came into contact with. This was evidenced in the theme 'Psychological impact of the treatment resistant label', with negative participant perceptions of themselves and their experiences mirroring research around other mental health diagnoses (Perkins

et al., 2018; Pitt et al., 2009; Repper & Perkins, 2003). As demonstrated in the subtheme ‘On sense of self’, there were, however, variations in the extent to which the TR label was incorporated as part of participants’ overall identity. A possible explanation for this is how participants perceived the explanations they were given for them receiving the label. For example, George, who earlier reports feeling blamed by staff members, describes how he felt dehumanised because of receiving the label, whilst Lisa who reported never feeling blamed, demonstrates a more optimistic view. As Foucault (1980) notes, language has the power to shape what is held to be true. These findings suggest that how responsibility for treatment resistance was talked about, and where participants perceived it to be placed, mitigated the impact it had on what they held to be true about themselves. In addition, participants appeared to question their own credibility after receiving the TR label, echoing both earlier discussion around diagnostic overshadowing and literature around the difficulties service users face in ensuring their voices are heard (Gilburt et al., 2008; Newman et al., 2015).

Other effects the TR label had on service user perceptions of themselves was most striking in reports of the impact on thoughts about having children in the future. This is not surprising given the wealth of research which claims both the TR label and diagnoses of S/SAD are due to genetic deficiency, along with those which discuss the notion of caregiver burden (e.g., Badrlou et al., 2021; Kogure et al., 2021; Miyazawa et al., 2021; Velligan et al., 2019; Verma et al., 2021a). Indeed, such ideas filter into public consciousness through media articles which associate family history with risk to future children (e.g., “I Don’t Think You Should Have Children” | Mental Health | The Guardian, 2011). As Read and Masson (2013) note, there are clear parallels between these ideas and those promoted by Eugenics, whereby risk to future children was thought to be so great that possible reproduction needed to be removed altogether. This reveals a stark psychological impact on those who received the TR label, who in effect considered a form of theoretical self-sterilisation due to the perceived risks of becoming a mother.

Further evidence of the psychological impact of the TR label is exemplified in the subtheme of ‘Hopelessness’. The study found that a permanency of distress was imparted to participants after receiving the TR label which effectively

removed hope for recovery and reclaiming a sense of ‘normalcy’. Whilst the diagnoses of S/SAD have benefitted from literature which highlights the possibility of recovery and therefore the temporary nature of distress (Leonhardt et al., 2020; Martins et al., 2018; Silva & Restrepo, 2019), there is a paucity of similar research for those with the TR label. Therefore, it is possible that any hope around recovery with participants’ first diagnoses was undone after receiving the additional label of TR. Adding weight to this idea is the seemingly infectious nature of hopelessness when expressed by mental health staff, serving to limit the attempts at recovery from both staff and service users themselves.

4.2.3.3 On the perceptions of others: The study found that the psychological impact of the TR label altered the perception of others, as outlined in the subtheme ‘On other’s perceptions’ which found that the label served to reinforce pre-existing stigma associated with the diagnoses of S/SAD. In particular, the societal stigma and adverse reactions participants faced appeared to be exacerbated by them receiving the label of TR. This is reflected in the similarity between earlier study findings around the effects of their pre-existing diagnosis and that related directly to the label, for example the sense of otherness experienced. Read et al. (2013a) reports that despite biogenetic models in theory reducing stigma by locating responsibility for distress in factors beyond service users’ control, in practice this serves to increase harmful stereotypes around people being unpredictably violent. This positions the TR label as a likely candidate for such stigma. Furthermore, the study finding of association between the TR label and individual responsibility could be seen as adding personal responsibility into, rather than out of, this mix. As a result, the harmful stereotype around danger and unpredictability associated with pre-existing diagnoses of S/SAD could be become viewed by others, just as harmfully, as the innate fault of service users themselves.

A particular aspect of this subtheme was the impact of the TR label on mental health staff’s reported reduction in expectations around participants’ futures. This led to participants perceiving a lack of encouragement in factors such as education, underscored by staff appearing to see no possibility of improvement in their experiences. This is unsurprising given the overwhelming focus on treatment and not outcomes outlined in the CA. Where outcomes are

discussed, recovery is calculated at 22% at best and apparent treatment resistance implicated in longer stays in forensic institutions (Perry & Fowler, 2021; Gosek et al., 2021). Furthermore, clinician perspectives around the label were either focused on Clozapine adherence or attempted to legitimise coercive treatment (Ahluwalia et al., 2021; Stoll et al., 2021). Whilst a systematic review on mental health diagnoses in general found an increasing awareness and encouragement of recovery in service users from staff (Gyamfi et al., 2020), participants in the current study reported how some staff appeared to view the label as negating the chance of recovery. However, Gyamfi et al. (2020) additionally found that there was a lack of understanding that such recovery could be non-linear, suggesting that staff may at times struggle to hold psychological flexibility around the nature of recovery. Therefore, it is possible that once the label of TR is received, staff may find it difficult to visualise recovery for service users and attach a finality to their distress, particularly if there is a lack of literature which presents an alternative. Such ways of thinking about recovery may explain the apparent potency of lack of hope reported to be experienced from staff in the subtheme of ‘Hopelessness’. Furthermore, perceiving those who have received the TR label in this way- as beyond help and recovery- is suggestive of the legacy of Eugenic thinking which values certain lives over others. As Pilgrim (2008) notes, Eugenics maintains an obscured but powerful presence in modern day mental health services.

Additional evidence for this potential lack of psychological flexibility in others comes from the focus on maintenance of current state, rather than forward progression, that participants reported in this study. The idea of maintenance is discussed by Harper (2021), who suggests that fear of exacerbation of a chronic problem at some point in the future forms the rationale for so-called maintenance medication. Whilst earlier discussion has demonstrated the association of the TR label with that of long-term medication use, the findings of the current study additionally suggest that this approach was experienced by the participants in relation to other aspects, for example being discouraged from finding a job for fear of relapse. Here, the continued impact of the lack of literature around recovery for those who have received the TR label is demonstrated, along with the potential rigidity around how the progress of recovery may pan out. As Walter (2015) notes, mental health labels can set up

expectations of how service users will behave. The TR label, associated with a permanency of distress, appears to limit staff expectations around recover with this focus on maintenance acting as a barrier to recovery, arguably trapping people in a state defined by disability (Shakespeare, 2006). Indeed, participants spoke of the label's associations becoming self-fulling prophecies which severely limited their attempts at recovery. Madon et al. (2018) found that people's actions were more aligned to negative stereotypes as the number of other people present who held this stereotype increased. Consequently, the overwhelmingly detrimental messages about the TR label may offer explanation for the self-fulling prophecies reported by participants in the current study.

4.3 Critical Review

4.3.1 Limitations

4.3.1.1 Ethnic diversity: Whilst the gender and age of participants mirrored that of previous studies with relative closeness (Beck et al., 2019), the sample demographic failed to capture diversity of ethnicity in that all participants were White. This is despite research which suggests no difference between racialised and non-racialised people receiving the TR label (Beck et al., 2019). As a result, the study's findings need to be treated with care to reduce the extent with which they presume the White experience as the norm (Fernando, 2017). Indeed, the study would be greatly improved with the inclusion of a more ethnically diverse sample. Possible reasons for this are the use of the terms S/SAD in the study advert which may have inadvertently aligned the study with the biogenetic model, along with the advert not explicitly naming racialised people as participants of interest. As Lawrence et al. (2021) notes, Black Caribbean people are more likely to report oppression in relation to the biogenetic model than their White counterparts, raising the possibility that potential participants of this ethnicity chose not to take part to avoid perceived harm. In addition, this harm is enacted by White people in the mental health system (Fernando, 2017), a demographic which I represent.

4.3.1.2 Sample size: Guest et al. (2016) found that in TA themes could be developed from as little as six interviews, with consistent patterns found in variability across the data, whilst there is evidence of critical realist TA conducted with seven participants (Harper & Timmons, 2021). Nonetheless, seven may have limited the breadth of perspectives represented in this study

data. As reported in the study, participants experienced adverse effects from others upon sharing the label of TR, therefore this may have limited willingness to share experiences for fear of being judged. Another potential factor was the requirement to conduct interviews via video call which requires both a comfortableness with this medium and access to an appropriate device. As the cost of living continues to increase in the wake of the ongoing effects of austerity (Mattheys et al., 2018), growing numbers of those in poverty means that the latter may be unaffordable. In addition, participants were required to have a confidential space available to them which some may not.

4.3.1.3 Recruitment: As mentioned, two of the participants were known to the researcher. McConnell-Henry et al. (2010) note this can engender an additional richness to data, speeding up the rapport building process. However, it could have placed limitations on both data collection, through assumed knowledge between researcher and interviewee, and analysis, through this knowledge then having to be left out of analysis due to not being referred to in the interview itself (Barnes, 1979). For example, the interviewee might not have talked about experiences as explicitly as with someone they didn't know, whilst the researcher may not have asked as explicit questions (see Appendix R). Recruitment was conducted largely on Twitter and some public figures who are known for critiquing the biogenetic model chose to retweet. This could have impacted the study by making it appear uninteresting to those who find solace in the biogenetic model and hence influenced the findings. In addition, it is possible that social desirability shaped the answers of all participants (Paulhus & Reid, 1991).

4.3.2 Quality assurance

4.3.2.1 Contribution: As demonstrated by the CA, there is a lack of research which explores the experience of being diagnosed with S/SAD and receiving the TR label from the perspective of service users. It is believed that this study begins to fill this gap and is an important step in encouraging further research. Ideas for future study direction and the implications of the findings of this study are outlined in a section below. In terms of dissemination, detailed descriptions of the themes and subthemes have been prepared (Appendix P) and will be sent out to study participants.

4.3.2.2 Credibility: The method of data analysis via TA was outlined in the Methods chapter to give transparency as to how the results were analysed. A process of consultation and refinement was carried out around themes and subthemes in supervision with the study supervisor. To lend the study transferability to other research which explores the experiences of people who have received the TR label, detailed descriptions of the themes and subthemes are provided to allow future researchers to compare findings (Appendix P). Finally, whilst only one participant received the TR label due to antidepressant, rather than antipsychotic, medication not producing the intended results, this was included as an important and valued part of the analysis.

