How do people taking antipsychotics long-term manage and cope with tiredness-related side effects?

Charley Hobson-Merrett

LLB (Hons) Law,
Post-graduate diploma in legal practice,
PGCE in teaching and learning in the lifelong learning sector,
MRes Health and Wellbeing

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy, Mental Health. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD programme.

Faculty of Health and Medicine Division of Health Research
Lancaster University

Submitted November 2025

Acknowledgements

A big thank you to all the participants who kindly shared their experiences.

This would not have been possible without the support of my friends, family, colleagues, and supervisors.

Hugs and cake for my friend Jo, Dr Doel, who showed ‘people like us do PhDs’. Thank you to Ski for ‘you got this’ and ‘proud of you’ support early on. Thank you to the ever kind and thoughtful Michelle for listening to random new ‘facts’ during the taught phase. A big, sweaty, thanks to my Team Hilarious cycling buddies for your patience in the last twelve-month run of this work: I promise we will actually ride somewhere when this is over. Thank you to little sister, Clare, for Sunday ‘work club’, well before ‘body doubling’ was a thing. Mum, thank you for always telling us we could do anything we really wanted to, and for wise words in my moments of panic: “just do one thing at a time, Babe”. A from-the-heart thank you to my colleagues at the University of Plymouth, especially Jo Smith, Richard Byng and Becky Hardwick for variously: helping me protect time, telling me to ‘just get it done’ and ‘I’m bored of hearing about it now’, weekly check-ins, and emotional propping up, financial support, and leading by example in managing people in mental health research. Thank you to Siobhan Reilly for her early supervision. A Tunnocks tea cake thanks to my supervisors, Jane and Nancy, for their patience with me, their gentle humour, and wisdom.

Nigel, my friend, thank you for inspiring this topic, being there every time I couldn’t open an email, listening to my frustrations, helping me when I’m stuck, your honesty and reflections, kindness, and always coming running when I drop an egg or my car falls in the river. Some friends become family, and I’m proud to have you as part of mine.

To my love, Andy, who refused to listen when I said I was “too busy doing a PhD to have a relationship”: your patience, kindness, support, meal prep, and endless ability to listen to me read baffling sections of draft text aloud over and over again have made bringing this to a close possible. I look forward to us having much more free time together!

Finally, to all my cats, for endless side eye, cuddles, sitting on laptops, and acting as a live paperweight/filing system. Sorry this took so long you didn’t all get to see the end, particularly Peeka Cat, whose wisdom definitely deserved to be recognised by Dr Peeka status. Big cuddles to Peeka, Wizzard, Jester, Odins, Donna, The Nightingale, and Miss Mary Pawpins.

Abstract

Antipsychotics are prescribed long-term to some people with mental health diagnoses. Some long-term antipsychotic users experience tiredness-related side effects (TRSEs), such as sedation and fatigue. For those who experience TRSEs this can cause distress, reduced functioning, and reduced social activity. Little is currently known about how people manage or cope with TRSEs. This study was designed with the aim of increasing understanding of the experiences of people taking antipsychotics long-term, as they manage and cope with TRSEs.

A scoping study was undertaken, mapping both the way in which researchers conceptualise and research TRSEs, and mapping strategies for coping with/managing TRSEs. The scoping study showed: (1) Studies often either treated antipsychotics as interchangeable or focused on one or two antipsychotics; (2) Many studies either treated diagnoses as unimportant or focused on one or two diagnoses; (3) Most studies did not define terms such as 'tiredness' or 'fatigue', with some studies using different terms interchangeably; (4) No current viable pharmacological solutions to TRSEs were identified, with inconclusive evidence as to whether professional support might improve management and coping, but some evidence that acceptance of TRSEs and lifestyle changes might help. This highlighted a research gap regarding the experience of coping with TRSEs.

Interpretative phenomenological analysis was used to design and undertake a study addressing this research gap. Ten people were interviewed about their experiences of managing and coping with TRSEs. Analysis showed that TRSEs and management/coping became a part of participants' everyday lives, but requiring participants to prioritise particular elements of their lives. Management/coping strategies were often detrimental to participants, and either partially or completely unsuccessful. This resulted in the need for participants to practise acceptance of TRSEs.

Antipsychotic users' attempts to manage/cope with TRSEs resulted in further burdens for people who were already living with mental health problems and distressing TRSEs. Being unable to discontinue antipsychotic use due to real or perceived lack of power and/or fear of symptom relapse may leave antipsychotic users with mental health problems continually attempting to balance coping with TRSEs against continued antipsychotic use.

Contents

Abbreviations

APA: American psychiatric association

DSM: Diagnostic and statistical manual for mental disorders

GET: Group experiential themes

ICD: International classification of diseases

IPA: Interpretative phenomenological analysis

NICE: National Institute for Health and Care Excellence

PET: Personal experiential theme

TRSEs: Tiredness-related side effects of antipsychotics

List of Tables

List of Figures

How do people taking antipsychotics long-term manage and cope with tiredness-related side effects?

Chapter 1: Introduction

In this chapter I provide an overview of this thesis. I begin with an explanation of how the topic was originally conceptualised. I then introduce the thesis aims and objectives and outline the research design. I provide an overview of the justification of the thesis topic. Finally, I provide an outline of the remainder of the thesis and conclude with an introduction to my personal positioning within this research topic.

1.1 Topic conceptualisation

In 2016 a friend who was struggling with depression, anxiety and voice hearing became my house mate. Subsequently, my friend was prescribed antipsychotics. Although these appeared to help in some ways, the side effects were challenging. In particular, my friend was tired: sleeping in the day, sleeping longer, needing lots of help waking up, unable to drive at night, and in an exhausted almost manic state when the antipsychotics wore off in the evening. In 2018 I began working at the University of Plymouth as a research fellow, recruiting people with psychosis to a cluster randomised controlled trial. When arranging data collection, and speaking to our researchers with lived experience, many spoke of similar challenges with antipsychotic use. Other friends also shared their difficulties caused by similar side effects. Working in research, my friend and I looked for solutions in existing research and by speaking to my friend's GP, to no avail. I asked my friend whether they would be comfortable with me exploring this topic further for my PhD; they kindly agreed.

1.2 Justification: an overview

Antipsychotics are a group of medications prescribed to people with mental health problems to help with the management of symptoms such as hallucinations, delusions, and voice hearing, together with the distress caused by living with such symptoms. As such, they are traditionally prescribed to people with schizophrenia and psychosis diagnoses but may also be prescribed for other mental health problems, such as depression and bipolar disorder. Evidence suggests that in most countries the percentage of the population prescribed antipsychotics is rising. For example, Hálfdánarson et al. (2017) found a 2.6% increase in antipsychotic prescriptions in the publicly-insured population of the US, and 91.2% increase in Columbia between 2005 and 2014. Shoham et al. (2021) report that antipsychotic prescriptions in England doubled between 2000-2014. This makes research into living with antipsychotic side effects important and timely.

Tiredness-related side effects of antipsychotics (TRSEs) are one of the top three most reported side effects (Cascade et al., 2010; Fakhoury et al., 2001; Hale et al., 2012; McEvoy et al., 2007). Additionally, TRSEs are psychologically distressing (Bessonova et al., 2020; Doane et al., 2020) and create disabling limits to people's lives (Llorca et al., 2017; Moncrieff et al., 2009; Morrison et al., 2015; Read, 2012). Unlike other side effects such as weight gain, the management of and coping with TRSEs is relatively under-researched. This suggests that research focusing on TRSEs is the next important topic to address regarding antipsychotic side effects. This thesis is designed to address this research gap. Further detail regarding mental health diagnoses, antipsychotic use and how these relate to the justification of this study is covered in chapter two.

1.3 Aim and objectives

The research question was:

What are the experiences of people with mental health conditions who report tiredness-related side effects of antipsychotics when attempting to manage or cope with these side effects?

Aim: to increase understanding of the experiences of people taking antipsychotics long-term for a mental health problem, as they manage and cope with side effects that make them tired, sleepy, sedated, fatigued, and/or sleep more (TRSEs).

This research aim was achieved by meeting the following objectives:

- Undertaking a scoping study to assist in the design of the primary study by:
    - Describing and mapping how researchers think about, design and undertake research regarding tiredness related side effects (nature of the existing evidence).
    - Describing and mapping existing evidence regarding managing and coping with TRSEs.

- Undertake an interpretative phenomenological analysis (IPA) to understand the experiences of people as they attempt to manage and cope with tiredness related side effects, including an exploration of:
    - What these management and coping strategies are like for participants to implement, and how they make participants behave and feel.
    - How and why participants undertake the coping/management strategies they use.
    - How and why participants think that these coping/management strategies are and are not successful and how they make sense of these strategies

1.4 Research design overview

Little existing research has been conducted regarding the management of and coping with TRSEs, and existing evidence has not been collated and mapped. Additionally, it was initially unclear how researchers exploring this area thought about and undertook research regarding TRSEs. Therefore, I began with a scoping study describing and mapping the nature of the evidence regarding TRSEs, and of existing evidence regarding the management of/coping with TRSEs (chapter three). I used the findings in the scoping study to assist in the design of the primary study (chapter four). I subsequently conducted a qualitative interpretative phenomenological analysis study of interviews with individuals who experience TRSEs when prescribed antipsychotics long-term for a mental health problem, which focussed on their experiences of attempting to manage and cope with these side effects (chapter five).

1.5 An introduction to my background (positionality)

A researcher's positionality can be understood to include their identity, experiences, views, and standpoints. Positionality influences research design, assumptions and the undertaking of research (Wilson et al., 2022), including implications for research rigour (Berger, 2015). Therefore, it is important to consider and make explicit one's positionality to create an awareness of how this may affect decisions such as what is important to research, how data are interpreted, and how analyses are reported. Here I introduce my background so that it can be understood how this relates to the design and undertaking of this thesis.

I work as a research fellow at the University of Plymouth, specialising in realist methodology and mental health service improvement. My journey to this position started with a breakdown in my mental health in 2013, where I struggled with depression, anxiety and suicidal thoughts; I was unable to work and when I returned to work, it was part-time and accompanied by absences. Although I was prescribed antidepressants and anxiolytics, at no point have I taken mental health medications, meaning that my shared experience with the target population is limited. Reasons for this include my mother's position of resisting taking any medication where possible, an explanation of limited effectiveness from the prescribing practitioner, and a desire to avoid the sexual and anxiety related side effects of these medications. This, alongside the experiences of others close to me, means that I am situated more in the position of avoiding the use of medication for mental health problems. However, I am, by nature, a person that believes different approaches work for different people, and I am conscious some have little choice in their medication use. Hence, I endeavour to undertake research from a position that is useful for those that do use antipsychotics.

During the process of feeling incrementally better, and perhaps in some attempt to bring a sense of purpose to bad experiences, I remember deciding that ‘it was the job of people who make it out of the dark to bravely light a torch and go back in for the others who are lost’. I remember phrasing this very distinctly in my head. Although my personal circumstances have changed, my own purpose within research remains to undertake research that, in some way, improves the lives for those who are still living in the dark. This affects the projects I am interested in undertaking and how they are undertaken: it is also important to me that being a research participant is a positive experience where one’s experiences are honoured. This positioning also makes it more challenging for me when results do not seem to show a clear pathway to improving the lives of people with mental health problems. How this positionality has impacted the undertaking of this research is discussed in the methodological and discussion chapters.

1.6 Overview of thesis contents

In Chapter two, I present the background to this thesis, including context regarding mental health problems, and the history and use of antipsychotics. Chapter three is a scoping study of empirical studies regarding TRSEs, aiming to justify and highlight the research gap this thesis fills and provide guidance for methodological decisions in relation to the empirical study in the thesis. Chapter four is a methodological chapter, where I discuss underlying theoretical assumptions for the empirical study, the methodological approach, methods, and ethical procedures. Chapter five includes the findings of the empirical study. In Chapter six I discuss the findings and offer strengths, limitations, recommendations for clinical practice, policy and further research, and overall conclusions.

Chapter 2: Background

In this chapter I introduce the concept of mental health problems: providing a definition of ‘mental health problems’, an overview of the diagnoses for which antipsychotics are prescribed, long-term prognoses for mental health problems, and an introduction to the debate around the causes of mental health problems. I then proceed to discuss antipsychotics: their development, how why and for whom they are prescribed, debates regarding effectiveness and mechanisms of action, and an overview of side effects. Finally, I discuss tiredness-related side effects of antipsychotics in detail, culminating in the importance of addressing TRSEs.

2.1 Mental health problems and diagnoses

In this thesis I explore the experiences of people with mental health problems. In order to address the research question, it is necessary to begin by defining ‘mental health problems’. Language around these experiences varies, with some using medical terminology and others using more colloquial and experiential language. For example, the World Health Organization defines "significant disturbances in thinking, emotional regulation, or behaviour" as “mental disorders” (World Health Organization, 2022). However, the UK charity Mind argues that when a person finds it difficult or impossible to cope with the way they are thinking, feeling or reacting, this is a sign of “mental health problems” (Mind, 2025b). Others use a mixture of language, for example the England, Wales and Northern Ireland National Institute for Health and Care Excellence (NICE) variably uses “mental health”, “common mental health problems” and “severe/serious mental illness” (NICE, n.d., 2011, 2016a, 2016b). Although some texts continue to use words such as 'mental illness' and 'disorder', many charities, service user groups, and peer researchers within the UK have been told by people experiencing these challenges that the language most people prefer is ‘mental health problems' or ‘mental health issues’ (Mind, n.d.; The McPin Foundation, 2025). Therefore, in this thesis I refer to ‘mental health problems', rather than illness.

Understanding and defining categories of mental health problems is challenging. International diagnostic manuals for mental health problems, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM), and the International Classification of Diseases (ICD), cluster mental health symptoms into diagnostic groups (American Psychiatric Association, 2022; World Health Organization, 2019). Debate continues concerning the objective 'realness' of distinct mental health diagnoses (Bentall, 2014), with some advocating for a movement towards treating clusters of symptoms, using a formulation approach (Campbell & Rohrbaugh, 2006), and others arguing that mental health symptoms exist on a spectrum, rather than being separate diagnoses

(Demily et al., 2009). However, many, including NICE, continue to use diagnostic processes and labels in deciding which treatments are appropriate for people with different mental health problems. Additionally, the introduction of antipsychotics predates this debate: antipsychotics were designed to address the cluster of symptoms understood to align with the diagnostic concept of psychosis. Therefore, it is useful to begin with a brief description of the main mental health diagnoses for which antipsychotics are prescribed; this is not intended to be exhaustive. The descriptions below draw on the ICD, rather than the DSM, as the ICD has an increased international focus. Notably, there is an increased convergence of the diagnostic descriptions offered by ICD and DSM (First et al., 2021), with decreasing differences between the two. The reasons why antipsychotics are prescribed for these mental health diagnoses, including non-psychotic disorders, are discussed in section 2.4.

2.1.1 Psychosis and schizophrenia

In ICD 11 schizophrenia and psychosis diagnoses are described as involving persistent impairments in understanding what is and is not reality (delusions, hallucinations, disorganised thinking). These symptoms may involve behaving in ways that do not make sense to others, and seeing or hearing phenomena that others do not. In schizophrenia this occurs alongside flattened emotion and motivation. Sometimes schizophrenia symptoms are divided into ‘positive’ and ‘negative’; positive symptoms are those additional to good mental health (delusions, hallucinations, etc.) and negative symptoms are the parts of good mental health that are missing (emotional intensity, motivation). It is the impairments in understanding what is and is not reality (psychosis) that antipsychotics were initially designed to address.

2.1.2 Bipolar disorder

In ICD 11 bipolar disorder is described as alternating depression and manic episodes. Manic episodes can include extreme moods, such as euphoria, irritability, self-esteem, impulsive behaviour, decreased need for sleep, and increased energy. Manic episodes can include hallucinations and/or delusions, leading to some describing bipolar disorder as a type of psychosis (Cromby et al., 2013).

2.1.3 Schizoaffective disorder

Schizoaffective disorder is described in ICD 11 as meeting the criteria for schizophrenia, alongside either a manic episode or a mixed manic/depression episode.

2.1.4 Depression.

Depression is described as a mood state such as sad, irritable, empty, or loss of pleasure, without manic experiences.

2.1.5 Borderline personality disorder

In ICD 11 borderline personality disorder is described as a pattern of instability in interpersonal relationships, self-image and mood affect (i.e. rapid cycles between depressive and manic mood states), with impulsivity. This includes short-term dissociation or psychotic symptoms when in high affect (manic) arousal state. Originally named ‘borderline’ due to the initial conceptualisation of the diagnosis as sitting between psychosis and anxiety/mood disorders, shifts in understanding have led some to call for a renaming based on the emotional instability and impulsivity experienced in this condition (Borderline Personality Disorder Treatment, 2010; Huston, 2023). The term ‘personality disorder’ is controversial and often not well received by people with lived experience (Centre for Mental Health, n.d.; Healthy London Partnership, n.d.; Huston, 2023), however the alternative term ‘complex emotional needs’’ does not indicate a diagnosable condition. Therefore, this document will continue to use ‘borderline personality disorder’ where a diagnosis is relevant.

2.2 Chronic and ongoing mental health problems

Much of the early work defining mental health diagnoses was undertaken by Kraepelin in the late 1800s/early 1900s, as he created two core classifications that later became known as bipolar disorder and schizophrenia (Kraepelin, 1919). During this work both diagnoses were considered to be conditions that inevitably got worse over time and were likely caused by degenerations in brain tissue; this has since been disproven (Rund, 2009; Zipursky et al., 2013). Indeed, some people have one episode of psychosis and appear never to have another, indicating that the condition is short-term for some. For example, an English study between 2001-2014 found that 21% of those having a first episode of psychosis did not have another episode within 10 years (Shoham et al., 2021); 23% of people in a Dutch five-year cohort study did not have a second episode (Linszen et al., 2001); and 16.5% of people in an Australian 7.5 year cohort study experienced only one episode of psychosis (Alvarez-Jimenez et al., 2011). Diagnostically, bipolar disorder requires at least one manic and one depressive episode, making it inappropriate to talk about single episodes of bipolar disorder. However, it is worth noting that in a UK cohort study, 74.5% of people with a bipolar disorder diagnosis did not experience any depression or manic episodes during the five-year study period (Hett et al., 2023). In conclusion, for some, these mental health problems are short-term or time bound.

However, many continue to have fluctuating symptoms throughout their lives, experiencing a chronic condition, with periods of more severe symptoms interspersed between periods of either no symptoms or less severe symptoms. Often these states are described as 'relapses'/'crises' and 'remission'/'recovery' respectively. There are no agreed definitions of these terms. For example, a systematic review of definitions of relapse within trials comparing antipsychotic maintenance treatment with antipsychotic discontinuation for people with a diagnosis of schizophrenia found 54 different definitions of 'relapse' across 81 papers (Moncrieff et al., 2020). Notwithstanding this, a bipolar disorder consensus group defined 'remission' as a period of a week or more with no or minimal manic or depression symptoms, and 'sustained remission' as longer term, likely twelve weeks or more (Hirschfeld et al., 2007). An international cohort study on long-term schizophrenia recovery suggested three possible indicators of recovery (Harrison et al., 2001): (1) an assessment of 'functioning' via the Global Assessment of Functioning Scale subscales for functioning and symptoms and/or World Health Organization Disability Schedule; (2) the Bleuler rating of recovered; and (3) whether there has been an episode of treatment in the last two years. A systematic review of the use of the term 'remission' in academic articles (Olivares et al., 2013) suggested the most common definitions for schizophrenia relapse are: (1) Symptoms that require hospitalisation; and (2) Symptoms assessed as schizophrenia on the Positive and Negative Syndrome Scale for schizophrenia. A consensus group defined a bipolar relapse as a return of an episode of mania, depression or both (Hirschfeld et al., 2007); a recent UK study on bipolar disorder relapse rates used both this definition of returning symptoms and the need for inpatient, home treatment, crisis team or liaison psychiatry referral (Hett et al., 2023). Regardless of definitions, ongoing fluctuating symptoms and the concept of relapse mean that schizophrenia, psychosis and bipolar disorder are understood to be chronic and ongoing health problems. Together with the lasting cultural impact of Kraepelin's (1919) work, this means that many consider it necessary to offer long-term treatment for these conditions, including ongoing 'maintenance' or 'prophylactic' medication to reduce the likelihood of relapse.

2.3 Causes of mental health problems

The exact causes of mental health problems are unknown. Discussions regarding aetiology draw on correlation rather than causation, making it difficult to draw definite conclusions. Potential causes explored by correlation studies include biological differences, and the effect of psychological or social difficulties. I explore these in more detail below.

In support of biological aetiology models, evidence suggests that mental health problems are more common in those who have family members with mental health problems (Lo et al., 2020; Özdemİr et al., 2016; Tozzi et al., 2008; van Sprang et al., 2022), with ongoing efforts to establish whether there are genetic links between those who experience mental health problems (Cardiff University et al., n.d.; Davies et al., 2019). Historically, biological models rested on Kraepelin's

(1919) assumption of brain degeneration but now often assume there is a chemical imbalance which causes symptoms (Howes et al., 2017; Mind, 2020b; Royal College of Psychiatrists, 2019; Stilo & Murray, 2019).

Psychological models rest on people having experienced events that prompted an inappropriate response, for example rates of mental health problems are higher in those who have experienced trauma (Kessler et al., 2010; Stilo & Murray, 2019; Varese et al., 2012). Social models assume that a lack of social resources contribute to mental health problems, such as highlighting the association between loneliness/isolation and mental health problems (Leigh-Hunt et al., 2017; Stilo & Murray, 2019). Although many presume a mix of causation (a bio-psycho-social model) (Bolton, 2023; Campbell & Rohrbaugh, 2006; Engel, 1977; Mahapatra & Sharma, 2024; Psychiatry DataBase, 2024), different understandings of causation affects the proposed appropriate treatment(s), and how those treatments are understood to work.

2.4 Antipsychotics

2.4.1 Development of antipsychotics

Antipsychotics are a group of drugs prescribed for mental health problems. They were initially developed in the 1950s with the advent of chlorpromazine, and new antipsychotics continue to be developed (Barman et al., 2021; Kaul et al., 2024). Antipsychotics developed in the 1950s and 1960s are often referred to as ‘typical’ or ‘old’ antipsychotics. Antipsychotics developed from the 1990s onwards are often described as ‘new’ or ‘atypical’ antipsychotics.

2.4.2 Mechanisms of action

Antipsychotics aim to reduce psychotic symptoms (i.e., hallucinations, delusions, mania) and behaviour resulting from psychotic symptoms (e.g., muddled speech, violent and self-harming behaviour, anxiety and feeling threatened). Some, newer, antipsychotics also aim to reduce the negative symptoms of schizophrenia (e.g. flattened affect, low motivation). However, some suggest that antipsychotics do not reduce symptoms, but instead ‘numb’ users to the distress caused by their symptoms (Healy, 2016).

All antipsychotics, typical and atypical, block receptors in the brain and body, thereby reducing response to certain hormones. This includes the dopamine receptors, but also a variety of other receptors: some antipsychotics block the histamine (H1) receptor; some block a variety of different norepinephrine/noradrenaline (5-HT) receptors (Grinchii & Dremencov, 2020); and many also block serotonin receptors (Healy, 2016). The way in which receptor blocking helps people with mental health problems is debated. The hormones blocked by antipsychotics perform multiple roles within the body, for example the role of histamine in the body includes immune response and inflammation (Branco et al., 2018; Thurmond et al., 2008); eating and taste (Ishizuka & Yamatodani, 2012); and the sleep and wake cycle (Shibuya et al., 2012). Therefore, it can only be speculated which of these elements play a role in how antipsychotics may reduce psychotic symptoms or reduce the distress caused by antipsychotic symptoms. Differing narratives as to the cause of mental health problems are reflected in understandings of how antipsychotics work. Those following a more biological understanding of aetiology consider antipsychotics to work by addressing a chemical imbalance, particularly of dopamine, which has caused the symptoms experienced (Brisch et al., 2014). Those with different understandings of aetiology assume antipsychotics reduce symptom intensity via neurological suppression, but without addressing the cause of distress (Moncrieff, 2009). This is akin to painkillers blocking the experience of pain, but not the actual cause of pain.

2.4.3 Prescriptions of antipsychotics

Prevalence of antipsychotic use varies widely by country, with 2005-2014 adult prevalence ranging from 0.28% in Colombia to 7.89% in the US (Hálfdánarson et al., 2017). However, evidence suggests that in most countries the percentage of the population prescribed antipsychotics is rising (Hálfdánarson et al., 2017). For example, in England prevalence rose from 0.6% in 2000, to 1.2% in 2014 (Shoham et al, 2021).

Antipsychotics are traditionally prescribed to those with schizophrenia and psychosis diagnoses. They are also prescribed to those with other mental health diagnoses (Glick et al., 2001), such as bipolar disorder (Calabrese et al., 2005; Endicott et al., 2008; Helene et al., 1996; Keck, 2005; Kemp, 2014); borderline personality disorder (Bridler et al., 2015); and depression (Mulder et al., 2018). Indeed, when reviewing all primary care antipsychotic prescriptions in the UK from 2007-2011, Marston et al. (2014) found that many patients (ranging from 36% to 62% depending on the specific antipsychotic) were prescribed antipsychotics for diagnoses other than bipolar or psychosis, with common diagnoses including anxiety, depression and personality disorders. Kovess-Masfety et al. (2020) found that 33.9% of French antipsychotics users were diagnosed with depression, and 10% with bipolar disorder. Within England, Wales and Northern Ireland, NICE guidelines allow for the prescription of antipsychotics to people with mental health problems other than psychosis, for example for depression, and bipolar disorder (NICE, 2022, 2025c).

It is difficult to pinpoint why antipsychotics are prescribed to people with mental health diagnoses other than psychosis/schizophrenia. It may be the lack of distinctiveness between diagnoses: antipsychotics may be prescribed because a person experiences psychosis-like symptoms, but who has a non-psychotic mental health diagnosis (Bentall, 2004). It may be because those following a biomedical model of aetiology have so far found little evidence of distinctiveness between brain chemistry models for different diagnoses. Perhaps, for those following a more psychosocial model of mental health problems and understanding antipsychotics to work by having a ‘numbing’ rather than ‘curative’ effect, antipsychotics may be considered useful across a spectrum of mental distress symptoms.

Antipsychotics are usually prescribed in a daily or multiple-times-a-day tablet form. Sometimes antipsychotics are administered by long-acting, monthly injection or ‘depot’, and the injections are administered by medical practitioners. Some antipsychotics (e.g., clozapine) can only be given by injection, and in other circumstances injection might be more appropriate because it is difficult for someone to take a tablet or remember to take a tablet (Mind, 2025c).

For people prescribed antipsychotics for a mental health problem, antipsychotic prescription begins during a severe episode of poor mental health. As people’s mental health symptoms reduce, the antipsychotic prescription usually continues, either with the intention of managing remaining symptoms, or with the intention of preventing symptoms from reoccurring (sometimes referred to as ‘relapse’) (Correll et al., 2018; NICE, 2025a). This ongoing use of antipsychotics are referred to by some as ‘maintenance’ or ‘prophylactic’ doses, and results in people being prescribed antipsychotics long-term.

Thompson and Grünwald's (2024) systematic review regarding consent in antipsychotic prescribing reports that people prescribed antipsychotics for mental health problems are often assumed to lack capacity and/or capability to consent to antipsychotic use, and may not be provided with sufficient information to give informed consent. This suggests that people may be disempowered in their antipsychotic use. Additionally, in some countries, including England, Scotland, United States of America, Canada, France, Denmark, New Zealand and Australia, antipsychotics are sometimes prescribed as part of a compulsory treatment order, where the user is legally obliged to take medication whether or not they wish to. Such treatment orders are often enacted by long-acting injection to ensure that antipsychotic users are ‘complying’ with the compulsory treatment order (Lambert et al., 2009). Within the UK, community treatment orders are reviewed initially at six months, and thereafter every twelve months, however, they can be extended indefinitely (Gupta et al., 2018; Mental Welfare Commission for Scotland, 2025). Such orders are considered controversial and coercive by many, yet continue to be used in many countries (Maylea et al., 2025). If an antipsychotic user breaches a compulsory treatment order they may be hospitalised and treated against their wishes (Mental Health Review Tribunal, 2025;

Mind, 2025a). Indeed, a systematic review of clinical and social risk factors for involuntary hospitalisation found non-adherence to medication to be a predictor of involuntary hospitalisation (Walker et al., 2019). Additionally, thematic analysis of qualitative interviews with 23 NHS clinicians identified non-adherence to medication as a common factor leading to involuntary hospitalisation (Kular et al., 2025). Overall, this means that those taking antipsychotics in some countries may feel or be disempowered as to whether they take them, which antipsychotic they take, what dosage they receive, and whether they are able to take part in equitable conversations regarding continued use and/or side effects.

2.4.4 Antipsychotic effectiveness

Effectiveness of antipsychotics for symptom management and relapse prevention is debated (Gray & Deane, 2016; Healy, 2016; Kinderman, 2014; Moncrieff, 2006, 2013, 2015; Moncrieff et al., 2023; Wunderink, 2017). However, some people report finding antipsychotics helpful in managing symptoms (Gray & Deane, 2016; Healy, 2016; Hughes & Cohen, 2011; Kinderman, 2014; Moncrieff, 2013), and prefer to take these drugs (Healy, 2016). Indeed, recruiting people to discontinuation trials has been challenging, and trials of antipsychotic discontinuation suggest that even gradually reducing antipsychotic use over several months increases the likelihood of mental health symptom relapse in the short term (Moncrieff et al., 2023; Wunderink 2017). Therefore, regardless of effectiveness, increasing antipsychotic medication tolerability is an important research and policy aim.

2.4.5 Antipsychotic side effects

Side effects can be understood as “unwanted symptoms caused by medical treatment” (NHS, 2018, no page number). Side effects of antipsychotics are common, distressing and can include extrapyramidal symptoms (e.g., muscular spasms, restlessness, Parkinsonism, tremors), weight gain, heart irregularities, increased blood lipids and glucose (leading to increased risk of heart attack and diabetes), reduced brain volume, increased prolactin hormones (leading to negative impacts on sperm production in men and unwanted production of breast milk in women), tiredness related problems (sleepiness/sedation, tiredness/fatigue/somnolence and excessive sleeping), cognitive impairment (impaired concentration, memory problems, mental slowness) and sexual problems (Healy, 2016; Moncrieff et al., 2009). This perhaps makes it unsurprising that Read and Williams (2019) found in an online Australian/UK/US survey of 832 participants that although 35% of antipsychotic users reported that antipsychotics improved their quality of life, 54% felt they reduced their quality of life. The participants included anyone living in a non-compulsory-detained environment, i.e., those living in the community, but also those living in supported housing or a voluntary or compulsory inpatient; 28.0% of their sample had schizophrenia diagnoses, 24.9% bipolar, and 24.3% depression.

2.5 Tiredness related side effects

2.5.1 Definition

I undertook pilot searches of existing research to inform the early-stage design of the research, including the systematic scoping study and the empirical study. These searches suggested that existing antipsychotic side effect research uses a range of tiredness-related terms, including tiredness, fatigue, sleepiness, weariness, desire to sleep, sedation, somnolence, drowsiness, and increased sleep duration. Some authors (e.g., Edwards & Smith, 2009; Hodge & Jespersen, 2008; Hofer et al., 2002a) consider three distinct categories: tiredness (synonymous with drowsy, fatigue, somnolence), sleepiness (synonymous with sedation), and increased (or excessive) sleep. However, other researchers in the field use these categories interchangeably (e.g., Achtyes et al., 2018a; Dell'Osso & Ketter, 2013; Meehan et al., 2011a). This makes it difficult to understand how to plan and undertake research in this area. Therefore, in this thesis I have coined the term *tiredness-related side effects* (TRSEs) in order to encompass all of the above terms. I also designed the scoping study to include an exploration of how TRSEs are approached in existing research regarding antipsychotic side effects.

2.5.2 Importance

Reported prevalence rates of TRSEs in long-term antipsychotic users vary, with studies reporting rates between 1.4% (Schreiner et al., 2014) and 86% (Doane et al., 2020). This variance does not appear to be accounted for by study design, mental health diagnosis, TRSE terminology, or antipsychotic prescribed. For example, Citrome et al. (2012) and Gaebel et al. (2010) both measured somnolence as a treatment emergent adverse event in people diagnosed with schizophrenia and schizoaffective disorder. However, Citrome et al. reported somnolence in 36% of risperidone users, Gaebel in 1.8%.

Notwithstanding this, TRSEs are regularly reported within the top three most common side effects, either as the most commonly reported (Covell et al., 2007; El-Mallakh et al., 2012; McEvoy et al., 2007); second to weight gain (Anand et al., 2015; Cascade et al., 2010; Hale et al., 2012); or second to increased depression and anxiety symptoms (Doane et al., 2020; Fakhoury et al., 2001). This suggests that these three groups of antipsychotic side effects are those to prioritise addressing via research. Arguably there is a higher need to investigate TRSEs compared to weight gain. A large volume of research has investigated the management of weight gain side effects of antipsychotics (McIntyre, 2002; Milano et al., 2007; Siskind et al., 2025; Zhang et al., 2019). By comparison, to the author’s knowledge, little evidence exists on effective strategies to manage fatigue, sedation and excessive sleep side effects. This suggests that research focusing on TRSEs is the one of the important topics to address in antipsychotic side effect management.

Additionally, existing evidence suggests that TRSEs are distressing, with cross-sectional surveys showing that 52% of people diagnosed with schizophrenia and bipolar disorder who take oral antipsychotics find TRSEs to be very or extremely bothersome (Bessonova et al., 2020; Doane et al., 2020). Cross-sectional surveys also suggest that for some, TRSEs are the most distressing side effect. For example, 19.51% of Katayi's (2014) Kenyan cohort of antipsychotic users reported sedation to be the most important side effect, and 37.52% of Achtyes et al.'s (2018) US study involving antipsychotic users with diagnoses of schizophrenia/schizoaffective disorder reported feeling drowsy/tired as the most important side effect.

Furthermore, existing studies indicate that TRSEs have negative impacts on the lives of people who experience them. For example, Llorca et al.'s (2017) focus groups and interviews with 42 people with schizophrenia and major depression found that people experiencing antipsychotic sedation reported that it caused reduced functioning, missed time with friends and family and social activities, poor eating habits, and led to low self-esteem. Moncrieff et al.'s (2009) content analysis of 439 internet comments from antipsychotic users reported that antipsychotic sedative effects made it difficult for people to go about their daily routines, and resulted in them sleeping more but not feeling rested. Read's (2012) ethnographic study of 67 people in Ghana found that people reported tiredness from antipsychotic use made them feel dizzy, weak, lazy and listless, meaning that they could not work, which in turn resulted in low self-esteem. In conclusion, TRSEs have negative day-to-day impacts on those who experience them.

Situating the above evidence within current common international policy for managing and improving mental health problems emphasises how better management/coping of TRSEs may improve the mental health of people experiencing these side effects. For example, policies in the UK and Australia highlight the need for mental health care which allows people to be supported by the community as a whole, with improved access to education, employment and physical health care (Australian health ministers’ advisory council, 2013; NHS England et al., 2019). This approach proposes that people need to participate in everyday activities, employment and education in order to become well (Drake & Whitley, 2014). Overall, this means that gaining an understanding in how to manage or cope with TRSEs is likely to improve the quality of life of people who experience them. Finally, pilot searches for the systematic scoping study suggests little current evidence exists regarding successful management/coping strategies for TRSEs. This adds further weight to the importance of exploring ways to manage or cope with TRSEs.

In summary, people with mental health problems continue to take antipsychotics long-term. Tiredness-related side effects are one of the most common side effects of antipsychotics. Increasing numbers of people internationally and in the UK are prescribed antipsychotics, people continue to take antipsychotics long-term, and there is an increased focus on undertaking everyday activities to improve mental wellness. This makes it important to understand both how TRSEs can be managed/coped with and the experience of managing/coping with TRSEs for people taking antipsychotics long term. Currently little evidence exists on how TRSEs experienced by long-term antipsychotic users living in the community can be managed, and no evidence as to the experience of antipsychotic users when attempting to manage/cope with TRSEs alongside undertaking everyday activities that contribute to good mental health. This study aims to address this knowledge gap, with the intention of providing evidence that can contribute to improving the wellbeing and treatment of people experiencing TRSEs.

Chapter 3: Scoping study

Title: What Are the Experiences of Adults Living in the Community who are Prescribed Antipsychotics for Mental Health Conditions and Report Tiredness-Related Side Effects? *A scoping study mapping the nature of the evidence and potential management and coping strategies*

3.1. Introduction

3.1.1 Role of the scoping study in this thesis

In this chapter I describe the scoping study I undertook to inform the design of the empirical study. In the early stages of designing this thesis, it was difficult to move from the conceptualisation of the problem to a well-evidenced research gap, with a soundly justified methodological approach. One challenge was understanding and justifying the appropriate scope and inclusion criteria for the empirical study: whether to focus on all people with a mental health problem who take antipsychotics, or a specific diagnosis; whether to focus on a particular antipsychotic, group of antipsychotics or all antipsychotics; whether to investigate TRSEs as a concept, or whether there were distinguishable differences in the existing conceptualisations of, for example, ‘tiredness’ and ‘sedation’ that would justify honing in on these terms. To help understand how to address these uncertainties, it was necessary to explore the existing evidence in relation to TRSEs. This included describing and mapping the nature of existing evidence regarding TRSEs (i.e., researcher language, assumptions and research design: how researchers think about, conceptualise, and undertake research regarding TRSEs). Additionally, in order to identify and justify the research gap for the empirical study, it was necessary to describe and map existing evidence about coping with/managing TRSEs. In this chapter I discuss the design of the scoping study, the findings of the scoping study, and the implications of these findings for the design of the empirical study.

3.1.2 Justification of this review

As part of designing and justifying this scoping study I undertook pilot searches, including looking at existing reviews and creating a brief understanding of the scope of the existing primary evidence.

As mentioned above, this review was primarily intended to inform the design of the empirical study in this thesis, including how to think about TRSEs and which diagnoses and antipsychotics to include. On inspecting the pilot searches I noted a vast quantity of existing empirical studies addressing TRSEs in antipsychotic users with a mental health problem. I also noted a wide range of methodological approaches and terminology/concepts, which have not been explored in detail in existing reviews. This justified using a review to explore the nature of the existing evidence in more detail.

Additionally, my examination of the pilot searches showed that existing reviews regarding management of TRSEs focused on only bipolar disorder diagnoses (Kemp, 2014), were not systematic in approach (Kemp, 2014), included only RCTs (Fang et al., 2016), and/or did not explore management strategies that specifically addressed TRSEs (Young et al., 2015). I could not locate any existing reviews that addressed how people were able to cope with TRSEs. This justified a review that mapped existing primary evidence regarding managing/coping with TRSEs.

Therefore, this scoping study was designed to address these two knowledge gaps, with the intention of both informing appropriate research design and preventing duplication of research. My aim in this scoping study was to identify and map the nature of existing evidence regarding TRSEs within those taking antipsychotics for a mental health problem, including methodology and reporting. I also aimed to identify and map existing primary research in relation to the management of/coping with TRSEs of antipsychotics, on those taking antipsychotics for a mental health problem. In accordance with the recommendations from the Joanna Briggs Institute for Evidence Synthesis (Peters et al., 2020), I have reported this scoping study to align with the PRISMA extension for scoping reviews (Tricco et al., 2018). A completed PRISMA checklist is provided in appendix A.

3.1.3 Scope of the review

Many of my early conversations with clinicians and researchers regarding this thesis focused around whether TRSEs were a sufficient enough problem to justify investigating the management/coping of them. For example, many clinicians and researchers that I spoke to expressed the view that TRSEs were only a problem for antipsychotic users during the early stages of their antipsychotic use, and did not have an impact on antipsychotic users long term. Therefore, I originally planned and undertook this review to include a description and mapping of the evidence regarding the prevalence of TRSEs in long-term antipsychotic users, and a description and mapping of the existing evidence regarding the impact of TRSEs on antipsychotic users. Ultimately this created a piece of work that was too big to report here: when added to the thesis as a whole, these sections proved unnecessary, added little to the final discussion chapter, and disrupted the narrative flow. However, the papers that I reviewed and included as part of these abandoned aims are still included in the aim addressing the nature of the evidence, as they increase the body of evidence helping to understand how TRSEs are researched. Additionally, some of this work informed section 2.5.2 in the background chapter.

3.2. Methodology

3.2.1 Scoping studies

The variety of possible approaches to reviewing existing literature and synthesising the evidence therein has expanded over recent years. A systematic, comprehensive, replicable search of the literature is expected by these approaches (Aromataris & Munn, 2020), as this reduces the likelihood of relevant data being missed. However, which types of evidence should be included, whether it is systemically assessed for quality, and how that evidence is synthesised varies by methodology. Choice of appropriate methodology is ultimately dependent on the purpose of the review (Aveyard et al., 2016).

This review was undertaken to inform primary research into the management of TRSEs of antipsychotics in people with mental health problems (i.e., the empirical study in this thesis), by gaining an understanding of what was already known about the topic of managing/coping with TRSEs, and how researchers were approaching and designing research about TRSEs. This required a review methodology with potential to include quantitative, qualitative and mixed methods empirical studies, such as an integrative review (Whittemore & Knafl, 2005), a critical interpretive synthesis (Dixon-Woods et al., 2006), or a scoping study (Arksey & O'Malley, 2005).

In most review methodologies, included evidence is systematically reviewed for quality, in order to understand the strength of the evidence. However, where the review aims to understand the way in which existing research is undertaken, and to empower further research, quality assessments may be unnecessary (Arksey & O'Malley, 2005; Tricco et al., 2018).

Scoping studies allow for a comprehensive, systematic, and replicable search of all available literature, yet make reviews of broad bodies of evidence more logistically manageable by removing the requirement to assess systematically the quality of every piece of included evidence (Arksey & O'Malley, 2005; Levac et al., 2010; McLuckie et al., 2019; Urina-Jassir et al., 2021). A scoping study was deemed appropriate due to the vast quantity of studies returned during pilot searches, the broad scope of the review question, and the purpose of the review.

In this scoping study, Arskey and O'Malley's recommended methodology was used, as further advanced by Levac et al. (2010). The work of Levac et al. was used to aid with the process of identifying the research question, adopt an iterative approach to study selection, and in drawing on qualitative thematic analysis techniques to categorise and report the data from included studies.

This approach involved five stages: (1) Identifying the research question/s; (2) Identifying relevant studies; (3) Study selection; (4) Charting the data; and (5) Collating, summarising and reporting the results. The methods described in 3.2.2 to 3.2.6 follow this approach.

3.2.1.1. Terminology

Methodologists note that terminology regarding reviews that aim to scope and map existing evidence is inconsistent (Levac et al., 2010; Peters et al., 2020). Arksey and O’Malley's methodological framework (2005) refers solely to ‘scoping studies’. However, Levac et al.'s advancement of this methodology refers interchangeably to 'scoping studies' and 'scoping reviews', with 'scoping studies' used more frequently (2010). Peters et al. (2015, 2020) draw heavily on both of these papers in their methodological guidance papers, and indeed they refer to Arksey and O’Malley’s 2005 paper as “the first framework for scoping reviews” (p.141). However, they refer interchangeably to ‘scoping reviews’ and ‘systematic scoping reviews’ in their early work, and later only to ‘scoping reviews’, as they expect *all* reviews to be systematic. This understanding that, despite shifting language, Peters et al.’s work discusses the same methodology as both Arksey and O’Malley and Levac et al. is mirrored in Tricco et al.'s (2018) PRISMA reporting extensions for scoping reviews. This states, “The Joanna Briggs Institute (JBI) published a guidance document for the conduct of scoping reviews [i.e., Peters et al.] based on earlier work by Arksey and O'Malley (and Levac and colleagues” (no page number). This suggests that all four papers refer to the same methodological approach but adopt different language to describe this approach.

Therefore, I found it necessary to make a conscious decision regarding how to refer to the methodology used in this chapter. Arguably, the term ‘scoping review’ may be clearer, as the activity undertaken is indeed a review of the existing evidence, and some may expect a ‘study’ to indicate a piece of primary research. Additionally, Tricco et al.’s reporting standards checklist begin with the recommendation that researchers identify their study as a ‘scoping review’. However, the methods I have used are based on the work of Arksey and O’Malley (2005) and Levac et al. (2010), making it more appropriate to use their language. Therefore, throughout this thesis I refer to the work in this chapter as a ‘scoping study’, but frame ‘scoping studies’ as a type of systematic review. However, this approach does create tension with the adoption of the PRISMA extension for scoping reviews, which I discuss in more detail in the reflection section of this chapter (section 3.5).

3.2.2 Identifying the research question

As suggested by Levac et al. (2010), I created a predefined scope of inquiry to help drive the search strategy and define the research question for this scoping study (table 1).

Table 1: Predefined scope of inquiry

Concept definition	Tiredness-related side effects of antipsychotics. A broad definition to include: sedation, fatigue, tiredness, drowsiness, sleepiness, excess sleep, somnolence
Population definition	People taking antipsychotics long-term for a mental health problem. Any antipsychotic to enable a mapping of the scope of the literature. Long-term to focus on people for whom side effects may limit their ongoing well-being and recovery. People with a mental health problem to exclude children, people taking antipsychotics for dementia, pain, management of neurodivergent difficulties, people who are in in-patient settings; these people may have different experiences of the importance of the side effects, its impact on their lives, and/or how the side effect may be managed.
Health outcomes of interest	1. Management strategies: how do people reduce or cope with experiencing tiredness-related side effects? 2. What is the nature of the above evidence, e.g., how was the research undertaken, and what assumptions and terminology did the researchers utilise?

Levac et al. (2010) further suggest considering the purpose of the scoping study when writing the review question. In this scoping study it was the intention to summarise the extent, range and nature of the existing literature regarding TRSEs and to map and identify gaps within that literature in relation to management of/coping with TRSEs, with the goal of informing the design of future research. The objectives of the scoping study were to:

1. Describe and map how researchers think about, design, and undertake research regarding tiredness-related side effects, including methodology and terminology (nature of the existing evidence).
2. Describe and map existing evidence regarding managing and coping with TRSEs.

Therefore, the finalised research question for this scoping study was: *What are the experiences of adults living in the community who are prescribed antipsychotics for mental health conditions* *and report tiredness-related side effects?: A scoping study mapping the nature of the evidence and potential management and coping strategies.*

3.2.3 Identifying relevant studies

Arksey and O'Malley (2005) highlight the importance of undertaking as comprehensive a search as possible, but to balance this against practical considerations regarding time, scope and language. I worked with a Lancaster University faculty librarian to design searches meeting these criteria. Together we selected the two concepts of "antipsychotic drugs" and "tiredness related side effects" to search. Restricting search terms to two concepts returned a larger number of search results, requiring more screening. However, we considered this approach appropriate in order to ensure studies relevant to this broad review question were not accidently missed during the search. We searched synonyms for the two concepts at key term, title and abstract level in Medline, CINAL, PsycINFO and EMBASE. Appropriate databases to ensure capture of the extent of the literature were selected with the help of the faculty librarian's expertise. Additionally, forward and backwards citation searches were conducted on included studies, and forward citation searches using Google Scholar. Searches were conducted on 5th April 2021, and an example search strategy from one database is presented in appendix B.

