An Exploration of Sedation and Sleepiness in Psychosis - A Systematic Review and Thematic Analysis

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Thesis Portfolio Abstract

Background: Antipsychotic medications are a key component of treatment for psychotic disorders, alongside psychological therapies. Whilst a necessary aspect of treatment for psychosis, the side effects of antipsychotic medications can impact treatment adherence and individual quality of life. Although one of the most common side effects of antipsychotic medication is sedation i.e., excessive sleepiness and oversleeping, there is little understanding of the impact of sedation or on how it is experienced by patients.

Method: This thesis portfolio contains a systematic review and empirical paper. The systematic review synthesised and appraised studies which explored the impact of the sedating side effects of antipsychotic medication on psychological wellbeing. The empirical paper developed a qualitative thematic analysis of the experience of an aspect of sedation, excessive sleepiness, in people with psychotic disorders.

Results: The systematic review found sedation to be a commonly reported side effect with broad impacts on psychological wellbeing including daily functioning, employment, socialising, and mood. The review highlighted a lack of uniformity in the way sedation is measured and conceptualised. The empirical paper found that patients experienced excessive sleepiness as highly detrimental to their ability to perform daily tasks, socialise effectively and work productively. The empirical paper also highlighted potential maintaining behaviours such as sleeping for emotion regulation and inactivity that may contribute to excessive sleepiness. Lastly excessive sleepiness was generally managed through self-help tactics or changes to medication, but patients reported shortcomings with these approaches.

Conclusion: The systematic review draws attention to sedation as a frequently reported side effect that is impactful on daily life and inconsistently measured. The empirical project emphasises the daily impacts of living with excessive sleepiness and how individual response to excessive sleepiness maintained its presence, alongside medication side

effects. Further research is needed to assess excessive sleepiness in the context of psychotic disorders and explore if existing treatments can ameliorate individual experience.

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Table of Contents:

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Chapter 1.

Introduction Chapter

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Psychotic disorders are severe mental illnesses where an individual experiences symptoms of psychosis, this can include diagnoses such as Schizophrenia Spectrum Disorders (DSM–5, 2013). Psychosis is broadly defined as losing touch with reality, often in the form of hallucinations and delusions (NIMH, 2020). Individuals can struggle with rational thought and develop paranoid ideations (NIMH, 2020). Over a lifetime, about 1% of the population will develop psychosis and schizophrenia (NICE, 2014). Symptoms tend to start in young adulthood but can occur at any age (NIMN, 2020). The recommended treatment for psychosis is a combination of psychological interventions (family intervention and cognitive behavioural therapy) in conjunction with oral antipsychotic medication (NICE, 2014).

Antipsychotic medication effectiveness in the treatment of psychotic disorders is well established (Chow et al., 2023). The medications provide relief from symptoms of psychosis such as hallucinations and delusions (Chokhawala & Stevens, 2023; Chow et al., 2023). First generation antipsychotics work by blocking D2 dopamine receptors in the brain (Chow et al., 2023). The mechanism of second generation (atypical antipsychotics) is by serotonergic modulation (Chow et al., 2023). Antipsychotic medications have several side effects which can vary between medication type, dosage, and individual tolerability (Stroup and Gray., 2018). A range of adverse effects can be experienced, including: weight gain, hypertension, cardiovascular effects, restlessness (akathisia), concentration difficulties, sedation/somnolence and sexual dysfunction (Young et al., 2015; Leucht et al., 2013; Chow et al., 2023; Sthal et al., 2020; Longden). The presence of adverse effects can impact medication tolerability and adherence to taking the medications as prescribed (Legge et al., 2016).

Sedation is a common effect of antipsychotic medication and was historically considered necessary for the clinical effect of antipsychotic medications in reducing positive symptoms of psychosis. However, less sedative, yet as effective atypical antipsychotic medications have highlighted that sedation is not an essential part of the therapeutic effect (Bourin and Briley., 2004). Sedation is thus considered an adverse effect of antipsychotic medication and is experienced commonly by patients, with one clinical

study finding rates of 46-64.7% (Fernandez-Egea et al., 2021; Ramos Perdigués et al., 2016). Sedation can impair a person's ability to function normally and may interfere with their ability to work, study, or socialise (Miller, 2004). A risk of the bothersome presence of sedation is that patients discontinue their medication as a result, as one study which found 20% of unplanned discontinuations of clozapine were due to sedation (Legge et al., 2016).

The level of sedation can differ between different antipsychotic medication type, dosages, and individual tolerability. Conventional antipsychotics are more sedating than second generation atypical antipsychotics. Generally, high-milligram, low-potency antipsychotics produce more sedation than low-milligram high-potency antipsychotics (Miller, 2004). Studies have indicated that sedative effect is determined by amount of the drug reaching Histamine 1 (H1) receptors in the central nervous system (Fang et al., 2016). Antipsychotic medications vary in their ability to block the receptors. Olanzapine and Clozapine are considered to have a higher affinity for the histamine H1 receptors than Quetiapine and Risperidone, resulting in the former being considered to have a larger sedative effect than the latter (Fang et al., 2016; Miller, 2004).

Sedation, as an adverse effect of antipsychotic medications, has no standardised definition in the literature (Young et al., 2014). Broadly, the sedating effects of antipsychotic medication can be grouped to include: excessive sleepiness, difficulty thinking/concentrating, lethargy and oversleeping (Tandon et al., 2020; Dibonaventura et al, 2012). Excessive sleepiness is defined as a 'propensity to fall asleep when a conscious effort may be needed to stay awake' (Reeve et al., 2021). Hypersomnia is excessive sleepiness 'presenting alongside extended sleep duration i.e., either >11 hours of sleep on average per 24-hour period, or >9 hours of nocturnal sleep in the absence of any other explanatory mental or physical health factors' (Reeve et al., 2021). A recent study found excessive sleepiness to be relatively common in people with psychotic disorders, with just under a quarter (23.3%) of participants with psychotic disorders screening positive for excessive sleepiness from diagnostic interview (Reeve et al., 2019).

Although commonly reported, there has been little exploration in the impact of the sedating side effects of antipsychotic medication on individual wellbeing. General presence of sleep disorders in psychosis is thought to negatively impact mental health and quality of life (Reeve, 2019). Research into insomnia in psychosis, has resulted in the development of

targeted treatments and more routine assessment of its presence (Freeman et al., 2015; Reeve, 2019). However, other sleep disorders, such as excessive sleepiness and extended sleep duration, and their combination, hypersomnia, have been overlooked within the research field and clinical domains. As it has been highlighted that aspects of sedation, such as sleepiness/oversleeping may be contributed to by factors outside of medication alone, such as depression or daytime activity – more in-depth investigation of the phenomena is warranted (Reeve et al., 2021).

To date there has been no in-depth exploration into the impact of aspects of sedation in people with psychotic disorders. The thesis portfolio aims to explore the broader impacts of sedating side effects in the systematic review, and the more specific experience of excessive sleepiness in the empirical paper.

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Chapter. 2

The Psychological Consequences of the Sedating Side Effects of Antipsychotic Medication: A Systematic Review

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Abstract

Background: Sedation is one of the most common side effects of antipsychotic medication. Sedation encompasses experiencing daytime sleepiness, difficulty thinking/concentrating, lethargy and oversleeping. Studies have suggested that sedation may impact domains of individual wellbeing and functioning. Despite these challenges being highlighted, no study to date has systematically investigated the sedating side effects of antipsychotic medication on psychological wellbeing.

Aims of review: This review aims to explore the impact of the sedating side effects of antipsychotic medication on factors which contribute to psychological wellbeing, such as impacts on daily functioning, social engagement, employment and mood regulation.

Methods: Papers were identified by searching the databases PubMed, PsycINFO EBSCO and Clarivate Web of Science. A narrative synthesis was conducted, and quality appraisal using the MMAT tool.

Results: Ten peer reviewed papers met the eligibility criteria. Sedation was found to be a commonly reported side effect which was impactful on the ability to perform daily tasks, employment, socialising, and mood. Clinician's perceived sedation as less bothersome than patients. Measurements of sedation are not uniform and contribute to the challenge of clinically conceptualising sedation and its impacts.

Conclusion: The sedating side effects of antipsychotic medications are commonly reported and are impactful on factors which contribute to psychological wellbeing. Further research is needed to understand how patients relate to aspects of sedation, clinician perspectives and approaches to measurement.

Keywords: sedation, somnolence, hypersomnia, schizophrenia, sleep, iatrogenic harm, systematic review

Introduction

Sedation is one of the most common side effects of antipsychotic medication (Stroup and Gray, 2018). Despite its prevalence, the impact of sedation on people who take antipsychotics is poorly understood (Ashoorian et al., 2015). The majority of studies investigating its presence focus on medication efficacy, tolerability, or adherence (Kishi et al.,2017). Whilst sedation is often cited as a reason for non-adherence and noted to be bothersome (Kassew et al., 2019; Lambert et al., 2004), to date there has not been a systematic investigation into the impact of sedation from antipsychotic medication on psychological wellbeing. Within this study psychological wellbeing is defined as a position whereby an individual has a level of daily functioning, can engage socially, is motivated to work productively, and feels equipped to manage fluctuations in mood. This domain-based approach is adapted from the work on defining psychological wellbeing by Ryff and Keyes (1995) whose domains of wellbeing have been utilised as the basis of wellbeing-based therapy and measurements of wellbeing. The study will examine how the sedating side effects of antipsychotic medications impact these domains.

Antipsychotic medications are prescribed for people who are experiencing symptoms of psychotic illnesses. The aim of the medication is to reduce and control psychotic symptoms, such as: delusions and hallucinations (Chow et al., 2023). Historically, sedation was considered a 'major therapeutic component' of first-generation antipsychotics (Bourin and Briley., 2004). Newer atypical antipsychotic medications are less sedative yet as or more effective in reducing psychotic symptoms, and thus have highlighted that sedation is not an essential part of the therapeutic effect (Bourin and Briley., 2004). The presence of sedation is now considered to be an adverse or unwanted effect of antipsychotic medication arising from interaction with the histaminergic system (Young et al., 2015; Leucht et al., 2013; Chow et al., 2023; Sthal et al., 2020; Longden., 2016). Through this neurobiological system, an individual will experience physiological effects of sedation which can impair a person's ability to function normally, socialise effectively and may interfere with psychological treatments (Miller, 2004). If sedation is reported, the standard treatment alteration is to change or reduce the antipsychotic

medication taken, however, this isn't always possible – for example in people prescribed clozapine (Fang et al., 2016).

Defining sedation is a challenge and previous reviews have concluded that there is no uniform definition of sedation (Young et al., 2015). However, typical descriptions of sedation include excessive sleepiness, difficulty thinking/concentrating, lethargy and oversleeping (Dibonaventura et al., 2012). The challenge in definition is mirrored in the lack of consistency in measurement of sedation in research trials or clinical practice. Often, the presence of sedation is self-reported and linked with the presence of somnolence (defined as a state of drowsiness) – e.g., 'are you feeling sedated or sleepy?'. Aspects of sedation, such as excessive sleepiness, can be measured using self-report measures such as the Epworth Sleepiness Scale or descriptions of hours slept at night (Johns et al., 1991). Visual analogue scales (VAS) can also be used, with variability, with some studies utilising VAS as a measurement of levels of alertness, ability to concentrate, calmness/agitation (as a proxy for sedation) (Datto et al., 2009; Bourin and Briley; 2009). This lack of uniformity in the way sedation is measured and understood reflects a wider point of how adverse effects are considered in the literature, where subjective (and in depth) measurement tools are in early stages of development and not yet widely used - such as the MY Medicine and Me Questionnaire (M3Q) (Ashoorian et al., 2015).

Reviews of the impacts of sedation have been limited to particular domains, specifically, social cognition and the impact of sedation on motherhood (Haime et al., 2021; Seeman et al., 2011). A recent systematic review included studies that explored how psychiatric medications with sedative effects might affect social cognition, highlighting the potential detrimental impact that impaired social cognition can have on social functioning (Haime et al., 2021). The review's findings highlighted that some sedative psychiatric drugs such as benzodiazepines can impair emotion recognition in healthy volunteers – overall the review concluded that the effects of antipsychotics remain unclear and calls for further research on the effect of sedative medications on social cognition. Seeman (2011) reviewed studies that investigated how the sedative load of antipsychotic medication may impact mothers with schizophrenia. The review highlighted how mothers may be at particular risk for daytime sleepiness and recommended for clinicians to consider the impact of sedation on mothers to mitigate the risk of losing custody. The reviews highlight how sedation can

impact aspects of an individual's day to day functioning in a potentially limiting way and the need for a broader exploration of the topic.

Given the prevalence of sedation as a side effect and the range of aspects of a person's life that it could impact, focusing on how this may be experienced on an individual level is important to increase understanding of the subjective experience of antipsychotic side effects. It is acknowledged that participants within the included studies will be diagnosed with a serious mental illness and antipsychotic medication will be a necessary aspect of their treatment. This paper does not advocate for a termination of medication, rather an examination of how medications may impact a person's level of psychological wellbeing and mood in the context of their illness and treatment. The study seeks to understand if there are impacts of medication side effects which, if better understood, could be improved upon, and improve the overall quality of life for people already coping with immense psychological difficulties.

Research Questions

The study aimed to investigate the primary research question of 'What is the impact of the sedating side effects of antipsychotic medication on factors which contribute to psychological wellbeing?

The study sought to understand how existing literature explored the impacts of sedation on factors related to the domains of daily functioning, social engagement, employment, and mood regulation which contribute to psychological wellbeing. The concept of psychological consequences is deliberately broad to encompass a range of domains which impact an individual's wellbeing. The domain of daily functioning is defined in this study as mapping on to 'Activities of Daily Living' which includes basic self-care tasks such as personal self-care, preparing and cooking meals, shopping, travelling and functional mobility (Noeleker and Browdie., 2014).

Methods

The systematic review was completed in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Page et al., 2021). The protocol for the systematic review was registered on the PROSPERO (International Prospective Register of Systematic Reviews) online database, including the inclusion and exclusion criteria for the review, screening strategies and methodological framework (reference ID: CRD4202342587)

Due to the methodological heterogeneity within the sample, a narrative synthesis approach is used to report the findings (Campbell et al., 2019; Popay et al., 2006).

Data Sources and Search Strategy

The available literature was reviewed by electronically searching three databases, PubMed, PsycINFO EBSCO and Clarivate Web of Science and manually searching the reference lists of the included studies. The Boolean Operators 'AND, OR' were used as conjunctions to combine words within the search to produce focused results (see Table 1). The truncation symbol '*' was also used to maximise the search range.

An initial search was run including search terms that related to psychological wellbeing and functioning, however, the terms were not specifically referenced in titles and abstracts. The search was therefore broadened to papers that mentioned sedation in relation to antipsychotic medication and the psychological wellbeing and functioning impacts were manually screened.

Table 1
Search Terms

Sedation or somnolence Terms		Antipsychotic medication terms
sedat* OR somnolence	**AND**	antipsychotic OR amisulpride OR aripiprazole OR asenapine OR benperidol OR cariprazine OR chlorpromazine OR clozapine OR flupentixol OR fluphenazine OR haloperidol OR levomepromazine OR lurasidone OR olanzapine OR paliperidone OR periciazine OR pimozide OR prochlorperazine OR promazine OR quetiapine OR risperidone OR sulpiride OR trifluoperazine OR zuclopenthixol OR neuroleptic OR atypical antipsychotic

Eligibility Criteria

The study aimed to encompass a broad a range of papers as possible on this topic. Peer-reviewed papers fulfilling the below criteria were included in this study:

- Sedation discussed as a side effect of antipsychotic medication.
- Sedation discussed in relation to psychological wellbeing utilising any psychometric measurement of psychological wellbeing or self-report of psychological wellbeing.
- Adult participants aged 18 and above. (Due to the differentiation in prescription guidelines of antipsychotic medications for adults and adolescents, only adults were included within this study)
- Sedation reported in a psychiatric population resulting from antipsychotic drugs as opposed to sedation relating to anaesthesia.
- Published in the English language.
- Paper must be primary research.
- Including human participants only.

- Published after 1980.
- Including all methodological approaches

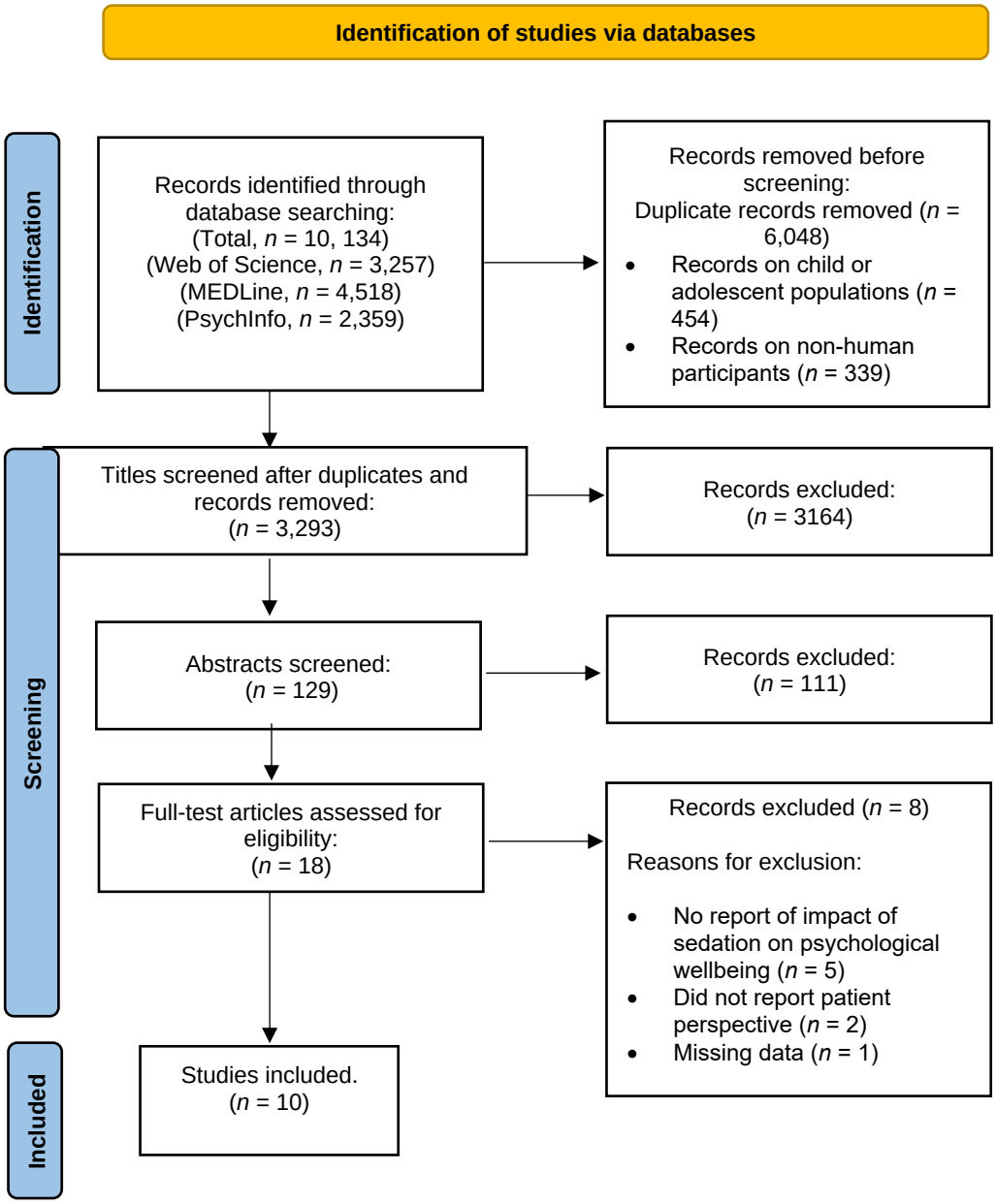
Screening and Selection of Studies

The final search was run from its creation until 28th February 2024, and generated a total of 10,134 results, with PsycINFO database producing 2,359 results and Web of Science and Medline producing 3,257 and 4,518 results, respectively (Figure 2). Screening was conducted using the Rayaan online software. The software identified duplicates and studies that were conducted in under 18s and on non-human participants. After de-duplication and the removal of studies in line with the exclusion criteria, 3,293 articles were retained for title and abstract screening. Following the title and abstract screening, 17 studies were retained for full text screening. The full text screening resulted in the retaining of ten studies to be included in the review, having met the inclusion criteria. Hand-searching from the reference lists of the included studies did not generate further studies for inclusion.