4.3.2.3 Rigour: Literature around the process of TA was read and guidance sought from the study supervisor who has experience in this analysis. A coded transcript extract is provided (Appendix K), along with an example of a coding framework (Appendix M), an outline of initial themes (Appendix N) and an audit of theme revision (Appendix O). A reflective journal was kept during data collection and analysis (Appendix R). This was useful to note areas of development as the researcher moved through the interviews and analysis. Reflexivity was considered further, from both a personal and epistemological position, in the section below.

4.3.2.4 Reflexivity: The methodology and epistemological position employed in this study were chosen as they appeared to offer the best means to answer the research questions. However, they could have inadvertently placed limitations on the findings. Discourse analysis may have been a useful alternative method of analysis, particularly considering how powerful the language of TR appeared to be for participants and their strategy of forming their own. In addition, a social constructionist epistemology could have offered a different stance on the findings.

In terms of personal reflexivity, it is useful to consider Crenshaw's (1989) notion of intersectionality, which draws attention to the effect of overlapping and intersecting layers of identities a person can have, some of which face discrimination. In doing so, I was able to consider how my different perspectives and identities, for example being a White, middle-class woman who is able-bodied and training to be a clinical psychologist, may have impacted on data collection and analysis. For example, one of the participants was a wheelchair

user. When they talked about detrimental experiences in both the physical and mental health systems as a result of the TR label, I held in mind the possible additional difficulties they may face in terms of physical access and the discrimination that is shown to people who have a disability. As they spoke, I noticed myself feeling anger on their behalf and a tension in myself around whether I was 'allowed' to express this in the context of the study interview. I made the decision to do so, and this appeared to be well received, sparking off more conversation. However, for another participant, this could have closed the conversation if they saw me as aligned with the very systems that had harmed them. Indeed, it is possible that my identity as a trainee acted to limit the number of participants I recruited due to people wondering if they could trust the intentions of a study which aimed to explore a highly stigmatised label.

Another factor that could have shaped data collection and analysis is that I had a pre-existing relationship with two of the participants. As outlined in the extract from my reflexive journal (Appendix R), this could have limited what was talked about in terms of assumed knowledge. In addition, it could have led John to feel like he needed to tell me what I wanted to hear given that he knows I am drawn more to personal models of recovery rather than clinical. As this was the first interview, it was helpful to reflect on this for the second interview with George, who was also known to me, and make it clear that I was interested explicitly in his experience prior to the interview beginning. I was additionally aware that my stance on the biogenetic model, namely an interest in embracing alternatives, could have shaped the analysis of the data and led me to dismiss times when participants spoke about this positively. Therefore, I made sure that these were included in the final write up e.g., highlighting causal explanations which drew on biological models as more credible and mention of medication as providing hope.

4.4 Future Research and Implications

The population of those who receive the label of TR in addition to their diagnoses of S/SAD is sizeable, estimated as up to 56% in UK community samples (Beck et al., 2019). Therefore, the implications outlined in this study require addressing at multiple levels.

4.4.1 Policy Implications

At present, NICE guidelines only discuss psychotherapeutic interventions as adjuncts to medication (NICE, 2014). This is despite research which found that psychotherapy is just as effective as antipsychotics for those with a S/SAD diagnosis (Morrison et al., 2018), suggesting that this may be an option for those with the TR label. This study demonstrates that policy needs to promote choice around the treatments available. For example, considering either alternative medications or alternative treatments, if desired by the service user. In addition, clearer recommendations around medication reviews need to be implemented which emphasise the possibility of medication reduction if it is reported as not working by the service user. In terms of funding, further research around the experience of service users who receive the TR label and training for staff which increases awareness of non-linear ideas around recovery would be beneficial. Co-production which rejects tokenism would provide valuable insights for policy development.

4.4.2 Research Implications

As demonstrated in the study CA, this small-scale study is one of the first of its kind to focus on subjective experiences associated with the label of TR. Therefore, there is a need for further research with explores these experiences, along with the concept of treatment resistance itself. In addition, the different treatments offered, to whom and to what effect, in the context of the TR label are worth further examination. This could begin with a challenge to the supposed efficacy of treatments which legitimise the use of the label to begin with. As Dimetindene (2019) notes, there is a gap between how the criteria for treatment resistance is outlined in the research and how it is operationalised in clinical practice. This is supported by the study findings and therefore is worthy of future research. However, the wisdom of the alternative Demyttenaere (2019) proposes, the concept of ‘difficult to treat’, is questionable in the context of findings from this study around the adverse associations of permanency, individual responsibility and reduction of hope which surround the TR label. Therefore, research around how to describe, rather than label, instances where service users may not respond to treatment would be useful, starting with consultation with service users themselves.

4.4.3 Practitioner Implications

There are many implications for practitioners from this study which mirror those outlined in previous studies, for example the need to develop sustainable avenues for peer support and the importance of offering alternatives to medication which make meaning from experiences, such as the Maastricht Interview (Castelein et al., 2008; Corstens & Romme, 2009). As with other studies, the importance of hope was outlined in the findings, however this takes on additional significance in the context of the profound effect messages of no hope were reported having on both staff and service users. Similarly, service user choice around treatment should be respected.

In relation to the specific context of TR, the study found that the label acted both to bar access to treatment and conversely to encourage staff to work collaboratively with service users to find a treatment that worked. This calls for practitioners to align themselves with the latter position, taking seriously service user descriptions of side effects and treatment (in)efficacy and making plans for medication reduction if desired. Crucially, practitioners should take a non-blaming stance when communicating about the label which moves away from any indication of individual responsibility, ensuring service users feel well informed from a range of sources which hold hope as a central tenet.

Clinical psychologists are key in promoting formulation of service user's difficulties which encourage personal meaning making and values their perspective. Alternative approaches to the bio-genetic model could be explored with service users if appropriate and with their consent, for example approaches such as the Power, Threat, Meaning Framework (Johnstone & Boyle, 2018) or narrative therapy principles, which can contextualise distress and centre subjective understandings. Whilst these approaches may be at odds with wider service approaches, they can offer helpful ways to think collaboratively about distress with clients. However, this should be done sensitively; clinicians should hold in mind that some service users will prefer biogenetic understandings of distress and this needs to be respected.

Furthermore, clinical psychologists are well placed in services to act as advocates for service users and to insist that meaningful co-production of service provision occur. This may involve being vocal about the harmful effects of psychiatric medication and other treatments for service users and therefore

may incur personal cost if clinicians are working within systems which remain wedded to bio-genetic models. In the context of the TR label, awareness of the effect and range of psychiatric medication would be beneficial. Finally, clinical psychologists can support practitioners in offering supervision for more challenging aspects of their work, for example holding onto compassion in the face of greatly reduced funding to services and burnout.

4.4.4 Service User Implications

The study adds to the pre-existing literature around factors that provide service users with sources of meaning and support in the context of mental distress. Of note, sharing experiences with supportive others was found to be particularly useful. In this study, this was valued in both online and in person settings and did not require the presence of mental health staff. This promotes the possibility of those with the TR label coming together of their own accord. Of particular importance in navigating the often punitive mental health system was relationships with staff who advocated on behalf of participants. Therefore, it is recommended that where possible, service users seek out these staff and make clear their wishes for treatment. It is recognised, however, that such advocacy will not always be a possibility for service users. Finally, it is hoped that this study offers hope to service users, not only for recovery, but in that it is a small step in bringing to light a conversation around the impact of the TR label which is long overdue.

4.4.5 Learnings For Future Research

There are several learnings for the researcher, not least that all study participants reported their ethnicity as White, therefore limiting the sample considerably. Future research should aim to explicitly recruit racialised people to broaden generalisability and, as outlined in the work of Lawrence et al. (2021), capture the likely different perspectives of this community of service users. In order to do this, location of recruitment should be carefully considered, for example advertising in community centres rather than just online. When using digital platforms such as Twitter, racialised people should be directly approached where appropriate to avoid a narrowly representative sample. Furthermore, although necessary for the current study due to the Covid-19 pandemic, where possible, all interviews should be conducted face to face rather than remotely to lessen the effect of digital exclusion.

4.5 Conclusion

This study explored the experiences of people who have been diagnosed with S/SAD and received the label of TR and has implications for future research and practice. The findings outline the sizeable impact such a label can have on the lives of service users, who face stigma due to the combination of their initial diagnoses and the additional TR label.

The study found that explanations which carry with them implications of personal responsibility were damaging both to how participants view themselves and how others view them. Notions of chronicity and a lack of hope had far reaching consequences for participants, affecting their daily lives and promoting medication as the only treatment. This medication was experienced as often ineffective and always accompanied with life-limiting side effects.

Despite this, participants demonstrated their resourcefulness and tenacity at keeping going. More research is required to expand the treatment options available for those who have received the label of TR, whose deserve their recovery to be invested in.

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APPENDIX A: OPERATIONAL CRITERIA FOR THE TREATMENT RESISTANT LABEL IN THE CONTEXT OF A SCHIZOPHRENIA DIAGNOSIS

A minimum of three periods of treatment in the past five years with neuroleptic drugs (from minimum of two chemical classes at dosages equivalent to or greater than 1000mg/day for six weeks), each not giving significant symptomatic relief

AND

No period of good functioning in the past five years

AND

Score of 45 minimum and ≥4 in ≥2 of in the Brief Psychiatric Rating Scale psychotic items: conceptual disorganization, suspiciousness, hallucinatory behaviour, unusual thought content, and score of at least 4 in the Clinical Global Impression-Severity

AN

After 6 weeks, no improvement of treatment with haloperidol at up to 60mg or greater as measured by a reduction of at least 20% of the Brief Psychiatric Rating Scale severity and Clinical Global Impression-Severity score.