3.2.4 Study selection

Full search results were imported into the Rayyan reviewing software (Ouzzani et al., 2016) and de-duplicated by hand with the aid of this software. I then screened results at title, abstract, and full text level. To increase the rigour of the scoping study, all full text screens were dual screened by a PhD supervisor (JS) and any inconsistencies were resolved by conversation and agreement (Levac et al., 2010). Screening involved applying the inclusion and exclusion criteria below.

3.2.4.1 Inclusion and exclusion criteria

As recommended by Arksey and O'Malley (2005), inclusion and exclusion criteria were defined at the outset, with a focus on breadth rather than depth. Due to the nature of the scoping study, some of the execution of these concepts was refined iteratively during the study selection process (Levac et al., 2010). Table 2 outlines the inclusion and exclusion criteria for the nature of the evidence and for management/coping strategies. To address the first aim of the scoping study (describing and mapping the nature of TRSE evidence) I included studies that investigated coping/managing TRSEs and also studies that addressed long-term prevalence of TRSEs, and the impact of TRSEs on those who experience them. Through this, I aimed to create a more thorough and detailed understanding of how researchers approached TRSEs. Initially, I had intended that the participants in all included studies would be long-term antipsychotic users, thus closely reflecting the target population for the empirical study in this thesis. However, search results demonstrated that the majority of studies did not report on the length of time participants had been using antipsychotics. Therefore, this requirement was removed for all studies apart from those addressing prevalence, as prevalence is inherently a time-bound concept.

Table 2: Inclusion and exclusion criteria

Inclusion	Exclusion
Participants with long-term antipsychotic use APPLIED TO PREVALENCE STUDIES ONLY. Long-term was defined as taking antipsychotics for twelve or more months. Pilot search results showed that effectiveness and efficacy trials reported prevalence during the trial, rather than at specific time point(s). Therefore, for randomised controlled trials, this was actualised as the study being twelve or more months in length. For all other prevalence studies participants needed to have been taking antipsychotics for twelve months or more.	**Participants taking antipsychotics for less than twelve months** APPLIED TO PREVALENCE STUDIES ONLY.
Participants taking antipsychotics for a mental health problem e.g. diagnoses of depression, anxiety, psychosis, schizophrenia, bipolar disorder, personality disorders.	**Participants taking antipsychotics for reasons other than a mental health problem:** e.g., pain, dementia, Parkinsons, behaviour management, neurodiversity, palliative care, neuro-development disorders, delirium, difficulty sleeping.
Adult participants eighteen or over. If a mixed sample, over 50% of the sample needed to be adult.	**Participants under 18 years of age**
Participants living in the community. Living in the community was deemed important, as (1) it was assumed the relative impact and importance of TRSEs on a person in recovery/remission would be different for people who were hospitalised; and (2) it was assumed that those living in the community would have more control over their responses and management of TRSEs. For mixed samples, over 50% of the sample needed to be living in the community. Residential homes to be classified as "living in the community".	**Participants who are hospitalised, or located within an in-patient setting, hospice, nursing home,** or other setting where the impact or management of side effects may differ from living in the community. Where the setting is not reported and cannot be inferred from the study context, the study was excluded from the prevalence part of the review. Where setting was not reported for other review outcomes the study was included.
Participants taking antipsychotics Any antipsychotic(s).	**Participants receiving polypharmacy with other sedating or mental health drugs:** if this

	polypharmacy was less than 50% of the sample, then the study was included. Pilot searches showed that most studies reporting impact and management did not report polypharmacy. Therefore, for practical reasons this criterion was removed for these outcomes.
Outcomes reporting on prevalence, impact and/or management of tiredness related side effects, including drowsiness, tiredness, sleepiness, increased sleep, sedation, somnolence, fatigue. To include trial measures of "adverse events" and other measures of harm/safety.	**Outcomes related to other side effects.** Combined side effects (e.g. sedation and confusion) to be excluded. Post injection delirium sedation syndrome (a highly dangerous rapid response to an injected antipsychotic) is excluded as this would indicate immediate discontinuation of the antipsychotic.
Studies reporting primary research including randomised controlled trials, single arm trials, naturalistic trials, cross-sectional studies, case series. To empower a thorough understanding of the nature of existing evidence, quantitative, qualitative and mixed methods studies were all included.	**Systematic reviews, single case studies, commentaries, clinical opinions.**

3.2.5 Charting the data

As recommended by Levac et al. (2010), I developed a data extraction form to address which data should be extracted from included studies (appendix C). This ensured a common framework for extraction, improving the rigour of this scoping study (Arksey & O'Malley, 2005). The form allowed for different extraction based on the methodology of the included study and whether the study addressed prevalence, impact, and/or management. As with Levac et al. (2010), I found this stage overlapped the collating and summarising stage of the scoping study process, particularly in relation to qualitative data. I extracted data solo, because dual extraction was not feasible in this PhD study. No data confirmation or additional data sourcing was sought from study investigators or authors.

3.2.6 Collating, summarising, and reporting the results

Arksey and O'Malley (2005) suggest results should focus on both a descriptive numerical summary of the extent, nature, and distribution of the evidence, and a narrative summary, organised around themes or categories, such as categories of interventions. They suggest a consistent approach within each category, for example: a table summarising the characteristics of included studies, followed by a narrative commentary that includes contradictions and evidence gaps. Arksey and O'Malley make it clear that this process is not a synthesis or aggregation of existing studies, because no assessment of the generalisability, weight, or robustness/rigour of the evidence is made. However, they also note that the creation of this commentary requires an “analytical framework or thematic construction” (2005, p.27), which Levac et al. (2010) interpret as a “thematic analysis” (p.6). Levac et al. recommend provision of further clarity on this process, saying that, in their experience, this process is similar to qualitative data analysis techniques.

Within this scoping study, there was no attempt to re-analyse the data from included studies. However, there was a process of creating the categories in order to organise the reporting of results. In concordance with Levac et al., this felt similar to creating cross-case themes in qualitative research. I took the results from included studies and grouped them together according to how they overlapped or covered the same topic, and used the resulting groups to create the narrative categories or themes that Arksey and O’Malley (2005) describe.

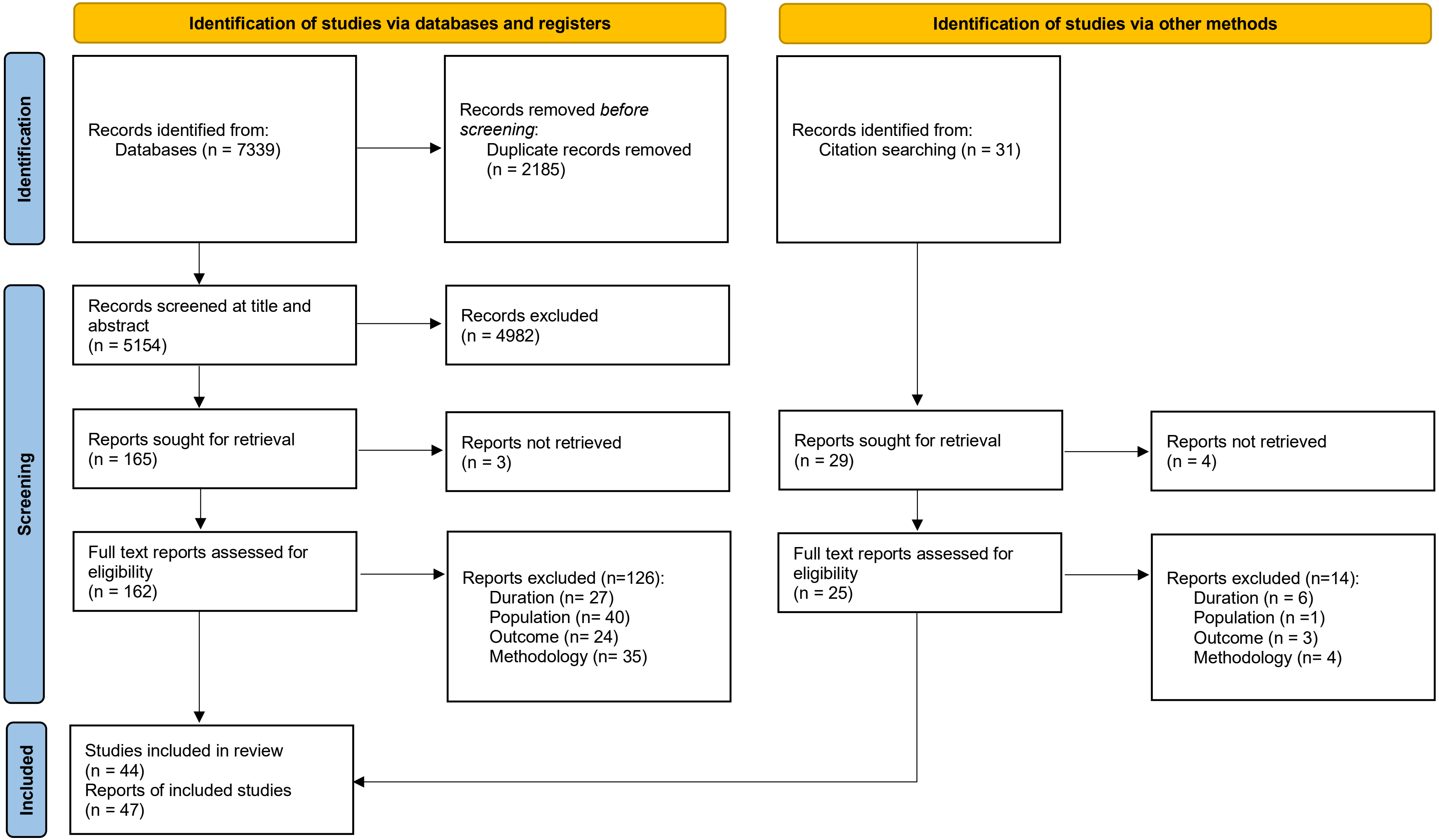
As suggested by Arksey and O’Malley (2005), the data extraction form acted as an initial framework for this qualitative construction of categories/themes. I undertook this process separately for each of the aims of the scoping study. For the aim of mapping management/coping evidence I created categories based on the type of intervention. For the aim of mapping the nature of the evidence, I created themes based on differences in how the authors of included studies treated or appeared to make assumptions about different TRSEs, different diagnoses, and different antipsychotics. For mapping the nature of the evidence, part of this process involved separating included study results that related to management/coping, those that addressed incidence/prevalence of TRSEs, and those that addressed the impact of TRSEs on those who experienced them. A reflection on this process can be found in section 3.5.

3.3. Results

3.3.1 Characteristics of studies

The search returned 7,370 results, of which 187 were screened at full text (see figure 1 PRISMA flowchart). Forty-four studies (47 reports) were included in this review. Thirty-four of these were quantitative, one was mixed methods, and nine were qualitative. All of these studies were used to map and describe the nature of the evidence.

Figure 1: PRISMA Flowchart.



Sixteen of these studies (seventeen reports) addressed the management of/coping with TRSEs. This results section comments on the nature of the evidence, and management of/coping with TRSEs.

3.3.2 Nature of the evidence

In addition to the sixteen studies regarding management of and/or coping with TRSEs, included studies also addressed the prevalence of TRSEs in long-term antipsychotic users, and the impact of TRSEs on those who experience them. I identified a large variety of approaches across included studies. Table 3 summarises the aims, brief methods, TRSEs of interest, included diagnoses, antipsychotics used, and outcome of interest for each included study. I identified two key themes/categories in relation to the nature of the evidence: terminology, and study design. These are discussed in more detail below.

3.3.2.1 TRSE terminology

Studies used a variety of terms that could be considered TRSEs, the three most common being sedation, somnolence, and fatigue. Only two studies offered definitions of the TRSE terminology used (Moncrieff et al., 2009; Morant et al., 2018), with Morant et al. creating this definition from a 'global state' of side effects described by participants. Some studies used terms interchangeably that other studies considered to be distinct concepts. For example, Makela et al. (2003) and Said et al. (2008) use 'sedation' and 'somnolence' interchangeably, whereas Kane et al. (2016) and McDonnell et al. (2014) treat these as separate concepts. Although 35 studies had some quantitative element, only 11 of the included studies utilised a validated measure to record TRSEs (see table 4). This variable use of terminology makes results difficult to compare across studies.

3.3.2.2 Study design

In many studies, TRSEs formed only a small part of the paper's scope; often the TRSEs represented were only a small portion of the study and outcomes reported. Thus, reporting of methodology in relation to the outcomes relevant to this review was often sparse. This makes it difficult to draw conclusions about the robustness and applicability of the evidence.

Two main approaches were used to describe which antipsychotics were included. One approach was to investigate or compare specific antipsychotics; this was most common in prevalence studies and quantitative management studies. The second approach was to include all antipsychotics and treat them interchangeably; this was more common among impact studies. This suggests tacit utilisation of opposing middle-range theories regarding how different antipsychotics might work (see background chapter, section 2.4.2). It also compounds difficulties in comparing results across studies.

Finally, included diagnoses followed a similar duality of approach. Some studies focused on individual diagnoses (usually, but not always, schizophrenia spectrum diagnoses); others treated diagnoses interchangeably. Although this is reflective of ongoing debates regarding the validity of mental health diagnoses (see background chapter, section 2.1), it again makes comparisons across studies difficult.

Table 3: Overview of included studies

Study	**Aim**	**Outcomes of interest**	**Methods**	**TRSE terminology**	**Diagnosis of interest**	**Antipsychotic of interest**
Achtyes et al. (2018)	*Assess patient attitudes towards antipsychotics and understand key factors about willingness to try a new medication*	Impact	Quantitative Cross sectional survey ranking importance of individual side effects	Measured tired/drowsy, but used this interchangeably with sedation in the text	*Schizophrenia; schizoaffective*	*Any antipsychotic*
Barbui et al. (2007)	*Investigate the sex differences in subjective tolerability of antipsychotics*	Prevalence	Quantitative Cross-section survey using LUNSERS	Tiredness; Difficulty staying awake; Sleeping too much	*Schizophrenia*	*Any antipsychotic*
Bessonova et al. (2020)	*Understand antipsychotic side effects, side effect burden, and perceived impacts of side effects on social functioning, adherence, and work*	Prevalence; Impact; Management	Quantitative Bespoke cross-sectional survey	Drowsy/tired	*Bipolar I*	*Any antipsychotic*
Bosch et al. (2018)	*Investigate the pharmacological treatment of long-term outpatients, how that treatment affects subjective quality of sleep, and whether gender differences exist*	Impact	Quantitative Pearson correlation of cross-section survey data and number of antipsychotics taken	Sleepiness (Epsworth Sleepiness Scale); Sleep quality (Pittsburgh Sleep Quality Index)	*Schizophrenia*	*Any antipsychotic*
Brooks et al. (2011)	*Evaluate the safety and*	Prevalence	Quantitative	Sedation	*Bipolar*	*Any atypical antipsychotic*

	tolerability of second generation antipsychotic polytherapy compared to second generation antipsychotic monotherapy in bipolar patients receiving open naturalistic treatment		Collection of adverse events during an observation of naturalistic treatment. Mean treatment: 21.4 months			
Carney (1984)	*No aim stated. A follow-up of patients treated with clopenthixol decanote*	Prevalence	Quantitative Collection of unwanted effects during a five-year trial	Drowsiness	*Schizophrenia*	*Clopenthixol*
Chartier et al. (2017)	*Better characterise patients receiving olanzapine pamoate and identify the conditions of use in real world-clinical practice*	Prevalence	Quantitative Collection of treatment emergent adverse events during two-year observation-al study	Fatigue (using MedDRA)	*Schizophrenia*	*Olanzapine*
Chaves et al.(2013)	*Compare effects of treatment with an atypical antipsychotic on quality of life and to document adverse effects*	Prevalence	Quantitative Mean severity scores of a cross-sectional survey	Increased duration of sleep; asthenia/lassitude/ fatigue; somnolence/sedation (UKU)	*Schizophrenia*	*Olanzapine vs risperidone*
Citrome et al. (2012)	*Evaluate the long-term safety and tolerability of lurasidone in the treatment of schizophrenia*	Prevalence	Quantitative Collection of treatment emergent adverse events during 12-month trial	Sedation; Somnolence	*Schizophrenia or schizoaffective*	*Lurasidone vs risperidone*
Cook & Hoogenboom (2004)	*Describe six case studies of patients who added on amisulpride to an existing (but reduced) clozapine dose*	Manage-ment	Case studies exploring the differences between clozapine, amisulpride, and both	Sedation/tiredness	*Schizophrenia; paranoid schizophrenia; schizoaffective disorder*	*Clozapine vs amisulpride*
Correll et al. (2016)	*Evaluate the safety and effectiveness of lurasidone in the long-term*	Prevalence	Quantitative Collection of adverse events during 22-month trial	Somnolence	*Schizophrenia*	*Lurasidone*

	treatment of patients with schizophrenia					
Davis et al. (2014)	*Characterise patterns and reasons for clozapine discontinuation in a public health system patient sample*	Manage-ment	Quantitative Extracted data from patient medical records	Somnolence	*Schizophrenia or schizoaffective (and considered treatment resistant or at significant risk of suicide)*	*Clozapine (and had interrupted usage for four or more days)*
Day et al. (1998)	*Investigate psychiatrists estimates of the prevalence and distress caused by the side effects of neuroleptics, and how these estimates affected their decision to inform patients about them. These were compared with patient side effect ratings*	Impact; Manage-ment	Quantitative Cross-sectional survey using LUNSERS to assess levels of distress caused by side effect	Sedation/tiredness	*Schizophrenia*	*Any antipsychotic*
Doane et al. (2020)	*Gather feedback regarding the treatment experiences of people who have taken antipsychotics in the last year*	Prevalence; Impact; Manage-ment	Quantitative Online cross-sectional bespoke survey.	Drowsy/tired	*Schizophrenia*	*Any oral antipsychotic*
El-Mallakh et al. 2012	*Evaluate the long-term efficacy and safety of aripiprazole monotherapy relative to lithium monotherapy*	Prevalence	*Quantitative* Collection of adverse events during 52-week study	Sedation; Fatigue	*Acute Bipolar I mania or mixed mania*	*Aripiprazole*
(Fakhoury et al. (2001); Wallace (2001)	*Elicit "sufferers'" perception of the effectiveness of their medication, distress caused by adverse effects and the impacts these might have on overall patient satisfaction with treatment:*	Impact	Quantitative Cross-sectional Linkert scale survey translated into a binary outcome	Sedation	*Schizophrenia or other psychosis*	*Any antipsychotic*

	identify from the patients' views the adverse effects that were most distressful, and investigate the relationship between extent of distress of adverse effects and patient satisfaction					
Freudenreich et al. (2009)	*Assess the tolerability and safety of modafinil as well as efficacy for negative and cognitive symptoms and effect on wakefulness and fatigue*	Management	Quantitative Eight-week pilot trial of modafinil vs placebo	Sleepiness; excessive daytime sleepiness (Epworth sleepiness scale); Wakefulness/fatigue (fatigue severity scale)	*Schizophrenia or schizoaffective*	*Clozapine*
Gaelbel et al. (2010)	*Investigate whether risperidone long-acting injectable would provide better effectiveness (time to relapse) than quetiapine*	Prevalence	Quantitative Collection of treatment emergent adverse events during two-year trial	Somnolence	*Schizophrenia or schizoaffective*	*Risperidone vs Quetiapine*
Hale et al. (2012)	Evaluate long-term safety and tolerability of sertindole treatment	Prevalence	Quantitative Collection of adverse events during an 18-month extension study	Somnolence; Fatigue	*Schizophrenia*	*Sertindole*
Hofer et al. (2002)	*Examine the influence of psychopathology, antipsychotic-induced side effects, and socio-demographic factors on attitudes towards antipsychotics*	Prevalence	Quantitative Cross-sectional survey	Sedation (UKU)	*Schizophrenia*	*Any antipsychotic*
Kane et al. (2016)	*Present analyses of safety and tolerability data*	Prevalence	Quantitative Pooled results from two long-term studies	Sedation; Somnolence	*Schizophrenia*	*Brexpiprazole*

Katayi (2014)	*Establish the relationship between antipsychotic side effects and their impact on patients' attitude and adherence*	Impact	Quantitative Cross-sectional survey	Sedation (GASS)	*Any diagnosis*	*Any antipsychotic*
Larsen & Gerlach (1996)	*Evaluate the attitude of patients on depot maintenance treatment to their treatment, side effects, mental state and quality of life*	Prevalence	Quantitative Cross-sectional survey	Sedation; Increased duration of sleep (UKU)	*Schizophrenia; paranoid schizophrenia; residual schizophrenia; hebephrenic schizophrenia; schizoaffective; simpli schizophrenia*	Ris(z)flupentixol decanoate; zuclopentixol decanoate; perfenazine decanoate
Llorca et al. (2017)	*Gain insight into the occurrence and burden of treatment emergent adverse effects associated with atypical antipsychotics*	Impact	Mixed methods Focus groups and interviews: people listed and ranked all the side effects they experienced	Sleepiness/excessive sleep/excessive sleepiness	*Schizophrenia; major depression*	Any atypical antipsychotic
Lohr et al. (2013)	*Assess the potential effects of modafinil on extrapyramidal symptoms, excessive daytime sleepiness, negative and cognitive symptoms in patients with schizophrenia or schizo-affective disorder, focusing on the first two*	Management	Quantitative Eight-week pilot trial modafinil vs placebo	Excessive daytime sleepiness (Epworth Sleepiness Scale)	*Schizophrenia or schizoaffective*	*Any antipsychotic*
Makela et al. (2003)	*Three case studies reporting use of modafinil to treat antipsychotic-induced sedation*	Management	*Case studies.*	Sedation, used interchangeably with sleeping too much/daytime somnolence/excessive sleepiness	*Schizophrenia*	*Clozapine*
McDonnell et al. (2014) (and post-hoc analysis	*Evaluate the long-term safety, tolerability, and effectiveness*	Prevalence	Quantitative Treatment emergent adverse events	Sedation; Somnolence	*Schizophrenia or schizoaffective*	*Olanzapine*

by Anand et al. (2015))	*of olanzapine long-acting injections*		during a 6-year trial			
Meehan et al. (2011)	*Establish the relationship between antipsychotic side effects and their impact on patients' attitude and adherence towards antipsychotic treatment*	Impact; Management	Quantitative Focus groups ranked side effects that had the highest impact on their functioning	Sedation/tiredness (GASS)	*Any diagnosis*	*Any antipsychotic*
Moncrief et al. (2009)	*Describe and compare the subjective effects produced by taking different sorts of antipsychotic drugs*	Impact	Qualitative Content analysis of internet database comments	Sedative effects, defined as including increased sleep, daytime drowsiness, fatigue, lethargy, difficulty waking	*Any diagnosis*	*Risperidone and olanzapine compared with older antipsychotics*
Morant et al. (2018)	*Explore service users' experiences of taking antipsychotics for psychotic disorders, and their perceptions of decision-making around this*	Impact; Management	Qualitative Thematic analysis of interviews	A global state characterised by lethargy, demotivation, and personality change, along with various physical complaints	*Schizophrenia; schizoaffective*	*Any antipsychotic*
Morrison et al. (2015)	*Understand people's lived experience of side effects resulting from antipsychotic medication*	Impact; Management	Qualitative. Content analysis of semi-structured interviews	Sedation	*Schizophrenia & bipolar*	*Any antipsychotic*
Morrison et al. (2000)	*Development of an educational intervention designed to explore attitudes and improve case managers' skills when assessing and managing antipsychotic side effects*	Management	Quantitative Pilot trial comparison of change in side effects between those people working with case managers receiving the new intervention and those not	Tiredness; Difficulty staying awake; Sleeping too much (using LUNSERS)	*Any. Sample mostly schizophrenia, but also included other psychosis, bipolar and psychotic depression*	*Any antipsychotic*
Prasuna & Sudhakar (2015); Sudhakar et al. (2008)	*Explore whether a non-amphetamine drug like modafinil would help in*	Management	Quantitative 12-week pilot trial of modafinil vs placebo	Quality of sleep; Daytime drowsiness (Excessive Daytime Drowsiness Scale)	*Any*	*Any atypical antipsychotic*

	reducing daytime drowsiness					
Ramos Perdigués et al. (2016)	*Understand factors associated with the number of hours sleep in clozapine treated patients and how efficient pharmacological strategies for decreasing sleeping hours*	Management	Quantitative Clinical records. Including Pearson's correlation of hours slept and dose	Sedation/hours slept (hours slept as a proxy for sedation)	*Schizophrenia spectrum diagnoses*	*Clozapine*
Read (2012)	*Provide a qualitative perspective on the limitations of antipsychotics as experienced by people with mental illness and their families*	Impact; Management	Qualitative Ethno-graphic study, including observations, interviews, visits and informal con-versations	Tired, fat, lazy, useless	*Any diagnosis*	*Any antipsychotic*
Read & Sacia (2020)	*Understand people's experiences with antipsychotics*	Impact; Management	Qualitative Thematic analysis of open-ended survey questions	Sedation	*Any diagnosis*	*Any antipsychotic*
Said et al. (2008)	*Examine the relationship between antipsychotic agents categorised by their potential for somnolence induction and the risk of unintentional injury*	Impact	Quantitative Using data from health insurance databases to calculate odds ratios of unintentional injury when taking different anti-psychotics	Somnolence/ sedation	*Schizophrenia; schizoaffective; depression; bipolar*	*Any antipsychotic*
Schennach et al. (2020)	*Examine the course of schizophrenia patients for two years after discharge*	Prevalence	Quantitative Two-year observational study	Sedation (using UKU)	*Schizophrenia including schizophreniform, delusional disorder and schizoaffective*	*Any antipsychotic*
Schreiner et al. (2014)	*Document prescribing patterns in clinical practice and assess long-term outcomes related to initiation of paliperidone*	Prevalence	Quantitative Adverse events during twelve months prospective study.	Fatigue	*Schizophrenia*	*Paliperidone vs other antipsychotics*

	ER compared to other oral antipsychotics in a naturalistic setting					
Sevy et al. (2005)	*Assess the effects of modafinil on fatigue, symptoms, attention, working memory, and executive functioning in schizophrenia patients treated with psychotropic medications*	Manage-ment	Quantitative Eight-week pilot trial of modafinil vs placebo.	Fatigue	*Schizophrenia*	*Any atypical antipsychotic*
Thompson et al. (2014)	*Understand the nature of caffeine use and its effect among individuals with schizophrenia; to better understand the subjective meanings associated with caffeine use among this group. Including motivations for consumption*	Impact	Qualitative Thematic analysis of semi-structured interviews.	Sedation/drowsy	*Schizophrenia; schizoaffective*	*Clozapine*
Windgassen (1992)	*Investigate how neuroleptic therapy is rated*	Impact	Qualitative Thematic analysis of interviews	Sedation	*Acute schizophrenia*	*Any antipsychotic*
Wubeshet et al. (2019)	*Assess the prevalence and management practice of side effects of first generation antipsychotics*	Prevalence	Quantitative Cross-sectional survey	Sedation (GASS)	*Schizophrenia*	*Typical antipsychotics*
Yusufi et al. (2007)	*Establish the nature and prevalence of side effects in patients prescribed clozapine maintenance treatment, and to*	Prevalence	Quantitative Cross-sectional survey	Sedation; Loss of energy. ANNSERS	*Schizophrenia or schizoaffective*	*Clozapine*

	examine the relationship between side effects and (i) clozapine dose and (ii) plasma concentration					

Table 4: Studies utilising a validated measure to record TRSEs

Scale name and authors	**Linkert**	**Tiredness related side effects captured**	**Studies using these scales.** *NB: some studies only reported prevalence of a side effect if it reached over a certain threshold, or only reported one side effect for unspecified reasons. Where this is the case the side effects reported are in brackets. Some studies reported using terminology that did not match that used by the validated scale. These are also recorded in brackets.*
Antipsychotic Non-Neuroleptic Side Effects Rating Scale (ANNSERS). (Ohlsen et al., 2008)	*Rate severity over the last month:* 0 = absent/no change 1 = mild 2 = moderate 3 = severe	Sedation (NB, version 2 of this scale replaces this with lethargy/lassitude); Daytime sleepiness; Loss of energy/drive	Studies reporting prevalence: Yusufi et al. 2007 (sedation, loss of energy)
Glasgow Antipsychotic Side Effect Scale (GASS). (Waddell & Taylor, 2008)	*How often have you experienced this side effect?* 0 = never 1 = once 2 = a few times 3 = every day *Level of distress caused by this side effect, (1= not very much, 10= very much)*	I felt sleepy during the day; I felt drugged or like a zombie	Studies reporting prevalence: Wuberschet et al. 2019 (sedation) Studies reporting impact of side effects: Katayi 2014 (sedation)
Liverpool University Neuroleptic Side Effect Scale (LUNSERS). (Day et al., 1995)	*How much have you experienced this side effect in the last month?* 0 = Not at all 1= Very Little 2 = A little 3 = Quite a lot 4 = very much	Difficulty staying awake; Tiredness; Sleeping too much	Studies reporting prevalence: Barbui et al. 2015 Studies reporting impact of side effects: Day et al. (1998) (tiredness) Studies reporting management strategies: Morrison et al. 2000
Udvalg for Kliniske Undersogelse Side Effect Rating Scale (UKU). (Lindström et al., 2001)	*Severity* 0 = Not present/as per average healthy person 1 = mild 2 = moderate 3 = severe	Sedation/somnolence; Asthenia/lassitude/fatigue; Increased sleep duration	Studies reporting prevalence: Larsen & Gerlach, 1996 (sedation & increased sleep); Hofer et al 2002 (sedation); Chaves et al. 2013; Schennach et al. 2020 (sedation)
Pittsburgh Sleep Quality Index (PSQI). (Buysse et al., 1989)	*Quality of sleep rated 0-21, higher score indicates worse quality of sleep.* Average global scores:	Quality of sleep	Studies reporting impact of side effects: Bosch et al. 2018

	Without a mental health problem: 2.67 (SD 1.70)		
Epworth Sleepiness Scale (ESS). (Johns, 1991)	*Likelihood of falling asleep during eight activities* Ranked on a 0-3 scale, giving an overall mark out of 24. 0 = would never doze 1 = sight chance of dozing 2 = moderate chance of dozing 3 = high chance of dozing Indicative 'normal' range for people without sleep disorders in the UK: 4.5 SD 3.3 (Chen et al., 1995)	Sleepiness/dozing	Studies reporting impact of side effects: Bosch et al. 2018 Studies reporting management strategies: Freudenreich et al. 2009; Lohr et al. 2013

3.3.3 Management strategies and coping responses

Eleven quantitative (tables 5 and 7) and five qualitative studies (table 6) reported possible management strategies for TRSEs. The methods, aims and population in these studies varied. I created four themes/categories of management/coping strategies. These were based on the type of management/coping strategy explored. Some qualitative studies discussed more than one strategy, thus appearing in more than one theme/category. These categories are explored in more detail below, but briefly comprise of:

1. Pharmaceutical solutions (nine quantitative studies, five qualitative studies)
2. Acceptance as a form of coping (two qualitative studies)
3. Professional support (one qualitative study)
4. Lifestyle changes (one qualitative study)

As a whole, this evidence suggests that there is not currently a viable pharmaceutical solution for addressing TRSEs. Included studies make some, underexplored, suggestions that acceptance may help with coping where they lack other viable strategies, and that lifestyle changes might help with the management/coping with TRSEs. It is unclear from these studies whether professional support may help the management of TRSEs.

Table 5: Quantitative studies reporting management strategies (other than modafinil)

Study authors and setting	**Aim**	**Methods Inc sample size**	**Diagnoses/antipsychotics included/TRSE**	**Theme** (relevant outcomes from included study) [scoping study category]
Bessonova et al. (2020), Online survey	To characterise the experiences of people with BD-I who had experience with an oral AP in the last year	Descriptive statistical analysis of bespoke survey with closed questions, including questions regarding impact of side effects. n=200	bipolar-I; any antipsychotics; drowsy/tired	**Increased likelihood of discontinuation or reduction** 66% of sample stopped taking APs, 48% of which was due to SEs, 25% of which was due to drowsy/tired. 52% of sample reduced dose, 47% of which was due to SEs, 25% of which was due to drowsy/tired. [pharmaceutical solutions]
Cook and Hoogenboom (2004), Australia	Describe six case studies of patients who added on amisulpride to an existing (but reduced) clozapine dose	Case studies exploring the differences between clozapine, amisulpride, and both n=6	Schizophrenia, paranoid schizophrenia, schizoaffective disorder; Sedation/tiredness; Clozapine vs amisulpride	**Amisulpride reduced TRSEs.** Adding to clozapine or replacing clozapine reduced hours slept and reports of tiredness, but one found increased symptoms. [pharmaceutical solutions]
Davis et al., (2014), USA	To characterise patterns and reasons for clozapine discontinuation in a public health system patient sample	Descriptive statistical analysis of medical record data n=320	Schizophrenia or schizoaffective disorder who were considered treatment resistant or a suicide risk and who had interrupted their clozapine for four or more days; somnolence	**Increased likelihood of discontinuation.** 3.13% discontinued due to somnolence [pharmaceutical solutions]
Doane et al. (2020), Online survey	To gather feedback regarding treatment experiences of individuals with schizophrenia who have taken an oral antipsychotic within the last year	Descriptive statistical analysis of bespoke survey with closed questions, including questions regarding impact of side effects. n=200	Schizophrenia; any antipsychotic; drowsy/tired	**Increased likelihood of discontinuation.** 56% of sample stopped taking APs, 67% of which was due to SEs, 21% of which was due to drowsy/tired [pharmaceutical solutions]
Morrison et al., 2000, Australia	Development of an educational intervention designed to explore attitudes and improve case managers' skills when assessing and managing antipsychotic side effects	Pilot trial: Comparison of sides effects between intervention and control arm, using LUNSERS n = 48 case managers, 44 antipsychotic users	Antipsychotic users; tiredness, sleeping too much, difficulty staying awake	**Educational intervention for professionals does not improve TRSEs**. The control arm had better outcomes than the intervention arm. [professional support]
Ramos Perdigués et al., 2016, UK	To understand actors associated with the number of hours of sleep in clozapine-treated patients	Pearson's correlation analysis of clinical records, including	Schizophrenia spectrum diagnoses; clozapine; hours slept as a proxy for sedation	**Reduced dose does not improve TRSEs.** 82% did not report any change in hours slept **Adding aripiprazole did not improve TRSEs.**

	and how efficient are pharmacological strategies for decreasing sleeping hours	hours slept and dose n=140		73.9% reported no change in hours slept. [pharmaceutical solutions]

Table 6: Qualitative studies reporting management strategies for TRSEs

Study authors and setting	**Aim**	**Methods** Incl.sample size	**Diagnoses/antipsychotics included/TRSE**	**Relevant findings from included study** [scoping study category]
Meehan et al., 2011, Australia	Identify the strategies perceived by consumers as helpful in the management of antipsychotic medication side effects	Descriptive statistical analysis of focus groups. Service users listed management strategies and ranked their usefulness on a scale of 0-10. n=48	People taking any antipsychotics; sedation/tiredness	*Antipsychotic users may be able to adjust their lifestyles to manage TRSEs [lifestyle changes]
Morant et al., 2018, UK	Explore service users' experiences of taking antipsychotics for psychotic disorders, and their perceptions of decision-making around this	Qualitative Thematic analysis of interviews n=20	Schizophrenia, schizoaffective; Any; A global state characterised by lethargy, demotivation, and personality change, along with various physical complaints	*Some antipsychotic users adjust medication to improve functioning. [pharmaceutical solutions] *However, many are disempowered to do this because they are fearful of symptom return or lack of agreement from clinicians [pharmaceutical solutions] *This may lead to people using acceptance as a coping mechanism instead. [acceptance as a form of coping]
Morrison et al., 2015, Australia	To understand people's lived experience of side effects resulting from antipsychotic medication	Content analysis of interviews, from this themes were devised n=10	Mental health consumers prescribed any antipsychotics and experiencing side effects	*Antipsychotic users switch antipsychotic to manage TRSEs. [pharmaceutical solutions] *Acceptance as a coping mechanism for TRSEs [acceptance as a form of coping]
Read, 2012, Ghana	Provide a qualitative perspective on the limitations of antipsychotics as experienced by people with mental illness and their families	Ethnographic study, including observations, interviews, visits and informal conversations. n=67	Tired/fat/lazy/useless; any diagnosis & antipsychotic	*Antipsychotic users stop using antipsychotics to improve functioning, but this sees a return of symptoms [pharmaceutical solutions]
Read & Sacia, 2020	To understand people's experiences with antipsychotic drugs	Thematic analysis of open-ended survey questions n=650 (19 mentions of sedation)	Sedation; any diagnosis & antipsychotic	*Antipsychotic users stop using antipsychotics to improve functioning [pharmaceutical solutions]

3.3.3.1 Pharmaceutical solutions

Pharmaceutical solutions included studies investigating whether the narcolepsy drug modafinil could successfully counteract TRSEs, the relationship between TRSEs and reducing/ discontinuing antipsychotic use, and changing the antipsychotic used.

Five quantitative studies explored whether taking modafinil reduced TRSEs (table 7). Although a case series of three patients suggested it might, four trials found that this approach was ineffective. Although these studies all had small sample sizes (*n* = 39, 72, 24, 24, with no commentary provided regarding whether this was appropriately powered), and addressed different antipsychotics, diagnoses and TRSEs, overall, there is no evidence supporting the use of modafinil in managing TRSEs.

Authors of these studies reported that experiencing TRSEs led to people choosing to discontinue or reduce antipsychotic use. Quantitative studies reported correlations between experiencing TRSEs and a reduction or discontinuation of antipsychotics; one of these reported this did not change the number of hours slept. Qualitative studies demonstrated that some people were choosing to reduce, discontinue or modify their antipsychotic use to manage TRSEs. However, some participants in studies in the UK felt unable to modify their antipsychotic usage to manage TRSEs, as they felt disempowered to act against the wishes of their clinicians or were worried about becoming unwell again. Additionally, participants in Ghana who did change their antipsychotic usage to manage TRSEs often became unwell again. Overall, although this suggests adjusting dosage may help manage some TRSEs, there are barriers that may make this approach impractical for some.

> *I did make a conscious effort a couple of times not to take it, because I knew I had quite a lot going on the next day, and I needed the energy… I knew I was going out during the day and I didn't want to be tired.*
>
> *I'd feel scared about stopping the medication because I'm scared of the hallucinations and the voices coming back*
>
> Morant et al., 2018, p.325

Studies described people either switching antipsychotic or adding an additional antipsychotic to manage TRSEs. Two of these investigated whether side effects improved. A case series found that TRSEs did improve, however, a study with a much larger population found no change. Therefore, current research is inconclusive as to whether this is a useful approach. Overall, these studies highlight there is not currently a viable pharmaceutical solution to addressing TRSEs.

Table 7: Studies reporting effectiveness of modafinil in reducing TRSEs

Study authors, setting (* highlights pharmaceutical funding)	**Population**	**Outcome (measures)**	**Methodology** Inc sample size	**Findings**
Freudenreich et al., 2009, USA*	People with schizophrenia/schizoaffective diagnoses taking clozapine	Sleepiness (Epworth Sleepiness Scale); Fatigue (Fatigue Severity Scale; Visual analogue scale of fatigue)	Double blind, 8-week, placebo controlled, flexible dose pilot trial. Sample size: 39: modafinil 16; placebo 19. Dropouts: 2.	**No significant effect of modafinil on wakefulness/fatigue.** ESS improved non-significantly more in the placebo group.
Makala et al., 2003, USA	People with schizophrenia taking clozapine	Sedation including excess sleep, daytime somnolence	3 case studies	**Reduction in hours slept, improved quality of life and self-image.**
Prasuna & Sudhakar 2015; Sudhaker et al., 2008, India	People taking atypical antipsychotics for less than two weeks, irrespective of diagnosis.	Quality of sleep (visual analogue scale of sleep quality); daytime drowsiness (Excessive Daytime Drowsiness Scale; Visual analogue scale of daytime drowsiness).	randomized, double-blind, 12-week, placebo-controlled study of 200mg of modafinil. Sample size: 72. dropouts: 9. Within the intervention group headaches and trouble falling asleep were main reasons for withdrawal.	**Modafinil did not improve quality of sleep; results in relation to excessive daytime drowsiness were inconsistent.** Statistical details are not reported. In both arms visual analogue quality of sleep improved "significantly". However, daytime drowsiness visual analogue increased in the placebo arm, but decreased in the modafinil arm. This result was not reflected in the excessive daytime drowsiness scale. Adverse effects: mild in intensity: Headache, disturbed sleep, mild gastro-intestinal disturbances, agitation, decreased appetite, exacerbation of psychosis.
Sevy et al., 2005, USA	People with schizophrenia/schizoaffective diagnoses taking atypical antipsychotics	Fatigue (CGI-severity of illness and CGI-improvement subscales, the fatigue severity scale (FSS) and a 10cm visual analogue fatigue scale (VAFS global rating of fatigue from 0 (worst) to 10 (normal, no fatigue))	Double blind, 8-week, placebo controlled, flexible dose (up to 100 mg) study. Sample size: 24: modafinil 13; placebo 11.	**Little difference between arms**
Lohr et al., 2013, USA*	People with schizophrenia/schizoaffective diagnoses taking any antipsychotic.	Excessive daytime sleepiness (Epworth	Double blind, 8-week, placebo controlled, trial.	**No statistically significant effect on daytime sleepiness.** Adverse effects: 1 person with increased paranoia in modafinil

		Sleeping Scale)	(50mg day 1, 100mg day 14, 200 mg day 28. Decreased if not tolerated.) Sample size: 12 per arm	group, 1 person increased delusions in placebo group, "one or two" people in each group neck/hip/back pain, heartburn, diarrhea [sic], skin rash or hypotension. Blood pressure rates higher in the modafinil group, but not clinically significant.

3.3.3.2 Acceptance as a form of coping

Studies reported some people using acceptance as a coping strategy for dealing with tiredness related side effects. The study authors suggested that this was sometimes demonstrated by participants using downplaying language, for example describing antipsychotics that resulted in excess sleep as "a very mild tranquilizer [because he only required] 12 hours sleep a day" (Morrison et al., 2015, p.256).

This may have been due to a sense of being disempowered to stop taking antipsychotics, either by lack of control and feeling 'forced' to take antipsychotics, or because taking antipsychotics was the "least worst option" (Morant et al., 2018, p.324). This suggests that acceptance may not be antipsychotic users' preferred management approach.

> *You have to adjust your mind, as I said, like it's getting to me. It got to me like I was really angry not like aggressive or nothing, but just annoyed that no one listens. And it just got to the stage that you're going to have to retrain your brain. They are not going to listen to you and you just gotta take this injection and make the most of what life you've got. It's not much of a life but you've got to make the most of it.*
>
> Morant et al., 2018, p.326

3.3.3.3 Professional support

One study reported on a pilot trial of an educational training intervention designed to help case managers support those experiencing side effects. This pilot trial did not show an improvement in TRSEs due to the intervention. However, as the study authors did not detail the intervention in their paper, and as the pilot trial involved a small sample size, it is hard to draw conclusions as to whether professional support in dealing with TRSEs is always likely to be unsuccessful.

3.3.3.4 Lifestyle changes

One study asked antipsychotic users to list and rank the usefulness of TRSEs' management strategies. These consisted of lifestyle changes such as planning exercise, medication, meal and bedtimes, having a reason to get up, and positive thinking. This offers some indication that people might form their own ways to manage TRSEs, but does not offer insights into how these strategies might be created or whether they work the same for all people experiencing TRSEs.

3.4 Discussion

The purpose of undertaking this scoping study was to inform and justify the planning of the empirical study in this review. As such, my aims were to describe and map how researchers think about, design, and undertake research regarding tiredness-related side effects, including methodology and terminology (nature of the existing evidence); describe and map existing evidence regarding managing and coping with TRSEs. Below I place the scoping study findings in the context of this overarching purpose.

The results of this scoping study are useful when designing future research in this area, including the design of the empirical study in this thesis. There is a large body of research in the area of TRSEs, however this evidence demonstrates a lack of cohesive approach and definitions within specific TRSE research. The duality of approach, both in relation to whether the type of antipsychotic and/or the person's diagnosis is important when researching TRSEs, has important implications for the design of future research. Researchers may benefit from explicitly stating their positioning in their methodology or introduction, i.e., why and whether their research is transdiagnostic or diagnostic focused; whether and why their research focuses on one/two antipsychotics, treating each antipsychotic differently; or treats antipsychotics as an interchangeable group. The approach of including people with all mental health diagnoses and using all antipsychotics has been adopted in the design of the empirical study within this thesis (see chapter 4). Discussions regarding different understandings of diagnosis, mechanisms of action of different antipsychotics, and evidence regarding different antipsychotics having different TRSEs profiles are covered in the background chapter in sections 2.1, 2.4.2, and 2.5.2.

The review of the nature of the evidence also highlighted a lack of coherence regarding whether terms such as 'sedation', 'fatigue', 'tiredness', 'drowsy' represent distinct concepts. This includes a scarcity of definitions of concepts within existing research. Researchers in this area would benefit from stating clearly the concepts they are researching, including sharing definitions with those from whom they collect data. In this thesis I have adopted this approach by creating and clearly defining the concept of 'tiredness-related side effects' (section 2.5.1) and sharing this definition with each participant at the beginning of the data collection process.

Despite the large body of evidence investigating TRSEs, only a small portion of this evidence investigates the management of/coping with TRSEs. This suggests that the area remains relatively underexplored. The majority of this evidence explores the use of pharmaceutical solutions, including changes to antipsychotic medication. Notwithstanding the lack of quality assessment in this review, this evidence suggests limitations to this management strategy. There is some indication that lifestyle changes and coping strategies such as acceptance may be useful in managing TRSEs, but how these might be created, if they require individualising, and what it is like for antipsychotic users to deploy them, is unclear. It is also currently unclear where mental health professionals may be able to play a useful role in helping antipsychotic users form and deploy these strategies. This highlights a clear need for research which may help people manage or cope with TRSEs, including what strategies people use, what these are like to use, and who they work for and how. The empirical study in this thesis has been designed to address this evidence gap.

3.4.1. Strengths and limitations

A strength of this review is the thoroughness of approach: the comprehensive search of the literature, and inclusion of all types of empirical study. The detailed description of the review process both adds to the replicability and rigour of this review.

A necessary limitation of this review was that the included evidence was not systematically assessed for quality. This limits the use of findings to those making clinical decisions, and some scoping studies that are interested in making clinical recommendations do undertake quality assessments (Daudt et al., 2013). However, for the primary purpose of this review, such a quality assessment was unnecessary. Due to the quantity of the included literature, synthesised data was based solely on the information published; no attempt to contact authors for clarifications was made.

3.5. Reflexivity

Planning and undertaking the review reported in this chapter was challenging. Conversations with clinicians and researchers, particularly those less familiar with transdiagnostic thinking (see section 2.1), made it clear that I would need a justifiable approach to which diagnosis/es and which antipsychotic(s) I aimed to include in my empirical study. Some people also suggested that tiredness and sedation were clearly defined and separate concepts, suggesting it would be best to focus on one and not another. Using this review to understand what choices to make in the planning of the empirical study created a considerable investment of time and knowledge development.