Random samples of 25% of papers at both title and abstract (N= 35) and full text screening (N =4) review stages were screened by an independent reviewer. The percentage agreements with the first author were high at title and abstract screening at 90% (N=32) and consensus at full text screening 100% (N=4). Debates on the inclusion of studies was focused on the extent to which a study explored impacts of sedation on aspects of wellbeing, this was resolved through use of the exclusion criteria and study definitions. Disagreements between the first author (KR) and independent reviewer were resolved by consensus and consulting the eligibility criteria. The second author (SR) reviewed the boundary papers for the study which were considered based on the extent sedation was discussed in relation to its impact on wellbeing or if wellbeing was being considered more broadly in relation to a spectrum of antipsychotic side-effects – consensus was reached through discussion and consultation of the inclusion criteria.

Figure 1

PRISMA Diagram



Data Analysis

Due to the methodological heterogeneity of the studies, a narrative synthesis approach was chosen as the most appropriate way to present the findings. A narrative synthesis approach is a way to summarise findings from a range of studies that have varying methodologies and present these findings in a textual, 'storytelling' format (Popay et al., 2006). The narrative synthesis approach used followed the 'six steps' guidance provided by Popay et al. (2006). Initially, this involved familiarisation with the ten selected studies through reading and annotating the content using a highlighting coding system of relevant data. Once completed, the key study characteristics and results of the studies were extracted and presented in separate tables. A written summary was produced to characterise the findings of the studies and extract key information, relevant to the research question. Finally, a critical appraisal of the strength of the approach was produced.

Assessment of Methodological Quality

The ten included studies include a range of methodological approaches with five qualitative studies, two cross-sectional studies, two secondary data studies and one longitudinal study. The 'Mixed Methods Appraisal Tool (MMAT)' was used for quality appraisal, as it can be used to appraise a range of methodological approaches (Hong et al., 2018). The use of the tool advises to have at least two reviewers independently involved in the appraisal process; therefore, an independent reviewer was involved in the quality appraisal process. The independent review and first author (KR) had a high rate of agreements (90%), any disagreements were resolved through consultation.

Results

Data Extraction Outcome

A summary of the included studies is presented in Table 3. In total the review included five qualitative studies, three quantitative studies and two secondary data studies. The majority of the qualitative (n = 4) and secondary data (n = 2) studies had a broader focus of looking at the experience of antipsychotic side effects, including sedation amongst others (Gray and Deane, 2016; Hughes and Matheson, 2016; Morant et al., 2017; Morrison et al., 2015; Moncrieff et al., 2009). One qualitative study examined the experiences of reducing and discontinuing antipsychotic medication, which was embedded within a Randomised Control Trial comparing reduction and discontinuation of antipsychotics against treatment maintenance (Morant et al., 2023). Two of the quantitative studies were focused on the relationship between taking antipsychotic medication and its impact on motivation (Fervaha et al., 2015; Wolpe et al., 2023). One quantitative study was focused on the impact on functioning of taking second generation antipsychotics (Tandon et al., 2020).

Five of the studies were in community mental health settings where participants were recruited directly from clinical teams (Gray and Deane, 2016; Morant et al., 2017; Morrison et al., 2015; Morant et al., 2023; Wolpe et al., 2023). One study was conducted from a research qualitative research facility (Llorca et al., 2017). One study was recruited participants via market research agencies (Medpanel, Instar and Global perspective) that utilised clinicians, patient panels and patient advocacy groups (Tandon et al., 2020). One study utilised data from participants who were initially recruited for the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) throughout clinical sites in the U.S (Fervaha et al., 2015). In the secondary data studies, both studies included responses from askapatient.com (a web-based forum where respondents discuss their experience of a range of medications) and one also included responses from webmd.com (a web-based health information site where people can review a range of medications) (respectively, Moncrieff et al., 2009; Hughes and Matheson, 2016).

Measurement of Sedation

Sedation was not measured uniformly throughout the studies. Nine of the ten studies relied on self-report of sedation from participants and accepted this as evidence of the presence of sedation (Fervaha et al., 2015; Gray and Deane, 2016; Hughes and Matheson, 2016; Llorca et al., 2017; Moncrieff et al., 2009; Morant et al., 2017; Morant et al., 2023; Morrison et al., 2015; Tandon et al., 2020). One study measured levels of sedation, as the total number of hours slept per day (overall daytime and night-time sleep), corroborated through additional questions about sleep habits (Wolpe et al, 2023).

Three studies used approaches to measuring the severity of self-reported side effects, including sedation. In one study severity was measured by the language used by the participants which was grouped in three levels of severity (Hughes and Matheson, 2016). In another study severity was measured using the Glasgow Antipsychotic Side-Effect Scale (GASS), where severity of side effects, including sedation was measured on a frequency scale ranging from 'never' to 'every day' (Tandon et al., 2020). Another assessed for severity of sedation and akinesia on a single item self-report 0-3 scale, where higher scores indicated greater severity (Fevraha et al., 2015).

Measurement of mood and wellbeing

Seven of the ten studies relied on subjective quotations to encapsulate the impact and experience of antipsychotic side effects, including sedation, in line with the qualitative or mixed methods methodologies (Gray and Deane, 2016; Hughes and Matheson, 2016; Llorca et al., 2017; Moncrieff et al., 2009; Morant et al., 2017; Morant et al., 2023; Morrison et al., 2015). Three of the studies used validated measures of psychological wellbeing (Fervaha et al., 2015; Tandon et al., 2020; Wolpe et al., 2023). Two of the studies included measurements of wellbeing within their studies, however, these scales were used to control for the positive symptoms of psychosis or as measurements of motivation and were not therefore used to measure the psychological impact of the antipsychotic medication side effects (Fevraha et al 2015; Wolpe et al., 2023). One study used the most robust

measurement of psychological wellbeing, the study included the Quality of Life and Enjoyment Scale Short Form to assess the degree of enjoyment and satisfaction experienced in life, in relation to antipsychotic medications (Tandon et al., 2020). The study also included the Glasgow Antipsychotic Side Effect Scale, where questions related to key side effects, including sedation, where created to provide detail on the day-to-day functional and emotional impact of the side effects, measured on a 0-100 visual analog scale (VAS).

Table 3

Key Study Characteristics

Author (s), Date and Country	Aims	Recruitment and Sample	Measures	Data Analysis	Conceptualisation of Sedation *(Sedation discussed in relation to)*	Summary of main findings
Fervaha et al (2015) **USA**	To examine whether motivational deficits were related to antipsychotic treatment in patient with schizophrenia in a dose-dependent manner	Cross-Sectional web-based survey Purposive recruitment technique 520 people with a diagnosis of schizophrenia	Heinrichs-Carpenter Quality of Life Scale The Positive and Negative Syndrome Scale (PANSS) Simpson Angus Scale Sedation severity was measured using a 'single item' which was rated on 0 to 3 scale	Covariance models Spearman rank-order correlation coefficients.	Sleepiness	• Clinical ratings of severity of sedation were not associated with the degree of motivational deficit. • Sedation was not linked to the level of amotivation within the sample. • Individuals may 'habituate' to the sedative effects of medications resulting in compensatory (neurobiological changes)

			where higher scores indicated higher severity.			
Gray and Deane (2016) **UK**	To explore the experience of taking antipsychotic drugs amongst young people experiencing a first episode of psychosis (FEP)	Qualitative Semi-structured Interviews Purposive recruitment technique 20 people experiencing First-Episode Psychosis	N/A	Thematic Analysis	Extended sleep duration	• Sedation was 'by far and away the most commonly reported side effect'. • Sedation reported to impact day-to-day functioning in being unable to get out of bed and feeling weakened by the need to sleep. • Sedation perceived to have a positive consequence in preventing one from

						being in dangerous situations through feeling too drowsy to leave the home.
Hughes and Matheson (2016) **USA**	To explore how antipsychotic users portray their drug experience in terms of the desirability or helpfulness of drug effects and the burden drug effects place on their lives	Mixed methods design using anonymous internet data. Purposive sampling based on characteristics. 819 reviews of antipsychotic medications	Sedation severity was reported through the authors analysing the language used by participants to group in to severity ranging from 'mild,' 'moderate,' to 'severe'	Data coding and descriptive analysis	Increased sleep, drowsiness, tiredness, extended sleep duration	• Psychological consequence of sedating side effects noted in the impact on the ability to function in day-to-day tasks such as attending college • Respondents reported welcome consequences of the sedating side effects when needing to sleep or wanting to escape feelings of anxiety or depression • The sedating effects of quetiapine were noted to produce

						‘intolerable difficulties’ with concentration and memory
Llorca et al (2017) **USA**	To explore patient and physician perspectives of the occurrence and burden of the treatment emergent adverse effects (TEAEs) of atypical antipsychotics	Qualitative Interviews and Focus-groups Purposive recruitment technique 42 people, 25 with a diagnosis of major depressive disorder, 17 with a diagnosis of schizophrenia	To measure TEAEs the following questions were given to participants: 1) exhaustive lists of TEAEs experienced, 2) frequency of each TEAE, and 3) bother ranking for the most bothersome TEAEs (“1” for most bothersome TEAE, “2” for	Qualitative findings were coded and summarised descriptively. Questionnaire responses were reported descriptively.	Somnolence, need to sleep/excessive sleep/excessive sleepiness, ‘zombie like/ out of it	• The impact of sedation/somnolence on participants was described as ‘significant’ and included: missing time with family and friends, missing social activities, lack of energy leading to not eating properly, poor self-esteem and feelings of sedation that interfered with proper functioning. • Sedation was commonly reported as a TEAEs across the sample: 71% overall,

			the next most bothersome, and so on; up to a number that seemed meaningful to the patient).			76% of participants with MDD diagnosis, 71% of participants with schizophrenia diagnosis. • Sedation was reported as amongst the top three most bothersome TEAEs across the sample: 36% overall.
Moncrieff et al (2009) **UK**	To explore the subjective effects associated with the antipsychotics: olanzapine, risperidone, and older antipsychotics through analysing anonymous internet data	Mixed methods design using anonymous internet data. Purposive sampling based on characteristics. Reviewed 439 reviews of	N/A	Chi-square test Content analysis	Increased sleep, daytime drowsiness, fatigue, difficulty waking	• The impact of sedation on participants was described as 'profound and disabling' by many respondents, sedation was the most commonly reported effect across all three of the drug types included.

	antipsychotic medication	• The consequence of sedation experienced as impacting the ability to function day-to-day and engage in self-care tasks such as: getting out of bed, to engage in normal day to day routines and to get dressed in the morning. • Sedation was perceived by some respondents as having positive consequences on their wellbeing in ending a cycle of insomnia and inducing feelings of calmness that

						helped reduce hallucinations
Morant et al (2017) **UK**	To explore service user's experiences of taking antipsychotic medication for psychotic disorders and their perceptions of decision-making about this.	Semi-structured interviews Purposive recruitment technique 20 people with diagnosis of schizophrenia	N/A	Thematic Analysis	Tiredness, lethargy, slowing effect	• Experience of sedating effects described as 'debilitating'. • The experience of sedating effects impacted negatively on participant's ability to participate in activities such as exercise and socialising and complete day to day tasks. • The sedating effect of the medication impacted participants motivation which in turn impacted their

						ability to 'function normally'
Morant et al (2023) **UK**	To explore participant's experiences of antipsychotic reduction or discontinuation at the 24 month follow up of the RADAR RCT which compared antipsychotic reduction/discontinuation with treatment maintenance	Semi-structured interviews Purpose recruitment technique 26 people diagnosed with schizophrenia/non-affective psychotic disorders	N/A	Thematic Analysis	Tiredness, low energy	• Reduction in sedation resulted in increased ability and motivation for daily activities. • Link between increased energy and levels of activity, social connection and more positive sense of self • Retrospective description of how sedating effects impact the ability to wake up and be productive at work
Morrison et al (2015) **Australia**	To explore people's experience of living with antipsychotic medication side-effects	Semi-structured Interviews	N/A	Phenomenological approach and content analysis	Zombie like, lethargy, extended sleep duration	• Sedation was the most commonly reported side effect. • The impact of the sedating effects was in

		Purposive recruitment technique 10 people prescribed antipsychotic medication (diagnosis not specified)				producing the fearful state of feeling 'zombie like' which resulted in participants losing a sense of self. • The authors summarised the impact of sedation to impair a person's ability to function effectively or rationally in a social context due to the detrimental impact on participating in conversations with others
Tandon et al (2020) **USA**	To understand how key side effects of second-generation antipsychotics impact the functioning and quality of life (QoL of	Cross-sectional web-based survey	The Glasgow Antipsychotic Side Effect Scale GASS and the Quality of Life	Spearman correlations Simple and multiple linear	Sleepiness, sedation, difficulty thinking or concentrating, dizziness	• A greater frequency of sedating side effects significantly predicted lower enjoyment and

patients with schizophrenia	Volunteer and snowball sampling technique 435 people with a diagnosis of schizophrenia	and Enjoyment Scale Short Form (Q-LES-Q-SF) [including severity of impact rated on a 0–100 visual analog scale (VAS)].	regression analyses	satisfaction with life (− 3.52, SE = 0.94) • Sedating side effects were the most frequently reported to impact functioning, "Feeling drugged or like a zombie" (75.1%) and "Sleepy during the day" (76.5%) • Sedating side effects were associated with feeling 'frustrated' and 'dissatisfied'. • The most frequently reported functional impact of the sedating side effects was 'ability to do or get a job'. • Sedation was most also strongly associated with

						impacting social domains and energy levels.
Wolpe et al (2023) **UK**	To examine the effect of antipsychotic-induced sedation on motivation and pleasure (MAP) and impaired emotional expressivity (EXP)	Naturalistic longitudinal study Purposive sampling technique 187 people with a diagnosis of schizophrenia, prescribed Clozapine	Positive and Negative Syndrome Scale (PANSS) Calgary Depression Scale for Schizophrenia (CDSS). Brief Negative Symptoms Scale (BNSS) To measure sedation: total number of hours of sleep per day (overall	Multilevel regression models	Extended sleep duration	• Increased levels of sedation were linked to reduced motivation and pleasure. • Sedation was not associated with emotional expressivity. • The impact of sedation on motivation and pleasure was independent of other sources of negative symptoms

		daytime and night-time sleep) and self-reported total numbers of hours slept

Quality Assessment Summary

All studies were assessed using the Mixed Methods Appraisal Tool (MMAT) (Appendix A), a summary of which can be seen in Table 4. All studies scored positively on the screening part of the tool (S1 and S2) which highlighted that each study had clear research questions and that the data collected allowed for the research question to be answered.

The studies ranged in their overall MMAT scores. Within the qualitative studies, one study scored comparatively lower than the other four included qualitative studies due to a lack of inclusion of the qualitative findings to substantiate the conclusions made (Gray and Deane, 2016). In the results section a list of impacts of sedation is included, however this is not reinforced with qualitative responses that were collected as a part of the methodology (Gray and Deane, 2016). The researchers were contacted to enquire if further qualitative data was available, however, no response was received. Amongst the quantitative descriptive studies, the lower scoring study was due to the use of unvalidated single item scales for measuring sedation and akinesia (Fervaha et al., 2015). Within the mixed-methods studies, one study scored lowly for not reporting a justification for using a mixed methods approach. Both mixed methods studies utilised extracts from the text to substantiate their qualitative findings and incorporated the outcome of the frequency tables. In one study a more comprehensive data base was stated to be available at request to the author, the authors have been emailed with no response to date (Moncrieff et al., 2009).

Table 4
Summary of Quality Appraisal MMAT Tool (Hong et al., 2018).

			Qualitative					*Quantitative Descriptive*					*Mixed Methods*					
Study	S1	S2	1.1	1.2	1.3	1.4	1.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5	Quality Percentage
Fervaha et al (2015)	Y	Y						Y	Y	N	N	Y						60%
Gray and Deane (2016)	Y	Y	Y	Y	Y	Y	Y											100%
Hughes and Matheson (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	N	Y	Y	N	Y	60%
Llorca et al (2017)	Y	Y	Y	Y	Y	N	N											60%
Moncrieff et al (2009)	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	N	Y	60%
Morant et al (2017)	Y	Y	Y	Y	Y	Y	Y											100%
Morant (2023)	Y	Y	Y	Y	Y	Y	Y											100%
Morrison et al (2015)	Y	Y	Y	Y	Y	Y	Y											100%
Tandon et al (2020)	Y	Y						Y	Y	Y	N	Y						80%
Wolpe et al (2023)	Y	Y						Y	Y	Y	N	Y						80%

Y = Yes, N = No.

Demographic Characteristics and Clinical Variation

All the included qualitative and quantitative studies were conducted in western samples with a majority white ethnicity and male participants (Gray and Deane, 2016; Llorca et al., 2017; Hughes and Matheson, 2016; Fervaha et al., 20; Morant et al., 2017; Morant et al., 2023; Moncrieff et al., 2009; Morrison et al., 2015; Tandon et al., 2020; Wolpe et al., 2023). The two secondary data studies were again primarily western and white, but the majority of respondents were female (Moncrieff et al., 2009; Hughes and Matheson, 2016).

Antipsychotic medication type was reported in three of the five qualitative studies, all three of the quantitative studies and both secondary data studies. The majority of studies focused on atypical antipsychotics (Gray and Deane, 2016; Llorca et al., 2017, Fevraha; Tandon et al., 2020; Hughes and Matheson, 2016) two studies included first and second-generation antipsychotics (Morant et al., 2017; Moncrieff et al, 2009) and one included only clozapine (Wolpe et al., 2023). One study referred to 'antipsychotic medication' and did not specify the type (Morrison et al., 2015).

Narrative Synthesis

The findings of the narrative synthesis are presented below. To note, the findings presented are extracted from the parts of the included studies which discussed sedation, the topic of sedation formed a small part of wider discussions on medication side effects.

Sedation mentioned as one of the most common side-effects.