Note:

Developed by Kane, J., Honigfeld, G., Singer, J., & Meltzer, H. (1988). Clozapine for the treatment-resistant schizophrenic: a double-blind comparison with chlorpromazine. *Archives of General Psychiatry*, *45*(9), 789–796. https://doi.org/10.1001/archpsyc.1988.01800330013001

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APPENDIX B: BREAKDOWN OF GENERIC CATERGORY 'INVESTIGATING LIVED EXPERIENCE' PAPERS

Study and subcategory	Study aim and sample	Method	Results	Conclusions	Quality criteria met and additional comment (see Appendix B)	Location
The impact of COVID-19 on a cohort of patients treated with clozapine Fahy, Y., Dineen, B., Mcdonald, C., & Hallahan, B. (Service user experience)	Aim: to investigate the psychological and social impact of COVID-19 on people receiving Clozapine 63 people attending a Clozapine clinic with a psychosis diagnosis and the treatment resistant label	The Beck Anxiety Inventory (BAI) and Hamilton Anxiety Rating Scale (HAM-A) administered cross-sectionally. Impacts of COVID-19 restrictions on anxiety and depressive symptoms, social and occupational functioning and quality of life gathered via Likert scale. Additional free text responses gathered.	Anxiety symptoms were low with a median BAI score of 4.0 and HAM-A score of 4.0. Likert scale measurements recorded only a modest adverse impact of COVID-19 restrictions on anxiety and depressive symptoms, quality of life and occupational and social functioning. Free-text comments from participants (n = 55), were grouped into five themes: neutral impact (n = 22), negative psychological impact (n = 13), negative social impact (n = 11), positive psychological impact (n = 5) and media coverage inducing anxiety (n = 4).	The impact of COVID-19 has been modest. Preliminary evidence demonstrates minimal increases in subjective symptoms of anxiety and reduced social functioning. Reduced social engagements and supports attainable both within the community and from mental health services were noted by some participants.	75% Small sample size Only those receiving Clozapine included	UK
Preliminary evidence for Heterogeneity of beliefs about Auditory verbal Hallucinations intent	Aim: Characterise the heterogeneity of beliefs about auditory verbal hallucinations and clinical correlates 78 people with a psychosis diagnosis	The Revised Beliefs About Voices Questionnaire was administered cross-sectionally and the results subject to a cluster analysis.	Cluster analysis yielded four subgroups of participants with distinct pattern of beliefs about auditory verbal hallucinations. These subgroups differed significantly in terms of affective disturbances, engagement, and resistance to their voices. No significant changes in beliefs about	Results of the current study suggest that the heterogeneity regarding the beliefs about auditory verbal hallucinations should be targeted in treatment to reduce	100% Assumption made that voices are unwanted phenomena	Switzerland

Zanello, A., & Dugré, J. R. (Service user experience)	referred to a Voices group therapy for refractory and distressing voices.		voices were observed after 6 weeks.	their associated negative outcomes.		
Patients' and psychiatrists' perspectives on clozapine treatment - A scoping review protocol Jakobsen, M. I., Storebø, O. J., Austin, S. F., Nielsen, J., & Simonsen, E. (Service user experience)	Aim: To address gap in knowledge around the perspectives on Clozapine from people who use this drug. Outline of scoping review protocol for completion of future scoping review	Preliminary literature search on Google Scholar and PubMed supporting outline of scoping review protocol.	Majority of research included in reviews around perspectives on Clozapine appears to be from clinician perspectives and neglects that of service users. However, a preliminary literature search revealed that additional literature on service user perspectives exists but is not included in the majority of reviews.	A scoping review is warranted in order to focus on mapping and synthesising primary literature on service users' perspectives on Clozapine treatment, and to identify gaps for future research. This will additionally include psychiatrist's perspectives.	100% Search limited to English language	Denmark
Navigating the mental health system: Narratives of identity and recovery among people with psychosis across ethnic groups Lawrence, V., McCombie, C., Nikolakopoulos, G., & Morgan, C.	Aim: To explore the difference in journeys through the mental health system for people of different ethnicities. 17 black Caribbean, 15 white British, and 3 non-British white people with psychosis as part of AESOP-10, a 10 year follow up of an	Semi-structured interviews, with data analysed using Thematic Analysis.	Thematic narrative analysis identified three overarching narrative categories: 'losing self within the system', 'steadying self through the system' and 'finding strength beyond the system'. Variation in narratives across ethnic groups with 'losing self within the system' and 'finding strength beyond the system' narratives most common, though not exclusive to, black Caribbean participants.	Distress appeared rooted in social structures that disadvantage black people, and psychiatry appeared to be experienced as a further form of oppression. These findings underline the necessity of interventions that target social disadvantage in this population.	100% Research, including analysis, constructed through White British perspective	UK

(Service user experience)	ethnically diverse cohort of individuals with first episode psychosis in the UK.					
Command voices and aggression in a Lebanese sample patients with schizophrenia. Salim, Z., Haddad, C., Obeid, S., Awad, E., Hallit, S., & Haddad, G. (Service user experience)	Aim: Evaluate association between command voices and violence, and voice beliefs, psychosis severity, treatment, demographic factors and command voices. 280 people with a schizophrenia diagnosis classified as chronic.	Multiple questionnaires administered: One which collected socio-demographic and clinical characteristics of participants, Positive and Negative Syndrome Scale, Chicago Hallucination Assessment Tool, The Beliefs About Voices Questionnaire-revised, Voice Compliance Scale, Aggression Scale	111 (39.6%) people with a schizophrenia diagnosis had auditory hallucinations, among whom 93 (83.8%) people had command voices; from these 93 people, 53 (57.0%) were compliant with voices. Higher positive and general psychopathology PANSS subscales scores were significantly associated with higher compliance to voices. A higher resistance to beliefs about voices (ORa=0.91) was significantly associated with lower compliance to voices.	The prevalence of command voices in people with a schizophrenia diagnosis that report auditory hallucinations, was high in our sample. The vast majority of violent acts committed by people was in compliance to command voices, with a significantly high rate of the violence committed being directed towards property. Findings were able to connect positive symptoms to higher probability of compliance to command voices.	88% Scales used have not been validated with a Lebanese sample	Lebanon
Rumination, intolerance of uncertainty and paranoia in treatment resistant psychosis.	Aim: Explore the association between depressive rumination, non-depressive rumination, intolerance of uncertainty and paranoia.	Multiple questionnaires administered: Rumination Response Scale, Perseverative Thinking Questionnaire, Positive and Negative Symptom	Non-depressive rumination demonstrated a specific relationship with paranoia, but not with delusions or positive symptoms generally. Moreover, paranoia was strongly associated with intolerance of uncertainty.	Rumination and intolerance of uncertainty may contribute to the maintenance of paranoid thinking and may be important in the treatment of paranoia and persecutory ideation.	100% Small sample size Use of only one item on PANSS to determine paranoia	UK

Lebert, L., Turkington, D., Freeston, M., & Dudley, R. (Service user experience)	24 people labelled with treatment resistant psychosis.	Scale, Psychotic Symptom Rating Scale, Intolerance of Uncertainty Scale and Calgary Depression Schizophrenia Scales				
Effect of clozapine on psychological outcomes of caregivers of patients with treatment resistant schizophrenia. Verma, M., Grover, S., & Chakrabarti, S. (Caregiver experience)	Aim: Evaluate the effect of short-term Clozapine treatment on caregiver burden, expressed emotions, caregiver abuse and psychological morbidity on caregivers. 52 people with schizophrenia diagnosis with treatment resistant label who were taking Clozapine, along with their primary caregiver (defined by being main care provider for 1 year minimum)	Multiple questionnaires administered at baseline to caregivers. These were then repeated after 3 months of those in their care receiving Clozapine. The questionnaires were: Family Burden Interview Schedule, Caregiver Abuse Screening Questionnaire, Perceived Criticism Measure and General Health Questionnaire-12. Those with the schizophrenia diagnosis and the treatment resistant label completed the latter two questionnaires at both time points.	Maximum caregiver burden was seen in the domain of disruption of routine family activities, and this was followed by the domains of disruption of family leisure, disruption of family interaction, and the effect on mental health on others. At the baseline assessment, three-fourth of the caregivers scored ≥12 on the objective burden. With 3 months of clozapine therapy, there was a significant reduction in the caregiver burden in all the domains of objective burden, subjective burden, and the global objective burden as per the clinician rating, in the expressed emotions as per both patients and the caregivers, caregiver abuse, and psychological morbidity among the caregivers.	Caregivers of people with a schizophrenia diagnosis and the label of treatment resistant experience significantly higher caregiver burden and a large proportion of them suffer from psychological morbidity and indulge in expressed emotions and abuse of the person in their care. Treatment with Clozapine for 3 months leads to a reduction in the caregiver burden, expressed emotions, caregiver abuse, and psychological morbidity among the caregivers.	56% Small sample size Non-blind assessment of participants	India

Listening to the Patient's Voice: A Patient-Centred Approach to Treatment-Resistant Schizophrenia. Ahluwalia, A., Rafizadeh, R., White, R. F., Bahji, A., & Danilewitz, M. (Clinician experience)	Aim: Outline client centred approach to therapeutic Clozapine monitoring 60 year old Caucasian man with schizophrenia diagnosis and treatment resistant label	Outline of how to adopt a patient-centred approach to clozapine monitoring based on case-study	Patient-centred care opens the way for patients who would benefit from clozapine yet are ineligible for treatment due to factors such as non-adherence to bloodwork. A potential approach involves: (a) assessing for potential suitability of reduced monitoring, (b) obtaining the second opinion and integrating shared decision making, (c) obtaining informed consent and (d) proceeding with reduced monitoring schedule and ongoing reassessment.	Implementing a patient-centred approach to hematologic monitoring may facilitate more people's acceptance of Clozapine and hence achieve greater symptomatic relief and improved quality of life for people with a schizophrenia diagnosis.	88% Description of current clinical condition did not mention psychosis experience	Canada
Compulsory Interventions in Severe and Persistent Mental Illness: A Survey on Attitudes Among Psychiatrists in Switzerland. Stoll, J., Hodel, M. A., Riese, F., Irwin, S. A., Hoff, P., Biller-Andorno, N., & Trachsel, M. (Clinician experience)	Aim: Investigate psychiatrist's attitudes to compulsory intervention for those with described as having severe mental distress. Cross-sectional survey of 457 psychiatrists.	Participants were asked about the care of people classed as having severe and persistent mental illness, including those with a schizophrenia diagnosis described as chronic and treatment refractory, in general, and about their attitudes with regard to compulsory interventions in particular, using case vignettes for this diagnosis.	91.0% found it important or very important to respect service user autonomy in decision making. 36.8% of psychiatrists would act against the wishes of the person with treatment refractory schizophrenia diagnosis, although all service users were stated to have preserved decision-making capacity. 41.1% considered compulsory interventions leading to a temporary reduction of quality of life acceptable in the patient with treatment refractory schizophrenia.	While most respondents respect the autonomy of service users, many saw the need to perform compulsory interventions even though it was clearly and prominently stated that two independent psychiatrists had ascribed the patients in the case vignettes decision-making capacity.	100% No definition of compulsory intervention given	Switzerland

APPENDIX C: QUALITY ASSESSMENTS FOR PAPERS FROM GENERIC CATEGORY 4 'INVESTIGATING SUBJECTIVE EXPERIENCE'

Please note that all papers were assessed for quality using the Joanna Briggs Institute 'Critical Appraisal Tools' checklists. References for these checklists are given below.