Articulating the approach used within this chapter also proved difficult. Although I knew I had followed the processes discussed by Arksey and O'Malley, (2005) and Levac et al. (2010), variations in use of language between methodologists made communicating what I had done difficult. This included, but was not limited to, the discussion regarding whether 'scoping reviews' differ from 'scoping studies', and which term to use (see section 3.2.1.1). For example, both Arksey and O'Malley (2005) and Levac et al. (2010) refer to the process of collating, sorting and organising included results as akin to qualitative analysis. Indeed, Arksey and O'Malley refer to the creations of 'themes', and acknowledge, like other qualitative analysis, that researcher assumptions and biases might affect the ordering of these 'themes' (see section 3.2.6). Certainly, the process by which I grouped categories of included data, particularly where looking for patterns in the nature of the evidence, felt reminiscent of qualitative cross-case analysis. However, Peters et al. (2015, 2020) clearly state that the process of charting, summarising and reporting the data does not include qualitative analysis. Additionally, arguably, qualitative researchers familiar with other review styles, such as realist synthesis or meta-synthesis, might expect a 'qualitative analysis' in a review to involve re-analysing included data. This meant that my initial version of this chapter was confusing and required much re-writing to aid clarity. Notwithstanding the edits made for this final version, there remain some challenges that do not feel possible to fully resolve, such as the use of the 'scoping review' PRISMA checklist whilst retaining the 'scoping study' terminology.

3.6 Conclusions

Reviewing the existing evidence suggests understandings of management strategies and coping responses for TRSEs are limited if people did not want to change their antipsychotic use. Changes to antipsychotic use may also be of limited use as they may be inaccessible to some, and/or cause relapse of symptoms. Existing studies suggest that lifestyle changes may help people manage TRSEs, but this is currently under-explored and effectiveness has not been measured in a fully powered randomised controlled trial. It is also unknown how these strategies might be formed, how they might work for different individuals, and what the experience of using them is like. Researchers looking to undertake research regarding TRSEs should be aware of current debates as to whether diagnosis and specific antipsychotic is important, and clearly define which TRSE(s) the study focuses on. These findings highlight the evidence gap addressed by the empirical study in this thesis, and have informed the design and methodology of the empirical study, as described in detail in the next chapter.

Chapter 4: Methodology and methods

In this chapter I explore the methodology and methods used within the present thesis. I begin with an exploration of my research paradigm, including positionality, ontology, epistemology, phenomenology, and methodology. I then detail the methods used to conduct the thesis, including data collection, analysis, participant recruitment, quality and reflectivity. Finally, I review the ethical considerations within the empirical study, including ethical approval, participant safety, and informed consent.

4.1 Research paradigm

A researcher's philosophical stance, or research paradigm, can be understood as the position from which they conduct research; it affects what research they think is important, how they undertake that research, and their expectations regarding the purpose and content of their findings (MacKenzie & Knipe, 2006). Therefore, in order to understand the appropriateness of the methodology and methods used within this thesis, it is first necessary to explore the research paradigm under which I conducted this work. Although different conceptualisations exist, for the purposes of this thesis a research paradigm can be understood to include the ontological, epistemological, and methodological assumptions a researcher makes (Weaver & Olson, 2006).

4.1.1 Positionality

In order to understand my assumptions and choices in my personal research paradigm, it is useful to note my personal positioning within mental health research. Therefore, this section begins with this positionality statement. It must be acknowledged that a researcher's world view will impact what research they undertake and how (Holmes, 2020). Consequently, to ensure transparency, it is important to note my position as the researcher in this thesis. As mentioned in chapter one, a researcher's positionality can be understood to include their identity, experiences, views, and standpoints. As also mentioned in the introduction chapter (section 1.1), I was drawn to this research topic because my close friend and housemate was taking antipsychotics and experiencing TRSEs that made their day-to-day life more challenging, and was offered no support on approaching clinicians with this problem. When working as a research assistant recruiting participants with diagnoses of severe mental illnesses to an unrelated study, conversations with other people using antipsychotics made it clear that my friend's experiences were not isolated, helping to consolidate this idea as a research topic. This close personal experience has impacted on my choice of research topic and philosophical position within this research. It is important to me that the experiences of people with mental health problems are acknowledged and explored directly with people experiencing them, rather than undermined or explored via clinicians' or others' experiences or words. It is also my assumption that the purpose of research in this area is to improve the lives of and/or care and support provided to people with mental health problems.

4.1.2 Ontological and epistemological position: critical realism

Ontology can be defined as the nature of reality and epistemology as the nature of knowledge, i.e. what is acceptable knowledge, or what can be known and how (Bunniss & Kelly, 2010; Crossan, 2003). Ontological positions are often split into positivist/realist and constructivist positions. The former is the assumption that there is one single, objective, knowable and 'real' reality. The latter is the assumption that reality is subjective, and we all have our own interpretations of it. Mixed positions also exist, for example: there is one real objective reality, but that we all understand it through individual subjective lenses (Bhaskar, 2014; Bunniss & Kelly, 2010). Epistemological positions are similarly split: knowledge needs to be observed empirically via the senses, can only be understood rationally via reasoning (interpretivism), or a mixture of both (Bhaskar, 2014; Bunniss & Kelly, 2010).

As a mental health researcher whose motivation lies in improving the lives of people with mental health problems, my ontological and epistemological position is mixed. The key components of mental health problems (see background chapter, section 2.1) can be understood to be inherently constructivist and interpretivist in nature: understanding a person's 'distress' can only be achieved subjectively, either via the person experiencing the distress, or through the lens of an observer. 'Disturbances in thinking/behaviour' are subjectively defined against a set of socially constructed normative behaviour, for example, one person's 'delusional voice hearing' is another's 'hearing the voice of God' (Moseley et al., 2022; Thompson, 2021). Within this thesis, this is compounded by the subjective nature of 'tired'. However, the early deaths, suicides, poor physical health, unemployment, financial and housing challenges people with mental health problems experience (Chan et al., 2023; Mason et al., 2024; National Mental Health Intelligence Network, 2023; Yang et al., 2024) are objective and real. Additionally, the actions one takes as a response to a voice others cannot hear, or the distress one feels, may still be empirically observable. Furthermore, a purely interpretivist approach makes it very challenging to create and utilise knowledge in a way that can be used to improve the lives of people with mental health problems: although distress and disturbances in behaviour compared to the norm are subjective, they are real to the person experiencing them and have real effects that are possible to observe empirically (Pilgrim, 2014, 2017).

Critical realism mirrors this philosophical position: from an ontological perspective there is an objective reality, but what we can know about reality can be derived both from empirical observation and via reasoning (Bhaskar, 2014). Bhaskar helps us think about the difference between observed events (the 'empirical'), the full available range of events that occur regardless of whether they are observed (the 'actual'), and the full range of events, objects and structures, and causal powers within actual and perceived events, objects, and structures (the 'real'). Here, the 'actual' plane encompasses the 'empirical' plane, but not the 'real' plane; the 'real' plane encompasses both the 'actual' and 'empirical' planes. For mental health research this 'generative ontology' allows us to explore the empirically observable (e.g., poor physical health outcomes, suicides, unemployment, tiredness, weight gain). However, it is also acknowledged that the observed is unlikely to capture the full range of experiences. For example, people may not be reporting TRSEs, or if one only recruits research participants who have discontinued antipsychotics this is unlikely to reflect the full range of experiences. Furthermore, the full extent of reality includes the unobservable and intangible. For example, antipsychotic users' perceptions of clinicians' potential responses to requests to discontinue antipsychotic use). Therefore, due to the ability to explore questions in relation to mental health problems in this nuanced way, this thesis has been conducted from a critical realist perspective.

4.1.3 Exploring first person experiences: Phenomenology

4.1.3.1 Overview of phenomenology

Phenomenology can be understood to be the study of consciousness and conscious experience from a first person perspective (Davidsen, 2013). Although not mentioned in the above definitions of research philosophical positions or paradigms, it is considered a philosophical discipline or movement, in the same way that epistemology (study of what can be known), ontology (study of what is the nature of reality), ethics and logic are. As such phenomenology is not necessarily considered an ontological or epistemological position, such as positivist, constructionist, or critical realist. However, adopting a phenomenological position will still affect a researcher's paradigm, including what research they conduct and how they choose to conduct it.

Phenomenologists study the structure of various experiences, including perception, thought, memory, imagination, emotion, desire, action, social activity, and linguistic activity. Husserl, considered to be the principle founder of phenomenology, argues that this should involve an element of intentionality: experiences/conscious are directed towards something (e.g., an object, event, tool, time, self, or others) (Husserl, 1963). This should involve studying first person experiences, focused on the subjective experience of that person. Heidegger, initially a student of Husserl's, who further expanded phenomenology and also integrated some key concepts from hermeneutics, uses hermeneutics to interpret these first person experiences in a social and linguistic context (Heidegger, 1982). Hermeneutics is the study of interpretation, originally used for religious texts. In the context of this thesis, this consists of the experience of TRSEs, and the experience of managing/coping with TRSEs, via my interpretation of participants' language.

4.1.3.2 Congruence of critical realism and phenomenology

There is some debate about whether critical realism and phenomenology are philosophically congruent. Some consider phenomenology to have, or even be, an inherent epistemological position (Lloyd & Antonino, 2022; Zahavi, 2018), understanding that worthy knowledge is that which is derived from human subjectivity (Giorgi, 2005). Notwithstanding this, it is argued by others that critical realism and phenomenology can be successfully combined (Budd, 2012; Sherman, 2025). Regardless, adopting a phenomenological position has implications for ontological and epistemological assumptions. Therefore, to adopt a phenomenological approach for this study it was necessary to explore whether this was congruent with the epistemological and ontological position of critical realism. The focus on subjective first-person experience implies an assumption that we all have different subjective understandings of reality; indeed, Husserl considered it impossible to separate the person having the experience from what is experienced, and, as above, Giorgi considers knowledge to be derived from human subjective experience. This is not incompatible with critical realism: although critical realism assumes an objective reality, the use of the 'empirical' and 'actual' planes acknowledges different subjective understandings of reality, and allows us to explore and utilise these understandings, but cautions us in confusing these with the objective 'real' plane of all that does exist. The phenomenological focus on consciousness, and Heidegger's interpretation through hermeneutics, suggests an epistemological position that knowledge is generated through reasoning, albeit that this reasoning is based on observation of sensory experiences. This is compatible with critical realism, which acknowledges both empirical observation and reasoning. Types of experience that are deemed worthy of study by phenomenologists include those which are intangible and consisting of internal events (perception, thought, memory, imagination, desire), those empirically observable (action) and those empirically observable but only given meaning by individuals and/or society (linguistic activity, social activity). This combination could be seen to be reflected in Bhaskar's understanding of what is 'real': not just observable events and objects, but also structures, concepts and perceptions with causal power. Therefore, I understood undertaking this thesis from a phenomenological position, within a critical realist ontological and epistemological paradigm, to be philosophically congruent.

4.1.3.3 Implications of phenomenology for thesis design

This positionality had several implications for the design of this thesis. Firstly, it solidified the focus on *first person experiences* of those who have TRSEs. Within the scoping study this was enacted via inclusion criteria: the experiences of, for example, clinicians and carers, were excluded. Within the empirical study this was enacted by methodological choices: interpretative phenomenological analysis (IPA) was used to explore first person experiences in context to do justice to the phenomenological position, with a critical realist lens to ensure findings acknowledged Bhaskar's three planes of reality. This methodological approach is discussed in more detail below, including section 4.2, in which I outline debates regarding the extent to which IPA is congruent with both phenomenology and critical realism.

4.2 Methodology

Methodology can be defined as how one might discover or create knowledge (Bunniss & Kelly, 2010; Crossan, 2003). Methodological approaches are often broadly categorised as quantitative, qualitative, and mixed methods. Choice of methodological approach is expected to be congruent with epistemology and ontological approaches: what can be known directly affects how you can know it, what can be known should be based on the assumed nature of reality (Bryman, 2016; Bunniss & Kelly, 2010). Generally, it is expected that objective reality can be empirically observed via analysis of quantitative data; subjective reality is best understood by interpreting detailed qualitative data (Bryman, 2016; Bunniss & Kelly, 2010). However, as a critical realist position considers both empirical observations and reasoning to contribute to knowledge, both quantitative and qualitative data are acceptable, and choices should be based on the nature of the research question (Bunniss & Kelly, 2010). The primary objective of this thesis was to explore people's experiences, including how they coped and what management strategies they deployed, what this felt like, and how and why they deployed these coping and management strategies. These are inherently questions about detailed reasoning, and are therefore best explored qualitatively (Bryman, 2016; Creswell & Creswell, 2018; Offredy & Vickers, 2010). However, in the scoping study I looked to explore what is already known about tiredness-related side effects: how other researchers have approached this topic, and existing evidence regarding management and coping strategies. This can be understood to be a mixture of empirically observable (nature of the research, prevalence, numerical understandings of how many people experience the impacts, and effectiveness of management strategies) and rationally reasoned (the nature of impacts, the nature and deployment of management strategies), all of which are viewed through the rationally reasoned lens of *'what does this mean for the empirical study I intend to conduct'*. Therefore, the scoping study includes quantitative, qualitative, and mixed methods studies, with some, limited, qualitative reasoning utilised in the creation of the categories used to summarise and report these studies (see sections 3.2.6 and 3.5). The methods used for the empirical study are explored below in this chapter, the methods used in the scoping study are explored in chapter three.

4.2.1 Interpretative phenomenological analysis

Although it was clear that qualitative data collection and analysis was the most appropriate approach for addressing the empirical research question within a critical realist and phenomenological paradigm, it was still necessary to identify the most appropriate qualitative approach. The plethora of qualitative methodologies and methods render it impossible to explore all approaches that would have been acceptable for conducting the empirical study.

The approach used needed to be appropriate for examining first-hand subjective experience (phenomenological exploration), while also being appropriate for exploring differences and reasons for differences between the subjective experiences in individual cases (Bhaskar's empirical plane with exploration/acknowledgement of the actual and real). The experience being explored is tightly defined: having a mental health problem, taking antipsychotics, and having sufficient agency and wellbeing to act with intent, while reasoning and responding with management and coping. Therefore, the approach needed to be designed for exploring narrow experiences of reasoning with intent within a complex social context. This section explores why Interpretative Phenomenological Analysis (IPA) was considered appropriate for the empirical study within this thesis. The process of IPA, including its use within this specific study and the implications for generalisability/transferability and quality, are discussed later in this chapter, in section 4.3.

Critical realism is not prescriptive regarding methodology and methods (Bhaskar, 2014), meaning philosophy-free approaches, such as Braun and Clarke's reflective thematic analysis (Braun & Clarke, 2019) may have been appropriate for this thesis. Indeed, reflective thematic analysis has been adapted to be deployed within a critical realist paradigm, focusing on the search for causal powers (Fryer, 2022). Additionally, although reflective thematic analysis is not specifically designed for exploring individual experiences, it can be used for this purpose, particularly if it is situated within a phenomenological framework (Braun & Clarke, 2021). However, Braun and Clarke suggest that reflective thematic analysis moves more rapidly to cross-case patterns than more phenomenologically-bound approaches, spending less time on the individual intricacies of individual cases (Braun & Clarke, 2021). This was considered undesirable as it could contribute to the silencing of individual voices within a stigmatised population. Additionally, as the scoping study highlighted the uncertainty as to whether diagnosis and/or nuances in antipsychotic use affects TRSEs, it was considered important to focus on individual experiences and differences across cases before moving to generalisable patterns. Therefore, approaches more grounded within the phenomenological framework were considered more appropriate.

Interpretative phenomenological analysis draws on phenomenology, hermeneutics, and idiography to explore people's experiences and perspectives to create a detailed understanding of a particular phenomenon in context (Smith et al., 2009). Phenomenology is used to focus on people's lived experiences by interpreting their attempts to create meanings out of their experiences, creating a detailed description of those experiences. Hermeneutics is used to undertake this interpretation: creating meanings by moving between the big and small picture within each sentence/paragraph/transcript and between individual cases, alongside acknowledging, and accepting and minimising the influence of the researcher's own experiences and assumptions. Sometimes this is described this as 'double hermeneutic', i.e. the researcher's attempts to make sense of the participants' own attempts to make sense of their experiences in context. Finally, idiography examines narrow and particular experiences from the perspective of a particular group of people in a particular context.

This analytical approach is appealing for several reasons. Firstly, as mentioned in my positionality statement (section 4.1.1), it is important to me that research regarding the experiences of people with mental health problems are explored directly with them. This could be seen to be particularly important because people with mental health problems often experience stigma and/or belong to minoritised groups (Kadri & Sartorius, 2005; Patterson et al., 2014; Thornicroft et al., 2013), increasing the risk of their voices being unheard and/or undermined. The phenomenological and double-hermeneutic elements of IPA create a focus on a holistic style of interpretation of participants' words in light of the individuality of the speaker, wider data set and wider theory, while acknowledging and attempting to set aside the assumptions of the researcher (Smith et al., 2009); this is likely to improve maintenance of the voices of under-represented people.

Secondly, the nature of the research question was important to consider, with its focus on the *experiences* of people as they manage/cope with TRSEs. The nature of the experience in question is narrow: having a mental health problem *and* taking antipsychotics for a long period *and* experiencing TRSEs. This means that the combination of phenomenology (to focus on participants' experiences) with idiography (to focus on narrow experiences) is particularly appropriate to this research question compared to other phenomenological approaches (for example Giorgi's (2009) descriptive psychological phenomenology). The complexity and contextually-bound nature of the experience explored in this research question makes the hermeneutic element of IPA useful: the complexities and individuality of each person as they try to navigate *their* life while having a mental health problem and experiencing TRSEs requires an understanding of both personal and social context. The hermeneutic element of IPA allows this exploration, in a way that may not be inherently part of more descriptive experiential approaches, such as descriptive psychological phenomenology (Davidsen, 2013) and Braun and Clarke's reflexive thematic analysis (2019).

4.2.2 Implementation of IPA within critical realist and phenomenological paradigm

Implementing IPA within a critical realist paradigm is not uncommon (Cuthbertson et al., 2020; Harris, 2010). However, arguably, this sometimes ignores the phenomenological philosophical underpinnings of IPA. In web discussions, Larkin suggests that the IPA community of practice situates IPA within an objective ontology. This is compatible with critical realism. However, Larkin (2022) goes on to say that the range of epistemological positions that are congruent with hermeneutic phenomenology mean that epistemological choices are best dictated by what is relevant to examining the data in question. Therefore, in this section I discuss how I implemented IPA in a manner congruent within both critical realism and phenomenology.

Fryer (2022) discusses the development of an approach to thematic analysis for use within a critical realism paradigm. This is also useful for thinking about how to conduct IPA within a critical realist paradigm. Drawing on Braun and Clarke's (2013, 2019, 2021) reflective thematic analysis, he adds a focus on answering a causal research question and exploring causation during analysis. He suggests the latter can be done via: (1) analysis of the participants' own understanding of causation; (2) drawing on existing theory and evidence; and (3) retroductive thinking by the researcher. He understands retroductive thinking to involve reflecting on whether the causal understandings of the researcher are plausible and appropriate. As a part of this approach, Fryer aims to return themes that speak to the causal mechanisms which address his causal research question(s).

Fryer's approach can be adapted to ensure that an IPA study conducted within a critical realist paradigm is true to and congruent with both IPA and critical realism. Within this study, although the research question focuses primarily on participants' experiences (congruent with IPA), there is also a focus on causation: how and why participants undertake the coping/management strategies they use; how and why these coping/management strategies are and are not successful. I designed the interview questions to allow participants to explore their understanding of causation: how and why they chose certain approaches and why they thought certain approaches worked or did not work. I explored these during analysis, and also undertook retroductive thinking to explore likely causation. My retroductive thinking also included looking for possible causes of difference in experiences across the participants. Unlike Fryer, I did not import existing evidence or theory as part of this exploration of causal explanation, as this would have risked undermining the phenomenological exploration of participants' first-hand experience. Instead, I explore findings within the context of existing evidence, including what this might mean for causation, in the discussion. For similar reasons, the group experiential themes (see section 4.2 for an explanation of group experiential themes) reported in the findings focus on the participants' experiences, with exploration of causation where relevant within the group experiential themes, rather than following Fryer's (2022) suggestion of causation being the main focus of each theme. This aligns with the aim of IPA and the research question, within the paradigm of critical realism: to focus primarily on experience, but also to explore the role of causation within these experiences.

4.3 Methods

4.3.1 Data collection

4.3.1.1 Semi-structured interviews

Smith et al. (2009) note that IPA data collection must create data that are suitable for IPA analysis of experience: it must be detailed and first person and collected from people who have directly experienced the phenomena in question. Consequently, IPA data collection is usually conducted by interview or diary. Interviews have a number of advantages over diaries. Using interviews allows participants to reflect back on long periods without requiring onerous and time-consuming multiple diary entries. Additionally, interviews also allow the researcher to prompt for more detail, ensuring sufficient richness of data. Finally, participants are likely to be familiar with the concept of interviews (Braun & Clarke, 2013; Bryman, 2016), perhaps making them feel more comfortable. These advantages may account for Reid et al.'s (2005) review of 65 peer reviewed papers, which show that interviews were the most common data collection method for IPA, and the use of interviews by other IPA studies exploring health-related coping (O'Mullan et al., 2014; Rafique & Hunt, 2015; Sim, 2020). Therefore, after considering this literature, data collection was conducted by interview.

Smith et al. (2009) note that to enable IPA to be conducted, interviews must avoid being overly structured, so that participants are able to speak freely, at length, with time to develop and express concerns, reflections, and ideas. A semi-structured interview schedule was created (appendix D) using the guidance provided by Smith et al. (2009), and refined by piloting the guide with two people who have experience of TRSEs. These two contributors were not invited to be study participants. This schedule focused on eliciting the experiences of the participants as they tried to cope with or manage TRSEs. To allow participants to tell their own stories via their own priorities (Smith et al., 2021) this schedule was treated as a guide, where the researcher omitted or returned to questions and prompts in response to the interview as it unfolded (Alase, 2017; Eatough & Smith, 2017).

4.3.1.2 Participant sampling

To explore a particular experience in detail, IPA samples must be sufficiently homogenous to allow for both detailed analysis and to enable the exploration of how case studies converge/differ (Murray & Wilde, 2020). This requires balancing a sufficiently homogenous sample that maintains some heterogeneous elements. In balancing homogeneity and heterogeneity, I followed Murray and Wilde's (2020) advice of aiming to ensure a sufficiently narrow experience to create homogeneity, while taking account of the social and theoretical factors relevant to this study. Homogeneous and heterogeneous recruitment criteria and justifications are outlined below; these informed the design of the inclusion and exclusion criteria in table 8.

Homogenous elements in this study were:

- Participants needed to be adults living in the community to ensure it was them, and not others, who were making decisions and life choices (including how and whether to utilise any management strategies for coping with TRSEs).
- Participants needed *not* to be currently severely unwell or in end-of-life care and/or lack capacity to consent, as this was again likely to affect their ability to make choices regarding TRSE management and coping, and their motivations and priorities in managing/coping with TRSEs.
- Participants needed to have been taking antipsychotics long-term (twelve months or more), ensuring sufficient experience of managing long-term TRSEs side effects that impact their long-term life and wellbeing.

- Participants needed to be taking antipsychotics for a mental health diagnosis, ensuring sufficiently similar experiences of symptoms and reasons for taking antipsychotics.
- Participants needed to be living in the UK to ensure their experiences of prescribing, health care, access to welfare payments, and other societal elements that might affect either the impact of TRSEs or the management and coping strategies available to them, were sufficiently similar.

Heterogeneous elements were: exact diagnosis, exact antipsychotic taken, and exact TRSEs being experienced. These heterogeneous elements were based on the results of the scoping study (chapter 3).

Table 8: Inclusion and exclusion criteria

Inclusion Criteria	**Exclusion Criteria**
Currently prescribed and taking antipsychotics for a mental health diagnosis	Lacks capacity to give informed consent
Reports current or past experiences of tiredness-related side effects	Under 18
Lives in the UK	Currently in an inpatient setting
Lives in a community setting	Currently severely unwell or in end-of-life care
Speaks English (there was no funding for translation services)	Prescribed antipsychotics for other diagnoses, e.g. dementia, ADHD, severe pain, autism.
	Prescribed antipsychotics for less than 12 months.
	Prescribed antipsychotics but not currently taking them due to TRSEs

4.3.1.3 Sample size

Sample sizes for IPA are not prescriptive. However, due to the detail of the analysis required, it is generally considered that sample sizes much above 10 dilute analysis quality (Smith et al., 2009). These sample sizes are reflected in other IPA studies related to health care coping; for example, O'Mullan et al., 2014 utilised a sample size of 10 to investigate coping with antidepressant side effects, and both Sim (2020) and Rafique and Hunt (2015) utilised sample sizes of eight to understand coping in visual impairment and alopecia. Therefore, this study aimed to recruit eight to 10 participants.

4.2.1.4 Recruitment procedure

Participants were recruited via social media (e.g. Twitter, Facebook), and the Lancaster University website. Social media postings were created for this purpose, using a poster approved via the university ethical procedure (appendix E). Potential participants expressed interest via email. I contacted potential participants with more information, including the participant information sheet (appendix F). Some participants who did not meet the criteria responded to me (i.e., no longer using antipsychotics, or who used antidepressants not antipsychotics); I contacted these participants to thank them for their interest and explain why they were not eligible. Information regarding informed consent and participant safety are detailed in the ethical considerations section 4.4.

4.2.1.5 Recruited Participants

As one participant appeared to meet the inclusion criteria during consent conversations, but during interview revealed that they were no longer prescribed antipsychotics, this required recruiting an additional participant, totalling eleven. This person was excluded from analysis as they did not meet the inclusion criteria, because their experiences did not match the homogeneity criteria (see section 4.2.2.2). Ten participant interviews were therefore taken forward to analysis.

Interviews were conducted via video conferencing (*n* = 9), or telephone (*n* = 1) according to each participant's preference. Interviews took place between 19th July 2023 and 13th July 2024, and lasted between 26 and 95 minutes (mean = 58 minutes). Interviews were transcribed verbatim by professional transcribers, and checked by myself.

The age range was 21-56, with a mean of 40.8. All participants were white, and all but one British. One participant was male. Details of diagnoses and antipsychotic use are shown in table 9. The names used in this table and subsequent chapters are pseudonyms, chosen by myself. Although all participants were prescribed antipsychotics for a mental health diagnosis, unprompted, four participants disclosed diagnosed or undiagnosed ADHD/autism which they found to impact on their experience of TRSEs and managing/coping with TRSEs. As these participants were clear that they were prescribed antipsychotics for a mental health problem, they were considered to meet the inclusion criteria.

Table 9: Participant diagnosis and antipsychotic use

Pseudonym	**Mental Health Diagnosis/es**	**Current antipsychotic**	**Previous antipsychotics**	**Time taking current antipsychotic**
Ava	Bipolar disorder. Complex PTSD.	Quetiapine 300mg extended release.	Quetiapine short release	1 year
Ash	Bipolar disorder.	Quetiapine 100mg at night, previously 150mg.	Olanzapine	12 years
Eilish	PTSD. Anxiety.	Quetiapine 75-100mg at night.	N/A	11 years
Emily	Bipolar affective disorder with rapid cycling	Quetiapine 75mg at night. Recently 100mg. Previously 300mg. At night. This is possibly slow release?	Olanzapine	10 years

Raven/ Bob	Post-natal depression. Anxiety and depression. Spiritual activity (hallucinations).	Quetiapine (Seroquel brand) 350mg: 50 in the morning, 300 at night.	Quetiapine (Seroquel brand) 400mg - 100mg of which in the morning	3 years
Sarah	PTSD. Anxiety. Reactive depression.	Quetiapine 150mg at night. Originally 500mg split dose. Then 350mg split dose.	Aripiprazole, then Quetiapine, then Risperidone, then Olanzapine	14 years, on and off
Suzanne-Jane	Schizoaffective disorder	Amisulpride	Olanzapine and then “few different ones in between”	4 years
Joanna	Psychotic depression	Aripiprazole 50mg	Originally on Aripiprazole, briefly took Olanzapine when pregnant as aripiprazole not recommended for pregnancy	17 years
Bryony	Schizoaffective disorder	Quetiapine: 200 mg at night, 100mg in the morning. Combination antipsychotic/antidepressant: Amitriptyline 25mg at night	“all of them” at some point	5 years
David	Paranoid delusional disorder	Paliperidone	Olanzapine	3-4 years

4.3.2 Data analysis

This study draws on Smith et al.’s (2009) steps for IPA analysis, which was the prominent text for IPA at the time the study was designed. These steps included: (1) Data familiarisation by repeated re-reading of data to ensure the participant’s individual experiences were the focus of the analysis and to think about how different parts of the interview interacted; (2) Initial noting of descriptive, linguistic and conceptual content; (3) Development of these notes into emergent themes for this participant; and (4) Exploration of connections across these emergent themes to create superordinate themes at individual participant level. Once I had completed analysis of each case, I undertook cross-case analysis, looking for patterns across cases to create final themes across the group. Throughout analysis I sought to find deeper meaning in the analysis in line with the hermeneutic and phenomenological underpinning of IPA. In line with IPA guidelines I sought to ‘bracket out’ my own experiences, and the experiences of other participants, to aid understanding and presentation of the experiences of the individual (Smith et al., 2009).

Towards the end of this analysis Smith et al. published a new edition of their IPA textbook (Smith et al., 2021). This textbook adds additional detail to their guidance on how to undertake analysis and offered new, more distinct, terminology for describing IPA analysis. This new terminology has been used for the remainder of the thesis: emergent themes are ‘experiential statements’, superordinate themes which relate to an individual participant are ‘personal experiential themes’, and final themes that relate to the group are ‘group experiential themes’.

As Smith et al. (2009; 2021) note, these steps are not prescriptive: analysis is less about following a set of steps, and more about understanding the underlying purpose of these steps. In particular, undertaking analysis highlighted the accuracy of Smith et al.’s comments that the steps are multi-directional and iterative; analysis was not fixed until final write-up. In practice the steps were undertaken as described below.

4.3.2.1 Participant level analysis

Following data familiarisation, I copied the transcript into a new document with three columns, the transcript filling the far-left column. I undertook further re-reading of the transcript, with initial noting of descriptive, linguistic and conceptual content in the central column. During this process I noted any possible impacts of my own assumptions in square brackets next to the notations. When undertaking these notations, I remained close to the verbatim words used by the interviewee in order to maintain focus on individual participant experience. To develop these notations into experiential statements I used the right-hand column to summarise the notations, while remaining true to the participant’s experience (see extract from experiential statement process for one participant in appendix G). To create personal experiential themes I copied the experiential statements into a new word document, and created a second new word document with a series of text boxes. I clustered experiential statements together in separate text boxes and moved experiential statements back and forth between text boxes to create sub-personal experiential themes and these were grouped together to create personal experiential themes. Once these personal experiential themes were finalised, I wrote a narrative paragraph describing each personal experiential theme and gave a title to each personal experiential theme (see extracts from personal experiential themes for one participant in appendix H).

4.3.2.2 Cross-case analysis

Initially I undertook cross-case analysis by looking for patterns across participants’ personal experiential themes, creating five group experiential themes. I wrote an overall narrative summarising these group experiential themes. However, reviewing this initial narrative I found that this initial approach did not sufficiently express the individual participants’ experiences: there was too rapid a jump to transferability/generalisability, and group experiential themes titles reflected my interpretation of causation (too much retroduction, too soon) more than each participant’s experience. I returned to each individual transcript alongside the initial group experiential themes, making hand-written notations that focused on the participant’s own words and creating typed narrative summaries that focused on the participant's experiences. During this iterative analytic process I focused on ensuring the analysis expressed how that group experiential themes was experienced by each participant, ensuring that the group experiential themes reflected the participant's experience, and was mindful that the initial group experiential themes may incorrectly or incompletely reflect the participants' experiences. As a result of this iterative process, four existing group experiential themes, narratives, and titles were then re-written by looking across the cases, being sure to express participant experience more accurately. During this process one initial group experiential theme was found to be insufficiently represented by participant experience, and to overlap with other group experiential themes: this was absorbed into the remaining group experiential themes. No new group experiential themes were identified during this process. This iterative process in creating group experiential themes reflects Smith et al.'s (2009, 2021) comments on the multi-directional approach undertaken in IPA analysis. Extracts from this final iterative process for one participant are presented in appendix I.

4.3.2.3 Timing of analysis

Advice regarding appropriate timing of analysis in IPA is not prescriptive. Smith and Shinebourne (2012) note that it is best to begin IPA analysis with whichever transcript is most "detailed, complete and engaging" (p.82). Although they do not explicitly state so, this creates a tacit suggestion that the data set should be complete prior to undertaking analysis. This is likely due to concerns that interim analysis might negatively impact future interviews, as preconceptions created by early analysis might lead to the interviewer shutting down possible lines of enquiry in future interviews (Murray & Wilde, 2020). However, as Murray goes on to note, if IPA assumes that researchers are able to 'bracket out' their own preconceptions during analysis of each individual case study (Smith 2009, 2011, cited by Murray & Wilde, 2020), researchers must surely be able to perform this same bracketing when interviewing. Such bracketing would prevent analysis negatively impacting on future interviews, removing this concern regarding the need to undertake analysis prior to the collection of the full data set.

In this PhD study I reviewed recordings and transcripts throughout data collection to refine my interview technique. Arguably, both the interviewing process and reviewing transcripts means the researcher unavoidably starts to form early analytical thoughts regarding each interview before the data set is complete, and these will need to be bracketed out regardless of when full analysis takes place. Analysing each interview as it was completed not only allowed me to capitalise on these early-stage thoughts, but also the act of changing these early thoughts into a full analysis of the transcript made it easier to bracket them out during subsequent interviews.

Finally, undertaking analysis after each interview allowed me to refine further my interviewing skills by reflecting on how best to conduct interviews that collect analysable data. Therefore, in this study I analysed interviews chronologically as each interview was completed, rather than once a full data set had been returned.

4.3.2.4 Implications for generalisability and transferability of findings

Generalisability can be understood to be the extent to which study findings can be applied outside the participant sample to the population that the sample is expected to represent; transferability can be understood to be the process of applying findings to situations and circumstances not directly studied (Drisko, 2025). In this study generalisability might be understood to concern the extent to which findings represent all people experiencing TRSEs, or even all people within the UK experiencing TRSEs. Transferability in this study might be understood to concern the circumstances under which findings represent people outside the sample. For example, perhaps people experiencing TRSEs in other countries and times, people experiencing other side effects of antipsychotics, or taking which other long-term medication for other chronic conditions.

Both the critical realist paradigm and the use of IPA have implications for the expected generalisability and transferability of findings. These implications are overlapping, but not contradictory nor completely aligned. Within critical realism, Bhaskar (2014) tells us to be cautious about what is truly generalisable and what is not: even within quantitative methods it is possible to confuse what one knows (empirical or actual), with the full extent of objective reality (the real). He describes this as ‘epistemic fallacy’: assuming that what you know is the sum total of reality, and making over ambitious generalisations based on (understandably limited) empirical or actual knowledge, rather than acknowledging the existence of the ‘real’. Danermark et al. (2002) suggest that when deciding on the applicability of findings to situations outside the study, one should acknowledge the person and societal level contexts in which those findings were created, thus avoiding confusing ‘what you know’ with ‘what is real’. This is consistent with how IPA methodologists conceptualise generalisability: Smith et al. (2009) state that the use of idiography to explore the experiences of a homogenous group within a specific context means that findings can have theoretical transferability within that context, i.e.: to others with sufficiently similar experiences. For both critical realism and IPA this transferability does rely on findings being of sufficient quality to reflect the experience of the participants (see section 4.3.2.6 on quality, below). This understanding of transferability is taken into account when discussing the wider implications of findings in chapter 6: the extent to which findings are considered to be applicable outside the sample is explored cautiously and with assumptions of transferability rather than generalisability.

4.3.2.5 Use of theory and theoretical assumptions

The phenomenological focus on participant experience in IPA, via the hermeneutic interpretation of the researcher, means that existing theory does not play a role in the analysis of data. Indeed, the bracketing approach is designed to aid the filtering out of researcher assumptions in analysis, including their knowledge of existing theory. Notwithstanding this, there are 'grand theory' theoretical assumptions in the design of this study. Grand theories can be applied at an abstract level, across different areas, highlighting assumptions and world views (Davidoff et al., 2015). When designing this research I assumed a rational choice grand theory. The use of rational choice theory implies that people use independent reasoning in order to make decisions to achieve their own aims (Hechter & Satoshi, 1997). This is congruent with critical realism, as people's rational choices will be based on their individual understandings of reality, thus different people may make different decisions for different reasons. When analysing the data, I assumed that people can and will make their own rational choices about how they manage and cope with TRSEs, although the choices available to each individual may differ due to individual and societal context.

4.3.2.6 Quality

Historically, it was difficult to pin down appropriate ways of assessing quality in qualitative research. Researchers have repeatedly reported having quantitative standards of quality inappropriately applied to their work, for example, having their sample sizes assessed as inappropriately small because they were not generalisable, and analyses described as not truly replicable because of the role of the researcher in interpretation and/or their own understandings and assumptions in analysis (Yardley, 2000). In response Yardley suggested a four-domain approach to assessing quality in qualitative research: sensitivity to context; commitment and rigour; transparency and coherence; impact and importance. Yardley explained impact and importance to include the practical and theoretical usefulness of the work; this is reflected upon in the discussion chapter. Sensitivity to context is partially addressed in the scoping study and discussion chapters, which place the study in terms of what is already known together with existing theory.

However, it becomes problematic to use Yardley's (2000) approach to assess quality in an IPA study when looking at the role of language, and the interaction between researcher and participant in the domain of sensitivity to context: IPA has its own guidelines on how to analyse the use of language and how to treat the interactions between researcher and participant. For similar reasons, the domains of commitment and rigour, and transparency and coherence are also difficult to apply to IPA: Yardley's approach to assessing quality cannot tell us to what extent an IPA study draws on the expected combination of phenomenology, hermeneutics, and idiography.

Smith (2011) addresses this challenge with his recommended assessment of IPA quality. This has recently been updated to create clearer indicators of 'good' IPA work (Nizza et al., 2021): (1) Constructing a compelling, unfolding narrative; (2) Developing a vigorous experiential and/or existential account; (3) Close analytic reading of participants' words; and (4) Attending to convergence and divergence. Therefore, quality of analysis was assessed using Nizza et al.'s (2021) four indicators of quality. Application of these criteria can be seen in the discussion chapter, section 6.9.

4.3.2.7 Critique

Common critiques of IPA include that it is time consuming to learn and undertake well (Miller et al., 2018). I did indeed find this a challenge, despite being familiar with other qualitative techniques. However, this challenge was arguably offset by the depth of the analysis achieved. A more detailed reflection on this learning process and the resulting analysis can be found in 4.3.2.8 below.

Others suggest that where the researcher offers interpretations of the participants' experiences this can sometimes result in a lack of transparency (Pringle et al., 2011). For some phenomenologists this invalidates IPA as a phenomenological approach, resulting in heated ongoing debate between some proponents of descriptive psychological phenomenology (van Manen, 2017, 2018) and proponents of IPA (Smith, 2018). In part this is addressed by applying Nizza et al.'s (2021) good quality criteria discussed in 4.3.2.6 above. Additionally, the ability to explore the complexity of aforementioned context (Davidsen, 2013) and to explore convergence and divergence of cases (Smith et al., 2021) were considered sufficient benefits to justify using IPA. Therefore, to resolve this phenomenological methodological debate it is useful to instead think about each use of IPA 'on its merits', as Halling (2021) suggests. Notwithstanding this, it must be acknowledged that IPA presents the researcher's understanding of the participants' experiences (Smith, et al., 2009).

4.3.2.8 Reflexivity

My positionality has affected the design of this research. It was important to me that the study explore participants' experiences first-hand, as often the voices of people with mental health problems are undermined. This may have impacted the research question: my personal focus on participant voice and experience possibly contributed to my interpretation of the evidence gap in the scoping review as being one of lived experience. It also impacted on research design: the desire to focus on lived experience meant the phenomenological underpinnings of IPA were of interest to me, and when choosing whose experiences to focus on I immediately focused on the experiences of people with mental health problems. Indeed, it did not occur to me to explore the experiences of others interested parties. It is only reflecting now that it has occurred to me that other researchers may have instead recruited participants who were carers or clinicians or policy makers.

Although the personal experiences outlined in the positionality statement impacted on the design of this research, they have arguably not negatively impacted on the quality of the research. It was incredibly important to me that my findings reflected participants' experiences as closely as possible. During interviews and analysis I was perhaps more mindful of the potential impact of my own experiences and assumptions than someone without lived experience. During interviews I made sure I gave participants time and space to explain experiences in their own words, and was cautious not to bring my own or others' experiences into the conversation. If I thought that meaning might be unclear during analysis or that my own experiences might later colour analysis, I cautiously asked participants for more detail to avoid making assumptions. During analysis, I was careful in interpreting participants' words, particularly in ascribing meaning to particular words or phrases. For example, I returned to the transcript as a whole to check that these interpretations were likely to be accurate based on how the participant expressed themselves as a whole; if I were uncertain or worried that a specific interpretation might be due to my own experiences, I would make a note in square brackets so that I could check this assumption later when moving across or between transcripts. To some extent this may have been possible because, although I am not experienced in IPA, I have been working as a researcher collecting qualitative data from people with mental health problems for several years alongside my PhD. I believe these processes allowed me to come as close as was possible for me, with my experiences and positionality, in understanding participants' own meaning making. In this respect, bracketing could be understood to be 'successful': completing the double-hermeneutic cycle of creating my best understanding of the participants' understandings. However, I would not expect my understandings, or the findings in this thesis, to be described an objectively completely true and 'real' reflection of participants' experiences: researchers' experiences and values mean that even when using the same research design, individual researchers ask different prompt questions in different orders, and understand participants' words in different ways. Therefore, inevitably the findings in this thesis are my interpretation of the participants' experiences. However, I believe this is congruent both with the aims of IPA (Smith et al., 2009), and Bhaskar's caution not to confuse the empirical with the real (Bhaskar, 2014), rather than a weakness in my conducting of the study.

During analysis and conversations with supervisors, it became clear that due to a desire to complete analysis rapidly, I had moved too quickly from individual transcripts to cross-case analysis. This may have also been due to having greater familiarity with realist evaluation, which aims to use retroduction to move rapidly between individual experiences and generalisable causation (Pawson & Tilley, 1997). As a result, the first-cut analysis was insufficiently focused on individual participants' experience. Thus, this first cut of analysis looked insufficiently different from that produced by reflective thematic analysis (Braun & Clarke, 2021).

In response to this I revisited the analysis of each individual transcript alongside the first-cut analysis (see section 4.3.2.2 above). This process took approximately 10 months part-time. Although the titles of the final group experiential themes are broadly similar, the extent to which they reflect participant experience in detail, and capture individual experiences and heterogeneity within the sample is vastly different. This leads me to reflect on Braun and Clarke's (2021, n.p.) comment about final analysis: perhaps IPA undertaken with undue haste or insufficient guidance may provide similar results to reflective thematic analysis. However, with sufficient time and focus on individual experiences, final IPA results can look vastly different to results produced by other methods.

4.4 Ethical considerations

I received ethical approval for this study from Lancaster University's Faculty of Health and Medicine ethics committee on 21st October 2021 (see appendix J). I conducted this research in line with the ethical principles within the Declaration of Helsinki (World Medical Association, 2024). In particular, I focused on ensuring that participants were able to give fully informed consent in spite of any potential power differentials between the researcher and participant (British Psychological Society, 2021).

4.4.1 Participant safety

I did not anticipate that participants would be harmed by taking part in this study, but I was aware that this was a possibility in that they might discuss a potentially distressing topic. This was highlighted in the participant information sheet. To balance minimising distress with enabling participants' rights to take part in research, I highlighted during consent conversations that participants were not required to answer every question asked of them; when asking a question that may be sensitive or distressing to the individual participant I ensured I clarified the voluntary nature of the question when asking it. If I perceived that the interview process was distressing to the participant, I would have suggested/offered to pause or stop the interview. A debrief sheet outlining useful contacts was provided to participants following interviews.

In practice, although experiencing and managing TRSEs was distressing to participants, this distress was a part of their day-to-day lives. Participants did not decline to answer any questions when offered this option. I did not perceive the need to pause or stop any interviews due to distress. None of the participants asked to skip a question or stop the interview early. During interview, several participants expressed they were tired or that their concentration had started to wane. I asked these participants whether they would like to continue, pause or stop the interview; all participants expressed they would like to continue the interview.

4.4.2. Participant recruitment and consent

Following initial e-mail conversations with potential participants, I invited them to meet with me via Microsoft Teams or a phone call for a consent conversation. Here I outlined the study verbally, checked participants' understanding, and gave the interested person the opportunity to ask questions. I focused on ensuring the participant had understood: the study; what they were consenting to; the voluntary nature of taking part; and the ability to withdraw their data up to two weeks after data collection. To address potential feelings of coercion caused by power imbalances, potential participants were invited to consent in that meeting, at a later point, or not at all. In practice I perceived no such power imbalances. In the event the potential participant did not decide whether to consent during the initial meeting, it was planned that the researcher and potential participant would agree a timescale and contact procedure. However, all potential participants that attended a consent meeting offered to give informed consent during that meeting. As consent meetings were held remotely, I read each statement on the consent form and consent was only be deemed to be given if the potential participant verbally agreed to each statement. These consent conversations were audio recorded and transcribed and stored separately from interview data.

It was planned that those I considered to lack capacity to consent would be excluded from the research. Excluding those without capacity to consent arguably impacts their ethical right to participate in research (Royal College of Psychiatrists, 2011). However, those with reduced capacity are likely to be differently affected by some of the impacts of TRSEs, and less likely to be able to contribute to the reflectivity required in an IPA interview. In practice, there were no concerns regarding capacity to consent within those who expressed an interest in taking part.

4.5. Summary

In summary, I conducted the empirical study within a research paradigm which acknowledged a critical realist ontology/epistemology, and a phenomenological exploration of first-hand experiences. I used Smith's (Smith et al., 2009, 2021) interpretative phenomenological analysis methodology. I recruited 10 participants to share their first-hand experiences via semi structured interviews, following ethical processes approved by Lancaster University. In analysis I focused on individual participants' experiences, including their own sense-making, feelings, and responses, and how this was the same or varied across the group. I made some exploration of causation, within the context of the research question and phenomenological position, including some retroductive thinking. The findings from this analysis are presented in chapter 5.

Chapter 5: Results

In this chapter I discuss the findings from the empirical study. My analysis demonstrated four group experience themes (GETs) regarding the experience of managing and coping with TRSEs:

- *"It's what I do. It's part of me now. It's like second nature"*: TRSEs and responses to TRSEs becoming a part of one's life.
- *"I've made a choice in my life that I want to be happy, I want to be mentally well and if that means I have to sacrifice some things, then I have to sacrifice some things"*: prioritising one element of one's life over another.
- *"I used to self-harm, which is not the best strategy"*: utilising detrimental management strategies and coping responses.
- *"There's an acceptance that I can't change it"*: coping with unmanageable TRSEs via acceptance.

These GETs are discussed in more detail below. The implications of these findings are discussed in chapter 6.

Although the findings reported in this section reflect common experiences across the participants, the exact nature of these experiences, including their priorities and values are framed within their individual contexts. Therefore, table 10 below outlines the demographics, living situation, employment status, and diagnoses of the study participants.