Sedation was reported as one of, or the most common side effect in five of the ten studies (Gray and Deane., 2016; Llorca et al., 2017; Moncrieff et al., 2009; Morrison et al., 2015; Tandon et al., 2020). The most reliable study in relation to prevalence included in this study was Tandon (2020). The study included a sample of 435 participants and a global scope for recruitment (recruiting from USA, Canada, Australia, Spain, Italy, Norway,

and Denmark) who were screened for recruitment if taking antipsychotic medication and experiencing one of the side effects on the Glasgow Antipsychotic Side-Effect Scale. Sedation was reported in the top three side effects, with 83.7% of the sample reported 'feeling sleepy during the day' (Tandon et al., 2020). This was mirrored in one internet-based study where sedative effects were reported by 93% of participants taking Risperidone and 95% of participants taking Olanzapine from an overall sample of 223 and 170, respectively (Moncrieff et al., 2009). A response bias is present in the included studies in inviting those who experienced medication side effects to respond or report on their experiences. However, the large sample sizes and geographical scope add weight to their claims.

Within the qualitative studies, sedation was also mentioned frequently. Three of the five qualitative studies reported a high prevalence of sedation within their sample. Each study had similar purposive sampling techniques where participants were invited if they were taking antipsychotic medications and experienced side effects (both positive and negative). In one study sedation was noted as "by far and away the most commonly reported side effect" within a sample of 20 young people with first episode psychosis who were asked about general medication side effects (Gray and Deane, 2016). Similar prevalence was acknowledged in another interview-based study where sedation was the "most commonly reported side effect" amongst a sample of ten participants, receiving 21 of the 94 mentions of side effects across the sample (Morrison et al., 2015). Llorca (2017) found similar reporting's of sedation amongst 71% of the overall sample of 42 participants.

The experience of sedation

The included qualitative papers (n = 5) offered subjective insight into individual experiences of antipsychotic side effects. Across three of the five qualitative studies, participants used descriptions of sedation that ranged from describing sedation in reference to the physical sensations or in using metaphorical language. For the former, descriptions included feeling "dark under the eyes, it makes me feel weak for hours" (Gray and Deane, 2016) or "lazy" (Morant et al., 2017). Metaphorical descriptions included "making me into a zombie" (Morrison et al., 2015) and "like walking in water" (Gray and

Deane, 2016). The use of these descriptive points across the studies adds weight to the challenge in describing sedation being reliable across different samples.

The way participants related to the presence of sedation varied between resistance and resignation. In one study, a participant described unironically that they felt sleeping 12 hours sleep a day reflected a "mild tranquilliser" which the researchers comment as being reflective of an acceptance of the sedating effects (Morrison et al., 2015). In another study participants showed both ends of the spectrum, with one participant commenting that "I have to somehow get used to it [sedating effects]" where another participant commented that "you have to fight the resistance" (Gray and Deane, 2016). The range of experiences across studies and within samples highlights the individual variation in how sedation is perceived.

The impact of sedation on day-to- day functioning

Impacts on day-to-day functioning was mentioned in three of the qualitative studies, both secondary data studies and one of the quantitative studies (Gray and Deane, 2016; Morant et al., 2017; Morant et al., 2023; Moncrieff et al, 2009; Tandon et al., 2020). The presence of sedating side effects impacted participants ability to perform everyday tasks, causing a "profound and disabling" and "debilitating" impact on participants. (Morant et al., 2017; Moncrieff et al, 2009; respectively). Across the studies participants highlighted how fundamental tasks such as getting dressed, washing, and cooking were impacted by the sedative side effects of antipsychotic medication. As one participant notes, "I could hardly go about my normal routines. I couldn't even get myself dressed to go out to the store." (Moncrieff et al., 2009). Another participant described a similar impact, "The first time after taking it I couldn't get up for 12 h. Now 2–4 h after taking it I can get up, but I can't get out of bed" (Gray and Deane, 2016).

In one study the impact of this challenge in performing everyday tasks was expressed in how they would miss college classes because of oversleeping:

"I would sleep through alarms and would just go back to sleep without even knowing. I would get up late, I missed a lot of college. . . I could not concentrate on work and my memory was bad. Hard to read large chunks of text." (Hughes and Matheson, 2016).

In one study reductions in sedation through reducing or discontinuing antipsychotic medication was associated with 'increased ability and motivation for daily activities' (Morant et al., 2023). As one participant described:

"… without medication I can wake up any time if I've got a job. With medication you feel very heavy early in the morning, you cannot get up when you need to work…" (Morant et al., 2023)

The impact of feeling sedated during the day was found to have effects on being able to get a job or doing a job. Participants reported a VAS score (where higher scores relate to higher severity of impact) of 70.5 of sedation's impact on 'getting a job/doing a job' (Tandon et al., 2020). Similarly high scores were found in participants rating of 'affected other aspects of daily functioning' with a VAS score of 67.8 (Tandon et al., 2020). A marginally lower score yet still within the moderate to severe range was found in the impact on 'taking care of self' with a VAS score of 58.4 (Tandon et al., 2020).

The impact of sedation on social engagement

The impact of sedation on the ability to engage socially was mentioned in all five of the qualitative studies, one of the secondary data studies and one of the quantitative studies (Gray and Deane, 2016; Hughes and Matheson et al., 2016; Morrison et al., 2015; Morant et al., 2017; Morant et al., 2023; Tandon et al., 2020; Llorca et al., 2017). From the findings, the researchers of one study concluded that the experience of sedation "grossly impair[s] the consumer's ability… to function effectively or rationally in a social context" (Morrison et al., 2015). In one study a participant noted how the sedating experience of feeling 'lazy' and without 'motivation' had contributed to them developing "social phobia" and not having many friends (Morant et al., 2017). In another study a participant summarises concisely the impact on their ability to socialise:

"[sedating side effects] caused me to have basically no social life because I just couldn't stay awake" (Hughes and Matheson, 2016).

The impact of not being able to engage socially was noted in one study where participants described how it impacted their "self-esteem" and they worried that friends may misunderstand their disengagement as being "rude" or "disrespectful," which reflected negatively on their feelings of themselves "the fact that they think it is deliberate destroys me" (Tandon et al., 2020).

However, one participant noted that the sedating impact of the antipsychotic medication could have a potentially positive effect socially, on reducing the risk of being in potentially dangerous situations:

"The fact that they made me drowsy might have taken me out of situations that were dangerous. I was thinking and doing odd things. It took them out of the equation and allowed me to find new directions for myself." (Gray and Deane, 2016, p. 11)

The impact of sedation on mood

Specific references to the impact of sedation on aspects of mood were scarcer within the findings, mentioned in three of the ten studies. The results highlighted a potentially complex relationship between sedation and mood. Within one of the secondary data studies, a participant experiences sedation as preferable to negative emotional states:

"… [antipsychotic medications] can be taken at times when sleep is needed and only other times when agitated, etc. . . . I find that [quetiapine] works best when alone, needing sleep, or in depressing episodes where sleep may be desired instead of further depression or anxiety." (Hughes and Matheson, 2016, p. 208)

The feeling of welcoming sleep was particularly positive for people who had previously experienced insomnia, as one participant notes, "the drug saved my life by getting me sleep so my nervous system could rest" (Moncrieff et al., 2009).

The link between mood and sedation was importantly highlighted in the larger sample (n=435) of Tandon (2020), offering insight into potential negative psychological consequences of sedation. In quantifying the emotional descriptors for the sedating side effects, the most reported emotional descriptors were: 'Frustrated, dissatisfied, hopeless, impatient/irritated/angry.' The finding of the study's regression analysis further summarises this negative emotional experience in response to sedation, in finding that a greater frequency of sedating side effects significantly predicted lower enjoyment and satisfaction with life (-3.52, SE = 0.94) (Tandon et al., 2020).

The impact of sedation on motivation

Two quantitative studies examined the role of antipsychotic medication's impact on motivation in people with schizophrenia, with differing findings (Fevraha et al., 2015; Wolpe et al., 2023). One study, examining the impact of clozapine induced sedation on motivation and pleasure (MAP), found a significant effect of clozapine induced sedation on motivation and pleasure ($\beta = -0.0011$, $P = 0.046$), suggesting that clozapine related-sedation worsened MAP in participants (Wolpe et al., 2023). The other study found that clinical ratings of sedation were not associated with the degree of motivational deficit in the sample, implying that levels of sedation did not have a significant interaction with motivation (r = -0.02, P = 0.63) (Fevraha et al., 2015).

In assessing the methodological quality of each study, both had large sample sizes and were conducted in samples of people with schizophrenia who had been invited to participate. Importantly both studies controlled for confounding clinical variables related to the association of amotivation with positive symptoms of psychosis, using multilevel mediation analysis (Wolpe et al., 2023) and covariance models adjusted for the severity of positive symptoms (Fervaha et al., 2015). The studies differed crucially in the medication examined and the way by which they measured sedation. On the medication front, Wolpe (2023) looked only at Clozapine whilst the Fevraha (2015) looked at a range of atypical

antipsychotic medications. In measuring sedation, Wolpe (2023) used the more robust measurement of total number of hours slept which was corroborated with questions related to sleep habits. By contrast, Fevraha (2015) measured sedation using a single item unvalidated 0-3 scale where higher scores indicated higher levels of sedation. The contrast between the measurement tool used and the medication examined result in it not being possible to make a conclusion on how sedating properties of antipsychotics impact motivation on a general scale.

Clinicians' response to sedating side effects

Four of the five the qualitative studies and one of the secondary data studies highlighted clinician's responses to sedation (Moncrieff et al., 2009; Morant et al., 2017; Morant et al., 2023; Morrison et al., 2015; Llorca et al., 2017). One qualitative study reported a discrepancy where clinicians did not include sedating effects in their list of the most bothersome side effects, in contrast to the clinical sample who included 'need to sleep/excessive sleepiness' in their ranking (Llorca et al., 2017). A misattribution of sedating effects as negative symptoms of psychosis was considered as a possible reason for the differing level of significance between clinicians and patients (Llorca et al., 2017; Morrison et al., 2015). One study described how mental health consumers could feel their concerns regarding sedative effects were often 'dismissed' and mistaken for schizophrenia symptoms such as 'a-sociality, withdrawal, anhedonia and cognitive impairment' (Morrison et al., 2015). The difficulty in measuring and accounting for side effects more generally was also highlighted (Llorca et al., 2017).

Four of the studies called for the subjective impact of side effects to be seriously considered by health professionals, in relation to their impact on consumers (Moncrieff et al., 2009; Morant et al., 2017; Morrison et al., 2015; Llorca et al., 2017). Changes to medication as a result of side-effects was reported by some respondents. However, others felt disempowered to speak about their medication side effects and, in relation to sedation, resorted to taking personally managing their treatment and discontinuing medication:

"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" (Morant et al., 2017).

The qualitative study exploring medication reduction and discontinuation, highlighted how open discussions with prescribers enabled a more 'partnership-like' relationship that was experienced as 'confidence building' or 'empowering.' Highlighting the beneficial effects of openly discussing medication impacts in patient care (Morant et al., 2023).

Discussion

This review has found that sedating side effects of antipsychotic medications are common and impactful on individual functioning. Assessment of sedation is not standardised. Self-report is largely relied upon for the presence of sedation and severity is measured without uniformity. The resulting outcome is a clearly impactful experience which is challenging to conceptualise at an individual level and can be overlooked clinically. A clearer conceptualisation of sedation and its impacts are needed to improve the daily detrimental effects that the side effects are having on individual psychological wellbeing.

Sedation was amongst the most experienced side effects of antipsychotic medications across the studies (Gray and Deane., 2016; Llorca et al., 2017; Moncrieff et al., 2009; Morrison et al., 2015; Tandon et al., 2020). This contrasts with a recent meta-analysis of 36 randomized placebo-controlled studies of antipsychotics in the treatment of schizophrenia, where the levels of somnolence reported showed greater variation and a much lower prevalence (Fang et al., 2016). For example, in the RCT's reporting on Aripiprazole in a total sample of 712 participants, 9.4% reported somnolence, Olanzapine showed a slightly higher incidence within, 746 participants, 18.9% reported somnolence (Fang et al., 2016). It is noted that the studies included in this review invited participants who were already experiencing medication side effects and therefore were biased towards the presence of side effects more broadly. The meta-analysis also highlights the variation between antipsychotic type and levels of sedation/somnolence, in addition to the individual differences that can contribute to the experience of antipsychotic medications,

which this review did not control for (Fang et al., 2016). The findings of this study's higher prevalence rates highlight an interesting contrast between reporting sedation rates within RCT's versus clinical practice. The results of prevalence in this study should be considered with caution, accounting for the smaller sample sizes and subjective ratings. Nonetheless, the high prevalence within the included studies demonstrates that when asked specifically on the instance of antipsychotic side effects, sedation is reported with high frequency.

In relation to daily functioning, the review found sedating side effects to have a detrimental impact. The results highlighted impacts on individual ability to self-manage day to day tasks such as cooking, washing, adhering to normal routines, and attending social engagements. A recent meta-analysis related to self-management in severe mental illness highlighted the importance of positive self-management on symptom severity and symptoms of depression and anxiety (Lean et al., 2019). To assess the degree of sedation's impact on functioning, understanding the experienced level of sedation is paramount. The results highlighted a lack of uniform approach to measuring and understanding levels of sedation on an individual level. Attending to this during the assessment process could help to highlight for an individual how the physiological mechanisms of antipsychotics may impact motivation and the ability to perform daily tasks.

On an individual level, the relationship of patients to the impacts of sedation is complex. The findings demonstrate how at times sleep can be welcome as way to avoid challenging emotions or potentially risky situations. Sleeping to deliberately escape challenging psychological experiences is noted within qualitative research in people with psychosis (Faulkner and Bee, 2017). In this context, a potential misattribution of the causality of sleepiness is highlighted. If individuals deliberately sleep to avoid difficult emotions, then it is reasonable to follow that this could be a contributing factor to the presence of sleepiness, that is not directly from antipsychotic medication. Findings in research have reflected this, a recent study investigating excessive sleepiness in patients with psychosis found that medication did not differ between those who experienced sleepiness, and those that did not (Reeve et al., 2021). It is possible therefore that other factors are contributing to the presence of sedating effects in psychotic disorders, where inviting sleep to cope could be a potential explanation. This is important, as if it is sedation is maintained by mechanisms beyond antipsychotic medication then there may exist

targets for intervention, beyond the current standard practice of changing medication dosage.

The challenges of describing and understanding sedating side effects, results in discrepancies between patient experience and clinician understanding. As discussed, sedation is challenging to define on an individual level, not systematically measured and could be contributed to by other factors. It is understandable therefore that there is distance between clinician understanding and patient experience without a common framework for characterising the presence of sedating side effects. An exploratory investigation into doctors' consultations with patients taking antipsychotic medication objectively highlights this discrepancy (Seale et al., 2007). In analysing audio recordings of 92 consultations in the UK, the presence of sedating effects were often overlooked or considered within a checklist of symptoms deemed to be positive, such as sleeping during the night (Seale et al, 2007). A range of studies have echoed this finding where clinicians can misattribute the presence of sedation as being helpful, favourable over insomnia or a sign medication is working (Nose et al., 2012; Miller et al., 2008). It follows that a more uniform way to measure, define and understand sedating side effects could benefit clinician and patient alike.

The sedating side effects of antipsychotic medications are an important area for further investigation. Whilst the use of antipsychotic medications is necessary in the treatment of psychotic illnesses, the impact of their side effects may have more scope for intervention than previously has been considered. Improving our understanding of an individual's experience and relationship to sedating side effects could help to improve long-term functioning and reduce the risk of medication non-adherence. To further our understanding, more in depth research is needed on the experience of sedation in psychosis to aid the development of more in depth assessment and potential treatments.

Clinical Implications

There are several clinical implications of this review which should be considered within the remit of current clinical practice. The results highlighted the potentially impactful experience of living with sedating side effects. Within current practice,

explorative conversations of the experience and impacts of sedation on the individual's wellbeing at assessment could highlight individual experiences. Within this conversation, clinicians should seek to explore the functional impact of sedation in relation to Activities of Daily Living and social engagement. Clinicians should not assume that over-sleeping or feelings of sleepiness are preferable over problems that limit sleep and take time to investigate how a patient may be relating to their sleep. An exploration of coping strategies is also indicated to highlight where a patient may be utilising sleep to escape difficult feelings and to support them in finding additional ways to manage or explore their emotions.

Future Research

This review highlighted several gaps in the literature regarding sedation and wellbeing. Whilst the review included responses from participants experiencing sedation, the responses were a small element of larger studies of antipsychotic medication side effects. Future research should focus more specifically on the sedating side effects of antipsychotic medication such as excessive sleepiness, extended sleep duration and concentration. Qualitative exploration of sedating side effects should seek to understand how patients relate to the side effects and what they subjectively believe the cause and contributors to be to support in our understanding of the extent of the role of medication and other possible contributors. A qualitative study on clinician perspectives of sedating side effects is also recommended to increase our knowledge of how clinicians perceive medication side effects within their clinical understanding. Finally, a more routine way to assess and measure sedation is needed to improve the current lack of uniformity in how sedation in the context of medication side effects is conceptualised.

Limitations

A key limitation to this study was the heterogeneity of the studies included as this limited the level of analysis which could be completed. The consequent use of the MMAT tool was appropriate for the range of studies included, however in its scope it is a less

detailed assessment of qualitative and quantitative studies. The MMAT tool may therefore have not picked up on methodological detriments in the studies which specific qualitative or quantitative studies may have picked up on. Nonetheless, the MMAT is a validated tool that is appropriate for the quality appraisal of a heterogeneity of studies and was the more appropriate choice for this review.

The limitations of the sensitivity of the MMAT should be considered when reading the critical appraisal section of this paper and when interpretating the review's conclusions. The MMAT generated largely positive results in methodological quality, particularly with the qualitative papers. Conclusions on the qualitative papers using the MMAT do not take in to account the ontological stance of the study amongst other methodological qualities, which can inform the reading of the study results and thus should be approached with caution. A future systematic review could repeat the appraisal within this study, separating by qualitative and quantitative papers and using specific screening tools for each approach, to further explore the methodological quality of the included studies.

The small sample sizes and inclusion criteria of the included studies is a limitation in the generalisability of the prevalence findings. The studies conducted on the experience of sedating side effects were also limited to mostly western samples, with majority white male population. Caution should be enacted when interpreting the prevalence findings and they should be considered contextually with the aims of the projects which were biased towards people already experiencing medication side effects in certain geographical regions that are not fully representative of the general population.

Conclusion

The findings of this review have highlighted the complexity of measuring, describing, and understanding the impacts of sedating side effects. Inconsistent terminology contributes to patients feeling disempowered to discuss the impact of their experiences of side effects and may, as evidenced in this review, resign individuals to an impactful experience of side effects that could be ameliorated. Whilst antipsychotics are an important part of treating psychosis, we shouldn't accept sedation as a side effect but

rather see it as an additional treatment target. If medication alone may not account for the presence of sedation, then targets for intervention may be present for which treatments already exist. Therefore, further research that investigates the individual experience, impacts and potential mechanisms for sedating side effects is needed, alongside research that can help in defining and measuring sedation. Both endeavours could help improve and reduce the experience and impact of the sedating side effects of antipsychotic medication on the vast cohort of people who consistently report the effects to be present and impactful.

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Chapter 3.