Analytical cross-sectional studies

Authors	1*	2	3	4	5	6	7	8	Quality criteria met and additional comments
Fahy, Y., Dineen, B., Mcdonald, C., & Hallahan, B.	Yes	Yes	Yes	Yes	No	No	Yes	Yes	75% Small sample size Only those receiving Clozapine included
Zanello, A., & Dugré, J. R.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100% Assumption made that voices are unwanted phenomena
Salim, Z., Haddad, C., Obeid, S., Awad, E., Hallit, S., & Haddad, G.	Yes	Yes	No	Yes	No	Yes	Yes	Yes	88% Scales used have not been validated with a Lebanese sample
Lebert, L., Turkington, D., Freeston, M., & Dudley, R.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100% Small sample size Use of only one item on PANSS to determine paranoia
Stoll, J., Hodel, M. A., Riese, F., Irwin, S. A., Hoff, P., Biller-Andorno, N., & Trachsel, M.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100% No definition of compulsory intervention given

Adapted from: Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. (2020). Systematic reviews of etiology and risk. In E. Aromataris & Z. Munn (Eds). *JBI Manual for Evidence*

Synthesis. Joanna Briggs Institute. Available from https://synthesismanual.jbi.global

*Critical appraisal questions:1= Were the criteria for inclusion in the sample clearly defined?, 2= Were the study subjects and the setting described in detail?, 3= Was the exposure measured in a valid and reliable way?, 4= Were objective, standard criteria used for measurement of the condition?, 5= Were confounding factors identified?, 6= Were strategies to deal with confounding factors stated?, 7= Were the outcomes measured in a valid and reliable way?, 8= Was appropriate statistical analysis used?

Text/opinion studies

Critical appraisal questions**	1	2	3	4	5	6	Quality criteria met and additional comments
Jakobsen, M. I., Storebø, O. J., Austin, S. F., Nielsen, J., & Simonsen, E.	Yes	Yes	Yes	Yes	Yes	Yes	100% Search limited to English language

Adapted from: McArthur A, Klugarova J, Yan H, Florescu S. (2020). Systematic reviews of text and opinion. In E. Aromataris & Z. Munn (Eds). *JBI Manual for Evidence Synthesis.* Joanna Briggs Institute. Available from https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-05

** 1= Is the source of the opinion clearly identified?, 2= Does the source of opinion have standing in the field of expertise?, 3= Are the interests of the relevant population the central focus of the opinion?, 4= Is the stated position the result of an analytical process, and is there logic in the opinion expressed?, 5= Is there reference to the extant literature?, 6= Is any incongruence with the literature/sources logically defended?

Case report study

Critical appraisal questions***	1	2	3	4	5	6	7	8	Quality criteria met and

									additional comments
Ahluwalia, A., Rafizadeh, R., White, R. F., Bahji, A., & Danilewitz, M.	Yes	Yes	No	Yes	Yes	No	Yes	Yes	88% Description of current clinical condition did not mention psychosis experience

Adapted from: Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. (2020). Systematic reviews of etiology and risk. In E. Aromataris & Z. Munn (Eds). *JBI Manual for Evidence Synthesis*. Joanna Briggs Institute. Available from https://synthesismanual.jbi.global

*** 1= Were patient's demographic characteristics clearly described?, 2= Was the patient's history clearly described and presented as a timeline?, 3= Was the current clinical condition of the patient on presentation clearly described?, 4= Were diagnostic tests or assessment methods and the results clearly described?, 5= Was the intervention(s) or treatment procedure(s) clearly described?, 6= Was the post-intervention clinical condition clearly described?, 7= Were adverse events (harms) or unanticipated events identified and described?, 8= Does the case report provide takeaway lessons?

Qualitative study

Critical appraisal questions****	1	2	3	4	5	6	7	8	9	10	Quality criteria met and additional comments
Lawrence, V., McCombie, C., Nikolakopoulos, G., & Morgan, C.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100% Research, including analysis, constructed through White British perspective

Adapted from: Lockwood C, Porrit K, Munn Z, Rittenmeyer L, Salmond S, Bjerrum M, Loveday H, Carrier J, Stannard D. (2020). Systematic reviews of qualitative evidence. In E. Aromataris & Z. Munn (Eds). *JBI Manual for Evidence Synthesis.* Joanna Briggs Institute. Available from https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-03

**** 1= Is there congruity between the stated philosophical perspective and the research methodology?, 2= Is there congruity between the research methodology and the research question or objectives?, 3= Is there congruity between the research methodology and the methods used to collect data?, 4= Is there congruity between the research methodology and the representation and analysis of data?, 5= Is there congruity between the research methodology and the interpretation of results?, 6= Is there a statement locating the researcher culturally or theoretically?, 7= Is the influence of the researcher on the research, and vice- versa, addressed?, 8= Are participants, and their voices, adequately represented?, 9= Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?, 10= Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Quasi-experimental studies

Critical appraisal questions*****	1	2	3	4	5	6	7	8	9	Quality criteria met and additional comments
Verma, M., Grover, S., & Chakrabarti, S.	Yes	No	No	No	Yes	Yes	No	Yes	Yes	56% Small sample size Non-blind assessment of participants

Adapted from: Tufanaru C, Munn Z, Aromataris E, Campbell J, Hopp L. (2020). Systematic reviews of effectiveness. In E. Aromataris & Z. Munn (Eds). *JBI Manual for Evidence Synthesis.* Joanna Briggs Institute. Available from https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-04

***** 1= Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?, 2= Were the participants included in any comparisons similar?, 3= Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?, 4= Was there a control group?, 5= Were there multiple measurements of the outcome both pre and post the intervention/exposure?, 6= Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?, 7= Were the outcomes of participants included in any comparisons measured in the same way?, 8= Were outcomes measured in a reliable way?, 9= Was appropriate statistical analysis used?

APPENDIX D: ETHICAL APPROVAL

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Claire Marshall

SUPERVISOR: David Harper

STUDENT: Jennifer Richards

Course: Prof Doc in Clinical Psychology

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

(Please indicate the decision according to one of the 3 options above)

APPROVED

The author states on p.6 ‘The supervisor will be consulted if there are any remaining concerns about the participant’s wellbeing.’ Just to highlight - if the video call gets cut off or the researcher is not able to properly debrief the participant there is a concern about the participants wellbeing, it would be important to consult their supervisor – as has already been indicated in the ethics form.

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student’s name *(Typed name to act as signature):*

Student number:

Date:

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Dr Claire Marshall

Date: 21.07.21

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

APPENDIX E: PARTICIPANT INFORMATION SHEET

Version 1 24/03/21

Exploring the experience of receiving the label of 'treatment resistant schizophrenia'

PARTICIPANT INVITATION LETTER

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Who am I?

I am a postgraduate student in the School of Psychology at the University of East London and am studying for a Professional Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in.

What is the research?

I would like to understand what it is like to have been given the label of 'treatment resistant schizophrenia. My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my research as someone who fits the kind of people I am looking for to help me explore my research topic. I am looking to interview people who have received the label of 'treatment resistant schizophrenia' at any point in their life, or who have been given a diagnosis of schizophrenia and been told that their experiences are 'resistant to treatment'. You must be over 18 years old to participate and live in the United Kingdom. As the interview will be online you will need to have access to the internet on a computer, smartphone or other device. I emphasise that I am not looking for 'experts' on the topic I am studying. You will not be judged or personally analysed in any way and you will be treated with respect. You are quite free to decide whether or not to participate and should not feel coerced.

What risks and benefits are there?

It is hoped your participation in the study will help to address a gap in research around the experiences of people who have been labelled in such a way. There may be some risks in that discussing experiences may be distressing for participants dependant on how they have experienced the label.

What will your participation involve?

If you agree to participate you will be asked to take part in an online interview with me about your experiences and the effect of this label on your life.

Your taking part will be safe and confidential

Your privacy and safety will be respected at all times. The interview will be recorded on a digital recording device which only the researcher will listen to. I will type up a transcript of the interview but I will change any names and other information which might identify you.

What will happen to the information that you provide?

Any personal contact details or personal data collected in the process of the study will be stored on a password protected computer file (UEL OneDrive). The interview will be recorded (so that I do not miss anything you say) and then I will transcribe it (i.e. type it up). However, in the transcript you will be given a pseudonym (i.e. a fictitious name) and no identifying information (your name, other potentially identifying details etc) will be included. Personal details (e.g. your email address) and the transcripts will be stored in password-protected files on a secure and encrypted university storage system (OneDrive). No-one other than my supervisor and I will have access to these and even they will not know your name. When the study is complete, the audio recordings will be deleted. When I write up my thesis, I may use quotes from your interview but you will only be referred to by a pseudonym and nothing that might identify you will be included.

The thesis will be publicly accessible in the University of East London's Institutional Repository (ROAR) but this will not include any information which might identify you. My research supervisor will keep the anonymised transcripts of the interviews for up to 5 years as I may wish to publish the findings of this research. The data gathered for this study will be retained in accordance with the University's Data Protection Policy

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within 3 weeks of the interview (after which point the data analysis will begin, and withdrawal will not be possible).