Table 10: Participant characteristics

Pseudonym	**Demographics**	**Age Range**	**Living/family situation**	**Employment**	**Mental Health Diagnosis/es**	**Previous mental health diagnosis/es**	**Other diagnoses mentioned during interview**
Ava	White British. Female.	20-24	Lives with housemates, boyfriend visits, spends a lot of time with father	Full time student, part time employed	Bipolar disorder. Complex PTSD.	Anorexia. PTSD (complex PTSD was not recognised as a condition previously)	ADHD.
Ash	White British. Female.	40-44	Shared custody of two children under 18	Full time parent to children with autism/Asperger's	Bipolar disorder.	N/A	Autism. Undiagnosed ADHD. Cancer survivor: currently in remission.
Eilish	White British. Female.	50-54	Lives alone, close to mother	Part time self employed	PTSD. Anxiety.	Complex (type 2) PTSD	Autism.
Emily	White British. Female.	55-59	Partner	Employed full time	Bipolar affective disorder with rapid cycling	Depression and anxiety, panic attacks	
Raven/ Bob	White British. Female.	50-54	Spouse	Not employed	Post-natal depression. Anxiety and depression. Spiritual activity (hallucinations).	Psychosis. Personality disorder	Suggested drug and alcohol misuse. Blood clots, degenerated disks, arthritis, ongoing severe pain. Has morphine patches to manage pain.
Sarah	White British. Female.	30-34	Spouse, three children under 18, until recently acted as main carer for mother	Full time student, part time-employed	PTSD. Anxiety. Reactive depression.	Psychosis in the last 12 months.	
Suzanne-Jane	White British. Female.	35-39	Alone	Not employed	Schizoaffective disorder	N/A	
Jane	White European. Female.	45-49	Spouse, children under and over 18. Younger son is autistic, but spouse does most of the childcare	Employed part time	Psychotic depression	Schizoaffective disorder. Cyclic depression.	
Bryony	White British. Female.	35-39	Two children under 18. Also acts as carer to grandmother	Employed part time	Schizoaffective disorder	Anxiety. Insomnia.	
David	White British. Male	40-44	Parents. Has long-term long-distance girlfriend from another country. They have never met in person.	Employed full time	Paranoid delusional disorder	Paranoid psychosis	

5.1 *"It's what I do. It's part of me now. It's like second nature"*: the experience of TRSEs and responses to TRSEs becoming a part of one's life

In this GET I describe the experience of TRSEs, management strategies, and coping responses becoming part of participants' everyday lives. This includes which TRSEs and management strategies became a part of participants' lives, what this felt like, and the impacts it had on participants.

Participants described how they had become accustomed to experiencing TRSEs; TRSEs had become a part of their lives. This included needing more sleep, being unable to sleep, daytime tiredness, difficulty concentrating, and difficulty functioning. Some became aware of this experience during the interview, while reflecting on how TRSEs impacted their lives. For example, Ash deliberated whether the severity of TRSEs had reduced: she decided this was not the case, in fact she had become accustomed to experiencing TRSEs:

> *The [side] effects are still the same. Maybe I'm just more used to them, I don't know. But no, it's exactly the same as it's always been.*

Some participants' language downplayed the severity of the impact of TRSEs on their lives, for example, *"not that bad"*, *"just"*, *"only"*. This downplaying language suggested that becoming accustomed to TRSEs could reduce the distress caused by TRSEs.

Some described current TRSEs in comparison to past, more severe, TRSEs. Examples included: difficulty getting up, difficulty concentrating, daytime tiredness. This suggests previous, more severe, experience of TRSEs made it easier for participants to downplay current TRSE(s), thus reducing any associated distress. For example, Suzanne-Jane found being unable to get up until 9am more tolerable than being unable to get up at all:

> *At one point I was struggling to do [get up] anytime, erm, but I suppose it's better now, cos most days I'm up by 9.*

Participants' language and tone when realising they had become accustomed to TRSEs suggested this realisation was neither pleasant nor desirable. Participants linked becoming accustomed to TRSEs with a negative interpretation of long periods of antipsychotic use. For example, Sarah's use of the word *"evil"* highlights extreme negative feelings created when associating becoming accustomed to side effects with long-term antipsychotic use:

> *I don't know whether my body's got used to it and the side effects don't affect me as much, or I've just got used to the side effects and this is just my way of life now. I don't know which evil it is.*

Some described the behaviours they used to reduce the impact of TRSEs as part of their lives. Often these behaviours had been adopted over long time periods, or a long time ago.

Behaviours included: bedtime routines, caffeine use, rearranging social lives, exercise, relying on help from others, and rearranging working patterns. For example, Sarah's husband helped her get up in the morning, enabling her to look after their children and be punctual for work:

> *We have now, I suppose, been doing this for 10 years […] So, now it's just got to the point that it's become a way of life. That's just what we do.*

Participants did not perceive behaviours which were part of their lives as management strategies. For example, Emily initially said she had not done much to manage TRSEs, but then reflected that her long-term experience of TRSEs meant her management strategies, such as changes to bed times and social life, were like habits:

> *I haven't really done an awful lot, nor had to. I think – do you know, I've been like this for so long, it's almost become a habit.*

Many participants used words such as *"I can't"*, and "*I don't"* to describe their responses to TRSEs. This language suggests that not undertaking these behaviours had become part of their lives. This included: not working or driving, limits to types of work and social activities undertaken, limits to when social activities, work and driving could take place, not drinking alcohol, reduced sex life, not having children, not contributing equally to childcare and not attending morning appointments. For example, Suzanne-Jane spoke of *"not being able to, erm, have a baby"*; Raven/Bob explained *"you won't even be able to drive your car"*; Ava was unable to socialise as others her age might (*"sometimes you want to actually feel like a 21-year-old, and you can't"*). This response of being unable to undertake activities caused some to experience negative emotional states, including feeling *"frustrated"*, *"sad"*, *"depressed"*, "*embarrassing"*, and "*awkward"*.

Some described other behaviours as required or "*essential"* to reduce the impact of TRSEs. For example: caffeine to reduce daytime fatigue, no caffeine in the afternoon to improve sleep, going to bed early to manage needing extra sleep. The language participants used when speaking about both the *"can't"/"don't"* and *"essential"*/required responses suggests that participants understood these behaviours as being outside of their control, rather than purposeful strategies. For example, Ash described caffeine use in the morning as necessary for reducing morning tiredness and being able to think in the morning:

> *Yeah, morning cup of tea. It's an essential. I never used to drink caffeine till I was 34 either, but now I… I… yeah, my morning cup of tea is an essential.*

Which behaviours became part of participants' lives varied between participants, according to personality and concurrent diagnoses. For example, Bryony described her bedtime routine to ensure she got enough sleep as, *"It's just my little routine. It's what I do. It's part of me now. It's* *like second nature"*. However, Ava and Ash found it difficult to go to bed at a consistent time, linking this to concurrent ADHD. Ava and Ash's descriptions suggested that they considered their inability to adopt this behaviour a disadvantage. Ash said:

> *It's generally better to take it [antipsychotic] earlier and go to bed earlier. But that doesn't mean I do it, or I do what's right for me […] but that's…again, I think that's my ADHD, because um, ADHD and executive function are a bastard, so, um, things just seem more exciting at night.*

Where behaviours became a part of participants' lives it was difficult for participants to reflect on how or why they had started using these behaviours, and/or how they felt about them. For example, Bryony found it difficult to reflect on how she felt about her bedtime routine, but described having negative feelings about the routine when she was adopting it. This suggests that adopting behaviours into their lives helped participants reduce negative feelings associated with changing behaviour to reduce the impact of TRSEs:

> ***Interviewer: and how do you feel about that [bedtime] routine?***
> *Bryony: I don't know […]*
> ***Interviewer: Has it always felt like that?***
> *Bryony: No. At the beginning it was very difficult to get into a routine.*

For some, behaviours became part of their identity. This made it difficult for participants to know if these ways of behaving were personal preferences, hindering their ability to reflect on the emotional impact of adopting these behaviours. Some expressed this explicitly: for example, Sarah discussed how, having not socialised in the evening for many years, she was unsure if this was now a personal preference:

> *Now I'm older it doesn't affect me [not socialising in the evening], it doesn't bother me so much because we don't have much of a social life now, probably because I stopped going out when I was younger, so it doesn't bother me much.*

Other participants gave confused accounts regarding whether behavioural responses that were part of their lives were personal preferences or had negatives impacts on them. For example, David described not drinking alcohol or having late nights because it increased TRSEs, but later said that he was not a big drinker or fond of late nights; Ash discussed limits to her sex life due to evening sedation, but also said she did not have a big sex drive. Ash said:

> *It's not very spontaneous [my sex life], because you'd have to take your meds after you went to bed. So, that would have to be a conscious decision to do that…otherwise you've got, like, a twenty-minute window and "that's it, sorry." […] But it's just not very sexy and… yeah, I d… I don't know. Like, when I dated my last boyfriend, I was just, like, "No, you can't stay over." [Laughs]. "Sorry". But a part of that is 'cause I like being on my own. I'm on the asexual spectrum as well, so I suppose I can't complain that much but, like, I just… [sigh]…*

Some participants described rearranging their lives to accommodate activities they were unable to undertake. For example, Joanna had rearranged her life so that she did not work in the mornings, reducing the impact of her needing more sleep on her ability to work. For Joanna, this was a positive experience: she felt proactive in solving problems:

> *It's taken me years to reach this stage, but now that I have reached it, I am very happy with it.*

Others were neutral about the experience of having rearranged their lives to accommodate TRSEs. Their descriptions suggested behaviour changes were a subconscious response that became apparent during interview. For example, Ava began by saying that her TRSEs had reduced, but then reflected she had made changes that may have altered her perception:

> *I guess maybe like the side effects have lessened a bit, but I've also just kind of learned to live with it, and I've kind of, I guess, slowly over time, just kind of organised my life around it, even like, if maybe, I didn't notice I was doing that.*

In summary, participants became accustomed to some TRSEs. Although this sometimes appeared to reduce the emotional burden of experiencing TRSEs, it was perceived negatively by participants because it highlighted the long-term nature of their experiences. The ways participants changed their behaviour in response to TRSEs had become a part of participants' lives. These behaviours were not considered management strategies and included responses that participants perceived as outside their control. Participants found it difficult to reflect on TRSEs and responses to TRSEs that had become part of their lives. Behaviours that became a part of participants' lives were easier to implement. Some participants had rearranged their lives to accommodate TRSEs; and whether this was viewed as a positive experience depended on whether this had been a conscious decision.

5.2 *"I've made a choice in my life that I want to be happy, I want to be mentally well and if that means I have to sacrifice some things, then I have to sacrifice some things"*: the experience of prioritising one element of one's life over another

In this GET I explore participants' experience of TRSEs preventing them from doing all they wanted, and their response of prioritisation. This prioritisation experience includes participants having the ability to reduce the impacts of TRSEs, but only at the expense of other parts of their lives. For example, taking antipsychotics earlier and going to bed earlier in order to be able to get up in the morning reduces the impact of TRSEs on being able to work, but negatively impacts social lives and relationships. I describe what participants prioritised, how they undertook prioritisation, what it felt like, and the impact of prioritisation on them.

Some prioritised specific areas in their lives over others because they were too tired or did not have the energy to undertake all activities. For example, Sarah described prioritising resting over volunteering:

> *When I started the Risperidone I was doing a voluntary job at a little charity shop, but I had to stop it for a while, because I couldn't actually get through the day, sort of thing, without feeling like I'd been just wiped out.*

Others prioritised one area of their lives over another because they had less time. For example, Ava explained how requiring more sleep meant she had less time than her boyfriend. She responded by prioritising employment, causing her to abandon some hobbies and preventing from taking her lunch break with her colleagues. This made her life seem less complete:

> *I've got less time to do things. I don't really have much, as much, like free time in the morning or evening […] My boyfriend [...] he has all these hours in the morning and evening when I'm just knocked out, that you can, I guess do things that aren't work, you know, can feel like, yeah it's…it's sleeping or working at times. Yeah.*

Some described prioritising reducing one TRSE over reducing another. For example, Emily described having a limited social circle because she reduced the impact of TRSEs on her sleep by taking her antipsychotics at a set time. She explained that she could address this by socialising after taking her antipsychotic. However, her desire not to be judged by others due to antipsychotic-induced slurred speech was stronger than the desire to increase her social circle:

> *We moved to [place] in 2019 […] I was hoping to be able to join some clubs, to meet some people here, because I really don't know anybody in this town. But, I can't really do that <u>and</u> take my medication, because there's a chance that if I take my medication and then go to meet people, I can seem slurry and that really bothers me, because I sound like I've had a few to drink […] and I just wouldn't want people thinking that.*

Many participants described prioritising mental health via continued antipsychotics use over the desire to reduce/eliminate TRSEs. This was an uneasy prioritisation, with participants such as Joanna often dissatisfied with results:

> *Antipsychotics have a great impact on my life. But, I just can't be without them.*

For some, prioritisation of continued antipsychotic use consisted of establishing a dose that compromised tolerable mental health symptoms and tolerable TRSEs. This often felt like a need to "*balance"* competing priorities. For example, Raven/Bob explained careful and difficult weighing of competing mental and physical health priorities, because the lack of movement and additional hours asleep caused by TRSEs increased her risk of blood clots:

> *I'm meant to take 100mg in the morning. But, like, that, because I've suffered blood clots […] it does knock you out and I can't then spend another 10 or 12 hours sleeping in the daytime, to be awake until, you know, bedtime, and then do it all again. Like, I'm too paranoid about getting my blood clots. So, and at the minute, I'm not taking my 100mg in*

> *the morning. I'm just taking 50 […] But I do need to take some, because I do still suffer hallucinations and stuff, so I'll try and keep that at bay.*

Different participants prioritised different elements of their lives; some participants prioritised elements that were deprioritised by others. For example, David prioritised employment over time with his girlfriend, whereas Ash prioritised child-care over employment. Emily and Sarah prioritised road safety over driving family members places at night, whereas Ash prioritised driving her children to school in the morning over feeling completely safe when driving.

Some experienced multiple, interacting priorities. For example, Ava prioritised work over hobbies, social hobbies over solo hobbies, and social activities at home over social activities outside the home. Others' prioritisations were simpler: one overarching priority directed how they organised their lives. For example, David prioritised employment above all else; Ash prioritised her children above all else, including employment and her own wellbeing. Ash said:

> *After the kids have left, I sit in a heap and do fuck all […] When they're here, I just have to survive every day. That's the rules. That's the rule I have for myself. […] It's for them, it's for them. Everything I do is for them.*

Many described complex interactions between prioritisations: priorities overlapped and/or affected other prioritisations. For example, where Ava prioritised work she had little free time in the evening. Therefore, she prioritised protecting her weekend free time, ensuring she did not work at the weekends; this was unusual in her field. She felt that this was better for her mental health, helping her prioritise protecting this time. However, her phrasing suggested she thought this might negatively impact her career progression:

> *I'll always make sure that I, like, never do work on a Saturday or a Sunday, because if I let myself kind of get in bad habits of doing work on a Saturday or Sunday, like, I think I'd just eventually lose all my free time […] I think, because, like, I don't, you know, have the evening so much. And so, I, like, that is my time […] I think it's actually quite beneficial in a way. Umm, because does probably actually keep me healthier because I've got protected time that maybe I wouldn't have otherwise if I didn't have the problem […] because I feel like [in her field of work], like, you know, there is kind of a pressure to work at weekends, evenings, and just be like constantly working.*

Some explained the reasons behind their prioritisations in the context of their life history. For example, Ash prioritised her children's needs because she wanted to emulate the relationship she had experienced with her deceased mother. Bryony prioritised people not hearing her slur her words over a social life because, in the past, her slurred speech caused her ex-husband to accuse her of being drunk.

Some prioritisations were described in a way that suggested these were without choice. For example, Emily said she "*can't really*" go out at night because she needs to take her antipsychotic; Joanna said she "*needs*" to go to bed early to have energy the next day, and "*couldn't"* be a normal mother or have a job with normal hours because she "*couldn't"* get up in the morning; David "*had"* to get up and go to work, which meant he "*can't"* stay up late to spend time with his girlfriend; Eilish said she "*can't"* get up and do tasks when she needed to prioritise recovering from being trapped in PTSD nightmares due to TRSEs. Several participants used this language to describe prioritising the need to continue to take antipsychotics to maintain mental health.

Some shared reasons for these no-choice prioritisations. The framing of these reasonings suggests they were centred on individuals' values and/or sense of self. For example, Ash explained how prioritisation of her children was based on her value of ensuring her children felt important and loved. David described how his need to work was partially based on how working improved his self-worth:

> *I've spent quite a lot of time off work because of my mental health and I found myself, when I wasn't working, I was tired generally all the time because I, I didn't keep active and stuff. I was just in the house all the time. And I put on quite a lot of weight […] It's helped me lose weight, it's given me a bit more self-worth.*

Some described competing prioritisations which were contrary to their sense of self, or made them feel uncomfortable. For example, Sarah and Emily spoke of not driving when experiencing severe TRSEs because they did not feel it was safe to do so. However, a strong sense of familial responsibility meant this decision was uncomfortable when a family member was relying on Sarah's ability to drive:

> *I am the only driver in the house. It does concern me that if my mum, my mum's disabled, if my mum had a fall at night, or my kids, God forbid, got really poorly at night, I would not be able to take them to hospital, and then I would feel the confliction [sic] between, 'do I risk driving or do I not?' You feel, kind of, I suppose, trapped in some ways because I know I would not be safe to drive after I've taken my quetiapine.*

Reasons for prioritising antipsychotic use centred around a fear of becoming mentally unwell. For example, Bob/Raven explained why she was "*too scared*" to drop her morning dose lower than 50mg.

For some this fear was caused by past experiences of having rapidly become mentally unwell following antipsychotic discontinuation. For example, Ava discussed previously discontinuing antipsychotic use, becoming unwell, and now being scared to discontinue antipsychotics:

> *Ava: When I tried to come off it myself, it's, it's gone really badly, and I've had to start taking it again […]*
> ***Interviewer: So how does how…was that [sic] left you feeling about stopping the antipsychotic?***
> *Ava: Bit scared, I guess, because it's like I feel a bit almost stuck, because I wanna get off it 'cos I don't like the side effects, but and then, almost feels it's going to be super dangerous to get off it.*

For some the prioritisation of antipsychotic use over TRSEs removal was because staying mentally well was necessary for their core value of good parenting. For example, Sarah described prioritising antipsychotic use in this manner:

> *I've made a choice in my life that I want to be happy, I want to be mentally well and if that means I have to sacrifice some things, then I have to sacrifice some things. Ultimately, in my life now, I'm a Mum to three kids, and they're the most important thing.*

Participants' prioritisations often had negative impacts on their lives. For example, Ava described *"missing out"* on social activities at work, suggesting negative impacts on her social life and on future job prospects. Ash described how prioritising her children's wellbeing left her unable to function, tired, and needing to spend time "*catching up"*:

> *When I have the kids I'm forced to get up. And I have no choice. And I get up […] but when they're not here, I sleep 11, 12 hours a day, because I'm on catch-up […] I need that catch-up, whereas other people don't seem to need that. They might lie in for an extra hour, not an extra three hours, four hours. I have to catch-up on my sleep, otherwise I'm a wreck.*

For some, these negative impacts affected their relationships and partners. For example, David described how prioritising work meant spending less time with his girlfriend, making her *"grumpy"* with him. Sarah explained how prioritising her mental health over discontinuing antipsychotics meant her husband had undertaken all the night-time childcare, leading to difficulties in their relationship:

> *This is a big one actually, it's a big one […] I suppose it did put a strain on our relationship at some points. I recall myself and my husband having some arguments about him being, quite rightfully, exhausted, because he's doing the nights, and saying, obviously, I don't know what it's like. I said, 'well, I'll have to come off the quetiapine then'. He's always said, 'no, don't do that', because he knows for me quetiapine helps my mental health. But, as a couple, we've always overcome those moments.*

Some who prioritised the need to rest used language which indicated that prioritisation felt like a "*gift"* they allowed themselves. For example, Eilish became *"trapped*" in PTSD nightmares due to sedation. She *"let"* herself prioritise rest over household chores following these nightmares. This did not detract from the feeling that prioritising chores was something she *"can't*" do. This suggests feelings of confusion within participants as to the extent to which prioritisations are a choice.

Many described experiencing negative emotional impacts from prioritisations. These were unique to each participant. For example, Ash said she "*misses"* working because it cuts at her sense of identity. Sarah used the words "*concern*", "*confliction*", "*scare"* and *"trapped"* to describe prioritising road safety over driving for her family at night. Bryony felt "*sad"* that prioritisation of her night-time routine meant she was unable to socialise at night. Emily described negative emotional impacts from experiencing the competing prioritisations of maintaining a social life, being judged for slurred speech, and ensuring she could sleep at night:

> *Emily: I can't sleep if I don't take them […] Even on the dose I take, I can sometimes be really slurry and I'm in bed by nine o'clock every night if I take them […] because I take the mediation at 6 o'clock, so I can eat at 7 o'clock, I can't go out. If we do want to go out, I don't take medication, and then I can't sleep when I come home. So, it's really a catch-22 situation of whether to take the medication or not […] I do feel like they're ruled my life for10 years.*
> ***Interviewer: and how does that make you feel?***
> *Emily: Angry, really angry.*

This included negative emotional impacts from prioritising continued antipsychotic use over TRSEs removal. For example, Ava described the "*need"* to continue antipsychotics use as leaving her feeling "*stuck"*, and *"scared"*. However, these emotions were often confused and conflicted. For example, Raven/Bob explained she was *"grateful"* that antipsychotics ensured she was "*safe"* and "*alive"*, but that she had "*no life"* and *"everything's just an effort"*. Ash explained a *"love/hate"* relationship with quetiapine. Sarah described how prioritising antipsychotic use was a *"choice"* to *"be happy"*, but that this choice felt like a "*sacrifice*":

> *I've made a choice in my life that I want to be happy. I want to be mentally well […] Even if it means that I now can't do the job that I want to do […], it will hurt because it makes me really sad because it does mean I'm missing out on those aspects of my life. But if it means that I can be mentally well enough that I can care for my three beautiful kids, then I think it's a sacrifice that I have to make.*

Some described feeling not *"normal"* or different to others because of their de-prioritisations. For some this was expressed explicitly. Others expressed this sense of difference by comparing themselves to people who did not take antipsychotics. For example, Ash described herself as different from other parents due to the amount of sleep she needed to *"catch up*". Emily described needing to take antipsychotics to sleep as *"I don't think it's natural"*, and Joanna said she felt unable to be a *"normal"* parent or have a *"normal"* job because she was unable undertake morning appointments:

> *I couldn't be a normal mother because I also wake up late […] so my husband had to take the children to school in the mornings. The fact that I couldn't work because I couldn't have a fixed hour job because of that [not being able to get up in the morning].*

Participants discussed the experience of prioritising elements of their lives in response to experiencing TRSEs. Prioritisations were sometimes simple, but often complex and interacting. Participants also prioritised their own mental health and the wellbeing of their family over the opportunity to reduce/remove TRSEs and impacts of TRSEs. Prioritisations varied by participant, and the participants' values and sense of self. Sometimes prioritisations were not perceived as a choice. Prioritisations could have negative impacts on participants and their partners. Prioritisations often resulted in negative emotions, conflicted feelings, and a sense of otherness.

5.3 "I used to self-harm, which is not the best strategy": the experience of utilising detrimental management strategies and coping responses

In this GET I explore the experience of utilising strategies or behaviours that were detrimental and/or difficult to implement. I investigate how it felt for participants to use these strategies and behaviours, and the extent to which participants felt able to utilise these approaches to reduce TRSEs and impacts of TRSEs.

Participants described the experience of using strategies and behaviours that had negative impacts on their health, work, relationships, social life, or emotions. Often participants gave long and detailed explanations of these negative impacts on their lives, using descriptors such as, *"frustrated"*, *"very stressed"*, *"very annoyed"*, *"really annoy"*, *"enslaved"*, *"sad"*, *"sadly"*, *"sucks quite a lot"*, *"anxious"*, *"not really a good thing"*, *"not the best"*, *"not great"*, *"bit burnt-out"*, *"stuck"*, *"made me feel like shit"*, *"heartbroken"*, *"disaster"*, *"scared"*, *"frightened"*, and *"really hard"*. These detailed explanations and descriptors suggest deploying these strategies and behaviours had detrimental effects on participants' wellbeing and lives.

Which strategies were detrimental varied by participant; some participants found a strategy detrimental when others did not. Sometimes this was due to nuances in implementation which affected the likelihood detrimental effects. For example, many discussed utilising caffeine to assist with waking and reducing daytime sleepiness; only Eilish and Suzanne-Jane were concerned that caffeine use was detrimental. They understood consuming caffeine with sugar and as a carbonated drink to have negative impacts on their health, as Eilish stated:

> *Sadly, I don't burn off the sugar [in the coffee] very quickly, and my body loves to store it*

Other strategies were considered detrimental by some and not others due to personal health risks. For example, Ava made the most of her limited working hours with the strategy of *"do everything really continuously and not really take a break"*. This strategy meant she did not eat properly; this was concerning to her personally due to an historic eating disorder.

Others described utilising behaviours that were detrimental because they had negative impacts on their social life, which created emotional burdens. The positive impacts of these behaviours meant participants continued to deploy them. For example, Ava described changing social activities from going out drinking alcohol to staying in and playing board games, as this made her less likely to fall asleep while socialising and meant it was acceptable if she did fall asleep while socialising. Although this allowed her to socialise, it meant her social circle narrowed, resulting in increased loneliness:

> *Sucks quite a lot to be honest […] this past year, like I've not really made any friends. Like, I've kept the friends that I already have, but I've not really been in social environments, and so I kind of feel a lot lonelier than I did before I started it [antipsychotic]. And that's not to say, like, I don't have friends and I'm completely alone. But, um, I just, in terms of meeting new people or being in these kind of social environments, and just kind of not there really.*

Some described behaviours as detrimental because of others' potentially negative perceptions. These perceptions made them feel negatively about themselves. For example, Sarah left social events early to enable her to attend events while take her antipsychotic at a set time, reducing daytime sleepiness the next day. She was concerned others would not understand why she was leaving early and was reluctant to explain her mental health diagnosis or medication to others. Although she used this strategy, it made her feel "*anxious*", *"enslaved"* to the antipsychotic, and different to others:

> *I am a bit anxious, the fact we have a wedding coming up that me and my husband are going to in a couple of weeks' time and I am anxious that we'll probably have to leave the wedding early because I know that I have to take my quetiapine. Again, that's one of the reasons why it makes me feel enslaved, because it dictates part of our lives, part of his life, as well, even though he doesn't take it […] I think it makes me anxious because it's almost, I never tell people why we're leaving early. I always tell them, 'sorry, I'm really tired,' is what I go with and then I say, 'oh, I've got to take my medication.'. But, I think it makes me anxious because it's not normal, it's not normal to have to leave somewhere early because you've got to go take some medication that's going to make you feel really tired and then [if you take it at the social event] you're going to be stuck there because you're not allowed to drive.*

Participants described experiences of abandoning some strategies and behaviours due to detrimental effects. This left them with TRSEs and impacts of TRSEs that were unmanageable, resulting in negative impacts on their emotional state and mental health. For example, Sarah described utilising a succession of strategies for coping with the emotional burden of being unable to undertake tasks due to TRSEs. Physical health concerns caused her to abandon each strategy in turn. The remaining, unmanaged, emotional burden affected her mental health:

> *I used to self-harm, which is not the best strategy, then I started smoking instead, quit smoking, then I started eating chocolates […] I had a big operation in December [bariatric surgery], they removed 80% of my stomach and then suddenly I couldn't use my coping skill of eating sugar [...] and my mental health plummeted.*

Participants also described experiences of continuing to use detrimental strategies and behaviours. Potential impacts on wider health and wellbeing left participants worried when implementing these approaches. Detrimental effects included potential negative impacts on participants' health, relationships or social life, and definite negative impacts on emotional states. For example, Raven/Bob was concerned that utilising alcohol to lessen the emotional burden of reduced social life and hobbies increased her cardiovascular risk, but continued to use alcohol as she lacked other approaches. This resulted in a continued state of worry about her health:

> *I do try and have a word with meself [sic] in the week, 'don't have them beers, come on, I, don't do it'. I keep getting [heart] palpitations and me heart keeps hurting. I think, 'slow down, don't hit the beer'.*

Some described continued use of detrimental strategies as a balancing act: attempting to minimise the detrimental effects while maximising reduction of TRSEs. These descriptions suggest further emotional load and cognitive burden from continually reassessing this balance, and from continuing to experience the impacts of the TRSEs and the detrimental effects of the strategies. For example, Ash reflected that reducing her antipsychotic dose made it easier to get up in the morning. However, her depressive symptoms had increased, resulting in increased tiredness. In response she attempted to balance increased depression against the improved TRSEs. Her description of this as *'ironic"'* suggests a frustration at both the detrimental nature of the strategy and the requirement to deploy it in this balancing manner:

> *I've noticed, actually, ironically, since I've reduced it this time, I've had less energy. Because I've been slightly more depressed, since I've reduced it, I've actually had less energy than I did at the higher dose. Which is…you know, that…one of the reasons I reduced it was so that I would have more energy. And it is easier to get up in the morning. Marginally. But, I've been more depressed in the day. It's harder to get in the shower. It's harder to be around people. Social media pisses me off […] it's a balancing act*

The detrimental nature of strategies led to some using these strategies sparingly, making these strategies of limited use for reducing the impact of TRSEs. For example, Emily described how she could omit an antipsychotic dose to socialise in the evening. However, this was constrained by negative impacts on her mental health, meaning that she used this strategy infrequently:

> *I mean, we do [go out]. It's just that I have to not take my medication […] but we do go. It's just that I don't take my medication that night. I couldn't do that every week […] it would be too much of a break in the medication.*

Participants did not explicitly describe how they decided whether or not to abandon a detrimental strategy. However, some compared detrimental strategies that they abandoned with ones they continued to use. These comparisons suggested abandonment decisions depended on the severity of negative impacts. For example, David described similar detrimental impacts when using both cannabis and the antidepressant fluoxetine to reduce the emotional burden of TRSEs, but discontinued only fluoxetine, due to more severe impacts:

> *I do smoke a little bit of weed occasionally and that sort of helps me with anything […] I would say the negative side of it is that drugs [cannabis] obviously make your mental health bad and that's probably a lot of the reason why people have mental health issues is because of drugs, so obviously smoking drugs to deal with issues isn't really a good thing […] I did take something called fluoxetine which probably does something similar to weed. And it just*

> *made me feel like shit to be honest, I felt really shit on it, so I just stopped taking it after a short while. Yeah, yeah, I didn't like the fluoxetine at all, it was really like one of the worst meds I've had […] and it just made me feel really tired and lazy and just defeated […] I was just really depressed*

Many described experiences of using some behaviours and strategies that were difficult to implement. The extra cognitive or emotional burden reported by participants when using some of these strategies and behaviours suggests that using them was detrimental to participants.

Sometimes participants found strategies and behaviours difficult to implement and detrimental because they required planning for multiple unknown variables, some of which were outside participants' control or knowledge. For example, Suzanne-Jane described using exercise to reduce daytime tiredness. She was unsure if exercise would reduce or increase daytime tiredness on a particular day, and could only speculate about the reasons for these variable results:

> *Suzanne-Jane: I think it definitely helps… erm… but there are some times when I'm just really tired and then I'll do a workout and it just makes me more tired and I end up just going to back to sleep, so sometimes it doesn't always work.*
> ***Interviewer: Mm, why do you think that is?***
> *Suzanne-Jane: I don't know, I think maybe if I'm like really, really tired, like, maybe I've had a really busy day the day before, or I haven't slept as well, and then I just need that extra sleep maybe.*

Participants' descriptions suggest that difficult to implement strategies created a cognitive burden, as participants tried to understand and adjust for the multiple variables and/or an emotional burden from the uncertainty about whether the approach would work. Often this interacted with the burden of balancing positive and negative impacts of the strategy, compounding the negative impacts of these strategies. For example, Ash described the difficulty and cognitive burden in deciding the appropriate time to take her antipsychotic to minimise TRSEs when socialising:

> *It's always like, 'do I take my quetiapine now, or when I get home?', and I have to factor in not just the 25 minute drive from [place], but also that I'm going to need 30 minutes when I get back in to take the quetiapine […] when I've been dancing or something like that […] when I get home, my quetiapine, I know it won't kick in the same [as when I have been at home] […] because I've been social, because I've got endorphins [from dancing] in my body […] should I leave earlier? How do I factor in…? Do I take my meds before I drive home? Is that dangerous? I don't know how long it's going to take for them to kick in. There's all sorts of factors, you know?*

Some described strategies which were difficult to implement because they required energy to undertake. This meant participants were less able to use the strategies when they would be most beneficial. This left participants with feelings of frustration and anger. For example, Ash explained her feelings about using exercise to increase energy:

> *And I noticed, for the next couple of days, I had way more energy – for housework, for everything. I really noticed a difference. And I was, like, this is bullshit, that these things people tell you, like you should do more exercise and whatever, it's bullshit that they actually work. I know I have to do them but, like, I still don't do them. The… You don't have the energy to do the thing that's going to give you more energy.*

Not all difficult to implement strategies were experienced as inherently detrimental. Some strategies were difficult to implement because they only worked sometimes. Again, the burden of implementing these strategies was compounded by uncertainty regarding how the strategy would work. For example, David, Bryony, and Emily described using caffeine to reduce daytime sleepiness; at an unpredictable time of day this strategy became detrimental, as caffeine made it difficult to sleep, increasing daytime sleepiness the next day:

> *David: It works sometimes and then it works really, really, well, it's going to keep me awake all night, but then I'm really tired in the morning.*
> ***Interviewer: why do you think it works sometimes and not other times?***
> *Daivd: Erm, I'm not sure, not sure, maybe if I've eaten more or drank more fluids or something. Or had a hard day at work.*

Some described utilising strategies that were difficult to implement due to personality or personal preferences; some participants linked these preferences to ADHD and/or autism. These strategies were impossible to implement consistently, or impossible to implement at all. Unlike other detrimental strategies, participants' language suggested an emotional burden from being *unable* to utilise strategies they perceived should be successful. For example, Ash found going to bed regularly to reduce daytime tiredness difficult due to ADHD making everything *"really interesting"* at night. Ava described taking her antipsychotic at a regular time to aid getting up the next day as difficult because planning was *"not something I'm good at"*. Eilish found using exercise to reduce daytime sleepiness difficult due to insufficient finances, being unmotivated to exercise solo, and having insufficient energy to socialise or exercise in the morning or evening:

> *I used to think 'did exercise work in the morning?' […] it actually just made me more tired and grumpy […] I've never been an early morning person, so no, committing to a 7 o'clock in a morning, getting up and getting into [place] for between quarter to and then set everything up and greet people […] not being able to afford doing all the fitness I would like I do have less energy […] I just find that managing my time to put in exercise because I don't have a friend literally on my doorstep to drag me out […] I've never been good at isolated, solo activities, so you'd never find me going running […] it has to be at the right time of the day. I'm not going to, again, I'm not good late at night.*

Some described strategies as difficult to implement and detrimental if being able to utilise them was outside of their control: they felt powerless, or trapped. If these strategies became within the participant's control then they ceased to be difficult to implement, and ceased to be detrimental. For example, Emily, described using flexible working to rest in the day when needed. Initially she found this difficult to implement, creating negative feelings; this changed as it became easier to accrue the flexi-time required to implement the strategy:

> *Emily: It used to really annoy me, but do you know, that what it's there for. It's there to help when things aren't right.*
> ***Interviewer: […] what changed?***
> *Emily: Having more flexi, actually clocking up more flexi-time than I used to.*

Others described strategies as difficult to implement because other people prevented them from using the strategies. Switching antipsychotic, changing doses and ceasing antipsychotic use were described in this way. Participants reported increased emotional burden because it was impossible to implement these strategies, including being *"stuck"*, and disempowered. For example, Ava explained lack of choice around antipsychotic use, and the resulting emotional challenges:

> *I've felt a lack of choice about being on quetiapine. For like quite…for maybe six months now, even longer, in fact, almost maybe like 10 months…I've been asking, I've been saying, like, 'I don't wanna take it anymore, 'cos the sedation's too much' and I've basically been told, 'no', or like, 'you'll get used to it', or 'this isn't an appropriate time to be taking you off, because you're too unwell' […] it's just like, trying to manage my emotions by being like, 'ohh, I'm gonna stop taking it', but then basically not being allowed to.*

For some this lack of choice created an emotionally driven need to take control, which also had detrimental effects. For example, Joanna, Sarah and Ava described experiences of reacting to this loss of control by ceasing antipsychotic use abruptly and without clinician assistance, resulting in rapid deterioration of their mental health. Sarah stated:

> *I was like, 'no, I'm not doing this anymore', so I completely stopped because that's when I was feeling really lethargic and I couldn't string my words together, couldn't think to the point that sometimes I couldn't see. I couldn't follow a TV programme even […] I just literally went cold turkey, I was like, 'no, come off it'. Obviously, that had a big detriment to my mental health and I got sectioned again, but I felt at that time no one would listen to me.*

To summarise, participants found some strategies and behaviours had detrimental effects on their health, social life, relationships, and emotional state. Which strategies and behaviours were detrimental varied according to participants' approach to implementation and personal health risks. Where participants continued to use detrimental strategies and behaviours this created emotional and cognitive burdens from deciding how to implement the strategy. Some strategies and behaviours were detrimental because they were difficult to implement. Participants found some difficult to implement strategies detrimental because attempts to understand the circumstances under which these strategies worked created additional cognitive and emotional burdens. Some strategies were difficult to implement due to energy deficit or other circumstances outside of participants' control. The inability to implement potentially useful strategies created emotional burdens, and attempts to reassert control often had detrimental impacts on participants' health.

5.4 *"There's an acceptance that I can't change it"*: the experience of coping with unmanageable TRSEs via acceptance

In this GET I describe the experience of accepting TRSEs and impacts of TRSEs that could not be otherwise managed or reduced. I discuss participants' varying understandings of acceptance, what participants applied acceptance to, how the experience of acceptance felt and how acceptance took place.

Participants described experiences of using acceptance to cope with TRSEs and the impact of TRSEs that could not be otherwise managed. This included accepting being un*"able"* to undertake activities. Some explicitly used the word acceptance to describe this experience. For example, Suzanne-Jane described how she managed feeling frustrated at being unable to do everything she wanted:

> ***Interviewer: I was just thinking now, [Suzanne-Jane], about sort of the feelings that are attached to the side effects: so you've said several times about frustrated and sometimes even angry about, erm, not being able to get things done or being very sleepy, erm, have you had any experiences trying to manage those feelings?***
> *Suzanne-Jane: Just accepting it really, erm, and accepting that it's OK, like, if I have to sleep a bit more.*

Others described experiences akin to acceptance, without using the word. For example, Raven/Bob discussed *"adjusting to this different life"* because she was unable to dance, play guitar, go shopping, or socialise. Similarly, Bryony explained attempting to persuade herself that her inability to undertake household tasks was permissible by using the words, *"it's OK".*

What participants attempted to accept varied by personal experience of how TRSEs impacted them, the severity of impacts, individual priorities, personal circumstances, and sense of identity. Participants discussed three situations to which they applied acceptance: continuing to take antipsychotics and therefore having to continue to experience TRSEs; being unable to undertake activities due to TRSEs; negative emotions arising as a result of the first two situations. For example, Sarah discussed acceptance throughout her interview, accepting that she could not contribute equally to childcare and was unable to undertake some household tasks. She also accepted the negative emotions from being unable to undertake tasks, needing to continue to take antipsychotics, and continuing to experience TRSEs:

> *We've just had to get on with it [husband taking responsibility for nighttime childcare] and it's kind of there's an acceptance that I can't change it, I can't stop it.*

Some described experiences of attempting to accept TRSE impacts that sat opposed to their sense of identity. This made acceptance harder. For example, being unable to work in an intellectually stimulating job when they perceived themselves as academic, needing to ask for help with household tasks when thought themselves independent, no longer being active and social when they saw themselves as a social party-goer. For example, Raven/Bob explained how she would like to adjust to being inactive, but she was unable to as it sat opposed to her sense of self:

> *This is…the most... I'm a very, I used to be a very, very active person, always partying, jumping around. It's being back on this medication. My life is literally stopped. And I'd like to adjust to it, which I can't adjust to, because I'm not that kind of person, but the medication makes you gonna do nothing.*

Some accepted TRSEs and impacts of TRSEs that others found unacceptable. For some, this was due to perceptions of control; participants were more likely to accept TRSEs and impacts of TRSEs they could not otherwise control. For example, Ash, Sarah, and Ava described having to continue antipsychotic use to stay mentally well, and the resulting need to accept they would continue to experience TRSEs. In contrast, Emily discussed gradually reducing her antipsychotic usage, aiming to discontinue and no longer experience TRSEs. Emily's different experience was due to a conversation with a clinician who changed her perception of whether antipsychotics were necessary to keep her mentally well. This created a choice about whether she continued to experience TRSEs. This move from acceptance towards choice was uneasy; it gave Emily hope for life without TRSEs, but left her without a strategy should her new perception prove incorrect:

> *We're just going to gradually, gradually come down, and I think that's the only way to do it. And I don't know what I'm going to do if I get to that point where I can't give them up.*

For some, the perception of choice overlapped with experiences discussed in other GETs: when the undertaking of detrimental prioritisations and every-day behaviours was perceived as without choice this helped participants apply acceptance and reduce the distress caused by these behaviours.

For some, their inability to control TRSEs shifted the role of acceptance to others. For example, Joanna felt little control over being able to undertake morning appointments, meaning that friends and employers had to accept her being late:

> *I meet with friends in the mornings. No. They need to be* patient*, I'm sorry. [Laughs]. And they are very patient.*

The need for others to accept the impacts of TRSEs could impact some participants' relationships. For example, although Joanna spoke of being *"lucky"* that people understood that she might be late, David spoke of his girlfriend needing to *"put up with"* the impacts of TRSEs on their relationship. This suggests her acceptance had negative impacts on their relationship.

Participants applied acceptance in different ways. Sometimes acceptance involved avoiding thinking about the TRSEs. For example, Eilish described busying herself in other thoughts to reduce the emotional load that she experienced from TRSEs:

> *I've learnt to just not dwell on them.*

Other times acceptance was via attempts to reframe experiences. For example, Sarah described accepting being unable to undertake household tasks by reframing the experience away from *"failure"* towards *"busy"*; Ava explained how she attempted to reframe changes she has made to her life to accommodate TRSEs by looking for alternative justifications and downplaying negative impacts on her lifestyle:

> *I guess in a way I was like, 'ooh, it's financially a good choice too'. I don't know or like, tried to be like 'I don't have the time for this', 'it's just how it is'. I just think I just framed it as, like, 'it is how it is', like, 'it's fine'.*

Participants discussed how it felt applying acceptance. Acceptance via not thinking about TRSEs was often accompanied by perceptions of insufficient alternatives. Participants' role in this acceptance was often passive, rather than deliberate. This was expressed by language such as "*have to*", *"just"*, *"guess"*, *"put up with"*, *"deal with"*, "*get over it"*. For example, David described how TRSEs reduced his ability to think quickly, making it impossible to have a job which required him to be *"intelligent"*:

> *I just sort of deal with it by just, just have to deal with it, yeah, just get on with life.*

For many the experience of applying acceptance is contrasted to the need to *"fight*" against TRSEs. Participant language suggested that continuing to fight TRSEs was unwise. Often this was in the context of participants accepting the needed to continue antipsychotic use, as Sarah stated:

> *I tried the other way, I tried not accepting it, I tried to fight it and say, 'No, there's nothing wrong with me mentally, there's nothing wrong, I don't want to take these drugs. I hate the side effects, I've tried it your way, I'm going to stop taking it'. Then I get sectioned and get sectioned [again]. Now I've just accepted that, actually, to be able to function normally I have to take it.*

Some aligned not fighting TRSEs with reductions in how much they "*cared*" about the impact of TRSEs. This reduction in fighting and caring supports the suggestion of passive acceptance. Ava said:

> *A lot of it is just kind of acceptance, not trying to fight it […] just like, I don't know, just accept it and not give a shit.*

For some applying acceptance affected how they perceived themselves. Resulting perceptions varied, being positive or negative. For example, David described accepting he had to spend less time with his girlfriend as *"selfish"*, whereas Bryony described accepting help as "*brave"*.

Being able to apply acceptance gave participants relief from the emotional burden of TRSEs, giving them space from thinking about the impacts of TRSES on their lives, or allowing them to be kinder to themselves. Some described this acceptance as *"important", "freeing"*, allowing them to *"not to punish myself about it"*.

Participants found acceptance difficult to apply: having to make conscious efforts to accept or not to think about the impact of TRSEs. Not caring could be difficult; some used humour and/or alcohol or cannabis to enable reductions in caring:

> *I'll just allow the beer to come in […] don't worry about it […] I'd never be able to do what I do without one or the other [alcohol and cannabis].*

Therefore, acceptance was not completely successful; it often required continuous application, with variable results. For example, Bryony described continually having to apply acceptance to being unable to undertake household tasks:

> *I'm reminding myself constantly that it's OK to not hoover for one day.*

Participants described acceptance as becoming easier over time, because they increasingly recognised it was helpful. For example, Eilish explained an increased ability to accept that she needed to allow herself rest after being trapped in nightmares due to TRSEs:

> *It used to be hard, but now I just think, 'no, I need to do it, it's important.'*

Some described acceptance as a skill they had learned from other difficult life experiences. Learning this skill involved working through difficult life experiences on their own or with a therapist who taught these skills. Positive experiences of utilising acceptance gave participants the desire and ability to apply these skills to TRSEs. For example, Ash described learning acceptance during her divorce and applying this to TRSEs:

> *It's [being more accepting] been a…a very freeing …and then you want to apply that sort of free feeling to the other things in your life.*

For some, acceptance by friends and family made their own acceptance easier. These friends and family either supported continued antipsychotic use, or knew how it felt to experience TRSEs, making it easier to accept the impacts of TRSEs. This reduced participants' internal and external perception of fault and/or laziness. For example, Raven/Bob spoke about it being more acceptable for herself and her friend to be tired and to rest more because her friend's husband had accidentally taken his wife's antipsychotics and experienced severe TRSEs:

> *I actually said to him the other day I said, 'I'm really glad you've actually experienced Seroquel now. OK, it was 900 mg, but….' He went, 'I couldn't talk, thought I was having a stroke.' 'Well, there you go'. […] he's like, [about] his wife, goes, [mock complaining voice] 'Ooh! She's always asleep in the afternoon!!'. But now he's like, 'now I know why she's like that'.*

Other participants were able to foster acceptance without others' acceptance. For example, Ash described becoming more accepting of being unable to work due to TRSEs, and other people's perceptions of her being unable to work. She explained this was because of changes in her attitude, her ability to live in the present, and positive experiences of applying acceptance elsewhere. This experience also demonstrates challenges in applying acceptance: Ash discusses caring *"less"* about being unable to work and people's perception of not working, but highlights she still cares and has residual feelings of frustration and loss of identity:

> *Other people don't understand. They look at you and they think… people look at me and they're, like, 'Well, you're not really ill, are you? Benefits scrounger'. Oh, I don't care anymore […] I used to care, it used to make me care, yeah. And I still feel… I still feel like I miss my job. […] I was good at it […] I would love to work, um it's so frustrating, for me, that I am on benefits in the first place, um, as someone who is an intellectual, who is a go-getter, who likes to be busy. And, so, part of being upset by people saying that……was feeling like… I guess I used to feel like, 'Oh, I'm not like those other people,' but I don't even feel that now, […] I care less about everything now. I think part of it is… I don't know if this is the quetiapine, but it's definitely age. Age has increased this, and my ADHD getting worse has increased this. […] I sort of got into Buddhism a bit, in about 2016, it was when I gave up alcohol and I changed my lifestyle a lot in 2016. But living in the present is part of that. And it definitely became something that I could do more, and it has made me happier and healthier to do that.*

Some explained they found it easier to accept feelings of loss if they could identify past or present experiences that were analogous to the experiences they were unable to undertake. For example, Raven/Bob and Ava used previous experiences of good social lives to help accept current poor social lives. Suzanne-Jane described life experiences that made it easier to accept being unable to have children. This acceptance, although helpful, did not eliminate negative feelings:

> *I guess part of it is accepting it again. Erm, and then part of its like I've got my nephews, and I, I see them, and I like, I work, I do my voluntary work with children. So, it's still a bit of experience it, but maybe in like a different way.*

The multiple factors that affected acceptance meant that some perceived acceptance as a journey, becoming easier over time. For example, Sarah described taking 15 years to accept she had to continue antipsychotic use and continue to experience TRSEs, the emotional impact of being unable to work, being unable to socialise outside, and being unable to contribute equally to childcare. She spoke of how removing undesirable management strategies left her without other strategies and a loss of choice, of acceptance and peer support from her friends and husband, of learning acceptance skills. Together, these factors led Sarah to a position of acceptance:

> *It's taken a long time to get there, it's taken a long time, it's taken 15 years to accept it, I think because I don't have any other choice […] I used to self-harm, which is not the best strategy, then I started smoking instead, quit smoking, then I started eating chocolates. […]I think it helps you to accept that it's okay because other people have that experience as well, it helps you to accept it […] I think having that, those other people like my husband who doesn't bat an eyelid that I take this drug and stuff like that really helps you to accept it yourself as well. […] Behaviour change therapy, which also helped with the whole self-acceptance stuff.*

Overall, acceptance brought participants some relief from the impacts of TRSEs they felt unable to otherwise manage. Whether applying acceptance could feel positive or uncomfortable depended on individual contextual factors. Participants applied acceptance both via efforts to not think about TRSEs and by attempts to reframe the negative impacts of TRSEs. Positive experiences of successfully applying acceptance were muted for some by challenges in creating acceptance and acceptance requiring constant application. Difficulty in applying acceptance meant some perceived acceptance as a journey which became easier as skills and accumulated life experiences increased participants' ability to accept.