Bridging Chapter

Word Count: 347

The systematic review highlighted that the sedating side effects of antipsychotic medications are impactful on domains related to individual wellbeing. The review included studies which touched upon evidence that sedating side effects can impact an individual's ability to perform daily tasks, gain and sustain employment, and engage socially (Gray and Deane, 2016; Llorca et al., 2017; Hughes and Matheson, 2016; Fervaha et al., 20; Morant et al., 2017; Morant et al., 2023; Moncrieff et al., 2009; Morrison et al., 2015; Tandon et al., 2020; Wolpe et al., 2023). For some, sedation could be experienced positively when sleep was preferable to emotional experiences (Hughes and Matheson, 2016, p. 208). For others, sedation was associated with negative feelings of frustration, dissatisfaction, and anger (Tandon et al., 2020). Sedation was found to predict lower enjoyment and satisfaction with life (Tandon et al., 2020).

Antipsychotic medications are a necessary aspect in the treatment of psychotic disorders and their side effects are well documented. Although necessary to treatment, maintaining a quality of life alongside medication side effects is important. What is evident from the systematic review is that sedating side effects can be impactful to an individual's quality of life and may currently be viewed as 'unavoidable' and therefore left without comprehensive exploration. Certainly, the lack of uniformity in the measurement of sedation highlights its potential to be overlooked within assessment and formulation processes.

Within the systematic review 'excessive sleepiness' and 'extended sleep duration' were the most referenced components of sedation, included in seven of the ten studies. Although an evident key aspect of sedation, no study to date has specifically focused on the experience of daytime sleepiness in people with psychotic disorders. As the wider results on sedation highlighted, feeling excessively sleepy during the day may be contributing to an impact in functioning, have a relationship to mood and a potential relationship to contributing to sleepiness (in sleeping to avoid emotions). These lines of enquiry warrant further exploration. The next chapter presents a qualitative empirical study which the explores the experience of excessive sleepiness and hypersomnia in people with psychotic disorders.

Chapter. 4

Empirical Paper: Understanding Excessive Sleepiness in People with Psychotic Disorders

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This paper has been developed for submission to PLOS ONE. Author guidelines are outlined (Appendix A). Word Count Limit: None.

Declarations of interest: None.

Word count, excluding titles, tables, and references: 6547

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Abstract

Background: Sleep disturbances are common in people with psychotic disorders, impacting individual functioning and wellbeing. The presence of sleep disturbances which extend sleep have been overlooked, despite their high prevalence, and potential impacts on wellbeing and recovery.

Objective: This study aimed to explore the experience of extended sleep duration and excessive sleepiness, or their combination (hypersomnia) in people with psychotic disorders through a broad exploration of the experience, impacts, contributors, and role of treatment.

Method: Ten qualitative interviews were held with people with psychotic disorders who screened for experiencing excessive sleepiness, extended sleep duration or their combination (hypersomnia). The interviews were analysed using thematic analysis.

Results: The results highlighted that excessive sleep is impactful on multiple domains on individual functioning and is contributed to by factors beyond medication side effects alone. Five major themes were developed: (1) *The Exhausting Everyday*, (2) *Medication is only part of the story,* (3) *Indescribable Tiredness, (4) Overruled by Sleep* and (5) *An Unfair Fight.*

Conclusion: Excessive sleep is impactful on multiple domains of individual wellbeing. Cycles of emotional avoidance and inactivity contribute to the presence of excessive sleep, in addition to medication side effects. Further research is needed to improve the assessment of excessive sleep and explore potential interventions.

Keywords: hypersomnia, excessive daytime sleepiness, extended sleep duration, functioning, antipsychotic medication, sedation, psychotic disorders

Introduction

Sleep disturbances are common amongst patients with psychotic disorders, with up to 80% found to have symptoms of sleep disorders (Faulkner & Bee, 2017; Wulf et al.,2012). They are present prior to and early in the course of psychosis, and often persist once psychotic symptoms are treated (Baandrup et al., 2012). Amongst the sleep disorders present in people with psychosis, excessive sleepiness, extended sleep duration and their combination, hypersomnia, have been overlooked due to research focusing on sleep disorders that limit sleep (such as insomnia). Nevertheless, sleep problems which extend sleep can also be impactful on individual functioning and emotional wellbeing. However, little is known on the experience of and potential mechanisms contributing to and maintaining excessive sleep, aside from a role of sedating side effects of antipsychotic medication.

Within the literature, excessive daytime sleepiness combined with extended sleep duration is referred to as hypersomnia. For this project, excessive sleepiness will be referred to throughout in as this terminology is commonly shared amongst patients and clinicians. Excessive sleepiness is defined as a 'propensity to fall asleep when a conscious effort may be needed to stay awake,' the experience contrasts to fatigue which is attributed to physical tiredness (Shen et al., 2006). Extended sleep duration is when an individual sleeps more than 11 hours in a 24-hour period (including napping) or more than 9 hours a night, in the absence of any other mental or physical health factors (ICSD-3). The gold standard measurement for excessive sleepiness is the use of the Multiple Sleep Onset Latency Test (MSLT), which is only accessible for use in specialist sleep centres. Studies exploring sleepiness to date have relied upon self-report of sleepiness and extended sleep duration, alongside measures such as the Epworth Sleepiness Scale (Johns et al., 1991).

Excessive sleepiness may be relatively common in patients with psychotic disorders. A recent study found that just under a quarter, 23.3% of patients with psychotic disorders, screened positive for excessive daytime sleepiness from diagnostic interviews (Reeve et al., 2018). Despite this high instance, sleep disturbances that extend sleep have been overlooked within the research field. Ascribing extended sleep to the sedating side effects of antipsychotic medications could account for this gap in the literature (Rehman et al., 2016). Antipsychotic medication has a known interaction with

neurotransmitter systems that are involved with sleep/wake regulation (Rehman et al., 2016). It is suggested that antipsychotics cause somnolence/sleepiness via the blockage of Histamine 1 (H1) receptors, which can vary between medications with the antipsychotics Olanzapine and Clozapine having a higher risk for sedation/somnolence (Fang et al., 2016; Miller, 2004). Qualitative research has highlighted how patients perceive their sleep disturbance as a permanent accompaniment to their diagnosis and side effect of antipsychotic medication (Faulkner & Bee, 2017). Current advice on reducing sedating effects of antipsychotic medication certainly mirrors this, with management largely focused on changing the medication type, dosage, or time of day the medication is taken (Fang et al., 2016).

Preliminary findings have suggested that factors outside of medication alone could be contributing to the experiences of sedation amongst people prescribed antipsychotic medications. A recent study found no differences in antipsychotic medication type or dosage between patients reporting excessive daytime sleepiness and those without (Reeve et al., 2021). The excessive sleepiness group reported higher levels of depression, anxiety, and reduced quality of life, although these findings were not significant, they highlight a route for further exploration of what may be accounting for individual experiences. The study also showed significantly lower levels of activity in the excessive sleepiness group, which also highlights the potential for further exploration. Although medication has a clear role in its contribution to excessive sleepiness, there may be other causal contributors alongside such as mood, activity levels, or sleep problems. Better understanding of these could improve potential intervention routes for those experiencing excessive sleepiness and psychotic disorders, adding to work already underway in mood disorders.

Currently, there is a gap in our knowledge of understanding how symptoms of hypersomnia are experienced and understood by those with psychotic disorders. To date, a specific qualitative study in this realm has not been undertaken. Given its prevalence and impact on clinically relevant factors there is an important goal to further our knowledge of clinical presentation, impact and understanding of excessive sleep. This is the first study to specifically explore excessive sleepiness, extended sleep duration and their combination (hypersomnia) through including participants with extended sleep and referring to patient expertise and lived experience.

Terminology

This study was developed with input from Public and Participant Involvement (PPI). In consultation with representatives from a PPI panel, the term 'excessive sleepiness' was considered by their experience to reference extended sleep duration and excessive daytime sleepiness, and their combination, hypersomnia. The topic guide and research questions were adapted to reflect this terminology.

Research Questions

The current study aimed to answer the following research question:

The broad question we aimed to answer was: *'How do people with psychotic disorders experience excessive sleepiness?".* This comprised several elements including understanding the symptoms and phenomenological experience of excessive sleepiness; the impacts of excessive sleepiness on patients; potential causes and contributors either noted by patients or interviewer; and healthcare experiences around assessment or treatment of excessive sleepiness.

Methods

Study Design

This study was a qualitative interview study based on a critical realist framework. Patients were recruited based on consent to follow-up from a cross-sectional survey (on sleepiness in psychosis) and fulfilment of excessive sleepiness criteria. Data was collected via semi-structured interviews with people experiencing excessive sleepiness, extended sleep duration or their combination (hypersomnia) in the context of a psychotic disorder. The data was analysed through thematic analysis using Braun and Clarke's framework (Braun and Clarke, 2006).

Participants

Participants were recruited via an online survey on sleepiness in psychosis which was advertised on invitation cards (provided by care team to eligible patients - Appendix A) and posters (Appendix B) within Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) and on online social media platforms (Facebook and Twitter).

Recruitment and Screening

For the online survey, eligible participants were required to be (a) aged between 18-65, (b) to have fluency of the English language (i.e., able to complete the online survey), (c) to have a diagnosis of first episode psychosis (FEP) or schizophrenia spectrum disorder. For the online survey, exclusion from the study included the diagnosis of a mood-related disorder or a learning disability (which would limit the ability to complete the online survey).

Within the online survey, participants were offered the opportunity to take part in a follow up interview which formed the data collection for this study. The interview aspect of the study required participants to fulfil criteria of excessive sleepiness or extended sleep duration or their combination (hypersomnia), in addition to the inclusion criteria of the survey. Participants were invited if they self-reported fulfilling any of the below additional criteria (Appendix C) (Reeve et al., 2021):

- Reporting 'feeling excessively sleepy during the day to the extent it was difficult to stay awake or take part in activities', 3 or more days a week.
  OR
- Reporting sleeping ≥ 11 hours within a 24-hour period, through self-reporting yes or no
  OR
- Reporting sleeping ≥ 9 hours at night over the last month, through self-reporting the number of hours slept.

Eligible participants were emailed with the interview information sheet (Appendix D) and consent form for the interview (Appendix E). Once consent had been gained, the researcher emailed the participant to arrange a time for the interview.

Data Collection

The data was collected via semi-structured interviews with consented participants who had been screened to meet the inclusion criteria. All the interviews were conducted online via Microsoft Teams and lasted between 30 minutes and 1 hour. Prior to the interviews, each participant was emailed the topic guide (Appendix F). The interviews were transcribed using transcribing software within Microsoft Teams and then checked by the primary researcher for any mistakes through re-listening to the recordings. The transcriptions were then anonymised and uploaded to NVivo software.

Interview Design

The topic guide (Appendix F) included questions which were designed to answer the research question and map on to the domains of the experience, impact, contributors, role of medication and treatment of excessive sleepiness. Within each broad domain prompting questions were listed in the topic guide to cover subdomains, if needed. At the end of the topic guide participants were invited to return to any of the questions answered or discuss any topic related to their excessive sleepiness that was important to them, which had not been asked in the preceding questions.

The topic guide was reviewed by a small sample of lived experience representatives, in line with Public and Participant Involvement (PPI) procedures. The PPI group was consulted to support that the language and content of the topic guide was appropriate to the intended sample. The group made suggestions on terminology, specifically to use 'excessive sleepiness' within the interviews to utilise lay language, the topic guide was adjusted to reflect this advice.

Data Analysis

The interview data was analysed using qualitative thematic analysis, using an inductive approach (Braun and Clarke, 2006). Following the steps of Braun and Clarke (2006), post transcription, the primary researcher began by familiarising themselves with the data through listening to the audio-recordings and re-reading the transcripts. Next, the researcher coded the data using a 'complete coding method,' coding all the data relevant to the research question. In line with the epistemological approach of the study, the thematic analysis utilised the reflexive approach, which acknowledged the

researcher's active role in the process (Byrne, 2021). The primary researcher then identified themes across the data, reviewing the codes and related data. Once the themes had been developed from active work with the data, extracts were selected to illustrate facets for each theme (Braun & Clarke, 2013). The development of the themes was reviewed and discussed between KR and SR. The final theme framework was reviewed and approved by KR, SR, and JH.

Reflexivity and Rigour

In line with the epistemological approach, the researcher's position in relation to the data collection and analysis process was considered. It was acknowledged that all authors have had prior and current experience working clinically with people with psychotic disorders.

The critical realist stance perceives data as not being a direct reflection of reality, rather, that the data need to be interpreted, to produce underlying structures. As an approach it is ontologically realist (assuming that there is a reality which exists beyond the minds of individuals) and epistemologically relativist (the process involved the researchers reading of the data and was thus influenced by their perspectives) (Willig, 2012). To ensure transparency and rigour, the primary researcher kept a reflective diary which they completed following each interview and within the analytic process (Morrow, 2005). The authors met regularly to discuss and agree on identified themes, re-working and updating the themes as necessary until a consensus between the authors was met.

Reflexive Statement

The critical realist stance adopted in the ontological approach of the empirical paper assumes the biases and subjective experiences of the researcher as a part of the research process. To reflect on this point, I acknowledge my position as a clinical researcher with previous experience of working clinically with people experiencing psychotic disorders and my dual role as a clinical researcher and a part of the NHS system. In line with the epistemology, I utilised a reflective diary alongside supervision and consultation with colleagues in the qualitative forum to discuss the processes I felt

within the interviews and the analytic process. The themes created within the analysis were consulted with the primary and secondary researchers to increase transparency and reduce bias. Through sharing within these spaces, I gained an awareness of these processes which enabled a critical reflection of my position.

Ethical Considerations

This study was approved by an NHS Research Ethics Committee (ref: 23/LO/0085) (Appendix G) and was sponsored by the Faculty of Medicine and Health Sciences at the University of East Anglia (Appendix H). In line with data protection legislation (Data Protection Act, 2018), participants confidentiality was preserved by anonymising the recorded interview data, transcripts, and verbatim extracts. Any information that could have identified a participant was removed from the transcripts.

Results

Sample

Demographic characteristics are shown in Table 1. Ten participants were included in the study. The majority of participants were female (60%), of white ethnicity (90%). Ages ranged between 19-47. The participants ranged in their diagnosis with a proportion diagnosed with first episode psychosis (FEP) (30%) and the majority with schizophrenia spectrum disorders (70%). Half of the participants self-reported taking a combination of antipsychotic medication and antidepressant medication, one participant reported only taking an antipsychotic medication, another participant specified that they were only prescribed Clozapine.

Hypersomnia (the combination of excessive sleepiness and extended sleep duration) was experienced by 60% of the participants. Excessive sleepiness was experienced by 20% of the participants. Extended sleep duration was experienced by 20% of the participants.

Table 1.

Demographic Characteristics

Participant Code	Recruitment Route***	Gender; Age*	Ethnicity*	Diagnosis*	Medication*, **	Employment *	Over the last month, how long did you typically sleep each night? *	How many days in a typical week do you feel excessive sleepy? *	Over the last month did you generally sleep over 11 hours in a 24-hour period? *	Excessive Sleepiness OR Extended Sleep Duration OR Hypersomnia
1	EIP	F; 19	White	FEP	Aripiprazole 10mg	Full time employed	10	4	N	Hypersomnia
2	Adult Locality	M; 47	White	Schizophrenia	Clozapine 450mg Aripiprazole 25mg Citalopram 40mg	Unemployed	10	N/A	N	Extended Sleep Duration
3	EIP	F; 33	White	FEP	Olanzapine 5mg Sertraline 100mg	Student	8	5	N	Excessive Sleepiness
4	EIP	M; 35	White	Schizophrenia	Did not specify	Full time employed	6.5	3	Y	Hypersomnia
5	EIP	M; 30	Black	Schizophrenia	Clozapine	Full time employed	9	5	Y	Hypersomnia
6	EIP	F; 45	White	FEP	Venlafaxine 150mg	Part time employed	8	4	N	Excessive Sleepiness
7	EIP	M; 35	White	Schizophrenia	Did not specify	Part time employed	7.5	5	Y	Hypersomnia
8	Adult Locality	F; 40	White	Schizotypal disorder	Risperidone 4 mg Fluoxetine 60 mg	Unemployed	10	N/A	Y	Extended Sleep Duration
9	Social Media	F; 31	White	Psychotic disorder NOS	Aripiprazole 15mg Sertraline 100mg	Full time employed	9.5	5	Y	Hypersomnia
10	Social Media	F; 46	White	Schizoaffective disorder	Aripiprazole 20mg Venlafaxine 225mg	Unemployed	6.5	3	Y	Hypersomnia

Demographic Characteristics

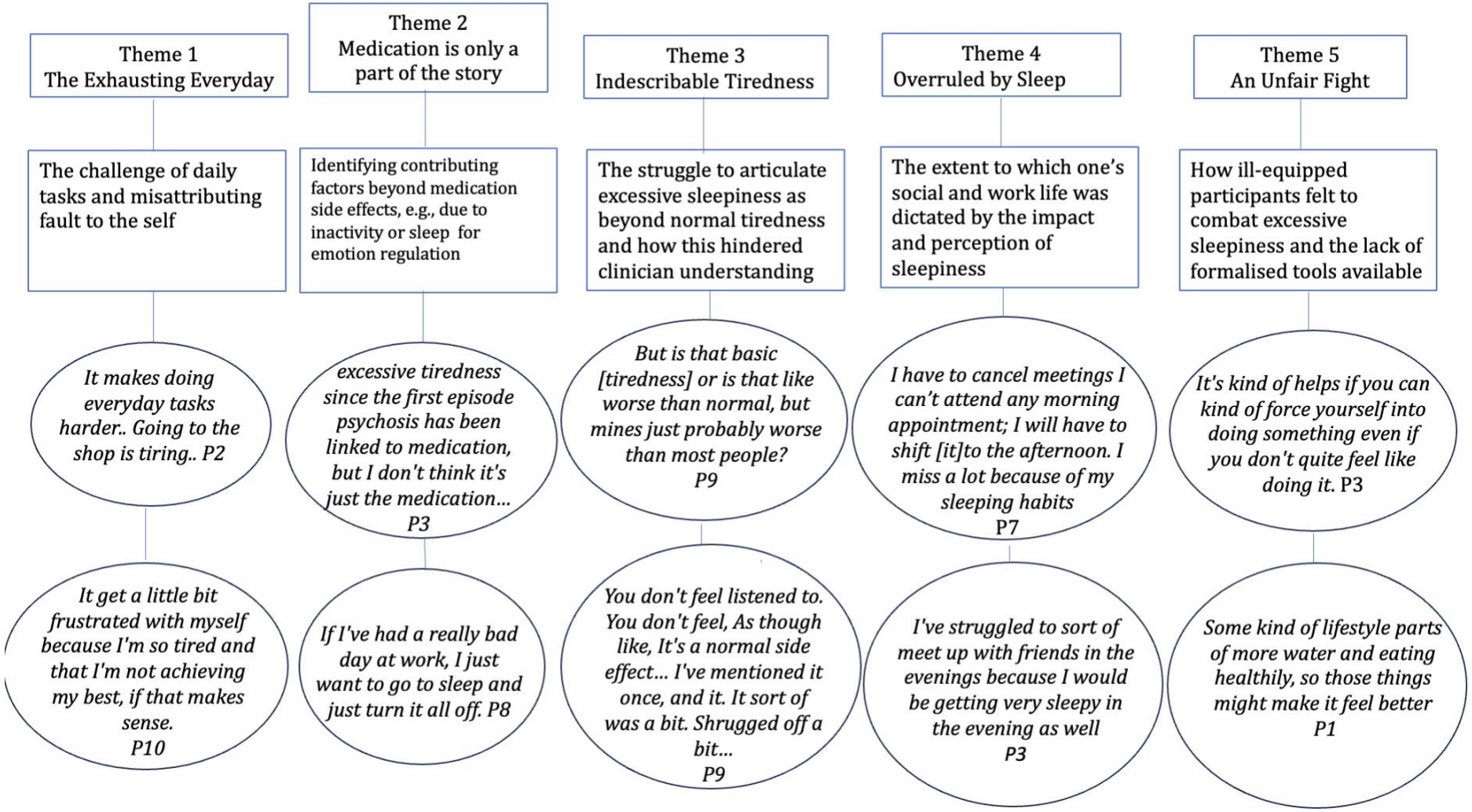
All participants demographic information was self-reported **All participants reported yes to taking antipsychotic medication, participants were not obliged to state the medication type and dosage * EIP = Early Intervention in Psychosis Team*

Data Analysis

From the results, five themes were developed as follows: (1) *The Exhausting Everyday*, (2) *Medication is only a part of the story,* (3) *Indescribable Tiredness, (4) Overruled by Sleep* and (5) *An Unfair Fight.* A diagram of the themes and their descriptions, alongside key quotes are presented in Table 2.