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me: Jen Richards (Email: u1945526@uel.ac.uk)

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dave Harper, School of Psychology, University of East London, Water Lane, London E15 4L. Email: d.harper@uel.ac.uk. Alternatively you can contact: Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)

APPENDIX F: CONSENT FORM

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Exploring the experiences of receiving the label of 'treatment resistant' for people with a diagnosis of schizophrenia

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

Participant's Name (BLOCK CAPITALS)

…….

Participant's Signature

……..

Researcher's Name (BLOCK CAPITALS)

……..

Researcher's Signature

……

Date: ……..…….

APPENDIX G: DATA MANAGEMENT PLAN

UEL Data Management Plan: Full

For review and feedback please send to: researchdata@uel.ac.uk

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Jennifer Richards
PI/Researcher ID (e.g. ORCiD)	U1945526
PI/Researcher email	U1945526@uel.ac.uk
Research Title	Exploring the experiences of receiving the label 'treatment resistant' for people with a diagnosis of schizophrenia
Project ID	N/A
Research Duration	6 months, proposed start date of March 2021

Research Description	1. How do people labelled with treatment-resistant schizophrenia describe the nature of their concerns and/or the reasons for referral to services? 2.What causal explanations do people give for their problems as they see them? 3. How do people describe the effects which the label of TRS has had on how they view themselves and on how others view them?
Funder	N/A- part of a professional doctorate
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	14/01/21
Date of last update (of DMP)	01/04/2021
Related Policies	UEL's Research Data Management Policy
Does this research follow on from previous research? If so, provide details	N/A
Data Collection	
What data will you collect or create?	The study is aiming for around 10 participants who have received the label of 'treatment resistant schizophrenia' or who have a diagnosis of schizophrenia and been told that their experiences are 'resistant to treatment'. Data are audio-recordings in .mp4 format and the transcriptions are in Word format. No analysis software will be used. Consent forms will collect personal data (names), whilst prior to interview the researcher will communicate via email with participants in order to arrange the interviews. No sensitive data will be

	collected and no further data will be collected in the analysis of the transcripts.
How will the data be collected or created?	Semi-structured interviews will be used, lasting around 60 minutes each. Interviews will take place over Microsoft Teams. Audio-recordings made on Teams are saved onto UEL's Microsoft Stream Library by default. The audio recordings will then be downloaded and uploaded to UEL OneDrive for Business, with any local copies destroyed. Microsoft Teams will be used from the researchers password protected computer. Interviews will be transcribed by the researcher and data anonymised at point of transcription. Any identifying details mentioned of services/organisations will be anonymised. Participants will be given a participation ID (in chronological research order) and any other names mentioned will be given pseudonyms. Participants will be given a participation ID (in chronological research order) and any other names mentioned will be given pseudonyms. Participants will approach the research to take part in the study via the researchers UEL email address. All correspondence will be via this, with participant consent forms being sent and returned via this email address. These forms will then be saved directly to UEL OneDrive for Business.
Documentation and Metadata	
What documentation and metadata will accompany the data?	Participant information sheet, consent forms, interview schedule and debrief sheet. There will be a file naming convention- The forms/sheets will be saved in a folder on the laptop titled 'Participant initials: Date of interview'.

Ethics and Intellectual Property	
How will you manage any ethical issues?	• Written consent will be obtained from all participants prior to interview. • The right to stop participation in the research study, without the need to provide a reason, will be outlined to participants on the information and consent forms. Should a participant choose to stop taking part in the study, any data collected will be withdrawn from the study and destroyed confidentially. Participants will be notified that this will be possible up to 3 weeks post-data collection, whereupon withdrawal will not be possible due to the data already having been analysed. • The debrief sheet will point participants in the direction of support organisations should any emotional distress occur as a result of the interview. Emotional harm will be minimised by several steps taken by the researcher: a) at the start of the interviews, it will be made clear that the participants can stop/pause the interview at any point b) some guidelines will be drawn up which outline how both the researcher and the participant will know that the interview is becoming too distressing and what both can do to address this c) the researcher will check in at regular intervals around how the participant is doing with the interview content d) support organisation contact details will be provided at the end of the interview e) if there are concerns over the psychological distress levels of participants after interview, a discussion will be held around if contacting the participant's GP or trusted supporter would be useful. Due to the online nature of the data collection, the participant will be encouraged to establish confidentiality for themselves to partake and a personal 'debrief' plan will be encouraged so they can 'wind down' from the interview after finishing. Any concerns about the participants wellbeing will be consulted on by the study supervisor • To protect confidentiality, audio recordings will be transcribed by the interviewer only and participants will be given a participant ID to ensure confidentiality. Any other

	identifiable names, e.g. services/places, will be anonymised.
How will you manage copyright and Intellectual Property Rights issues?	N/A
Storage and Backup	
How will the data be stored and backed up during the research?	Participants will approach the research to take part in the study via the researchers UEL email address. All correspondence will be via this, with participant consent forms being sent and returned via this email address. Immediately prior to interview, the researcher email a copy of a consent form to the participant and then await the return of a signed copy before beginning the interview. These forms will then be saved directly to the UEL OneDrive for Business and any local copies of the forms deleted. The laptop is a personal, non-networked laptop with a password known only to the researcher. Research data (audio recordings and transcriptions) will be saved in their own folders using UEL storage (UEL OneDrive for Business) which is accessed from the researcher's laptop. No data will be saved on the researcher's laptop hard drive. The audio files will be saved under date of collection and participant initials. Audio-recordings made on Teams are saved onto UEL's Microsoft Stream Library by default. The audio recordings will then be downloaded and uploaded onto UEL OneDrive for Business, with any local copies destroyed. Microsoft Teams will be used from the researchers password protected computer. For transcriptions, each participant will be assigned a chronological participant ID number (e.g. P1) in order of interview and saved under this ID number. There will be no record kept of which ID numbers link to personal identifying information. Audio files will be stored on the H: Drive post-transcription, in a separate and encrypted folder from the consent forms.

	Back-up data will be saved on the UEL H: Drive. Electronic consent forms will be saved in a separate H: Drive folder to other research data and will be encrypted.
How will you manage access and security?	These transcriptions will only be available to the researcher, supervisor and examiners. Audio files of the interviews will be downloaded from Microsoft Teams onto the researcher's personal password protected laptop immediately after the interview, before being deleted from Microsoft Teams. The files will then be saved in a folder on UEL OneDrive for Business on the laptop titled 'Participant initials: Date of interview'. The anonymised transcripts will be shared with the research supervisor via UEL's OneDrive for Business, with files named with participant ID numbers, e.g, P1. T
Data Sharing	
How will you share the data?	In the final research thesis and possible publication, transcript extracts will be utilised however all identifiable information will be anonymised. The transcripts will not be deposited via the UEL repository due to security concerns. The Thesis will be publicly available via UEL's Research Repository
Are any restrictions on data sharing required?	N/A
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	Until the thesis is examined and passed, audio recordings and electronic copies of consent forms will be kept securely on the UEL Onedrive for Business and backed up on the UEL H:Drive. However, they will then be deleted from the UEL servers.

What is the long-term preservation plan for the data?	Anonymised transcripts will be kept on the UEL OneDrive of the researcher's Director of Studies for 3 years for possible future publication.
Responsibilities and Resources	
Who will be responsible for data management?	Jennifer Richardsr Professor David Harper (retention of anonymised transcripts post-project)
What resources will you require to deliver your plan?	N/A
Review	
Date: 01/04/2021	[name of staff] Research Data Management Officer

APPENDIX H: DEBRIEF LETTER

Version 1 24/03/21

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study on **Exploring the experiences of receiving the label of 'treatment resistant' for people with a diagnosis of schizophrenia.**

This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

- Any personal contact details or personal data collected in the process of the study will be stored on a password protected computer file which only the researcher has access to.
- When the study is completed, the audio recordings will be transcribed by the researcher only and the transcripts saved on a password protected computer file accessible only to the researcher.
- You have three weeks after data collection to request a withdrawal for your data.
- When the study is complete, the audio recordings will be deleted. The transcriptions will be stored for three years and then deleted.

- Any names or identifying details will be anonymised. Participants will be given a study ID and any names mentioned will be given pseudonyms.
- Some of the data may be reviewed by the research supervisor in the analysis process, or by examiners through course requirements, however this will remain anonymised. A small selection of anonymised quotes from the interviews will be present in the final research write up which may be published in academic journals.

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

- Mind- mental health charity offering support and advice
  - 0300 123 3393
  - info@mind.org.uk
- Samaritans- mental health helpline open 24/7
  - 116 123
  - jo@samaritans.org
- Sane Line- mental health helpline, support and advice
  - 07984 967 708
  - support@sane.org.uk
- Hearing voices network- support organisation for people who 'hear voices, see visions or have unusual experiences'
  - info@hearing-voices.org

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me: Jen Richards (Email: u1945526@uel.ac.uk)

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dave Harper, School of Psychology, University of East London, Water Lane, London E15 4L. Email: d.harper@uel.ac.uk. Alternatively you can contact: Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)

APPENDIX I: INTERVIEW SCHEDULE

1. When did you receive the label of ‘treatment resistant schizophrenia/schizoaffective disorder’ or have your experiences described as ‘resistant to treatment’?