Chapter 6: Discussion

In this chapter I begin by summarising the findings of the empirical study, and outlining the impact and implications of conducting the empirical study within a critical realist paradigm. I then place empirical findings in the context of existing evidence, first from the scoping study (chapter 3), the wider evidence, and then within the context of theory. I consider the implications of these findings for policy, practice, and future research. Empirical study strengths and limitations are then discussed, including a statement of quality. I also present some reflections on my learning, including a final reflexive piece. The chapter concludes by outlining how the scoping study and empirical findings offer original contributions to knowledge.

6.1 Summary of findings

I aimed to explore the experiences of people with mental health conditions who report long-term antipsychotic tiredness-related side effects (TRSEs). From the empirical study I produced four group experiential themes which explored the experience of managing/coping with TRSES:

1. *"It's what I do. It's part of me now. It's like second nature"*: the experience of TRSEs and responses to TRSEs becoming a part of one's life.

2. *"I've made a choice in my life that I want to be happy, I want to be mentally well and if that means I have to sacrifice some things, then I have to sacrifice some things":* the experience of prioritising one element of one's life over another.

3. *"I used to self-harm, which is not the best strategy"*: the experience of utilising detrimental management strategies and coping responses.

4. *"There's an acceptance that I can't change it"*: the experience of coping with unmanageable TRSEs via acceptance.

These group experiential themes are based on my understanding of the participants' words. As such, they report the researcher's interpretation of the participants' experiences. As stated within the methodology chapter, although these findings are not considered generalisable, their transferability allows scope for tentative discussion of implications for theory and wider practice.

6.2 Implications and impact of critical realist paradigm on findings

I conducted this study within the context of a critical realism paradigm. This has several implications for the findings:

1. Aligning with Fryer's arguments regarding the value and purpose of adopting a critical realist approach (Fryer, 2022), the issue of causation was considered, including:
    a. The search for causes
    b. The use of retroductive thinking (i.e., the most likely/best explanation for what must have happened for the event to occur)
2. Aligning with Bhaskar (2014), in the discussion of findings I acknowledge the difference between the empirical, actual, and real. This includes the understanding that findings, while not generalisable, are tentatively transferable within context.

To do justice to the phenomenological position, the exploration of causation within this study was assumed to reflect participants' perceptions of causation, rather than necessarily an objective understanding of causation. Some examples of causation were offered directly by participants, for example, offering their personal values, other diagnoses, or other life experiences, as reasons for their responses to TRSEs, and why certain coping/management strategies did or did not work. Analysis of and acknowledgement of these have contributed to the richness of these findings: this has allowed for a detailed exploration of individual first-hand experience in line with IPA and phenomenology, while also creating tentatively transferable causal understanding: findings from Bhaskar's 'empirical' plane of knowledge that can be transferred to Bhaskar's 'real' plane of knowledge. For example, it may be useful for people whose priorities are paid work to prioritise employment in order to cope with TRSEs, but it is likely that this approach will not be seen as feasible for people whose priority is parenting.

Retroductive thinking within the analysis involved applying the most likely reasons for participants' use of language and different experiences. Examples of retroductive thinking included: where the findings report that participants' use of downplaying language was understood to suggest that becoming accustomed to TRSEs helped reduce the distress caused by experiencing TRSEs; the interpretation of 'I can't'/'I don't' language as meaning participants felt a lack of choice about their behaviour. To acknowledge the first-person focus of phenomenology, this retroductive thinking is cautious; it is presented within the hermeneutic approach of exploring language and societal context, and the double-hermeneutic cycle of the findings representing the researcher's interpretations of participants' experiences: i.e., language use is *suggestive.* These examples of retroductive thinking, while cautious, identify intangible elements of causation that may be missed via other causal approaches, such as choice and power, the wider implications of which are explored in more detail later in this chapter. Bhaskar's (2014) planes of reality allow us to explore the wider implications of these findings while retaining philosophical congruence. For example, while findings are not expected to represent the full range of experiences, or the full nature of the 'real', careful thinking about in which context(s) the empirical experiences reported in this study are relevant allows for cautious generalisability/transferability. Undertaking an IPA study from a constructionist paradigm would have made these discussions more challenging and perhaps philosophically incongruent. In deference to this transferability, sections 6.3 to 6.6 below discuss the transferability of findings within the context of existing evidence, wider evidence, and theory.

6.3 Findings within the context of existing evidence

In this section I place the empirical study findings in the context of existing evidence regarding managing and coping with TRSEs from the scoping study, and other existing evidence regarding the impact of TRSEs on people who experience them. In section 6.4 I place the findings of the empirical study within the context of wider evidence.

6.3.1 *"It's what I do. It's part of me now. It's like second nature"*: the experience of TRSEs and responses to TRSEs becoming a part of one's life

Participant responses to TRSEs interpreted to have become part of their everyday lives included lifestyle/behavioural changes. This mirrors, yet adds detail to, the evidence detailed in the scoping study. For example, the use of some lifestyle/behavioural changes to manage TRSEs (exercise, routine times for medication, meal and bed) are mirrored in Meehan et al. (2011) (section 3.3.3.4). In the present study participants also discussed making other lifestyle/behavioural changes to cope with TRSEs, including changes to socialising, changes to sexual and romantic relationships, changes to employment and working patterns, changes to childcare responsibilities, and no longer drinking alcohol; these are novel and not reflected in the evidence detailed in the scoping study.

The focus on participant experience in this present study adds detail to what it is like to utilise these lifestyle/behavioural changes. For example, although participants reported that these changes were difficult to implement, changes were easier to make if they became understood as being part of one's everyday life. Furthermore, as a result of lifestyle changes becoming part of participants' lives over a long period of time, it was difficult for participants to reflect in detail about these changes and difficult to understand whether lifestyle changes were a response to TRSEs or due to personal preferences. Participants were often distressed by realising they had subconsciously rearranged their lives to accommodate TRSEs; more purposeful changes to manage TRSEs were perceived more positively.

6.3.2. "I've made a choice in my life that I want to be happy, I want to be mentally well and if that means I have to sacrifice some things, then I have to sacrifice some things": the experience of prioritising one element of one's life over another

The analysis of experience in this group experiential theme adds further detail regarding how lifestyle changes are deployed: often the lifestyle/behavioural changes participants made in response to TRSEs meant that they had to choose to change one element of their lifestyle in order to maintain another. For example, they felt they had to choose whether maintaining their bedtime routine was more important than socialising or having a sexual relationship. Constantly needing to assess and prioritise different elements of their lives to deploy lifestyle changes was emotionally burdensome. Deploying lifestyle changes left participants feeling sad, frustrated, and with a sense of otherness. This adds further, deeper understanding of the experience of deploying the lifestyle/behavioural changes identified by Meehan et al. (2011).

Participants in the present study also discussed experiences of reducing or discontinuing antipsychotic use in order to manage TRSEs. This aligns with existing evidence, which shows that people experiencing TRSEs were more likely to discontinue or reduce antipsychotic use (Bessonova et al., 2020; Davis et al., 2014; Doane et al., 2020), and the evidence collated in the scoping study which suggests that people experiencing TRSEs might reduce, switch or discontinue antipsychotic use in order to improve their ability to undertake daily activities (Morrison et al., 2015; Read & Sacia, 2020; Read, 2012) (section 3.3.3.1). In this present study several participants described a fear of mental health symptoms returning, which prevented them from making these changes to antipsychotic use; these findings also align with the evidence collated in the scoping study (Morant et al., 2018) (section 3.3.3.1). The present study helps us understand why: for many this fear was based on past experiences of changes to antipsychotic use being followed by mental health symptom relapse. This had led participants to a position where they perceived continued antipsychotic use as a prioritisation of mental health wellbeing over TRSE reduction.

6.3.3. *"I used to self-harm, which is not the best strategy"*: the experience of utilising detrimental management strategies and coping responses

Analysis in the empirical study showed that participants found many strategies and coping responses detrimental and difficult to implement. Some of these strategies were lifestyle/behavioural changes identified by Meehan et al. 2011 within the scoping study (section 3.3.3.1). However, understanding of how difficult participants found these to implement, and the resulting emotional fallout, is novel. For example, for many, exercise was a difficult strategy to implement; it was unpredictable whether it would increase or decrease energy, could not be deployed when it was needed most, required financial resources, and needed to match personal preferences in the way it was deployed. Lack of success in deploying exercise as a management strategy could lead to frustration. Participants found using medication and bedtime routines difficult to implement, especially if they had concurrent neurodivergent diagnoses. Utilising caffeine to combat TRSEs was experienced as difficult because effectiveness varied unpredictably on a daily basis, and because use of caffeine later in the day could interfere with sleep, increasing future TRSEs. Participants also reported other lifestyle/behavioural changes not reflected in Meehan et al.'s work as having negative impacts on them (e.g., changes to working patterns, reduced socialising, fewer childcare responsibilities, and accepting help from family with childcare and chores). This included feelings of missing out, negative impacts on relationships with partners/family, lack of relief from the emotional burdens of TRSEs, and negative emotional impacts from a lack of choice in whether to use these strategies.

Coping responses that participants understood to have negative impacts on their health were experienced as detrimental or undesirable. These included, use of caffeine, use of certain antidepressants, use of cannabis, overeating, alcohol, skipping meals and self-harm. Some of these responses appeared to be understood as inherently detrimental, regardless of the context of their use (e.g., cannabis, overeating, self-harm). Others were only perceived as detrimental if the participant perceived themselves to be at increased risk of negative impacts on their health (e.g., caffeine, alcohol, skipping meals). The focus on experience in the empirical study highlighted in detail the experience of using responses that could have detrimental impacts: detrimental impacts only prevented participants from using a coping response if the detrimental effects reached an intolerable severity. Where participants continued to use responses with detrimental impacts, this created an emotional burden on participants as they worried about the impact of these strategies on their physical and mental health. Most of this was novel: only the use of caffeine was predicted by the existing evidence collated in the scoping review (Meehan et al., 2011; Thompson et al., 2014). Notwithstanding this prediction, Thompson et al. conducted their study with an apparent assumption that caffeine use was inherently detrimental to health, without exploring participants' experiences and perceptions of using caffeine as a coping response.

As mentioned above, participants in the present study also discussed experiences of reducing or discontinuing antipsychotic use in order to manage TRSEs, but for many, their fear of mental health symptom relapse and/or disempowerment by their clinicians prevented them from using this approach. This was predicted by the evidence including in the scoping study (section

3.3.3.1): some included study participants reported both the return of symptoms following discontinuation and/or disempowerment regarding antipsychotic changes (Morant et al., 2018; Read, 2012). The present study adds detail here: the resultant increase in mental health symptoms made it difficult for participants to create improvements in energy, tiredness and functioning, as increased mental health symptoms could also make it difficult to get up in the morning, to feel awake, and to undertake daily activities. A further subtlety in understanding added by the present study was participants' past experiences of discontinuing antipsychotics. In response to clinicians creating barriers to antipsychotic changes, participants had previously stopped antipsychotic use suddenly and without clinician support, resulting in severe mental health relapse. A final additional understanding created by this present study was the experience of reducing antipsychotic doses in an attempt to find a balance between symptom management and minimising TRSES; this felt like an unsatisfactory compromise. Overall, attempting to change antipsychotic use to manage TRSEs left participants feeling disempowered, trapped and frustrated.

6.3.4. *"There's an acceptance that I can't change it"*: the experience of coping with unmanageable TRSEs via acceptance.

Participants in the empirical study discussed using acceptance to cope with TRSEs when they lacked alternative strategies. For example, where detrimental strategies left participants with residual challenges and emotional burdens, or prioritisations resulted in some impacts of TRSEs being otherwise unmanageable, participants' only alternative approach was to utilise acceptance. To a certain extent, the use of acceptance to manage TRSEs was predicted by the evidence included in the scoping study: some participants accepted the amount of extra sleep required and the extent to which antipsychotics sedated them, as they perceived they had no other available approaches (see section 3.3.3.2) (Morant et al., 2018; Morrison et al., 2015). However, analysis in the present study showed participants applying acceptance not just to the existence of TRSE, but also the impact of TRSEs on their lives. This included: accepting being unable to undertake household chores and activities, reduced social life, reduced ability to contribute to parenting, reduced ability to be employed, needing to continue to take antipsychotics, continuing to experience TRSEs, and increased emotional burdens from these experiences.

Additionally, this present study offered an opportunity to explore the experience of accepting TRSEs. Similarly to Morrison et al., analysis in the present study demonstrated participants deploying acceptance both explicitly and by downplaying the severity of the impact of TRSEs on their lives. However, the present study added greater detail to the experience of applying acceptance. For example, analysis showed that acceptance was not participants' immediate response, took time, and could be considered a journey. To some extent this reflects Morant et al.'s (2018) finding that for some there was a "difficult journey of acceptance" (p.234). However, in the present study this difficult journey was a common experience across all participants. Additionally, as acceptance was experienced as a response that could only be applied to aspects that were impossible to manage in other ways, participants had to choose between practical attempts to address and change TRSEs, and using acceptance to reduce the emotional burden of experiencing TRSEs.

Finally, the present study offers new insights into how applying acceptance to TRSEs may feel. Although participants discussed acceptance resulting in emotional relief, many described acceptance as difficult to apply, requiring constant application and sometimes requiring participants to think in ways contrary to their sense of sense. A novel finding is that participants described acceptance as if it were a skill that needed to be learned before it could be applied. These acceptance skills were gained through life experiences or working with professionals to accept other difficult aspects of their lives. Participants explained that support by friends and family could also help participants in deploying acceptance; where friends and family were understanding and accepting of the impacts of TRSEs, participants felt less judged by others, and were more able to apply acceptance.

6.4 Wider implications of findings

Although the findings in this study cannot be considered generalisable, the insights into the experience of coping with/managing TRSEs offered by this study may be useful in aiding understanding of the experience of managing similar experiences. This section places the empirical study findings in the context of what is known about the experience of managing antipsychotic side effects other than TRSEs, and the experience of managing antidepressant side effects. Within each section, empirical study findings are compared with existing evidence to explore to what extent evidence might be transferable across these different, but possibly overlapping, experiences.

6.4.1 The experience of managing other side effects of antipsychotics

Existing qualitative studies have reported antipsychotic users' experiences of managing side effects other than TRSEs, with (Morrison et al. (2015) looking across all side effects, and Fitzgerald et al. (2024) and Usher et al., (2013) focusing on weight gain. To understand whether it is useful to compare the findings in these three studies to the current study, it is first helpful to explore whether the strategies participants discussed for managing TRSEs is similar to managing other antipsychotic side effects. These studies discussed some management strategies that did not arise in the present study, such as diet, hot baths, prescription of weight loss medication, self-help books and relaxation techniques. However, as with the participants in the present study, participants in these three studies discussed making changes to antipsychotic use, using cannabis to feel side effects less, changing medication times, avoiding alcohol, behavioural changes, and support from family. Morrison et al.'s participants also discussed use of distraction techniques and jokes, which, in the current study, related to use of acceptance and TRSEs becoming part of people's everyday lives. With the exception of making changes to medication time, none of these approaches were specifically described as being used for managing TRSEs in these three studies. As there is overlap in management strategies between these three studies and the present study, this suggests it is useful to explore to whether there is an overlap in the experience of deploying these strategies across different side effects.

Some findings in the present study are mirrored in existing research regarding the management of/coping with other side effects of antipsychotics. For example, in the present study participants reported that support from their family was more possible where family members understood the need to take antipsychotics and what it was like to experience side effects; this is seen in existing evidence regarding wider management of antipsychotic side effects (Morrison et al., 2015). Likewise, the participants' concerns for their physical and mental health when using cannabis to cope with side effects is also reflected in existing evidence (Morrison et al., 2015). Additionally, the participants' experiences of management strategies being difficult to deploy and working incompletely, and emotional challenges resulting from attempts to manage antipsychotic side effects, are mirrored in existing studies regarding antipsychotic weight gain (Fitzgerald et al., 2024; Usher et al., 2013). However, the application of these experiences directly to TRSEs is novel.

Nevertheless, other findings in this present study are contrary to the existing evidence regarding other antipsychotic side effects. For example, the exact nature of negative emotions in response to difficulties in managing side effects differs. Although, similar to the present study, those managing weight gain reported anger and anxiety (Usher et al., 2013), the feelings of frustration reported by this present study's participants are missing from evidence regarding weight gain. Instead, feelings of guilt, worthlessness, shame, and failure are reported in existing evidence (Fitzgerald et al., 2024; Usher et al., 2013). This suggests that where there are challenges in managing side effects, this is likely to lead to experiencing negative emotional responses regardless of side effect, but the exact nature of these negative emotional responses may vary by side effect.

Findings regarding making changes to antipsychotic use to manage side effects reflect some, but not all, existing evidence regarding the experience of managing antipsychotic side effects. Participants in this present study discussed challenges in making changes to antipsychotic use. This mirrors the findings in Morrison et al.'s study regarding the experience of managing antipsychotic side effects generally, but not regarding the experiences of managing antipsychotic weight gain specifically (Fitzgerald et al., 2024; Usher et al., 2013). However, the challenges experienced by Morrison et al.'s participants appear muted in comparison to the present study: where Morrison's participants experienced clinician disapproval, participants in the present study experienced disempowerment and lack of agency in interactions with clinicians; where Morrison's participants experienced fear of symptom reoccurrence, participant fear in the present study was due to actual experiences of extreme mental health symptom relapse. Study setting could explain some of these differences in experience: Morrison et al.'s and Usher at al.'s studies took place in Australia; Fitzgerald at al.'s in the Republic of Ireland. For example, there may be different clinician/service user balances of power where people pay for health care compared to care that is free at the point of access. However, the high rates of compulsory treatment orders in Australia (Light, 2019) suggests this is unlikely. The funding in the Republic of Ireland's health system is similar to England's, but it is important to note that there are differences in provision of care that mean findings in the two countries cannot be directly compared.

Overall, this comparison does suggest some overlap and transferability in the experiences of managing TRSEs and managing other antipsychotic side effects, but with differences caused by use of different management strategies and differences in the experience of the side effect itself. This supports the position of continuing to explore the management and coping strategies of different antipsychotic side effects separately, for example, the focus on TRSEs in this study.

6.4.2 Coping with antidepressant medication side effects

Placing this study's findings in the context of what is known about coping with side effects from other mental health medications is useful in understanding to what extent knowledge about managing side effects is transferable between different mental health medications. Little evidence exists regarding the experience of coping with/managing antidepressant or mood stabilisers (such as lithium) side effects. However, O'Mullan et al. (2014) used IPA to investigate the experience of Australian women when coping with sexual side effects of antidepressants, and Kikuchi et al. (2012) undertook a quantitative analysis of a Japanese internet survey to investigate the use of active coping strategies for managing antidepressant side effects by those with a diagnosis of depression, including somnolence and fatigue.

The findings in these two studies on the whole agree with the findings in this present study. For example, participants in the present study found it difficult to find useful coping and management strategies, and much of their coping responses to TRSEs consisted of *not* doing (I can't/don't/won't). This broadly aligns with Kikuchi et al.'s (2012) findings regarding antidepressant somnolence and fatigue side effects: participants did not have active coping strategies, but would rest and be accepting instead of 'fighting'. Furthermore, the detailed experience of accepting side effects that could not be otherwise managed is reflected in O'Mullan et al.'s (2014) study. This includes the experience of acceptance stemming from unsuccessful attempts to manage side effects, acceptance being aiding by the acceptance of others, attempts to look for positives, and the time taken to be accepting. Finally, the experiences of rearranging one's life to reduce the impact of side effects, balancing the positives and negatives of medication use and stigma, and non-disclosure of medication use making it difficult to deploy some coping responses are also reflected in O'Mullan et al.'s (2014) study.

A difference between this current study and existing evidence regarding the experience of coping with/managing antidepressant side effects is again the use of changes to medication to manage side effects. In the present study participants found it difficult to deploy changes to medication use in order to manage side effects. However, Kikuchi et al. (2012) found that 31.8% made changes to their antidepressant prescription to manage sedation, and 36.8% made changes to their antidepressant prescription to manage fatigue; this suggests that making medication changes was easily within their control. This difference in findings may be due to the focus on the *experience* of coping, differences between antipsychotics and antidepressants, differences in how requests to adjust prescriptions are received (either due to diagnosis, symptoms, or the country's culture), or due to the present study's focus on including people who continue to use medication. Notwithstanding this, the overall overlap in the experience of managing different side effects for different mental health medications may be useful when understanding the experiences of managing/coping with multiple side effects, and for the many people who take both antipsychotics and antidepressants.

6.5 Findings within the context of existing theory

In order to focus on participants' experiences, and because of the exploratory nature of this study, I designed this study without drawing heavily on existing theories (see methodology chapter, section 4.3.2.3). However, exploring the findings in the context of wider theory demonstrates to what extent findings align with or add to existing relevant theoretical perspectives, exploring in greater depth the potential transferability of results. The design of this study is based on the assumption that people will use their ability to make rational choices to manage/cope with TRSEs. Therefore, in this section I begin by exploring the findings in the context of coping theory. This allows for an exploration of whether the findings regarding coping with TRSEs are transferable to coping with other stressors. I use transactional coping theory (Lazarus & Folkman, 1984) here because the foundational elements that coping responses may be conscious or sub-conscious, are not inherently 'good' or 'bad', and may take the form of either problem-focused or emotional-focused coping are broadly reflected in the findings of this primary study. To explore whether the experiences of participants in this study might be transferable to the experiences of coping with/managing other long-term illnesses, I then proceed to explore findings within the context of two theories relating to living with chronic health problems. I chose reconceptualised uncertainty in illness theory (Mishel, 1990), and the unified theory of adjusting to chronic illness (Moss-Morris, 2013) because of their focus on living with the challenging impacts of chronic illnesses (see section 2.2), and because they draw on and are considered congruent with transactional coping theory.

6.5.1 Transactional coping

In their theory of transactional coping, Lazarus and Folkman (1984) argue that coping occurs via conscious or subconscious appraisal of stressors and responses to these stressors which are either problem-solving focused or emotion-focused. In the context of this present study, TRSEs can be understood to be a stressor to which people apply coping. Folkman and Lazarus do not utilise the concept of inherently 'good' and 'bad' coping in their theory, suggesting that this will depend on the individual circumstances in which the coping strategy is deployed. These fundamentals of transaction coping are broadly reflected within the findings of the present study. For example, some 'responses' to TRSEs were purposeful and conscious, others were not. Additionally, some responses took the form of management strategies or planned attempts to solve the problem, but many focused on reducing the emotional load caused by TRSEs. Finally, individual circumstances meant that some responses that were considered 'good' by some participants were considered 'bad' by others.

Transaction coping theory describes both problem-solving ways of coping ('planful problem solving', 'seeking professional help', 'confrontative coping') and emotion-focused ways of coping ('accepting responsibility', 'distancing', 'escape-avoidance', 'positive reappraisal') (Folkman et al., 1986). Regarding problem solving ways of coping, some examples of participants being able successfully to utilise 'planful problem solving' to cope with the impacts of TRSEs on their lives were evident; however, these were limited. Participants' problem-solving strategies were mostly limited to attempted changes to antipsychotic use. 'Seeking professional help' was of limited use to participants here; clinicians were often unwilling to support changes to antipsychotic use, and participants' experiences of being supported in utilising acceptance were limited to education regarding acceptance that was provided for other life elements. This lack of professional support led to some participants using 'confrontative coping', i.e., expressing anger to clinicians, threatening to leave the country, and threatening to or actually discontinuing antipsychotic use rapidly without clinical support. The focus on experience in this study showed that seeking professional help created further stressors for participants if help was not forthcoming. Analysis showed that the experience of confrontative coping could lead to resolution of TRSEs if professionals responded by providing support, or could lead to further stressors if sudden withdrawal was undertaken, leading to relapse and adding frustration, anger and fear to participants' experiences of continuing to attempt to cope with/manage TRSE. The lack of available planful problem-solving ways of coping further contributed to the feelings of fear and entrapment reported by participants; the limited occasions where participants were able to plan and execute a problem-solving strategy improved participants' satisfaction with their management of TRSEs.

Participants also discussed experiences of using emotion-based coping strategies that aimed to reduce the emotional burden of continuing to experience TRSEs and the impacts of TRSEs. In line with transactional coping, these were utilised where problem-solving was unsuccessful. These included using 'acceptance' and 'positive reappraisal' to cope with TRSEs and impacts of TRSE that could not be changed. Often 'distancing', for example making light of the situation or trying not to think about it, was used to enable acceptance. Distancing was also used to cope with the emotional burden of having to prioritise one element of their life over another, as participants searched for 'silver linings' in this experience. Participants used 'escape-avoidance', for example, eating, drinking, smoking, using drugs, medication, and self-harm. Escape-avoidance approaches were perceived by participants as negative where there was a real or perceived risk of harm to their mental or physical health. However, participants' concerns about the potential effects on their health created additional emotional stressors that required further coping responses.

Perhaps unexpectedly, participants found that deploying both problem solving and emotional focused ways of coping strategies was often challenging and emotionally burdensome, and few strategies worked completely and consistently. These challenges, burdens, and limited successes acted as further stressors to which participants applied emotion-focused coping, including accepting responsibility, distancing and escape-avoidance.

In summary, placing this present study within the context of transactional coping theory is helpful in understanding the study's results: participants consciously and subconsciously appraised the stressors related to TRSEs and applied both problem-focused and emotional-focused coping. This study supports the concept of coping strategies not being inherently good or bad. However, an additional understanding from the experiential focus is that deploying coping strategies that were difficult to use, had real or perceived detrimental effects, worked partially or inconsistently, often created new stressors. These new stressors require the application of further coping strategies, creating a challenging cycle of attempting to cope that is not reflected in transactional coping.

6.5.2 Reconceptualised uncertainty in illness

Reconceptualised uncertainty in illness theory (Mishel, 1990) describes coping strategies for those living with illnesses that require constant management or may reoccur. It is based on Mishel's (1988) uncertainty in illness theory, refined for those with long-term conditions. In uncertainty in illness theory it is proposed that uncertainty in illness exists where events are ambiguous, complex and unpredictable, and where situations make it difficult to determine the meaning of illness related events. According to uncertainty in illness theory people apply coping strategies with the aim of returning to previous levels of functioning; as such UIT is congruent with transactional coping.

According to reconceptualised uncertainty in illness theory, coping strategies aim to help the person change their value system to manage living with uncertainty. This change is perceived as personal growth. This coping consists of biopsychosocial behaviours from within one's normal range of behaviours to reduce uncertainty and/or manage the emotions arising from uncertainty, and activities to maintain uncertainty. This can include self-organising by integrating uncertainty into the natural rhythm of one's life, and probabilistic thinking where people expect uncertainty and act accordingly.

In reconceptualised uncertainty in illness theory the extent to which uncertainty is experienced depends on previous life experience, psychological status, social resources and health care providers. Which coping strategies are adopted is dependent on the perception of danger, available opportunities to adapt strategies, and to what extent uncertainty is a preferred state. People focus on multiple alternatives, what is important in life, vary their personal investment, and appreciate the fragility of life. There is a paucity of existing evidence applying RUIT to coping strategies for mental health medication side effects. However, Baier (1995) successfully applied uncertainty in illness theory to a case study of six people with diagnoses of schizophrenia.

Additionally, there is a large body of evidence which applies reconceptualised uncertainty in illness theory to the side effects associated with cancer treatment, reporting sources of uncertainty, unmet needs in relation to uncertainty, and recommendations for the management of uncertainty. This is collated in the system review by Langmuir et al. (2023). As cancer and mental health problems can be ongoing conditions (see section 2.2), this suggests it is worth exploring the extent to which reconceptualised uncertainty in illness theory can be applied to the present study. Finally, analysis in the present study demonstrated that interviewees were constantly managing their mental health via antipsychotics, and were in fear of recurrence of symptoms. As suggested by others (Langmuir et al., 2023), this means reconceptualised uncertainty in illness theory can be applied to this present study because participants were constantly managing side effects.

In this present study, uncertainty focused around whether coping strategies were successful, or how to best apply them. This included: when to time medication in order to socialise, at what time to stop caffeine use to optimise a balance between daytime alertness and ability to sleep, whether to attend social events, whether exercise would increase or decrease TRSEs and what the optimum antipsychotic dose was to balance minimising TRSEs with minimal mental health symptoms. Participant experiences broadly aligned with RUIT. Some participants tried to assert certainty by speculating why the success of coping strategies varied. Some shifted to probabilistic thinking, for example, exploring the many variables that could impact how to best deploy a coping strategy. This probabilistic thinking was a burden on participants. As a result, these participants did not seek to maintain uncertainty. Some participants sought to remove uncertainties, adding extra controls, such as routines to make every evening the same and not attending social events. Participants utilised acceptance to cope with uncertainties they could not affect. The ways in which managing TRSEs contributed to uncertainty also concorded with the management of side effects in the chronic condition of advanced cancer (Langmuir et al., 2023). For example, loss of confidence in social interactions, loss of autonomy, difficulty planning, and questioning to what extent medication was effective all contributed to uncertainty both for participants in this present study and in Langmuir et al.'s (2023) thematic synthesis of the experience of uncertainty in people receiving treatment for advanced cancer.

To summarise, the application of RUIT to the findings in this study is helpful in providing a framework that highlights the emotional and cognitive burden that participants in the present study experienced while attempting to manage TRSEs. From a clinical perspective, it highlights the lack of support from services that these participants received in managing these challenges. Although the findings in this study cannot be considered generalisable, application of this theory to findings tentatively suggests that improved supporting information and social support to navigate uncertainty may enhance ability to cope with TRSEs.

6.5.3 Unified theory of adjusting to chronic illness

In her unified theory of adjusting to chronic illness Moss-Morris (2013) suggests that adjusting to chronic illness includes successful adjustment to ongoing illness stressors, including managing stressful/ongoing treatments, such as TRSEs. She outlines cognitive and behavioural factors which indicate good adjustment to chronic illness. Cognitive factors consist of: self-efficacy/sense of control regarding disease management and generic life situations, benefit finding, acceptance, high perceived social support. Behavioural factors consist of: coping by using problem-focused coping or seeking social support, engagement in good health behaviours, adherence to medical and self-management regimes, maintaining activity levels in the face of illness, and appropriate expression of emotion.

Mostly, the analysis of participant experience in this present study broadly aligns with Moss-Morris' (2013) theory: often participants had poorly adjusted to TRSEs, for example, with little sense of control over disease and life situations, struggles in engaging problem-focused planning and good health behaviours, and challenges in maintaining activity levels. In line with this theory, participants expressed that this resulted in increased distress levels and sometimes had negative impacts on participants' relationships. Where participants were able to make changes to life situations, find benefits in utilising acceptance and undertaking prioritisations, and employ good health behaviours such as exercise, they reported reduced stress levels. However, some deviations from the theory were evident, likely as a result of exploring adjustment to side effects rather than chronic illness as a whole. For example, acceptance of illness and medication could increase distress and maintaining activity levels was often not possible. The exploration of *experience* also added nuance to the application of the theory: acceptance is difficult and takes time, meaning its application can cause distress; use of social support can have negative impact on relationships; difficulties in implementing management strategies meant that problem focused planning, engagement in good health behaviours, and adherence to medication could increase distress; where there was a lack of effective problem solving downplaying the emotional impact of TRSEs could be helpful in adjusting to TRSEs, reducing distress. A further understanding added by this study is that participants expressed difficulty in achieving a sense of control over disease management, often disempowered from doing so by their clinicians. As lack of power and agency are known challenges for people with mental health difficulties (Tew et al., 2012), this difference between experience reported in the present study and theory may be due to different experiences in mental and physical health problems.

In summary, the application of Unified Theory of Adjusting to Chronic Illness to the findings in this study is helpful in providing a framework that highlights the how participants' difficulties in managing/coping with TRSEs lead to distress. Although findings cannot be considered generalisable, it suggests that support in coping with TRSEs could improve the wellbeing and quality of life for those struggling with TRSEs.

6.6 Clinical and policy implications

6.6.1 Supporting antipsychotic users in managing and coping with TRSEs

To some extent international mental health clinical practice is steered by guidelines and publications, such as NICE in England and Wales, the American Psychiatric Association, and the Maudsley Prescribing Guidelines, which have international reach via the Maudsley Prescribing Guidelines International Conference (Maudsley Prescribing Guidelines, 2025). Advice offered by UK national voluntary organisations, such as Mind and Rethink Mental Illness, may also guide the support provided by health providers, informal careers and self-support. Therefore, reviewing these guidelines in light of the findings of the empirical study is helpful for making tentative suggestions for clinical and policy implications.

Current guidance from NICE, Maudsley Prescribing Guidelines and the American Psychiatric Association (APA) (American Psychiatric Association, 2020; NICE, 2014; Taylor et al., 2024) recommend that when patients begin antipsychotic use they should be provided with details of possible side effects, and there should be a discussion regarding which side effects they are most willing to accept. The American Psychiatric Association and Maudsley also suggest these conversations should continue throughout treatment as side effects and symptoms fluctuate. Rethink Mental Illness suggests talking to clinicians about making changes to antipsychotic use to manage side effects (Rethink Mental Illness, 2024). The American Psychiatric Association and Rethink Mental Illness suggest the use of recognised scales, such as Udvalg Kliniske Undersogelser and Glasgow Antipsychotic Side Effect Scale (Bock et al., 2020; Lindström et al., 2001) for assessing side effect severity. All these sources of guidance state that patients usually develop tolerance to sedation. When implementing these guidelines, practitioners may benefit from considering participants' experiences in the present study, i.e., participants did not discuss having conversations with clinicians regarding which side effects they are willing to accept. TRSEs become part of their everyday lives and their coping mechanisms include downplaying the severity of TRSEs. This should not be confused with a reduction in the existence of sedative effects. When attempting to ascertain the severity of ongoing TRSEs, practitioners may need to apply professional judgement and careful questioning/listening to ascertain the true nature of

TRSEs for an individual. They may benefit from being mindful that quantitative scales may not account for changing perceptions in severity, due to TRSEs and management strategies having become part of everyday life, and that participant recognition of the true impact of TRSEs may disrupt participants' coping strategies.

The Maudsley Prescribing Guidelines (Taylor et al., 2024) state antipsychotic switching is a sound course of action for managing all side effects, as the number of available antipsychotics should mean an antipsychotic with a side effect profile that the user finds acceptable is available. The analysis of participant experiences in the current study suggest challenges with this approach, as some participants felt disempowered from discussing changes to their antipsychotic use with their clinician. Although these experiences may be UK-centric, this study suggests that practitioners should consider imbalances in power in order to hold honest conversations with antipsychotic users about switching antipsychotic in response to TRSEs. This builds on existing commentary by UK psychiatrist Healy (2016), in his guide to psychiatric drugs. He suggests prescribers should be mindful to ensure informed consent is genuinely given in psychiatric drug prescription conversations, and that practitioners may wish to approach prescribing conversations as a 'negotiation' to empower genuine informed consent. However, Healy's advice to drug users to consider changing providers if their prescriber does not listen to their concerns sits in contrast to the challenges in making antipsychotic changes experienced by participants in this study.

Maudsley and APA highlight the importance of minimising side effects, including sedation, in aiding adherence to antipsychotics, as lack of adherence may lead to relapse. This guidance is supported by the participant experiences in the current study, where several participants discussed discontinuing antipsychotic use without clinician support in response to TRSEs and lack of other helpful management/coping strategies. Practitioners may benefit from understanding the emotional fallout for participants here: feeling trapped and frustrated by the need to continue to take antipsychotics to prevent symptom relapse, resulting in feeling they have no choice but to continue to experience TRSEs. Guidelines could be updated to reflect this knowledge. Notably, the recent addition to the Maudsley collection, regarding deprescribing (Horowitz & Taylor, 2024), does not include deprescribing of antipsychotics. This may be due to the results of the RADAR trial (Moncrieff et al., 2023), which demonstrated higher relapse rates in those discontinuing antipsychotics. The experiences in this present study support this exclusion and sub-text within the guidance of not deprescribing, however, it should be noted that the inclusion criteria excluded participants who had successfully stopped taking antipsychotics.

Little guidance has emerged on managing TRSEs specifically. NICE advice regarding maintaining a healthy lifestyle while taking antipsychotics, focuses on maintaining metabolic health, particularly exercising and eating well, in light of antipsychotic-induced weight gain. Despite discussing other side effects in detail, the Maudsley Advanced Prescribing Guidelines for Psychosis (Morrison et al., 2019) and the NICE Clinical Knowledge Summaries for antipsychotics (NICE, 2025b, 2025c) offer no advice for managing TRSEs. MIND offer no advice regarding the management of sedation/sleepiness, and, unlike for other side effects, little in the way of explanation of how this side effect may impact people's lives (Mind, 2020a). The American Psychological Association do offer some suggestions for managing sedation and its potential consequences, i.e. changing medication times, switching antipsychotic, lowering dose, use of caffeine in the morning, not driving and avoiding hazardous activities. The experiences reported in this present study suggest other management strategies may be of use here too, including exercise, resting, acceptance, and help from friends and family.

More importantly the experiences in the current study suggest that practitioners would benefit from being aware of the difficulties in managing TRSEs: the emotional burden of using detrimental strategies and strategies that work inconsistently, the emotional burden of needing to continue to take antipsychotics despite TRSEs, the limitations to quality of life caused by, for example, not driving and changing medication times. Although the American Psychological Association briefly note that sedation can affect functioning and Morrison et al.'s (2015) interviews with antipsychotic users also conclude that side effects are disabling and clinicians should not expect too much of people, the current study suggests this vastly underestimates the experiences of some antipsychotic users. The narrative in the current guidance that sedation usually only affects people in early stages of prescribing and that some people find sedation therapeutic may or may not hold for the majority of antipsychotic users, but is unhelpful for guiding clinicians in working successfully with those who do continue to experience TRSEs. It would therefore be beneficial to update guidance to reflect the challenges and emotional burden for those who continue to experience TRSEs with long-term antipsychotic use; if few practical management strategies for TRSEs can be evidenced, guiding clinicians in helping antipsychotic users navigate these challenges is a useful addition to policy and practice.

6.6.2 Implications for promoting recovery from mental health problems

For several decades there has been an understanding that a diagnosis of a severe mental illness, such as schizophrenia and bipolar, does not represent a certain ongoing decline in mental health: symptoms fluctuate, and people can get better. This is represented by the Recovery model (Anthony, 1993; Australian health ministers' advisory council, 2013; Higgins & McBennett, 2007;

Mental Health America, 2025; Shepherd et al., 2008), which is reflected in mental health provision policy such as Australia's 2021 National Framework for Recovery Orientated Practice and England's Community Mental Health Framework for Adults and Older Adults (Australian health ministers' advisory council, 2013; NHS England et al., 2019). Although definitions of recovery vary, the concept includes being able to live a meaningful life, undertake meaningful activities, and contribute to one's community. This present study suggests that mental health recovery may be difficult for antipsychotic users who are experiencing TRSEs: coping via prioritising some activities over others may leave antipsychotic users finding it difficult to be a part of their communities and undertake the activities that would improve their quality of life. This means that it may be more challenging to support service users with personal recovery without addressing how to improve coping/management of TRSEs.

6.6.3 Management of weight and metabolic antipsychotic side effects

Antipsychotic use also carries the risk of other, 'metabolic health' side effects, such as severe weight gain (Leucht et al., 2013), thought to lead to increased risk of diabetes (Holt, 2019) and poor heart health (Andor et al., 2024). NICE, APA and Maudsley guidelines (American Psychiatric Association, 2020; NICE, 2014; Taylor et al., 2024) focus on maintaining physical activity, healthy eating and reducing smoking in order to minimise the risks from these side effects. However, this study suggests that maintaining these healthy lifestyle elements may be difficult when managing TRSEs. People experiencing TRSEs may be less able to undertake physical activity and healthy eating, and unhealthy eating and smoking may form part of people's coping responses for living with TRSEs. This may make it more challenging to support antipsychotic users who experience TRSEs in reducing the impacts of weight and metabolic side effects.

6.6.4 Continued use of antipsychotics

It is not the intension of this thesis to contribute to the debate around the desirability of long-term antipsychotic use. However, within the sample it was clear that participants had experiences of being disempowered to make changes to the specific antipsychotic they were using and/or the dose they used. Some participants felt unable to have equitable conversations with clinicians about changing antipsychotic use. Although the sample size and inclusion criteria must be taken into account, only one participant was working with a clinician to reduce/stop antipsychotic use to better manage TRSEs. Some participants had past experiences of feeling so disempowered from being able to make changes to antipsychotic use in response to TRSEs that they had suddenly stopped antipsychotic use without clinician support, resulting in severe mental health symptom relapse. These relapses had left participants afraid to make changes to future antipsychotic use.

These findings have implications for policy and practice: it is likely that patients will have long standing experiences of being disempowered from making decisions around their antipsychotic use, making it difficult to implement reduction or change of use strategies to tackle TRSEs. Some patients may be reluctant to make changes, or unable to precipitate successful and equitable conversations with clinicians regarding changes to antipsychotic use. Both of these findings are reflected in Morant et al., (2018), and also in the challenges recruiting both patients and clinicians to antipsychotic reduction trials (Moncrieff, 2023). If one places these findings in the context of the necessity-concerns framework (Horne, 2003) of why people with chronic conditions may or may not continue to take medication, despite the concerns of TRSEs, there is a perceived necessity to continue antipsychotic use due to patient/clinician power imbalances and symptom relapse. Utilising changes to antipsychotic use to reduce TRSEs, or for other reasons, requires addressing the perceived necessity to continue antipsychotic use.

6.7 Further research

The background chapter highlights the lack of certainty regarding the prevalence of TRSEs in long-term antipsychotic users (section 2.5.2). In light of the empirical study, future research regarding TRSE prevalence should account for the possibility that coping/management strategies may lead to antipsychotic users downplaying the impact and distress caused by TRSEs. This may make it challenging to measure whether TRSEs do reduce over time in long-term antipsychotic users.

Placing the empirical study in the context of Mischel's UIT and RUIT highlights an opportunity for future research to explore whether it is possible to implement interventions which improve antipsychotic users' ability to cope with uncertainty arising from TRSEs and coping with TRSEs. Mishel et al., (2002, 2005) created and tested interventions to improve management of illness uncertainty in long-term cancer survivors; participants received education in emotion-focused and behavioural strategies to aid in improving coping with possible reoccurrence and long-term medication side effects. They found this intervention improved participants' cognitive reframing, and increased both the range of coping skills deployed and problem-solving coping. Future research could explore developing and testing similar interventions for antipsychotic users experiencing TRSEs.

Finally, the scoping study demonstrated the need for researchers investigating TRSEs to be clear in their position regarding whether there are potential differences in TRSEs related to diagnosis, exact antipsychotic prescribed, and TRSE concepts (e.g. sedation vs tiredness).

6.8 Study strengths and limitations

Strengths and weaknesses of the scoping study are discussed in chapter 3, section 3.4.1. A strength of the empirical study is the in-depth focus on participants' experiences, utilising analysis that meets Nizza at al.'s definition of good quality IPA. The focus on convergence and divergence within the data allows, within the philosophical perspective of critical realism, for cautious generalisations/transferability (Smith et al., 2009), meaning the results of this experiential study are of use to policy, practice, and future research. To create a homogenous sample appropriate for exploring in-depth experiences (Smith et al., 2009), the empirical study had tight inclusion criteria; only those currently taking antipsychotics were invited to take part. Consequently, this study cannot comment on the experiences of any who successfully discontinued antipsychotic use to manage TRSEs.

6.8.1 Limits to Transferability as a Result of the Sample.

The sample size in this study is appropriate for the use of IPA, enabling a detailed and rich exploration of participants' experiences (see section 4. 3. 1. 3). However, it cannot be expected that a sample of this size is sufficient to represent the experiences of the population as a whole. This creates some limitations as to the transferability of the findings. For example, as can be seen in the participant characteristics table (table 10, p-76), there are limits in the diversity of the sample. Although the sample includes a range of ages, employment statuses, and family and relationship situations, there is less diversity in terms of gender, nationality, colour, and ethnicity. This may limit transferability to those with different characteristics from those involved in the study. The practical decision to recruit participants via social media compounds these limitations; findings may not be transferable to those not engaged with social media, including those who are digitally excluded or digitally isolated. The research gaps created by these limitations should be explored in future research.

6.9 Quality

I assessed quality using Nizza et al. (2021)'s four indicators of 'good' quality IPA: (1) Constructing a compelling, unfolding narrative; (2) Developing a vigorous experiential and/or existential account; (3) Close analytic reading of participants' words; and (4) Attending to convergence and divergence. Below, the thesis compares these criteria to the analysis in this current study. Overall, the comparison below suggests that this present study has adopted a robust quality of analysis.