Table 2.

Presentation of thematic analysis themes, corresponding descriptions, and quotes



Theme 1: The Exhausting Everyday

The first theme described the impact that excessive sleepiness had on participants ability to perform day to day tasks and how this could be internalised and misattributed to the self. Participants described how challenging day to day living could be:

> *… it makes doing everyday tasks harder. It also means that it just doing simple task like going to the shop is just tiring. And it meant that it took me longer to do certain tasks… where is one task that should take 20 minutes, it takes me an hour.* P10

The challenge of everyday tasks was a point laboured by many of the participants. Participants emphasised how tasks such as shopping or housekeeping would feel momentous in the face of sleepiness, as the exhaustion and time consumption would result in a feeling of lost time during the day. Unhelpful comparison with what other people were capable of in the same time frame was also evident:

> *I feel like I've got I've got like missing potential that other people have so don't feel like I'm good enough. P8*

> *I had to deal with the disappointment of missing hours in the day* P9

The impact of not being able to achieve the day-to-day tasks considered straightforward by others resulted in a detrimental impact on participants emotional wellbeing. Frustration and self-criticism were evident, and some participants spoke emphatically about feeling they were not reaching their full potential and feelings of sadness and worry around this:

> *I would say that it makes me feel down because you [are] constantly taking longer to do stuff which makes you feel down because, where some people would do three or four tasks and you compare to your one if that makes sense.* P9

I want to do things but that's kind of what I'm worried about… I have all these things I want to achieve and I'm worried in a sense because I find them difficult due to the excessive sleepiness. P2

I feel very worried. Because of the things that I am supposed to do, I don't feel able to do them P5.

Strikingly, participants would attribute the responsibility of not being able to do enough during the day to their personal abilities, as opposed to the mental health challenges they were experiencing. This had a consequent impact on participants self-esteem in feeling comparatively less capable than other people. For some, this could also lead to feelings of embarrassment. Overall, the private daily battle of not being able to do enough appeared to contribute to a societal comparison where participants would unfairly view themselves as less capable than others and internalise feelings of shame as a result:

Yeah, I was quite hard on myself, so I used to think well, other people are at work now like they're I'm not achieving enough, you know, stuff. It was impacted in my on my self-esteem a bit. P8

Theme 2: Medication is only part of the story.

This theme outlined the uncertainty that people felt in relation to the cause of the excessive daytime sleepiness or hypersomnia that they experienced. Medication was discussed by participants as a contributing factor to their excessive sleepiness, alongside other factors, such as utilising sleep to block out from emotions and inactivity resulting in increasing feelings of sleepiness.

Participants varied in the emphasis that they placed on medication being the cause of excessive sleepiness. When asked on the cause of their sleepiness, three participants responded directly that they believed it to be due to their medication side effects. Six of the ten participants mentioned medication alongside other factors. One participant did not mention medication in the cause of their sleepiness:

I think that being on the Olanzapine has made me excessively sleepy as well… but I think that there's an element to the excessive sleepiness that has nothing to do with the Olanzapine… P3.

I do think that there's other factors that aren't medication related that I've made me more tired, especially the last six months P6

Directly attributing the cause of the sleepiness to medication was also outlined by some participants, who were careful to point out that using medication was the reason for the sleepiness and not something they were doing themselves:

…As a result of clozapine… I really would say that it's mainly the clozapine it's not like I'm kind of losing sleep in the evening or something, going out clubbing... No, it really is the clozapine P2

However, in addition to medication, emotional wellbeing was frequently referenced as another relevant factor. The participants described significant levels of anxiety and depression alongside psychotic symptoms, with their own interaction with sleepiness. Participants described how they would often manage feelings of worry or sadness through inviting sleep in and utilising it was a way to escape their feelings or re-set. This was felt to be effective, as when asleep one was able to shut off from their emotions:

if there's something I'm dreading, then I feel sleepy and I kind of like I just wanna nap until the world feels like a better place… for example, I was worried about a phone call with a friend, which was happening last week and the day before I was due to have that phone call I was feeling very sleepy and I went and had a nap because I was just like, ohh, I can't face it P3

A cyclical relationship was described by participants where emotional states could also cause feelings of sleepiness:

Because I do a high impact job and the stress of just like doing the job having what you suffer with and stuff like that It makes me more sleepy. P9

Beyond the emotional aspect, participants described inactivity as being another contributing factor to excessive sleepiness. A cyclical relationship was described whereby sleepiness would impact motivation and result in doing less which in turn would result in stronger feelings of sleepiness. This cycle could also include sleepiness preventing the ability to engage in a full-time career which in turn would result in doing less and feeling sleepier as a result:

I think I often don't do enough during the day and then I'm not doing enough and then I don't sleep very well, and it just sort of snowballs from there. Feeling sleepy during the day and then not being active enough as a result. Um, yeah, I think that can be a sort of negative spiral I can be in. P3

I think because I am unemployed, I don't have something driving me to fight through the tiredness. P8

Theme 3: Indescribable tiredness

This theme captures the pervasive challenge that participants had in articulating their reality of excessive sleepiness to others and the consequent impact on feeling misunderstood by healthcare professionals. This challenge was also evident in the interviews – in many cases participants would pause and emphasise tonally how they were feeling, with a felt sense of desperation to be heard. Participants often emphasised how the tiredness they felt was beyond that of 'normal' tiredness. For the participants the sleepiness experienced was beyond comprehension to those who had not had to endure it:

I think everybody has days where they feel tired but that isn't what excessive sleepiness is it's worse than that and it's more pervasive. It was not one night of feeling tired, it's a week or month's worth of feeling tired, where you're just kind of feeling on adrenaline. And you

just, maybe I didn't say this quite as well as I could … Like it's almost like you're just existing rather than being the person you could be. P10

In the endeavour to translate the experience of excessive sleepiness, some participants drew on the physiological aspects. Experiences of brain fog and trouble concentrating were discussed, in addition to a feeling of 'heaviness.' The 'heaviness' described related to a feeling of being weighed down by sleep, where one's whole being feels compressed beneath the burden of tiredness:

I'll feel a lot more heavier to carry myself you know P4.

I just feel tired and get this general feeling of brain fog because I'm so tired and lack of focus on what I'm doing. P2

To facilitate an understanding of the daily experience of excessive sleepiness, participants attempted to relate to common sleep experiences that are more widely recognised. In the example, the participant uses the allegorical explanation of being woken up in the night and the feeling of disorientation as a result. The sense of wanting to really translate the experience to everyday experiences was felt here, in an attempt to make the unrelatable, relatable:

*It feels like if there's some reason you're woken up in the middle of the night. You would feel like there's that sort of sleep inertia where it's hard to wake up. It feels like that. That's what it feels like is I just really wanna go back to sleep, but obviously I've been awake for some time, so it I really shouldn't be having that feeling..*P2

Similarly, to the use of common sleep experiences, participants also tried to explain excessive sleepiness through the use of similes:

…. it's almost like a form of, you know, feeling bad and form of torture. P2

it's like a big heavy blanket on my back P8.

Their difficulty in conveying the experience also carried through to medical care, with some participants reporting feeling dismissed or misunderstood in their discussions with healthcare professionals:

You don't feel listened to. You don't feel, As though like, It's a normal side effect... I've mentioned it once, and it. It sort of was a bit. Shrugged off a bit. And in terms of like, just feeling generically, like I said, I said to my psychiatrist that I was tired, and basically it was like, yeah, it's just it's getting darker nights and cold weather, and it was a bit like ohh, ok, don't really wanna talk anymore about that. P9

In contrast, some participants did report health care professionals taking action on their sleepiness, although in all cases the solutions provided were medication-related.

When I went on the olanzapine, and then kind of switched over to the aripiprazole. So, I was with a really good psychiatrist who's really helpful, was very understanding of what I was going through was not dismissive. P10

No participants reported discussion with healthcare professionals on sleepiness outside of a medication context.

Theme 4: Overruled by Sleep

The fourth theme captured how participants lives could be dictated by sleep, in planning time around sleeping, cancelling plans, and missing out on work opportunities. The greatest impact was felt in participant's social lives where they described feelings of detachment and self-blame for prioritising rest:

Basically, I kind of have very few relationships, so I think that's kind of me being more insular because of my schizophrenia and my excessive sleepiness. I don't have any friends due to the excess sleepiness, which prevented me forming social contact P2.

Participants described the extent they had to schedule their time around either the hours of sleep they needed or the levels of tiredness they expected themselves to feel.

For some this meant scheduling all their important appointments to the afternoons, for other's adjustments were more ad-hoc due to the unpredictability of how sleepy they might feel:

…and in the times when I'm really struggling with morning sleepiness and struggling to get up at a sensible time, I arrange everything for the afternoon basically P3.

As a result of the sleep needs of the participants, some reported missing out on job opportunities, promotions or having a job at all. Participants described a sense of loss at not being able to fill their potential or take opportunities. A cyclical nature to work and sleepiness was discussed in feeling fearful of how one would manage in a job due to the added stress of needing to adjust their work to their sleep needs or having to discuss this with a manager. For one participant, the amount of sleep needed had resulted in the termination of a previous contract and present unemployment:

Obviously, I don't work at the moment. and that's a big concern of mine, because I want to try and get back into work. But I'm very conscious of how that what that will look like if I'm having a bad day. And I previously lost a job. Because, you know, the sleepiness and the illness was so bad that I couldn't work at all. And that's a real worry for me as well is re-joining the workforce and what that looks like. P10

Outside of the realm of employment and education, the dominance of needing to sleep had a significant impact on participants ability to engage socially. Participants reported how extreme tiredness, especially in the evenings, would result in missing out on social plans due to a need to rest:

…and I think there have also been times when I've struggled to sort of meet up with friends in the evenings because I would be getting very sleepy in the evening as well.. and so, yeah, so there have been times when it's really interfered with my social life. P3

Similarly, to Theme 1 where participants self-attributed blame for not performing day to day tasks, participant accounts reflected self-criticism on missing social opportunities due to sleepiness. A fear of what others might think of sleepiness being a reason for

absence was highlighted. Once more, in the challenge of explaining sleepiness outside of normal tiredness, there was a worry that one would be misunderstood and felt to be giving a poor excuse for social disengagement. As a result, a cycle of avoidance could occur, where social interactions would be avoided due to fear of judgement:

So, I don't know if they think that I'm being lazy… or that I should just try and push through it. More that, that that isn't a sufficient reason not to P10.

Rather than actually having time to spend with my friends, you know I don't wanna be one of these people that just goes out with their friends and complains about being tired or being exhausted. I just stay at home and have a cup of tea. P6

Finally, participants lamented how sleepiness had resulted in a withdrawal of activities previously enjoyed. Accounting for this, participants cited the general experience of sleepiness as impactful on the motivation to do recreational activities:

And then also I've been struggling to go to as many activities as I used to do… I don't do as much ballet or as many cool things as I used to… P1.

Theme 5: An Unfair Fight

The final theme concerns how participants felt outmatched by their sleepiness and had few tools to combat it. Where resources were drawn upon, participants referred to tactics that they had learnt themselves which mapped on to basic advice for sustaining wellbeing such as getting fresh air or drinking water:

When I'm first up and I push myself to walk the dogs. And I actually feel quite energised during a dog walk and afterwards. P6

… getting out actually helps. So, if I'm really, really, really tired, sometimes the act of physically pulling myself out house and having some fresh air can kind of give me a little bit of energy. P10

The language used by participants in describing ways they sought to remedy excessive sleepiness was illustrative of the challenge they felt. Many participants referred to 'fighting' the sleepiness through engaging in activities that were beneficial to their mental health such as getting fresh air, exercise or going for a walk. However, these endeavours were impeded by the physiological experience of excessive sleepiness. As described in Theme 3, the physiological experience of heaviness would result in participants feeling a lack of energy and motivation. A sense of needing to force oneself in to action was explained when descriptions of fighting the sleepiness were discussed:

…. I think it's actually countering the lack of focus, lack of motivation which comes from excessive tiredness…. It kind of helps if you can force yourself into doing something even if you don't quite feel like doing it. P3

Participants largely drew on self-help tactics when describing how they may combat the sleepiness. Avoiding napping was cited as helpful although objectively challenging given the afore mentioned physiological sleepiness and emotional heaviness. Participants also drew on self-help tactics that they had learnt such as using distraction techniques. A number of participants described drinking coffee or caffeinated drinks to combat the sleepiness, although with potential side-effects of increasing anxiety:

But I do fight it like I've said before, you know, I've got my distraction techniques which, you know, hopefully are helping me. And, you know, sometimes when reading newspaper, I make a special effort to kind of read every article in it, instead of, kind of letting my tiredness stop me from reading it altogether. P2

caffeine helps me not feel as tired. But the flip side of that is that it makes my anxiety worse, the more caffeine I have P10.

In two cases participants described having taken specific therapeutic techniques and used them to tackle their sleepiness. Psychoeducation was felt to be beneficial in normalising the experience of sleep inertia on waking:

[the psychologist] recommended some handouts on sleep hygiene… talked about sleep inertia, which is a really helpful context. So basically, when I get up in the morning and I'm feeling like ohh, I can't face it like I I'm clearly too sleepy to get up and like, no, this is just sleep inertia P3

One of the most effective tactics described by a participant was a simple task of goal setting within cognitive behavioural therapy (CBT). The process of having a therapeutic goal that was geared towards skills building whilst taking in to account the sleepiness, was described positively. The therapeutic accountability also was deemed to be helpful and the positive sense of achievement afterwards which helped to counter the afore mentioned feelings of damaged self-esteem at not being able to achieve enough:

[In] CBT [the therapist] did try say you should try and achieve things. For instance, I wanted to learn how to cook, and I made gains in that area, … the important thing is you set yourself these tasks every week and you then achieve them. You kind of do them even if you're really tired, or if you're motivation is really low and you feel you can't. It forces you to kind of get that focus back. And I would say that is certainly something that's helping with regards to excessive sleepiness P2

Although the relationship between sleep and hearing voices was mentioned infrequently, one participant highlighted an important way by which sleepiness could interfere with therapeutic progress. In the example, the participant describes how sleepiness made using therapeutic techniques such as CBT based evidence evaluation more challenging:

Because the sleepier I am, the harder it is for me to say to myself or to the voices, what evidence is there to support that? I mean, I sleep, because I'm so exhausted. It's just it dreamless sleep. And so, it's just everything else goes away P10

Discussion

This study was the first examination of the specific experience of excessive sleepiness in people with psychotic disorders. The findings to the study are threefold.

Firstly, excessive sleepiness is a broad phenomenon that affects a range of domains in people's lives. Secondly, cycles of behaviour, such as avoidance and inactivity, contribute to the presence of excessive sleepiness, supporting that medication may not be the only cause. Thirdly, excessive sleepiness is challenging to articulate at an individual level which limits ability for it to be assessed or addressed in clinical services and consequently, patients are left to manage these chronic difficulties on their own. The discussion will address each of these points in turn.

Excessive sleepiness and oversleeping are impactful on daily living. As a result of excessive sleepiness, people can feel inadequate in what they are able to achieve during the day which leads to feelings of anxiety in not doing enough, frustration at the self and a sadness at potential that has been lost. These factors are important as they have indications for contributing to depression, anxiety, and lowered quality of life. The findings highlight the extent that an individual might be experiencing secondary symptoms within their psychotic disorder, such as poor motivation and low mood. As demonstrated, the impact of sleepiness had indications for the ability to participate in the workplace, and to socialise effectively. Addressing the functional impacts of sleepiness more accurately could help improve longer term quality of life. Incorporating these considerations would be in-keeping with the recovery model approach to psychosis which emphasises the role of holistically examining living with a psychotic illness beyond the reduction of symptomology alone (Leonhardt, 2020).

Cycles of avoidance and inactivity were highlighted as maintaining excessive sleepiness, illustrating causes of the phenomenon beyond medication alone. The results support previous research which highlighted that excessive sleepiness is not solely explained through the sedating side effects of antipsychotic medication (Reeve et al., 2021). What has not been previously known is what is contributing to excessive sleepiness at an individual level. This study has evidenced that people may be unintentionally contributing to excessive sleepiness by utilising sleep as a coping strategy for difficult emotions or becoming stuck in a cycle of inactivity, caused by the impacts of sleepiness. Existing treatments e.g., those within cognitive behavioural therapy such as emotional regulation approaches and behavioural activation, could target these maintenance cycles. As a finding from this study emphasises, where CBT approaches enabled one participant to feel increases in personal productivity and consequent improvements in their sleepiness. Further research will be needed to

examine if doing so ameliorates the experience of excessive sleepiness generally, alongside current evidence of improvements to symptoms of depression and anxiety.

Assessment and measurement of sedation and excessive sleepiness is a key challenge. Previous studies have highlighted the lack of uniformity in measuring the sedating side effects of antipsychotic medications (Longden., 2016). This study has highlighted how an individual challenge of articulating the experience may have also contributed to its current clinical conceptualisation. Where measures are used, they are often directed towards symptomatology without an exploration of functional impacts or individual experiences. The results indicate that a more comprehensive examination of the individual impacts of excessive sleepiness is needed. Further research is needed to develop tools of measurement which can capture the experience and effects of excessive sleepiness at an individual level.

Clinical Implications and Recommendations

The development of a specific validated tool is recommended, which can measure/explore excessive sleepiness in line with its functional impacts and relationship with emotional regulation. An exploration of excessive sleepiness should be carried out at assessment and at key points within treatment to map how an individual may be relating to their sleepiness. The permission to speak about sleepiness has the potential to validate and empower individuals to explore if their sleepiness is contributed to by factors outside of their medication alone. This has the potential to change individual experiences of misattributing the experience of excessive sleepiness to the self and reducing stigma around its presence as a result.

Following a sufficient measurement of excessive sleepiness, potential patterns related to sleepiness should be considered as targets within therapy. Existing treatments such as behavioural activation work and goal setting should be considered. Individual daily functioning should be assessed in relation to their sleepiness to highlight where unemployment or lack of social support may be contributing to or impacted by sleepiness.