    1. How did this happen?

    2. What were you told about this label/description?

2. What is/was your understanding of having your experiences described in these terms?

    1. Where was the responsibility placed for the treatment resistance?

3. How do you make sense of your experiences?

4. What effect did this have on how you saw yourself?

5. What effect did this have on your interactions with others?

APPENDIX J: DEMOGRAPHIC INFORMATION SHEET

Demographic information

Age:

Ethnicity:

Nationality:

Gender:

APPENDIX K: EXAMPLE OF TRANSCRIPTION AND CODED EXTRACTS

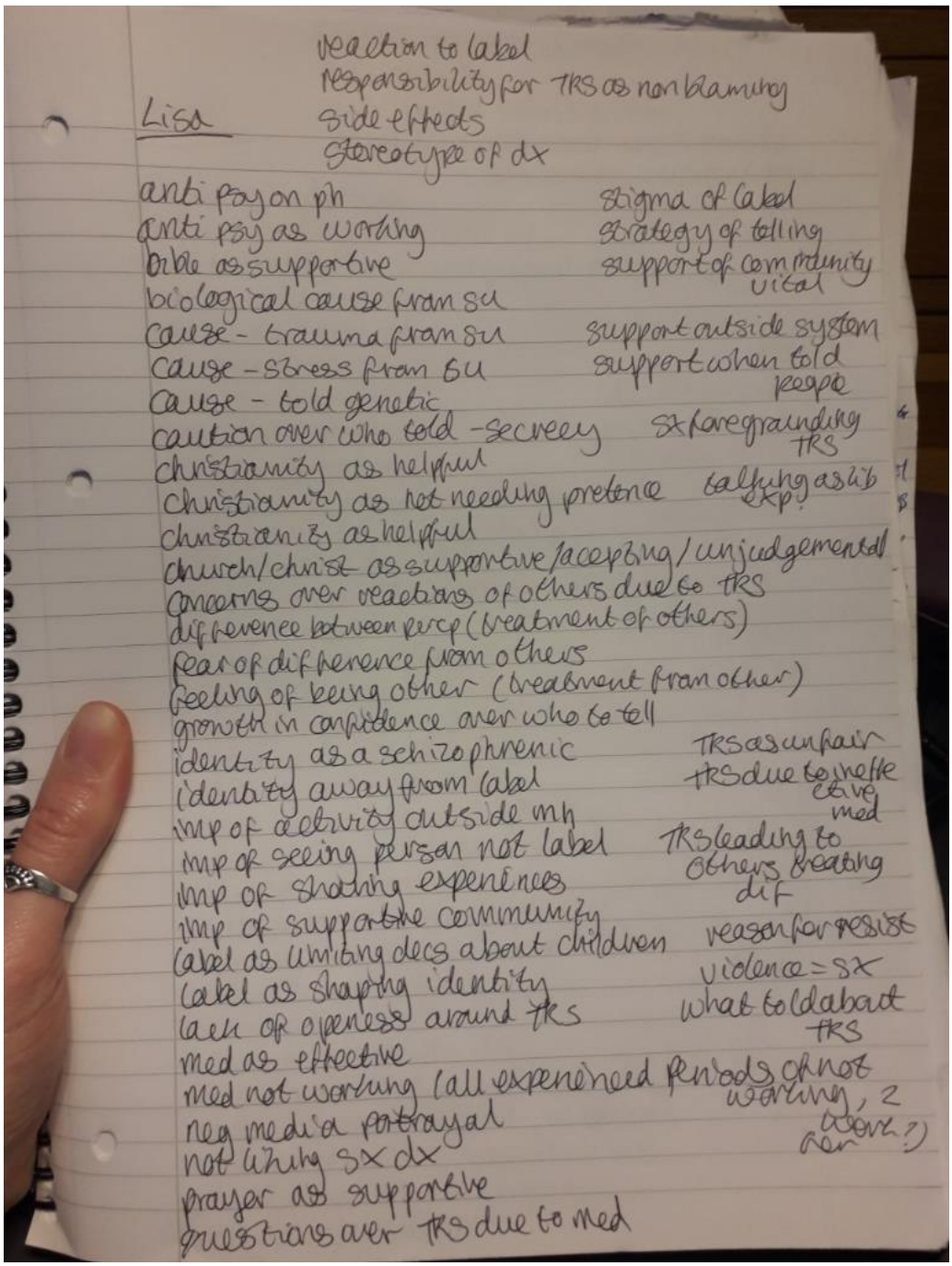
Interview with Ian (from p.1)	Codes
Jen: You were just saying something then [reference to comment made pre-recording] about feeling quite angry, I think. Ian: (2) Yeah, no, definitely with (.) about the Clozapine.	Reaction to Clozapine
Jen: Uh-huh. (2) Yeah, and did you feel able say bit more about that? Ian: Well they tried to put me on it because I was treatment resistant apparently and erm, err (.) Yeah, (.) I'm just trying to think. Erm the side effects were very similar to Olanzapine, which I was on for about two years, and then I put on 35 kilos when I was on that drug.	Weight gain Clozapine side effects TR= clozapine
Jen: //Right I Ian: Bearing in mind I only weighed 60 when they put me on it so it's more (.) More than 50% increase in my body weight because of it and I was lucky I didn't get diabetes.	Weight gain Risk to physical health- meds
Jen: Mmm. Ian: (2) So the thought of the the gold standard drug was just not not anything I was prepared to erm entertain.	Reaction to Clozapine
Jen: Uh-huh. Ian: And because I wasn't actively trying to kill myself or anyone else, they let me sort of like play around	Multiple meds Trial and error Medication efficacy

and go on different drugs until they found one that finally did something.	
Jen: Mmm. (2) And when was this Ian, was this you said something about a few years that you were on Olanzapine for? Ian: Erm yeah, that was in 2013, I think they put me on that. Jen: OK, yeah. (2) And. I guess, erm, when did you kind of receive the label of? Did you say it was treatment resistant? How was the label kind of said to you? Ian: Erm well, they just basically said they didn't expect. Well in the hospital. So I had my first psychosis when I was like 16, 17 which was back in 2004 or whatever.	Psychosis experience History of psychosis diagnosis Where TR given
Jen: Uh-huh. Ian: And I was on antipsychotics for couple years and then I came off them. And then I went. And then I had to another episode (.) and when went to discharge from the hospital, they basically tried to say to me ‘look you're not going to fully recover from this. So we're not going to be able to fully treat you, and our recommendation is that you go on housing benefit and’. Whatever it was, they tried to get me to sign up for. And erm, luckily my [family member] let me sleep in her loft. So I slept there for about six months and	Psychosis experience Change in social situation Change in medication Removing hope from recovery Being untreatable

erm. You know ‘cause I had some sort of delusions about my [family members] at the time and so I didn't feel comfortable living with them anymore.	
Jen: Yeah. Ian: And err (.) yeah, it just got to a point where this situation just became untenable and I just got so angry I just, I just ended up getting a job and just going back into my [family members]. And it took me quite a few years to save enough money to move out and get my own place to live, escape that situation so.	Anger at social situation Change in social situation Gaining employment
Jen: Mmm. And when you were saying you getting angry, what was it that you were angry about? Ian: Erm it was mainly my [family member] that ‘caused the problem, ‘cause we used to fight a lot and stuff and erm (.) I always found that very difficult to sort of live with him basically. (.) And I can't remember exactly what the specifics, the specifics of the delusion was’ cause I was very ill at the time. Erm. And then. Just like I found the report from that, from that time erm probably about a year ago. And it said that I had word salad and I I remember I was talking to the doctors and I thought I was having a normal conversation with them (.) and they	Difficult family situation Experience of psychosis MH staff report Difference in perception of communication

reciprocate in the conversation, but apparently I wasn't making any sense, so I don't know how that works.	
Jen: Mmm. And what do you make of that? That kind of? Uhm? I guess yeah, the the doctors writing word salad and you feeling like you're having a normal conversation. Ian: Well, I don't know, it just made me sort of think for us, it gave me a bit of insight to be honest, 'cause I was like. This is written down here in an official medical report and there's nothing I can do about it.	Experience of psychosis Gaining insight MH staff report

APPENDIX L: EXAMPLE OF INITIAL ANALYTIC IDEAS



APPENDIX M: EXAMPLE OF CODING FRAMEWORK

Below is an example of the coding framework for the theme ‘Antipsychotic medication in the treatment resistant context’. Note that not all codes are shown, nor all extracts relating to each code.

Code	Extract
Antipsychotic inefficacy	Cillian: The quetiapine was put up to 600 milligrams and that did take me out of psychosis. But it replaced the visual hallucinations and delusional thinking and paranoid, extreme paranoid thinking, with chronic depression. (p.5) George: Some people get benefit from that [taking antipsychotic medication], you know, I’m not arguing that, but I think I would probably argue the majority don't. (p.11) John: I tried loads and loads of drugs and the voices were getting worse. The paranoia was getting worse. They weren't helping. (p.4) Sarah: I mean, it did nothing. I'm as well have been, you know, taking placebo or something and then they put me on to Aripiprazole. And I was probably very lucky to get that in some ways, but then it didn't really work all that well. (p.3)
Antipsychotic trial and error	Ian: That's how long it took. It took nearly five years to erm (.) to finally, I think I switched six times before I found a medication that actually did something useful. (p.17) Rosie: I went through every antipsychotic in nine months. So they trialled every antipsychotic in nine months, then labelled me treatment resistant. But how did they give medication even a time to work in nine months? (p.18)

Clozapine side effects	Rosie: I was on things like some like top dose of Clozapine for a long time, like that made me wet the bed like I don't even know went through these doctors' minds. (p.18) Lisa: And uhm, when I went to start the clozapine, I had to go into hospital and uhm. So I had to take time off work um, it was, it was odd being in hospital when I felt well physically, so I felt like I didn't need to be there, but obviously they were monitoring all of the the white cells and so on. (p.4)

APPENDIX N: OUTLINE OF INITIAL THEMES

Theme	Subthemes	Codes
Circumstances of receiving the label	Initial contact with services	Psychosis experience Self harm Medication inefficacy
	Reason for treatment resistance	Persistent experiences
	Responsibility	Feeling blamed Responsibility-meds Responsibility- self
Causality of experiences	Service user models	Biogenic Psychosocial Biopsychosocial
	Professional models	Little explanation
Effects of antipsychotics	Efficacy of antipsychotic medication	Antipsychotic efficacy Antipsychotic trial and error
	Side effects	Weight gain Lactation Obscuring experience Risk to physical health-meds
	Medication = treatment	Medication as only offer Medication despite resistance

Implications of label for self	Effect on self-perception	Being flawed Sense of responsibility Removing hope for recovery Detrimental addition
	Decisions about communicating	Need for secrecy Telling mitigated by others Strategy over who/how to tell Negative reaction Mutual support
	Changes in perception	Initial acceptance Rejection of label Medication working= questioning label Shift of responsibility
Experience in the system	Detrimental impact of the system	Exacerbation of mental health Exertion of power Lack of choice/control Coercive treatment Lost credibility No investment in future Maintenance/static recovery
	Effect of biomedical model	Label as obscuring Label as meaningless Self-fulling prophecies

	Power of individual workers	Advocacy Seeing person not label Meaning making
Treatment outside the system	Friends/family	Adverse treatment Relationship breakdown
	Media	Violence Media stereotypes
	Physical health	Diagnostic overshadowing

APPENDIX O: EXAMPLE OF THEME REVISION

Below are three examples of how themes and subthemes were restructured through a process of revision. These examples form part of the audit trail for the Thematic Analysis. Themes were also discussed and refined in consultation with the study supervisor.