6.9.1. Constructing a compelling, unfolding narrative

Nizza states that this involves telling a progressive story across the analysis, where there is coherence within and across themes, and each carefully selected quote and interpretation adds novelty to the story.

Applying this standard to the present study suggests a good level of quality, as a coherent, progressive narrative emerges both within and across themes. For example, across group experiential themes the narrative shows that participants found that managing and coping with TRSEs had often become part of their everyday lives, but this did not necessarily reduce the distress of TRSEs because managing and coping with TRSEs often required prioritising different elements of their lives over one another and deploying strategies and responses that were detrimental. In turn, the lack of available successful problem-solving strategies, the emotional distress from experiencing TRSEs themselves, from managing/coping with TRSEs becoming part of participants' everyday lives, from prioritising one element of their lives over another, and from deploying detrimental management/coping responses led to participants utilising acceptance as a coping mechanism. Overall, this shows a difficult, often distressing, and often unsuccessful experience of managing/coping with TRSEs, that required participants to accept the challenges of experiencing and managing TRSEs.

Within group experiential themes the narrative is also coherent and progressive: the narrative progresses as each quote and accompanying interpretation adds additional detail. For example, within the group experiential theme *"It's what I do. It's part of me now. It's like second nature": the experience of TRSEs and responses to TRSEs becoming a part of one's life*, the narrative begins with "Participants had become accustomed to experiencing TRSEs", and breaks down this experience in detail, including when this happened, how it felt, and the implications of this for participants (appendix K).

6.9.2 Developing a rigorous experiential account

In line with Nizza, in this this study I focus on what is important to participants, paying attention to their meaning making, to create depth of analysis. For example, in the group experiential theme *"I've made a choice in my life that I want to be happy, I want to be mentally well and if that means I have to sacrifice some things, then I have to sacrifice some things": the experience of prioritising one element of one's life over another*, the analysis explores this experience within the participants' own lives and priorities. Different elements of prioritisation are placed in the context of what is important to each participant, adding greater depth to analysis than merely describing the act of prioritisation. This includes Joanna's description of the impact of her prioritisations on her life, how prioritisations by Raven/Bob were situated in the context of concerns about her physical health, and the different prioritisations of David, Ash, Emily, and Sarah undertaken due to their own, distinct, meaning making (appendix L).

6.9.3 Close analytic reading of participants' words

I made a commitment to a careful reading and interpretation of participants' words to reveal deeper meaning during this analysis, while still working to ensure transparency in the reasons for my interpretations. For example, in the group experiential theme *"There's an acceptance that I can't change it": the experience of coping with unmanageable TRSEs via acceptance*, I examined both participants' choice of individual words and sentence construction to explore how the need for friends and family to be accepting could impact on relationships, how the experience of accepting TRSEs contrasted with the experience of fighting TRSEs, and how the experience of accepting TRSEs impacted on participants' perceptions of themselves (appendix M).

6.9.4 Attending to convergence and divergence

I used convergence and divergence to show higher connections, while maintaining participants' unique characteristics and experiences. For example, in the group experiential theme *"I used to self-harm, which is not the best strategy": the experience of utilising detrimental management strategies and coping responses*, I used convergence to demonstrate that across participants strategies were perceived as detrimental and having negative impacts, and divergence to demonstrate how different participants' experiences of detrimental management strategies varied (appendix N).

6.10 What have I learned

Much of my learning focused around methodological skills and the practical elements of undertaking research. For example, when planning the scoping study, I discussed with my supervisors the appropriateness of the size and scope of the review. As discussed in the reflexivity for regarding the scoping study (section 3.5), early presentations of the plan for my thesis to staff and students were often met with responses such as: is this an issue worth addressing, do long term antipsychotic users experience TRSEs that negatively impact their lives, should this issue should be addressed from a diagnostic-specific standpoint, and are fatigue, sedation, tiredness, sleepiness and excess sleep (as examples) distinct concepts that should be researched separately? My early scoping work showed that the answers to these questions were not clear cut. Therefore, in order to justify the necessity of the primary study, it felt necessary to include the prevalence of TRSEs, the impact of TRSEs on antipsychotic users, and an exploration of the nature of the existing evidence in the scoping study. This meant that the review was a large and time-consuming piece of work to undertake; it was difficult to maintain motivation and momentum when undertaking this during part-time study. The extent to which parts of the scoping study have been useful varies. The exploration of the nature of the evidence has informed the justification and design of the primary study, and has allowed for the development of the concept of tiredness-related side effects. However, the exploration of the prevalence of TRSEs and the impact of TRSEs on antipsychotic users formed limited contributions to creating an understanding of how to manage and cope with TRSEs and the experience of managing and coping with TRSEs. Indeed, the results from these parts of the scoping study are not presented in this thesis, instead being used to inform sections 2.5.1 and 2.5.2 of the background chapter. It is difficult to reflect on whether I would do things differently: at the time it felt necessary to address these uncertainties. A learning point for me is whether there might have been other, more efficient and equally effective ways to address this without undertaking such a large review.

While undertaking the primary study, my main learning focused around the timescales required to undertake detailed experiential analysis. My previous experience of qualitative analysis was limited amounts of thematic analysis and large amounts of realist evaluation. I found IPA to have a very different pace to realist evaluation. Realist evaluation aims to use any and all available data to create generalisable understandings of causation across all data. As such there is a rapid movement to looking across cases, even during data collection, to understand overall meaning. Realist researchers search for connections and use pattern recognition that highlight demi-regularities across different people's experience to create usable theories that can be deployed to improve care. This feels fast-paced, macro-picture and creates a usable output with practical application. The purpose, and therefore, process of IPA is very different. Some elements were easier for me to adapt to, for example treating each data point/person separately and bracketing off the experiences of others to focus on the individual. Others I found are challenging to learn to do: spending more time focusing on individual experience rather than jumping to wider patterns and 'what could this mean for findings overall?' or 'how could this inform practice?' was difficult. There was a sense of having to 'hold' this thinking back for the discussion. This resulted in needing to revisit my analysis to ensure focus on *individuals'* experiences, rather than the group as a whole. Reflecting on the process now, and speaking to others as they begin their first IPA analysis, it is clear that I have much improved my skills in this style of analysis, more able to slow down and 'spot' individuals' experiences within a transcript, more able to represent these individual experiences within cross-case analysis and narrative reporting of findings.

Finally, I continue to learn about the timescales of a project of this size. Moving from ideas to workable plans, the timescales to screen and extract the data for a scoping study, multiple iterations of ethics documents, slowing down to undertake good quality experiential analysis, understanding how different elements of the thesis hang together, and comprehending and writing a document of this size, have all been challenges and opportunities for learning. Overall, I have learned that when you're leading a research project everything takes much longer than you might expect!

6.11 Reflexivity

As I proceeded through this study, I realised I had brought my optimistic outlook to the design and undertaking of this work; I thought that that undertaking the study would reveal useful, easy to implement, coping and management strategies that, if shared wider, could easily improve the quality of life of people experiencing TRSEs. It quickly became apparent during interviews and analysis that this was not the case: people related difficult experiences of living with and coping with TRSEs. The overt nature of these experiences meant that my preconceptions did not affect analysis. However, the difficulties experienced by the participants, and the sense of there being no ‘solution’ unearthed by the results, created a sense of nihilism that made it difficult to maintain motivation and momentum through analysis. This did not lift until writing the discussion: on placing the findings in a wider context, it felt both useful and important to communicate the challenging experiences of the participants to a wider audience. Although I believe that these preconceptions and desire for ‘useful’ results did not affect the findings of this study, it is useful to be aware of my positioning and motivations in order to maintain quality in my future work.

6.12 Changes to Positionality

Due to the part-time nature of my PhD, I began this work in September 2020, and undertook my viva voce in January 2026. During this time I have also worked on many other mental health research projects in my job as a researcher at the University of Plymouth. This means it may be useful to reflect on changes in positionality during the lifetime of this work.

Many overarching elements of my position remain the same. For example, my initial motivations in respect of personal experiences remain in tact, and I still hold the assumption that the purpose of research in this area is to improve the lives of people with mental health problems. Additionally, it is still important to me that research engage directly with people with mental health problems in order to do justice to their experiences, and reduce the undermining of their voices. Indeed, to this end, at work I am now leading the patient and public involvement team across the university's new Mental Health Research Group. However, I am perhaps, more cautious in my optimism as to how much impact early stage qualitative work can have on the lives of people with mental health problems. For example, I am conscious there is much to do in the way of knowledge mobilisation, and intervention design and testing before the work in this thesis is likely to have impact on patient care and the quality of life of people taking antipsychotics.

A challenging positionality reflection for me is my understanding of the role of antipsychotics in appropriate patient care. When designing this research I sat in an almost pragmatic position: some people find antipsychotics useful, some don't, it is helpful to explore how we can support those people who choose to take them (section 2.4.4, antipsychotic effectiveness). This position was born out of a desire to acknowledge an assumed agency of people taking antipsychotics to make their own decisions. In light of the discussion regarding community treatment orders above, this now feels quite naïve. This position was probably a result of my experiences with my housemate, who had only ever been treated within the community setting, and their experiences of the benefits and limitations of taking antipsychotics. As my study progressed, other research by the RADAR team made it seem possible that people might benefit from not taking antipsychotics long term at all, rendering my findings unhelpful. However, the final results from this study indicated this was not the case (Moncrieff et al., 2023). On a personal level, my housemate tappered off of antipsychotics during 2023/24, with few challenges. Their position on antipsychotics has changed from 'they saved me' to 'I don't know what difference, if any, they made'. Additionally, at work, I increasingly speak to patients and practitioners who suggest that antipsychotics are not an important part of what keeps them well. Therefore, as I finalise this thesis, I am unsure where I sit in this space. Leaning towards a heavily critical psychiatry position doesn't feel quite right, and still concerns me in terms of undermining the mixed experiences people report. However, I am involved in several deprescribing bids and projects at the moment, particularly around polypharmacy. I expect this position will continue to evolve, but at the moment, perhaps it can be described as 'heavily sceptical' of the use of medication for mental health problems. This change to a 'heavily sceptical' position may have impacted the tone of the discussion chapter compared the introduction and background chapters.

6.13 Final statement of contribution to knowledge

The review and empirical study make original contributions to knowledge both by collating existing information to highlight what is and is not already known, and by offering new findings.

The scoping study has:

- Revealed the lack of coherence in how TRSEs terminology is used and defined.
- Revealed how the different perspectives on the definitions of mental health diagnoses and distinctiveness of different antipsychotics appear to inform TRSE research design.
- Highlighted a lack of knowledge regarding successful approaches to managing TRSEs.
- Highlighted a lack of understanding regarding the experience of attempting to manage or cope with TRSEs.

The empirical study has:

- Revealed the challenges people face in managing and coping with TRSEs, and the negative impacts this has on people's wellbeing and day-to-day lives.
- Highlighted how TRSEs, the impact of TRSEs, and coping with/managing TRSEs becomes part of people's everyday lives.
- Revealed how managing/coping with TRSEs requires people to prioritise areas of their lives, impacting on people's ability to live a full and satisfying life.
- Revealed the important role of acceptance in coping with TRSEs that cannot be otherwise mitigated or managed.

Together this work demonstrates the need for future research to create and test interventions to improve management strategies and coping for TRSEs. Thus, in this thesis I was unable to fully answer one of my fundamental queries at its inception regarding how we can improve the quality of life for people taking antipsychotics through developing our understanding of their experience of tiredness related side effects. However, I have shown that qualitative approaches can provide a layered and insightful depth of understanding which contribute to the incremental steps required for the creation of larger scale change.

Bibliography

Achtyes, E., Simmons, A., Skabeev, A., Levy, N., Jiang, Y., Marcy, P., & Weiden, P. J. (2018). Patient preferences concerning the efficacy and side-effect profile of schizophrenia medications: A survey of patients living with schizophrenia. *BMC Psychiatry*, *18*(1). https://doi.org/10.1186/s12888-018-1856-y

Alase, A. (2017). The Interpretative Phenomenological Analysis (IPA): A Guide to a Good Qualitative Research Approach. *International Journal of Education and Literacy Studies*, *5*(2), 9–19. https://doi.org/10.7575/aiac.ijels.v.5n.2p.9

Alvarez-Jimenez, M., Gleeson, J. F., Henry, L. P., Harrigan, S. M., Harris, M. G., Amminger, G. P., Killackey, E., Yung, A. R., Herrman, H., Jackson, H. J., & McGorry, P. D. (2011). Prediction of a single psychotic episode: A 7.5-year, prospective study in first-episode psychosis. *Schizophrenia Research*, *125*(2), 236–246. https://doi.org/10.1016/j.schres.2010.10.020

American Psychiatric Association. (2020). *The American Psychiatric Association Practice Guideline for the Treatment of Patients With Schizophrenia* (3rd edn). https://psychiatryonline.org/doi/book/10.1176/appi.books.9780890424841

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders: Vol. 5th edn*. https://doi.org/10.1176/appi.books.9780890425787

Anand, E., Berggren, L., Deix, C., Tóth, Á., & McDonnell, D. P. (2015). A 6-year open-label study of the efficacy and safety of olanzapine long-acting injection in patients with schizophrenia: A post hoc analysis based on the European label recommendation. *Neuropsychiatric Disease and Treatment*, *11*, 1349–1357. https://doi.org/10.2147/NDT.S79347

Andor, M., Dehelean, L., Arnăutu, D. A., Neagu, M. N., Nistor, D., Manea, M. M., Romosan, A.-M., & Kundnani, N. R. (2024). Schizophrenia and Heart Health: Are Antipsychotics a

Friend or Foe? *Journal of Personalized Medicine*, *14*(8), Article 8. https://doi.org/10.3390/jpm14080814

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, *16*(4), 11–23. https://doi.org/10.1037/h0095655

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*. https://doi.org/10.1080/1364557032000119616

Aromataris, E., & Munn, Z. (2020). *JBI manual for evidence synthesis*. Joanna Briggs Institute.

Australian health ministers' advisory council. (2013). *A national framework for recovery-oriented mental health services: Guide for practitioners and providers*. https://www.health.gov.au/sites/default/files/documents/2021/04/a-national-framework-for-recovery-oriented-mental-health-services-guide-for-practitioners-and-providers.pdf

Aveyard, H., Payne, S. A., & Preston, N. (2016). *A postgraduate's guide to doing a literature review in health and social care*. Oxford University Press.

Baier, M. (1995). Uncertainty of Illness for Pers with Schizophrenia. *Issues in Mental Health Nursing*, *16*(3), 201–212. https://doi.org/10.3109/01612849509006935

Barbui, C., Mulè, S., & Cipriani, A. (2007). Haloperidol, risperidone and olanzapine are similarly effective for first-episode non-affective psychosis but have differing side effects. *Evidence Based Mental Health*, *10*(3), 74. https://doi.org/10.1136/ebmh.10.3.74

Barman, R., Majumder, P., Doifode, T., & Kablinger, A. (2021). Newer antipsychotics: Brexpiprazole, cariprazine, and lumateperone: A pledge or another unkept promise? *World Journal of Psychiatry*, *11*(12), 1228–1238. https://doi.org/10.5498/wjp.v11.i12.1228

Bentall, R. (2004). *Madness Explained: Psychosis and Human Nature*. Penguin.

Bentall, R. (2014). *A prescription for psychiatry: Why we need a whole new approach to mental health and wellbeing*. Palgrave Macmillan.

Berger, R. (2015). Now I see it, now I don’t: Researcher’s position and reflexivity in qualitative research. *Qualitative Research*, *15*(2). https://doi.org/10.1177/1468794112468475

Bessonova, L., Velligan, D. I., Weiden, P. J., O’Sullivan, A. K., Yarlas, A., Bayliss, M., Baranwal, N., Rychlec, K., Carpenter-Conlin, J., Doane, M. J., & Sajatovic, M. (2020). Antipsychotic treatment experiences of people with bipolar I disorder: Patient perspectives from an online survey. *BMC Psychiatry*, *20*(1), 354. https://doi.org/10.1186/s12888-020-02767-x

Bhaskar, R. (2014). *The Order of Natural Necessity: A kind of Introduction to Critical Realism (G. Hawke ed)*. CreateSpace Independent Publishing Platform.

Bock, M. S., Achter, O. N. V., Dines, D., Speed, M. S., Correll, C. U., Mors, O., Østergaard, S. D., & Kølbæk, P. (2020). Clinical validation of the self-reported Glasgow Antipsychotic Side-effect Scale using the clinician-rated UKU side-effect scale as gold standard reference. *Journal of Psychopharmacology*, *34*(8), 820–828. https://doi.org/10.1177/0269881120916122

Bolton, D. (2023). A revitalized biopsychosocial model: Core theory, research paradigms, and clinical implications. *Psychological Medicine*, *53*(16), 7504–7511. https://doi.org/10.1017/S0033291723002660

Borderline Personality Disorder Treatment, B. P. D. (2010). *BPD Name Change Is Being Considered* [Clearview Women’s Centre]. https://borderlinepersonalitytreatment.com/bpd-name-change/

Bosch, P., Lim, S., Staudte, H., Yeo, S., Lee, S.-H., Barisch, P., Perriard, B., & Noort, M. V. den. (2018). Pharmacological Treatment for Long-Term Patients with Schizophrenia and Its Effects on Sleep in Daily Clinical Practice: A Pilot Study. *Medicines*, *5*(2), 44. https://doi.org/10.3390/medicines5020044

Branco, A. C. C. C., Yoshikawa, F. S. Y., Pietrobon, A. J., & Sato, M. N. (2018). Role of Histamine in Modulating the Immune Response and Inflammation. *Mediators of Inflammation*, *2018*, 9524075. https://doi.org/10.1155/2018/9524075

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A practical guide for beginners*. SAGE.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37–47. https://doi.org/10.1002/capr.12360

Bridler, R., Häberle, A., Müller, S. T., Cattapan, K., Grohmann, R., Toto, S., Kasper, S., & Greil, W. (2015). Psychopharmacological treatment of 2195 in-patients with borderline personality disorder: A comparison with other psychiatric disorders. *European Neuropsychopharmacology*, *25*(6), 763–772. https://doi.org/10.1016/j.euroneuro.2015.03.017

Brisch, R., Saniotis, A., Wolf, R., Bielau, H., Bernstein, H.-G., Steiner, J., Bogerts, B., Braun, K., Jankowski, Z., Kumaratilake, J., Henneberg, M., & Gos, T. (2014). The role of dopamine in schizophrenia from a neurobiological and evolutionary perspective: Old fashioned, but still in vogue. *Frontiers in Psychiatry*, *5*, 47. https://doi.org/10.3389/fpsyt.2014.00047

British Psychological Society. (2021). *BPS Code of Human Research Ethics*.

Brooks, J. O., Goldberg, J. F., Ketter, T. A., Miklowski, D. J., Calabrese, J. R., Bowden, C. L., & Thase, M. E. (2011). Safety and Tolerability Associated With Second-Generation Antipsychotic Polytherapy in Bipolar Disorder: Findings From the Systematic Treatment

Enhancement Program for Bipolar Disorder. *J Clin Psychiatry*, *72*(2), 240–247. https://doi.org/10.4088/JCP.09m05214yel

Bryman, A. (2016). *Social Research Methods* (5th ed.). Oxford University Press.

Budd, J. M. (2012). Phenomenological critical realism: A practical method for LIS. *Journal of Education for Library and Information Science*, *53*(1), 69–80.

Bunniss, S., & Kelly, D. R. (2010). Research paradigms in medical education research. *Medical Education*, *44*(4), 358–366. https://doi.org/10.1111/j.1365-2923.2009.03611.x

Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index: A new instrument for psychiatric practice and research. *Psychiatry Research*, *28*(2), 193–213. https://doi.org/10.1016/0165-1781(89)90047-4

Calabrese, J. R., Elhaj, O., Gajwani, P., & Gao, K. (2005). Clinical highlights in bipolar depression: Focus on atypical antipsychotics. *The Journal of Clinical Psychiatry*, *66 Suppl 5*, 26–33.

Campbell, W. H., & Rohrbaugh, R. M. (2006). *The biopsychosocial formulation manual; a guide for mental health professionals* (1st Edn). Routledge. Taylor and Francis Group.

Cardiff University, The University of Edinburgh, King's College London, & South London and Maudsley NHS Foundation Trust. (n.d.). *About the Study | GLAD Study*. Genetic Links to Anxiety and Depression. Retrieved 5 June 2025, from https://gladstudy.org.uk/about

Carney, M. W. (1984). A 5-year follow-up study of chronic schizophrenics treated with clopenthixol decanoate. *Pharmatherapeutica*, *4*(1), 57–63.

Cascade, E., Kalali, A. H., Mehra, S., & Meyer, J. M. (2010). Real-world Data on Atypical Antipsychotic Medication Side Effects. *Psychiatry (Edgmont)*, *7*(7), 9–12.

Centre for Mental Health. (n.d.). *Dismissed on the basis of my diagnosis*. Centre for Mental Health. Retrieved 5 June 2025, from https://www.centreformentalhealth.org.uk/publications/dismissed-basis-my-diagnosis/

Chan, J. K. N., Correll, C. U., Wong, C. S. M., Chu, R. S. T., Fung, V. S. C., Wong, G. H. S., Lei, J. H. C., & Chang, W. C. (2023). Life expectancy and years of potential life lost in people with mental disorders: A systematic review and meta-analysis. *eClinicalMedicine*, *65*. https://doi.org/10.1016/j.eclinm.2023.102294

Chartier, F., Rouillon, F., Berggren, L., Jamonneau, I., Falissard, B., & Llorca, P. M. (2017). Follow-up study of patients treated with olanzapine pamoate in France in real-life treatment situation. *L'Encephale*, *43*(4), 303–310. https://doi.org/10.1016/j.encep.2017.05.004

Chaves, K. M., Serrano-Blanco, A., Ribeiro, S. B., Soares, L. A. L., Guerra, G. C. B., do Socorro Costa Feitosa Alves, M., de Araújo Júnior, R. F., de Paula Soares Rachetti, V., Filgueira Júnior, A., & de Araújo, A. A. (2013). Quality of life and adverse effects of olanzapine versus risperidone therapy in patients with schizophrenia. *The Psychiatric Quarterly*, *84*(1), 125–135. https://doi.org/10.1007/s11126-012-9233-3

Citrome, L., Cucchiaro, J., Sarma, K., Phillips, D., Silva, R., Tsuchiya, S., & Loebel, A. (2012). Long-term safety and tolerability of lurasidone in schizophrenia: A 12-month, double-blind, active-controlled study. *International Clinical Psychopharmacology*, *27*(3), 165–176. https://doi.org/10.1097/YIC.0b013e32835281ef

Cook, B., & Hoogenboom, G. (2004). Combined use of amisulpride and clozapine for patients with treatment-resistant schizophrenia. *Australasian Psychiatry: Bulletin of Royal Australian and New Zealand College of Psychiatrists*, *12*(1), 74–76. https://doi.org/10.1046/j.1039-8562.2003.02064.x

Correll, C. U., Cucchiaro, J., Silva, R., Hsu, J., Pikalov, A., & Loebel, A. (2016). Long-term safety and effectiveness of lurasidone in schizophrenia: A 22-month, open-label extension study. *CNS Spectrums*, *21*(5), 393–402. https://doi.org/10.1017/S1092852915000917

Correll, C. U., Rubio, J. M., & Kane, J. M. (2018). What is the risk-benefit ratio of long-term antipsychotic treatment in people with schizophrenia? *World Psychiatry*, *17*(2), 149–160. https://doi.org/10.1002/wps.20516

Covell, N. H., Weissman, E. M., Schell, B., McCorkle, B. H., Summerfelt, W. T., Weiden, P. J., & Essock, S. M. (2007). Distress with medication side effects among persons with severe mental illness. *Administration and Policy in Mental Health*, *34*(5), 435–442. https://doi.org/10.1007/s10488-007-0131-1

Creswell, J. W., & Creswell, D. J. (2018). *Research Design: Qualitative, quantitative & mixed methods approaches* (5th edn). SAGE Publications Ltd.

Cromby, J., Harper, D., & Reavey, P. (2013). *Psychology, mental health and distress*. Palgrave.

Crossan, F. (2003). Research philosophy: Towards an understanding. *Nurse Researcher*, *11*(1), 46–55. https://doi.org/10.7748/nr2003.10.11.1.46.c5914

Cuthbertson, L. M., Robb, Y. A., & Blair, S. (2020). Theory and application of research principles and philosophical underpinning for a study utilising interpretative phenomenological analysis. *Radiography*, *26*(2), e94–e102. https://doi.org/10.1016/j.radi.2019.11.092

Danermark, B., Ekström, M., & Karlsson, J. C. (2002). *Explaining Society: Critical Realism in the Social Sciences*. Routledge. https://doi.org/10.4324/9781351017831

Daudt, H. M., van Mossel, C., & Scott, S. J. (2013). Enhancing the scoping study methodology: A large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC Medical Research Methodology*, *13*(1), 48. https://doi.org/10.1186/1471-2288-13-48

Davidoff, F., Dixon-Woods, M., Leviton, L., & Michie, S. (2015). Demystifying theory and its use in improvement. *BMJ Quality & Safety*, *24*(3), 228–238. https://doi.org/doi.org/10.1136/bmjqs-2014-003627

Davidsen, A. S. (2013). Phenomenological Approaches in Psychology and Health Sciences. *Qualitative Research in Psychology*, *10*(3), 318–339. https://doi.org/10.1080/14780887.2011.608466

Davies, M. R., Kalsi, G., Armour, C., Jones, I. R., McIntosh, A. M., Smith, D. J., Walters, J. T. R., Bradley, J. R., Kingston, N., Ashford, S., Beange, I., Brailean, A., Cleare, A. J., Coleman, J.

R. I., Curtis, C. J., Curzons, S. C. B., Davis, K. A. S., Dowey, L. R. C., Gault, V. A., … Breen, G. (2019). The Genetic Links to Anxiety and Depression (GLAD) Study: Online recruitment into the largest recontactable study of depression and anxiety. *Behaviour Research and Therapy*, *123*, 103503. https://doi.org/10.1016/j.brat.2019.103503

Davis, M., Fuller, M., Strauss, M., Konicki, P., & Jaskiw, G. (2014). Discontinuation of clozapine: A 15-year naturalistic retrospective study of 320 patients. *Acta Psychiatrica Scandinavica*, *130*(1). https://onlinelibrary.wiley.com/doi/10.1111/acps.12233

Day, J. C., Kinderman, P., & Bentall, R. (1998). A comparison of patients' and prescribers' beliefs about neuroleptic side-effects: Prevalence, distress and causation. *Acta Psychiatrica Scandinavica*, *97*(1), 93–97. https://doi.org/10.1111/j.1600-0447.1998.tb09969.x

Day, J. C., Wood, G., Dewey, M., & Bentall, R. P. (1995). A self-rating scale for measuring neuroleptic side-effects. Validation in a group of schizophrenic patients. *The British Journal of Psychiatry: The Journal of Mental Science*, *166*(5), 650–653. https://doi.org/10.1192/bjp.166.5.650

Dell'Osso, B., & Ketter, T. A. (2013). Use of adjunctive stimulants in adult bipolar depression. *International Journal of Neuropsychopharmacology*, *16*(1), 55–68. https://doi.org/10.1017/S1461145712000326

Demily, C., Jacquet, P., & Marie-Cardine, M. (2009). [How to differentiate schizophrenia from bipolar disorder using cognitive assessment?] L'évaluation cognitive permet-elle de distinguer la schizophrénie du trouble bipolaire ? *L'Encéphale*, *35*(2), 139–145. https://doi.org/10.1016/j.encep.2008.03.011

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R., & Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, *6*, 35. https://doi.org/10.1186/1471-2288-6-35

Doane, M. J., Sajatovic, M., Weiden, P. J., O'Sullivan, A. K., Maher, S., Bjorner, J. B., Sikora Kessler, A., Carpenter-Conlin, J., Bessonova, L., & Velligan, D. I. (2020). Antipsychotic Treatment Experiences of People with Schizophrenia: Patient Perspectives from an Online Survey. *Patient Preference and Adherence*, *14*, 2043–2054. https://doi.org/10.2147/PPA.S270020

Drake, R. E., & Whitley, R. (2014). Recovery and Severe Mental Illness: Description and Analysis. In *CanJPsychiatry* (Vol. 59, Issue 5).

Drisko, J. W. (2025). Transferability and Generalization in Qualitative Research. *Research on Social Work Practice*, *35*(1), 102–110. https://doi.org/10.1177/10497315241256560

Eatough, V., & Smith, J. A. (2017). Interpretative phenomenological analysis. In *Handbook of Qualitative Psychology, Eds: Willig, C. and Stainton-Rogers, W.* (2nd edn, pp. 193–211). Sage.

Edwards, S. J., & Smith, C. J. (2009). Tolerability of atypical antipsychotics in the treatment of adults with schizophrenia or bipolar disorder: A mixed treatment comparison of randomized controlled trials. *Clinical Therapeutics*, *31*, 1345–1359.

El-Mallakh, R. S., Marcus, R., Baudelet, C., McQuade, R., Carson, W. H., & Owen, R. (2012). A 40-week double-blind aripiprazole versus lithium follow-up of a 12-week acute phase study (total 52 weeks) in bipolar I disorder. *Journal of Affective Disorders*, *136*(3), 258–266. https://doi.org/10.1016/j.jad.2011.11.043

Endicott, J., Paulsson, B., Gustafsson, U., Schiöler, H., & Hassan, M. (2008). Quetiapine monotherapy in the treatment of depressive episodes of bipolar I and II disorder: Improvements in quality of life and quality of sleep. *Journal of Affective Disorders*, *111*(2/3), 306–319.

Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science*, *196*(4286), 129–136. https://doi.org/10.1126/science.847460

Fakhoury, W. K., Wright, D., & Wallace, M. (2001). Prevalence and extent of distress of adverse effects of antipsychotics among callers to a United Kingdom National Mental Health Helpline. *International Clinical Psychopharmacology*, *16*(3), 153–162. https://doi.org/10.1097/00004850-200105000-00004

Fang, F., Sun, H., Wang, Z., Ren, M., Calabrese, J. R., & Gao, K. (2016). Antipsychotic Drug-Induced Somnolence: Incidence, Mechanisms, and Management. *CNS Drugs*, *30*(9), 845–867. https://doi.org/10.1007/s40263-016-0352-5

First, M. B., Gaebel, W., Maj, M., Stein, D. J., Kogan, C. S., Saunders, J. B., Poznyak, V. B., Gureje, O., Lewis-Fernández, R., Maercker, A., Brewin, C. R., Cloitre, M., Claudino, A., Pike, K. M., Baird, G., Skuse, D., Krueger, R. B., Briken, P., Burke, J. D., … Reed, G. M. (2021). An organization- and category-level comparison of diagnostic requirements for mental disorders in ICD-11 and DSM-5. *World Psychiatry*, *20*(1), 34–51. https://doi.org/10.1002/wps.20825

Fitzgerald, I., Crowley, E. K., Dhubhlaing, C. N., O’Dwyer, S., & Sahm, L. J. (2024). Informing the development of antipsychotic-induced weight gain management guidance: Patient experiences and preferences – qualitative descriptive study. *BJPsych Open*, *10*(5), e136. https://doi.org/10.1192/bjo.2024.725

Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Ways of Coping—Revised. *APA PsycTests*. https://doi.org/10.1037/t14761-000

Freudenreich, O., Henderson, D. C., Macklin, E. A., Evins, A. E., Fan, X., Cather, C., Walsh, J. P., & Goff, D. C. (2009). Modafinil for Clozapine-Treated Schizophrenia Patients: A Double-Blind, Placebo-Controlled Pilot Trial. *The Journal of Clinical Psychiatry*, *70*(12), 1674–1680. https://doi.org/10.4088/JCP.08m04683

Fryer, T. (2022). A critical realist approach to thematic analysis: Producing causal explanations. *Journal of Critical Realism*, *21*(4), 365–384. https://doi.org/10.1080/14767430.2022.2076776

Gaebel, W., Schreiner, A., Bergmans, P., de Arce, R., Rouillon, F., Cordes, J., Eriksson, L., & Smeraldi, E. (2010). Relapse prevention in schizophrenia and schizoaffective disorder with risperidone long-acting injectable vs quetiapine: Results of a long-term, open-label, randomized clinical trial. *Neuropsychopharmacology*, *35*(12). https://doi.org/10.1038/npp.2010.111

Giogri, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach*.

Giorgi, A. (2005). The Phenomenological Movement and Research in the Human Sciences. *Nursing Science Quarterly*, *18*(1), 75–82. https://doi.org/10.1177/0894318404272112

Glick, I. D., Murray, S. R., Vasudevan, P., Marder, S. R., & Hu, R. J. (2001). Treatment with atypical antipsychotics: New indications and new populations. *Journal of Psychiatric Research*, *35*(3), 187–191. https://doi.org/10.1016/S0022-3956(01)00020-6

Gray, R., & Deane, K. (2016). What is it like to take antipsychotic medication? A qualitative study of patients with first-episode psychosis. *Journal of Psychiatric and Mental Health Nursing*, *23*(2), 108–115. https://doi.org/10.1111/jpm.12288

Grinchii, D., & Dremencov, E. (2020). Mechanism of Action of Atypical Antipsychotic Drugs in Mood Disorders. *International Journal of Molecular Sciences*, *21*(24). https://doi.org/10.3390/ijms21249532

Gupta, S., Akyuz, E. U., Baldwin, T., & Curtis, D. (2018). Community treatment orders in England: Review of usage from national data. *BJPsych Bulletin*, *42*(3), 119–122. https://doi.org/10.1192/bjb.2017.33

Hale, A. S., Azorin, J. M., Lemming, O. M., & Mæhlum, E. (2012). Sertindole in the long-term treatment of schizophrenia. *International Clinical Psychopharmacology*, *27*(4), 231. https://doi.org/10.1097/YIC.0b013e328354dcda

Hálfdánarson, Ó., Zoëga, H., Aagaard, L., Bernardo, M., Brandt, L., Fusté, A. C., Furu, K., Garuoliené, K., Hoffmann, F., Huybrechts, K. F., Kalverdijk, L. J., Kawakami, K., Kieler, H., Kinoshita, T., Litchfield, M., López, S. C., Machado-Alba, J. E., Machado-Duque, M. E., Mahesri, M., … Bachmann, C. J. (2017). International trends in antipsychotic use: A study in 16 countries, 2005-2014. *European Neuropsychopharmacology : The Journal of the European College of Neuropsychopharmacology*, *27*(10), 1064–1076. https://doi.org/10.1016/j.euroneuro.2017.07.001

Halling, S. (2021). Phenomenology as fidelity to phenomena: Moving beyond the Van Manen, Smith, and Zahavi debate. *The Humanistic Psychologist*, *49*(2), 342–353. https://doi.org/10.1037/hum0000195

Harris, K. (2010). *Service users' experiences of an early intervention in psychosis service: An interpretative phenomenological analysis* [DClin Psych Thesis, Nottingham]. https://eprints.nottingham.ac.uk/11490/1/Thesis_Katy_Harris.pdf

Harrison, G., Hopper, K., Craig, T., Laska, E., Siegel, C., Wanderling, J., Dube, K. C., Ganev, K., Giel, R., an der Heiden, W., Holmberg, S. K., Janca, A., Lee, P. W., León, C. A., Malhotra, S., Marsella, A. J., Nakane, Y., Sartorius, N., Shen, Y., … Wiersma, D. (2001). Recovery from psychotic illness: A 15- and 25-year international follow-up study. *The British Journal of Psychiatry : The Journal of Mental Science*, *178*, 506–517. https://doi.org/10.1192/bjp.178.6.506

Healthy London Partnership. (n.d.). *Personality disorders: Increasing awareness and raising hope*. Transformation Partners in Health and Care. Retrieved 5 June 2025, from https://www.transformationpartners.nhs.uk/programmes/mental-health-transformation/support-for-adults/personality-disorders/

Healy, D. (2016). *Psychiatric Drugs Explained* (6th ed.). Elsevier.

Hechter, M., & Satoshi, K. (1997). Sociological Rational Choice Theory. *Annual Review of Sociology*, *23*, 191–214.

Heidegger, M. (1982). *The Basic Problems of Phenomenology. Translated by Albert Hofstader*. Indiana University Press.

Helene, V., Gonzales, B., Takei, N., & Bourgeois, M. (1996). A survey of prescribing practice of antipsychotic maintenance treatment for manic-depressive outpatients. *Journal of Affective Disorders*, *38*, 81–87.

Hett, D., Morales-Muñoz, I., Durdurak, B. B., Carlish, M., & Marwaha, S. (2023). Rates and associations of relapse over 5 years of 2649 people with bipolar disorder: A retrospective UK cohort study. *International Journal of Bipolar Disorders*, *11*(1), 23. https://doi.org/10.1186/s40345-023-00302-x

Higgins, A., & McBennett, P. (2007). The petals of recovery in a mental health context. *British Journal of Nursing*, *16*(14), 852–856. https://doi.org/10.12968/bjon.2007.16.14.24322

Hirschfeld, R. M., Calabrese, J. R., Frye, M. A., Lavori, P. W., Sachs, G., Thase, M. E., & Wagner, K. D. (2007). Defining the clinical course of bipolar disorder: Response, remission, relapse, recurrence, and roughening. *Psychopharmacology Bulletin*, *40*(3), 7–14.

Hodge, K., & Jespersen, S. (2008). Side-effects and treatment with clozapine: A comparison between the views of consumers and their clinicians. *International Journal of Mental Health Nursing*, *17*(1), 2–8.

Hofer, A., Kemmler, G., Eder, U., Honeder, M., Hummer, M., & Fleischhacker, W. W. (2002). Attitudes toward antipsychotics among outpatient clinic attendees with schizophrenia. *The Journal of Clinical Psychiatry*, *63*(1), 49–53.

Holmes, A. G. D. (2020). Researcher Positionality—A Consideration of Its Influence and Place in Qualitative Research—A New Researcher Guide. *Shanlax International Journal of Education*, *8*(4), Article 4. https://doi.org/10.34293/education.v8i4.3232

Holt, R. I. G. (2019). Association Between Antipsychotic Medication Use and Diabetes. *Current Diabetes Reports*, *19*(96). https://doi.org/10.1007/s11892-019-1220-8

Horne, D. (2003). Treatment perception and self-regulation. In *The self-regulation of health and illness behaviour, Eds: L. D. Cameron & H. Leventhal* (pp. 138–153). Routledge.

Horowitz, M., & Taylor, D. M. (2024). *The Maudsley Deprescribing Guidelines: Antidepressants, Benzodiazepines, Gabapentinoids and Z-drugs*. Wiley-Blackwell. DOI: 10.1002/9781394291052

Howes, O. D., McCutcheon, R., Owen, M. J., & Murray, R. M. (2017). The Role of Genes, Stress, and Dopamine in the Development of Schizophrenia. *Biological Psychiatry*, *81*(1), 9–20. https://doi.org/10.1016/j.biopsych.2016.07.014

Hughes, S., & Cohen, D. (2011). Can online consumers contribute to drug knowledge? A mixed-methods comparison of consumer-generated and professionally controlled psychotropic medication information on the internet. *Journal of Medical Internet Research*, *13*(3), e53. https://doi.org/10.2196/jmir.1716

Husserl, E. (1963). *Ideas: A General Introduction to Pure Phenomenology. Translation by W.R. Boyce*. Collier Books.

Huston, M. (2023, June 6). *There's a growing case for renaming 'personality disorders'*. Pysche Know Your Self. https://psyche.co/ideas/theres-a-growing-case-for-renaming-personality-disorders

Ishizuka, T., & Yamatodani, A. (2012). Integrative role of the histaminergic system in feeding and taste perception. *Front. Syst. Neurosci.*, *6*(44). https://doi.org/10.3389/fnsys.2012.00044

Johns, M. W. (1991). A new method for measuring daytime sleepiness: The Epworth sleepiness scale. *Sleep*, *14*(6), 540–545. https://doi.org/10.1093/sleep/14.6.540

Kadri, N., & Sartorius, N. (2005). The global fight against the stigma of schizophrenia. *PLoS Medicine*, *2*(7), e136. https://doi.org/10.1371/journal.pmed.0020136

Kane, J. M., Skuban, A., Hobart, M., Ouyang, J., Weiller, E., Weiss, C., & Correll, C. U. (2016). Overview of short- and long-term tolerability and safety of brexpiprazole in patients with schizophrenia. *Schizophrenia Research*, *174*(1–3), 93–98. https://doi.org/10.1016/j.schres.2016.04.013

Katayi, E. O. (2014). *Impact of Side Effects of Antipsychotics on Attitude and Adherence to Treatment among Adult Psychiatric Outpatients at Mathari Hospital in Kenya* [University of Nairobi]. https://erepository.uonbi.ac.ke/handle/11295/75802

Kaul, I., Sawchak, S., Correll, C. U., Kakar, R., Breier, A., Zhu, H., Miller, A. C., Paul, S. M., & Brannan, S. K. (2024). Efficacy and safety of the muscarinic receptor agonist KarXT (xanomeline-trospium) in schizophrenia (EMERGENT-2) in the USA: results from a randomised, double-blind, placebo-controlled, flexible-dose phase 3 trial. *Lancet (London, England)*, *403*(10422), 160–170. https://doi.org/10.1016/S0140-6736(23)02190-6

Keck, P. E. (2005). Bipolar depression: A new role for atypical antipsychotics? *Bipolar Disorders*, *7*, 34–40.

Kemp, D. E. (2014). Managing the side effects associated with commonly used treatments for bipolar depression. *Journal of Affective Disorders*, *169 Suppl*, S34-44. https://doi.org/10.1016/S0165-0327(14)70007-2

Kessler, R. C., McLaughlin, K. A., Green, J. G., Gruber, M. J., Sampson, N. A., Zaslavsky, A. M., Aguilar-Gaxiola, S., Alhamzawi, A. O., Alonso, J., Angermeyer, M., Benjet, C., Bromet, E., Chatterji, S., Girolamo, G. de, Demyttenaere, K., Fayyad, J., Florescu, S., Gal, G., Gureje, O., … Williams, D. R. (2010). Childhood adversities and adult psychopathology in the WHO World Mental Health Surveys. *The British Journal of Psychiatry*, *197*(5), 378–385. https://doi.org/10.1192/bjp.bp.110.080499

Kikuchi, T., Suzuki, T., Uchida, H., Watanabe, K., & Mimura, M. (2012). Coping strategies for antidepressant side effects: An Internet survey. *Journal of Affective Disorders*, *143*(1), 89–94. https://doi.org/10.1016/j.jad.2012.04.039

Kinderman, P. (2014). *A Prescription for Psychiatry: Why we need a whole new approach to mental health and wellbeing* (1st ed.). Palgrave Macmillian.

Kovess-Masfety, V., Balusson, F., Leray, E., Husky, M., & Scailteux, L.-M. (2020). Prescription patterns of first- and second-generation antipsychotic drugs in the French population. *Fundamental & Clinical Pharmacology*, *34*(5), 603–611. https://doi.org/10.1111/fcp.12553

Kraepelin, E. (1919). *Dementia Praecox and Paraphrenia*. Chicago Medical Book Co. https://archive.org/details/dementiapraecoxp00kraeiala/page/4/mode/2up

Kular, A., Birken, M., Wood, L., Parkinson, J., Bacarese-Hamilton, T., Blakley, L., Hutchings-Hay, C., Nyikavaranda, P., Alam, D., Ogbolu, R., Bendall, C., Tang, L., Nickson, A., Revell, C., Mbeah-Bankas, H., Mitchell, L., Fraser, K. L., White, V. C., Lobban, F., … Johnson, S. (2025). Exploring pathways to compulsory detention and ways to prevent repeat compulsory detentions in England; clinician perspectives. *PLOS Mental Health*, *2*(6), e0000314. https://doi.org/10.1371/journal.pmen.0000314

Lambert, T. J., Singh, B. S., & Patel, M. X. (2009). Community treatment orders and antipsychotic long-acting injections. *British Journal of Psychiatry*, *195*(S52), s57–s62. Cambridge Core. https://doi.org/10.1192/bjp.195.52.s57

Langmuir, T., Chu, A., Sehabi, G., Giguère, L., Lamarche, J., Boudjatat, W., & Lebel, S. (2023). A new landscape in illness uncertainty: A systematic review and thematic synthesis of the experience of uncertainty in patients with advanced cancer receiving immunotherapy or targeted therapy. *Psycho-Oncology*, *32*(3), 356–367. https://doi.org/10.1002/pon.6093

Larsen, E. B., & Gerlach, J. (1996). Subjective experience of treatment, side-effects, mental state and quality of life in chronic schizophrenic out-patients treated with depot neuroleptics—Larsen -. *Acta Psychiatrica Scandinavica*, *93*(5), 381–388. https://doi.org/0.1111/j.1600-0447.1996.tb10664.x

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping*. Springer Publishing Company.