Strengths, Limitations, and Areas for Future Research

This study had strengths in being carried out within a clinical population who provided immense insight into the experience of excessive sleepiness. The recruitment strategy to the project was successful in recruiting from clinical teams and through social media which provides scope to the included sample. The study is strengthened by the in-depth quotations provided by participants who responded positively to the topic guide questions, which demonstrates a success to the interview process. The findings have clear clinical implications and are a notable contribution to the research field.

The sample in the study is representative of a proportion of people experiencing excessive sleepiness in the context of a psychotic disorder. The sample is not representative of the general population of people who experience psychotic disorders, which is noted to be more predominately male and with a higher ethnic diversity than this study. Future research should aim to explore the experiences of a wider range of people with psychotic disorders to continue to enhance the understanding of excessive sleepiness.

This study did not screen participants on the type of antipsychotic medication taken, specific psychotic disorder or duration of treatment. Medication was self-reported by participants, although most of the sample was recruited from clinical settings. The range of medication profiles in this study could account for variations in the experience of excessive sleepiness in line with evidence that the relationship with the sedating side effects of antipsychotic medication can change over the course of treatment (Miller, 2004). This study was deliberately broad in the inclusion of all types of medication to understand the scope of the experience of excessive sleepiness. Future studies could recruit participants based on medication type – for example, specifically clozapine - to understand these individual differences or record changes to the relationship to antipsychotic medication over time, for example through a mixed methods longitudinal study.

This study used self-report to screen for sleepiness and did not use a validated measure for screening purposes. In hypersomnia and depression studies, self-report of excessive sleepiness has been shown to be higher than when measured on a validated scale. Including a validated measure in the screening process would add an objective aspect and account for the potential over-estimation of sleepiness at a subjective level.

The study focused upon the experience of people experiencing excessive sleepiness in the context of a psychotic disorder and was therefore limited to this

perspective. Future research could use qualitative methods to explore clinician perspectives on excessive sleepiness and hypersomnia. Additionally, understanding carer perspective could also improve our understanding of the role and perspectives of the network around people experiencing excessive sleepiness.

Conclusion

This was the first specific exploration of the experience of excessive sleepiness in people with psychotic disorders, despite sedation being a known side-effect of antipsychotic medication since inception. The findings highlighted that experiencing excessive sleepiness is impactful on daily functioning, emotional wellbeing, and social connections. The results demonstrated that sleepiness is contributed to through inactivity and as an emotion regulation strategy, alongside the physiological side effects of antipsychotic medication. The interrelated nature of this relationship requires adequate in-depth assessment that can help characterise the contributors and impacts of excessive sleepiness at an individual level. Improved assessment of excessive sleepiness would enable patients and clinicians to validate and address this important aspect of their wellbeing through utilising existing treatments or develop novel approaches to support patients with this chronic issue.

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Chapter 5.

Discussion and Critical Evaluation

Word count (excluding references): 3781.

This chapter aims to further discuss the findings of the systematic review and empirical paper, providing a critical evaluation of their methodological strengths and weaknesses and suggesting areas for future research.

Overview of findings

Systematic Review

The systematic review aimed to synthesise studies exploring the psychological consequences of the sedating side effects of antipsychotic medication. Nine studies with a range of methodological approaches met the eligibility criteria and were included in the review. A quality appraisal and narrative synthesis was carried out.

The findings highlighted that sedation is a commonly experienced side effect that can be impactful on individual wellbeing and is need of more thorough assessment. Sedation was reported frequently by patients as one of the most common side effects of antipsychotic medication (Tandon et al., 2020; Moncrieff et al., 2009; Gray and Deane, 2016; Morrison et al., 2015; Llorca er al., 2017). By contrast, sedation was assumed to be less commonly experienced or experienced as non-bothersome when clinicians reported on side effect burden (llorca et al., 2017). Sedation was associated with a wide range of impacts on individual ability to function in everyday tasks, socialise effectively and was associated with negative emotions (Gray and Deane, 2016; Hughes and Matheson, 2016; Moncrieff et al, 2009; Morant et al., 2017; Tandon et al., 2020). The presence of sedation as a medication side effect was a predictor of lower quality of life (Tandon et al., 2020).

The results showed that sedation is not uniformly measured and is contributed to by factors outside of medication alone. Sedation was measured primarily through self-report or non-validated Likert scales (Fervaha et al., 2015; Tandon et al., 2020). Where sedation was assessed, the measures did not take in to account potential casual factors outside of medication alone, such as the use of sleep as an emotion regulation strategy or because of inactivity (Hughes and Matheson, 2016; Moncrieff et al., 2009). Sedation was viewed differently by patients and clinicians with the latter viewing it as

favourable to a lack of sleep or misattributed to negative symptoms of psychosis (Llorca et al., 2017; Morrison et al., 2015).

Empirical Project

The empirical paper explored the experience of excessive sleepiness in people with psychotic disorders. Data was collected through semi-structured interviews, which were then transcribed and analysed using a thematic analysis methodology (Braun and Clarke, 2006).

The findings highlighted that the experience of excessive sleepiness is impactful on individual functioning and wellbeing, contributed to by factors outside of medication alone and in need of comprehensive assessment to align clinicians and patients on its functionality and impact. Thematically, the experience of excessive sleepiness was summarised as being impactful on daily functioning, beyond normal tiredness and dominating of the ability to participate fully in everyday living. Adding to previous research, excessive sleepiness was found to be contributed to by factors outside of medication alone (Reeve et al., 2021). Participants identified other causal factors such as sleep as an emotion regulation strategy, a result of inactivity/unemployment or as a response to stress. The results highlighted that without a framework to jointly understand excessive sleepiness, individually it is misattributed to the self and clinically it can be misunderstood as 'normal sleepiness' or solely due to medication side effects. A final theme highlighted how those experiencing excessive sleepiness were ill-equipped to remedy the sleepiness due to the lack of understanding of potential contributing factors, which could be ameliorated through existing treatments.

Thesis Portfolio

A finding of the combination of the systematic review and the empirical paper is within the role that excessive sleepiness plays in sedating side effects. As highlighted in the systematic review, sedation is a broadly defined construct. The empirical project highlights how patients, in relating to excessive sleepiness, were also referencing medication side effects in the realm of sedation, it follows therefore that excessive sleepiness could be an important and potentially routine aspect of sedation. The papers

complement one another in the emphasis placed on how sedating side effects, including excessive sleepiness, impacts on daily functioning, the ability to socialise and engage in employment. Both papers touch on clinician's perspectives differing from patient experience and the need for future research into clinician's views.

Critical Appraisal

Systematic review

The systematic review had several strengths. The review protocol was registered on PROSPERO, an international database of prospectively registered systematic reviews, which promotes transparency, reduces potential for bias and avoids potential duplication of reviews (Stewart et al., 2012). To the researcher's knowledge, this was the first systematic review which looked specifically at the consequences of sedation on factors related to individual wellbeing. The review benefitted from a second reviewer within the paper screening process and quality appraisal which helped to reduce bias and increase the number of relevant studies included (Stoll et al., 2019).

The lack of a uniform definition within the topic of sedation underlined an inherent limitation in the accuracy of the systematic review. An accurate definition of a phenomena ensures that the construct being measured or evaluated is uniform across different contexts or descriptions. Whilst the medical physiological presentation of sedation is well understood, its subjective experience is a challenge to conceptualise. The lack of a robust approach to defining sedation was present in the studies within the review with defining structures ranging to include 'sedating side effects' of concentration and excessive sleepiness, to studies with a narrower focus of the physiological more medicalised understanding of being 'sedated.' The lack of routine measurement presented within the studies reflects this hinderance, where some studies used validated measures of constructs such as excessive sleepiness (and thus including this in their definition) whereas other studies used highly subjective unvalidated Likert scales of how sedated a person might feel, thus leaving the definition to an individual basis. The study held a broad scope in its review of sedation to be able to capture the range of definitions used and the lack of uniformity in its measurement, this decision however acknowledges an inherent lack of definitive accuracy over the construct of

'sedation' that was being reviewed. What this means is that as the studies included have different conceptualisations of sedation, the review will include understandings of sedation that are more subjective than within an objective framework.

Due to the limitations of the field being assessed the scope of the included studies was limited. The majority of the studies included in the review were qualitative studies with small sample sizes (ranging from 10-20 participants). Although the secondary data studies which also included qualitative responses had larger samples sizes, the results of the studies are biased towards those who likely already had negative appraisals of their antipsychotic medication, due to the use of the websites in providing a space to discuss challenges to medication. The included quantitative studies had a larger recruitment scope; however, these were general side-effect and motivation studies (where sedation was included) thus the sample was not directly recruiting from people who were experiencing challenges of sedation specifically. Tandon (2020) finding of 83.7% of 435 participants across multiple countries offers the most robust prevalence estimate, however, this was still self-report. The impact of the range of samples lies in the extent to which the prevalence of sedation can be interpreted. Sedation was reported most commonly in the qualitative studies which had small sample sizes. Sedation was a less commonly reported side effect in the quantitative studies that had larger sample sizes and a broader focus. The lower prevalence is reflected in the literature where general users of antipsychotic medication report sedation x% of the time. Whilst this limitation does not discount the experience within the qualitative sample, generalisation of the prevalence findings needs to be considered cautiously.

Empirical Project

An overall critique of the qualitative study is presented, considering its strengths and limitations, guided by the qualitative research evaluation CASP tool. The methodology, sample and analysis are discussed.

A strength of the study was the broad scope of the research question and qualitative methodology employed. The limiting prior research into the experience of excessive sleepiness in people with psychotic disorders called for a study which developed rich initial data into the topic. The use of interviews as a data collection

approach was considered successful in achieving in depth responses from participants. As demonstrated in prior research, focus groups, although able to include a larger sample, are poorly attended in people with psychotic disorders (Llorca et al., 2017). Although sleepiness was a topic that was not overtly sensitive to speak about, the discussions did include the impacts on personal wellbeing and beliefs about the self that could have been harder to achieve in a focus group setting. The researchers prior experience working within an early intervention psychosis team is considered a strength of the research, due to their approach and prior understanding of the sensitivity of the topic.

A second key strength was the inclusion of a Patient and Public Involvement panel (PPI) in the formative stages of the research. The PPI panel consisted of people with lived experience of psychosis who reviewed the topic guide, information sheets and study design. Of specific relevance to the qualitative study, the panel's feedback on the topic guide was invaluable in altering the language to layman terms, inputting prompting questions and ensuring the general readability of the document. Emailing this to participants in advance is considered a strength of the methodological approach in reducing potential anxiety around the interview topics and addressing an aspect of the power dynamics that exist in conducting qualitative research. Through consulting the PPI panel and sharing the document, the researcher invited the participant to feel considered an active role in the study process from the outset.

The recruitment process of the study through the quantitative arm and survey aided the richness of the overall data collected, however a critique of the screening process is necessary. The study recruited via the survey which resulted in each participant included in the interviews also having completed questionnaires on their sleeping patterns, mood and psychotic symptoms, as included in Appendix I. Although the screening process reflected the self-report approach used in previous research, the screening could have been made more accurate by also evaluating scores on the Epworth Sleepiness Scale. As a validated measure of sleepiness, it would have been appropriate to include this as a part of the screening process to increase the validity of the recruitment process beyond self-report alone.

An additional critique of the study was the included sample and the small part of the population of people with psychotic disorders that it represented. The boroughs of Cambridgeshire and Peterborough are noted to be a small part of the UK, with

Cambridgeshire being of a particular level of affluence. The sample generated was largely white British and female, thus not representative of a wider population of people with psychotic disorders, particularly men of black ethnicity, who are overrepresented in people with psychosis. The use of online recruitment via Facebook forums enabled a wider reach of the recruitment, however, this was introduced later in the recruitment process and biased towards those with access to the internet.

Coherence in the study was achieved through the appropriate use of qualitative analytic approach to the ontological stance of the study, and the research question. The study employed a critical realist approach which acknowledges that while an objective reality exists, it can only be experienced through specific perceptions, structures, and contexts (Bhaskar, 2008). The use of reflective thematic analysis aligned with the ontological approach of the study, in considering that the researcher is a part of the world that they are attempting to study (Pilgrim, 2004; Braun and Clarke textbook). As discussed, the researcher acknowledged their role as a clinical researcher with prior experience in the field and the potential for bias in their subjective interpretation.

Theoretical and Clinical Implications

Contribution to the research field

The findings of the empirical project contribute to our understanding of excessive sleepiness in people with psychotic disorders. Firstly, the findings add to existing research which has highlighted that side effects of antipsychotic medication are not the sole contributor to the presence of excessive sleepiness in people with psychotic disorders (Reeve et al., 2021). The study adds evidence to the findings of Reeve (2021) in the participants responses to the cause of excessive sleepiness. Although mentioning antipsychotic medication and the role that it has in the physiological experience of sleepiness, the participants highlighted additional contributors to the presence of the phenomena. The results indicate that individual factors such as using sleep as an emotional regulation strategy, feelings of sleepiness in response to stress and inactivity/unemployment contribute to excessive sleepiness. The results add to our knowledge of the cyclical nature of these factors in how contributors, such as inactivity,

can become maintaining factors that are self-influential and detrimental to individual wellbeing.

The findings contribute to our understanding of how sleep can be utilised as an emotion regulation tool in psychosis, as highlighted in previous research (Faulkner and Bee, 2017). Both the systematic review and the empirical project highlighted how sleep can be an emotional regulation tool in the daily reality of living with a severe mental illness. Inviting sleep in to cope with challenging emotions or hearing voices can result in a maintenance cycle of sleep being relied upon to escape, and therefore not challenge or understand difficult emotions. Excessive sleepiness is noted to also be highly prevalent in people with major depression (Hein et al., 2019). It is possible that similar mechanisms are operating in people with psychosis, where sleep is utilised and preferable to being awake and coping with emotional states that can feel overwhelming. The role of this strategy highlights the importance of thorough assessment of sleepiness to comprehensively evaluate an individual's relationship to their sleep to provide alternative strategies to oversleeping. As indicated in the results, the need to sleep can be highly impactful to daily functioning and could be ameliorated if a greater understanding of individual use of sleep was known.

The findings of the empirical project and the systematic review contribute to the existing literature on how antipsychotic medication side effects can impact an individual's social interactions. In a recent systematic review, it was suggested that taking psychiatric drugs (including antipsychotics) could impair emotion recognition in people with severe mental illness such as bipolar disorder and schizophrenia (Haime et al., 2019; Daros et al., 2015). The systematic review and empirical project add to the impact of antipsychotic medication side effects and socialising in the challenges that participants faced in their social lives. The results showed that feeling excessive sleepy could result in an avoidance of social situations due to the need to sleep or the fear of judgement in complaining about their sleep. An impact on concentration and following conversations was also reported which furthered a feeling of detachment in social situations. This is an important finding as social isolation is a risk factor within psychosis, understanding the role of sleep, in relation to social withdrawal, is an important factor for future consideration.

Finally, the findings contribute to the explanation of the distance between clinician and patient understanding of excessive sleepiness. The empirical project

results demonstrate a potential root cause, emerging from a lack of a language to express the extent of sleepiness, beyond that of normal tiredness. The struggle to translate the experience could have contributed to clinicians misunderstanding sleepiness as 'normal tiredness,' preferable to insomnia or as a negative psychotic symptom. This finding adds to previous literature that has highlighted the differing levels of importance placed on sleepiness by clinicians and patients (Llorca et al., 2017).

Contribution to the defining of sedation

Within the systematic review a range of descriptors were included in reference to sedation. The most common were 'excessive sleepiness' and 'extended sleep duration,' (referenced in seven of the ten studies) in addition to 'drowsiness,' 'tiredness,' 'lethargy,' and 'somnolence.' In the empirical paper the participants most closely associated the feeling of being 'sedated' with that of being powerless to an overwhelming feeling of needing to sleep, being unable to wake up once asleep and having to actively combat the urge to sleep. The findings of both studies highlight a range of factors that are associated with sedation. Future studies may look to utilise the terms identified in these studies within a larger and more diverse sample to further investigate defining sedation.

Clinical Implications

The findings of the study indicate that a more comprehensive assessment process of excessive sleepiness is needed. The development of an assessment tool which considered the range of contributing factors to sleepiness would aid more in-depth assessment. The use of the assessment in an individual's formulation could create a joint understanding of how a person relates to their sleepiness and the areas which it impacts. The use of the assessment and formulation could highlight areas for intervention which could be adapted from existing treatments such as behavioural activation or cognitive restructuring in cognitive behavioural therapy. This re-evaluation of individual sleepiness could help in reducing stigma and improving aspects of personal wellbeing that can be impacted by sleepiness.

Future research

The findings of the systematic review indicated a line of enquiry relating to clinician perspectives of the sedating side effects of antipsychotic medication. Additionally, the review highlighted a lack of uniformity in the measurement of sedation which warrants further exploration. Building on the findings of the empirical paper, more research is needed in understanding excessive sleepiness in more diverse populations and how the relationship to sleepiness may alter over time. The findings of this study were drawn from a sample that was largely female and from white British ethnicity. A study which aimed to understand the experience of excessive sleepiness in more diverse populations would increase the understanding of the phenomena. Future studies could use longitudinal mixed methods designs to assess the relationship of an individual to their sleepiness over time to further understand how individual perceptions may change over the course of treatment. Qualitative studies exploring clinician and carer perspective are also indicated. Finally, a suggestion of further research into the views of clinicians in their understanding and appraisal of excessive sleepiness in psychotic disorders, through a mixed methods or qualitative approach.

Reflective Account on the Research Process

Ontology and Epistemology

The critical realist stance adopted in the ontological approach of the empirical paper assumes the biases and subjective experiences of the researcher as a part of the research process. I found reflecting on this position throughout the research process was illuminating and challenging. In the early stages of the research, I felt myself highly aware of the sensitivity of the topic being discussed and the extent to which I could safely ask questions of participants in a way that was containing and did not branch too far into the clinical realm. I acknowledge the challenge I felt in being a position speaking about clinically relevant difficulties and not being in the role of a clinician who was able to help individual suffering. As the results demonstrate, the participants in the study suffered immensely in their daily living because of their sleepiness and were without formal support. It felt challenging to hear potential avenues for treatment which would

be potentially left un-explored due to the current understanding of sleepiness. I perhaps felt in these moments a great empathy with the participant and a transference of their frustration at current service provisions.

I was acutely aware throughout conducting the interviews of how the participants may perceive my dual role as a clinical researcher and a part of the NHS system. I felt aware that I had previously worked in one of the teams that participants were recruited from and thus had my own predictions of how they might have found care within that service. In line with the epistemology, whilst the role of the researcher's inherent biases is noted as unavoidable, however it would have been unacceptable to the research process to influence that participant's thoughts on any aspect of their treatment or the NHS. I found the use of the reflective diary helpful to note the feelings that negative views of care bought up for me and remain neutral in the interview process to allow these important views to be recorded.

Supervision and consultation with colleagues in the qualitative forum provided a reflective space to discuss the transference I felt within the interviews. Through sharing within these spaces, I was aided through the normalisation of hearing other's experiences and made aware of how I might be switching into a clinical stance through empathising within the interviews. Having an awareness of these processes in-vivo was invaluable to the interview process and enabled a critical reflection of my position as the interview process was ongoing.