Example 1: Dismantling initial two initial themes to create one new theme

The initial themes of 'Circumstances of receiving the label' and 'Causality of experiences' were dismantled and aspects of each combined to make the revised theme of 'Explanatory models of distress and treatment resistance'. This was achieved as outlined below:

- After consulting the research questions again, it was decided that the subtheme of 'Initial contact with services' could be dismantled as it was not the focus of the research and participant responses on the whole did not relate to the treatment resistant label. However, from this subtheme, the code of 'Medication inefficacy' was held on to and put into the 'Reason for treatment resistance' subtheme as this referred to times when participants had spoken more directly about the receiving the treatment resistant label in response to medication failing to provide the desired effect.
- The remaining subthemes and codes were revised from two initial themes to the new theme name after re-reading the extracts associated with the codes and deciding that they all referred to explanatory models in some way, hence 'Explanatory models of distress and treatment resistance'.
- The subtheme 'Reason for treatment resistance' was renamed 'Explanation for treatment resistance' to fit with the name of the theme and the code of 'Medication inefficacy' was split into two separate codes; 'Antipsychotic failure' and 'Antidepressant failure' to reflect the variation in the data. The code of 'Persistent experiences' was dismantled, and the data refined to go under either 'Antipsychotic failure' or 'Antidepressant failure'.

- The subtheme ‘Professional models’ was dismantled, and the code ‘Little explanation’ moved to the subtheme ‘Explanations of treatment resistance’.
- The subtheme ‘Service user models’ was renamed ‘Causal explanations for distress’ but all associated codes remained.
- The subtheme ‘Responsibility’ was renamed ‘Locus of responsibility’ and all associated codes kept, however there was the addition of ‘Shift of responsibility’ to capture a change in the locus of responsibility as seen by the participants.

Example 2: Refocusing the analysis around the treatment resistant label

There was a process of revision around the initial themes after a realisation that it was unclear which codes specifically referred to the treatment resistant label and which to participant’s experience of a psychosis diagnosis more generally. The solution was to have some themes which clearly outlined which aspect of participant experience they were referring to. Below is an outline of part of this process, focusing on the initial theme of ‘Implications of the label for self’, however further revisions were made to the analysis after this point.

- The extracts associated with the codes under the subtheme ‘Decisions over communicating’ were re-read and revised for those that referred specifically to treatment resistant or those which referred more generally to a psychosis diagnosis.
- As a result of this, the codes ‘Need for secrecy’, ‘Telling mitigated by others’ and ‘Strategy over who/how to tell’ were moved to the theme of ‘Effects of a psychosis diagnosis’. Additionally, the code ‘Mutual support’ was moved to the theme ‘Sources of meaning and support’ which was also not treatment resistant specific.
- The code ‘Negative reaction’ was split into extracts which related to the treatment resistant label, named ‘Adverse reaction (TR)’, and extracts which related to a psychosis diagnosis. The code ‘Adverse reaction (TR)’ went into the theme ‘Effect of the treatment resistant label on others’.

Example 3: Dismantling the theme ‘Experience in the system’

Refocusing the analysis around the different experiences associated with the treatment resistant label and that of psychosis was useful in dismantling the

initial theme of ‘Experience in the system’ as this theme included codes referring to both experiences. Therefore this theme was revised, with some subthemes and codes going to treatment resistant specific themes (‘Effect of treatment resistant label on service user perception’ and ‘Effect of treatment resistant label on others’) and others going to the more general psychosis themes (‘Effects of a psychosis diagnosis’ and ‘Sources of meaning and support’). Below is an outline of this process:

- The subtheme of ‘Detrimental impact of the system’ was moved to the theme of ‘Effects of a psychosis diagnosis’. The associated codes of ‘Exacerbation of mental health’ and ‘Exertion of power’ moved too, however were renamed ‘Exacerbation of distress’ and ‘Reduced power’ respectively. The codes ‘Lack of choice/control’ and ‘Coercive treatment’ also moved to fit with the theme of ‘Effects of a psychosis diagnosis’.
- The codes of ‘Lost credibility’ and ‘No investment in future’ moved to the treatment resistant specific theme of ‘Effect of the treatment resistant label on others’, as did the code of ‘Maintenance/static recovery’. This was due to the content of the extracts being specifically related to the sense of permanency which the treatment resistant label brought for participants.
- The codes of ‘Label as obscuring’ and ‘Label as meaningless’ went to the treatment resistant specific subtheme of ‘Removing meaning from experiences’, which sat under the theme of ‘Effect of the treatment resistant label on service user perceptions’.
- The code of ‘Self-fulling prophecies’ went to the subtheme of ‘On sense of the future’. Despite referring to interactions with others, it was felt that the content of the extracts noted the impact on service user perception to a greater extent that the effect on others, hence the inclusion in the theme ‘Effect of the treatment resistant label on service user perceptions’ rather than ‘Effect of the treatment resistant label on others’.
- All of the codes under the initial subtheme of ‘Power of individual workers’ went to the subtheme of ‘Mental health staff’ as whilst not specific to the treatment resistant label, these were thought to reflect important aspects of support for service users and hence went under the more general theme of ‘Sources of meaning and support’.

APPENDIX P: DESCRIPTION OF THEMES

Below are descriptions of the themes which aim to assist the study findings in being transferable to other research which explores the effect of the treatment resistant label for those with a schizophrenia or schizoaffective disorder diagnosis.

Theme 1: Effects of a psychosis diagnosis

- This theme captured the effect receiving a diagnosis of psychosis had on participants. The effects of this diagnosis were wide ranging, including changing their interactions with others, impacts on their physical health and coercive experiences in the mental health system and beyond. The different aspects of this theme are outlined below.
- **Subtheme 1.1: *'I'm Immediately Dismissed On The Basis Of My Mental Health':* Altering Interactions With Others**
- This subtheme notes the secrecy which surrounded participants' psychosis diagnosis, consideration of which was a prevalent factor despite some of the participants choosing to share their diagnosis with others. A sense of otherness was common for participants, who reported being seen as different from other people due to their diagnosis, along with experiencing a power imbalance between themselves and staff. Participants found that other people's understanding of their psychosis experience was drawn from a reliance on media stereotypes which promoted violence and the need for a lack of agency.
- **Subtheme 1.2: *'[…] The World Interacts Differently Cause You're Fat, You Know, So It's Just Like. It So Adds Insult.'*: Physical Health Impacts**
- This subtheme outlines the physical health impact that receiving a psychosis diagnosis had on participants. These included severe psychiatric medication side effects, including weight gain, which was felt as adding to societal discrimination, lactation and a risk to physical health due to diabetes and high cholesterol. Some participants named Clozapine as having particularly adverse effects on their physical health, along with experiencing diagnostic overshadowing long after their initial diagnosis.

- **Subtheme 1.3: *'I Generally Felt I Had No Choice 'Cause It Would Be Forced On Anyway.'*: Coercion In The Mental Health System**
- This subtheme highlights the adverse impact being in the mental health system had on participants, leading to them experiencing coercion around a number of factors including treatment and how they understood their experiences. Participants found that the system served to increase their distress through its failure to take time to understand their concerns. This coercion had a wide ranging impact and effected how participants represented themselves to wider systems, such as welfare agencies.

Theme 2: Antipsychotic medication in the treatment resistant context

- This theme included participant experiences of antipsychotic medication specifically in relation to them receiving the label of treatment resistant. The theme presents a range of reports on efficacy and outlines experiences of refusing to take antipsychotics. Experiences which led to participants questioning the treatment resistant label are additionally included in this theme. A breakdown of this theme is outlined below.
- **Subtheme 2.1: *'It's Not Just Me, This These Medications Don't Work On Many, Many People'*: Efficacy Of Antipsychotic Medication**
- This subtheme exemplifies the efficacy of antipsychotic medication for participants. There were a range of experiences from finding the medication as failing to produce the desired results to experiences of partial effectiveness. There were reports of periods of trial and error with varying results. Participants additionally reported that antipsychotic medication was found to obscure voice hearing in a way that was unhelpful.
- **Subtheme 2.2: *'Why Would You Spend Money On A Lost Cause'*: Effects Of The Treatment Resistant Label On Treatments Offered**
- This subtheme exemplifies how receiving the treatment resistant label influenced what treatment participants were offered. This was primarily medication, with alternatives such as psychotherapies offered as adjuncts. Participants additionally found that the treatment resistant label appeared to bar access to them receiving further medication, or conversely to mean that they continued to be prescribed it despite experiencing little benefit.

- **Subtheme 2.3: *'I Don't Know How You Can Say A Human Is Treatment Resistant. Like Have You Tried Everything?'*: Experiences Which Led To Questioning The Label**
- This subtheme depicts different experiences that the participants had in relation to receiving the treatment resistant label which led to them questioning its accuracy. Antipsychotic medication being effective and successful self-management of their experiences led to questions over the accuracy of the label, as did recovery without the use of medication. Participants also reported that the inefficacy of medication, along with the lack of variety of treatment offered, was where the locus of responsibility for treatment failure should fall and these factors led them to debate the accuracy of the label. In addition, the apparent lack of outcome or meaning associated with the label led to questions over it utility.

Theme 3: Explanatory models of distress and treatment resistance

- This theme refers to understandings of distress and the label of treatment resistant as reported by participants. The theme includes descriptions of causal explanations of distress from participants, along with explanations given to them by mental health staff about why they received the treatment resistant label. Where responsibility for treatment failure was deemed to be placed is additionally captured. Below is further detail on theses subthemes.
- **Subtheme 3.1: *'Things Have Got Worse The Less I've Been Listened To, The Less I've Been Heard'*: Causal Explanations For Distress**
- This subtheme exemplifies the different models that participants used to explain their experiences of distress, namely biogenic, psychosocial and biopsychosocial.
- **Subtheme 3.2: *'I've so many medications just won't work with them, and that's the conclusion'*: Explanations for treatment resistance**
- This subtheme captures the multitude of explanations that participants were given by mental health staff for them receiving the label of treatment resistant. These were the failure of medication, which included both antipsychotics and antidepressant medication. Participants additionally reported receiving little explanation around why they had

received the label, leading to them doing their own research around medication and possible explanations and outcomes.