Leigh-Hunt, N., Bagguley, D., Bash, K., Turner, V., Turnbull, S., Valtorta, N., & Caan, W. (2017). An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health*, *152*, 157–171. https://doi.org/10.1016/j.puhe.2017.07.035

Leucht, S., Cipriani, A., Spineli, L., Mavridis, D., Örey, D., Richter, F., Samara, M., Barbui, C., Engel, R. R., Geddes, J. R., Kissling, W., Stapf, M. P., Lässig, B., Salanti, G., & Davis, J. M. (2013). Comparative efficacy and tolerability of 15 antipsychotic drugs in schizophrenia: A multiple-treatments meta-analysis. *The Lancet*, *382*(9896), 951–962. https://doi.org/10.1016/S0140-6736(13)60733-3

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, *5*(1), 69. https://doi.org/10.1186/1748-5908-5-69

Light, E. (2019). Rates of use of community treatment orders in Australia. *International Journal of Law and Psychiatry*, *64*, 83–87. https://doi.org/10.1016/j.ijlp.2019.02.006

Lindström, E., Lewander, T., Malm, U., Malt, U. F., Lublin, H., & Ahlfors, U. G. (2001). Patient-rated versus clinician-rated side effects of drug treatment in schizophrenia. Clinical validation of a self-rating version of the UKU Side Effect Rating Scale (UKU-SERS-Pat). *Nordic Journal of Psychiatry*, *55 Suppl 44*, 5–69. https://doi.org/10.1080/080394801317084428

Linszen, D., Dingemans, P., & Lenior, M. (2001). Early intervention and a five year follow up in young adults with a short duration of untreated psychosis: Ethical implications. *Schizophrenia Research*, *51*(1), 55–61. https://doi.org/10.1016/s0920-9964(01)00239-0

Llorca, P.-M., Lancon, C., Hartry, A., Brown, T. M., DiBenedetti, D. B., Kamat, S. A., & Francois, C. (2017). Assessing the burden of treatment-emergent adverse events associated with atypical antipsychotic medications. *BMC Psychiatry*, *17*(1), 67. https://doi.org/10.1186/s12888-017-1213-6

Lloyd, C. E. M., & Antonino, R. (2022). “A gentle balance of pushing, pulling and sitting with”: An interpretative phenomenological analysis of psychological therapists’ experiences of working with goals in adult pluralistic private practice. *Counselling Psychology Quarterly*, *35*(1), 190–214. https://doi.org/10.1080/09515070.2021.1954881

Lo, L., Kaur, R., Meiser, B., & Green, M. J. (2020). Risk of schizophrenia in relatives of individuals affected by schizophrenia: A meta-analysis. *Psychiatry Research*, *286*, 112852. https://doi.org/10.1016/j.psychres.2020.112852

Lohr, J. B., Liu, L., Caligiuri, M. P., Kash, T. P., May, T. A., Murphy, J. D., & Ancoli-Israel, S. (2013). Modafinil improves antipsychotic-induced parkinsonism but not excessive daytime sleepiness, psychiatric symptoms or cognition in schizophrenia and schizoaffective disorder: A randomized, double-blind, placebo-controlled study. *Schizophrenia Research*, *150*(1), 289–296. https://doi.org/10.1016/j.schres.2013.07.039

MacKenzie, N., & Knipe, S. (2006). Research dilemmas: Paradigms, methods and methodology. *Issues In Educational Research*, *16*. http://www.iier.org.au/iier16/mackenzie.html

Mahapatra, A., & Sharma, P. (2024). Biopsychosocial Approach to Mental Health. In M. Anand (Ed.), *Mental Health Care Resource Book: Concepts and Praxis for Social Workers and Mental Health Professionals* (pp. 87–100). Springer Nature. https://doi.org/10.1007/978-981-97-1203-8_5

Makela, E. H., Miller, K., & Cutlip, W. D. (2003). Three case reports of modafinil use in treating sedation induced by antipsychotic medications. *The Journal of Clinical Psychiatry*, *64*(4). https://doi.org/10.4088/jcp.v64n0420h

Marston, L., Nazareth, I., Petersen, I., Walters, K., & Osborn, D. P. J. (2014). Prescribing of antipsychotics in UK primary care: A cohort study. *BMJ Open*, *4*(12), e006135. https://doi.org/10.1136/bmjopen-2014-006135

Mason, K. E., Alexiou, A., Li, A., & Taylor-Robinson, D. (2024). The impact of housing insecurity on mental health, sleep and hypertension: Analysis of the UK Household Longitudinal

Study and linked data, 2009–2019. *Social Science & Medicine*, *351*, 116939. https://doi.org/10.1016/j.socscimed.2024.116939

Maudsley Prescribing Guidelines. (2025). *Maudsley Prescribing Guidelines International Conference 2025*. https://www.maudsley-prescribing-guidelines.co.uk/conference2025/

Maylea, C., Zirnsak ,Tessa-May, Edan ,Vrinda, Armitage ,Paul, Robert, Hannah, & and Brophy, L. (2025). Ensuring compulsory treatment is used as a last resort: A narrative review of the knowledge about Community Treatment Orders. *Psychiatry, Psychology and Law*, 1–20. https://doi.org/10.1080/13218719.2024.2421168

McDonnell, D. P., Landry, J., & Detke, H. C. (2014). Long-term safety and efficacy of olanzapine long-acting injection in patients with schizophrenia or schizoaffective disorder: A 6-year, multinational, single-arm, open-label study. *International Clinical Psychopharmacology*, *29*(6), 322–331. https://doi.org/10.1097/YIC.0000000000000038

McEvoy, J. P., Lieberman, J. A., Perkins, D. O., Hamer, R. M., Gu, H., Lazarus, A., Sweitzer, D., Olexy, C., Weiden, P., & Strakowski, S. D. (2007). Efficacy and tolerability of olanzapine, quetiapine, and risperidone in the treatment of early psychosis: A randomized, double-blind 52-week comparison. *The American Journal of Psychiatry*, *164*(7), 1050–1060. https://doi.org/10.1176/ajp.2007.164.7.1050

McIntyre, R. S. (2002). Psychotropic drugs and adverse events in the treatment of bipolar disorders revisited. *The Journal of Clinical Psychiatry*, *63*(Suppl3), 15–20.

McLuckie, A., Landers, A. L., Curran, J. A., Cann, R., Carrese, D. H., Nolan, A., Corrigan, K., & Carrey, N. J. (2019). A scoping review of mental health prevention and intervention initiatives for infants and preschoolers at risk for socio-emotional difficulties. *Systematic Reviews*, *8*(1), 183. https://doi.org/10.1186/s13643-019-1043-3

Meehan, T., Stedman, T., & Wallace, J. (2011). Consumer Strategies for Coping With Antipsychotic Medication Side Effects. *Australasian Psychiatry*, *19*(1), 74–77. https://doi.org/10.3109/10398562.2010.539612

Mental Health America. (2025). *Recovery & Support*. https://mhanational.org/resources/recovery-support/

Mental Health Review Tribunal. (2025). *Community Treatment Orders*. NSW Mental Health Review Tribunal. https://mhrt.nsw.gov.au/civil-patients/community-treatment-orders.html

Mental Welfare Commission for Scotland. (2025). *Laws and Rights | Mental Health Act*. https://www.mwcscot.org.uk/law-and-rights/mental-health-act

Milano, W., Grillo, F., A, D. M., M, D. R., Sanseverino, B., Petrella, C., Capasso, A., Milano, W., Grillo, F., Mastro, A. D., Rosa, M. D., Sanseverino, B., Petrella, C., & Capasso, A. (2007). Appropriate intervention strategies for weight gain induced by olanzapine: A randomized controlled study. *Advances in Therapy*, *24*(1), 123–134. https://doi.org/10.1007/bf02850000

Miller, R. M., Chan, C. D., & Farmer, L. B. (2018). Interpretative Phenomenological Analysis: A Contemporary Qualitative Approach. *Counselor Education and Supervision*, *57*(4), 240–254. https://doi.org/10.1002/ceas.12114

Mind. (n.d.). *Mental health language*. Mind | Media. Retrieved 15 May 2025, from https://www.mind.org.uk/media/7582/mental-health-language.pdf

Mind. (2020a). *Antipsychotics: What side effects can they cause?: Sedation (sleepiness)*. Information and Support | Drugs and Treatments | Antipsychotics | Side Effects | Sedationsleepiness. https://www.mind.org.uk/information-support/drugs-and-treatments/antipsychotics/side-effects/#SedationSleepiness

Mind. (2020b). *What's the science behind antipsychotics?* Mind | Information and Support | Drugs and Treatments | Antipsychotics | About Antipsychotics.

https://www.mind.org.uk/information-support/drugs-and-treatments/antipsychotics/about-antipsychotics/

Mind. (2025a). *Community Treatment Orders (CTOs)*. Mind | Information and Support | Legal Rights. https://www.mind.org.uk/information-support/legal-rights/community-treatment-orders-ctos/recall-to-hospital/

Mind. (2025b). *What are mental health problems?* Mind | Information and Support | Types of Mental Health Problems | Mental Health Problems - an Introduction. https://www.mind.org.uk/information-support/types-of-mental-health-problems/mental-health-problems-introduction/about-mental-health-problems/

Mind. (2025c). *What is a depot injection?* MInd | Information and Support | Drugs and Treatments | Antipsychotics. https://www.mind.org.uk/information-support/drugs-and-treatments/antipsychotics/depot-injections/

Mishel, M. H. (1988). Uncertainty in illness. *J Nurs Scholarsh*, *20*(4), 225–232. https://doi.org/10.1111/j.1547-5069.1988.tb00082.x

Mishel, M. H. (1990). Reconceptualization Of The Uncertainty In Illness Theory. *Journal of Nursing Scholarship*, *22*(4), 256–262. https://doi.org/10.1111/j.1547-5069.1990.tb00225.x

Mishel, M. H., Belyea, M., Germino, B. B., Stewart, J. L., Bailey, D. E., Robertson, C., & Mohler, J. (2002). Helping patients with localized prostate carcinoma manage uncertainty and treatment side effects. *Cancer*, *94*(6). https://doi.org/10.1002/cncr.10390

Mishel, M. H., Germino, B. B., Gil, K. M., Belyea, M., LaNay, I. C., Stewart, J., Porter, L., & Clayton, M. (2005). Benefits from an uncertainty management intervention for African–American and Caucasian older long-term breast cancer survivors. *Psycho-Oncology*, *14*(11). https://doi.org/10.1002/pon.909

Moncrieff, J. (2006). Does antipsychotic withdrawal provoke psychosis? Review of the literature on rapid onset psychosis (super sensitivity psychosis) and withdrawal-related relapse. *Acta Psychiatr Scand*, *114*, 3–13.

Moncrieff, J. (2009). A Critique of the Dopamine Hypothesis of Schizophrenia and Psychosis. *Harvard Review of Psychiatry*, *17*(3). https://doi.org/10.1080/10673220902979896

Moncrieff, J. (2013). Interventions: Psychiatric Medication. In J. Cromby, D. Harper, & P. Reavey (Eds.), *Psychology, Mental Health and Distress* (pp. 160–168). Palgrave.

Moncrieff, J. (2015). Antipsychotic Maintenance Treatment: Time to Rethink? *PLOS Medicine*, *12*(8), e1001861. https://doi.org/10.1371/journal.pmed.1001861

Moncrieff, J. (2023). Lessons from the RADAR trial. *Joanna Moncrieff: Books, Papers, and Blogs*. https://joannamoncrieff.com/2023/10/02/lessons-from-the-radar-trial/

Moncrieff, J., Cohen, D., & Mason, J. P. (2009). The subjective experience of taking antipsychotic medication: A content analysis of Internet data. *Acta Psychiatrica Scandinavica*, *120*(2), 102–111.

Moncrieff, J., Crellin, N. E., Long, M. A., Cooper, R. E., & Stockmann, T. (2020). Definitions of relapse in trials comparing antipsychotic maintenance with discontinuation or reduction for schizophrenia spectrum disorders: A systematic review. *Schizophrenia Research*, *225*, 47–54. https://doi.org/10.1016/j.schres.2019.08.035

Moncrieff, J., Crellin, N., Stansfeld, J., Cooper, R., Marston, L., Freemantle, N., Lewis, G., Hunter, R., Johnson, S., Barnes, T., Morant, N., Pinfold, V., Smith, R., Kent, L., Darton, K., Long, M., Horowitz, M., Horne, R., Vickerstaff, V., … Priebe, S. (2023). Antipsychotic dose reduction and discontinuation versus maintenance treatment in people with schizophrenia and other recurrent psychotic disorders in England (the RADAR trial): An open, parallel-group, randomised controlled trial. *The Lancet Psychiatry*, *10*(11), 848–859. https://doi.org/10.1016/S2215-0366(23)00258-4

Morant, N., Johnson, S., Moncrieff, J., & Azam, K. (2018). The least worst option: User experiences of antipsychotic medication and lack of involvement in medication decisions in a UK community sample. *Journal of Mental Health*, *27*(4), 322–328. https://doi.org/10.1080/09638237.2017.1370637

Morrison, P., Meehan, T., Gaskill, D., Lunney, P., & Collings, P. (2000). Enhancing case managers' skills in the assessment and management of antipsychotic medication side-effects. *The Australian and New Zealand Journal of Psychiatry*, *34*(5), 814–821. https://doi.org/10.1080/j.1440-1614.2000.00821.x

Morrison, P., Meehan, T., & Stomski, N. J. (2015). Living with antipsychotic medication side-effects: The experience of Australian mental health consumers. *International Journal of Mental Health Nursing*, *24*(3), 253–261. https://doi.org/10.1111/inm.12110

Morrison, P., Taylor, D. M., & Mcguire, P. (2019). *The Maudsley Guidelines on Advanced Prescribing in Psychosis*. Wiley-Blackwell. https://www.wiley.com/en-us/The+Maudsley+Guidelines+on+Advanced+Prescribing+in+Psychosis-p-9781119578437

Moseley, P., Powell, A., Woods, A., Fernyhough, C., & Alderson-Day, B. (2022). Voice-Hearing Across The Continuum: A Phenomenology of Spiritual Voices. *Schizophrenia Bulletin*, *48*(5), 1066–1074. https://doi.org/10.1093/schbul/sbac054

Moss-Morris, R. (2013). Adjusting to chronic illness: Time for a unified theory. *British Journal of Health Psychology*, *18*(4), 681–686. https://doi.org/10.1111/bjhp.12072

Mulder, R., Hamilton, A., Irwin, L., Boyce, P., Morris, G., Porter, R. J., & Malhi, G. S. (2018). Treating depression with adjunctive antipsychotics. *Bipolar Disorders*, *20*, 17–24.

Murray, C. D., & Wilde, D. J. (2020). Thinking about, doing and writing up research using interpretative phenomenological analysis. In *Handbook of Theory and Methods in Applied Health Research. Ed: Catherine Walsh & Sarah Brearly* (pp. 140–166). Edward Elgar Publishing Limited.

National Mental Health Intelligence Network. (2023). *Premature mortality in adults with severe mental illness*. UK Office for Health Improvement and Disparities. https://www.gov.uk/government/publications/premature-mortality-in-adults-with-severe-mental-illness/premature-mortality-in-adults-with-severe-mental-illness-smi

NHS. (2018). *What are side effects?* https://www.nhs.uk/common-health-questions/medicines/what-are-side-effects/

NHS England, NHS Improvement and the National Collaborating, & Central for Mental Health. (2019). *The community mental health framework for adults and older adults*. https://www.england.nhs.uk/wp-content/uploads/2019/09/community-mental-health-framework-for-adults-and-older-adults.pdf

NICE. (n.d.). *Adult mental health: Serious mental illness, community, acute and crisis care*. Retrieved 5 June 2025, from http://stpsupport.nice.org.uk

NICE. (2011). *Common mental health problems: Identification and pathways to care | Guidance | CG123*. NICE Cliinical Guideline; NICE. https://www.nice.org.uk/guidance/cg123

NICE. (2014). *Antipsychotic medication | Information for the public | Psychosis and schizophrenia in adults: Prevention and management | Guidance | CG178*. NICE Cliinical Guideline. https://www.nice.org.uk/guidance/cg178/ifp/chapter/antipsychotic-medication

NICE. (2016a). *Coexisting severe mental illness and substance misuse: Community health and social care services | Guidance | NG58*. NICE Guidelines; NICE. https://www.nice.org.uk/guidance/ng58

NICE. (2016b). *Mental health problems in people with learning disabilities: Prevention, assessment and management | Guidance | NG54*. NICE Guidelines; NICE. https://www.nice.org.uk/guidance/ng54

NICE. (2022). *Depression in adults: Treatment and management | Guidance | NG222*. NICE Guidelines. https://www.nice.org.uk/guidance/ng222/chapter/Recommendations

NICE. (2025a). *Psychosis and schizophrenia: Scenario: Primary care Management | Basis for recommendation | Length of treatment with an antipsychotic*. Clinical Knowledge Summaries. https://cks.nice.org.uk/topics/psychosis-schizophrenia/management/primary-care-management/

NICE. (2025b). *Topic | Psychosis—Schizophrenia | prescribing information | adverse effects*. NICE Clinical Knowledge Summaries; NICE. https://cks.nice.org.uk/topics/psychosis-schizophrenia/prescribing-information/adverse-effects/

NICE. (2025c). *Topics | Bipolar disorder | Prescribing Information | Antipsychotics*. NICE Clinical Knowledge Summaries. https://cks.nice.org.uk/topics/bipolar-disorder/prescribing-information/antipsychotics/

Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, *18*(3), 369–386. https://doi.org/10.1080/14780887.2020.1854404

Offredy, M., & Vickers, P. (2010). *Developing a Healthcare Research Proposal: An interactive student guide* (1st edn). Wiley-Blackwell.

Ohlsen, R. I., Williamson, R., Yusufi, B., Mullan, J., Irving, D., Mukherjee, S., Page, E., Aitchison, K. J., & Barnes, T. R. E. (2008). Interrater reliability of the Antipsychotic Non-Neurological Side-Effects Rating Scale measured in patients treated with clozapine. *Journal of Psychopharmacology*, *22*(3), 323–329. https://doi.org/10.1177/0269881108091069

Olivares, J. M., Sermon, J., Hemels, M., & Schreiner, A. (2013). Definitions and drivers of relapse in patients with schizophrenia: A systematic literature review. *Annals of General Psychiatry*, *12*(1), 32. https://doi.org/10.1186/1744-859X-12-32

O’Mullan, C., Doherty, M., Coates, R., & Tilley, P. J. M. (2014). Women’s experiences of coping with the sexual side effects of antidepressant medication. *Psychology and Health*, *29*(12), 1388–1406. https://doi.org/10.1080/08870446.2014.940951

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—A web and mobile app for systematic reviews. *Systematic Reviews*, *5*(1), 210. https://doi.org/10.1186/s13643-016-0384-4

Özdemİr, O., Coşkun, S., Aktan Mutlu, E., ÖzdemİR, P. G., Atli, A., Yilmaz, E., & Keskin, S. (2016). Family History in Patients with Bipolar Disorder. *Archives of Neuropsychiatry*, *53*(3), 276–279. https://doi.org/10.5152/npa.2015.9870

Patterson, S., Trite, J., & Weaver, T. (2014). Activity and views of service users involved in mental health research: UK survey. *The British Journal of Psychiatry : The Journal of Mental Science*, *205*(1), 68–75. https://doi.org/10.1192/bjp.bp.113.128637

Pawson, R., & Tilley, N. (1997). *Realistic evaluation*. SAGE.

Peters, M. D., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D., & Soares, C. B. (2015). Guidance for conducting systematic scoping reviews. *JBI Evidence Implementation*, *13*(3), 141. https://doi.org/10.1097/XEB.0000000000000050

Peters, M. D., Godfrey, C., McInerney, P., Munn, Z., Tricco, A. C., & Kahlil, H. (2020). Scoping Reviews. In *Editors: Aromatis E, Lockwood C, Porritt K, Pilla B, Jordan Z, JBI Manual for Evidence Synthesis*. https://jbi-global-wiki.refined.site/space/MANUAL/355862497/10.+Scoping+reviews

Pilgrim, D. (2014). Some implications of critical realism for mental health research. *Social Theory & Health*, *12*(1), 1–21. https://doi.org/10.1057/sth.2013.17

Pilgrim, D. (2017). The Perils of Strong Social Constructionism: The Case of Child Sexual Abuse. *Journal of Critical Realism*, *16*(3), 268–283. https://doi.org/10.1080/14767430.2017.1303928

Prasuna, P. L., & Sudhakar, T. P. (2015). Impact of Modafinil Add-on with Atypical Anti-psychotics on Excessive Daytime Drowsiness. *Indian Journal of Psychological Medicine*, *37*(4), 388–392. https://doi.org/10.4103/0253-7176.168561

Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: A discussion and critique. *Nurse Res*, *18*(3), 20–24. https://doi.org/10.7748/nr2011.04.18.3.20.c8459

Psychiatry DataBase. (2024). *Biopsychosocial Model and Case Formulation*. PsychDB. https://www.psychdb.com/teaching/biopsychosocial-case-formulation

Rafique, R., & Hunt, N. (2015). Experiences and coping behaviours of adolescents in Pakistan with alopecia areata: An interpretative phenomenological analysis. *International Journal of Qualitative Studies on Health and Well-Being*, *10*(1), 26039. https://doi.org/10.3402/qhw.v10.26039

Ramos Perdigués, S., Sauras Quecuti, R., Mané, A., Mann, L., Mundell, C., & Fernandez-Egea, E. (n.d.). An observational study of clozapine induced sedation and its pharmacological management. *European Neuropsychopharmacology : The Journal of the European College of Neuropsychopharmacology*, *26*(1), 156–161. https://doi.org/10.1016/j.euroneuro.2015.11.006

Read, J., & Sacia, A. (2020). Using Open Questions to Understand 650 People's Experiences With Antipsychotic Drugs. *Schizophrenia Bulletin*, *46*(4), 896–904. https://doi.org/10.1093/schbul/sbaa002

Read, J., & Williams, J. (2019). Positive and negative effects of antipsychotic medication: An international online survey of 832 recipients. *Current Drug Safety*, *14*. https://doi.org/10.2174/1574886314666190301152734

Read, U. (2012). "I want the one that will heal me completely so it won't come back again": The limits of antipsychotic medication in rural Ghana. *Transcultural Psychiatry*, *49*(3–4), 438–460. https://doi.org/10.1177/1363461512447070

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, *18*(1), 20–23.

Rethink Mental Illness. (2024). *Antipsychotics—What you need to know. Antipsychotic fact sheet*. Advice and Information | Living with Mental Illness | Medications | Antipsychotics. https://www.rethink.org/advice-and-information/living-with-mental-illness/medications/antipsychotics/

Royal College of Psychiatrists. (2011). *Ethics of psychiatric research*.

Royal College of Psychiatrists. (2019). *Mental health | treatments and wellbeing | antipsychotics*. How Do We Believe Antipsychotics Work? https://www.rcpsych.ac.uk/mental-health/treatments-and-wellbeing/antipsychotics

Rund, B. (2009). Is there a degenerative process going on in the brain of people with schizophrenia? *Front. Hum. Neurosci.*, *3*(36). https://doi.org/10.3389/neuro.09.036.2009

Said, Q., Gutterman, E. M., Kim, M. S., Firth, S. D., Whitehead, R., & Brixner, D. (2008). Somnolence effects of antipsychotic medications and the risk of unintentional injury. *Pharmacoepidemiology and Drug Safety*, *17*(4), 354–364. https://doi.org/10.1002/pds.1559

Schennach, R., Riedel, M., Obermeier, M., Jäger, M., Schmauss, M., & Laux, G. (2020). What happens with schizophrenia patients after their discharge from hospital? Results on outcome and treatment from a “real-world” 2-year follow-up trial. *Eur Arch Psychiatry Clin Neurosci*, *270*(6), 661–671. https://doi.org/10.1007/s00406-019-01055-4

Schreiner, A., Hargarter, L., Hitschfield, K., Lee, J. L., Lenskaya, I., Sulaiman, A. H., & Diels, J. (2014). Clinical effectiveness and resource utilization of paliperidone ER for schizophrenia: Pharmacoepidemiologic International Longitudinal Antipsychotic Registry (PILAR). *Current Medical Research and Opinion*, *30*(7), 1279–1289. https://doi.org/10.1185/03007995.2014.898630

Sevy, S., Rosenthal, M. H., Alvir, J., Meyer, S., Visweswaraiah, H., Gunduz-Bruce, H., & Schooler, N. R. (2005). Double-blind, placebo-controlled study of modafinil for fatigue and cognition in schizophrenia patients treated with psychotropic medications. *The Journal of Clinical Psychiatry*, *66*(7), 839–843. https://doi.org/10.4088/jcp.v66n0705

Shepherd, G., Boardman, J., & Slade, M. (2008). *Making recovery a reality*. Salisbury Centre for Mental Health.

Sherman, G. L. (2025). Integrating phenomenology and critical realism in qualitative research in psychology. *Journal of Theoretical and Philosophical Psychology*. https://doi.org/10.1037/teo0000315

Shibuya, K., Funaki, Y., Hiraoka, K., Yoshikawa, T., Naganuma, F., Miyake, M., Watanuki, S., Sato, H., Tashiro, M., & Yanai, K. (2012). Doxepin binding to histamine H1 receptors in living human brain: Reproducibility during attentive waking and circadian rhythm. *Front. Syst. Neurosci.*, *6*(45). https://doi.org/10.3389/fnsys.2012.00045

Shoham, N., Cooper, C., Lewis, G., Bebbington, P., & McManus, S. (2021). Temporal trends in psychotic symptoms: Repeated cross-sectional surveys of the population in England 2000–14. *Schizophrenia Research*, *228*, 97–102. https://doi.org/10.1016/j.schres.2020.11.057

Sim, I. O. (2020). Analysis of the Coping Process among Visually Impaired Individuals, Using Interpretative Phenomenological Analysis (IPA). *International Journal of Environmental Research and Public Health*, *17*(8), Article 8. https://doi.org/10.3390/ijerph17082819

Siskind, D., Baker, A., Arnautovska, U., Warren, N., Russell, A., DeMonte, V., Halstead, S., Iyer, R., Korman, N., McKeon, G., Medland, S., Parker, S., Stedman, T., & Trott, M. (2025). Efficacy and safety of semaglutide versus placebo for people with schizophrenia on clozapine with obesity (COaST): A phase 2, multi-centre, participant and investigator-blinded, randomised controlled trial in Australia. *The Lancet Psychiatry*, *12*(7), 493–503. https://doi.org/10.1016/S2215-0366(25)00129-4

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, *5*(1), 9–27. https://doi.org/10.1080/17437199.2010.510659

Smith, J. A. (2018). “Yes It Is Phenomenological”: A Reply to Max Van Manen’s Critique of Interpretative Phenomenological Analysis. *Qualitative Health Research*, *28*(12), 1955–1958. https://doi.org/10.1177/1049732318799577

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. SAGE.

Smith, J. A., Flowers, P., & Larkin, M. (2021). *Interpretative phenomenological analysis: Theory, method and research* (2nd Edn). SAGE.

Smith, J. A., & Shinebourne, P. (2012). Interpretative phenomenological analysis. In *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 73–82). American Psychological Association. https://doi.org/10.1037/13620-005

Stilo, S. A., & Murray, R. M. (2019). Non-Genetic Factors in Schizophrenia. *Current Psychiatry Reports*, *21*(10), 100. https://doi.org/10.1007/s11920-019-1091-3

Sudhakar, T. P., Prasada Rao, G., Lakshmi Prasuma, P., & John Vijay Sagar, K. (2008). Study of Effects of Modafinil Add-on Therapy on Excessive Day Time Drowsiness and Weight Gain in Patients on Atypical Antipsychotics. *Indian J Psychol Med*, *30*(1), 24–31. https://doi.org/10.1177/0975156420080105

Taylor, D. M., Barnes, T. R. E., & Young, A. H. (2024). *The Maudsley prescribing guidelines in psychiatry* (15th edn). Wiley-Blackwell.

Tew, J., Ramon, S., Slade, M., Bird, V., Melton, J., & Le Boutillier, C. (2012). Social Factors and Recovery from Mental Health Difficulties: A Review of the Evidence. *The British Journal of Social Work*, *42*(3), 443–460. https://doi.org/10.1093/bjsw/bcr076

The McPin Foundation. (2025). *Support physical and mental health: Communication, stigma & a holistic approach | stigma & language*. https://mcpin.org/physical-mental-health/

Thompson, J., & Grünwald, L. M. (2024). A systematic review exploring challenges of informed consent processes in antipsychotic prescribing. *Psychosis*, *16*(4), 425–438. https://doi.org/10.1080/17522439.2023.2285967

Thompson, L., Pennay, A., Zimmermann, A., Cox, M., & Lubman, D. I. (2014). "Clozapine makes me quite drowsy, so when I wake up in the morning those first cups of coffee are really handy": An exploratory qualitative study of excessive caffeine consumption among individuals with schizophrenia. *BMC Psychiatry*, *14*(1), 116. https://doi.org/10.1186/1471-244X-14-116

Thompson, M. (2021). Social Construction of Mental Illness. In *The Blackwell Encyclopedia of Sociology* (pp. 1–5). John Wiley & Sons, Ltd. https://doi.org/10.1002/9781405165518.wbeosm141.pub2

Thornicroft, A., Goulden, R., Shefer, G., Rhydderch, D., Rose, D., Williams, P., Thornicroft, G., & Henderson, C. (2013). Newspaper coverage of mental illness in England 2008-2011. *British Journal of Psychiatry*, *202*(s55), s64–s69. https://doi.org/10.1192/bjp.bp.112.112920

Thurmond, R. L., Gelfand, E. W., & Dunford, P. J. (2008). The role of histamine H1 and H4 receptors in allergic inflammation: The search for new antihistamines. *Nature Reviews. Drug Discovery*, *7*(1), 41–53. https://doi.org/10.1038/nrd2465

Tozzi, F., Prokopenko, I., Perry, J. D., Kennedy, J. L., McCarthy, A. D., Holsboer, F., Berrettini, W., Middleton, L. T., Chilcoat, H. D., & Muglia, P. (2008). Family history of depression is associated with younger age of onset in patients with recurrent depression. *Psychological Medicine*, *38*(5), 641–649. https://doi.org/10.1017/S0033291707002681

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., … Straus, S. E. (2018). PRISMA

Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine*, *169*(7), 467–473. https://doi.org/10.7326/M18-0850

Urina-Jassir, M., Herrera-Parra, L. J., Hernández Vargas, J. A., Valbuena-García, A. M., Acuña-Merchán, L., & Urina-Triana, M. (2021). The effect of comorbidities on glycemic control among Colombian adults with diabetes mellitus: A longitudinal approach with real-world data. *BMC Endocrine Disorders*, *21*(1), 128. https://doi.org/10.1186/s12902-021-00791-w

Usher, K., Park, T., & Foster, K. (2013). The experience of weight gain as a result of taking second-generation antipsychotic medications: The mental health consumer perspective. *Journal of Psychiatric and Mental Health Nursing*, *20*(9), 801–806. https://doi.org/10.1111/jpm.12019

van Manen, M. (2017). But Is It Phenomenology? *Qualitative Health Research*, *27*(6), 775–779. https://doi.org/10.1177/1049732317699570

van Manen, M. (2018). Rebuttal Rejoinder: Present IPA For What It Is—Interpretative Psychological Analysis. *Qualitative Health Research*, *28*(12), 1959–1968. https://doi.org/10.1177/1049732318795474

van Sprang, E. D., Maciejewski, D. F., Milaneschi, Y., Elzinga, B. M., Beekman, A. T. F., Hartman, C. A., van Hemert, A. M., & Penninx, B. W. J. H. (2022). Familial risk for depressive and anxiety disorders: Associations with genetic, clinical, and psychosocial vulnerabilities. *Psychological Medicine*, *52*(4), 696–706. https://doi.org/10.1017/S0033291720002299

Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., Read, J., van Os, J., & Bentall, R. P. (2012). Childhood Adversities Increase the Risk of Psychosis: A Meta-analysis of Patient-Control, Prospective- and Cross-sectional Cohort Studies. *Schizophrenia Bulletin*, *38*(4), 661–671. https://doi.org/10.1093/schbul/sbs050

Waddell, L., & Taylor, M. (2008). A new self-rating scale for detecting atypical or second-generation antipsychotic side effects. *Journal of Psychopharmacology*, *22*(3), 238–243. https://doi.org/10.1177/0269881107087976

Walker, S., Mackay, E., Barnett, P., Rains, L. S., Leverton, M., Dalton-Locke, C., Trevillion, K., Lloyd-Evans, B., & Johnson, S. (2019). Clinical and social factors associated with increased risk for involuntary psychiatric hospitalisation: A systematic review, meta-analysis, and narrative synthesis. *The Lancet Psychiatry*, *6*(12), 1039–1053. https://doi.org/10.1016/S2215-0366(19)30406-7

Wallace, M. (2001). Real progress—The patient's perspective. *International Clinical Psychopharmacology*, *16 Suppl 1*. https://doi.org/10.1097/00004850-200101001-00005

Weaver, K., & Olson, J. (2006). Understanding paradigms used for nursing research. *J Adv Nurs*, *25*(3), 459–469. https://doi.org/10.1111/j.1365-2648.2006.03740.x. PMID: 16448489.

Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546–553. https://doi.org/10.1111/j.1365-2648.2005.03621.x

Wilson, C., Janes, G., & Williams, J. (2022). Identity, positionality and reflexivity: Relevance and application to research paramedics. *British Paramedic Journal*, *7*(2), 43–49. https://doi.org/10.29045/14784726.2022.09.7.2.43

Windgassen, K. (1992). Treatment with neuroleptics: The patient's perspective. *Acta Psychiatrica Scandinavica*, *86*(5), 405–410. https://doi.org/10.1111/j.1600-0447.1992.tb03288.x

World Health Organization. (2019). *International statistical classification of diseases and related health problems. 11th edn*. https://icd.who.int/en/

World Health Organization. (2022). *Mental disorders*. https://www.who.int/news-room/fact-sheets/detail/mental-disorders

World Medical Association. (2024). *WMA Declaration of Helsinki – Ethical principles for medical research involving human participants*. https://www.wma.net/policies-post/wma-declaration-of-helsinki/

Wubeshet, Y. S., Mohammed, O. S., & Desse, T. A. (2019). Prevalence and management practice of first generation antipsychotics induced side effects among schizophrenic patients at Amanuel Mental Specialized Hospital, central Ethiopia: Cross-sectional study. *BMC Psychiatry*, *19*(1), 32. https://doi.org/10.1186/s12888-018-1999-x

Wunderink, L. (2017). Who needs antipsychotic maintenance treatment and who does not? Our need to profile and personalize the treatment of first episode psychosis. *Schizophrenia Research*, *197*, 65–66. https://doi.org/10.1016/j.schres.2017.11.007

Yang, Y., Niu, L., Amin, S., & Yasin, I. (2024). Unemployment and mental health: A global study of unemployment's influence on diverse mental disorders. *Frontiers in Public Health*, *12*. https://doi.org/10.3389/fpubh.2024.1440403

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215–228. https://doi.org/10.1080/08870440008400302

Young, S. L., Taylor, M., & Lawrie, S. M. (2015). 'First do no harm' A systematic review of the prevalence and management of antipsychotic adverse effects. *Journal of Psychopharmacology*, *29*(4), 353–362. https://doi.org/10.1177/0269881114562090

Yusufi, B., Mukherjee, S., Flanagan, R., Paton, C., Dunn, G., Page, E., & Barnes, T. R. E. (2007). Prevalence and nature of side effects during clozapine maintenance treatment and the relationship with clozapine dose and plasma concentration. *International Clinical Psychopharmacology*, *22*(4), 238–243. https://doi.org/10.1097/YIC.0b013e32819f8f17

Zahavi, D. (2018). Getting It Quite Wrong: Van Manen and Smith on Phenomenology. *Qual Health Res*, *29*(6), 900–907. https://doi.org/10.1177/1049732318817547

Zhang, L., Long, M., & Xu, L. (2019). Comparative studies on the therapeutic and adverse effects of mirtazapine and fluoxetine in the treatment of adult depression. *Tropical*

Journal of Pharmaceutical Research, *18*(1), 135–139. https://doi.org/10.4314/tjpr.v18i1.20

Zipursky, R. B., Reilly, T. J., & Murray, R. M. (2013). The Myth of Schizophrenia as a Progressive Brain Disease. *Schizophrenia Bulletin*, *39*(6), 1363–1372. https://doi.org/10.1093/schbul/sbs135

List of Appendices

List of appendices:

A. Completed scoping review PRISMA checklist
B. Scoping study example search strategy
C. Scoping study data extraction form
D. Empirical study interview schedule
E. Empirical study recruitment poster
F. Empirical study participant information sheet
G. Example of experiential statement analytical process
H. Example of personal experiential theme analytical process
I. Example of subsequent iterative analytical process
J. Ethical approval letter
K. Quality: an example of constructing a compelling, unfolding narrative
L. Quality: an example of developing a rigorous experiential account
M. Quality: an example of close analytic reading of participants' words
N. Quality: an example of attending to convergence and divergence

Appendix A: Completed scoping review PRISMA checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	P25 (see p28 for explanation of terminology)
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	P3 (within abstract for whole thesis)
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	P25-26
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	P29-31
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	P30-32
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	P30
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix B
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	P30-32
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any	P32

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Appendix B
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	P32-33
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	P33035
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	P36-44 (table 3)
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	P36-44 (table 3), p47-48 (table 4), p48-49 (table 5), p47 (table 6), p49-50 (table7)
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	P35, 45, 47-49, 50
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	P51-52
Limitations	20	Discuss the limitations of the scoping review process.	P52
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	P53
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.
§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

Appendix B: Scoping study example search strategy

Final search string for psychinfo

(TI somnolence OR TI weary OR TI drowsiness OR TI drowsy OR TI (tiredness or fatigue or exhaustion) OR TI (sedation or sedative or sedate) OR TI (sleepiness or fatigue)) AND (TI antipsychotics or antipsychotic medication or antipsychotic drug or psychotropic)

OR

(AB drowsiness OR AB drowsy OR AB weary OR AB (tiredness or fatigue or exhaustion) OR AB (sedation or sedative or sedate) OR AB (sleepiness or fatigue) OR AB somnolence) AND (AB antipsychotics or antipsychotic medication or antipsychotic drug or psychotropic)

OR

DE "neuroleptic drugs" AND (DE fatigue OR DE sleepiness)

Appendix C: Scoping study data extraction form

1. Study details

Authors:
Year published:
Title:
Year:
Aims:
Funders:

2. Research Participant details

- **Diagnoses:**
- **Original sample size**:
- **Dropouts** (longitudinal only):
- **Setting:**

3. Study design details

- **Quantitative, qualitative, or mixed methods:** *(if qualitative go to 4, if quantitative got to 5, if mixed methods complete both if appropriate)*
- **Method:**
- **Data collection method**:
- **Which concept is used and how is defined:** Tired/somnolence/sedation/other
- **Patient rated or clinician rated:**
- **If a measure for tiredness is used, which measure:**
- **Type of antipsychotic:**

4. Qualitative results

- **Key concepts:**
- **Key themes**:
- **Relevant quotes**:
- **Conclusions:**

5. Quantitative results
    a. – longitudinal

- **Intervention:**
- **Control:**
- **Time frame:**
- **Follow ups:**
- **Relevant outcomes:**
- **Results relevant to this review question:**

Side effect frequency
Side effect impact (how bothersome)
Side effect impact (effects on life)
Side effect reduction strategies (pharmacological)
Side effect reduction strategies (psychosocial)

b. – cross sectional

- **Relevant outcomes:**
- **Results relevant to this review question:**

Side effect frequency
Side effect impact (how bothersome)
Side effect impact (effects on life)
Side effect reduction strategies (pharmacological)
Side effect reduction strategies (psychosocial)

Notes:
Limitations of study as identified by authors:
Limitations of study as identified by review team:

Adapted from:

M Richardson, D Moore, R Gwernan-Jones, J Thompson-Coon, O Ukoumunne, M Rogers, R Whear, T Newlove-Delgado, S Logan, C Morris, E Taylor, P Cooper, K Stein, R Garside and T Ford. Non pharmacological interventions for Attention Deficit Hyperactivity Disorder (ADHD) delivered in school settings: Systematic reviews of quantitative and qualitative research. In publication. *Health Technology Assessment*.

Appendix D: Empirical study interview schedule

Notes

In line with Smith, Flowers and Larkin (2009) this interview guide is flexible and may be adapted during the interview to ensure collection of rich data. It aims to allow the interviewee to share their experiences, to reflect and develop their ideas. As such it aims to give the interviewee more time to talk, whilst the interviewer listens.

Topic Guide

The interviewer will start by defining tiredness-related side effects as: "side effects from antipsychotic medication that include being tired, fatigued, drowsy, sleepy, sedated, and sleeping more often."

Experience of tiredness related side effects

➔ **Could you tell me about your experience of tiredness related side effects of antipsychotics?**
Prompt for:

- Did you/how did you know that these experiences were side effects of the antipsychotics? (phrase carefully to avoid sounding like the researcher is undermining the participant experience). Ask more questions if the person is taking several medications to try and establish their experience/understanding of cause.
- How did these side effects make you feel (eg, emotional reaction)?
- How did the TRSEs impact on you and your life (eg, relationships, social life, job, responsibilities). Did you do anything differently in your life because of these side effects?
- You mentioned earlier that these side effects impacted on your [X], did this experience change as how your feelings about these side effects changed?
- Is there anything else about the experience of tiredness related side effects of antipsychotics that would be helpful/interesting for me to know?
- Tell me more about…
- You mentioned earlier that these side effects impacted your life in [x ways], what was that experience like? Prompt for long/short term consequences, how controllable these were.
- How do feel these side effects relate to your antipsychotics, your mental health, or your life as a whole? What has this been like for you?

➔ **Can you tell me about any experiences you may have had trying to make these side effects reduce, go away, or affect your life less?**

- What was your experience of this approach? Did it change your experience of [x tiredness related side effect]? How? What was this like for you?
- You mentioned earlier that these side effects impacted on your [X], did this experience change after you tried this approach?
- How did this approach make you feel?
- Reflecting on your own personal experiences, why do you think you chose to try this strategy?

- Reflecting on your own personal experiences, why do you think this approach worked or did not work?
- If the participant perceives their approach didn't work: how did they feel about this experience?
- Prompt for any other strategies

➔ **Can you tell me about any experiences you may have had trying to change your feelings or reaction in response to these side effects?**

- Did this change your experience of [x tiredness related side effect]?
- You mentioned earlier that these side effects impacted on your [X], did this experience change after you tried this approach? How? What was this like for you?
- How did you this approach make you feel?
- Reflecting on your own personal experiences, why do you think you chose to try this strategy?
- Reflecting on your own personal experiences, why do you think this approach worked or did not work?
- If the participant perceives their approach didn't work: how did they feel about this experience?
- Prompt for any other strategies

➔ **Over time, has anything changed about your experience of these side effects?**

- Has anything about how these side effects make you feel (eg, emotional reaction) changed over time? What was this like for you?
- Did the impact of TRSE on you and your life (eg, relationships, social life, job, responsibilities) change at all over time? What was this like for you?
- Has how you deal with or think about these side effects changed over time? What was this experience like for you?
- Do you think there are any benefits to these side effects?
- You mentioned earlier that these side effects impacted on your [X], did this experience change at all over time?

Appendix E: Empirical study recruitment poster

Do you take antipsychotics? Do they make you feel drowsy, sleepy, sedated or make you sleep more?

We'd like to hear about your experiences for our research study

Many people who take antipsychotics experience tiredness related side effects, such as sleepiness, fatigue, drowsiness, sedation, and increased sleep. This research study aims to understand how people with a mental health diagnosis cope with these side effects.

Who can take part?

Who can take part	Who cannot take part
Over 18 years old	Currently an inpatient
Live in the UK	Extremely unwell with a physical health problem
Currently prescribed antipsychotics for a mental health diagnosis, for example, schizophrenia, bipolar, depression, borderline personality disorder, or other psychosis	Under 18
Speak English	Do not speak English
Currently experiencing, tiredness related side effects of antipsychotics	

- **What does taking part involve?**
  A voice recorded interview of 60 to 90 minutes about your experiences of coping with tiredness-related side-effects, and what you have found works well or does not work, and why.
- Interviews can be by phone or video-conferencing.

Interested in taking part or finding out more information?
Please contact the researcher, Charley Hobson-Merrett, for more information:

Appendix F: Empirical study participant information sheet

Participant Information Sheet

How do users of antipsychotic medication cope with tiredness related side effects?

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Charley Hobson-Merrett. I am conducting this research as a student on the Mental Health PhD programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

Current research shows that many people who take antipsychotics for a mental health diagnosis experience tiredness-related side-effects, and these side-effects have negative impacts on their lives. The purpose of this study is to understand how people try to deal with these side-effects, what they find works and does not work, and why. It is hoped that the information from this study can be used to help other people deal with these side-effects.

Why have I been approached?

You have been approached because the study requires information from people who are prescribed antipsychotics for a mental health diagnosis and have experienced side-effects such as drowsiness, tiredness, fatigue, sedation, and increased sleep.

Do I have to take part?

No. It is completely up to you whether you choose to take part or not. Your decision to take part or not will not affect your health care. If you do choose to take part you can change your mind at any point, but it may not be possible for us to remove any data you have provided up until that point.

What will I be asked to do if I take part?

If you decide you would like to take part, I will meet with you to answer any questions you may have, and you can formally decide if you would like to take part by signing a consent form. If you sign a consent form I will ask you to take complete a short form about you and take part in one interview with me. In the interview I will ask you to explain any methods you have used to manage tiredness-related side-effects, and your experiences about how and whether these management strategies work. Interviews will take between 30 and 60 minutes. If you wish we can split this interview into two sessions. You can choose whether your meetings take place by telephone, video conferencing, or face to face.

Will my data be identifiable?

Your interview will be audio recorded, and typed into a written transcript by a professional transcriber. If your interview is via video conferencing we will use the automatic transcribing provided to in the video conferencing software to create a transcript instead. Transcripts will be anonymous and any data that identifies you will be removed from the transcript. This type of research uses quotes from the people who are interviewed to explain and demonstrate results. Therefore, although your name will be removed, it may be possible for people to recognise you from the context of quotes from your interview. To minimise this quotes that include obvious identifying information will not be used in write up or dissemination. The data collected for this study will be stored securely and only the transcriber and researchers conducting this study will have access to these data. The transcriber has signed a confidentiality agreement. Audio recordings will be destroyed once the project has been submitted for publication and examination.

- Audio files on the computer will be encrypted (so that is no-one other than myself and the transcriber will be able to access them) and the computer itself is password protected.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, your name will not be attached to these. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

However, if anything in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to my supervisor about this. If possible, I will tell you if I have to do this.

You will have the choice to undertake interviews by telephone, or by video-conferencing. Any electronic communication cannot be guaranteed to be a completely secure means of communication.

What will happen to the study results?

The results will be summarised and reported in a thesis submitted to the university as part of my PhD. Results may be submitted for publication in an academic or professional journals. A summary of results will also be sent to anyone who agrees to take part and any bodies that have helped us identify people who might want to take part.

Are there any risks?

There are no risks anticipated with participating in this study. However, some people may find it difficult or distressing to reflect on their experience of taking mental health medication.

Are there any benefits to taking part?

Although you may find participating interesting, there are no expected direct benefits of taking part. Some people may find it beneficial to reflect on their experience of taking mental health medication.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:
Charley Hobson-Merrett
e-mail: c.hobson-merrett@lancaster.ac.uk

Supervisors:

Prof Nancy Preston *e-mail: n.j.preston@lancaster.ac.uk*	*Prof Jane Simpson* *e-mail: j.simpson2@lancaster.ac.uk*

Postal address: Division of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster, United Kingdom, LA1 4YG.