Research Process

The research process held several challenges. Recruitment to the study was a steady and intensive process which needed continuous monitoring and re-evaluation to reach an appropriate sample. The study design had two pathways for recruitment, one via the survey and another that was for clinicians to approach potential participants directly and verbally consent them to the study. It was anticipated that the latter pathway would be necessary due to the potential participant fatigue of completing the survey and then being asked to participate in further research. It was a surprise that the latter research pathway was not needed and that all the participants were recruited directly from the survey. It was anticipated that asking people with a severe mental illness about their sleepiness could have been an inherently challenging group to recruit

from, however, the number of participants recruited to the interviews countered this assumption. It was perhaps a reflection of the lack of previous acknowledgement of the challenges of sleepiness which invigorated the participants to want to speak in more depth - certainly the rich data obtained from the interview's highlights sleepiness as a topic where individuals had a desire to be heard.

The analytic process was a lengthy and illuminating task. It was challenging in the analysis to move away from summarising the data and mapping the themes on to the questions, to the reflexive process of the themes encapsulating experiences across the participants. Research supervision was invaluable in aiding this process in gaining a different perspective on the data collected, one which was able to take in the 'bigger picture' of the data. I found an interesting experience in creating the themes of struggling at points the same challenge to describing sleepiness as the participants were expressing. Given the extent of the impact that sleepiness was having on their daily living, I felt a responsibility to ensure that their voices and challenges were translated to the final themes. Having gained consent from the participants, I am planning to share the findings of this research with them, so they are able to see the highly valuable outcome of their generous time and contributions.

Thesis Portfolio Conclusion

In conclusion, the experience of aspects of sedation such as excessive sleepiness are common and impactful for people with psychotic disorders. The domain of daily functioning is most highlight impacted, alongside detrimental impacts on the ability to socialise effectively and establish/maintain employment. Excessive sleepiness is contributed to through using sleep as an emotion regulation tool and because of inactivity, in addition to antipsychotic medication side effects. Further research is needed to investigate if existing treatments can improve the impacts of excessive sleepiness, in addition to research exploring the assessment and measurement of sleepiness and sedation to fully account for its impacts and refine its clinical conceptualisation.

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Appendices

Appendix A
PLOS ONE Submission Guidelines

PLOS ONE

Submission Guidelines | PLOS ONE

Style and Format

File format Manuscript files can be in the following formats: DOC, DOCX, or RTF. Microsoft Word documents should not be locked or protected. LaTeX manuscripts must be submitted as PDFs. Read the LaTeX guidelines.
Length Manuscripts can be any length. There are no restrictions on word count, number of figures, or amount of supporting information. We encourage you to present and discuss your findings concisely.
Font Use a standard font size and any standard font, except for the font named “Symbol”. To add symbols to the manuscript, use the Insert → Symbol function in your word processor or paste in the appropriate Unicode character.
Headings Limit manuscript sections and sub-sections to 3 heading levels. Make sure heading levels are clearly indicated in the manuscript text.
Layout and Manuscript text should be double-spaced. **spacing** Do not format text in multiple columns.
Page and line Include page numbers and line numbers in the manuscript file. Use continuous line numbers (do not restart the **numbers** numbering on each page).

Footnotes Footnotes are not permitted. If your manuscript contains footnotes, move the information into the main text or the reference list, depending on the content.
Language Manuscripts must be submitted in English. You may submit translations of the manuscript or abstract as supporting information. Read the supporting information guidelines.
Abbreviations Define abbreviations upon first appearance in the text. Do not use non-standard abbreviations unless they appear at least three times in the text. Keep abbreviations to a minimum.
Reference PLOS uses “Vancouver” style, as outlined in the ICMJE sample references. **style** See reference formatting examples and additional instructions below.
Equations We recommend using MathType for display and inline equations, as it will provide the most reliable outcome. If this is not possible, Equation Editor or Microsoft's Insert→Equation function is acceptable. Avoid using MathType, Equation Editor, or the Insert→Equation function to insert single variables (e.g., “a2 + b2 = c2”), Greek or other symbols (e.g., β, Δ, or ′ [prime]), or mathematical operators (e.g., x, ≥, or ±) in running text. Wherever possible, insert single symbols as normal text with the correct Unicode (hex) values. Do not use MathType, Equation Editor, or the Insert→Equation function for only a portion of an equation. Rather, ensure that the entire equation is included. Equations should not contain a mix of different equation tools. Avoid “hybrid” inline or display equations, in which part is text and part is MathType, or part is MathType and part is Equation Editor.

Submission Guidelines | PLOS ONE

Manuscript Organization

Manuscripts should be organized as follows. Instructions for each element appear below the list.

Beginning section

Middle section

Ending section

Other elements

The following elements are required, in order:

- Title page: List title, authors, and affiliations as first page of the manuscript
- Abstract
- Introduction

The following elements can be renamed as needed and presented in any order:

- Materials and Methods
- Results
- Discussion
- Conclusions (optional)

The following elements are required, in order:

Acknowledgments
References
Supporting information captions (if applicable)

Figure captions are inserted immediately after the first paragraph in which the figure is cited. Figure files are uploaded separately.

Tables are inserted immediately after the first paragraph in which they are cited. T
Supporting information files are uploaded separately.

The introduction should:

- Provide background that puts the manuscript into context and allows readers outside the field to understand the purpose and significance of the study
- Define the problem addressed and why it is important
- Include a brief review of the key literature
- Note any relevant controversies or disagreements in the field
- Conclude with a brief statement of the overall aim of the work and a comment about whether that aim was achieved

Materials and Methods

The Materials and Methods section should provide enough detail to allow suitably skilled investigators to fully replicate your study. Specific information and/or protocols for new methods should be included in detail. If materials, methods, and protocols are well established, authors may cite articles where those protocols are described in detail, but the submission should include sufficient information to be understood independent of these references.

Supporting reproducibility with protocols

To enhance the reproducibility of your results, we recommend and encourage you to make your protocols public. There are several options:

Protocols associated with Research Articles

Protocol documents may be uploaded as Supporting Information or linked from the Methods section of the article. For laboratory protocols, we recommend protocols.io. Include the DOI link in the Methods section of your manuscript using the following format: http://dx.doi.org.uea.idm.oclc.org/10.17504/protocols.io. [PROTOCOL DOI]. This allows editors and reviewers to consult the detailed step-by-step protocol when evaluating your manuscript. You can choose to keep the protocol private on the protocols.io platform until your article is published—at which time it will be published automatically.

Protocols published in their own right

PLOS ONE offers two options for publishing stand-alone protocol articles: Lab Protocols that describe reusable methodologies and Study Protocols that describe detailed plans and proposals for research projects. Specific guidelines apply to the

submission of Lab Protocol and Study Protocol manuscripts. Read the detailed instructions for submitting Lab Protocols and Study Protocols.

Results, Discussion, Conclusions

These sections may all be separate, or may be combined to create a mixed Results/Discussion section (commonly labeled “Results and Discussion”) or a mixed Discussion/Conclusions section (commonly labeled “Discussion”). These sections may be further divided into subsections, each with a concise subheading, as appropriate. These sections have no word limit, but the language should be clear and concise.

Together, these sections should describe the results of the experiments, the interpretation of these results, and the conclusions that can be drawn.

Authors should explain how the results relate to the hypothesis presented as the basis of the study and provide a succinct explanation of the implications of the findings, particularly in relation to previous related studies and potential future directions for research.

PLOS ONE editorial decisions do not rely on perceived significance or impact, so authors should avoid overstating their conclusions. See the *PLOS ONE* Criteria for Publication for more information.

Acknowledgments

Those who contributed to the work but do not meet our authorship criteria should be listed in the Acknowledgments with a description of the contribution.

Authors are responsible for ensuring that anyone named in the Acknowledgments agrees to be named.

Any and all available works can be cited in the reference list. Acceptable sources include:

- Published or accepted manuscripts
- Manuscripts on preprint servers, providing the manuscript has a citable DOI or arXiv URL. Do not cite the following sources in the reference list:

- Unavailable and unpublished work, including manuscripts that have been submitted but not yet accepted (e.g., “unpublished work,” “data not shown”). Instead, include those data as supplementary material or deposit the data in a publicly available database.
- Personal communications (these should be supported by a letter from the relevant authors but not included in the reference list)
- Submitted research should not rely upon retracted research. You should avoid citing retracted articles unless you need to discuss retracted work to provide historical context for your submitted research. If it is necessary to discuss retracted work, state the article’s retracted status in your article’s text and reference list.

- Ensure that your reference list includes full and current bibliography details foevery cited work at the time of your article's submission (and publication, if accepted). If cited work is corrected, retracted, or marked with an expression of concern before your article is published, and if you feel it is appropriate to cite the work even in light of the post-publication notice, include in your manuscript citations and full references for both the affected article and the post-publication notice. Email the journal office if you have questions.
- References are listed at the end of the manuscript and numbered in the order that they appear in the text. In the text, cite the reference number in square brackets (e.g., "We used the techniques developed by our colleagues [19] to analyze the data"). PLOS uses the numbered citation (citation-sequence) method and first six authors, et al. Do not include citations in abstracts. Make sure the parts of the manuscript are in the correct order *before* ordering the citations. **Formatting references**

  PLOS uses the reference style outlined by the International Committee of Medical Journal Editors (ICMJE), also referred to as the "Vancouver" style. Example formats are listed below. Additional examples are in the ICMJE sample references.

  Journal name abbreviations should be those found in the National Center for Biotechnology Information (NCBI) databases.

Systematic Review

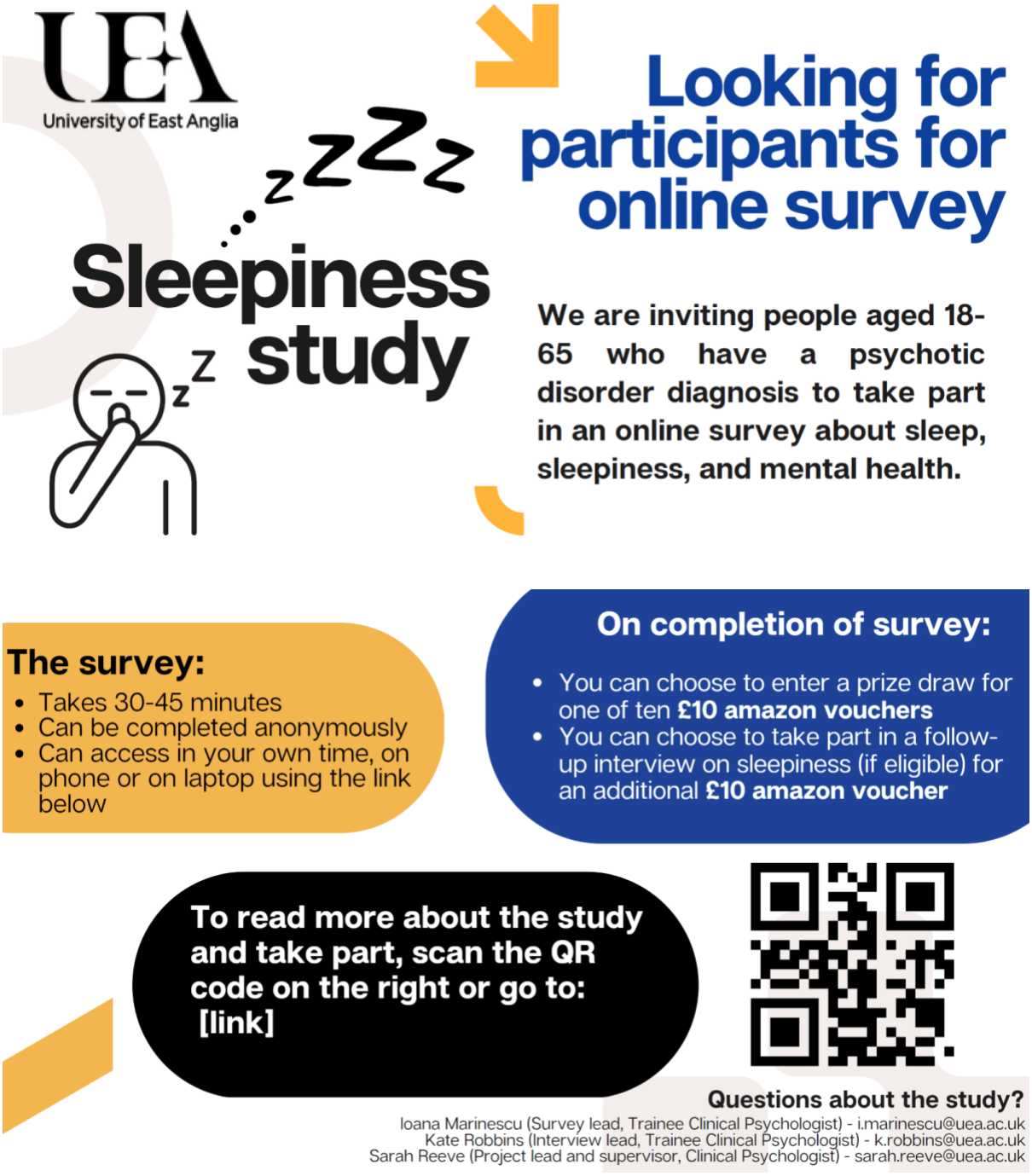
Appendix A
Mixed Methods Appraisal Tool (MMAT), Hong et al., 2018

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Empirical Project

Appendix A
Recruitment Card



Appendix B
Recruitment Poster

University of East Anglia

Sleepiness study

Looking for participants for online survey

We are inviting people aged 18-65 who have a psychotic disorder diagnosis to take part in an online survey about sleep, sleepiness, and mental health.

The survey:

- Takes 30-45 minutes
- Can be completed anonymously
- Can access in your own time, on phone or on laptop using the link below

On completion of survey:

- You can choose to enter a prize draw for one of ten **£10 amazon vouchers**
- You can also choose to take part in a follow-up interview on sleepiness (if eligible) for an additional **£10 amazon voucher**

To read more about the study and take part, scan QR code on right or go to: [link]

Questions about the study?

Ioana Marinescu (Survey lead, Trainee Clinical Psychologist) - i.marinescu@uea.ac.uk
Kate Robbins (Interview lead, Trainee Clinical Psychologist) - k.robbins@uea.ac.uk
Sarah Reeve (Project lead and supervisor, Clinical Psychologist) - sarah.reeve@uea.ac.uk

This study was approved by [ethics committee, reference number]

Appendix C
Criteria for screening for sleepiness included in the online survey

Sleepiness questions:

1. Over the last month, did you typically sleep over 11 hours in a 24- hour period? (including overnight sleep and any daytime sleep) (Y/N)
2. Over the last month, did you typically sleep over 9 hours at night? (Y/N)
3. Over the last month, how long did you typically sleep each night? (HH:MM)
4. Over the last month, did you feel excessively sleepy during the day, to the extent it was difficult to stay awake or take part in activities? (Y/N)
5. If yes – how many days in a typical week? (0-7)

Appendix D
Information Sheet for Empirical Project

Participant Information Sheet Version 2:06/02/2023

IRAS N. 321546

Understanding the experience of excessive sleepiness in people with psychotic disorders: A qualitative thematic analysis

My name is Kate Robbins, and I am a Trainee Clinical Psychologist at the University of East Anglia. As a part of my Doctorate in Clinical Psychology, I am conducting an interview study to understand the experience of excessive sleepiness in people with psychotic disorders.

I would like to invite you to take part in this research. Before you decide whether you wish to take part, it is important that you understand the purpose of the research and what it would involve. Please read this information carefully.

This is a project being undertaken by a trainee on the Doctorate in Clinical Psychology at University of East Anglia (UEA), who are the sponsor organisation for this project. Where 'we' is written, reference is to the researcher who is conducting this study (Kate Robbins) who studies at UEA.

Do I have to participate in this study?

Your participation in this study is entirely voluntary, it is up to you if you decide to take part or not. If you do decide to take part, then you will be asked to complete a form so that your consent for participation can be taken.

What is the purpose of the research?

The primary aim of this research is to understand the experience of excessive sleepiness for people with psychotic disorders. Research encourages further investigation into this topic in order to increase our clinical knowledge of how excessive sleepiness is experienced. We hope to learn how to better support

those who experience excessive sleepiness and understand how it may interact with their day-to-day living, wellbeing and treatment.

Why have I been invited?

You were contacted for the study as you are aged 18-65, have a diagnosis of a psychotic disorder and experience either excessive sleepiness, extended sleep duration or both.

What does the study involve?

You would be asked to participate in a recorded interview lasting up to one hour. The interview will be conducted and recorded via Microsoft Teams. The recording software in Microsoft Teams will video and audio record the interview. However, you can join with your camera off if this is your preference. The interview will involve a discussion with me about your experience of excessive sleepiness. The interview will explore your experience of excessive sleepiness and the impact that it has on factors that interact with your wellbeing. The questions I will ask are in the 'Topic Guide' you will have received alongside this information sheet.

Are they any possible benefits to taking part?

If you agree to be interviewed, we will email you a £10 Amazon voucher to thank you for your time. This study will give you the opportunity to share your experience of excessive sleepiness. This information will help us to understand how people experience excessive sleepiness and the impact that it may be having for them. The more we know on this the better able researchers and clinicians are in finding the right approaches and support for individuals.

What are the potential risks of taking part?

Sometimes, speaking about our experiences can be uncomfortable or cause distress. Whilst we think that talking about excessive sleepiness should hold a low risk for participants, there may be times where someone feels upset or distressed following the interview. If we are worried about your wellbeing, we will discuss this with you and direct you to support. If we are concerned that you might be at risk of harm from yourself or to or from others, then we will notify the study supervisor (Dr Sarah Reeve) and the relevant clinic teams. We will discuss this with you first.

If you do feel upset at any point of the interview, please let the researcher know so that they can help you access the support you need. Should you wish to stop the interview at any point please tell the researcher, you do not need to give a reason for this. Should any further advice or support be needed, please see the additional sources of support at the end of this information sheet.

How will your data be processed in the study?

The interview is recorded via Microsoft Teams and will be downloaded to a secure drive to be transcribed. In the transcription your name and any identifying information you mention (e.g., place names, names of others) will be removed. Once the transcription is complete your interview recording will be deleted.

The transcript will then be combined with other interviews for analysis. In reports resulting from the study, selected quotes from individual interviews will be presented. You may recognise quotes from your interviews, but they will not have your name attached so will not be identifiable to others. We will write our report in a way that no one can work out that you took part in the study.

The full transcription of your interview will only be accessible to the research team. Once we have finished the study, your data will be stored for ten years following the final submission of the project, after which they will be destroyed. Your contact details will be stored in a separate password protected file and deleted once the study is complete.

A note will be added to your clinical records to notify that you have taken part in a research study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason. Within the two weeks after your interview, you can decide to remove your data from the study. After two weeks, the data will have been incorporated into the analysis and cannot be removed. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Are there any exceptions for breaching confidentiality?

The information that you tell us within the study will be kept confidential to the study. We would only discuss any information with your clinical team if you asked us to, or if something arose that caused you

distress. We would inform you of this. The only exception to this would be if we have significant concerns about a risk to you or others. In this case we would follow clinical guidance and communicate appropriately with your clinical team. We would let you know if we needed to discuss risk with your team.

Findings of the study

This study forms a part of my doctoral thesis with the University of East Anglia, and we will aim to publish the findings as an academic paper in peer-reviewed scientific journal. If you wish to read about the findings of the study, you will need to provide your e-mail address and we can send you the results.

Who has organised and reviewed this study?