- **Subtheme 3.3: *'It's Not Our Drugs That Are Wrong, It's You'*: Locus Of Responsibility**
- This subtheme highlights different reports of where the responsibility for treatment failure was deemed to be placed by participants. There were different aspects to this subtheme; one locus of responsibility was outlined as ineffective medication, whilst another was participants themselves. For the latter, participants reported staff stating that their attitude or response to medication had influenced the adverse outcome of the treatment in some way. This led to participants feeling blamed and reporting a shift of responsibility away from treatment or mental health services to their detriment.

Theme 4: Psychological impact of the treatment resistant label

- This theme depicts the psychological impact that the label of treatment resistant had on the perceptions of participants and those of others. This theme covers a number of aspects, namely changes to how participants saw themselves, a feeling of hopelessness associated with the label and the psychological impact on others. The different subthemes are presented below.
- **Subtheme 4.1: *'I Didn't Have Another Child (.) Because I Felt That Would Be Too Risky'*: On Sense of Self**
- This subtheme captures the impact the treatment resistant label had on participant's sense of self. The label shaped identity to varying extents, ranging from a sense of being flawed in some way to it co-existing alongside other identities. Participants reported seeing themselves as less credible after receiving the label, along with sharing concerns over risk and caring capabilities for future children. Consequently, the label's impact on participant's sense of themselves was undeniable.
- **Subtheme 4.2: *'[…] Like A Poor Prognosis, Like A Terminal Illness In Many Ways'*: Hopelessness**
- This subtheme describes the impact of the treatment resistant label on reducing participant's sense of hope for the future in relation to regaining a sense of 'normalcy' and lending a permanency to their distress.

Participants also reported how such hopelessness appeared to be transferable from staff to themselves.

- **Subtheme 4.3*: ‘’Your Son’s Got Treatment Resistant Schizophrenia. We Just Don't Know What To Do For Him Now’’*: On Other’s Perceptions**
- This subtheme outlined how receiving the treatment resistant label appeared to impact how other people perceived and interacted with those who had received it. Participants found that the label exacerbated pre-existing stigma they faced after receiving their psychosis diagnosis. Mental health staff were reported to have lower expectations for the participants and focus on maintaining their current state rather than supporting future progress. Participants reported how such thinking associated with the label impacted them to become self-fulling prophecies about their abilities.

Theme 5: Sources of meaning and support

- This theme captures factors that participants reported provided them with hope and support. Within this theme, there were a number of aspects, including the actions of mental health staff, relationships with chosen communities and the development of alternative meaning frameworks. Below is further description of these subthemes.
- **Subtheme 5.1: *‘[…] Just looked at me and just treated me’*: Mental Health Staff**
- This subtheme outlines the importance that instilling hope and seeing the person, not the label, had for participants. Alongside this, mental health staff who were prepared to dedicate time and speak up for participants were greatly appreciated, as were those who invested in their future progression. Also mentioned was the value in staff beginning to facilitate meaning making from participant experiences.
- **Subtheme 5.2: *‘At Last I Could Take This Mask Off I’d Been Wearing For Years’*: Chosen Communities**
- The importance of communities outside the mental health system which were chosen by participants is evidenced in this subtheme. Here, participants spoke of the value in mutual sharing and the freedom to be

themselves. Also noted was the role these communities played in beginning to facilitate alternative understandings about their experiences.

- **Subtheme 5.3: *'Voices That Have Got Messages That I Need To Listen To':* Using Alternative Meaning Frameworks**
- This subtheme outlines how participants formed their own language for, and ways of being with, their experiences which differed from that associated with the biogenetic underpinnings of the treatment resistant label. Participants spoke of voice hearing as a meaningful experience, actively embracing alternatives to the biogenetic model.

APPENDIX Q: PARTICIPANT INCLUSION IN THEMES AND SUBTHEMES

Theme with participants	Subtheme with participants
1. Effects of a psychosis diagnosis (Cillian, Ian, Rosie, John, George, Sarah, Lisa)	1.1: *'I'm immediately dismissed on the basis of my mental health'*: Altering interactions with others (Ian, Rosie, John, George, Sarah, Lisa) 1.2: *'[…] The World Interacts Differently Cause You're Fat, You Know, So It's Just Like. It So Adds Insult.'*: Physical Health Impacts (Cillian, Ian, Rosie, John, George, Sarah, Lisa) 1.3 *'I generally felt I had no choice 'cause it would be forced on anyway.'*: Coercion in the mental health system (Cillian, Ian, Rosie, John, George, Sarah)
2. Treatment in the treatment resistant context (Cillian, Ian, Rosie, John, George, Sarah, Lisa)	2.1 *'It's not just me, this these medications don't work on many, many people'*: Efficacy of antipsychotic medication (Cillian, Ian, Rosie, John, George, Sarah, Lisa) 2.2: *'Why Would You Spend Money On A Lost Cause'*: Effects Of The Treatment Resistant Label On Treatments Offered (Cillian, Ian, Rosie, John, George, Sarah) 2.3 *'I don't know how you can say a human is treatment resistant. Like have you tried everything?'*: Experiences which

	led to questioning the label (Ian, Rosie, John, George, Sarah, Lisa)
3. Explanatory models of distress and treatment resistance (Cillian, Ian, Rosie, John, George, Sarah, Lisa)	3.1 *'Things have got worse the less I've been listened to, the less I've been heard'*: Causal explanation for distress (Cillian, Ian, Rosie, John, George, Sarah, Lisa) 3.2 *'I've so many medications just won't work with them, and that's the conclusion'*: Explanations for treatment resistance (Cillian, Ian, Rosie, John, George, Sarah, Lisa) 3.3 *'It's not our drugs that are wrong, it's you'*: Locus of responsibility (Cillian, Rosie, John, George, Lisa)
4. Psychological impact of the treatment resistant label (Cillian, Rosie, John, George, Sarah, Lisa, Ian)	4.1: *'I Didn't Have Another Child (.) Because I Felt That Would Be Too Risky'*: On Sense of Self (Rosie, John, George, Sarah, Lisa) 4.2: *'[…] Like A Poor Prognosis, Like A Terminal Illness In Many Ways'*: Hopelessness (Cillian, Rosie, John, George, Sarah, Lisa) 4.3: *''Your Son's Got Treatment Resistant Schizophrenia. We Just Don't Know What To Do For Him Now''*: On Other's Perceptions (Rosie, John, George, Ian, Sarah)

5.Sources of meaning and support (Cillian, Ian, Rosie, John, George, Sarah, Lisa)	5.1 *"[…] Just looked at me and just treated me"*: Staff in the mental health system (Cillian, Ian, Rosie, John, George) 5.2 '*At last I could take this mask off I'd been wearing for years'*: Chosen communities (Ian, John, George, Lisa) 5.3 *'Voices that have got messages that I need to listen to'*: Alternative meaning frameworks (Ian, Rosie, John, George, Sarah)

APPENDIX R: EXAMPLE EXTRACTS FROM REFLEXIVE JOURNAL

Example 1

General thoughts following the first interview with John

I got a real, vivid sense of how much value and meaning John draws from his experiences of voice hearing in this interview. He is a powerful speaker and had the ability to really make examples and stories come to life. I could hear how detrimental the label of TR has been to him, as has his schizophrenia diagnosis and interactions with services more generally. In a way, his strong assertions that he doesn't believe in schizophrenia/TR or the biogenetic model exposes the tensions in my using these terms at all. I wonder if it's enough to note that I don't endorse them/outline the difficulties using/not using them in this study when this participant, and perhaps others later down the line, are so opposed to them. Then again, other people may find use in them and I want to be careful to not discount that.

Thoughts on method/data collection

I think perhaps at some points there might have been some assumed knowledge between us due to our existing relationship which potentially limited my asking and perhaps his telling. Perhaps when he was talking about not ascribing to the biogenetic model I could have paused and asked more about that, rather than move on as I 'know' what he means. This would have given richer answers possibly. I also wonder if I was being too leading at points- I remember saying 'I agree' when he talked about the medical model feeling punitive and I'm not sure if that could have led to him saying more about this when he wouldn't have initially. Something to bear in mind for the next interview and keep an eye on- maybe as it felt less 'formal'??

Initial thoughts about analysis ideas

- Real focus on meaning making and the value of voice hearing
- Importance of alternative frameworks
- Hearing voices network as having a central part in recovery of self, of purpose and of life- this ties to rejecting biogenetic model but I wonder if other people have other avenues of support which fill the same purpose whilst perhaps ascribing to more biological frameworks?

- Very strong message about not working due to label/diagnosis received by staff- is this shared by others?

Example 2

General thoughts following second interview with Lisa

A shorter interview than that previously and I wonder if our not knowing each other contributed to this, although it felt like the interview flowed naturally. Perhaps less well versed in speaking on the topic?

A sense of how important going to church and Christianity in general are came through really strongly. I wonder how it felt for Lisa to talk to me, as someone who is not religious. I felt quite moved when she was sharing her experiences in church and the acceptance she feels from God.

Thoughts on method/data collection

Internet issues for the whole 10 minutes prior to joining the video call so I think I joined a bit flustered- hope it didn't come across too much but note to join earlier next time to avoid that. Not having my own faith or religious beliefs could have limited how much I asked/the direction I took the conversation or even my understanding of how this could help Lisa with her experiences associated with the label. Need to think again perhaps about what other blindspots I may have as this is one I often miss.

Initial thoughts about analysis/ideas

- Definitely mutual support as a powerful experience
- How medication has been helpful for her
- Secrecy around her diagnosis of schizophrenia and label of tr in some contexts but then a real openness in church groups which has been positive
- Sense of not being 'resistant' anymore- questioning the label/shift in thinking?