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Prof Fiona Lobban
Research Director
Email: f.lobban@lancaster.ac.uk
Division of Health Research
Lancaster University
Lancaster
LA1 4YG
Tel: 01524 593752

If you wish to speak to someone outside of the Blended Learning PhD in mental health, please contact:

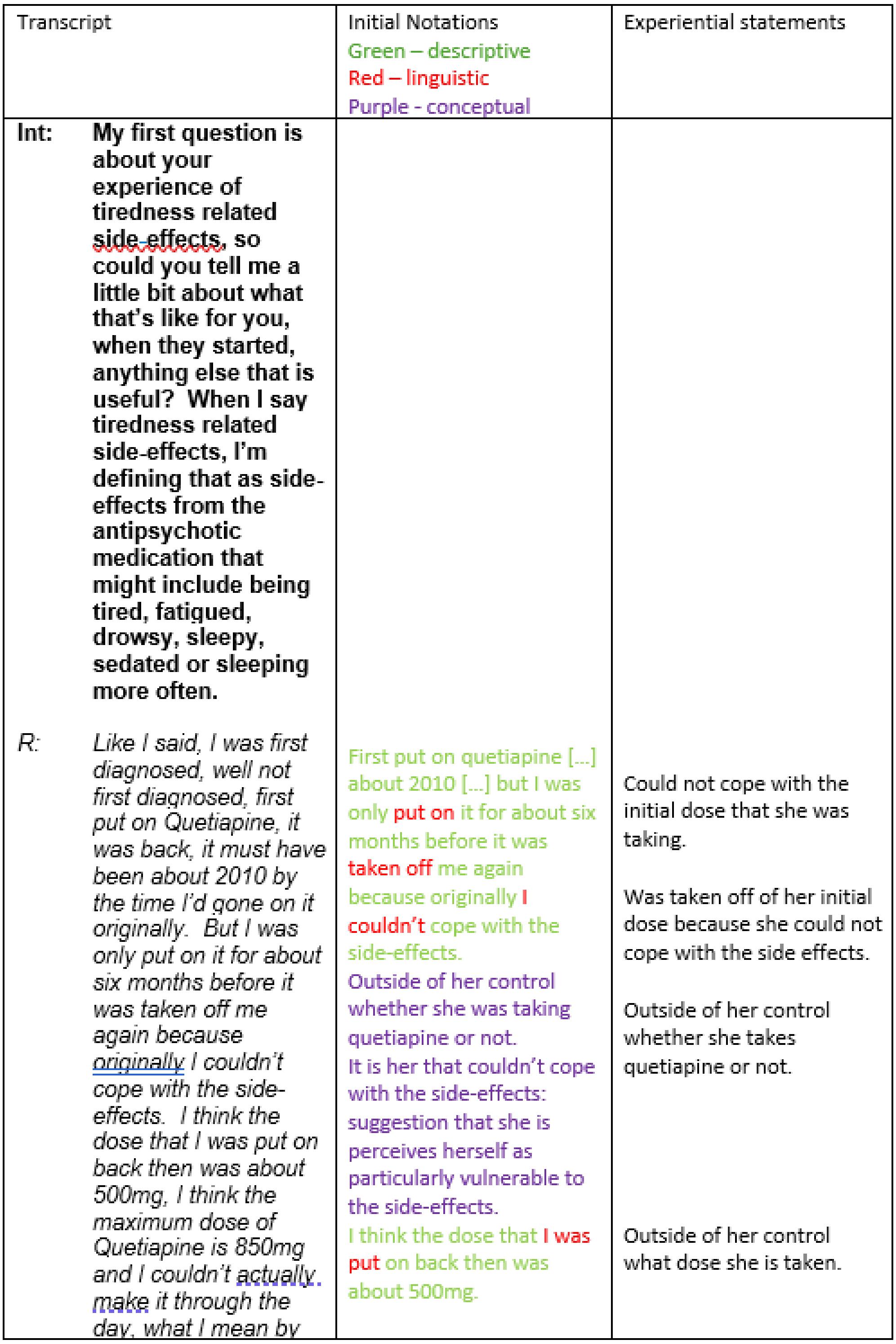
Dr Laura Machin
Chair of FHM REC
Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine (Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG
Tel: 01524 594973

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, we recommend you contact your GP or other mental health care provider. You may also find the following resources helpful:
https://www.mind.org.uk/
https://www.samaritans.org/

Appendix G: Extract from example of experiential statement analytical process



Transcript	Initial Notations Green – descriptive Red – linguistic Purple - conceptual	Experiential statements
Int: My first question is about your experience of tiredness related side-effects, so could you tell me a little bit about what that's like for you, when they started, anything else that is useful? When I say tiredness related side-effects, I'm defining that as side-effects from the antipsychotic medication that might include being tired, fatigued, drowsy, sleepy, sedated or sleeping more often.		
R: Like I said, I was first diagnosed, well not first diagnosed, first put on Quetiapine, it was back, it must have been about 2010 by the time I'd gone on it originally. But I was only put on it for about six months before it was taken off me again because originally I couldn't cope with the side-effects. I think the dose that I was put on back then was about 500mg, I think the maximum dose of Quetiapine is 850mg and I couldn't actually make it through the day, what I mean by	First put on quetiapine […] about 2010 […] but I was only put on it for about six months before it was taken off me again because originally I couldn't cope with the side-effects. Outside of her control whether she was taking quetiapine or not. It is her that couldn't cope with the side-effects: suggestion that she is perceives herself as particularly vulnerable to the side-effects. I think the dose that I was put on back then was about 500mg.	Could not cope with the initial dose that she was taking. Was taken off of her initial dose because she could not cope with the side effects. Outside of her control whether she takes quetiapine or not. Outside of her control what dose she is taken.

that is being awake through the day. *I would take it at night, about 10 o'clock at night and they used to recommend I split the dose, so it would be 100mg around 5.00pm/6.00pm and then it would have been the rest of it about bedtime, when I went to bed about 10. Then I'd wake up in the morning but I wouldn't be really awake, I'd feel like I hadn't slept the night before, even though I had slept. Then I'd probably wake up about half past seven, eight o'clock and then by midday I was exhausted and I would spend the rest of the afternoon in and out of napping type sleep, so I was taken off it.* *I was also getting a horrible shaking, what do you call it, can't think what it's called but constantly like restless legs type thing and I was just constantly shaking and couldn't sit still when I was put on it originally, so that was then swapped back out. Then I went back on it in the, when was it, it must have been the April of 2013, I'd just been released from a psychiatric hospital and I was put back on the Quetiapine. They put me on 250mg, so they worked their way up, they don't just whack*	I couldn't actually make it through the day, what I mean by that is being awake through the day. Would take it at night, about 10 o'clock at night and they used to recommend I split the dose, so it would be 100mg around 5pm/6pm, and then it would have been the rest of it about bedtime, when I went to bed about 10. I'd wake up in the morning, but I wouldn't be really awake, I'd feel like I hadn't slept the night before, even though I had slept. I'd probably wake up about 7:30/8 o'clock and then by midday I was exhausted, and I would spend the rest of the afternoon in and out of napping type sleep. So I was taken off of it. I went back on it [...] April of 2013. I'd just been	Could not stay awake through the day on 500mg. At 500mg, would take 100mg at 5pm, the rest at 10pm. At 500mg would wake up in the morning but wasn't really awake, felt like she hadn't slept the night before. At 500mg would wake up at 730/8am and be exhausted by midday, spending the afternoon napping. Was taken off of quetiapine.

you on it, they put it on slowly and they put me on 250mg. *I was taking, again I was almost halving the dose, so it was about 100mg at about, it must have been again about five o'clock-ish and then it would have been the other 150mg at 10 o'clock. That was a lot better than taking the 400mg that I was on but it was nowhere near, it still wasn't good. I would take the 100mg at about dinner time and then I would need to have a nap, then I would probably be awake again about eight, then I'd wake up about 10 o'clock.* *I'd wake up at eight and then about 10 o'clock I'd need to take the rest of it, then I would obviously go to bed at night, go to sleep. Never had a problem getting to sleep with Quetiapine, I'll always be asleep within 30 minutes of taking my medication, it makes me that tired. It makes me that tired when I first take it that it literally zonks me out, my husband jokes because he says it's almost like I'm dead, that's how much it completely throws me completely off asleep.* *Basically, I fell pregnant with my daughter, my first born in the July of 2013 and I had to have meetings*	released from a psychiatric hospital and I was put back on the quetiapine. No choice. They put me on 250mg, so they worked their way back up. They don't just whack you on it, they put it on a slowly and they put me on 250mg. Again, I was almost halving the dose, so it was about 100mg at about, it must have been again about 5 o'clock and then it would have been the other 150mg at 10 o'clock. That was a lot better than taking the 400mg. I would take the 100mg about dinner time and then I would need to have a nap, then I would probably be awake again about 8[pm], then I'd wake up about 10 o'clock. I'd wake up at 8[pm] and then about 10 o'clock I'd need to take the rest of it, then I would obviously go to bed at night, go to sleep. Never had a problem getting to sleep with quetiapine, I'll always be asleep within 30 minutes of taking my medication, it makes me that tired. It makes me that tired.	After hospitalisation was put on quetiapine a second time. Lack of choice regarding being on quetiapine. She was put on 250mg to start with the second time. Split dose: 100mg at 5pm, 150mg at 10pm. 250mg was better that 400mg. At 250mg split dose she would sleep from 5pm to 8pm, 10pm to 10am. Asleep within 30 minutes of taking quetiapine. It was make her tired. It zonks her out.

Appendix H: Example of personal experiential theme (PET) analytical process

Extract: one of eleven PETs

Sub PET	**Experiential statements from transcript**
Could not cope with the side effects of the high initial doses	Could not cope with the initial dose that she was taking. Was taken off of her initial dose because she could not cope with the side effects. At 500mg, would take 100mg at 5pm, the rest at 10pm. Was taken off of quetiapine. After hospitalisation was put on quetiapine a second time. She was put on 250mg to start with the second time. Split dose: 100mg at 5pm, 150mg at 10pm. It was awful, she could not cope with the side effects. On discharge she would not be able to maintain the high doses due to side effects. At high doses she would rather be mentally unwell than experience the side effects. One of the reasons she has taken so many different antipsychotics was because she could not cope with the side effects of them. Because she kept becoming psychotic the clinicians kept trying to up antipsychotic doses.
Decisions on dose taken by others until she fell pregnant	Outside of her control whether she takes quetiapine or not. Outside of her control what dose she is taken. Lack of choice regarding being on quetiapine. They/others control her dose.
High doses was mostly asleep and tired	Could not stay awake through the day on 500mg. At 500mg would wake up in the morning but wasn't really awake, felt like she hadn't slept the night before. At 500mg would wake up at 730/8am and be exhausted by midday, spending the afternoon napping. At 250mg split dose she would sleep from 5pm to 8pm, 10pm to 10am.
Lower doses meant less side effects	250mg was better that 400mg. 150mg at 10pm is more manageable for her mental health symptoms and the side effects. Also helps that the dose has gone down over the 10 years.
It makes her tired	It was make her tired. Really, really, sleepy. Before quetiapine was not tired in the day. Early on and higher doses she was sleeping in the afternoon.

	On lower doses stopped needing a nap in the afternoon. 150mg just the night-time sleepiness. Has bounced between 150-100mg over the last 10 years. 150mg doesn't get the mental fogginess. Side effects means she would wake up exhausted for no reason.
She falls asleep quickly	Asleep within 30 minutes of taking quetiapine. In bed between 10 and 11. Now it only the night-time that is an issue.
She sleeps deeply and cannot be woken from sleep	It zonks her out. It's almost like she is dead. Even at 150mg she cannot wake up in the morning. She has the phone by her ear for the alarm, and it would not wake her. Nothing would wake her apart from shaking her. Completed zoned out.
When she was pregnant the psychiatrist worked with her to agree a dose	When she was pregnant the risk to the baby meant the psychiatrist re-evaluated her quetiapine dose. Risk to the baby is more important to the psychiatrist than the impact of the side effects to the antipsychotic user. They lower her dose down to protect the unborn baby. Lower dose was 150mg at 10pm
Positives: doesn't dream, so cannot remember her nightmares, but cannot wake up from nightmares	Doesn't dream, or cannot remember her dreams on quetiapine. Cannot remember content of nightmares due to quetiapine, but still has panic attacks due to them. Did not realise why she was feeling really anxious when she woke up because of the quetiapine. It was only when she was being watched one-on-one when recently sectioned that anyone realised she was having nightmares. She wakes from nightmares and falls straight back to sleep. Taking prazosin to stop nightmares. Quetiapine prevents memory of the nightmares. Grateful that quetiapine blocks out the memory of the nightmares.
Can no longer sleep without quetiapine	If late taking dose cannot sleep or gets to sleep really late. If late taking dose, sleep is fragmented. Brain is addicted to needing the quetiapine in order to sleep. Without quetiapine she cannot sleep. Because cannot sleep without quetiapine she assumes that the quetiapine causes the extreme sleep and not being able to wake up.

	When mentally and physically exhausted can sleep without quetiapine, but this is not the norm.
Could not do night feeds or other night time parenting because does not wake up	Was not able to do the night feeds for her children because she would not hear the child cry and so would not wake up. Hurts her that was not able to do night feeds for her children. Even now the children are older, she will not hear them cry after she has gone to sleep. Is upset that she cannot hear them cry once she has gone to sleep. When first child was born she did not know what she was going to do if the child cried in the night, because she knew she would not wake up. When was in hospital after giving birth the midwives had to feed the baby in the night, because she did not wake up. Even if husband woke her up to give her baby in the night she did not feel like she could safely hold the baby because she felt dizzy, could not sit up and could not see properly. Missed out on every single night feed and every need her children has after she has gone to bed. Feeling of missing out. Feels sad the did not do the terrible nights that other parents have done. She already didn't feel good enough because she couldn't do the night feed with her children. Upset that not been able to do some things for her children. Feels like she has not been a good enough mum, because mum's should be able to be there 24/7. If she takes her quetiapine, she's not there. She is worried she cannot wake up for the children when husband is not there. Worried because she is not there if the children need her. She cannot be there if the children need her. It hurts her to know that she cannot be there for the children. It is easier now the children are older. Not as much impact now because the children are older and don't wake up much in the night.
Difficulties socialising in the evening	[not TRSE: Does not go out in the evening as she gets bad withdrawals from quetiapine if she does not take it on time.] [Withdrawals if does not take it on time are mostly physical, rather than tiredness related.] Knows that quetiapine and alcohol do not react well together, but this does not affect her because she has never been much of a drinker.

	Is not allowed to drive for the six hours after taking quetiapine because it makes her sleepy. Was not able to go out with friends when she was younger, because it was not worth the hassle. Anxious when they do have to go out because she has to leave early in order to take the quetiapine. It makes her anxious when they go out because she does not want to & does not explain why they are leaving early. Makes her anxious because it is not normal to leave events early in order to take medication that is going to make you really tired. If took quetiapine at social events would be stuck there because she is not allowed to drive. Husband doesn't drive, which makes this harder, because she cannot take quetiapine at events because she will need to drive them back. It is socially awkward to attend social events. It is difficult to explain why she doesn't feel normal because of how quetiapine affects social events. She thinks the not feeling normal might be a personal perception. She does not feel normal because she perceives others are able to go out for however long they choose without repercussions. At social events she feels like a ticking bomb, because she has to take quetiapine at 10pm, and can only stay til 11pm at the latest. At social events it is always at the back of her head that she has to get home to take quetiapine, and its normal to have these thoughts at the forefront of her mind when she is supposed to be enjoying herself. She can never completely relax at social events. Avoids going to social events. Going to social events makes her really tired and stressed by the idea that she may not make it back to take the quetiapine. Will avoid doing social events in the evening because she doesn't want to deal with the side effects.
Cannot work night shifts	Is not allowed to do night shifts. Is outside of her control whether she can do night shifts. After meeting with occupational health it was decided that she was not allowed to do night shifts because of when she needs to take the quetiapine. Not being able to do nights is outside of her control. Has made it difficult with her placements on her training. The placements have been understanding that she cannot do night shifts. Worried that placements have only been understanding because she is training and not an essential member of staff. Is worried that when fully qualified her inability to do night shifts will make it difficult to get a job. She is very stressed and annoyed that not being able to do night shifts due to the quetiapine might affect ability to get a job.

Thinks has just got used to how her life is now, but might also be that her body has adjusted to the side effects	Doesn’t know if her body has got used to the side effects or whether this is just her way of life now. Thinks it is more a case that over time she has learned to live with it. During 10 years her body has adjusted to the quetiapine side effects. Is better now because her body has acclimatised and adjusted to it.
Brain fog has got better over the years	It’s got a lot better over 10 years. She now does not get fogginess unless she wakes up really early. Early on and higher doses she was feeling mentally foggy all day. On lower doses mental fogginess went.
Was not able to breast feed her children	If he children did appear disadvantaged by not being breast fed then this would increase her hatred and resentment towards quetiapine. Because she hears the advantages to children of being breast fed. If one of her children was more ill she would worry that this was because she had not been able to breast feed them. Doesn’t feel like has put children at disadvantage by not breast feeding. Breast feeding is an experience she will not have another opportunity to experience. Thinks it is selfish in some ways to worry about not breast feeding because her children are healthy. It would have just been too exhausting to breast feed. They are not having any more children, so she is gutted that she missed out on breast feeding. She wasn’t able to breast feed even though she wanted to, because of the night feeds and feeling exhausted. If she was feeling exhausted and didn’t want to breast feed she would have used this an excuse to beat herself up. This would have started a downward spiral of not feeling good enough. The main reason she didn’t breast feed was because she knew she couldn’t do night feeds. She chose not to breast feed second baby because of not being able to wake at night.
Mental fogginess	The main side effects were tiredness, mental fogginess, and a bit of confusion. Brain fog contributed to inability to work and financial difficulties.

	Did not feel able to ring in sick to work because of brain fog: it is less acceptable than physical health problems. Brain fog meant that she was too scared to go to appointments, even well she was well Brain fog meant that she couldn't even make breakfast because she felt so exhausted and tired. Brain fog was horrible because it meant that she had to give up her voluntary job. Feeling mentally foggy like she cannot get her thoughts together or think properly. Cannot think properly about how to describe mentally foggy. Use of humour. Mental fogginess is like being exhausted from a really busy day and brain is not working. You cannot start thinking. It was like she was so tired/exhausted that her brain could not put things together. She was so tired that her brain could not think clearly.
Love/hate relationship with quetiapine	Loves and hates quetiapine. Loves quetiapine because it prevents her becoming mentally unwell and being sectioned. Loves quetiapine because it helps her have mental clarity and reduce symptoms. Love/hate relationship with quetiapine. Loves how it affects her mental health. Hates how it affects her physical health. Hates that she has to take quetiapine.
Feels enslaved to quetiapine	Quetiapine controls and takes her life. Feels enslaved to the quetiapine. Feels enslaved to quetiapine because has to take it. Feels enslaved to quetiapine because she is really poorly if she doesn't take it. Five days to recover from messing with the timings of quetiapine. Went on holiday and the quetiapine got lost along with her luggage. Without quetiapine is ill. Dictation of her social life and her husband's social life is one of the reasons she feels enslaved to quetiapine. It feels a bit like enslavement, because I am somebody that needs to be in control of my life and what is happening. Has had lots of periods in her life where she is not in control, and it feels like quetiapine has control over parts of her life. Panic at the bank holiday to make sure isn't going to run out, makes her feel enslaved to it, and makes her want to stop taking it.

Cannot drive after taking quetiapine, affecting her ability to work, socialise or care for family in the evening	Is not allowed to drive after taking quetiapine. She cannot get home after taking too much quetiapine. Psychiatric doctor in the hospital said not to drive after 30 mins, because the drowsiness would make it not legal to drive. Also feels within herself that she would not be safe to drive within 30 minutes of taking quetiapine. In some ways it is ok that she cannot drive after taking quetiapine because she knows she'll be going to sleep. Being the only drive in the house makes her concerned about what she would do if something happened to children or her mum after she had taken her quetiapine. Feels trapped because she knows she would not be safe to drive after taking quetiapine. Sometimes does not feel fully safe to drive in the morning. Has lots of coffee in the morning if isn't feeling fully safe to drive. To wake herself up to drive to work she has to have strong coffee to wake herself up; she is worried this is not safe. It scares her that she has to do that to wake up early for work. It concerns her that she wouldn't be able to get the children to hospital at night because she would not be able to drive.

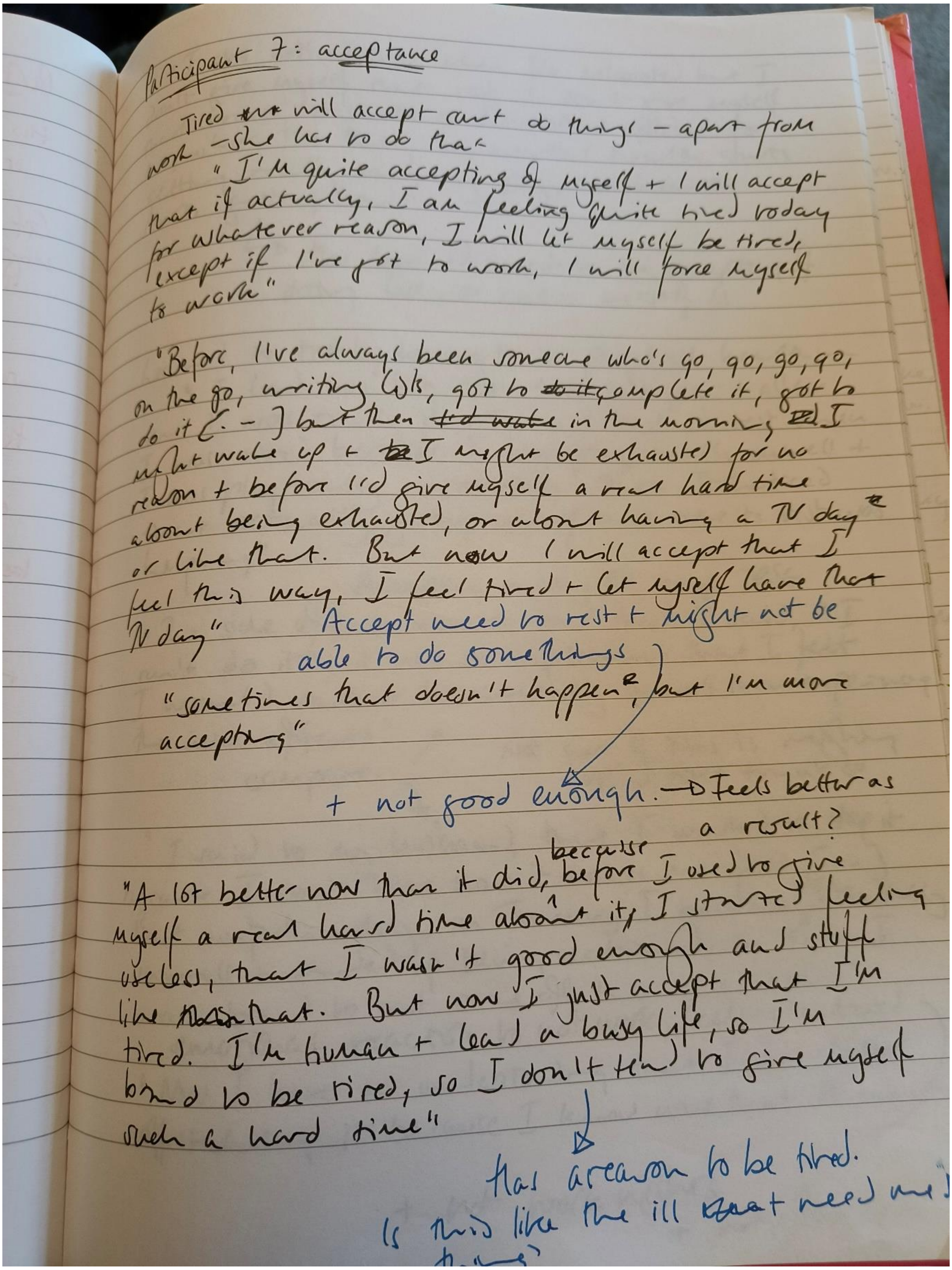
Summary

Quetiapine makes her tired, fall asleep quickly at night and be impossible to wake. There is some brain fog in the morning. She can no longer sleep without quetiapine. These side effects are better at lower doses (100-150mg). At higher doses (400mg) side effects were intolerable: brain fogginess much worse, she was sleeping during the day. At very high doses (450mg+) she could not see or watch TV on function. Initially decisions on how high the dose was were taken by clinicians and she was not empowered to make dose decisions until she fell pregnant. Side effects meant that she could not do the night feeds for her children and is still unable to do any night time parenting. This makes her feel sad, upset, inadequate and like she has missed out. She is also unable to drive after her dose, socialising in the evening is difficult, and she is unable to do night shifts at work, which may affect her career progression opportunities in the future. Side effects affect her less than the used to, due to a combination of lower dose, her body adjusting, and living her life with the side effects for a long time. She has a love/hate relationship with the quetiapine because of the tiredness related side effects but the fact that it keeps her mentally well. She feels enslaved to the quetiapine because side effects means it controls/runs her life. A positive/mixed impact of the side effects is that she cannot remember her nightmares; this is good because she cannot remember the upsetting content, but bad because she did not realise they were causing night time panic attacks.

Appendix I: Example of subsequent iterative analytical process: one GET

I.i. Acceptance GET: iterative return to transcript

I.i.i. Handwritten notes focusing on participants own words



Participant 7: acceptance

Tired ~~[illegible]~~ will accept can't do things – apart from
work – she has to do that
"I'm quite accepting of myself + I will accept
that if actually, I am feeling quite tired today
for whatever reason, I will let myself be tired,
except if I've got to work, I will force myself
to work"

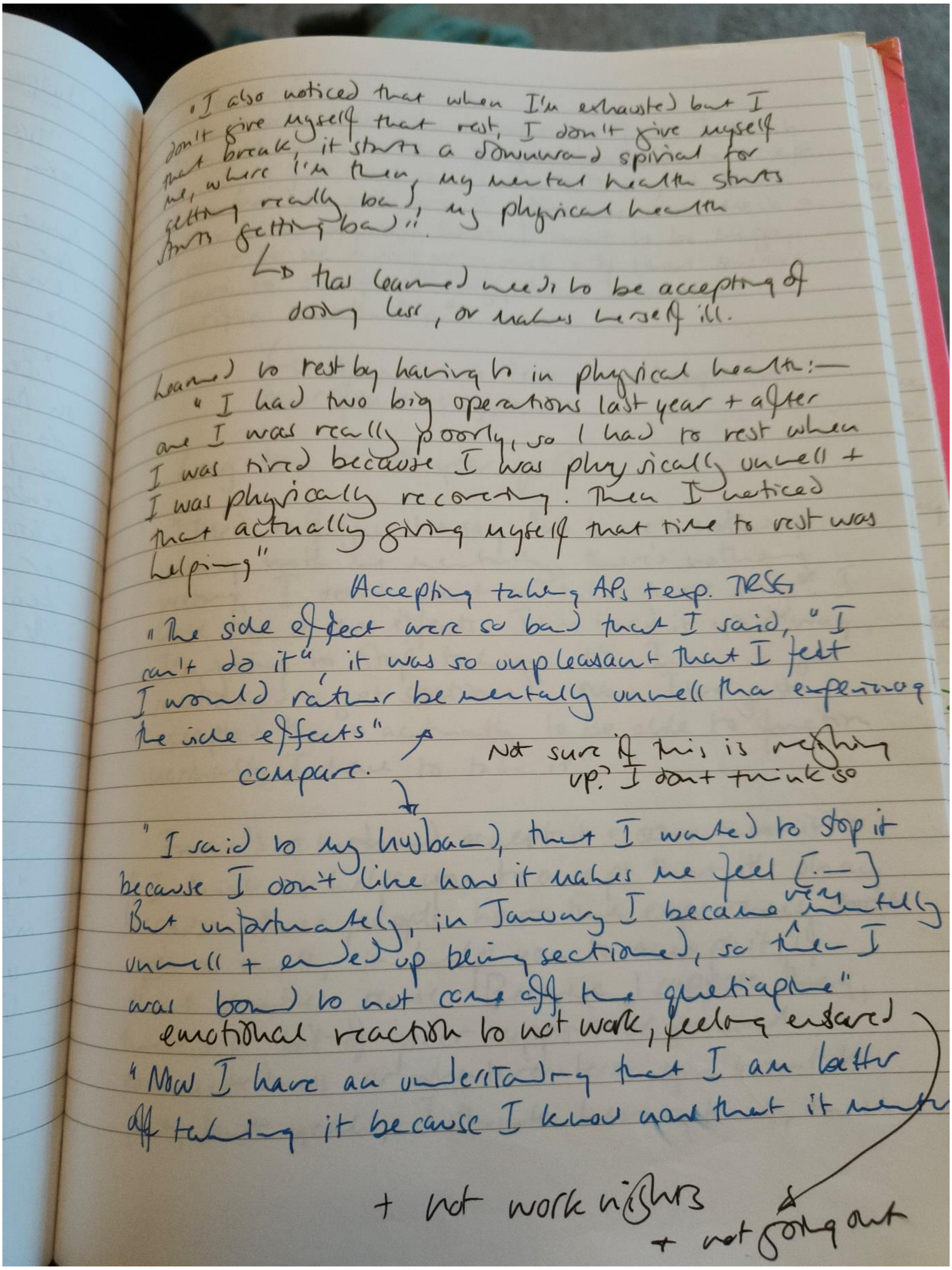
"Before, I've always been someone who's go, go, go, go,
on the go, writing lists, got to ~~do it~~ complete it, got to
do it [. –] but then ~~I'd wake~~ in the morning, ~~[illegible]~~ I
might wake up + ~~[illegible]~~ I might be exhausted for no
reason + before I'd give myself a real hard time
about being exhausted, or about having a TV day[2]
or like that. But now I will accept that I
feel this way, I feel tired + let myself have that
TV day" Accept need to rest + might not be
able to do some things

"sometimes that doesn't happen[2], but I'm more
accepting"

\+ not good enough. → Feels better as
a result?

"A lot better now than it did, because before I used to give
myself a real hard time about it, I started feeling
useless, that I wasn't good enough and stuff
like ~~that~~ that. But now I just accept that I'm
tired. I'm human + lead a busy life, so I'm
bound to be tired, so I don't tend to give myself
such a hard time"

Has a reason to be tired.
Is this like the ill ~~[illegible]~~ need me
things?



"I also noticed that when I'm exhausted but I don't give myself that rest, I don't give myself that break, it starts a downward spiral for me, where I'm then, my mental health starts getting really bad, my physical health starts getting bad".

↳ has learned needs to be accepting of doing less, or makes herself ill.

Learned to rest by having to in physical health:—

"I had two big operations last year + after one I was really poorly, so I had to rest when I was tired because I was physically unwell + I was physically recovering. Then I noticed that actually giving myself that time to rest was helping"

Accepting taking APs + exp. TRSEs

"The side effect were so bad that I said, "I can't do it", it was so unpleasant that I felt I would rather be mentally unwell than experiencing the side effects" ↗ compare.

Not sure if this is matching up? I don't think so

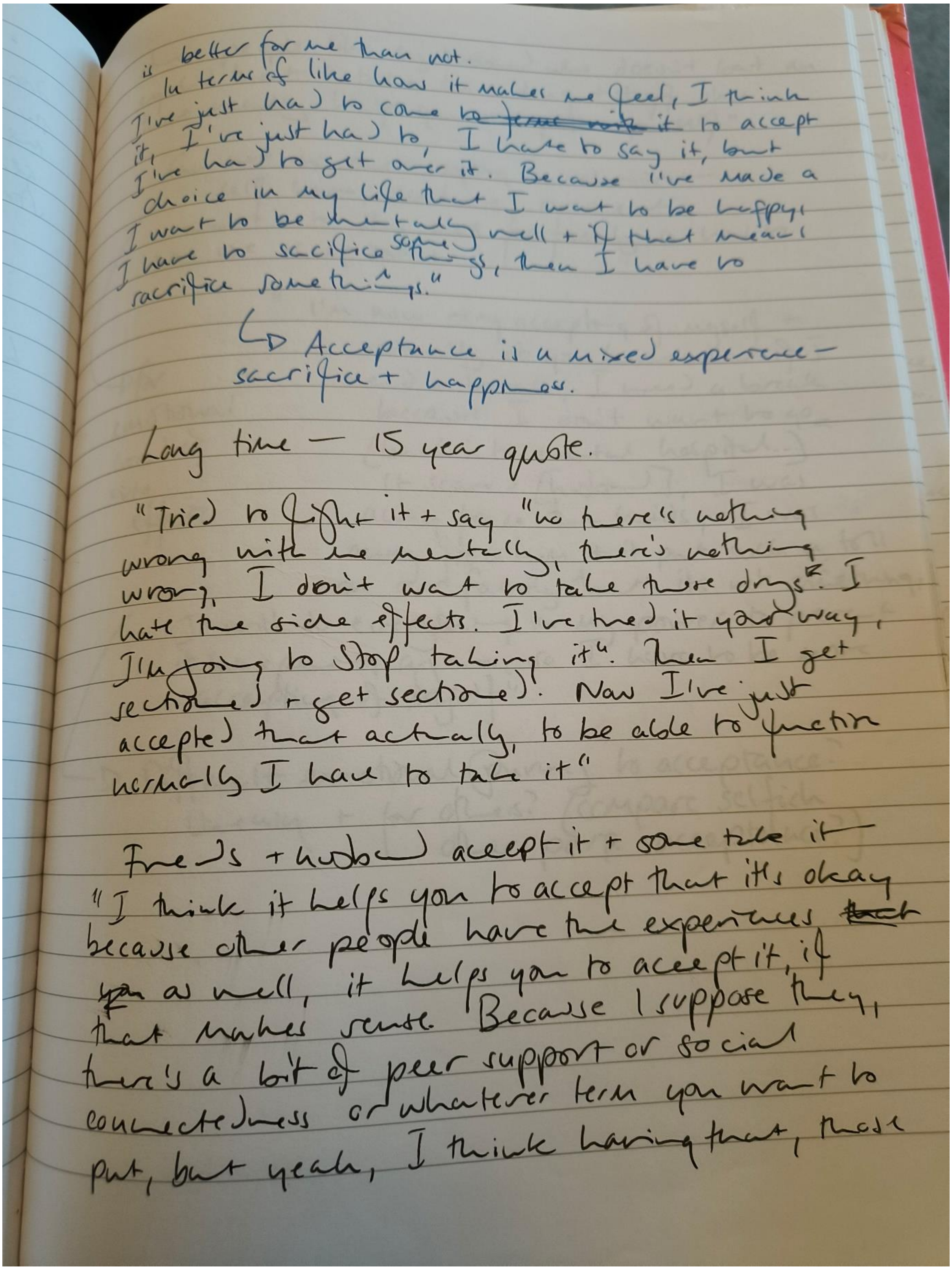
"I said to my husband, that I wanted to stop it because I don't like how it makes me feel [...] But unfortunately, in January I became very mentally unwell + ended up being sectioned, so then I was bound to not come off the quetiapine"

emotional reaction to not work, feeling endured

"Now I have an understanding that I am better off taking it because I know now that it mea

+ not work nights

+ not going out



is better for me than not.

In terms of like how it makes me feel, I think I've just had to come ~~to terms with~~ it to accept it, I've just had to, I hate to say it, but I've had to get over it. Because I've made a choice in my life that I want to be happy, I want to be mentally well + if that means I have to sacrifice some things, then I have to sacrifice somethings."

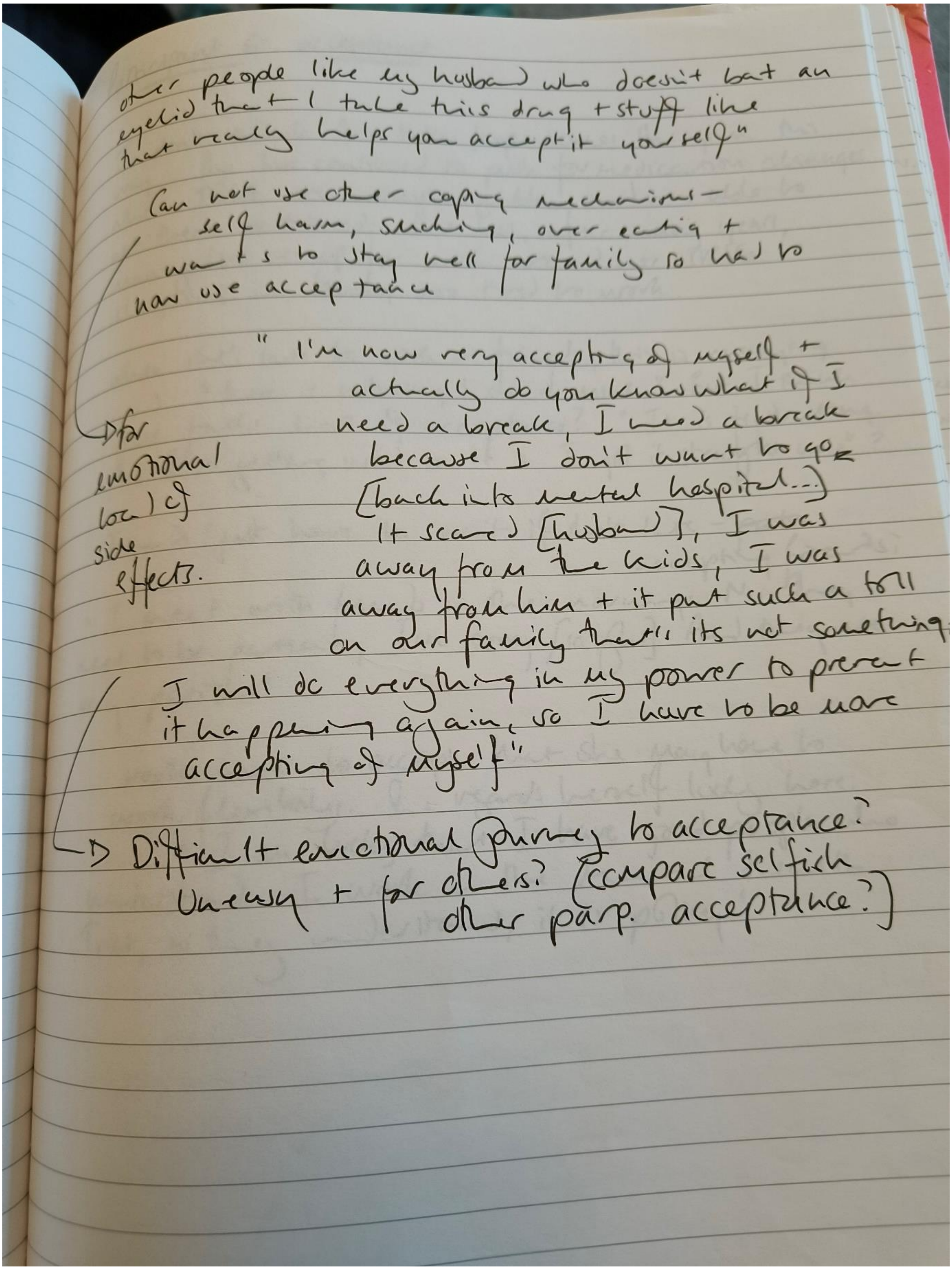
↳ Acceptance is a mixed experience – sacrifice + happiness.

Long time – 15 year quote.

"Tried to fight it + say "no there's nothing wrong with me mentally, there's nothing wrong, I don't want to take these drugs". I hate the side effects. I've tried it your way, I'm going to stop taking it". Then I get sectioned + get sectioned. Now I've just accepted that actually, to be able to function normally I have to take it"

Friends + husband accept it + some take it

"I think it helps you to accept that it's okay because other people have the experiences ~~that~~ it helps you to accept it, if ~~you~~ as well, that makes sense. Because I suppose they, there's a bit of peer support or social connectedness or whatever term you want to put, but yeah, I think having that, that's



other people like my husband who doesn't bat an eyelid that I take this drug + stuff like that really helps you accept it yourself"

Can not use other coping mechanisms – self harm, smoking, over eating + wants to stay well for family so had to now use acceptance

→ for emotional load of side effects.

" I'm now very accepting of myself + actually do you know what if I need a break, I need a break because I don't want to go [back into mental hospital...] It scared [husband], I was away from the kids, I was away from him + it put such a toll on our family that... its not something I will do everything in my power to prevent it happening again, so I have to be more accepting of myself"

→ Difficult emotional journey to acceptance? Uneasy + for others? [compare selfish other parp. acceptance?]

I.i.ii. Acceptance GET iterative summary

<u>(GET final name:</u> the experience of coping with unmanageable TRSEs via acceptance)

What is the experience of acceptance like for her?

It has taken a long time to be able to accept that she needs to take antipsychotics and therefore will have to continue to experience TRSEs. It has been made possible because episodes of poor mental health and being hospitalised mean that she has decided to prioritise her family by continuing to take antipsychotics and experience TRSEs in order to stay out of hospital and be with her family. This acceptance is made easier because she has friends that also take antipsychotics and because her husband is accepting of her taking antipsychotics.

Accepting not getting everything done involves a reframing by her: it's not that she's not good enough, but that she is human and busy and its logical that she would get tired.

The opposite to accepting taking antipsychotics and experiencing TRSEs is fighting taking antipsychotics because she doesn't like the side effects and doesn't think she needs to take antipsychotics.

How she feels about acceptance appears to be mixed: She has chosen to use acceptance to manage how not being able to do somethings makes her feel (and being enslaved feeling) because she has decided to be happy and stay mentally well, but this has meant she has had to make sacrifices – she will not be able to do those things. This has felt like a 'just get over it' – a sense of not allowing herself to not accept it?

She has had to use acceptance because her other coping mechanisms for not being able to do things & the negative feelings associated with not doing things no longer worked or were inappropriate to use: therapist discouraged her away from self harming, gave up smoking when pregnant, had gastric band surgery due to weight gain & wants to stay well for her family

What is she trying to accept?

- That she can't do things and might need to rest & take a break – apart from work, which is necessary
- Accepting that she can't do things and that this doesn't mean that she's not good enough
- Accept that she needs to take antipsychotics and that this will mean she will experience TRSEs
- Accepting that (in the past) she couldn't work, that she still can't work nights, and that she is not able to go out in the evening
- Feeling enslaved to the antipsychotics

Appendix J: Ethical Approval Letter

Lancaster University

Applicant: Charley Hobson-Merrett
Supervisor: Jane Simpson; Nancy Preston
Department: DHR
FHMREC Reference: FHMREC20193

21 October 2021

Re: FHMREC20193
How do UK users of antipsychotic medication cope with tiredness related side effects? An interpretative phenomenological analysis.

Dear Charley,

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

T. Morley

Tom Morley,
Research Ethics Officer, Secretary to FHMREC.

Appendix K: Quality: an example of constructing a compelling, unfolding narrative

Each line in the table represents a summary of a quote and interpretative analysis that progresses the narrative in one group experiential theme.

Progression in the narrative
Participants had become accustomed to experiencing TRSEs.
Use of downplaying language suggests that becoming accustomed to TRSEs reduces the distress caused by TRSEs.
It is easier to downplay TRSEs and thus reduce distress if one has previously experienced worse TRSEs.
Becoming accustomed to TRSEs is not pleasant nor desirable.
Behaviours that people used to reduce the impact of TRSEs were also something participants had become accustomed to: they had become a part of participants' lives.
Behaviours that had become part of participants' lives were often not perceived as management strategies by participants.
Behaviours that participants had become accustomed to included where participants were not able to undertake certain activities or behaviours: participants' "couldn't" or "wouldn't" undertake them.
Behaviours that participants had become accustomed to included were participants deemed certain activities or behaviours as "essential".
Both couldn't/wouldn't and essential responses to TRSEs were deemed by participants' to be outside of their control.
Which behaviours became a part of participants' lives varied by participant, according to their personality or concurrent diagnoses.
Where behaviours had become a part of participants' lives it was difficult for them to reflect on these behaviours.
Some participants found behaviours became a part of their identity.
Other participants were confused as to whether behaviours were part of their personal preferences or had negative impacts on them.
Some participants described purposely rearranging their lives to accommodate activities they were no longer able to undertake. This problem-solving was positively perceived.
Those who had subconsciously rearranged their lives in response to TRSEs were more neutral about this experience.

Appendix L: Quality: an example of developing a rigorous experiential account

An example of development of a rigorous experiential account from one group experiential theme.

Many participants described prioritising mental health via continued antipsychotics use over the desire to reduce/eliminate TRSEs. This was an uneasy prioritisation; participants were often dissatisfied with results:

> *"Antipsychotics have a great impact on my life. But, I just can't be without them."*
>
> *-- Joanna*

For some prioritisation of continued antipsychotic use consisted of establishing a dose that compromised tolerable mental health symptoms and tolerable TRSEs. This often felt like a need to "*balance"* competing priorities. For example, Raven/Bob explained careful and difficult weighing of competing mental and physical health prioritises, because TRSEs increased her risk of blood clots:

> *"I'm meant to take 100mg in the morning. But, like, that, because I've suffered blood clots […] it does knock you out and I can't then spend another 10 or 12 hours sleeping in the daytime, to be awake until, you know, bedtime, and then do it all again. Like, I'm too paranoid about getting my blood clots. So, and at the minute, I'm not taking my 100mg in the morning. I'm just taking 50 […] But I do need to take some, because I do still stuffer hallucinations and stuff, so I'll try and keep that at bay."*

Different participants prioritised different elements of their lives; some participants prioritised elements that deprioritised by others. For example, David prioritised employment over time with his girlfriend, whereas Ash prioritised child-care over employment. Emily and Sarah prioritised road safety over driving family members places at night, whereas Ash prioritised driving her children to school in the morning over feeling completely safe when driving.

Some experienced multiple, interacting priorities. For example, Ava prioritised work over hobbies, hobbies involving others over solo hobbies, and social activities at home over social activities outside the home. Others' prioritisations were simpler: one overarching priority directed how they organised their lives. For example, David prioritised employment above all else; Ash prioritised her children above all else, including employment and her own wellbeing:

> *"After the kids have left, I sit in a heap and do fuck all […] When they're here, I just have to survive every day. That's the rules. That's the rule I have for myself. […] It's for them, it's for them. Everything I do is for them."*
>
> -- Ash

Appendix M: Quality: an example of close analytic reading of participants' words

An extract from one group experiential theme that demonstrates a close analytic reading of the participants' words.

The need for others to accept impacts of TRSEs could impact some participants' relationships. For example, although Joanna speaks of being *"lucky"* that people understand, David's girlfriend had to *"put up with"* the impacts of TRSEs on their relationship. This suggests her acceptance had negative impacts on their relationship.

[…]

For many the experience of applying acceptance is contrasted to*"fight*"ing against TRSEs. Participant language suggested that continuing to fight, TRSEs was unwise. Often this was in the context of participants accepting the needed to continue antipsychotic use:

> *"I tried the other way, I tried not accepting it, I tried to fight it and say, 'No, there's nothing wrong with me mentally, there's nothing wrong, I don't want to take these drugs. I hate the side-effects, I've tried it your way, I'm going to stop taking it,'. Then I get sectioned and get sectioned. Now I've just accepted that actually, to be able to function normally I have to take it."*
>
> -- Sarah

Some aligned not fighting TRSEs with reductions in how much they "*cared*" about the impact of TRSEs. This reduction in fighting and caring supports the suggestion of passive acceptance:

> *"A lot of it is just kind of acceptance, not trying to fight it […] just like, I don't know, just accept it and not give a shit."*
>
> -- Ava

For some applying acceptance affected how they perceived themselves. Resulting perceptions varied, being positive or negative. For example, David described accepting he had to spend less time with his girlfriend as *"selfish"*, whereas Bryony described accepting help as "*brave"*.

Appendix N: Quality: an example of attending to convergence and divergence

An extract from a group experiential theme that demonstrates attendance to convergence and divergence.

Participants described the experience of using strategies and behaviours that had negative impacts on their health, work, relationships, social life, or emotions. Often participants gave long and detailed explanations of these negative impacts on their lives, using descriptors such as, *"frustrated"*, *"very stressed", "very annoyed"*, *"really annoy"*, *"enslaved"*, *"sad"*, *"sadly"*, *"sucks quite a lot"*, *"anxious"*, *"not really a good thing"*, "*not the best"*, *"not great"*, *"bit burnt-out"*, "*stuck"*, "*made me feel like shit"*, "*heartbroken"*, "*disaster"*, "*scared", "frightened"*, and *"really hard"*. These detailed explanations and descriptors suggest deploying these strategies and behaviours had detrimental effects on participants' wellbeing and lives.

Which strategies were detrimental varied by participant; some participants found a strategy detrimental when others did not. Sometimes this was due to nuances in implementation increasing the likelihood detrimental effects. For example, many discussed utilising caffeine to assist with waking and reducing daytime sleepiness; only Eilish and Suzanne-Jane were concerned that caffeine use was detrimental. They understood consuming caffeine with sugar and as a carbonated drink to have negative impacts on their health:

> *"Sadly, I don't burn off the sugar [in the coffee] very quickly, and my body loves to store it"*
>
> -- Eilish

Other strategies were considered detrimental by some and not others due to personal health risks. For example, Ava made the most of her limited working hours with the strategy of *"do everything really continuously and not really take a break"*. This strategy meant she did not eat properly; concerning in the context of an historic eating disorder.