This study is funded and organised by the University of East Anglia. It has received full NHS Ethics Approval.

What happens next?

If you would like to take part in this study, or if you have any questions, please see the contact details below and contact Kate Robbins who will be in touch with you to arrange an interview time. Before your involvement in the study, you we will ask you to read and sign a consent form.

Principal Investigator: Kate Robbins

Email: k.robbins@uea.ac.uk

Primary Supervisor: **Dr Sarah Reeve**

Email: s.reeve@uea.ac.uk

For further information on data protection please see:

- https://www.uea.ac.uk/about/university-information/statutory-and-legal/data-protection
- www.hra.nhs.uk/information-about-patients/

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

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/

- By asking one of the research team:
    - Kate Robbins (Researcher – interviews lead), k.robbins@uea.ac.uk
    - Dr Sarah Reeve (Supervisor, Chief Investigator), sarah.reeve@uea.ac.uk

By viewing the UEA data protection policy at: https://www.uea.ac.uk/about/university-information/statutory-and-legal/data-protection

Support Services – Contact Details

Between 9am-5pm, Monday–Friday:

CPFT Care Co-ordinator: If you are already receiving support from CPFT services, the first point of contact should be your care co-ordinator or named nurse. Your care plan will contain information on how to contact them. If they are not available, ask to speak to the clinician on duty

Your GP: If you need immediate help, then please contact your GP

Out of hours:

Lifeline: An out-of hours mental health telephone support service, run by Lifecraft, is available for CPFT's service users who are experiencing a crisis in their mental health. The service is also available for carers who are concerned about the mental health of a service user. The out-of-hours telephone number is 0808 808 2121. This is weekdays 11am-11pm, 7 days a week.

Emergency doctor: All GP surgeries have an out-of-hours number that you can call in an emergency. The out-of-hours doctor may assess the situation over the phone, ask you to attend a clinic/service, or may come out to assess the service user. They will be able to arrange any necessary specialist assessments.

Local walk-in centre: Most centres are open 365 days a year and outside office hours. Some newly opened centres may offer different opening hours during their first few months.

Samaritans: If you feel you urgently need to speak to someone, the Samaritans are available 24 hours a day, seven days a week on 116 123.

Thank you for taking the time to read this information sheet

Appendix E
Consent Form for Empirical Project

Participant Consent Form – Version 2: 06/03/2023

'Understanding the experience of excessive sleepiness in people with psychotic disorders: A qualitative thematic analysis'

IRAS N. 321546
Name of researcher: Kate Robbins, Trainee Clinical Psychologist

	Tick to agree
I confirm that I have read and understood the Participant Information Sheet dated 14.02.2023. I have had the opportunity to consider the information provided and have any questions answered to my satisfaction.	
I understand that my participation in the study is entirely voluntary and that I can withdraw from the study at any time without giving a reason. I understand that if I withdraw two weeks or more after the interview date it will not be possible to erase my interview data.	
I understand that my interview video-recorded using the recording function in Microsoft Teams (through the researcher's university account), and I consent to this recording.	
I have been told and I understand how any information about me or related to my involvement in the study will be handled: I understand how it will be stored and kept secure, who will have access to it and how it will be used.	
I understand that should I disclose any information that raises significant concerns about my safety or the safety of other people, appropriate third parties and/or my clinical care team might be contacted. A note will be added to my clinical records to reflect my participation in this interview study.	
I agree to take part in the above study.	
I am willing to be contacted about the results of the study.	

Signature of participant _____
Name of participant _____Date_____
Signature of principal investigator _____
Name of principal investigator _____Date_____

Appendix F
Topic Guide

Topic Guide

Overview

This Topic Guide is for use by the primary researcher conducting the qualitative semi-structured interview.

Public and Participant Involvement (PPI)

The topic guide will be reviewed by a PPI group in July 2022.

Topic 1: Experiences of excessive sleepiness

I would really like to learn what this experience is like for you and I will start by asking you about your experience of excessive sleepiness. Following this, I will have some questions to gain more detail on what you have told me (these will be guided by what they described)*. What is important to me is to really understand your experience, nothing is irrelevant, I'm interested in what this experience is like for you. You don't have to answer any questions that you don't want to answer. I will try to listen as much as possible and not interrupt you, but if you have any questions as we go along please do ask me.*

Please tell me about your experiences of excessive sleepiness?

Topic 2: Impact of excessive sleepiness

What is it like to experience excessive sleepiness ?
What impact does experiencing excessive sleepiness have on you?

- *Prompts, explore impact on:*
    - *Day to day living*
    - *Mood – anxiety, sadness, anger, frustration*
    - *Wellbeing*
    - *Relationships*
    - *Treatment*

Topic 3: What may cause or contribute to excessive sleepiness
What do you think could be the cause of the excessive sleepiness that you experience?
Is there anything that you do that can make it better?
Is there anything that you do that can make it worse? more severe

Topic 4: Role/Experience of medication
What role does your medication have in your experience of excessive sleepiness?

Topic 5: Experience with healthcare professionals

Topic 6: What helps with excessive sleepiness
What do you find helpful in your experience of excessive sleepiness?

Ending the session
Is there anything that I haven't asked / we haven't discussed about excessive sleepiness that you think is important for health professionals to know?
Is there anything you would like to talk about that we haven't talked about?

Appendix E
NHS Research Ethics Committee

Dr Sarah Reeve
Norwich Medical School
University of East Anglia
Norwich
NR4 7TJ

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

10 March 2023

Dear Dr Reeve

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

Study title:	**Sleepiness in psychosis: a mixed-methods exploration**
IRAS project ID:	**321546**
Protocol number:	**N/A**
REC reference:	**23/LO/0085**
Sponsor	**University of East Anglia**

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

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

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

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

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **321546**. Please quote this on all correspondence.

Yours sincerely,
Anna Martin
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Polly Harrison*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Contract/Study Agreement template [PIC]	1	19 December 2022
Copies of materials calling attention of potential participants to the research [Appendix A - Advertisements]	2	06 March 2023
Covering letter on headed paper [Response to Committee]	1	06 March 2023
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		
Interview schedules or topic guides for participants [Topic Guide (Interview)]	2	06 March 2023
IRAS Application Form [IRAS_Form_20122022]		20 December 2022
Letter from sponsor [Sponsor Letter]		
Other [Public liability insurance]		
Participant consent form [Consent Form (Survey)]	2	06 March 2023
Participant consent form [Supplementary Consent Form (interview)]	2	06 March 2023
Participant information sheet (PIS) [Information Sheet (Survey)]	2	06 March 2020
Participant information sheet (PIS) [Supplementary information sheet (Interview)]	2	06 March 2023
Research protocol or project proposal [Protocol]	2	06 March 2023
Summary CV for Chief Investigator (CI) [Academic CV - Sarah Reeve]	1	19 December 2022
Summary CV for student [CV - Ioana Marinescu]	1	19 December 2022
Summary CV for student [CV - Kate Robbins]	1	19 December 2022
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Appendix G - Study Flowchart]	2	06 March 2023
Validated questionnaire [Appendix H - Questionnaires (Survey)]	2	06 March 2023

Appendix H
University of East Anglia Sponsorship

Research & Innovation
University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
United Kingdom

www.uea.ac.uk

TO WHOM IT MAY CONCERN

20 December 2022

Dear Sirs

Study: Sleepiness in psychosis: a mixed-methods exploration

Chief Investigator: *Sarah Reeve*

This is to confirm that the University of East Anglia shall act as sponsor for the above study.

Further the University of East Anglia and Subsidiary Companies have arranged insurance cover as detailed on the attached Company Public Liability and Professional Negligence Insurance certificates.

The cover is subject to the terms and conditions of the policy. If you require further details, please contact the undersigned.

It is fully expected that UEA shall renew its insurance policies with at least the equivalent cover going forward.

Yours faithfully

Polly Harrison
Contracts Officer
Research and Innovation

E-mail: researchsponsor@uea.ac.uk

Please note that due to the pandemic we are working remotely and operating digitally wherever possible.

Appendix I
Questionnaires included in online survey

Epworth Sleepiness Scale (ESS)

How likely are you to doze off or fall asleep in the following situations, in contrast to feeling just tired?
This refers to your usual way of life in recent times. Even if you haven't done some of these things recently try to work out how they would have affected you.
Use the following scale to choose **the most appropriate number** for each situation.
0 = would **never** doze
1 = **slight chance** of dozing
2 = **moderate chance** of dozing
3 = **high chance** of dozing
It is important that you answer each question as best you can.

Situation	Chance of Dozing (0-3)
Sitting and reading	
Watching TV	
Sitting, inactive in a public place (e.g. a theatre or a meeting)	
As a passenger in a car for an hour without a break	
Lying down to rest in the afternoon when circumstances permit	
Sitting and talking to someone	
Sitting quietly after a lunch without alcohol	
In a car, while stopped for a few minutes in the traffic	

Hypersomnia severity index (HSI)

1. For these next few questions, please consider your SLEEP IN THE PAST MONTH. To what extent do you think that you:

	Not at All	**A Little**	**Somewhat**	**A Lot**	**Very Much**
Sleep too much at night?	0	1	2	3	4
Have difficulty waking up in the morning or from naps?	0	1	2	3	4
Sleep during the day?	0	1	2	3	4
Feel sleepy during the daytime?	0	1	2	3	4

2. How SATISFIED/dissatisfied are you with your current sleep pattern?
   - Very satisfied 0
   - Satisfied 1
   - Moderately satisfied 2
   - Dissatisfied 3
   - Very dissatisfied 4

3. To what extent do you consider your sleep problem to INTERFERE with your daily functioning (e.g., daytime fatigue, ability to function at work/daily chores, concentration, memory, mood, etc.)?

Not at all	A little	Somewhat	Much	Very much
0	1	2	3	4

4. How NOTICEABLE to others do you think your sleeping problem is in terms of impairing the quality of your life?

Not at all Noticeable	Barely	Somewhat	Much	Very much Noticeable
0	1	2	3	4

5. How WORRIED/DISTRESSED are you about your current sleep problem?

Not at all	A little	Somewhat	Much	Very much
0	1	2	3	4

6. Do you ever have “sleep attacks,” defined as unintended sleep in inappropriate situations?

- Not at all 0
- A little 1
- Sometimes 2
- Often 3
- All the time 4

The Integrated tiredness index (ITI)

This questionnaire assesses the impact of tiredness. In the last week, how much of an issue have you had with….					
(circle as appropriate)	**0 (none)**	**1 (slight)**	**2 (moderate)**	**3 (very much)**	**4 (extreme)**
1. **Feeling worn out**	0	1	2	3	4
2. **Feeling dozy**	0	1	2	3	4
3. **Feeling half awake**	0	1	2	3	4
4. **Feeling drained**	0	1	2	3	4
5. **Feeling sleepy**	0	1	2	3	4
6. **Feeling low in energy**	0	1	2	3	4
7. **Feeling fatigued**	0	1	2	3	4
8. **Feeling drowsy**	0	1	2	3	4

Items 1,4,6,7 – fatigue
Items 2,3,5,8 – sleepiness

Fatigue Severity Scale (FSS)

Please circle the number between 1 and 7 which you feel best fits the following statements. This refers to your usual way of life within the last week. 1 indicates “strongly disagree” and 7 indicates “strongly agree.”

Read and circle a number	Strongly Disagree -> Strongly agree						
My motivation is lower when I am fatigued	1	2	3	4	5	6	7
Exercise brings on my fatigue	1	2	3	4	5	6	7
I am easily fatigued	1	2	3	4	5	6	7
Fatigue interferes with my physical functioning	1	2	3	4	5	6	7
Fatigue causes frequent problems for me	1	2	3	4	5	6	7
My fatigue prevents sustained physical functioning	1	2	3	4	5	6	7
Fatigue interferes with carrying out certain duties and responsibilities	1	2	3	4	5	6	7
Fatigue is among my most disabling symptoms	1	2	3	4	5	6	7
Fatigue interferes with my work, family, or social life	1	2	3	4	5	6	7

Insomnia severity index (ISI)

The following questions ask about your sleep in the past two weeks. For each question please CIRCLE the number that best describes your answer.

Please rate the following in relation to your CURRENT sleep (in the past *two weeks)*.

Sleep problem	None	Mild	Moderate	Severe	Very Severe
1. Difficulty falling asleep	0	1	2	3	4
2. Difficulty staying asleep	0	1	2	3	4
3. Problem waking up too early	0	1	2	3	4

4. How satisfied/ dissatisfied are you with your current sleep pattern?

- Very satisfied 0
- Satisfied 1
- Moderately satisfied 2
- Dissatisfied 3
- Very dissatisfied 4

5. To what extent do you consider these sleep problems to interfere with your daily functioning (e.g. daytime fatigue, mood, ability to function at work/daily chores, concentration, memory, mood etc.).

Not at all interfering	A little	Somewhat	Much	Very much interfering
0	1	2	3	4

6. How noticeable to others do you think these sleep problems are in terms of impairing the quality of your life?

Not at all noticeable	Barely	Somewhat	Much	Very much noticeable
0	1	2	3	4

7. How worried/distressed are you about these sleep problems?

Not at all worried	A little	Somewhat	Much	Very much worried
0	1	2	3	4

Depression Anxiety Stress Scale (DASS)

Please read each statement and select the option that best indicates how much the statement applies to you. There are no right or wrong answers. Try not to spend too much time on any statement.			
Did not apply to me at all	***Applied to me to some degree, or some of the time***	***Applied to me to a considerable degree, or a good part of the time***	***Applied to me very much or most of the time***
0	***1***	***2***	***3***
1. I was aware of dryness of my mouth			
0	*1*	*2*	*3*
2. I couldn't seem to experience any positive feeling at all			
0	*1*	*2*	*3*
3. I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)			
0	*1*	*2*	*3*
4. I found it difficult to work up the initiative to do things			
0	*1*	*2*	*3*
5. I experienced trembling (e.g. in the hands)			
0	*1*	*2*	*3*
6. I was worried about situations in which I might panic and make a fool of myself			
0	*1*	*2*	*3*
7. I felt that I had nothing to look forward to			
0	*1*	*2*	*3*
8. I felt down-hearted and blue			
0	*1*	*2*	*3*
9. I felt I was close to panic			
0	*1*	*2*	*3*
10. I was unable to become enthusiastic about anything			
0	*1*	*2*	*3*
11. I felt I wasn't worth much as a person			
0	*1*	*2*	*3*
12. I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)			
0	*1*	*2*	*3*
13. I felt scared without any good reason			
0	*1*	*2*	*3*
14. I felt that life was meaningless			
0	*1*	*2*	*3*

The Revised Green et al. Paranoid Thoughts Scale (R-GPTS)

R-GPTS Part A (Reference) scale

Please read each of the statements carefully. They refer to thoughts and feelings you may have had about others over the last month. Think about the last month and indicate the extent of these feelings from 0 (Not at all) to 4 (Totally). (Please do not rate items according to any experiences you may have had under the influence of drugs.)

	Not at all		Somewhat		Totally
1. I spent time thinking about friends gossiping about me.	0	1	2	3	4
2. I often heard people referring to me.	0	1	2	3	4
3. I have been upset by friends and colleagues judging me critically.	0	1	2	3	4
4. People definitely laughed at me behind my back.	0	1	2	3	4
5. I have been thinking a lot about people avoiding me.	0	1	2	3	4
6. People have been dropping hints for me.	0	1	2	3	4
7. I believed that certain people were not what they seemed.	0	1	2	3	4
8. People talking about me behind my back upset me.	0	1	2	3	4

R-GPTS Part B (Persecution) scale

Please read each of the statements carefully. They refer to thoughts and feelings you may have had about others over the last month. Think about the last month and indicate the extent of these feelings from 0 (Not at all) to 4 (Totally). (Please do not rate items according to any experiences you may have had under the influence of drugs.)

		Not at all		Somewhat		Totally
1.	Certain individuals have had it in for me.	0	1	2	3	4
2.	People wanted me to feel threatened, so they stared at me.	0	1	2	3	4
3.	I was certain people did things in order to annoy me.	0	1	2	3	4
4.	I was convinced there was a conspiracy against me.	0	1	2	3	4
5.	I was sure someone wanted to hurt me.	0	1	2	3	4
6.	I couldn't stop thinking about people wanting to confuse me.	0	1	2	3	4
7.	I was distressed by being persecuted.	0	1	2	3	4
8.	It was difficult to stop thinking about people wanting to make me feel bad.	0	1	2	3	4
9	People have been hostile towards me on purpose.	0	1	2	3	4
10	I was angry that someone wanted to hurt me.	0	1	2	3	4

SPEQ hallucinations scale

Please read each statement and click the number that best indicates how frequently you have each of these experiences. There are no right or wrong answers. Try not to spend too much time on any statement.					
Not at all	***Rarely***	***Once a month***	***Once a week***	***Several times a week***	***Daily***
0	*1*	*2*	*3*	*4*	*5*
1. Hear sounds or music that people near you don't hear?					
0	*1*	*2*	*3*	*4*	*5*
2. See things that other people cannot?					
0	*1*	*2*	*3*	*4*	*5*
3. Feel that someone is touching you, but when you look nobody is there?					
0	*1*	*2*	*3*	*4*	*5*
4. Hear noises or sounds when there is nothing around to explain them?					
0	*1*	*2*	*3*	*4*	*5*
5. Detect smells which don't seem to come from your surroundings?					
0	*1*	*2*	*3*	*4*	*5*
6. See shapes, lights, or colours even though there is nothing really there?					
0	*1*	*2*	*3*	*4*	*5*
7. Notice smells or odours that people next to you seem unaware of?					
0	*1*	*2*	*3*	*4*	*5*
8. Experience unusual burning sensations or other strange feelings in or on your body that can't be explained?					
0	*1*	*2*	*3*	*4*	*5*
9. Hear voices commenting on what you're thinking or doing?					
0	*1*	*2*	*3*	*4*	*5*
Overall, how distressed are you by these experiences?					
0 (not distressed)		***1 (a bit distressed)***	***2 (quite distressed)***		***3 (very distressed)***

Recovering quality of life (REQOL)

For each of the following statements, please tick one box that best describes your thoughts, feelings and activities over the last week

Over the last week	None of the time	Only occasionally	Sometimes	Often	Most or all of the time
I found it difficult to get started with everyday tasks					
I feel able to trust others					
I felt unable to cope					
I could do the things I wanted to do					
I felt happy					
I thought my life was not worth living					
I enjoyed what I did					
I felt hopeful about my future					
I felt lonely					
I felt confident in myself					
	No problems	Slight problems	Moderate problems	Severe problems	Very severe problems
Please describe your physical health (problems with pain, mobility, difficulties caring for yourself or feeling physically unwell) over the last week					

None of the time = 0, Most or all of the time =4

Items 1, 3, 6, 9 and the physical health item are reverse scored

Physical activity questions (adapted SIMPAQ)

We are interested in your physical activity levels over the past seven days. These questions are optional, so you can skip them by selecting the appropriate option.
Over the past week, how long did you spend...
Sleeping or in bed (hours and minutes) e.g. 8 hours would be "8", 9 and a half hours would be "9.5"
Sitting or lying down (e.g. napping, eating, reading, watching TV, using electronic devices (hours and minutes)
Walking (hours and minutes)
Doing active exercise (e.g. jogging, running, swimming, bike riding, going to the gym, yoga) (hours and minutes)